



# HEALTH CARE IN THE INFORMATION SOCIETY

VOL. 2

FROM ANARCHY OF TRANSITION TO  
PROGRAMME FOR REFORM

DAVID INGRAM

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INFORMATION SOCIETY

VOLUME 2



# Health Care in the Information Society

Vol. 2: From Anarchy of Transition to  
Programme for Reform

*David Ingram*

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*For Boženka, whose love and encouragement  
made it possible, and in respectful memory of  
John Dickinson and Jo Milan, whose insight  
and friendship guided and supported me along  
the way*



## VOLUME 1

### Part One—Adventure of Ideas

*Bolder adventure is needed—the adventure of ideas, and the advantage of practice conforming itself to ideas. The best service that ideas can render is gradually to lift into the mental poles the ideal of another type of perfection which becomes a programme for reform.*

—Alfred North Whitehead (1861–1947)<sup>1</sup>

## VOLUME 2

### Part Two—Anarchy of Transition

*In every age of well-marked transition there is the pattern of habitual dumb practice and emotion which is passing, and there is the oncoming of a new complex habit. Between the two lies a zone of anarchy.*

—Alfred North Whitehead<sup>2</sup>

### Part Three—Programme for Reform

*Human nature is so complex that paper plans for society are to the statesmen not worth even the price of the defaced paper. Successful progress creeps from point to point, testing each step.*

—Alfred North Whitehead<sup>3</sup>

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1 *Adventures of Ideas* (New York: Macmillan, 1933), p. 248.

2 *Ibid.*, p. 14.

3 *Ibid.*, p. 27.





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# PART TWO—ANARCHY OF TRANSITION

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*In every age of well-marked transition there is the pattern of habitual dumb practice and emotion which is passing, and there is the oncoming of a new complex habit. Between the two lies a zone of anarchy.*

—Alfred North Whitehead (1861–1947)<sup>1</sup>

The five chapters of Part One have followed a common pattern: building from historical context and example, and charting change over time, into and through the Information Age and connecting with health care.

Part Two adopts a different viewpoint: that of the impact of the adventure of ideas of Part One on life and medical sciences and health care services, in their connected transitions into and through the Information Age. Its two chapters might arguably comprise and merit books of their own. They tell stories of anarchic transition in which the author has been both eyewitness and participant and are thus integral with the songline that the book traverses.

As expressed by Alfred North Whitehead (1861–1947), radically new ideas and the anarchic transitions they unleash create new contexts and opportunities that become the focus of programmes for reform. Part Three of the book peers ahead, imaginatively, towards a new era where the experiences and learning that feature in Parts One and Two will lead us to understand, create and sustain health care and its services differently.

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<sup>1</sup> *Adventures of Ideas* (New York: Macmillan, 1933), p. 14.



# 6. Life and Information— Co-evolving Sciences

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This chapter steps away from the practical engineering of Chapter Five into a new dimension, to consider where information itself, as an idea, now connects within life science and medicine. The current era has seen radical transition in scientific understanding of the nature of both information and life. Like particles and waves in quantum theory, perhaps they will come to be seen, in some emergent way, as another example of complementarity. Life as somewhere between material entity and immaterial essence. Information as somewhere between material and measurable entity and immaterial abstraction.

The question 'What is Life?', and its connection with the nature of information as a scientific concept, has captivated luminary thinkers, who have informed and challenged one another, and written landmark books on this theme. I have a collection of these, written from physics, life science, mathematics, computer science and cognitive neuroscience perspectives. I look in turn at an eclectic selection, over time. My purpose is to illustrate how these great and imaginative contributors have applied their evolving insights to elucidate connection of their disciplines with ideas about the nature of information and life.

The chapter concludes with a reflection on information policy for health care services in the present era of still extremely rapid transition on all fronts of information technology and life science. There can be no more important global goals than those that seek balance, continuity and governance of the natural environment. In health care, these three also predominate as concerns of our age. They pose challenges that can only be tackled based on shared knowledge and methods that connect coherently and transcend from local to global scale, building on common ground.

What is mind? No matter.

What is matter? Never mind.

—attributed to George Berkeley (1685–1753)<sup>1</sup>

‘What is’ questions are not new! What is reality? What is life? What is information? These, too, perplex! Erwin Schrödinger (1887–1961) opened a new window and provided insight into (or should that be outlook onto?) the first of these questions, in the theoretical physics of the quantum era. The Schrödinger equation started wheels turning and gained experimental traction. In later years, he peered into the misty future in raising the second question and made some suggestions, too, about the Berkeley question, which he considered even harder. ‘Leave it to the computer’, as an answer to the third question, does not really equate to ‘leave it to the Schrödinger equation’, in answer to the first! And resolving to ‘never mind’ about it may turn out to matter a lot more in the computer age!

I used to sit eating with physics student colleagues, tired after a day battling problems connecting with quantum theory and the ‘What is reality?’ question. Nearby, a group of lawyer colleagues were often in more lively debate over their ‘What is law?’ question. I do not recall discussion among the mathematicians about ‘What is mathematics?’ No doubt, they were resting after their days deeply immersed in theory of number, topology and symmetry; like us aspirant physicists, numbed by our mental struggles with vector calculus, tensor algebra and analytical solutions of differential equations!

The question ‘What is life?’ became a preoccupation of mathematics, physics and chemistry, as they cross-fertilized with one another and spread their interests and influence further around the circle of knowledge, to biology and medicine. And now filtering to the top of the pile of ‘what is’ questions in both physical and life science is the question ‘What is information?’ Theory of information has evolved in multiple contexts of mathematics, science and engineering over the past one hundred and fifty years. Some believe it holds the key to clarity about other ‘What is...’ questions in science. It may have significant impact on what comes next in the evolution of life science and health care. Peering into the mists for an Occam’s razor moment, perhaps an answer could only ever emerge alongside the untangling of the first great unknown: ‘What is reality?’ Perhaps the Hitchhiker’s Guide answer, ‘forty-two’, will prove the best we can do!<sup>2</sup> Now that we know more about

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1 Sometimes also attributed to Samuel Johnson (1709–84).

2 D. Adams, *The Hitch Hiker’s Guide to the Galaxy: A Trilogy in Five Parts* (London: Random House, 1995).

information and what we can make and do, by way of data and knowledge, do we know more about life? *Zobaczymy [we will see]*<sup>3</sup>

What is matter? Maybe it's information

What is information? Maybe it's matter

How does information matter in life?

Does any of this connect with health care?

As we have seen throughout Part One, the Information Age has been one of disruptive transition in science, technology and society. The anarchy has played out into health care services. Uncertain and experimental, new and evolving insight into the science of life has coupled with the equally new and evolving science and technology of information systems, which have themselves underpinned this scientific revolution. It looks rather like an engineering control system (with information feeding forward in some way into science, and science feeding back in some way into information), and such systems can be unstable. This scene in health care, and its context, look to have some features in common with what happened to the world's monetary system in 2008, a thought that I explore further in Chapter Eight.

In such times, we must be cautious about digging too rapidly or deeply into 'What is?' conundrums. They can be tiring, costly and a bit beside the point. As the quotation leading into Part Three emphasizes, sustainable progress comes iteratively and incrementally, with the need for careful testing at each stage. The Information Age of science and technology can readily dig bottomless holes and endless tunnels of discourse, excavating more and more data, ever faster. There are swallow holes lurking when we dig deeply into 'What is?' questions—it is easy to fall in and get stuck underground. Swallow holes are called solution features in the technical jargon because they dissolve underlying chalk, and the earth above falls in. In some places, chalk is what supports our houses and swallow holes can undermine these foundations, when our intent in digging is to underpin and make them better. There was once a very small one halfway down our garden, which is maybe why that analogy came to my mind!

As we survey our current era of anarchic transitions in science, technology and society, we need to shore up their necessary foundations that have become exposed and weakened. How we do this, matters. We need to focus more on the practicalities of how, and less on what we're trying to achieve and why. Health care at the front line is clearly operating

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3 On this Polish expression, see Preface.



on expensive and shaking foundations at present. Part Three proposes one approach to the 'how' question of health care information policy, about how to make and do things better.

Finding good answers will matter for health care. We must neither fall under the spell of Siren voices of technological utopia nor fail to find a safe course through the gap between beckoning rocks, which health care must navigate, seeking a way onto a stronger and more resilient future home base. We're not like Odysseus; his story is mythical, although the seascape he tells of maybe not. Our encounter with an anarchic seascape of health care information is all real. The difference is that we create the sea and can navigate it better.

The range of ideas embraced in postulated answers to the 'What is information?' and 'What is life?' questions is considerable and continuously evolving. Here, I can only seek to outline and connect their history and scope. We can look at life in evolutionary, historical and scientific contexts. We can look at information in the context of physical science and engineering, and how it has interfaced with life science and health care. This is the scope I will now venture to outline. It is a challenge better tuned to my physics brain of yesteryear and I set it out, here, only to encourage more flexible and knowledgeable modern brains to reflect on it, pick it apart and improve it.

## Life in Evolutionary Context

Our understanding of life may in time arise from way beyond our tiny Earth. Search for extra-terrestrial life is fascinating astrobiology of our time, highlighted by the report, last week as I write, of the possible discovery of phosphine in the Venusan atmosphere, as a potential marking of microbial life there. Accounts of the experiments planned for the automated Mars lander when it arrives on Venus in a few years' time also stir speculation. It will drill to collect samples and use Raman spectroscopy to characterize their minerals, looking for imprints of carbon-based materials that might also prove indicative of life.<sup>4</sup> As I first revised this chapter on 18 December 2021, the *National Geographic* had an excited article about a pre-publication announcement of a strong candidate SETI intelligent signal from space,

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4 The name here connects to the experiments, a hundred years ago, of the Indian physicist Chandrasekhara Venkata Raman (1888–1970), on the interaction of phonon and photon in scattering of light in the solid state, for which he was awarded the Nobel Prize in 1930. I encountered the quantum theory of the Raman effect, in my university days. Its place now, in a robot-controlled experimental laboratory on Mars, is astonishing to think about! There is a man still alive in Japan, today, who was a teenager when Raman reported his findings.

emanating from Proxima Centauri, our nearest stellar neighbour.<sup>5</sup> In more recent months, the James Webb telescope has been successfully launched and positioned, starting to focus such investigation much further away. I will focus, here, on life on Earth and the connections made from mathematics and science to information and life.

Stephen Jay Gould (1941–2002) coined the term punctuated equilibrium to describe periods of quiescence and slow change, and periods of rapid and disruptive change in the natural world. Over such eons, humankind has played almost no part in evolution. We are the tiniest of dots on this landscape. The Information Age is punctuated evolution of a new kind, in which humans are, or should be, in control.

Earth as a planet has a 4.6-billion-year history within the solar system and the earliest life forms may have originated between 3.77 and 4.5 Ga (billion years) ago, 100 million years or so after the first appearance of liquid water. These dates are continuously under review and are recalibrated as new evidence emerges and gains sway. With increasing complexity and diversity, life evolved and emerged from the sea onto land and into the sky. By the time of the carboniferous period, 363 Ma (million years) ago, the earth began to look a bit like the earth today. Major extinction events 251.4 Ma and 66 Ma years ago destroyed and rebooted life, eliminating ninety to ninety-five percent of marine species in the first event and half of animal species in the second event. Life flourished again and *genus homo* appears 2 Ma years ago in the fossil record. Anatomically, modern humans appeared in Africa around 250 Ka (thousand years) ago, colonizing the other continents, replacing Neanderthals in Europe and other hominins in Asia.

Landscape can usually be relied on to evolve very slowly. Tectonic plates drift and collide, sometimes grumblingly in tremors and localized earthquakes, sometimes creating pressure valves released in volcanoes that spread their effects more widely around the planet. Humankind can do little if anything to influence geodynamic punctuations of our planetary history, save to seek out and build in safer places and employ robust and resilient construction methods and defences. The information landscape is now, and increasingly, intertwined with the physical environment, and shaping the living world and human experience. Its construction methods and defences are often proving inadequate for combatting the attrition it has engendered.

Major punctuations of evolution arise from beyond the earth as it is buffeted from elsewhere in the solar system. Meteors arrive in different sizes, as daily events. Much larger asteroid strikes, as at Chicxulub in

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5 N. Drake, 'Alien Hunters Detect Mysterious Radio Signal from Nearby Star', *National Geographic* (18 December 2020), <https://www.nationalgeographic.com/science/article/alien-hunters-detect-mysterious-radio-signal-from-nearby-star>

Mexico, associated with the second major extinction of life 66 Ma years ago, burned and scarred the earth for thousands of miles around and precipitated climate change that impacted life everywhere, immediately and over very long periods. This one's size has been estimated in tens of kilometres and the energy it dissipated in tens of yottajoules—physical estimates of events on earth do not yet have units much larger! Sunspots, arising in the chaotic surface dynamics of the star, flare radiation that disrupts information systems on earth, nine minutes later.

We learn about such events in history from the science of our era. This learning shapes and illuminates our understanding of Earth, and life on Earth. We can now predict and assess some such external risks, but, like Nassim Taleb's black swans,<sup>6</sup> they also arrive unannounced and unpredicted. We hope that we will be spared from them, and mostly do not think about them, or adopt self-comforting denial. We are consumed with surviving present storms and our perspectives and decisions are biased by recency.

## Life in Historical and Scientific Context

The nature of life is of enduring interest to conscious minds. Ancient chemists sought an elixir of life. Mystics and worshippers found meaning in patterns of the world they inhabited, and ascribed hardships and extreme events to the will of all-powerful gods. Living and dying were understood and ritualized in relationship with unseen creators and takers of life.

Greek philosophers found beauty and symbolic order in the material world and living creatures, expressing this in their writing and through the arts. Other cultures decried this as idolatrous imagery. Mechanisms of living organisms and their dysfunctions provided rich material for these pursuits and preoccupations. Birth and death, the transition into and out of life, now occupy centre stage—illness and disease likewise. The extant writings attributed to Hippocrates (c. 460 BCE–375 BCE)<sup>7</sup> and those of Galen (c. 130 CE–210 CE),<sup>8</sup> whose ancestral home was in Aesculapian (Aesculapius, the

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6 N. N. Taleb, *The Black Swan: The Impact of the Highly Improbable* (London: Random House, 2007).

7 Just this month, as I write, the classical historian Robin Lane Fox, a fellow student of mine at Magdalen College, University of Oxford, published *The Invention of Medicine* (London: Penguin Books, 2020), tracing this story to manuscripts of Hippocrates dating from an earlier time than previously believed by scholars of ancient history.

8 Galen was a highly accomplished Greek physician, surgeon and philosopher, working in Rome. He was personal physician to some Roman Emperors, and a prolific author: about 20,000 pages of his work survive. He is still known among other things for his discovery of blood in human arteries and for his dissection

Roman god of medicine), tell the story of the stirrings of medical discipline and practice, as symbolized in the classical iconography of the caduceus—a sword or staff with twin venomous serpents entwined around it.

Skipping forward many centuries, the Italian Renaissance imagery of Leonardo da Vinci (1452–1519) captured human anatomy in artistic detail and his polymath range of interests made connections with mathematics, engineering, botany and astronomy. Jumping again, to the era of William Harvey (1578–1657), the inner function of the body was explored, and the circulatory system of blood discovered, as described in his book *de Motu Cordis* (1628). Medical practice slowly evolved from the mystical and pragmatic—leeching of blood and herbal medicaments and preoccupation with extracting vapours, seen as poisons—to an experimentally balanced science. The surgical profession started with the Barber-Surgeons in the mid-sixteenth century, as a trade guild and livery company of the City of London. As invasiveness of interventions increased, they battled infection and outcomes were poor. Surgery separated into its own domain and acquired its Royal Charter in the mid-nineteenth century.

Identification of patterns of disease and their classifications by pathologists such as Thomas Hodgkin (1798–1866), dissecting the bodies of deceased patients, opened insight into a new world of ordered and disordered bodies, and the time course of their life, from birth to death. This branch of science was predicated on advances in optical devices for magnifying minute detail. Experienced clinical observation remained central to professionalism.

Health and disease were increasingly of wider interest in society. Adverse outcomes as well as beneficial ones attracted attention and were related to good and bad standards of the professions as well as good and bad prognoses of patients. Reputation and remuneration were at stake. The legal profession became more active on the scene.

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of the human cranial nerves. Some years ago, my wife and I visited Bergamo (Pergamon) in Turkey and the Aesculapian of Pergamon, where classical Greek medicine played out alongside ancient practices of religion and civic power. The guide told us of ill treatment of mental illness by priests, an illustration of the interplay of mysticism and early science. They whispered suggestions, as if from gods, through holes in the roof of the tunnel through which patients walked on their way for treatments, to destabilize and control them. Galen was a surgeon. Surgical interventions, the earliest thought to have been trepanation, dated from many centuries before. This remarkable historic site—described to us by a very knowledgeable guide who went with us for the day trip from our sailing club (which was the real reason we were there!)—inspires awe. The principal remaining artefacts from its Temple of Zeus were taken to Germany and remain in the Pergamon Museum, in what was East Berlin. That is where I saw them, in 1984, when visiting to give a conference talk.

As with any innovation impacting on established skills and practice, there was kickback. Stethoscopes were an unproven irrelevance—the physician’s hand and a chronometer were all that was needed—thus ruled the rulers of the times. Limitations in what can be done to support patients and improve their clinical situation may render additional measurement irrelevant. But, if new measurement can potentially cast new light on a clinical situation, or open new opportunities for treating it effectively, there is a case for experiment. In striking a balance in what was done to and for a patient, with many interests in play, the patient’s interest—only slowly well-represented—became of greater concern. How people concerned about loss of livelihood or influence may see that balance, may differ significantly from how the eager innovator or the patient may see it.

Evolving science and technology ushered in a new era of measurement devices. Physicists became increasingly interested and involved in medicine, heralding new methods of investigation and treatment of disease. X-ray imaging devices, recording penetrating radiation on photographic emulsions, allowed visualization of internal organs. New devices, such as for radiation therapy, required significant engineering expertise to design and operate them safely. Medical and surgical procedures increased in ambition, alongside widening knowledge of pharmacology and pharmaceuticals. Other devices of potential relevance to medical practice continued to appear. An increasing range of national bodies extended the regulation of medical practice.

An innovative thrust came from a different direction in the first half of the twentieth century, again, in part, from the cross-fertilization of physics and mathematics with physiology. At the turn of the century, the electrophysiology of the integrated nervous system was the experimental domain of Charles Sherrington (1857–1952). With Edgar Adrian (1889–1977), he was awarded the Nobel Prize in 1933 for their work at the University of Cambridge on the function of neurons. At the start of my songline, another illustrious Hodgkin, Alan Hodgkin (1914–98), and Andrew Huxley (1917–2012), were Nobel Prize winners in 1963 for their work at the University of Cambridge and the Marine Biological Laboratory in Plymouth, which included the development of the original mathematical model of the propagation of nerve action potential. And in the 1970s, towards the end of his career, the zoologist and neurophysiologist John Zachary Young (1907–97), at University College London (UCL), updated Sherrington’s concept of an integrative nervous system in his 1975–77 Gifford Lectures on the Programs of the Brain, an inukbook that I discuss below. I shared his academic affiliation with Magdalen College at the University of Oxford and UCL, although my tiny and invisible village school was very different from

the visible majesty of his Marlborough College, which I know from friends was also a wonderful academic environment to experience.

The scientific understanding of living organisms has advanced beyond recognition in the past seventy years. Foremost among the discoveries that opened a new window onto the unknown, in the memorable phrase of the physicist Max Born (1882–1970), was that of the double helix structure of DNA, by Francis Crick (1916–2004) and James Watson in 1953. Max Born's son, Gustav Born (1921–2018), worked alongside the pharmacologist John Vane (1927–2004), in my years at St Bartholomew's Hospital (Bart's). Advances in laboratory science and technology and insights gained from the tracking of genetic mutations through successive generations of reproduction of living organisms were developed and brought to fruition by an outstanding generation of scientists, many of them Nobel Prize winners, combining with the emerging capabilities and analytical methods of information technology and computer science. Together, these paved and led the way to astonishingly rapid advances in the sequencing of genomes and mapping of their component structures and functions.

Over much the same period, parallel insights from mathematics, physics, computer science and engineering, linking with biology and cognitive neuroscience, have shone new light on ideas about the nature of living systems and the human brain, framed within concepts of information networks. The studies of information networks—computer networks, gene networks, health information networks, social networks—have proliferated and cross-fertilized.

These multidisciplinary efforts have brought increasing focus on the nature of information itself. We are in a scientific era that seeks understanding of complex systems by building models that draw on many domains of knowledge: the mathematics of symmetry, topology and calculus; the physics of order, information and energy; computer science and formal logic; and the engineering of control systems. It is marrying these with chemistry and life science, from the level of atoms, molecules and cells to organs, bodies, populations and ecosystems. Information in this holistic perspective is conceived as fundamental and quantifiable, and even perhaps a physical property of matter.

Underlying such quests for unification, nature seems to place some restrictions—energy is conserved, it is impossible to travel faster than light, the universe proceeds towards states of increasing disorder. Physics looks for theory consistent with such appearances and constraints—if there is breakage, the experiment is flawed, or it is the theory that is broken. Fragmented ideas about information, from many domains, are distilling and evolving towards a coherent core of information theory and methods. They

have a two-hundred-year songline dating from the time of the early steam engines—nice to have a train of thought connecting steam with information!

In whatever way these ideas may ultimately connect within the practical domain of health informatics, there is urgency to progress ideas on multiple fronts to improve understanding. We need good and enabled teams and environments in which to draw them together. Downplaying the complexity and challenges involved in unifying health informatics, and opting for single and fragmented communities, cannot work. Left to academia, health informatics becomes distracted into more and more disengaged words and airmiles. Left to governments and NGOs, it becomes corralled into political power struggles. Left to consultants and industry, it engenders wasteful gold rush. Left to managers and regulators it becomes disconnected and unimplementable. Left to clinicians and technologists, it has remained intractable.

To date, an Institute of Life Science and Health Care Informatics with this broad scope would likely be seen as both unworldly and unacademic. It would be worth a try! How we tackle what we do not know about (but must act on, learn about and implement) boils down to good ideas, tractable goals, capable teams and richly endowed and protected environments fostering creativity, experiment and learning. Multiprofessional and interdisciplinary teamwork and good environments are crucial. I seek to draw these thoughts together and show them in action in Part Three of the book.

## Information in Context of Physical, Engineering and Life Sciences

Bertrand Russell (1872–1970) thought of mathematics and logic as one and the same—the basis of clear, precise and consistent thought and reasoning about the world. The answer to the ‘What is mathematics?’ question seems to encompass whatever you need in your armoury, to support you in achieving that lofty goal—as fully as you can, but not with a sense of completeness or perfection. Mathematics is what mathematicians decide to do, as it were—quite an attractive perspective for the academic mind, and important for the rest of us to enable them to get on with it, unhindered! New problems encountered may require new ideas and methods of mathematics. In this way of thinking, mathematics is akin to a model of logical reasoning (not a model of the way the human brain works, although neuromorphic computation seems on the up again, now). Its corpus of ideas and methods is its discipline, positioned close by to philosophy around the circle of knowledge.

Early science rattled the cages of religion and philosophy and was allowed out under the guise of the label ‘natural philosophy’. It entails many ‘What is?’ questions that still baffle. It evolves models and methods—ways of describing and reasoning—seeking to understand better, as times change, and the world moves on. The ‘What is reality?’ question may be destined never to be resolved, but theoretical physics continues to posit ideas and keep trying.

Physics poses other ‘What is?’ questions—what is gravity, quantum entanglement, dark matter, dark energy, entropy, time? Armed with the ideas and methods of mathematics to help keep it on track, it ventures to describe and tame the observed physical world, in the shape of theory and experiment that embrace manifolds of space and time, fields, forces, energies, elementary particles, nuclei, atoms, molecules and their ensembles, and now of information. Unanswered or partially answered questions spur new endeavours.

New mathematics and science are discovered, to model and simulate patterns and behaviours encountered, and bring rigour to their analysis. As Karl Popper (1902–94) is reported to have said, the essence of modelling is to discover what can safely be left out. Faced with increasing complexity, how can a problem be reframed, drawing on new ideas and methods, to achieve a goal of simplifying perhaps hitherto intractable descriptions, and enhance understanding and ability to reason consistently.

William of Ockham’s (c. 1285–1347) Razor points to virtue in simplicity in this process. In the physical world, there is poetic simplicity and profound science in hydrogen—the simplest element, just one proton and one electron, and the origin of all the other elements in the evolving universe. Its name means maker of water, itself a quite simple molecule—an assembly of two hydrogen and one oxygen atoms. The polarized charge distribution of the water molecule gives rise to its complex physical behaviours—solid ice expands from and floats on liquid water, and aqueous solutions exhibit complex behaviours which play out throughout the chemistry and complexity of life.

Early in my postgraduate career, I read beyond classical and quantum physics into the connections from mathematics into computer science and electrical engineering. A pivotal stage was the mathematician Claude Shannon’s (1916–2001) characterization of the information content of electrical signals and their digital communication through transmitted messages. John von Neumann (1903–57) advised him of the parallel with Ludwig Boltzmann’s (1844–1906) and James Clerk Maxwell’s (1831–79) earlier ground-breaking connection of theory of order and disorder of physical systems with the concept of entropy, which unfolded in the field of statistical mechanics and thermodynamics. Thus arose the term information



entropy, and ideas connecting order, information and life, as I further describe, below. This has evolved into a complex chain of ideas, probing at the limits of what we know and can know, with new ideas extending into life science, medical science and health care. The early history is a great example of the pioneering connections that von Neumann made, between mathematics, science and engineering, leading into the Information Age. His early death from cancer was a great loss. The book of his 1956 Silliman Lectures on *The Computer and the Brain*, which he worked on as he came close to death, is one of the landmark contributions I introduce in this chapter.

I read further through the connections from mathematics and physics into theory of complexity, and emergent properties of physical systems in states of thermodynamic disequilibrium and irreversible change. Ilya Prigogine (1917–2003) and René Thom (1923–2002) are remembered storytellers. The Belousov–Zhabotinsky reaction (Boris Belousov (1893–1970) and Anatol Zhabotinsky (1938–2008)) was a captivating chemical example of non-equilibrium thermodynamics appearing as an oscillating *perpetuum mobile*. A hypothesis of the times was of life as an emergent property of dynamical systems far from equilibrium. And other conjectures arose.

Around the same time that Shannon alighted on his concept of information entropy, there was increasing cross-over into study of the living world, where the ‘What is life?’ question was in search of an answer. Human life plays out from the physics and chemistry of energy and membrane into the biology of organelles and cells, and into organs and organ systems, bodies, families, populations and species. The quest is for increasing precision and traction in ways of describing and reasoning about living systems. It may require new science and new mathematics. It is a field in which mathematics bridges into informatics, and physical science into biology and medicine, around the circle of knowledge. Informatics in this broad context might be characterized as a science of information that spans from mathematics, through natural science to engineering science.

‘What is informatics?’ is a question that I was teased about in my early medical school academic post. I decided to stick it out and not retreat to a safe distance from this sometimes indulgent, sometimes slightly menacing mockery, sheltered in the mathematics or science establishments. I wanted to find out what informatics is, by working inside the world of life science and medicine, engaging as broadly as possible with problems I came across there. I was given *carte blanche* to live out an experimental enactment of ‘informatics is what informaticians do’, in the way that the Nobel Laureate physicist, John Archibald Wheeler (1911–2008) was content with mathematics being what mathematicians do.

As mentioned above, early perspectives about the scientific nature of information connected with the study of the behaviour of physical

ensembles (groupings) and systems of things that interact with one another. This evolved from the study of the properties of gases and connected the experimental study of thermodynamics, as classically expressed in the laws governing their physical behaviour (measurements of pressures, volumes, temperatures and so on) with theory of statistical mechanics, which modelled the behaviour of the gas in terms of ensembles of gaseous molecules.

A key, but elusive concept of classical thermodynamics, relating to the capacity of a heated gas in a steam engine to expand and thereby be organized to perform useful work, was entropy. This was quantified in terms of properties that could be measured, but the answer to the ‘What is entropy?’ question was elusive. No one knew the answer to that question. Conjectures about its connection with other ‘What is?’ questions persist today. But, as with quantum theory battling the ‘What is reality?’ question, today, there was theory and method that enabled the classical thermodynamic system to be modelled mathematically and used to simulate and predict its observed behaviours, making use of this concept and calculating its changing value. In his kinetic theory of gases, Boltzmann’s crowning achievement in 1877 was to connect the entropy of the gas, seen as a macrosystem state in classical thermodynamics, with theory of statistical mechanics and the number of equiprobable microsystem states of the component gas molecules in which the system could exist. This was a measure of the order exhibited by the description of the microsystem: if highly ordered, only a few descriptive states are possible; if highly disordered, very many. Entropy emerged as a measure of disorder—increasing entropy being in a negative logarithmic relationship to the Boltzmann quantification of order. James Clerk Maxwell and Max Planck (1858–1947) shared in the later mathematical formulation of these ideas.

Many decades later, as presaged above, a further connection was made between concepts of order and information, in the context of communication of electrical signals. This seminal contribution was made by Shannon, who arrived on the scene as the Third Industrial Revolution of electronics and communication devices came into view. He thought about electrical signals and their faithful transmission within telecommunications systems. Electronics was opening into the new world of digitization and communication of signals. In 1948, he published his seminal paper entitled ‘A Mathematical Theory of Communication’.<sup>9</sup> For Shannon, the thing communicated by the signal (its content) was information. Thinking about how to quantify this information, he alighted on a logarithmic transform

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9 C. E. Shannon, ‘A Mathematical Theory of Communication’, *The Bell System Technical Journal*, 27.3 (1948), 379–423.

of binary numbers that looked useful. Shannon's fellow mathematician, von Neumann, knew the physics history and was deeply engaged with the emerging fields of computer science and engineering—and thinking about how brains worked, as well! Unbeknown to Shannon, but pointed out to him by von Neumann, his quantification of information content of a communication was a mirror of that discovered by Boltzmann for entropy. 'What is entropy?' and 'What is information?' started to share common foundations. Information content became an entropy.<sup>10</sup> Shannon took von Neumann's advice and called his construct information entropy. This idea started to permeate into methods of statistical data analysis.

The burgeoning electronic and information technology worlds extended into characterizing and analyzing the behaviour of ever more complex electrical circuits and communications networks, and then, in recent decades, into the study of quantum computation and quantum circuits. Physics and informatics 'What is?' questions became further entrained. The enmeshing of theoretical and experimental quantum physics with theory of information brought imaginative new conjectures about these connections, and extraordinarily precise new methods of experimental measurement arrived to test these ideas. Perhaps theory of information and entropy will emerge further as a unifying conceptual framework linking from thermodynamics and its second law, through to the nature of time, and other 'what is' unknowns of physics and universal physical law. Where will theory of information come to sit in relation to the basic measures of length, time, amount of substance, electric current, temperature, luminous intensity and mass? Is information an abstract concept or is it real? Is it an energy? Is it the same as entropy? And how may new discoveries about life and living systems reflect into new physics of the organization of complex systems? *Zobaczmy!*

Wheeler is remembered for his words of wisdom about the 'What is' of reality and information, which he characterized as 'It from Bit'.<sup>11</sup> He described

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10 Von Neumann, in recommending the term 'information entropy' to Shannon, suggested that: 'You should call it entropy, for two reasons. In the first place your uncertainty function has been used in statistical mechanics under that name, so it already has a name. In the second place, and more important, no one really knows what entropy really is, so in a debate you will always have the advantage' (quoted in M. Tribus and E. C. McIrvine, 'Energy and Information', *Scientific American*, 225.3 (1971), 179–88 (p. 180)). It is amusing that physicists struggle to understand the meaning of theories but are confident in computing with and accepting their predictions, and informatics now likewise struggles. I live in hope of seeing what comes next in unifying the theories of general relativity and quantum reality, with theory of information.

11 J. A. Wheeler, 'Information, Physics, Quantum: The Search for Links', in *Feynman and Computation*, ed. by A. Hey (Boca Raton, FL: CRC Press, 2018), pp. 309–36, <https://doi.org/10.1201/9780429500459-19>

his career in three stages—‘Everything is Particles’, ‘Everything is Fields’, and ‘Everything is Information’. In summarizing this perspective, he wrote:

It from bit symbolises the idea that every item of the physical world has at bottom—at a very deep bottom, in most instances—an immaterial source and explanation; that what we call reality arises in the last analysis from the posing of yes-no questions and the registering of equipment-evoked responses; in short, that all things physical are information-theoretic in origin and this is a participatory universe.<sup>12</sup>

Biology has connected ever more closely with the physical sciences, mathematics and computer science. Mathematical and computational biology have extended into the modelling of networks of genes, and biochemical pathways were reimagined as information circuits, by analogy with circuits in electronic engineering. Conjecture has extended to the connection of quantum level processes with biological mechanisms and from the emergent properties of complex systems to the evolution of living systems. Informatics has extended into the study of all manner of networks of communication—physical, biological and social.

At the start of my life and songline, Schrödinger was grappling with the question ‘What is Life?’ With amazing prescience, he reasoned on the grounds of physics and genetics of the time to envisage an information code of life, embodied in the chromatin and chromosomes of the cell nucleus. DNA was at that time revealing itself through the crystallographers’ images of X-ray diffraction patterns. And von Neumann, who, as we have seen in Chapter Five, conceived a simple model for the architecture of electronic computational machines, that bears his name, was grappling with analogy between the computer and the brain. The double helix of DNA was described and characterized as information—as both Turing machine paper tape and von Neumann universal constructor, embodying also the self-referencing ability to reproduce itself. Here, the analogy made is that DNA is, in a sense, all three of knowledge, program and data. It is knowledge that enables growth, maintenance and reproduction of the living world. It is program code that bootstraps those abilities, functions and actions. It is data on which those programs operate.

Skipping along the timeline to the 2020s, the language of life science is now the language of biomathematics, biophysics, biochemistry and bioinformatics. Electron transfer and energy gradients across membranes are minutely described as the flux and driving force of life. Quantum chemistry and bioinformatics have transformed pharmacology. And the

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<sup>12</sup> Ibid., p. 311.

nature of information, at the heart of all this, is a much-debated issue. The mathematics of symmetry and topology has advanced within particle physics and field theory. It has illuminated general principles and how simple rules and constraints can determine the envelope through which complex living systems emerge and evolve.

As well as ‘What is?’ questions there are also ‘Why are things the way they are?’ questions that relate to life and information. This pairing of questions is illustrated in the progression in physics from the ‘What is reality’ question to the question ‘Why is reality the way it is?’ as a mathematical and scientific, as well as a philosophical, question. The laws that appear to govern the physical world appear finely tuned to basic constants, such that, were they even slightly different, the best current models we have would break apart, predicting a destructive physical Armageddon that would have prevented anything of the observed universe from ever happening. Are there scientific principles that underpin the observed reality revealed by these constants, and are other realities possible and do they exist?

My inukbook by Nick Lane, described in the section below on landmark contributions, argues that ‘Why is life the way it is?’ is as important a question as ‘What is life?’ and suggests how we should balance the two. Does biology need to look further than current physics—are more abstract models of information needed, bearing in mind the advice only to keep what is needed in the models we create? These questions cross into the realm of metaphysics and belief. Mathematics and science will always push on the boundaries of how fully and accurately they can describe the pattern of observed living systems, building on these insights and methods. In 2000, John Maddox (1925–2009) summarized *What Remains to Be Discovered*, and in 2019, Marcus du Sautoy summarized how such ambition eventually runs into the sands of *What We Cannot Know*.<sup>13</sup> Others have speculated about how all this may connect over time with health care. I introduce inukbooks expressing these ideas in the section below on landmark contributions.

## New Frontiers of Information

Just before I started studying physics at Oxford, Rolf Landauer (1927–99) showed something quite unexpected, I think. That when we destroy information, we increase physical entropy. Information sounds abstract, but maybe it is real. That was 1961 and this insight registered nowhere within

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13 J. Maddox, *What Remains to Be Discovered: Mapping the Secrets of the Universe, the Origins of Life, and the Future of the Human Race* (New York: Macmillan, 1998); M. du Sautoy, *What We Cannot Know: Explorations at the Edge of Knowledge* (London: Fourth Estate, 2016).

the information feeding to my heated brain, battling theoretical physics at that time. What was taking shape was the revisiting of a conundrum first explored by the Scottish physicist James Clerk Maxwell, who looked at Clausius's entropy law and wondered whether intelligent life could defeat it. He envisioned this intelligent entity in the shape of a demon that he described, that could sit in the middle of a gas chamber and route gas molecules in a manner to sort them into a lower entropy order, thus defying the second law of thermodynamics. Could life overcome thermodynamic law in this sort of way? A hundred years later, Charles Bennett showed it to be a consequence of Landauer's insight about the connection between information destruction and entropy production, that no intelligent entity can defeat the second law.

We have seen how entropy is related to increasing disorder. Since order and disorder are inversely related, the mathematics of logarithms enables us to relate order to negative entropy, termed negentropy. If living systems cannot buck physics, how do they acquire and sustain their order from their environment, thus compensating for the entropy they produce with the negentropy they acquire? It is apparent that they do succeed in 'cheating' this fundamental law, at least for a while. From the fertilized egg to the developing embryo and the growing and living body, animal life maintains its low entropy order and cohesion, and disorder of bodily function is in the realm of error rather than natural and progressive growth of entropy. Is there some unknown physics that can reconcile the observation of increasing disorder in physical systems with the observation of sustained order in living systems? What is the life that makes a system alive, and how can it be characterized and described within experimentally verified and consistent theory?

This was the conundrum that Schrödinger addressed, and his reasoning was set out seventy years ago, in the landmark inukbook discussed in the section below, in which he described a living system as feeding on negative entropy from its surroundings. Today, the argument, which Schrödinger himself agreed with, would be phrased in terms of free energy exchange and this aligns more clearly with the now better understood biophysics of electron transfer and electrochemical energy gradients, characterizing the bioenergetics and biochemistry of life science.

In this evolving story, the study of information has permeated from mathematics, physics and engineering, through life science and into the bioinformatics of living systems, as a unifying concept of science. It is now debated in the realm of neuroscience and is moving into medical science and towards health care. What is unknown, at this stage of the story, is how far this science will connect with the concept of information as a utility in everyday life, and specifically in support of health care. In this direction,

the discussion of the nature of life moves up further levels in the brain, to the concept of mind—to consciousness and artificial intelligence. Here the contemporary interplay of neuroscience and computer science is very much alive.

As we drill down like this on information, we must keep in mind its dark side; it is not an assured good. It is sometimes harmful, and sometimes better not to know. Economy based on energy creates utility of food, shelter and safety. It consumes oil to generate power and that consumption pollutes environment—and oil runs out. There are no free meals and no free wheels. Francis Bacon (1561–1626) said that knowledge itself was a kind of power, and David Deutsch’s characterization of knowledge as information with causal power conveys much the same idea. Information is closely coupled with energy, health and economy and articulation and appreciation of these links is rapidly unfolding. Economy based on information systems consumes electrical power and thus pollutes. The Cloud is now said to be consuming some twenty percent of the energy distributed through the world electricity grid. Bitcoin mining currently consumes electrical power equivalent to the entire economy of Argentina, and ocean and ice-buried data centres are warming the planet. Information technology consumes rare earths and these, too, run out. Data-ism creates noise and bias in actions based on information, and thus interacts with the power of knowledge.

## From Life and Information to Mind and Intelligence

It is at the level where multidisciplinary science extends into matters of mind that the model and analogy of life as an information engine merges with matters of philosophy. Along my songline, this connected with Gilbert Ryle (1900–76) at Magdalen College, and his philosophy of mind. Another luminary figure encountered was Willard Van Orman Quine (1908–2000), whose perspective has been described as ‘naturalistic, empiricist, and behaviourist’.<sup>14</sup>

There is much drawing and defending of red lines. One common dividing line is that consciously felt sensory experience is the hard problem to understand, and unrelated to the mathematics of information flow, which has little to say about the deep problems of neuroscience and cognitive psychology. This perspective has been championed today by the neuropsychologist Nicholas Humphrey. Accusations of egregious error talk past one another in these circles, as they do in all manner of deep discussions

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14 B. Duignan, ‘Willard Van Orman Quine’, *Encyclopedia Britannica* (21 June 2023), <https://www.britannica.com/biography/Willard-Van-Orman-Quine>

of the many ‘What is?’ and ‘Why is?’ questions that remain unplaced around the circle of knowledge. There is now either a great deal more or very little left to be said on the topic of ‘What is mind?’—a topic that Berkeley gave up on in the quotation that headed this chapter! *Zobaczmy!*

Rather than trespassing foolishly onto these enduringly shifting philosophical sands, risking being swallowed there, it seems relevant to start from the perspective of an engineer. Placed at the interface of neuroscience, computer science and cognitive psychology, and with a keen eye on the health care needs of society, what can be built there using the insights and methods from these disciplines to improve and contribute usefully to health care? It seems much clearer, now that artificial intelligence is advancing in such leaps and bounds, that there is a lot that can be done in this spirit—the challenge is to keep faith, and in balance with both the science and the values in play. As ever, how this balance is approached will be crucial to success and sustainability. As we have begun to see, and will see more, these are potentially very harmful and costly places in which to get things wrong.

The interplay of computer science, neuroscience and cognitive psychology presents a Popperian Open Society of the mind. An unbounded set of possibilities. A place for humble learning. Discussion of human and machine intelligence has brought experiment in this forest to forking paths in the way ahead. This was foreseen by Richard Feynman (1918–88), writing that:

Some people look at the activity of the brain in action and see that in many respects it surpasses the computer of today, and in many other respects the computer surpasses ourselves. This inspires people to design machines that can do more. What often happens is that an engineer makes up how the brain works in his opinion, and then designs a machine that behaves that way. This new machine may in fact work very well. But I must warn you that it does not tell us anything about how the brain actually works, nor is it necessary to ever really know that in order to make a computer very capable. It is not necessary to understand the way birds flap their wings and how the feathers are designed in order to make a flying machine. It is not necessary to understand the lever system in the legs of a cheetah, that is an animal that runs fast, in order to make an automobile with wheels that goes very fast. It is therefore not necessary to imitate the behaviour of nature in detail in order to engineer a device which can in many respects surpass nature's abilities.<sup>15</sup>

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15 Quoted in R. E. Susskind and D. Susskind, *The Future of the Professions: How Technology Will Transform the Work of Human Experts* (Oxford: Oxford University Press, 2015), p. 276.



There is an analogy, here, with how physics has come to terms with the extent of its unknowing, as previously described. Experimental and theoretical quantum science reached a boundary of understanding of the nature of reality and decided to duck the question and get on with calculating well-corroborated solutions of the Schrödinger equation, to learn what they tell us in specific cases. Continuing perplexity about the nature of the entanglement of quantum states has not held back advances in quantum computing, and this in turn has led to new ways of thinking about the issue. Continuing perplexity about the nature of gravity alongside the other fundamental forces and the relationships of concepts of mass, energy and time in the observed universe have not impeded space travel. Likewise, perplexity about the nature of mind has not held back interplay of computer science and neuroscience. There is rich potential for exploring the interplay of machine intelligence with theory of mind, and with other still perplexing problems in mathematics, science and medicine. There is similar potential to explore its interplay with problems of social and environmental policy and practice. Machine intelligence has the potential to change life in almost every way, but it cannot be allowed just to happen. It requires the mixture of enterprise and innovation anchored in a common ground of values, principles and goals.

## Artificial Intelligence

The seventy years of my songline have seen the emergence of artificial intelligence (AI). It has variously been described and referred to in every chapter of this book. I came across it from the time of its origins in the expert systems of the 1960s: in Dendral, Meta-Dendral and Heuristic Dendral at Stanford University and Massachusetts Institute of Technology (MIT);<sup>16</sup> in the LISP language, a pioneering language of computational method designed by John McCarthy (1927–2011); in concerns about computer science and human reasoning (Joseph Weizenbaum (1923–2008));<sup>17</sup> in Donald Michie's

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16 B. G. Buchanan, G. Sutherland and E. A. Feigenbaum, *Heuristic DENDRAL: A Program for Generating Explanatory Hypotheses in Organic Chemistry* (Stanford, CA: Stanford University Department of Computer Science, 1968); R. K. Lindsay, B. G. Buchanan, E. A. Feigenbaum and J. Lederberg, 'DENDRAL: A Case Study of the First Expert System for Scientific Hypothesis Formation', *Artificial Intelligence*, 61.2 (1993), 209–61; B. G. Buchanan and E. A. Feigenbaum, 'DENDRAL and Meta-DENDRAL: Their Applications Dimension', *Artificial Intelligence*, 11.1–2 (1978), 5–24.

17 J. Weizenbaum, *Computer Power and Human Reason: From Judgment to Calculation* (Harmondsworth: Penguin Books, 1993).

(1923–2007) work that developed from his wartime connections with Alan Turing (1912–54) in the United Kingdom.<sup>18</sup>

Generic and domain-specific systems of medical decision logic and decision making came and went: Caduceus/Internist-1,<sup>19</sup> Iliad,<sup>20</sup> DxPlain,<sup>21</sup> MYCIN.<sup>22</sup> Methods of image classification—for example automated chromosome karyotyping and identification of abnormal histopathology slides—came and went, too. The power of the computer industry created and disseminated powerhouse systems such as Watson and Jeopardy. And seemingly more generic and agile methods, such as underpin AlphaFold and ChatGPT, for example, are gaining traction.

Theory of machine learning has drawn on and evolved from the mathematics of Bayesian networks, neural networks, genetic algorithms and more. It is proving of increasingly high economic significance for the world of automation, robotics and autonomous systems. Demonstrations of its powerful applications are causing increasing concern about governance and impact on human society. The number of words said and written about AI systems is the latest explosion of the Information Age. Such patterns of verbal excess tend to reflect chaotic times and correlate inversely with what is known, experimentally. The problem is that the knowledge they draw on and express tends to be cloaked or hidden, often for reasons of commercial propriety. Mathematical methods are not patentable—if kept secret they convey no advantage to mathematicians or to those who depend on mathematics. AI methods are being pursued as protected intellectual property. Kept secret, they confer commercial advantage but do not advance the common ground of knowledge on which all depend, in the way that shared and co-developed mathematics discipline and mathematical methods do. This is a revolution where assessment of its implications and consequences (Zhou Enlai-like, about the French Revolution!) is ‘too early to decide’!<sup>23</sup>

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- 18 S. Muggleton, ‘Obituary: Donald Michie’, *The Guardian* (10 July 2007), <http://www.theguardian.com/science/2007/jul/10/uk.obituaries1>
  - 19 R. A. Miller, ‘INTERNIST-1/CADUCEUS: Problems Facing Expert Consultant Programs’, *Methods of Information in Medicine*, 23.01 (1984), 9–14.
  - 20 H. R. Warner Jr., ‘Iliad: Moving Medical Decision-Making into New Frontiers’, *Methods of Information in Medicine*, 28.04 (1989), 370–72.
  - 21 E. P. Hoffer, M. J. Feldman, R. J. Kim, K. T. Famiglietti and G. O. Barnett, ‘DXplain: Patterns of Use of a Mature Expert System’, *AMIA Annual Symposium Proceedings* (2005), 321–24.
  - 22 E. Shortliffe, *Computer-Based Medical Consultations: MYCIN* (New York: Elsevier, 2012).
  - 23 See Chapter Two.

In his recent televised discussion with Alan Yentob, the prize-winning novelist Kazuo Ishiguro spoke softly and clearly about these concerns.<sup>24</sup> They talked about his novels in context of his life and times in Japan and England. Roughly one novel every five years—I like him for that and his explanation of why his creativity evolves in five-year epochs. The most recent novel, *Klara and the Sun*, explores an evolving (he says it is not far in the future) world of humans and artificial friends (AFs).<sup>25</sup> Klara is Lucy's AF and Lucy is ill and may not live. The book is Klara's account. Her concern is, will she evolve to become and continue sick Lucy's life? Ishiguro was pensive.

## Landmark Contributions

Many who have specialized in mathematics, science and engineering have reflected on how their different disciplines can connect with and illuminate the origins and fundamental nature of life and living systems. As we have seen, the term information has travelled widely through these connections, in the search for greater understanding of what life is, how it came into being and how it functions and evolves. These connections link theory and experiment with concepts such as symmetry, topology, calculus, order, communication, control, energy and computation.

It seems fitting to celebrate here some of these pioneers, decade by decade over nearly eighty years. Some inukbooks that remind me of them every day are: *What Is Life?* by Schrödinger; *The Computer and the Brain*, by von Neumann; *Programs of the Brain*, by Young; *Feynman Lectures on Computation*, by Feynman; *Life's Other Secret*, by Ian Stewart; *I Am a Strange Loop*, by Douglas Hofstadter; *Information Theory and Evolution*, by John Scales Avery; *The Vital Question*, by Lane; *The Creative Code*, by du Sautoy; and *The Demon in the Machine*, by Paul Davies.

In drawing together this selection—a synthesis of syntheses—I risk making an even greater than usual fool of myself as their individual contents are, in themselves, wide-ranging and well beyond my detailed knowledge, such is the range and pace of advance. I have collected these books around me and consulted them for inspiration, as I write. Here they are:

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24 Available at 'Kazuo Ishiguro: Remembering and Forgetting', *BBC One* (28 March 2021), <https://www.bbc.co.uk/programmes/m000tqn0>

25 K. Ishiguro, *Klara and the Sun* (New York: Knopf, 2021).



Fig. 6.1 The inukbooks that draw together a number of career-long contributions that have illuminated the ‘what is’ and ‘why is’ questions about life and information, discussed in this chapter. Photograph by David Ingram (2023), CC BY-NC.

The books track back over a century in exploring information as a fundamental concept in relation to living systems. This is a domain that Schrödinger brought to life in his series of landmark lectures published in 1944, entitled ‘What is Life?’.<sup>26</sup> I then introduce the Silliman Lectures on *The Computer and the Brain*, which looked at the brain from the perspective of computer science, as a computational machine.<sup>27</sup> These lectures were delivered by the mathematician von Neumann, the originator of the eponymous von Neumann architecture of the computer Central Processing Unit (CPU).

I move next to *The Programs of the Brain* by Young, remembered for his treatise of the times on the life of mammals and research on nerve function.<sup>28</sup> The book is based on his 1975–77 Gifford Lectures at the University of Aberdeen. I remember this tousled grey-haired figure, a legendary UCL personality, striding along Gower Street outside the medical school where

26 E. Schrödinger, *What Is Life?* (Cambridge, UK: University Press, 1948).

27 J. von Neumann, *The Computer and the Brain*, Mrs. Hepsa Ely Silliman Memorial Lectures (London: Yale University Press, 1958).

28 J. Z. Young, *Programs of the Brain: Based on the Gifford Lectures, 1975–7* (Oxford: Oxford University Press, 1978).

I worked in my PhD days. His is the broadest ranging review, embracing philosophy of mind and revisiting the pioneering work of Sherrington, a hundred years ago, who was the first to characterize the integrative nature of the human nervous system.

Next in the selection is the *Feynman Lectures on Computation*, edited by Anthony Hey and first published in 1996, which is the best entry route I know to the science of computation.<sup>29</sup> Following this, Stewart's *Life's Other Secret* stands out by bringing a mathematical perspective on the subject.<sup>30</sup> I also visit the polymath Hofstadter and his book *I Am a Strange Loop*, which weaves Gödel numbers with cognitive psychology in an imaginative conjecture about the nature of conscious thought.<sup>31</sup> I include next the book by Avery, *Information Theory and Evolution*.<sup>32</sup> This is a good source of reference that collates a wide range of materials and provides more mathematical content than the other books in the selection. I then introduce another UCL life science colleague, Lane, and his *The Vital Question*, which sets biology, bioinformatics and bioenergetics side by side in context of his question.<sup>33</sup>

Coming back to mathematicians, du Sautoy wrote *The Creativity Code*, which reaches beyond computation and machine intelligence to machine creativity.<sup>34</sup> And coming back to physics, Davies has brought things up to date in 2020 with *The Demon in the Machine*, opening the subject out into speculation about how the story will evolve into medicine of the future.<sup>35</sup> He was a physics PhD student at UCL at the time I was doing my own PhD there, as he told me when we met very briefly, when I was collecting this inukbook directly from him, at a New Scientist Live event in London where I heard him speak.

### 1944–Erwin Schrödinger: *What Is Life?*

Schrödinger has an amazing and vivid biography. It extends through two World Wars and the turmoil between them, studying physics in Vienna in

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29 R. P. Feynman, *Feynman Lectures on Computation* (New York: CRC Press, 2018).

30 I. Stewart, *Life's Other Secret: The New Mathematics of the Living World* (New York: John Wiley and Sons, 1998).

31 D. R. Hofstadter, *I Am a Strange Loop* (New York: Basic Books, 2007).

32 J. S. Avery, *Information Theory and Evolution*, 2nd ed. (Singapore: World Scientific Publishing, 2012).

33 N. Lane, *The Vital Question: Energy, Evolution, and the Origins of Complex Life* (New York: W. W. Norton and Company, 2015).

34 M. du Sautoy, *The Creativity Code: How AI Is Learning to Write, Paint and Think* (Cambridge, MA: Harvard University Press, 2019).

35 P. Davies, *The Demon in the Machine: How Hidden Webs of Information Are Solving the Mystery of Life* (Chicago, IL: University of Chicago Press, 2021).

1906, working in a succession of appointments in Austria, Germany, England and Ireland, succeeding or in parallel with the great names of Boltzmann, Einstein, Planck and Born. The intermissions for military service came first in 1910–11 (which he spent in what he describes as the beautiful old town of Krakow), and then from 1914, during subsequent service in Italy (which he describes as uneventful and giving plenty of time for study of Einstein's 1916 paper on relativity theory, a subject which he struggled to understand). From 1933–36, he was a fellow of Magdalen College, Oxford, sponsored there by Frederick Lindemann (1886–1957—later Lord Cherwell, Winston Churchill's science advisor). Around this time, he started to turn his mind to the connections of physics and chemistry with biology. Later, when settled in wartime years in Ireland, and working at Trinity College Dublin, he delivered a set of lectures on the question, 'What is Life?' In subsequent years, Trinity was a leading European centre in Health Informatics, under the computer scientist and my colleague, Jane Grimson, for whom I acted as a visiting examiner for some years. Jane was subsequently Vice-Provost of the College and a leader of the engineering profession across Europe. In the history of Trinity College, there is thus a close connection between the three dimensions of information—information and life science, information for health, and information technology. Schrödinger supplemented his lectures on life with further lectures on mind and matter, which he considered an even more exacting intellectual challenge!

The following excerpt is quoted at length from the Preface to *What Is Life?* to showcase his magnificent clarity of thought and style:

Let me use the word 'pattern' of an Organism in the sense in which the biologist calls it 'the four-dimensional pattern' meaning not only the structure and functioning of that Organism in the adult, or in any other particular stage, but the whole of its ontogenic development from the fertilized egg cell to the stage of maturity, when the organism begins to reproduce itself. Now, this whole four-dimensional pattern is known to be determined by the structure of that one cell, the fertilized egg. Moreover, we know that it is essentially determined by the structure of only a small part of that cell, its nucleus. This nucleus, in the ordinary 'resting state' of the cell, usually appears as a network of chromatin, distributed over the cell. But in the vitally important processes of cell division (mitosis and meiosis) it is seen to consist of a set of particles, usually fibre-shaped or rodlike, called the chromosomes [...]<sup>36</sup>

To reconcile the high durability of the hereditary substance with its minute size, we had to evade the tendency to disorder by 'inventing

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36 Schrödinger, *What Is Life?*, p. 20.

the molecule', in fact, an unusually large molecule which has to be a masterpiece of highly differentiated order, safeguarded by the quantum rod of quantum theory. The laws of chance are not invalidated by this 'invention', but their outcome is modified. The physicist is familiar with the fact that the classical laws of physics are modified by quantum theory, especially at low temperature. There are many instances of this. Life seems to be one of them, a particularly striking one. Life seems to be orderly and lawful behaviour of matter, not based exclusively on its tendency to go over from order to disorder but based partly on existing order that is kept up [...]<sup>37</sup>

What is the characteristic feature of life? When is a piece of matter said to be alive? When it goes on 'doing something', moving, exchanging material with its environment, and so forth, and that for a much longer period than we would expect an inanimate piece of matter to 'keep going' under similar circumstances.<sup>38</sup>

He wrote of the chromosome as containing a 'code-script', the entire pattern of the individual's future development and of its functioning in the mature state.

Schrödinger's was, as he himself acknowledged, a bold foray into the domain of living systems. He argued from the outset that a living organism requires exact physical laws, otherwise life would be impossible to sustain and for humans to be capable of orderly thought. He recognized the incompleteness of his analysis and the implication that greater understanding would reveal a need for new physics.<sup>39</sup>

The question he posed at the outset of his lectures was: 'How can the events *in space and time* which take place within the spatial boundaries of a living organism be accounted for by physics and chemistry?' He took the issue of brain organization into the subsequent lectures on *Mind and Matter*, in 1956.

Schrödinger reasoned from principles of statistical thermodynamics, the quantum physics of the atom and the chemistry of molecules, showing the need for new scientific insight into how orderly life succeeded in persisting and reproducing, given the composition, size and sensitivity of the materials from which it was made.

The science of genetics had evolved to that point through experiment: selective breeding, microscopic analysis and studies of mutations induced by X-rays. And from these, a picture of genes structured within chromosomes had emerged, with experimental methods to relate changes in the band

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37 Ibid., p. 68.

38 Ibid., p. 69.

39 Ibid., p. 68.

patterns in images of the chromosomes with changes in the molecular structure of specific genes. From microscopy images revealing the pattern of the fertilized egg cell, to the patterns of inheritance in breeding experiments, to the effect of different doses of ionizing radiation on mutation of the gene as revealed in images of subsequent development of the organism, he brought together estimates of numbers of genes present, and their sizes, in terms of number of atoms they contained.

From the quantum theory and experimental science of molecular mutations, he reasoned about the challenge living systems overcome in persisting for many years and over generations, inherited and communicated through fertilized eggs. He reasoned, from physical principles, about the scale and composition of the genetic material of the cell and its persistence over time. He argued that the classical statistical physics of the preceding century could not account for such reliable persistence over time being generated from the amount of material present at such small scale. Reasoning then at the level of molecular chemistry, and using the explanation provided by quantum theory for the stability of chemical bonds and molecular structures, he went on to show this theory to also be deficient for explaining genetic variety of expression. Reflecting on X-ray crystallographers' insights on material structure, he reasoned that a regular periodic crystal structure for the chromatin would not suffice to account for the observed patterns of scale, variety and persistence.

From the estimates of the size of the genes he reasoned that they must have the form of what he termed an 'aperiodic solid molecule' (as opposed to liquid or gas). This molecule was non-repeating, in the sense that every element would be capable of carrying information (his coding script), enabling the relatively small number of atoms and genes comprising the molecule to code for the growth and variety of structures and functions of the living organism, as evidenced by the development of the embryo from a single egg cell, as observed in life.

Here were the origins of a theory that made connections between information and living systems. Schrödinger also reviewed in depth the connections of classical with statistical thermodynamics. To recap from the sections above, in the former, the measurable physical quantity of entropy is calculated in linear proportion to heat energy flux and inversely in proportion to temperature. Boltzmann's fundamental advance described this system in terms of the dynamic distributions of gas molecules and their natural evolution from orderly towards disorderly states. He invented a mathematical model to characterize this order, which he connected with entropy measurement. In this way, entropy is characterized by a logarithmic relation with Boltzmann derived disorder, and likewise, since order and disorder are inversely related to one another (high disorder implies low



order, and vice versa), it follows that order may be quantified as a negative entropy. This opens the door for an image of living systems that defy the second law of thermodynamics, whereby entropy always only increases. At issue was the question of how to reconcile the observed sustained order of living systems, from cell to embryo and living organism, with the classical physics of entropy as expressed in the second law of thermodynamics. In looking at the energy balance of living systems, the thermodynamics view expressed was that a living organism ‘feeds’ from order, and the associated negative entropy acquired balances the natural production of entropy in its everyday functions, thus preserving its living state of order. It was a subtle and contested argument, and he later adjusted it, in response to criticism.<sup>40</sup>

### 1956—John von Neumann: *The Computer and the Brain*

In this book, based on a manuscript prepared for the Yale University Silliman Lectures of 1956, we encounter the voice of the Hungarian mathematician and early pioneer of computer science and technology, von Neumann. He was unable to deliver the lectures and died of cancer in early 1957. His wife, Klara, completed the manuscript and added a wonderful Preface, connecting the book with her husband’s work on mathematics and later as an early pioneer of electronic computer architecture. He made many contributions in pure and applied mathematics through the era in which Kurt Gödel (1906–78) upset the apple cart of *Principia Mathematica*, approving of his reasoning about its incompleteness. This was the era in which mathematics and formal logic found its way into the foundations of computer science. After wartime work on the Manhattan Project, he was a member of the

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40 From the thermodynamics perspective argued by Schrödinger, the system of living organism and its environment is viewed as one. The heat energy of the sun’s radiation incident on the living organism is associated with a low entropy component of this one system, because of the extremely high temperature at which it originates in the sun (entropy being calculated as heat energy divided by temperature). The same quantity of heat generated in a living organism constitutes a much higher entropy component because it is associated with a very much lower temperature—that of the living organism. In this way, the same heat input and output components are associated with different entropy components, and thus the system as a whole is seen to have increasing entropy, as required by the second law of thermodynamics, without an associated increase in disorder of the living component. Discussed without all the mathematics, this is inevitably a rather convoluted verbal handwaving, and probably not a very satisfying one from either physics or life science perspectives. Schrödinger qualified his position in response to criticism about his coverage of entropy, arguing later that the system should be analyzed from the perspective of Gibbs energy—a concept associated with Josiah Gibbs (1839–1903), a pioneer of statistical mechanics and thermodynamics and their application to physical chemistry.

team at Princeton University that produced the early prototype electronic calculator, called JONIAc. This work led him to study the brain and nervous system, looking for inspiration there for its design principles. He was clearly a towering figure in the optimistic postwar era of America—recognized in senior roles in the government of President Dwight Eisenhower.

As the title describes, the topic of the book is an analogy between brain and computer, seen from the perspective of computer science, as a computing machine. It is interesting in how it reveals the thinking that bootstrapped early machine architecture. It is a mindset focused on crafting technology to perform mathematics. This technology-inspired thread has been taken forward by Raymond Kurzweil in his *How to Create a Mind*, in 2012.<sup>41</sup>

Von Neumann's book is quite short—just eighty-two pages—and in two halves. I read it again last night. The first is about machinery of numeric calculation. That is, about arithmetic and logic—the basic operations involved and how these have been enacted by different machines, starting from mechanical analogue computers, and translating on into the early world of electronic computers and hybrids of the two. He was clearly closely involved with the engineering involved, as he gives chapter and verse about kinds and numbers of components and the precision with which they worked and were coupled together in the machines. The picture is one of a selection from a toolbox of components, choosing and customizing them to perform calculations. He describes the requirements for arithmetic, memory and programming, and for honing these together. In the analogue case, he makes a connection with the Babbage engine-like world of differential gears used in car transmissions, showing their utility in combining and averaging inputs, and of rotating discs driven to integrate inputs, and how these were used as basic operations of the mechanical machine. He places himself in the middle, knowing what he needs as a mathematician and what the engineer can provide him with, as component methods, and marries the two.

Moving to electronic computers, he gives details of circuits of thermionic valves, rectifiers, capacitors, resistors and their component magnetic and electrical properties, size and speed of operation, and precision with which they worked. He sketches a hierarchy of devices for storing, processing and transporting data around the machine, considering which of these needed to operate rapidly on the critical path of the calculation, and which needed to operate more slowly in support, in the background of the calculation. The options ranged widely over acoustic delay lines, electromechanical storage devices and electronic components based on ferromagnetic and ferroelectric materials.

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41 R. Kurzweil, *How to Create a Mind: The Secret of Human Thought Revealed* (New York: Viking Books, 2012).

Von Neumann focuses on the fast-acting memory registers used for number crunching, showing the scale of logic operations required for the digital arithmetic that had to be performed on the numbers they contained. For example, he talks of a twelve decimal digit number system requiring 196-tube (thermionic valve) registers. These were huge, power hungry and heat-producing machines. The ENIAC at Los Alamos had twenty-two thousand such valves. He works through design considerations around data and program, starting from early 'plug and play' programming, where the program consisted of wires patched between electronic components. From there he moves on to stored programs and the greater sophistication of calculations they enabled.

The first part of the book is interesting in showing the creative engineering involved in matching capability of components with design of machine, to meet requirements of calculation. The second part of the book is interesting in a completely different way—it reveals how von Neumann, as computer architect, was deeply engrossed in the structure and understanding of the human nervous system. In creative engineering, it is common to work from a prototype model, treating this as a test bed in which to explore further necessary refinement. The final design may have born limited resemblance to the prototype but arriving at that design depended on going through the prototype stage. It cannot be reasoned into existence because its design is an art of the possible, and possibility is only explored experimentally, by making and doing things, working with models and improving or rejecting methods.

Neurology at that time was much focused on sensory mechanisms, the action potential through which information is transmitted and the pathways of connection and interaction within the brain and nervous system. Neuroscience and philosophy of mind are in a wholly different era today, compared with the time of von Neumann, as is the world of nanoscale semiconductor and optical technology compared with that of thermionic valves and acoustic delay lines.<sup>42</sup> Functional brain imaging methods have been pivotal to the evolving science. Von Neumann touches lightly on the connections of mathematics,

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42 M. Cobb, *The Idea of the Brain: The Past and Future of Neuroscience* (New York: Basic Books, 2020). This historical overview of the brain and neuroscience appeared in 2020, as I wrote. In it, Matthew Cobb describes how brains have observed brains and reasoned about their function: Galen pressing on a pig's brain to render it unconscious; surgery of 1940 to relieve temporal lobe epilepsy; electrical stimulation creating scenes of piano playing, a man and dog walking, a telephone conversation. He describes how early ideas of brain function focused on electrophysiology and coding mechanisms linking stimulus to action of neurons (the work of the 1932 Nobel Prize winners Adrian and Sherrington), and on the

physics and chemistry with description of sensory mechanisms. His commentary is interesting in the eye he casts over the analogy of computer and brain:<sup>43</sup>

- The speed of the computer processing unit being  $10^4$ – $10^5$  times faster;
- The natural component of the brain being smaller by the order of  $10^8$ – $10^9$ ;
- The brain as having more numerous processing units, operating slower and in parallel, as compared with the computer operating with fewer units, faster and serially;
- The neuron as the ‘basic digital organ’ of the brain, which he characterizes and compares with the computer circuits, in terms of threshold of activation and time to stabilize (‘summation time’);
- In discussing the nature and location of memory, he describes the modern computer as needing  $10^5$ – $10^6$  bits of memory;
- He suggests ‘genetic memory’ in chromosomes as a component of the brain’s memory;
- He suggests a parallel between analogue/digital, hybrid processes and genes connecting with enzyme processes;
- In considering logical structure and arithmetic function, he compares the propagation of error in digital arithmetic, requiring 10–12 decimal points of precision of number representation to alleviate this acceptably, to the human brain, which he describes as doing mental arithmetic with just 2–3 decimal points of precision. By comparison he believes the brain to achieve greater reliability in logical operations;
- He talks about messages in the brain communicated as periodic pulse-trains, conjecturing that statistical relationships between such time-series might also convey information—thinking there of ‘correlation-coefficients, and the like’.

In his summary,<sup>44</sup> he talks about the language of the brain and how this differs from the language of the machine. He talks of the nervous system

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characterization of the stimulus itself. These led to later ideas of the brain in some way creating, as opposed to just representing, information.

43 Von Neumann, *Computer and the Brain*, pp. 50–70.

44 *Ibid.*, p. 80.

being based on two types of communication—what he calls orders (logical ones) and numbers (arithmetic ones). He suggests that variety of spoken language might indicate that there is nothing absolute and necessary about them, and that logic and mathematics are themselves, historical and accidental forms of human expression, which might exist in other forms than those we are accustomed to. He uses the example of visual perception and compares what the brain achieves in three synapses of logical processing along the optic nerve, and subsequent low precision arithmetic in the central nervous system, with a machine built in an analogous manner, which would, he says, clearly fail to perform at all. His conclusion is that ‘logics and mathematics in the central nervous system, when viewed as languages, must structurally be essentially different from those languages to which our common experience refers’.

It would be so interesting to have him sitting here, now, reviewing how technology, computer science and machine architecture, neuroscience and machine intelligence have evolved in the sixty years that followed the sadly so shortened sixty years of his own life.<sup>45</sup> It would be interesting to have Noam Chomsky with us, as well, to add his thoughts on the language of the brain. It would be interesting to see how the two human personalities would have gelled. Von Neumann died a year after a diagnosis of prostate cancer that quickly spread to bone and brain. What he pioneered was instrumental

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45 Just ten years after von Neumann’s death, the emerging semiconductor industry was fabricating transistor-based electrical circuits on wafers of silicon, as this new era of computer technology gained scale and traction. The mighty Intel Company pioneered by Gordon Moore saw its capabilities doubling every year, in terms of the density with which circuit elements could be fabricated and connected in two dimensional arrays, onto a silicon wafer substrate. Within the subsequent decade, this number settled and remained at a doubling every two years, over four decades—a phenomenon characterized as Moore’s Law. In his 1964 paper, Moore described the packing of seventy circuits on a single silicon chip, and today that number is two billion. The circuit dimension achievable today is around ten nanometres—a red blood cell has a four thousand nanometre diameter and that corresponds to four hundred such circuits. New and more efficient semiconductor technologies continue to emerge from advances in devices exploiting quantum physics phenomena, and ability to compress them continues to evolve through the three-dimensional packing of circuit layers, which moves the metric of circuit density to a volume, rather than area, basis of comparison. The William Blake poem quoted in Chapter Two, in which he saw the world in a grain of sand, is now a new kind of metaphor of the evolving virtual world of information. Silicon-based semiconductor technology still cannot approach the information storage density of DNA in the living cell, however, as noted in Paul Davies’ *inukbook*, covered below! The wider application and impact of this technology is also now stretching towards a one-hundred-fold reduction in the cost of solar cell energy conversion, achieved since its early stages of development.

to the ability today to prolong and save the lives of such patients that followed him.

### 1978—John Zachary Young: *Programs of the Brain*

The UCL anatomist Young is remembered for his major work, *The Life of Mammals*, a book I read when expanding my learning from mathematics and physics into biology, medicine and computer science, in 1971. This later inukbook is based on his Gifford Lectures of 1975–77 at the University of Aberdeen.<sup>46</sup> He was for twenty-seven years the Head of the Department of Anatomy—quite a stint but in a different era when academic leaders answered to themselves, by and large, leading and managing royally. A bit like hospital consultants! Times have changed in academia, and in medicine, too—leaders cannot, should not and would not wish to persist that long. They answer more widely and lose energy through the exigencies of being royally managed, more than managing royally. Creative souls keep their heads down and away from management pressures, if they wish to survive the time it takes to make an enduring difference in their field of endeavour, the likes of which Young brilliantly exemplified.

Notwithstanding the advance of anatomical neuroscience since its publication in the late 1970s, unleashed by new experimental methods such as nuclear magnetic resonance (NMR) imaging, this book is still spellbinding in its breadth and majesty. I speed-read it again, last night, getting ready to write about it today. The chapter titles summarize the scope embraced and the author’s immense knowledge and wisdom:

1. What’s in a brain?; 2. Programs of the brain; 3. Living and choosing; 4. Growing, repairing, and ageing; 5. Beginning; 6. Evolving; 7. Controlling, coding and communicating; 8. Repeating; 9. Unfolding; 10. Learning, remembering, and forgetting; 11. Touching, feeling, and hurting; 12. Seeing; 13. Needing, nourishing, and valuing; 14. Loving and caring; 15. Fearing, hating and fighting; 16. Hearing, speaking, and writing; 17. Knowing and thinking; 18. Sleeping, dreaming, and consciousness; 19. Helping, commanding, and obeying; 20. Enjoying, playing, and creating; 21. Believing and worshipping; 22. Concluding and continuing.

The material draws widely on human biological science and places it within the framework of an integrated information system. It spans from nerve cells and human physiology to psychology and philosophy of mind. It seems invidious to paraphrase the author’s intent. Here are his words:

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<sup>46</sup> Young, *Programs of the Brain*.

I propose to say that the lives of human beings and other animals are governed by sets of programs written in their genes and brains. Some of these programs may be called 'practical' or physiological and they ensure that we breathe, eat, drink, and sleep. Others are social, and regulate our speaking and other forms of communication, our agreeing, and our loving or hating. Perhaps the longest-term programs are those that ensure continuing not of ourselves but of the race, programs for sexual activity and mating, programmes for growth, adolescence, and, indeed, for senescence and dying. Perhaps the most important programs of all are those used for the activities that we call mental, such as thinking, imagining, dreaming, believing, and worshipping.<sup>47</sup>

Acknowledging that the nature of language underlies all discussion of knowledge, he embraces language as consisting of sets of signs, and the study of signs (semiotics) as throwing light on the nature of life and on the communication that pervades all of living. He quotes Charles Peirce (1839–1914), who originated the study of signs, writing in answer to the question, 'What is man?', that 'Man is a symbol'.<sup>48</sup> Young sees important truths contained in this, perhaps rather mysterious, way of looking at things. He describes the essence of a living thing to be that it is organized and maintains its organization and can only do so because it receives, from its past history, a plan, or as he puts it, a program, of what to do to keep alive. As an aside, it looks that he would have found interest in Hofstadter's later description of consciousness as an interacting ensemble of symbols.

By program (this spelling actually having preceded the French inspired programme), he means and follows the definition of: 'a plan of procedure; a schedule or system under which action may be taken towards a desired goal'. He distances this program from purely logical steps of enactment of algorithm in computer software. But he reasons that the information in the program must have a physical embodiment as a system of signs, that maintain the living system in line with its environment and provide a symbolic representation of what goes on there. He says: 'I want especially to emphasize the importance of selection of objectives and of the historical influence on everything that we do. Some of the influences on selection of plans are recent, depending on what has happened in the last few minutes, hours, or day. Other influences stretch back through selections made in the years of our life, in childhood, and in prenatal life and in the DNA of our genes, by natural selection over countless generations'.<sup>49</sup>

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47 Ibid., p. 7.

48 Ibid., p. 10.

49 Ibid., p. 8.

The book develops a synthesis extending from programs governing biological mechanisms to programs conditioning and influencing human choices. This he illuminates as an information system that organizes and regulates the biological function of all living organisms and provides a framework of choices in human life. In this he wished to connect knowledge about cells in the brain and how it can help our daily lives. He traces how René Descartes (1596–1650) compared operations of the brain with those of automata worked by hydraulics and Sherrington’s 1937 description of it as an enchanted loom, with lights flashing as messages weave around the brain.<sup>50</sup> Again, akin to Hofstadter’s imagination!

Young distinguishes programs in four main languages followed in human life, expressed in distinct media, and the first two shared by all mammals:

1. The fundamental program is inherited written in the triplets of bases of the DNA code.
2. The second language in a mammal is embodied in the structure of the brain. Its units are the groups of nerve cells so organized as to produce the various actions at the right times.
3. Speech and culture represent the third level of the human life program, largely embodied in the organized sounds of spoken language.
4. These programs find their physical expressions and codes not only in human habits and speech sounds but also in writing and other forms of recorded speech. These provide a fourth level of coding, also peculiar to man, enabling some of the information for living to be recorded outside of any living creature.<sup>51</sup>

In thinking about the origin of codes and their meanings, he describes mapping of brain structures to body anatomy (drawing on his deep knowledge of octopus and squid axon) and how brain function ‘must provide a faithful representation of events outside, and the arrangement of the cells in it provides a detailed model of the world. But the function of this model is to provide action suitable for survival, so this topographically organized representation somehow provides a set of hypotheses about what is likely to happen, and of programs for dealing with these events’.<sup>52</sup>

Through this, he joins language of information, symbol, sign and code, from cellular function and signal to knowledge and thinking, where a

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50 *Ibid.*, p. 7.

51 *Ibid.*, p. 10.

52 *Ibid.*, p. 11.



great deal of conscious life consists of testing hypotheses. He writes that: 'complicated internal thinking probably involves processes similar to the active search for the meaning of sights or sounds'.<sup>53</sup>

His concluding chapter summarizes his thesis that: 'Progress in evolution by accumulation of information is especially revealing to mankind because humans have achieved an exceptional capacity for gathering information'.<sup>54</sup> With a beautiful sense of language and imagery, he writes:

We need all the knowledge we can collect about ourselves and our propensities for good and evil. We can see the biological foundations for these, but for wisdom about how to act we must continue to look largely to the traditional skills of philosophy, theology, and politics and the newer ones of anthropology, psychology, and sociology. These are cultural problems, and they require investigation mainly by those who study people as individuals and in groups, and their relations to each other. [...] Anatomical studies provide the most valuable of all clues to the functioning of the cortex. They show that the information about the features of the world is projected onto the cortex and recombined in a series of detailed *Maps*. This analogue or model of the world is the basis of all powers of computation. So, we can combine the detailed knowledge of the sequence of events in a few nerve cells, that is given by the microelectrode, with the knowledge about the arrangement of many of them that is provided by the microscope. We may thus begin to decipher how individual cells and groups of them interact to provide the coded script in which the programs of the brain are written.<sup>55</sup>

### 1996–Richard Feynman: *Feynman Lectures on Computation*

The first volume of Feynman's Lectures on Physics opened me to the world of physics in 1964.<sup>56</sup> The maths was not too difficult, and I devoured the book in the summer before starting the physics course at Oxford. It was not until three decades later that Tony Hey edited and published this inukbook, based on a course of lectures on computation that Feynman had developed and recorded in the early 1980s, again for the students of California Institute of Technology (Caltech).<sup>57</sup> It exemplifies a similar *tour de force* of the Feynman mind, connecting the mathematics, physics and engineering of computation

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53 Ibid., p. 193.

54 Ibid., p. 262.

55 Ibid., p. 264.

56 R. P. Feynman, R. B. Leighton and M. Sands, *The Feynman Lectures on Physics* (Beijing: Beijing World Publishing Corporation, 2004).

57 Feynman, *Lectures on Computation*.

and computing machines. He was a postdoctoral student at Caltech in the early 1970s, having studied physics at Oxford and overlapping my years there. He was Feynman's choice as editor and started work in the year that Feynman died from cancer. Our paths crossed again, briefly, in the UK e-Science Programme that he led in the early 2000s.

Feynman had a unique ability to work things out from first principles. Here, he connects theory of computation and theory of information with theory of physics. It discusses the links with thermodynamics and lays prophetic foundations for the advent of quantum computation. Feynman also developed early ideas on parallel computation. It is not a computer science textbook but a masterly example of interdisciplinary connections that have shaped and are still transforming computer science and theoretical physics, connecting them through the higher-level abstraction of quantum information theory.

The book is equally impactful in shedding light on the environment that Feynman and his many illustrious colleagues created and worked in at Caltech. Surely one of the most exciting crucibles of physical science, ever. Feynman did not extend his interests into the world of bio- and life science. These connections are pursued in some other inukbooks I have drawn together, here. Some tread the same path as Feynman in connecting information with physics, before extending on to the 'what is' and 'why' questions about life and living systems.

### 1998—Ian Stewart: *Life's Other Secret*

Stewart believes mathematics will have a lot more to say about life's secrets. He quotes Galileo Galilei as an impressive provenance of that belief: 'The book of Nature is written in the language of mathematics'. In his own words, Stewart says that 'mathematics is the study of patterns, regularities, rules, and their consequences—the science of significant form—and nowhere is form more significant than in biology'.<sup>58</sup>

This book is a story of symmetry and pattern in the living world and the deep and simple principles that underlie the form and formation of living systems. These principles are expressed in their purest form in the language of mathematics and address the question of what life *is* by reframing it as a question of what life *does*. Stewart is fluent in the science of life and its languages in physics, chemistry and biology. The book is richly populated with examples that frame the study of a living system in terms of 'the stuff that it happens to be doing right now', within a context descriptive

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<sup>58</sup> Stewart, *Life's Other Secret*, p. 30.

of all possible things that might happen to that system—a phase-space. He describes the approach thus: 'Instead of looking at one water wave and wondering why it does what it does, we look at an entire space of possible shapes and movements for water, seek relationships among them, and work out how simple natural rules pick out the behaviour that actually occurs'.<sup>59</sup>

This level of knowledge cannot, he argues, be found rooted in the science of genetics, without taking on board the mathematics of patterns which constrain possible life forms and are observed in living systems. This abstract endeavour is termed 'morphomatics' and the possible designs of living systems populate 'morphospaces'. In this domain, mathematical language expresses principles of continuity, connectivity, feedback, information, order, disorder, bifurcation, learning, autonomy and emergence of living systems and the symmetries of their patterns.

The book is anchored in examples from the plant and animal worlds, ranging from molecular and cellular level systems and processes, through to ecosystems and their simulation. Examples that struck me most vividly were those tracing plant structures to Fibonacci numbers and magic numbers to the structure of viruses.

The governing principle of the three-dimensional structure of viruses is akin to that of a crystal, where atoms adopt a lattice structure constrained to minimize energy. Many viruses are observed to form in a pattern of approximately spherical icosahedrons. This is a minimum energy structure, much as a drop of water constrained by intermolecular forces at the surface adopts a spherical form exhibiting minimum energy, within the pattern of all possible forms that a drop of that volume might potentially adopt.

Likewise with the multiple copies of different protein units that form a virus, a spherical form is preferred and the mathematics of the icosahedron with increasing numbers of six sided faces is illuminating. The angular icosahedron is smoothed in the truncated icosahedron—as in a football which mixes twelve five-sided faces with six-sided faces. The number of six-sided faces allowed mathematically, that will fit together (tesselate) smoothly and approximating increasingly towards a sphere, follows a number series called magic numbers. The series up to 300 is 12, 32, 42, 72, 92, 122, 132, 162, 192, 212, 252, 272.

Turnip yellow mosaic virus has 32 units, human wart virus has 72 units, reovirus has 92 units, Herpes simplex has 162 units, chicken adenovirus has 252 units, and infectious canine hepatitis has 362 units, another magic number. As Stewart says, 'It would be difficult to find more compelling evidence than this pattern of DNA, RNA, and viruses to show the importance

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<sup>59</sup> Ibid., p. 246.

of mathematical patterns in making life possible—certainly earthly life, the only kind we know'.<sup>60</sup>

The branching structure of Fibonacci number series has long found success in describing branching hierarchical structures of the developing plant world. The Game of Life program shows how simple repeating rules applied across a two-dimensional lattice, can lead to images traversing and replicating on the computer screen. Stewart draws on examples of cellular division in embryos, showing patterns of numbers that shape and constrain their three-dimensional symmetry. The precise correspondence of what the mathematics of symmetry would suggest, and what is observed in successive generations of cells is, again, striking.

We further find an illuminating perspective on how symmetry constrains possible patterns of life forms but does not homogenize living systems.<sup>61</sup> The diversity of life forms evolves as transformations arise. There is mathematics descriptive of these transformations of systems—those that maintain symmetry (rotation, translation, reflection and dilation) and those that break symmetry. Instabilities arise that break symmetries and lead to new life forms. Physical laws are also understood in the mathematical language of symmetry and broken symmetry.

A system constrained to spherical symmetry and form can break into a new form, following a new symmetry, when it experiences a perturbing force that breaks the spherical structure. Stewart uses the example of a squashed ping-pong ball being distorted into a circular symmetry as it becomes unstable and collapses under an applied pressure. Life forms maintain stability but undergo a change of pattern as they grow. Spherical symmetry encapsulates the growing frog embryo to a size of about one thousand cells. At the stage of gastrulation, the pattern of development breaks from this symmetry into the circular symmetry, described mathematically in like manner to that governing symmetry breakage in the compressed ping-pong ball. The embryo and living frog come into being as a stable living entity, through the breakages and transformations of symmetry that govern its permitted forms and stability at different stages of development.

The book poses challenges to the pursuit of human knowledge and understanding on several levels. The breadth of examples is evidence of the importance of multidisciplinary in science. But Stewart is critical of what he sees as the genetic determinism of our times, where everyone is 'determined' (maybe predetermined), whether it be in arguments of philosophy, mathematics, science, engineering or health care. There is an important debate about connection—of measurement and modelling of

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60 Ibid., p. 71.

61 Ibid., p. 38.

systems studied, perspective of discipline applied, and to what end, and how these cross-fertilize with one another to achieve insightful and useful ends. Here lie perennial problems of finding tractable mathematics that can unify basic principles of living systems from the level of molecules and cells to human and global ecosystems. One argument goes that the pursuit of such knowledge should proceed through disciplines characterized by their purity of pursuit, leaving aside other cooperative endeavours characterized as 'trade'. The counter argument is that this approach comes to mean less and less about more and more. Determinism is in part philosophy and in part mindedness—holistic or narrow.

Mathematicians as accomplished as Stewart, and interested as widely across disciplines, are amazing people. But they are fewer and further between in worlds that constrain choice and narrow perspective. His book is a lifetime of application and an invaluable songline of links among the people and disciplines he has connected with. His academic awards and prominence in communication of science attest to that. He is an extraordinary polymath. Further big questions arise after 'What is life?' which he reframes into the question, 'What does life do?' This is also a question of *how*.

Stewart's vision is of a unified theory of deep mathematical laws behind growth and form. How might we connect such a powerful and persuasive pattern of knowledge, in depth, with living systems and social life, in breadth. How can we picture such a time? Does society of the Information Age exhibit such mathematical pattern of instability and breaking symmetry—what might mathematics tell us about patterns of its future symmetry and stability?

### 2007—Douglas Hofstadter: *I Am a Strange Loop*

Hofstadter is another polymath inukbook author, spanning computer and cognitive sciences. His quest as a cognitive scientist was first expressed in the symphony in numbers, pictures and music of the book that made his name: *Gödel, Escher, Bach*.<sup>62</sup> In that book, he explored patterns that persist through mathematics, art and music, associated with human creativity. Hofstadter's Law states that 'It always takes longer than you expect, even when you take into account Hofstadter's Law'. It is a clever play on self-reference, and he sees analogy with self-reference in human consciousness.

In *I Am a Strange Loop*, he embraces an imaginative conjecture about the nature of conscious thought, seen from the perspective of computer

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62 D. R. Hofstadter, *Gödel, Escher, Bach: An Eternal Golden Braid* (New York: Basic Books, 1979).

science. Drawing on theory of Gödel numbers and self-reference in logical statements, he makes the analogy of the concept of 'I', and its expression of consciousness, as a self-referential system. *Cogito, ergo sum*, as it were. Hofstadter describes the brain as a 'Ceranium' billiard table with ricocheting 'Simballs'—a play on cranium and symbol.<sup>63</sup> He pictures symbols as the driving force of brain function, top down, rather than the physics of cells and signals driving bottom up. I mentioned the synergy I discovered between his ideas and those of Young and his imagined programs of the brain. The 'I' drives human consciousness. Is it real? Can multiple 'strange' self-referential loops occupy a brain? Does the strange loop illuminate feelings?

Hofstadter answers that consciousness is the dance of symbols in the brain, consciousness is thinking, *cogito, ergo sum*.<sup>64</sup> He discusses how the dance of symbols enables the brain to simplify its models, while holding on to the essence needed to operate in the world.<sup>65</sup>

### 2012—John Scales Avery: *Information Theory and Evolution*

Avery's book is included for its coverage of both historical and mathematical detail, brought together, now, in a second edition. It brings discipline of theoretical chemistry to the table, joined with that of mathematics, physics, computer science and bioscience.<sup>66</sup>

The scope of the book is the most wide-ranging of all the selection here. It has chapters on Charles Darwin's life and work, molecular biology and evolution, statistical mechanics and information, information flow in biology, cultural evolution and information, information technology and bio-information technology, and a glimpse into the future. There are appendices on entropy, information, biosemiotics and economics.

### 2015—Nick Lane: *The Vital Question*

The biochemist Lane both challenged and inspired with his book—just read the superlatives of those who reviewed it across the world. The book is another breath-taking *tour de force* among my inukbooks. His vital question—why is life the way it is?—is a grand challenge, and the book a UCL-centred story of wide-ranging collaborations of people, connections of discipline

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63 I have taken my liberty to invent words like 'omnuscle' and 'inukbook' from the liberty he expresses!

64 Hofstadter, *I Am a Strange Loop*, p. 276.

65 *Ibid.*, p. 279.

66 I learned from the book that Avery has been a stalwart of the Pugwash peace movement, led from Bart's in my time there, by Joseph Rotblat (1908–2005).

and synthesis of insights that he presents as evidence for his answer. It resonates with Young's story of the programs of the brain, but is a contrast, with Lane still at a formative stage of his research career, intent on new questions and experiments and not yet ready for the grandee status of the 'philosophypause'. He was awarded patronage and given free rein to explore his ideas at UCL, resulting over the following six years in the publication of this book. It touches only lightly on the concept of information, and I include it here to provide context for and balance with the more information-centred perspectives of my other inukbooks.

Reading it took me back to the first time I listened to the British chemist Leslie Orgel (1927–2007) describing his experiments directed towards understanding the origins of life, in the years from 1964, working under the blue skies of the Chemical Evolution Laboratory at the Salk Institute in California.<sup>67</sup> There he created experimental simulations of lightning in a primeval atmosphere and observed spontaneous creation of organic molecules.

Lane is refreshingly bold and clear in setting out his wares: 'Few biologists are more than dimly aware of the black hole at the heart of their subject', he says. Contrasting the billions of dollars now spent each year in measuring and unravelling the complexity of system of genes, proteins, and regulatory networks, he asks 'How can we hope to understand disease if we have no idea of why cells work the way they do?'<sup>68</sup> He sees the understanding of how the component parts of living systems evolved as biology's grand challenge, and the book as his attempt to frame and start a journey into this conceptual black hole. This is quite an opener!

Lane describes the living cell in the language of energy and bioenergetics. He places this description alongside, and in contrast to, what he sees as the present-day over-preoccupation with genetic determinism. The structures and functions of living cells are described in terms of protons and electrons and the electrical potential field gradients that shape and facilitate their flux-across membranes, through internal spaces, in exchanges with local environments, along cascades of connected transport mechanisms and chemical reactions that power and enact living processes. He describes a landscape characterized by energy equilibria and disequilibria.<sup>69</sup> His *forte* and focus is evolution and the stages through which the components and behaviours of living systems came to be. He quotes the biochemist Albert

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67 Orgel graduated from Oxford in 1948 and was made a fellow of Magdalen College in 1951, two years before gaining his PhD. An unconstrained and unencumbered, Guyton-like, meteoric rise!

68 Lane, *The Vital Question*, p. 2.

69 *Ibid.*, p. 28.

Szent-Györgyi (1893–1986), who observed that ‘life is nothing but an electron looking for a place to rest’.

Lane is challenging, in the spirit that his UCL sabbatical award was designed to encourage. He talks about textbooks and journals that fail to engage with the question at this basic level and an Internet that overloads and swamps with ‘indiscriminate facts, mixed with varying proportions of nonsense’.<sup>70</sup> There is, he says, a huge knowledge base about natural selection and random processes that ‘sculpt genomes’, all consistent with the evolution of cells. Adding, however, that this ‘encyclopaedia’ of facts and knowledge becomes a ‘straitjacket’ when it fails to address the question why life took the course it did. Bioenergetics is the theme and unifying signal he is seeking to identify and tune from within the resulting noise.

The book places its subject within a firm historical and evolutionary context, quoting Crick and Watson’s *Nature* paper of 1953.<sup>71</sup> He quotes their conclusion that ‘It therefore seems likely that the precise sequence of the bases is the code which carries the genetical information’, asserting that ‘that sentence is the basis of modern biology today. Biology is information, genome sequences are laid out *in silico*, and life is defined in terms of information transfer’. He dissents from this worldview, and, in support of his own, which is centred on bioenergetics, responds as follows: ‘Well, biology is not only about genes and environment, but also cells and the constraints of their physical structure, which we shall see have little to do with other genes or environment directly. The predictions that arise from these disparate worldviews are strikingly different’.<sup>72</sup>

Lane is fulsome and careful in his acknowledgements of landmark revolutionary contributions from the 1960s of Lynn Margulis (1938–2011), Carl Woese (1928–2012), Peter Mitchell (1920–92) and Bill Martin. The book describes stepping-stones towards a synthesis of knowledge about life and living systems in the unfolding and connecting stories of biology, biochemistry, biophysics, biomathematics and bioinformatics. It adopts a position close to that of Stewart, in its downplaying of genetics and emphasis on the spatial and physical pathways and constraints underlying the components, shaping the patterns in and through which life and living systems have evolved.

Lane’s team is intent on building new experimental bioenergetic devices for his research. His focus is that of an experimentalist and he is not tuned to mathematics and models and is firmly in the camp of doubters that information holds the key to answer his question. He maintains: ‘If life is

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70 *Ibid.*, p. 2.

71 *Ibid.*, p. 22.

72 *Ibid.*, p. 32.



all about information, these are deep mysteries. I do not believe this story could be foretold, predicted as science, on the basis of information alone. The quirky properties of life would have to be ascribed to the contingencies of history the slings and arrows of outrageous fortune. We would have no basis for predicting the properties of life on other planets'.<sup>73</sup>

Lane picks up on Schrödinger's book, saying, from seventy years on, that it 'asked the wrong question altogether. Add in energy, and the question is much more telling: What is living?'<sup>74</sup> This rhymes with Stewart's disdain for genetic determinism and his reframing of Schrödinger's question about what life is, into a question about what life does. The categorical phrase 'wrong altogether' surprises, here—incomplete is certainly true, but Schrödinger did himself recognize that he would better have discussed the tendency towards disorder in terms of Gibbs energy rather than negative entropy and he was, as Lane acknowledges, reasoning very far ahead of present-day knowledge of bioenergetics, played out in proton and electron transport in the cell. Schrödinger's incisive analytical mind would have had much to say about bioenergetics in the context of present-day bioscience. And, certainly, quantum tunneling would not have found its coverage in Lane's book, nor the discussion of entropy and order, unshaped by Schrödinger's scientific legacy that endures to this day.

In setting out his own scope, Lane acknowledges of Schrödinger that:

When he was writing, nobody knew much about the biological currency of energy. Now we know how it all works in exquisite detail, right down to the level of atoms. The detailed mechanisms of energy harvesting turn out to be conserved as universally across life as the genetic code itself, and these mechanisms exert fundamental structural constraints on cells. But we have no idea how they evolved, nor how biological energy constrained the story of life. This is the question of this book.<sup>75</sup>

Elsewhere, he traces the rise of genetic determinism to Schrödinger's aperiodic crystal and its 'code-script', saying 'Yet DNA, the beguiling code-script which seems to promise every answer, has made us forget Schrödinger's other central tenet—that life resists entropy, the tendency to decay'.<sup>76</sup> Lane sets out a fascinating and persuasive case for bioenergetics as a complementary core discipline of biology. He looks at evolution in terms of core mechanisms that power and enact living systems and why and how these came to be. It is a story of sunlight, minerals, water, carbon dioxide

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73 Ibid., pp. 51–52.

74 Ibid., p. 52.

75 Ibid., p. 52.

76 Ibid., p. 51.

and other key molecules; of carbon, hydrogen and oxygen, and other key atoms, bound together in organic matter; and of protons and electrons, pumped and pumping across membrane barriers, shunted and shunting along chemical pathways and across distances within the cell and between cells. It abuts quantum tunneling of electrons over Angstrom distances in the cell but the journey of physical reality into quantum entanglement and computation is not (yet!) in his scope. So, the probing of linkage with other domains of mathematics, computer science, information, mind and intelligence, which absorbed the writing of others of my inukbook writers, here, does not feature.

Lane writes vividly, of pumps and pulsating power stations as metaphors for the systems of the cell, likening them to the engine and engineering that underpin life and living. He writes of the water molecule splitting into a two-electron supplemented oxygen ion, eager to offload those electrons once more, and two protons, each eager to share again an electron partner. It is a scientific story of energy gradients and fluxes, of protons and electrons, oxidative (electron loss) and reductive (electron gain) chemical reactions, and chains of chemical reactions that pump and channel electrons through conformational and related energy state changes of proteins, mediated through permeability and impermeability of narrow membranes. With millivolt electrical potentials, these protons exert forces over short distance through potential gradients equal to those of lightning, in trillions and quadrillions of events within every cell. Protons are pumped across membranes and release energy back in cycles. Electrons flow in cascades, channeling and energizing this flux of protons and energizing molecules and reactions that channel and enact the chemistry of oxidation and reduction, whereby the body feeds, breathes, lives and works, and where the dictates of physics and constraints of mathematics are followed, and order is preserved.

Lane's central question is rhetorical but its challenge to the scientific relevance of information is important—in what kinds of way will the answer matter, in practical terms? How does lack of knowledge of what lies within the 'conceptual black hole' that Lane identifies in biology impact on the science and practice of medicine, where action or inaction are central concerns. The worry expressed implicitly in Lane's critique of biological dataism (it used to be dismissed as stamp collecting, I recall!), in its framing of the science of medicine, is that being devoid of an answer to his question, it spends too much on acquiring detail that explains wrongly or inadequately, and thus guides action inappropriately and achieves too little. But bioinformatics has transformed capacity for medicine to do better—in designing and proving vaccines in record time, for example. Time will tell if a different worldview, focused through the lens of bioenergetics, might

direct attention differently and better. It seems that the two perspectives are mutually consistent and differently, but both usefully, explanatory—rather as, in my time studying these matters, quantum mechanical and liquid drop models of the nucleus cast differently useful light on experimental data in nuclear physics.<sup>77</sup> Reading this book again made me think of Robert Oppenheimer's (1904–67) remarks about complementarity, in his 1953 Reith Lectures, as discussed in the introduction of Chapter One.

### 2019–Marcus du Sautoy: *The Creativity Code*

The mathematician du Sautoy combines a razor-sharp mind with wide-ranging and penetrating vision. He wears distinguished hats, as both Professor of Mathematics and Professor of Public Understanding of Science at Oxford. His books *What We Cannot Know* and *The Creativity Code* engage, entertain and educate a very wide audience.<sup>78</sup> He keeps his focus humbly in the world of knowledge and understanding and asks questions to elucidate issues. His writing style is not quite as magisterial and combative as that of his predecessor in the latter role, Richard Dawkins, who, equally brilliant and incisive in his field of human evolution, appeared rather to stoke and revel in controversy. *The Selfish Gene* and *The God Delusion* challenged and expressed strong views on religious belief about what we do not, and possibly also cannot know.<sup>79</sup> Du Sautoy does not enter this territory as a gladiator—Dawkins agitated and du Sautoy soothed.

*The Creativity Code* explores beyond machine intelligence to machine creativity and identifies creativity as a product of the conscious mind. He asks whether machine intelligence can move to machine creativity. Its accomplishments in games, writing, painting and music-making are now of a quality that passes empirical test, whereby a blinded observer might take them as exhibiting human creativity (just as, early on, machine intelligence was judged by whether a blinded user concluded that they were interacting with a human being, rather than a machine). Joseph Weizenbaum

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77 And today, as modelling of weather systems combines with machine intelligence, both are proving differently advantageous in forecasting of weather and what is being called its 'nowcasting.' For an immediate (now) prediction of local weather trends, machine intelligence can nowcast based on measurements of the current weather, including wind, temperature, cloud cover and time of day, to outperform complex physics-based model predictions. Longer-term and wide-area forecasts are still the preserve of complex models of atmospheric physics

78 M. du Sautoy, *What We Cannot Know: Explorations at the Edge of Knowledge* (London: Fourth Estate, 2016); du Sautoy, *The Creativity Code*.

79 R. Dawkins, *The Selfish Gene* (Oxford: Oxford University Press, 1976); R. Dawkins, *The God Delusion* (Boston, MA: Houghton Mifflin Company, 2006).

(1923–2008), a founder of modern-day AI who I introduce in Chapter Seven, demonstrated with his ELIZA program that quite simple program heuristics were sufficient to dupe human users into behaving as if they were in conversation with another human. And Cass Sunstein, who comes on the scene in Chapter Nine, reasoned persuasively about how humans easily fall foul of bias, through dysfunction of the groups deliberating issues and problems, failing to share information effectively, and propagating bias because of perceived reputation, expertise and behaviour of actors.

### A Pause for Reflection

Both Schrödinger and Davies, whose inukbook is discussed next, take their physics to the level of the workings of the mind, and park their thoughts in the realm of unknown physics, and that which is possibly unknowable. Davies and Stewart both chart a still largely hidden pathway towards greater understanding, beyond the level of the machinery of the cell to the properties of networks of cells and organs, and to the symbols they operate and function with and are constrained by, described in language of mathematics and information theory.

Just as the logic and operation of a high-level computer program is implemented through a computing machine and its machine code, so nervous systems and brains are described in terms of machinery of life and living systems. The functions and capabilities of a computer program depend for their enactment on the functions and capabilities of the computer machine on which they run. One can go back further and observe the design that this machine embodies and the component electrical circuits, which involves language of logic, filters, rectifiers, amplifiers and so on. One can dig deeper and observe the electrical potentials and currents, and the component resistors, capacitors, inductors and transistors comprising each electrical circuit of the computer machine. And from there we can step down to description of each such component in the language of the physics of electromagnetism, which determines electron flow throughout.

Abstraction of biological machine as information circuit is analogous to abstraction of electrical circuit above electrical component, and computer program above computer machine, to understand and inform understanding of their designs and integrated functions. Young uses analogy of computer program to describe function of the integrated nervous system and brain machine. In cell biology, it is the information network of genes that Davies looks towards, as a higher level of abstraction required, over and above the machinery of cells and organs, to understand their integrated function.

There is then another jump to understand all of this, again as machinery, when taken to the level of the conscious and creative mind.

Hofstadter rose to this level in *I Am a Strange Loop*. What it is to be conscious, intelligent and creative are symbols in play within his concept of 'I'; symbols ricochet on his mental billiard table and round his 'Strange Loop' of consciousness. They are waves flowing in an ocean of ideas and appearances. We map and describe them with functional MRI and locate and ascribe them to regions of the brain machine, much as we might track the symbols manipulated in a computer program to the active registers, memory addresses and logic circuits of the computer machine or to the regions of the cell and the machinery of cell function that Lane describes. With Davies, we inch upwards to information networks and the functions and meanings they drive and oversee. We piece together the sailors, the ships, the waves and the oceans, and seek to infer about charts, weather, voyages and storms. There is an interesting experience to learn from in the design of computer processor chips. These are now so minutely complex and extensive that no human designer understands it all—the computer manages and guarantees the whole. Perhaps human understanding of the biology of living systems will reach a similar tipping-point, too.

### 2020—Paul Davies: *The Demon in the Machine*

Davies has taken on the mantle of guru connecting theories of information, life and mind, from the perspective of physics. The timely publication of this book enables my collection of inukbooks, here, which started with Schrödinger, to end with Davies. His periscope peers further into the medical science of the future, projected as an information science and technology—in this perspective, gene therapy arguably already is.

This inukbook is the most fluent and up-to-date account that I know of, explaining how information is defined and measured experimentally, and how, as a concept, it has gravitated to the centre-ground of theory of physical and biological science. Indeed, some envisage an information theory connecting concepts spanning from mathematics and physics to cellular function of the body, and even beyond, to social and economic domains. As he observes, 'the challenge to science is to figure out how to couple abstract information to the concrete world of physical objects'.<sup>80</sup>

Working from Shannon's 1949 paper on *The Mathematical Theory of Communication*, which he describes as 'a pivotal event in science', he gives a powerful example of its application to the information content of DNA:

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<sup>80</sup> Davies, *Demon in the Machine*, p. 35.

Every cell in your body contains about a billion DNA bases arranged in a particular sequence of the four letter or logical alphabet. The number of possible combinations is 4 raised to the power of 1 billion, which is 1 followed by about 600 million zeros. Compare that to the paltry number of atoms in the universe—one followed by about 80 zeros. Shannon’s formula for the information contained in this strand of DNA is to take the logarithm, which gives about 2 billion bits—more than the information contained in all the books in the Library of Congress. This information is packed into a trillionth of the volume of a match head. And the information contained in DNA is only a fraction of the total information in a cell. All of which goes to show how deeply life is invested in information.<sup>81</sup>

The demon of his title is the Maxwell demon—after James Clerk Maxwell, the physics great—reenvisioned in the light of thought experiments of Leo Szilard (1898–1964) and Rolf Landauer (1927–99). He explores the three-way trade-off, as he describes it, between information, work and heat energy, and the ways in which information shares some of the properties of energy. He poses the question ‘So is information real, or just a convenient way to think about complex processes?’ and finds, ‘There is no consensus on this matter, though I am going to stick my neck out and answer yes, information does have a type of independent existence and it does have causal power’.<sup>82</sup>

Citing theory of the generation of entropy in the erasure of information, and recognizing the continuing controversies about its meaning, he goes on to describe an imaginary device called an ‘information engine’, as imagined by Christopher Jarzynski and colleagues,<sup>83</sup> that ‘systematically withdraws energy from a single thermal reservoir, delivers that energy to lift a mass against gravity, while writing information to a memory register’. This is theory inching towards David Deutsch’s causative power of information, in an area of fundamental principles of science. He brings together examples from the realm of nanoscale engineering that are likewise inching towards real information engines—‘applied demonology’, he calls it!—reporting conversion of information into energy with twenty-eight percent efficiency and envisaging a future nano-engine running on ‘information fuel’. Quantum computing has also entered the world of statistical thermodynamics and information, using entangled particles to induce heat flow from a colder to a hotter system.

Davies lays out his conception of the future digital doctor as follows:

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81 *Ibid.*, pp. 38–39.

82 *Ibid.*, p. 47.

83 Z. Lu, D. Mandal and C. Jarzynski, ‘Engineering Maxwell’s Demon’, *Physics Today*, 67.8 (2014), 60–61.

The study of information flow and information clustering would provide a diagnostic tool far more powerful than the battery of chemical tests used today. Treatment would focus on establishing healthy, balanced information patterns, perhaps by attending to, or even re-engineering, some defective modules, much as an electronic engineer (of old) might replace a transistor or a resistor to restore a radio to proper functionality.<sup>84</sup>

He reasons beyond the DNA triplet code towards a higher-level computer language of life. Just as software engineers use higher level language and have left the underlying binary machine code far behind, so he suggests that:

The cell as a unit operates at a much higher level to manage its physical and informational states, deploying complex control mechanisms. These regulatory processes are not arbitrary but obey their own rules, as do the higher-level computer languages used by software engineers. And just as software engineers are able to reprogram advanced code, so will bioengineers redesign the more sophisticated features of living systems.

Paul Nurse, founding Director of the Francis Crick Institute, linked with UCL, was awarded the 2001 Nobel Prize in Physiology or Medicine, with Davies's colleague Leland Hartwell, and his UCL colleague Tim Hunt, for their work on gene networks that control the cell cycle of yeast. This approach has evolved into the tracking of patterns of information flow in gene networks. These appear to follow their own rules, independently of what Davies calls the 'circuit topology'—like the function performed by a computer program bearing little relationship to the hardware on which it is run. 'Only if something goes wrong is it necessary to worry about the actual wiring', he says. And then, 'Cells are beginning to look like bottomless pits of complexity. The discovery of all these causal factors which are not located on the actual genes is part of the field known as epigenetics. It seems that epigenetics is at least as important as genetics as far as biological form and function are concerned'.<sup>85</sup>

In drawing to his conclusions, Davies writes:

Looking back over the past 3.5 billion years, the origin of life was the first, and most momentous, transformation. However, the history of evolution contains other major transitions, critical steps without which further advance would be impossible [...] Eukaryogenesis, sex and multicellularity: all involved marked physical alterations. But the true significance lay not with changes in form or complexity but with

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<sup>84</sup> Davies, *Demon in the Machine*, pp. 92–93.

<sup>85</sup> *Ibid.*, p. 113.

the concomitant reorganization of *informational architecture*. Each step represents a mammoth ‘software upgrade’. And the biggest upgrade of all began about 500 million years ago with the appearance of a primitive central nervous system. Fast-forward to today, and the human brain is the most complex information processing system known. From that system stems what is undoubtedly the most astonishing phenomenon of all in life’s magic puzzle box—consciousness.<sup>86</sup>

His epilogue appropriately quotes Einstein as its banner: ‘One can best feel in dealing with living things how primitive physics still is’.

## The Magic Mirror of Maurits Escher

I conclude my landmark book list, rather quirkily, perhaps, with *The Magic Mirror of M. C. Escher*, by Bruno Ernst, which is rich in symbolism of life.<sup>87</sup> The eminent mathematician Roger Penrose engaged with Escher’s visual paradoxes, so I feel in good company in the way I, too, use these images. The historian, Norman Davies, who featured in the Introduction, wrote of the importance of presenting history through art and poetry, saying that the historian must collate the widest range of sources, that every source of information is a distortion, and absolute objectivity unattainable: ‘Every technique has its strengths and its weaknesses. The important thing is to understand where the value and the distortions of each technique lie, and to arrive at a reasonable approximation’.<sup>88</sup> Mervyn King wrote about the importance of getting to grips with complex issues of monetary policy, through storytelling as much as analysis. Effort to understand, live with and work through complex problems can also benefit from this breadth of approach. And communication of personal health care histories, through narrative, adds important detail and context that goes beyond data and analysis.

Works of art are expressions and experiences of life, connecting artist, subject, media and audience. They are works of hedgehogs and foxes—those who connect deeply and those who connect widely, in Isaiah Berlin’s (1909–97) classification of great authors. Some are simple, some very complex. Our mappings of knowledge and reason with health care systems and services are partial pieces of an unclear picture puzzle. The pieces fit together up to a point, shaped by our vision of the picture itself. The description and

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86 *Ibid.*, p. 183.

87 B. Ernst, *The Magic Mirror of M. C. Escher*, trans. J. E. Brigham (New York: Barnes and Noble, 1994).

88 N. Davies, *Europe: A History* (Oxford: Oxford University Press, 1996), p. 5.



relevance of the pieces may change and fit together differently, according to a different vision of the picture. We talk about a picture of health. In all connections there is limitation and imprecision of representation and reason, and bias in presentation and interpretation.

One of my great friends during my nearly twenty years at Bart's was the medical artist Peter Cull (1927–2012). He had spent some of his early career working in Africa and had a highly individual artistic style, producing striking pictures of human anatomy of disease, to complement pathology museum sample collections. He and his colleague David Tredinnick (1922–2005) were leaders of their time in the medical artist and medical photography professions.<sup>89</sup> Before the computer era, preparation of slides for projection at meetings used the skills of both these arts. I worked closely with them in finding a pathway for each of their departments into the computer age, which was a tricky and sometimes fraught professional transition. We worked on computer-based learning, where Peter's team produced illustrative visuals of complex clinical procedures for display within the software and in creating computer methods to support creation of thirty-five-millimetre projector slides and computer archives from the huge photographic image collections used for teaching and publication.

I discovered from them the power of visual image in illustrating the wicked problems of health informatics. For example: reconciling privacy concerns with the need to aggregate and share data; central and global versus distributed and local policy for implementation of IT systems; market-based versus politically mandated adoption of data standards. In this quest, I alighted on the mathematically inspired woodcuts and lithographs of Escher. These play with competing geometrical perspectives within a single design. For me, they illustrate competition among different perspectives in a more human way. Escher was loved by mathematicians but ostracized for most of his career by the arts community. Here I give a wider appreciation, drawing on the published compendium of Ernst.

The idea of using these images came to me when planning the presentation of the GEHR project to the final conference of the AIM 2 Programme, in Brussels in 1993. I decided to show two of them. The first was *Ascending and Descending* (1960), depicting two groups of people: one walking up a staircase around the outside of a tower and the other walking down the

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89 David's dedication to the National Medical Slide Bank is recorded in an appreciation in 'David Tredinnick Fbpa, Frps, Hon Fimi (1922–2005), *Journal of Visual Communication in Medicine*, 28.4 (2005), 166–67, <https://doi.org/10.1080/01405110600575928>

steps. The geometry of the tower was an illusion.<sup>90</sup> The successive flights of stairs that the eye is tricked into following, connect from top to bottom. The ascenders reaching the top emerge onto the bottom of the staircase and the descenders reaching the bottom, emerge at the top. I used this image to parody the purposeful activities of standards makers and innovators in health care IT of those times. All striding purposefully, passing one another on the steps at each circuit round the tower, and neither ascending nor descending. The need was for a realistic staircase where there could be common ascending, and their two essentially connected endeavours could play out in concert.

The second slide, which I introduced in Chapter Five, was the illusion of *Drawing Hands* (1948), depicting two hands: each clasping a pencil, and each appearing to be drawing the other hand. I used this when talking about medicine and information technology, saying that the study of medical informatics was a middle ground where insights from information technology were leading to new methods in medicine and the challenge of accommodating the complexity of medicine was leading to new methods of information technology. This was a visual metaphor for the coevolution of information technology and health care, with each in some part writing the other's story.

After the talk in Brussels, the stand we had set up in the conference exhibition to show the work of the project was attended by a huge number of people from that audience, several hundred strong, coming to see what we had done in creating the GEHR (Good European Health Record) architecture for electronic health records. Numbers came to talk to me about the impact of the Escher slides I had shown.

Here are some further artistic metaphors I have found in other Escher images, illustrating themes encountered along the songline of the book.

*Tower of Babel* (1928) illustrates the confusion of tongues.<sup>91</sup> A building progressing upwards towards ever-increasing structural instability, with increasing panic of bricklayers at each higher level, mushrooming from a narrow base into a toppling upper edifice. Woe is the tower of hundreds of thousands of terms in medical terminology!

In *Relativity* (1953), Escher builds three separate perspectives of a hallway and connecting staircases, into a single incongruous whole.<sup>92</sup> Woe is

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90 M. C. Escher, 'Ascending and Descending', *Digital Commonwealth*, <https://ark.digitalcommonwealth.org/ark:/50959/3r076s51v>

91 M. C. Escher, 'Tower of Babel', *Digital Commonwealth*, <https://www.digitalcommonwealth.org/search/commonwealth:3r076t25f>

92 M. C. Escher, 'Relativity', *Digital Commonwealth*, <https://www.digitalcommonwealth.org/search/commonwealth:3r076s67r>

the information engine combining multiply redundant information models in one program! In *Up and Down* (1947), he depicts a courtyard that is being viewed from high up and at ground level in a single integrated image.<sup>93</sup> This is of a small boy looking up and his parent looking down. Woe is the lot of the clinician, seeing and coping with the world they connect with at ground level, constrained to work within an architecture framed by the helicopter view of an information system designer or service manager peering down from high up! In other images, Escher illustrates information systems where information cannot flow (*Waterfall* (1961))<sup>94</sup> and a both bounded and infinitely variable organic information system (*Circle Limit III* (1959)),<sup>95</sup> discussed further below.

## The Singularity

A landmark on the other side of the transition into the Information Age is embodied in the concept of ‘the singularity’. It is the topic addressed by Ray Kurzweil in his book *The Singularity Is Near: When Humans Transcend Biology*; the term refers to the point in evolution when information technology can model and mirror biology at scale and detail that matches human form and human reasoning capacity.<sup>96</sup> This vision is also described by James Lovelock, author of *The Ages of Gaia*, in his 2019 book *Novacene*,<sup>97</sup> which I return to in Chapter Ten.

Kurzweil credits von Neumann as the first to envisage this point in the evolution of life.<sup>98</sup> The power and significance of such a vision is now highly influential in conjecture about the rapid evolution of AI. The mathematician Roger Penrose is a notable doubter that such a stage of evolution can or will ever occur. He was right about the emergence of black holes (another kind of singularity), as his recent Nobel Prize award attests. However, the nature of consciousness and mind remain controversial matters, in philosophy as much as science, and are probably not early candidates for Nobel Prizes!

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93 M. C. Escher, ‘Up and Down’, *National Gallery of Art*, <https://www.nga.gov/collection/art-object-page.47950.html>

94 M. C. Escher, ‘Waterfall’, *Digital Commonwealth*, <https://ark.digitalcommonwealth.org/ark:/50959/3r076s93c>

95 M. C. Escher, ‘Circle Limit III’, *Wikimedia Commons* (3 February 2015), [https://en.wikipedia.org/wiki/Circle\\_Limit\\_III#/media/File:Escher\\_Circle\\_Limit\\_III.jpg](https://en.wikipedia.org/wiki/Circle_Limit_III#/media/File:Escher_Circle_Limit_III.jpg)

96 R. Kurzweil, *The Singularity Is Near: When Humans Transcend Biology* (New York: Viking Books, 2005).

97 J. Lovelock, *The Ages of Gaia: A Biography of Our Living Earth* (Oxford: Oxford University Press, 2000); J. Lovelock, *Novacene: The Coming Age of Hyperintelligence* (Cambridge, MA: MIT Press, 2019).

98 Kurzweil, *Singularity Is Near*, p. 194.

Many predict and imagine this future reality. Novelists like Ian McEwan and Ishiguro write and worry about it.<sup>99</sup> Along my songline, the analogy of the evolution from the early chess-playing machines to AlphaGo, AlphaFold and ChatGPT has been instructive. The human brain employs a somewhat nonlinear calibration of the quality of its own achievements compared with those of the machine. Early efforts amused and attracted derision. Machines performing nearer to human capability were yet judged rather dense. When starting to perform competitively with humans, they quickly caused alarm and sweat! And passing beyond that stage, they quickly progressed to inspire human awe, when they started to beat human experts and win world tournaments, communicate with humans in fluent natural language, solve hitherto intractable puzzles, and baffle and bemuse us. Today, quantum computation is forecast to bring potential to solve hitherto intractable combinatorial problems in seconds and minutes that would take today's most powerful mainframes many thousands of years.

We may speculate how machines that win at the game of Jeopardy and can instantly synthesize material collected from across encyclopaedias of modern-day knowledge will influence health care over the next fifty years and beyond. How will the health care revolution of today appear, looking back, Edward Gibbon-like, should we get to such a reflective place, from hundreds of years ahead? How will the science and engineering, and the beliefs, myths and magical thinking of our own age stand up? As von Neumann purportedly speculated, when foreseeing the singularity where machines overtake humans, 'The ever-accelerating progress of technology and changes in the mode of human life give the appearance of approaching some essential singularity in the history of the race beyond which human affairs, as we know them, could not continue'.<sup>100</sup>

My inukbooks on the future to come are numerous and varied. They bridge technological and human perspectives. McEwan wrote *Machines Like Me* to explore the interface and relationship between humans and cyborg beings. Du Sautoy wrote *The Creativity Code* to re-explore ideas of creativity in thought and art: especially pertinent, since machines have begun to extend through and beyond winning at chess, Go and Jeopardy, to paint pictures and make music, as well as solve mathematical problems and mimic

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99 I. McEwan, *Machines like Me* (Toronto: Knopf Canada, 2019); Ishiguro, *Klara and the Sun*; L. Allardice, 'Kazuo Ishiguro: AI, Gene-editing, Big Data ... I Worry We Are Not in Control of These Things Anymore', *The Guardian* (20 February 2021) <https://www.theguardian.com/books/2021/feb/20/kazuo-ishiguro-klara-and-the-sun-interview>

100 S. Ulam, 'John von Neumann 1903–1957', *Bull. Math. Soc.*, 64.3 (1958), 1–49, <https://www.ams.org/journals/bull/1958-64-03/S0002-9904-1958-10189-5/S0002-9904-1958-10189-5.pdf>

verbal and literary styles. Maddox's *What Remains to Be Discovered*, written on his retirement as Editor of *Nature*, is about the extraordinary stretches of mind and imagination up to the Year 2000, and what lies beyond.<sup>101</sup> The magic of the present era is captured in Marcus Chown's *Infinity on the Palm of Your Hand*.<sup>102</sup> The Escher's *Circle Limit III* (1959) woodcut is a striking image of life and art that is finitely constrained and infinitely variable.<sup>103</sup> *On the Future of Humanity*, by the UK Astronomer Royal and former President of the Royal Society Martin Rees, is a 2020 *tour d'horizon* of what may lie ahead.<sup>104</sup> He was kindly and indulgent in signing copies for me and all my children, as Christmas presents, when he spoke at New Scientist Live last year. And most recently, I have Lovelock's *Novacene* vision of future artificial intelligence, which may prove our making or breaking as humans, or hopefully remaking.

## Parenthesis–Information Policy

The duty of tolerance is our finite homage to the abundance of inexhaustible novelty, which is awaiting the future, and to the complexity of accomplished fact which exceeds our stretch of insight.<sup>105</sup>

This quotation reflects a patient and careful perspective about how we should approach the future. A tolerant balance of speculation and scepticism. How well does it stand up against experience of the dramatically anarchic transition of society through the Information Age? How should it reflect in policy adopted for addressing and coping with the potentially breaking changes in the everyday practice of its health care services, poised midway in this transition?

Insurance policies help protect us from future downside risks that we could not face alone. The actuaries who underwrite insurance policies are good at mathematics and cautious about risk. They are brainy people. A close friend from student days switched from a PhD unravelling numerical solutions of Schrödinger's equation to a stellar career as an actuary. They know a lot about life and death, know what they cannot know, and are

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101 J. Maddox, *What Remains to Be Discovered: Mapping the Secrets of the Universe, the Origins of Life, and the Future of the Human Race* (New York: Macmillan, 1998).

102 M. Chown, *Infinity in the Palm of Your Hand: Fifty Wonders That Reveal an Extraordinary Universe* (London: Michael O'Mara Books, 2018).

103 M. C. Escher, 'Circle Limit III', *Wikimedia Commons* (3 February 2015), [https://en.wikipedia.org/wiki/Circle\\_Limit\\_III#/media/File:Escher\\_Circle\\_Limit\\_III.jpg](https://en.wikipedia.org/wiki/Circle_Limit_III#/media/File:Escher_Circle_Limit_III.jpg)

104 M. Rees, *On the Future: Prospects for Humanity* (Princeton, NJ: Princeton University Press, 2018).

105 A. N. Whitehead, *Adventures of Ideas* (New York: Macmillan, 1933), p. 56.

seasoned accordingly to act wisely, cautiously and safely. If not, their insurance policies fail.

Information policy for health care needs a careful balance of both upside potential and downside risk, combining imagination, creativity, realism and caution. In this, it must combine the Barack Obama audacity of hope and the Mervyn King audacious pessimism that have already cropped up several times in the book. The influential philosopher, Antonio Gramsci (1891–1937) famously wrote of pessimism of the intellect and optimism of the will. To cope well, information policy must be informedly pessimistic about downside risk and optimistically determined about upside potential. Such policy can fail, too—overestimating future benefit and underestimating related harm, proving inadequate to the task in both capability and will. We need an information policy for health care that readies us as a society, as best possible, to cope with and use gainfully the unfolding insights of life and medical science and new information technology, and their impact on the health care needs and services of the Information Society. These fields will likely continue as an unfolding anarchy, through transition still to come.

Alfred North Whitehead talked of the anarchy of transitions, but experience of the Information Age might have blown even his tolerant and sanguine mind off course. Would he have been with George Orwell (1903–50) and Aldous Huxley (1894–1963) in imagining a technology that became a vehicle of malign official censorship, restricting access to information to control and enchain society, or that conditioned human life to become trivialized and egotistical, surrounding itself and drowning in a sea of false, misleading and irrelevant information? What would he have had to say about the downside risk combined with upside potential of a universal communication network? That it would give rise so swiftly to global cybercrime, political manipulation and titanic battles in the law courts? That academia from east to west coasts in the United States, would inflate and conflate so rapidly into the global powerhouses of IBM, Apple, Microsoft, Google, Meta and Amazon? That machines would master chess and Go, and unfold maps of the molecular biology of life, playing out in a Cloud of calculating machines and data stores persisting deep in the sea? That computers would fluently translate language, mimic literary and artistic style and content, and write program code, as they now do?

This chapter has ranged widely over theory of information and science of life. It has collected diverse ideas and perspectives: order and disorder, equilibrium and disequilibrium, symmetries and broken symmetries, and the emergent behaviours of complex systems. It has connected insights from the mathematical, physical, biological and computer sciences. It has traced hierarchies of abstraction, ascending towards description of biological systems and their functions in terms of information networks and an

integrated nervous system ascending into the conscious mind. It has gone a long way beyond DNA coding sequence characterized as information, and life thought of, by analogy, as combining the characteristics of the Turing machine, an abstract model of computation conceived in the 1930s, and the von Neumann universal constructor, an abstract model of self-replicating cellular automata conceived in the 1940s.

AI and quantum computation dangle promises of playing into unfathomable new worlds of insight and capacity that will outshine everything we currently know and experience. The subconscious and conscious processes of the human brain and mind, shape and determine the actions whereby they pursue their purposes and goals. Discoveries in the virtual world are connecting the human body with information that flows within and around it and characterizes its functions. We are seeing ever closer connections of these real and virtual worlds.

How these insights and capacities will connect with everyday health care in the future Information Society is unknown, but potentially highly consequential. There is much speculation and a mix of perspectives about future health care. These face towards concern to remedy the health inequalities summarized in the Michael Marmot Reviews, which have provided a modern-day overview in the same spirit that motivated William Beveridge (1879–1963).<sup>106</sup> They face, in parallel, towards the prospect of radically improved prevention, surveillance, mitigation and treatment of disease, powered by new therapeutic interventions made possible by science of the Information Age, and the prospect of a coming era where AI exceeds the capability of humans.

The interaction of information with health care impacts immediately and personally on each of us and those we care for, who in turn care for us. It has immense professional, societal and economic contexts. Much of today's information policy has focused towards improving the industrial age of hospital medicine and linking this, from the top down and centre outwards, with primary care, and towards new technology, such as for population level informatics and artificial intelligence, that remain to be created, implemented, proven and adjusted to at scale. And, all the while, unsafe environments and behaviours impact balance, continuity and governance of the health care of citizens, making some of their lives, cumulatively, rather worse. This policy focus leaves more immediate service needs relatively

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106 M. Marmot, *Fair Society, Healthy Lives: The Marmot Review: Strategic Review of Health Inequalities in England Post-2010* (London: Marmot Review, 2010); M. Marmot, 'Health Equity in England: The Marmot Review 10 Years On', *BMJ*, 368 (2020), m693, <https://doi.org/10.1136/bmj.m693>

unattended to and unmet, but to be coped with, and burdening services, nonetheless.

Information policy for health care in the UK has been established in what has often been a high-level battleground of related professions, services and politicians. Solutions that cohere and are sustainable have not, and likely will not, come from the top down in this way. They will be created by the enablement of individuals, organizations and industries, with goals focused through closer engagement with the wishes and needs of citizens and their local communities, connecting outwards and upwards, iteratively, and incrementally. Complementing this local endeavour, national information policy should best be directed towards enablement and governance, focusing on the discovery, support and protection of a new common ground of values, principles, methods and approaches to care services, supported by a care information utility that reflects and mirrors them. This poses challenges that can only be tackled with methods that can transcend between local and global scale.

Having embarked on this connecting chapter into Part Two of the book, describing transition in understanding of both information and life in the Information Age, the storyline of the book now comes back down to earth with a bump. Chapter Seven focuses on the transition of health care services in the Information Age, and the role of information technology in services that guide, enable and support health. Reflecting, again, Deutsch's sense of information as a causative agent, we must consider the wider context of *what* things we need and wish to create or cause to happen, *how* new knowledge and capability can help and equip us to make them happen, *how* we choose to generate and use information to these ends, and *how* well we are succeeding. These comprise one question of *what*, and three questions of *how*. Current dilemmas have substantially derived from policies preoccupied with conjecture about *what* might be; yet, over decades, there has been serial a consistent lack of attention to learning about and improving the *how* of its becoming. It has been a costly and bumpy transition.





# 7. Health Care and Information Technology–Co-evolving Services

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This chapter tells a story of seventy-five years of coevolution that has connected the practice of health care with the science and technology of information. It moves from experience of health care in the remote village life of my childhood to that in global village life today. It explores decades of transition onto a new landscape of disciplines, professions and services, played out within rapidly changing social, economic and political contexts. This transition has been described as turning the world of health care upside down, from an Industrial Age to an Information Age—the former grouped around service providers and the latter with a more patient-centred focus. Changing means and opportunities for preventing and combating disease have succeeded in saving lives and extending lifespans, albeit with increased years of ageing life often spent living with chronic and incurable conditions. The contributions of good nutrition, clean environment, shelter, sense of community and security to longer lifespan and healthier lifestyle, understood now in greater detail, give pause for thought about the balance, continuity and governance of health care services. Three contrasting commentaries on this era of change are introduced—from industry, science and social commentators of the times.

With the arrival of new measurement and computational methods, spanning from genome to physiome science and to population level informatics and now machine intelligence, the Information Age has pressured health services with continually changing challenges, characterized by what has been described as ‘wicked problems’, the nature of which is discussed. Wholly new industries, providing products and services for diagnosis and treatment, many of these increasingly offered directly to citizens, have grown in scope and scale. In an era when powerful new treatments have come with increased risk of harm to patients, ethical and legal aspects of care services and their governance frameworks have come under increasing public and regulatory scrutiny. The changing scenes of education, assessment of competence to practice, accountability for care services, clinical risk, patient safety and research, are introduced, all dependent on the quality of relevant sources of information.

This kaleidoscopic image of change sets the scene for discussion of the increasingly centre stage focus on information policy. The timeline of wide-ranging policy initiatives and related organizational changes in the UK NHS, such as sought to improve safety, contain costs, and improve outcomes for patients, is reviewed. This starts with seminal documents and policy goals from fifty years ago, highlighting issues then identified that have remained unresolved through the intervening years, despite huge public and international investment and opportunity cost in relation to competing priorities. Changing needs and increased expectations of citizens continue to challenge the *status quo*. This situation is reassessed, fifty years on, setting the scene for the programme for reform envisaged in Part Three of the book. The chapter concludes with a rueful reflection on the rush to computerize that has contributed significantly to the anarchy experienced in health care of recent decades, characterized as a gold rush.

The most conspicuous example of truth and falsehood arises in the comparison of existences in the mode of possibility with existences in the mode of actuality.

–Alfred North Whitehead (1861–1947)<sup>1</sup>

In the legend of Daedalus and Icarus, Icarus flew too close to the sun and his waxed-together wings melted and brought him down. By flying too low, in his escape over the sea from Crete, he would have risked the wings becoming waterlogged by spray, also risking bringing him down. There was a narrow range of viable altitudes. The flux of energy emitted from the sun sustains life on earth and provides and enables us with the energy and wings needed to fly. It can also bring us down. Physics toys with the idea of information as a form of energy. Information is in continuous flux in life, and its corruption or misuse can bring us down, too. Genetic mutations, epidemics, manipulative distortions of news and financial crashes all have common threads of information in flux.

Tracking photons from the sun into the cascades of mechanisms in living organisms is fascinating science. Tracking information of all kinds through environment and human society is hard to think about logically and carefully, but important, too. It is not experimental science, in the same way that economics or sociology are not and cannot be. There is only one laboratory and there is little rigorous controlled experiment possible. We can base decisions on an imagined and projected reality, but Whitehead's caution about this, headlined again, above, must be heeded. In times

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1 *Adventures of Ideas* (New York: Macmillan, 1933), p. 234.

of great change—and contemporary information anarchy signifies great change—black swans arrive, flap their powerful wings, and multiply.

In seeking health care benefit from investment in information technology, we should take heed of the story of Icarus, and rather avoid flying too high or too low, buoyed too high on hubristic wing and feeble prayer, or staying too low, unimaginative, incurious or cripplingly risk averse. In the slowly maturing landscape of health care information systems, there lurks much ageing and obsolescent string and sealing wax.

The scope of this chapter is very large, as was that of Chapter Two on knowledge, which led into Part One of the book. It seeks to provide a historical context for the changing face of health care, in its transition into and through the Information Age. The chapter sets the scene and provides the basis of the perspective and proposals of Part Three of the book, which is concerned with the goal of creating an information utility that can meet and sustain the evolving needs of health care in a wished-for, more mature and settled future Information Society.

Thus far, health care services have tended to bend to the limited capabilities and exigencies of embryonic and immature information technology. The challenge today is to refocus attention on the values, principles and goals of health care services, making use of today's considerably different and increasingly mature information technology, to live up to and improve on these, while continuing the exploration of new needs and potential that arise. As of today, the words of national information policy continue to mirror much of what was set out fifty years ago, dressed now in the dazzle and hubris of contemporary discovery and hype. Meanwhile, throughout the National Health Service (NHS), especially in remote locations far from London and other major cities, teams struggle with obsolete desktop computers and user interfaces, by far lagging those that they use in their personal lives at home. How can efficiency and improvement be truly the focus of policy when basic tools of personal productivity, available now, remain withheld, and much of the resource for innovation that is available is focused on futuristic ambitions of yet unknown efficacy and efficiency?

The next chapter, Chapter Eight, which leads into Part Three of the book, focuses on the changing nature of health care and an information utility matched to its evolving requirements. This is turning the world upside down, from what has been described as an Industrial Age preoccupation with disciplines, professions and institutions, to an Information Society focused on citizens and professionals, and their co-creation of health care in the communities they live in and serve. This brings a new perspective on roles and responsibilities at all levels, from the local to the global, with new focus on the balance, continuity and governance of trusted services, and

on teams and environments capable to lead and deliver them, including in support of education, research and innovation.

To be brazenly provocative for a moment, just to highlight the challenge and cost of wasted opportunities: we have sometimes spent ten times too much, badly, ten times too slowly, and achieved a tenth of what we can and must now realize from investments in information technology if we are to emerge from the past decades of information pandemic in health care. A paper from the Humana Foundation, highlighted in a recent report on health care trends by the Deloitte Consultancy, concluded that a quarter of expenditure on health care in the United States is wasted money.<sup>2</sup> That in a health system that spends much more, and is rated to achieve rather less, overall, for its citizens than international comparator systems. The report signalled a major reorientation of expenditure over coming decades, away from 'process and money' focused services to 'outcome and value' focused services, very much in line with the vision I am peering towards in Part Three of the book.

In Chapter Eight and a Half, mirroring Julian Barnes's parenthetical Chapter Eight and a Half in his *A History of the World in 10½ Chapters*, I describe major initiatives into which I have placed much of my personal creative efforts of the past thirty years. For me, these hold the key to reimagining the current Pandora's box of health informatics, to support an oncoming reinvention of health care services. They hold important lessons about *how* we should set out to make and do things, as much as about *what* we set out to make and do. In saying this, I fully recognize and welcome the fact that such ideas must become embedded within viable and successful supporting businesses, as well as in new health care services. I, myself, have not been a person sufficiently interested or capable to give such a commercial lead. I have, though, worked without financial reward, to support and collaborate with people brave and competent to do so, and been fortunate to have had role and remuneration from academic employment to enable me to do so. From this position, I have all the while argued for and held to a vision of the common ground on which I believe future commercial endeavours must be based, if they are to succeed in their mission of supporting a now essential programme of reform and reinvention of health care, matched to the evolving needs of the coming Information Society.

The question then arises as to how to create and sustain an information utility which serves the wishes and needs of citizens, by achieving greater and enduring rigour, engagement and trust in health care information

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2 K. Gebreyes, A. Davis, S. Davis and M. Shukla, 'Breaking the Cost Curve', *Deloitte Insights* (9 February 2021), <https://www2.deloitte.com/xe/en/insights/industry/health-care/future-health-care-spending.html>

and infrastructure, based on standards of consistent, coherent, affordable, well governed, safe and sustainable systems. This is the theme of Chapter Nine, which ventures into the sometimes-contentious world of Creative Commons, open standards and openly shared tools, methods and software.

Health care services seem always to be a work in progress and in an agitated state of flux. Circumstances, and ways of thinking about them, change continuously, as do political ends and means for achieving and financing them. If the reorganization of health care services at a national level might be compared with passage through the gate described in T. S. Eliot's (1888–1965) poem *Little Gidding*, it seems that we have gone full-circle several times, seeing the gate anew each time.<sup>3</sup> From the centre of government, it is inevitably a high-level view, as if from a helicopter circling above the fray. A bit like the image of President George Bush, filmed viewing the Katrina hurricane-induced floods from the encircling Airforce One presidential jet!

In contrast with the poet, we cannot reasonably claim that, based on experience and learning gained in each circuit, we are seeing the gate more clearly, as if for the first time. We are seeing a different gate in different context. Some of its structures are old and some are new; changing times rot and weather them. Some of them are hardy and others less so. Maybe different materials would fare better, but the downsides of new materials arrive with them, too. The enduring thought and perception after each circuit remains, however, of a rickety gate in need of fixing. We should always strive to make things better and more equitable, while recognizing that life itself tends towards becoming a rickety gate, and that health care services cannot always fix them!

This chapter now traces the recurring dilemmas about health care experienced through the Information Age, alongside the social, scientific and professional contexts of their times, the advent of information technology, and the information revolution it heralded. I draw on my childhood experience of social care and my career-long engagement in academic and professional communities of health care around the world. I start with some memories of health care in my childhood, revisiting the remote English village life I lived then.

## Village Medicine—Snapshots from Earlier Times

The detective in Agatha Christie's (1890–1976) novels, Miss Marple, was an amateur detective sleuth who lived her life in a small village. She claimed

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3 T. S. Eliot, *Little Gidding* (London: Faber and Faber, 1943).

that all human nature was revealed in observation of village life, and this was all she had, or needed to go on, in solving its crimes. Village doctors did not have or need a lot more, either, in diagnosing its illnesses.

Two of my great aunts lived in a tiny village, Hawkesbury Upton, on the Cotswold Hills in rural Gloucestershire. The family ran the village shop, which doubled as the pharmacy and bakery, and their uncle was the village doctor. The shopfront window had large glass flasks on display, each filled with a different coloured water, the trademark of a pharmacy. The doctor's surgery was immediately behind the shop and the family lived in a small cottage, in a row of them behind the shop building. Each cottage had a large back garden, and a small driveway led from the front of the cottages out onto the road, for horses and carts—originally no electricity and no cars, of course, just water and limited local drainage. In their living memory, relatives had walked the twenty or so miles, to and fro to the city of Bristol, to sell their wares in the markets there. I recall my aunts' mention of the famed Dr. Jenner, in their stories of village life.

Edward Jenner (1749–1823), the pioneer of vaccination and founder of the science of immunology, had lived and worked nearby in Berkeley. He trained in London at St George's Medical School. In his early village life, he observed the immunity conferred on women milking the cattle, immunized by their close contact with cowpox, against infection by smallpox. He had himself been painfully inoculated with pus collected from patients infected with smallpox. This led him to conduct experiments on combating smallpox through vaccination. A person of very wide scientific interests, he devoted much of his time to development of the method.

Smallpox is thought to have emerged ten thousand years ago in Africa, then spread to Europe in the fifth to seventh centuries. It was frequently epidemic in the Middle Ages and was taken to the Americas, by the Conquistadors, and spread elsewhere around the world. A spread occurring over centuries, that nowadays occurs in weeks and months. In 1797, Jenner submitted a paper seeking to alert the Royal Society to the importance of vaccination, but the idea was rebuffed as too revolutionary, and he was told to go away and do more work. There was a powerful anti-vaccination movement in those times, too! Vaccination was subsequently recognized as of huge benefit to the country's health, but Jenner did not pursue it for his personal gain—his income from other sources suffered as a result.<sup>4</sup>

My family often visited these great aunts as they lived on into their mid-nineties, hauling themselves up and down the very steep staircase

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4 The history is told in S. Riedel, 'Edward Jenner and the History of Smallpox and Vaccination', *Proc (Bayl Univ Med Cent)*, 18.2 (2005), 21–25, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1200696/>

in the cottage, cooking on a coal-fired range, gardening and talking. My grandmother from the same family had diabetes. Equipped with tiny weighing scales and spirit flame to sterilize insulin injection needles, she showed us grandchildren how to manage her medication and diet. Pneumonia struck and killed her, in the same village, in her early eighties.

In their childhood, my great aunts told us, patients would come to their doctor uncle, for such insight, advice and medicine for their ailments that could be provided, and often comfort and encouragement was the most useful. But there was trust and expectation for medicine and cure, and this had to be addressed, too. At the completion of the consultation, a note or prescription was written out and sent through to the shop. Among these, they said, was sometimes a request to dispense doses of ADTWD, which was duly acted upon. Laughingly, they joked that this stood for Any Da... Thing Will Do!

It sounded a bit harsh and unkind to our ears, no doubt, but it was probably not so much dismissive prescription for the worried well as rueful reflection of the reality that the problem was beyond medical scope or means. It is easy for a stage play to laughingly dismiss the craft of the physicians managing 'the madness of King George', and his unknown-about porphyria, by extraction of vapours, or regulation of high blood pressure by letting blood, but ways of thinking about illness and attempts to combat disease are very much the art of the possible, in time, place and wider context.

There are and have been many doctors in my immediate family. I wrote in the Introduction about my polymath uncle Geoffrey, a casualty surgeon, as the Emergency Medicine speciality of today was then known. My mother's other brother, Jack, a general practitioner (GP), sadly took his own life at a young age. Medicine can be a very tough profession. Those of today are from a different mould; no longer living on or placed on pedestals. The medical arts have been demystified in the Information Age, while the expectations placed on them have grown.

I recall another family visit in the garden of my great uncle Edwin, a retired GP, at his house in Southsea on the coast of Hampshire. My father was a keen gardener. He gardened on a large scale, feeding twenty-five children and staff from a huge, partly walled kitchen garden in the twenty acres of land belonging to the children's home we grew up in, run by my parents. He produced enough to send to other children's homes in the county. I can see us, now, gathered in the garden in Southsea and Uncle Edwin talking about his life as a GP. He showed us the device used for excising infected tonsils. In early times, this was commonly done by a GP, with the patient, usually a young child, lying chloroformed on a table in the surgery. He pulled up a cabbage and demonstrated the procedure by chopping off the stalk. I can



still see that image in my mind. I was six years old and had recently had my own tonsils removed, after a long period with persistent sore throats, so my experience of the episode and the post-operative pain was still fresh. Maybe he was thinking it might make me realize that I had come off lightly!

My own most serious childhood brush with acute medicine was a major concussion and bruising, remaining unconscious for a long time, after crashing while riding my new bicycle. I had been racing along the long gravel drive from the gate to the house of the children's home, against one of the other children, who was running. The beloved bike had been renovated and painted by my dad, for a birthday present when I was about nine years old. I came to, lying on my parents' bed with village GP in attendance and worried parents and others around. I was sick, aching, cut and sore, severely concussed and confined to bed for days, and then slowly nursed back to recovery at home. No ambulance, accident and emergency department, or hospital attendance. Just the one GP covering several local villages, his box of tricks, bed rest and my parents' care at home.

In everyday life, care was largely based on domestic skills and country folklore, gargling salt for throat infection, inhaling menthol vapour for colds and lung congestion, and taking aspirin for pain relief. My great aunts took half an aspirin tablet every day throughout their adult lives, as anticoagulant, they told me. In my village, such remedies were available at the small village general store, which doubled as post-office, bakery and grocery, although most families grew vegetables. Village communication centred around the primary school for fifty pupils, church and church hall, pub, sweets shop, farmyard, woodyard and the village bobby's (policeman) house. School dentistry came in the form of a dental team, who extracted numerous rotten teeth in their mobile caravan-based surgery parked in the school playground. Those awaiting their turn for so called 'laughing gas', were not laughing, but subdued.

## Health Care Services Today

My childhood village is no more; it now has quite different global contexts and connections. Geography no longer functions in the same way as a moderator of information, service, expectation and demand. And health care services today are more complex, beyond recognition. They are separated but not separable; managerially segregated more than integrated. The village health services of my childhood were largely centred on care, as when dealing with my severe concussion after the bicycle accident. They are now more heavily focused on treatment. Resolution and palliation of exacerbated chronic back pain, in city and village today, is predicated on

access to and length of queue for physiotherapy, X-ray or magnetic resonance imaging (MRI) scan, surgery and tolerance of powerful analgesics. Regular exercise classes to guide and support are mostly out of scope, save for those who can pay.

The fragmentation of efforts to treat and care has highlighted and exacerbated the difficulties in maintaining resilient balance and continuity in what is done and sustaining ethical governance of the services and technologies employed. Especially so for services working at the interface of mental health problems, physical disability and what are termed illnesses of poverty. With increasing range and effectiveness of interventions have come increasing needs for care, especially in relation to chronic and incurable diseases, and lengthier old age. Much of the caring load is shouldered by families and friends at home, and by the goodwill of neighbours and community volunteers.

### Aftermath of War and Seven Decades On

In the UK, experience and attrition of the Second World War was followed by years of hardship in the reconstruction of economy, buildings and lives, buoyed by a spirit of relief and hope for the future. The cost and destruction of wartime created a new ground zero. It opened the way to radical new thinking, with openness expressed through mutual trust in common endeavours.

The hope for transforming change was notably stimulated by William Beveridge's (1879–1963) report on social services, that had been published in 1942. Politically and professionally contentious at the time, but striking a chord in the country at large, this advocated and came to underpin the reframing of health care services. Its wider focus echoed the social deprivation experienced in the years of recovery from the 1914–18 war and the economic collapse of the 1930s, that impacted and influenced my parents' lives. My father's brother, once successful in his work, never recovered zest for life after many years of unemployment and poverty. The report was a powerful signal that shaped policy of the early post-war years. It used graphic language to describe the need for battle on five fronts—want, disease, ignorance, squalor and idleness. Elimination of poverty, a national health service, universal education, good housing and full employment were adopted as essential elements of national reconstruction.<sup>5</sup>

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5 These issues echo in the Marmot Reviews of recent years, on social inequalities of health, today (M. Marmot, *Fair Society, Healthy Lives: The Marmot Review: Strategic Review of Health Inequalities in England Post-2010* (London: Marmot Review, 2010); M. Marmot, 'Health Equity in England: The Marmot Review 10 Years On', *BMJ*,

The UK National Health Service was established in 1948, when I was not yet three years old. It was thought of as a central organization of the professional practice of medicine. Nurses and nursing care were generally thought of as subservient to doctors and medicine, in both gender and professional terms. A generation of young men had died or were severely disabled in warfare and this loss echoed sadly in the lost life opportunities of many women of those times, and of returning soldiers.

In later decades, and battle-scarred in his efforts to promote international focus on climate change, my university physics lecturer John Houghton (1931–2020), who died early in the pandemic from complications of Covid-19 infection, wrote that humankind might only take such major issues seriously after experiencing a disaster. In the information era, advancing technology has increased the potential scale, spread, impact and cost of destructive human-made mess-ups. The experience, today, of disease and threat to livelihood in a viral pandemic may also prove a spur to new thinking. It is in no way the same experience as armed conflict and deprivation of wartime, but in the response to the fears and uncertainties of the times, expressed through mutual support within close neighbourhoods, there is similarity.

In 2020, when for the first time there were more people aged over sixty-five than under five, David Goodhart's characterization of the social and political crisis of today is again radical in its thinking.<sup>6</sup> His diagnosis is of an accumulating underlying imbalance of head, hand and heart, in social, economic and political life. Goodhart observes that society has split between poles of globalism (characterized by what he calls 'anywhere') and localism (this characterized as 'somewhere'). He describes imbalance in social status, value and reward accorded to the contributions of all citizens, reflecting head (cleverness), hand (skill in making and doing) and heart (care). His anywhere and somewhere are metaphors for interacting global and local contexts, that play out in people's lives. The curriculum of medical education, today, emphasizes integration of knowledge, skills and attitudes, mirroring Goodhart's triangle of head, hand and heart.

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368 (2020), m693, <https://doi.org/10.1136/bmj.m693>. Michael Marmot was a senior colleague at UCL when I returned there in 1995). Marmot combined academic aristocracy with sustained research focus on public health. Like many epidemiologists I got to know, he had trained as a doctor but did not pursue a clinical career. He has been an assiduous gatherer and publisher of data, using his passion and organizing skills to create and sustain long-term longitudinal studies and engage widely and internationally in health policy issues of the day.

6 D. Goodhart, *Head Hand Heart: The Struggle for Dignity and Status in the 21st Century* (London: Penguin Books, 2020).

The 1942 Beveridge Report and the 2020 Goodhart book combine observation of ailing society in two different eras with account and reasoning about how these came about and what needed to be, could and should be done about them. Diagnosis and prescription of treatment for ailing society and for an ill patient bear some comparison.

In a clinical setting, with a patient who presents as sick, the professionals' goal (on which the patient tends to concur!) is to help them cope and get better, as best possible. Easily said—sometimes clearly, straightforwardly and quickly achieved, but often not. Treatment and clinical management goals set, actions taken and their reasoned basis articulated, evolving context monitored, progress made and outcomes resulting: all of these provide evidence to inform the review of what was done, how and why, and possible need for adaptation and change of approach—maybe more of the same, or a different medicine, and maybe less.

In clinical practice, failures tend to disappear out of focus. Patients die, problems of acute concern are resolved, or they dissolve into longer term concern for the effective treatment of chronic illness, adjustment of lifestyle and supportive care. They move beyond clinical professional scope into scope of the coping ability and capacity of patient, family and their local community, and both local and global support services available to them. In society more widely, failures of health care policy may lead to crisis and breakdown, persist, adapted to or unchanged, amplify or decline. Global policy and decision makers perceived to have failed or to be no longer relevant, lose credibility and power. Wider ailments of society become local problems of personal health care—the Beveridge giants, and the Marmot inequalities of health. Policy for health care easily goes astray in the noise and bias of changing times.

Chaotic presentation of illness in a patient has first to be assessed, and immediate priorities coped with, before underlying problems identified can be treated and managed clinically—usually, the earlier addressed the better. Health care starts with patients, family and community. These people are on the frontline of early awareness and experience of the signals and noise generated by the onset of disease. The health care systems must first connect with, cope with and reflect that reality, and be demonstrated and observed to do so. The global and local realities of health care policy, systems and services need to cohere—and be seen to do so, for citizens and professional teams alike—if they are to prove efficient and effective, both in deciding on and achieving their goals. Beveridge, Goodhart and Marmot attest that they do not cohere. The advent and anarchic patterns of adoption of information technology have played a significant part in both revealing and exacerbating this situation.

In the light of recurrent failure, questions arise and persist concerning not only what was aimed for, but also how it was approached and whether it has proved to be, and remains, a realistic goal. They persist in the context of information policy for health care. What and where is the common ground on which citizens, local communities and professionals engage? What and where is the common ground on which health care systems and services engage? What and where is the common ground of information technology and information for health care?

In such deliberations there are helicopter views and views from ground level. High-level views look further, but less specifically and sensitively. Ground-level views may not see beyond the reality that lies nearby in their focus of interest, and can thus obscure, dominate or preclude wider perspectives. Economists talk of macro- and microeconomics. Macroscopic focus is on whole systems, broad brushes and big picture, and head-up overview. Microscopic focus is on parts of systems, fine details and the hard, head-down graft of coping with and implementing action, close at hand. They may be pursuing the same or quite similar goals, in one way or another. One is mainly about what is sought, the other mainly about how to achieve it. These are matters of head and hand, and success often depends on a good heart. Head, hand and heart cannot always be balanced but they need to connect how macro-level goals are tackled at the micro-level. Where they fail to do so, they easily stir angry feelings on all sides.

An incident comes to my mind, involving a rather cantankerous professor of surgery, whose weekly ward round I was invited to attend in about 1969, as I mentioned briefly in Chapter Five. I was also invited to attend an operating theatre, to observe the innovative open-heart surgery of the times, made possible by extracorporeal blood gas exchange. I have vivid memories of those wavering first encounters with acute medicine services! The surgical professor specialized in a technique of gastric surgery that severed the vagus nerve, to treat patients suffering from stomach ulcer—a common approach, then, in combatting the erosions stemming from stomach acidity.<sup>7</sup> He approached the bed of a clearly very unwell and

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7 This was in the years before H2 receptor antagonist, proton pump and H-Pylori, the science of which was developing in tandem collaborations between academic pharmacology departments and industry, led by James Black (1924–2010). Black was a colleague at University College London (UCL) in a triumvirate of supremos, with John Vane (1927–2004) and Salvador Moncada. They shared common working links with the Wellcome Foundation pharmaceutical company and London Universities, laying scientific foundations for the future global pharmaceutical industry. Black is remembered for the invention of the cimetidine and propranolol drugs and was awarded the 1988 Nobel Prize for Physiology or Medicine. Vane led the unravelling of the mechanisms of aspirin

seemingly very depressed patient he had operated on a week before and enquired of his wellbeing. Seeing and hearing the patient's considerable distress, he offered crisp words of sympathy and turned quickly to the ward sister, suggesting she might offer him a glass of sherry each day! Walking to the next bed, closely followed by his senior registrar, he turned to him and said, loudly and angrily, that he did not expect to see that patient still there at the next ward round, and to 'get that patient well!' I can see the scene in my mind as I write.

Those were different times and more normalized to what, for us, seems a chillingly autocratic, archly detached and 'Doctor in the House' manner in directing clinical teams, but the relevant concern was, and remains, how? This situation, in microcosm, is what can easily happen with health care. If one cannot cope, another one gets reprimanded, and rides the punch as best they can. People do get angry when even their best efforts and intentions run aground. As with the irate professor, intractable challenges give rise to a good deal of anger and finger-pointing within health care—from the top floor of the NHS in Whitehall and its politician and managers to the most remote parts of the community served. As with the hapless senior registrar, teams at the bedside and in the community are all too easily chastized, resulting over time in them losing motivation and sometimes, themselves, falling ill. It takes considerable and invaluable dedication and balance of heart and mind to steady the hand and keep going. Those facing these situations can easily become like the depressed patient in bed. Senior doctors in that long-ago cantankerous professor's team told me that he drank heavily in his office at work and operated unsafely. He was maybe depressed, too—he died quite young. Health care, like teaching and policing, is a tough profession—tough to organize and tough to cope with.

The Information Age is revealing the inequalities and imbalances of health care in a new light. To the extent that computerization fails to engage

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and angiotensin-converting enzymes inhibitors. He was a co-recipient of the 1982 Physiology or Medicine Nobel Prize for discovery of prostaglandins. Moncada worked with Vane at the Royal College of Surgeons, then at The Wellcome Foundation, where he played a seminal role in unfolding the biological function and metabolism of nitric oxide. Many puzzled as to why he was not recognized for this in the 1998 Nobel Prize in Physiology or Medicine, which celebrated that field of discovery. After leaving the Wellcome Foundation, Vane came to establish the William Harvey Institute at St Bartholomew's Hospital (Bart's), in the building adjacent to my office at the time. I worked with Moncada when he came to UCL in the mid-1990s, as founding director of the William Harvey Research Institute, where he also led the work to draw together and coordinate UCL's then rapidly growing range of specialist biomedical research institutes. We conferred on the development of a common strategy and team for their IT support services, that I was leading for the Biomedicine Executive Group.

realistically with their resolution, it exacerbates them. To be a creative agent of their resolution within the oncoming Information Society, the information utility this book is arguing for must be conceived and created as a balance between local and global services, and the needs and experiences of those they serve. Resilient balance, continuity and governance are central themes it must pursue. BCG (Bacillus Calmette–Guérin) vaccination was highly effective against the tuberculosis epidemic. Information utility must focus on another BCG–Balance, Continuity and Governance–to counter the current plethora of unbalanced, discontinuous and unregulated sources of information. Citizen engagement, professional teamwork, education, innovation and professionalism in health care services are all in need of the common ground that a good information utility can enable and support.

### The National Health Service

In *Medical Nemesis*, Ivan Illich (1926–2002) described how in the fervour of the French revolution, it was promised that liberty equality and fraternity would banish sickness—a national health service would take charge.<sup>8</sup> The promises of the UK National Health Service were lofty ideals, but not quite that elevated!

The founding father of the NHS, Aneurin Bevan (1897–1960), was a beacon in my parents' lives. They were strong believers in the Beveridge and Bevan missions and relied and acted on this belief, thereafter. As mentioned before, my dad left school at fourteen—his father had disappeared to Australia and his mother died of cancer when he was a teenager. My mother left her domestic science college, and a subsequent period on the staff at Gordonstoun School (including looking after Prince Philip when he was a schoolboy there), to head off to Catalonia to look after refugees from the Spanish Civil War. The ever-changing landscape and experience of health care services over the following decades bemused and upset them in equal measure as they grew older. They experienced the evolving science and technology underpinning its methods, and the professions and organizations delivering its services, through the decades of challenged and changing post-war society. It was a kaleidoscope of images and feelings—gratitude, trust and hope mixed with growing experience of incoherence, inconsistency and disappointment.

From the Beveridge Report had emerged the policy and plan for a comprehensive national system of social insurance 'from cradle to grave',

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8 I. Illich, *Limits to Medicine: Medical Nemesis: The Expropriation of Health* (London: Boyars, 1995), p. 109.

paid for by working people and providing benefits for those unemployed, sick, retired or widowed. It laid the foundations of the NHS in a society where medicine was less capable, diseases more often short-lived and ageing more rapid. Childcare, and other care services, such as convalescent care, were organized in residential settings, such as the children's home where I grew up. Mental hospitals provided last resort containment of the uncontained or uncontrollable problems of mental illness. They were awful places to experience. I did so in a volunteer work camp in my teens, making a garden for the residents to enjoy, and, in later years, visiting family and friends unlucky to need their care.

In this policy framework, power over the management of the health system and practice of medicine became an increasing concern of central government. Specialization of services, and their associated professional skills, increased alongside advances in knowledge of disease and availability of effective treatments, reinforcing the case made for centralization. Specialism and its associated research, education and regulation could only advance, and be afforded, for the whole population, when organized at district and regional levels and in national centres.

Specialist services are primarily acute and episodic in nature. Even people living in a remote village can and will, for a time, be able to accompany a child being cared for within the unique and necessary environment of a national centre.<sup>9</sup> But it is not home, and life must continue at home. There is a natural wish for acute services to be conducted as close to home as possible, and this brings tension—communities campaign for and defend against loss of nearby hospital facilities. Effective acute services delivered at or near home are much desired. A better balance of hospital and home is increasingly within scope of the Information Age.

Social care services are, by their nature, longer term and predominantly less specialized. They are needed, and need to operate, near to home. They have nationally defined frameworks that guide and support good practice, but the management of these services rests with local government. And the disjunction of operation and governance of health and social care services is destabilizing and inefficient. It has reflected lesser social and professional status of care services, seen as priority of heart more than head. Care services are matters of hand, as much as are those of the surgeon's hand, but, as with many such skills, in Goodhart's view, not valued as such. A patient looked after with thought and kindness may cure themselves of a stomach ulcer and not require surgical or pharmaceutical intervention. Their health and life may never fully recover from laparotomy and section of the vagus nerve

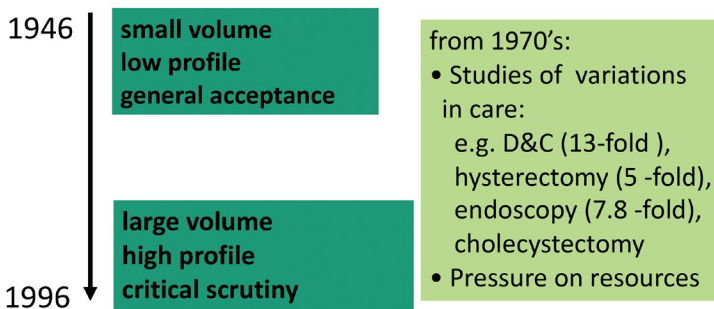
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9 Disproportionately, that meant the capital city, London—but therein lies another story, persistent to this day, about the connection of medicine with politics!



or may experience harmful side-effects from prolonged drug treatment. The cost and benefit from helping a patient cope with and find resolution of a stomach ulcer in a caring community and home setting, with due diligence that nothing more sinister is evolving, and the cost of the potential medical and surgical alternatives, bear no comparison. The achievement of such a win-win scenario for patient and health system will depend significantly on a better connection between these different worlds of health care—a more individual citizen- and patient-focused information utility will be central to the pursuit of that goal.

## The changing UK health service



Reasons multi-factorial: pressure of medical advance, recognition of variances in care, public/patient pressure

J. Swales, NHS Director of R&D, 1996

Fig. 7.1 The changing NHS from 1946 to 1996—after a lecture of John Swales, Head of the NHS Research and Development directorate, 1996. Image created by David Ingram (2010), CC BY-NC.

In celebrating the coming fifty-year anniversary of the NHS, halfway through my career, the then head of Research and Development of the NHS, John Swales (1935–2000), gave a seminal lecture at St Bartholomew's Hospital (Bart's), charting the changes in the service since its inception. He was a colleague Professor of Medicine of John Dickinson, and came there to conduct final examinations, I recall. They shared an interest in the aetiology and treatment of hypertension. In the lecture, a slide from which I made notes (see Figure 7.1), he observed that medicine at the outset of the NHS might be characterized as small, with low public profile, and enjoying general and uncritical acceptance—its interventions often being relatively ineffective but harmless. By comparison, fifty years on, it was much larger

and more effective, while, at the same time, at greater risk of doing harm. It was a high-volume service and under much increased critical scrutiny. He highlighted the pressure of medical advance, variance in pattern and quality of care provided, and public and private pressure as underlying this changing pattern.

Risk and safety have become overarching concerns in medicine. As the tools and methods available have increased in power to do good, they have also increased in power to do harm if misapplied, either by misguided design or unlucky accident. New balances of risk and opportunity, cost and benefit, unfold alongside innovation. As we saw in Chapter Five, new ideas and designs often stretch the boundaries of welcomed, accepted, and trusted practice. Engineering experience and expertise is central in partnering scientific creativity and focusing and guiding its fruits to useful ends.

There has been significant change, also, in the demographic diversity of the UK population. Diversity and inequality of health care among different socio-economic and ethnic population groupings, has emerged more clearly as of major significance and concern. It manifests in prevalence of disorders, effectiveness of interventions and inequity in their provision. It has many determinants and Marmot at University College London (UCL) has been a formidable champion of this important research and advocacy. In another dimension, there is considerable genetic diversity—as studied by my colleague Bernadette Modell in the context of her pioneering work, centred in North London and now influential through the World Health Organization (WHO), internationally, which I profile in Chapter Nine. She focused on integrated community and hospital services for people who have inherited or are likely to inherit haemoglobin gene variants associated with the blood disorder, thalassaemia. The ethnic diversity of this variant, globally, and the diversity of socio-economic stratification in one London Borough, are illustrated in Figure 7.2.

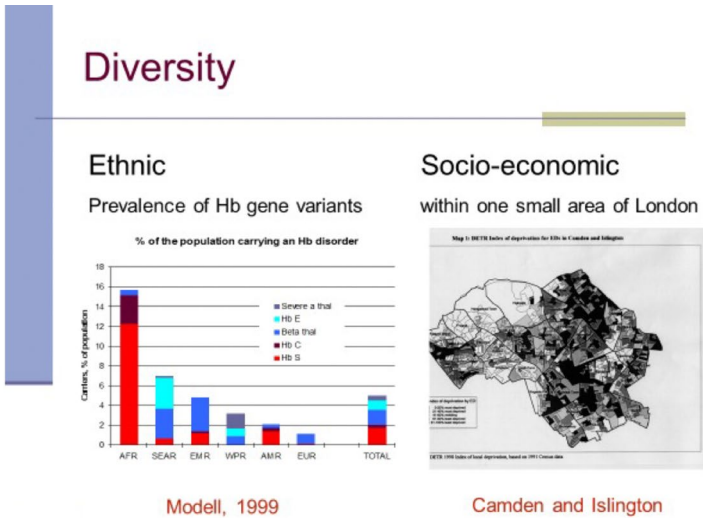


Fig. 7.2 Maps of ethnic genetic diversity, internationally, and diversity of socio-economic stratification in one London Borough—after Bernadette Modell, 1999. Image created by David Ingram (2010), CC BY-NC.

Since its inception, the NHS has featured continuously at the centre of UK national and local politics. Different political perspectives have battled one another, aligning with different models of how services should be scoped, organized and managed—operationally, financially, commercially and professionally. In recent decades, ideas have swung like a windvane, buffeted by centralizing, localizing, nationalizing and privatizing winds.

It has become a habit to impose additional breaking changes on ailing services. Review and reorganization have led to costly and unproductive waste of time and resource, at onerously frequent intervals. This has increased the burden on services that were already struggling to keep pace with scientific and technological advances, to improve, achieve and sustain continuity of care. Resource needed at the coalface of care has been diverted to new organizations defining, pushing for, managing and regulating change imposed from above. The standard of ward level accommodation on the ground has been let down—in too many hospitals across the country it is old, decrepit and unclean. This is not a conducive environment for treatment and recovery.

Many people work and seek meaning in their lives through service within the NHS: those that engage clinically and in social care, those that provide and administer support services, and those that manage services and their relationships with organizations beyond the NHS. They constitute

a tremendous asset. But such appetite for and commitment to the NHS has tired noticeably in recent times. I have seen this when working with clinical colleagues, close-by to wards, through our clinical family's experience, and in visits to family and friends being cared for.

These endemic problems of the NHS reflect its scale, range and diversity. It encompasses both laudably leading, and unacceptably and worryingly wayward, facilities and services. Viewed as a whole, governance is also fragmented and unwieldy, hampered by the separation of health and care policy and practice. And as a result, information systems are unfitted to connect with and respond flexibly to local health care needs, and advances in underpinning science and technology. As with the super-tanker delivering oil that cannot slow or change course for many miles, even with the application of maximum thrust generated from its power source, it is set in its course. It would be an unimaginable nightmare to reroute the delivery of oil by running a full tanker aground, mopping up the spillage and sending for another one! Repetitive rerouting of the delivery of health care services is a perilous course.

It is not good sense to project the responsibility for this complexity onto information technology (IT), either as cause or panacea; it is and can be neither. IT mayhem typically reflects poor understanding, inadequate capacity and capability, and poor practice. As a colleague sitting on an overseas national policy board for health IT remarked to me recently, its members know things are not good, have a limited sense of why, have little idea how to improve, but above all fear that what they decide to do will prove a mistake. It is little surprise that senior health managers tend to view too close a connection with IT as career suicide!

When I sat for a period on the equivalent national IT board for the NHS—populated it seemed, mainly by battle weary and sometimes rather cynically resigned managers—I was quietly removed for introducing what I saw as root causes of their dilemmas, that were perhaps too difficult to hear. Or perhaps my thoughts and ideas made no sense to their ears, and they knew better. The then Prime Minister was persuaded to commit many billions to a programme of investment for which the basic tenet and promise from the industry—in simplest terms, pay us enough and we will do it—proved substantially unsound. I watched this path develop in surreal meetings of consultants, companies, health managers and bemused IT departments in our local health economy around UCL. The consultants and companies were very well paid, the real costs in the health economy were hidden, and those keeping services running were distracted and wearied. It was not all bad—some good infrastructure did emerge, but too distant from the direct support of patient care that was needed.

Given that the NHS, corporately, speaks of itself as a learning organization, it is amazing that it retains so little knowledge of past policies and programmes which have gone through multiple groundhog days of rebooted information strategy. Some things are, no doubt, best forgotten, but some of the experience could and should have been learned from, better. The root cause of the problems of IT legacy and underperformance in health lie in inadequacy of method, capability and culture—all problems of connection. They are all problems in need of a good and proven answer to the primary question: How? Answers to What? and Why? questions are endlessly rehearsed and reframed, with little added meaning, as evident from the track of policy statements over fifty years that I lay out below.

The *how* answers proffered to entice the opening of the public purse were typically slides and spreadsheets, presented by people who had never designed, implemented and operated such systems. Those listening to proposals for significant scale of action pursuant to policy implementation should be guided by a principal imperative—to be informed and critical when reviewing what is being talked about and promised. The response to the challenge of ‘show me’ was, too often, like pointing to a car at a motor show, hidden under covers before launch, to appetize but not reveal. And in any case, there were few experienced mechanics around, to recognize and understand an engine under a bonnet when they saw one. The who, when and where answers were a mixture of assumption and delegation. The domain had become a minefield of political, commercial and managerial mayhem.

It is a good goal to seek to use IT to help and support people, services and organizations as they adapt and grow, locally and across the now almost fully connected world. Wisdom in pursuing this would be to recognize a new culture of information as an organic entity, best served by identifying ways to nurture and help it grow well. How we do that matters as much as, if not more than, what we do. The only route to doing things better is to learn how to do them better. The NHS should have identified and learned from IT pioneers, who were already charting the way and building it around them. In practice, it marginalized them and placed its trust in hubristic and unmet promises from people and vested interests of less relevant track record, placing its chips on squares where burden was often added, more than relieved.

## Balance

There are many kinds of balance and imbalance in play in health care. They reflect the complex contingencies of individual, family, community and

environment. They span personal, professional, scientific, social, economic and political domains, and changes among them over time. Imbalance and inequality of health care have persisted and become further highlighted in the anarchy accompanying transition through the Information Age.

The human body is an autonomous entity, evolved to preserve homeostasis—resilient immediate bodily balance and long-term sustainability. Medicine is focused on supporting or restoring this homeostasis. Accidents and disorders of all kinds disturb and threaten this balance—mutation of genes and accident and shock of traumatic events can grow to overwhelm both physiological and emotional balance. There is ever-growing scientific and clinical knowledge of the body's homeostasis and how best to cope with and treat the disturbances and threats that arise. Metabolic and physical balance and resilience get harder to sustain with age—I know that experimentally at my age, when dance and Pilates are proving amazing examples of how one can help oneself to maintain balance of body and mind, while keeping fit and having fun.

Good health care is a balance of giving and receiving, of what can and should be offered and done in support, and what can and should be expected and accepted, by and from whom. Everyone professionally involved in that balance is bringing themselves, and their knowledge, experience and expertise, to bear on supporting health and providing care. They are often exposed to extremes of human need and suffering of those they serve, and difficult to achieve expectations vested in them, as the supporting professionals. They themselves have special needs. We all need to be cared for and we all need to give and receive care. There is, as ever, a balance of rights and responsibilities.

The centre of gravity, or point of balance, of the expectations and experience of patients and professionals receiving and delivering health care services is not a fixed point and has changed considerably over time, as has the trust that holds things together; very much so in the context of the Information Age. The fulcrum has not easily adjusted in keeping with this change, and health care systems have become overburdened and swung increasingly out of balance. This instability has led to overloaded services and related critically adverse events, litigations and enquiries, reflecting failure, dissatisfaction and public concern. Inevitably, such imbalance does sometimes ramify in thoughtless, incompetent and uncaring action of service personnel, with potentially unhappy, harmful and inequitable consequences for patients. But the high level of personal commitment of its coalface workforce is a common ground on which the professions pride themselves and the NHS depends, and that workforce sometimes experiences overwhelming personal pressure in delivering and sustaining wished for high standards of care. Health care services look to be at their

affordable limits in society. Something more than money is needed to restore balance.

The state of the health care system and the state of health of the individual citizen are connected. Governments may issue White Papers about 'The Health of the Nation' but, in their essence, health and care are personal matters. As with clinical decisions about the health of an individual patient, policy for health care services often does not have clearly right and wrong answers. It reflects a balance of advocacy and decision on behalf of both citizens and services. Patient care is nowadays seen, more explicitly, as a balance of a patient's individual needs and wishes, the roles of professionals and services that are there to treat and support them, and the roles they themselves can and should play, in sustaining and maintaining their own health. Whatever the choices made, decisions reached and actions taken or not taken, there are consequences, for better and for worse. These balances have become more evident and explicit in the Information Age.

## Continuity

Continuity of health care services is a central concern in need of closer attention. The anecdotes from my family's village life were examples of the limited range of what was possible in the countryside, with radio but no television, and with the small community hospital, dentist, pharmacy, library and bookshops five miles away. Very few people possessed the rudimentary small cars of the era and there were only twice-daily buses to the nearby town. The next level of hospital service was centred twenty-five miles away. But there was, despite that, good continuity of care and communication, in community life and through local visit and telephone. By and large, people expected and were expected, to cope as best they could. Villagers feeling ill suffered more than they perhaps should or might have, accepted the realities of what was, and generally trusted in the good intentions of all concerned, with limited expectations and a generally good spirit, in my recollection. Expected lifespan was a lot shorter, of course. There were many inequalities of village life in the countryside, including burdens of disability and poverty, but the lone, multi-village doctor was not in the firing line of people's dissatisfactions.

Health care services through the intervening decades since then have become more expensively capable and more extensive, specialized and fragmented. Specialized services exist within more tightly managed boundaries of professional roles and responsibilities. Consequently, the patient and their ongoing care and support needs are partitioned across many interfaces of specialism and organization. These interfaces are often

seemingly ownerless. Each side has its own image and perception of the world on the other side of the interface. Admission and discharge across the interface seem akin to steps through the magic window of Phillip Pullman's trilogy, *His Dark Materials*, between different physical and emotional worlds of bodily health and continuing care.<sup>10</sup>

ConCaH, which stood for Continuing Care at Home, was a small national organization set up in the mid-1980s by an amazing GP pioneer, Bob Jones, working in Seaton on the southwest coast in Devon. He was a bundle of good humour and immense energy. In the 1980s, we worked together under the auspices of the Marie Curie Foundation, developing a videodisc-based professional educational resource entitled 'Cancer Patients and Their Families at Home'.<sup>11</sup> He asked me to become one of the ConCaH patrons, to represent the potential of IT to transform the then current scene in improving continuity of care.

One of the activities Bob pioneered was a series of one-day meetings, linked with the national Parkinson's Disease Society, in which he was also active. The purpose was to bring together patients with Parkinson's disease and the different professionals providing them with health care support, to share their different perspectives and experiences of their services. In the mornings, the professionals each separately described their roles and contributions—secondary and primary care doctors and nurses, community nurses, occupational health and social care teams—sometimes seven key workers for a single patient. In the afternoon session, patients being looked after by these people shared their experiences of the care and support that they received. This led into further discussion and re-visiting of the morning session.

One notable case study was of a family with whom education and employment services were also involved, and their description of a week in which there were twenty-seven unannounced and uncoordinated visits to their home. It was an extreme example but differences in mutual awareness among professionals, and lack of coherent information and continuity of support for patients, was a recurring theme.

There is something reminiscent, here, of the Thomas Lincoln (1929–2016) story I recounted in the Introduction, where the extent of data collection in the management of severe pneumonia correlated with an inability to act effectively to combat the disease. There is also something of the example mentioned in Chapter Four, on the modelling of clinical diagnosis, where

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10 P. Pullman, *His Dark Materials Trilogy* (London: Scholastic, 1997).

11 D. Ingram et al., 'An Interactive Videodisc "Cancer Patients and Their Families at Home"', Designed for Education in Primary Health Care', *Journal of Audiovisual Media in Medicine*, 15.2 (1992), 73–76.



information overload was seen to confuse rather than clarify decision and action. And something of the information and entropy thread followed in Chapter Six, descriptive of order and disorder of systems.

Chaotic times can reveal underlying strengths as well as lurking problems. Personal crisis experienced can reveal and engender self-reliance and a stoic capacity to cope, as well as an inability to do so. But the discontinuity of care highlighted in the ConCaH story is costly and inefficient, as well as ineffective and unnecessary. We should not complain too loudly, though. This is a future we have created, and it can be created differently. Edmund Burke (1729–97), the Irish politician whose statue stands outside Trinity College Dublin, and which I often passed by when attending meetings to examine students at the College, wrote in 1770 about the ‘cause of the present discontents’. He wrote that ‘To complain of the age we live in, to murmur at the present possessors of power, to lament the past, to conceive extravagant hopes of the future, are the common dispositions of the greatest part of mankind’.<sup>12</sup>

Disjoint sources of information foster the noisy complexity of information systems, obscuring signals that need to be seen and heard, and leading to the fragmentation of services that depend on them. There is an example to learn from, of things managed better than this. Within single and more acutely urgent professional domains, managed and treated by one well-led and focused team, services seem more often to be enabled to perform well. This was a key theme of Atul Gawande in his book, *Better*, where he described his survey and visits to regional centres of excellence in the USA, for patients treated for cystic fibrosis. His goal was to understand what made one better than another, in terms of their organization, leadership and teamwork, and the quality of service they provided.<sup>13</sup>

In chronic disease management, which interfaces hospital and community-based services and self-care, isolated records have not connected well, with gaps persisting and little continuity. Such disconnection has pervaded more widely in the Information Age. On average, of the order of twenty percent of professional time, it has been estimated, is spent in managing information. Assembling good and useful data costs time and effort, of course, but twenty percent is a considerable overhead and imposes significant operational burdens on teamwork. If the information systems being fed are not well-tuned in support of health care needs, the loss of

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12 E. Burke, *The Works of the Right Honorable Edmund Burke*, vol. I (New York: Little, Brown, 1877), p. 437.

13 A. Gawande, *Better: A Surgeon's Notes on Performance* (New York: Metropolitan Books, 2007).

resource and capacity to treat and care is disabling—potentially making things worse, overall, not better.

## Governance

Governance, which I take to include issues of professional ethics and regulation as well as oversight of services, has assumed heightened importance in the Information Age. The needs and legal requirements to handle personal data confidentially and meet more exacting standards for demonstrating the effectiveness of services and safety of medicines and devices, have multiplied in recent decades. Professions are nationally regulated. Medicines and devices are overseen by national bodies, consistent with international agreements which govern the markets and industries that supply them. Information systems are slowly being assimilated within this framework. Health services embody a mixture of local and national governance and accountability, within the organizations that manage them and the communities they serve. Each level of governance has different requirements and views of operational records of care. Health services are, in the main, governed nationally, high up, and care services locally, low down. Both are experienced locally, by patients, carers and professionals. There is one operational reality to observe, record and account for. There are many and inconsistent accounts, which can then easily misrepresent and confuse.

Regarding local services, the situation is well symbolized by the Escher lithograph entitled *Up and Down* (1947; discussed in Chapter 6). The world as a small boy sees it, looking from low down, and the small boy as the world seems him, from high up. The small boy on the ground might be a patient. The viewer above a governor or regulator, of one sort or another. The join of perspectives is seamlessly fantastical.

Systems of governance seek to provide balance and continuity between the dual perspectives represented in this image. For this to succeed, they need trusted common ground on which to operate. To be effective, this requires coherent data collected with a minimum of burden on practice. Critical incident reporting across the NHS, involving thirty different formats of data collection, is not a happy state-of-affairs, as I refer to in the section below on the ‘wicked problem’ of health policy. It reflects a general lack of coherence of data and record, and that has become progressively unmanageable and ungovernable.

People do not doubt the good motives and intentions in play on all these levels. But the picture one sees and the evidence one collects depends on where one is looking from and the spectacles one is wearing. It is a

picture in which the viewer is also a participant, as the Escher *Up and Down* lithograph depicts. The boy pictured looking from bottom up, sees himself in the picture seen looking from top down. A similar illusion features in *Print Gallery* (1956), where the picture is of a boy looking at a picture in a gallery, which morphs, as one's eye moves (through top left, top right, bottom right, bottom left) into a picture of himself, within the gallery, viewing the picture.<sup>14</sup>

The experience and resources on which all services draw, is best shared efficiently, cooperatively and collaboratively, and supported with coherent data, not beset by unnecessary duplication of effort. This requires common ground of information systems, not just a postal service between different ones. Although that too can be useful, it is not enough. Policy failure at this level reinforces damaging professional and organizational boundaries, and the failure of resilient balance and continuity of services for those in need. The information utility required can only grow from this common ground. Common ground is open ground, and it is governance of this open ground, on which we need to focus, as we progress from Information Age to Information Society.

## From Local to Global Village

There were advantageous characteristics of the village community of my childhood, which it would be good to see revived and renewed in the global village community of today. A principal aim of Part Three of the book is to propose and show how an ecosystem of health care information can be imagined and created, to meet the needs of the global villager and village, as a utility that realizes and adapts to new benefits achievable in the Information Age and avoids falling into new bear traps. This is a tale of two villages.

I have lived in both these villages. The first was the tiny village of my childhood, which I have already described—let us call it Localton, with its nearby local hill of challenges faced in everyday life there. A mountain of wider national challenges loomed from afar but were only sparingly connected with the local hill that dominated and most affected local lives.

The nineteenth-century pattern of remote and isolated village life of Localton is no more in the English countryside, but still lived in much of the world. In my great aunts' village, movement between villages was conducted by horse and cart and Shanks's pony (on foot), as described in Chapter Five

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14 M. C. Escher, 'Print Gallery', *Digital Commonwealth*, <https://ark.digitalcommonwealth.org/ark:/50959/3r076s71b>

when discussing the arrival of information technology. Night-time reading was by oil or gaslight. Roughly laid out paths made for bumpy rides on early bicycles, arriving from Germany. Discovery and new means of travel and navigation between countries had been arriving slowly within local awareness, over hundreds of years, through conflict and commerce. Mass transport by ship, car and aeroplane, and their enabling and supporting infrastructures and regulation, started slowly and then arrived in waves over a century or so.

The second village is the city village in which I now live, called Fleetville. It is a distinct and now quite prosperous central area of the city of St Albans, having once been a poorer area, housing families working in the factories nearby. I will call it Globalton. It is in some ways quite like the Localton of my childhood—almost all daily needs within walking distance—but very different in its transport connections and links within multiple global virtual communities. It has its local hill of challenge in everyday life—keeping the community centre alive, regulating local car parking—but is immediately connected, through the Internet and other media, with the global mountains of challenge further afield.

Characterizing such village community today, as described in the *Sunday Times* newspaper yesterday, is central Walthamstow in East London—of interest and memory to me as it is where my father grew up. This kind of village is now described as a ‘twenty-minute neighbourhood’, and comprises:

- Home, children’s play areas, amenity green space, bus stop—within walking distance of five minutes;
- Shops, bakery, butcher, cafes, nursery, pub/restaurant, hairdresser, primary school, village green, elderly day care centre, medical centre, community allotments/orchard—within walking distance of ten minutes;
- Employment opportunities, workshops, shared office spaces, secondary school, gym and swimming pool, sports pitches, large green spaces in woodland—within walking distance of fifteen minutes;
- Multifunctional community centre, business academy, college, bank, post office, place of worship, garden centre—within walking distance of twenty minutes.

A work in progress, opposed with scepticism and objection five years ago, and still no doubt with teething problems and troubles anew. It has been pedestrianized, and cars are owned by only forty-nine percent of households, compared to seventy-seven percent for the whole of the UK.

Although quite small, it has proved viable and resilient in fostering new growth, its community strengths providing a foundation for reconstruction and rebirth.

Goodhart discussed the challenge of finding a new balance of status and reward, between the 'anywhere' and 'somewhere' of life today. His anywhere is big and global in scope and application, and his somewhere is small and local in everyday life. Globalton is both local and virtual community, and Globalton villagers live double lives. In the everyday, Globalton villagers share and navigate their 'somewhere' activities and the challenges of the local hill. In their virtual lives, work and travels, they connect with and engage with village communities elsewhere, and in the 'anywhere' challenges on global mountains, experienced and framed more widely. In the Covid months, local group exercise and dance classes switched, with impressive dexterity and success, to individual Zoom participation from the home. Much group activity was transferred online but is eager to return onto local ground.

In *Small is Beautiful*, Ernst Schumacher (1911–77) used the phrase 'think globally and act locally' to bridge responses to the big challenges of global mountain with local community and business, contributing towards their solution by acting on a small scale on the local hill.<sup>15</sup> The phrase is attributed originally to the Scots biologist, town planner and social activist Patrick Geddes (1854–1932). Some very successful charitable endeavours have achieved synthesis of this kind, bridging local lives and wider concern to contribute practically to solution of problems on the global hill. The Oxfam and Amnesty International movements have been creative and successful with this approach, although not without their own problems on both these hills. The Internet has been a great enabler of local sharing and support in our global village—WhatsApp groups have bubbled into life along many streets.

The reverse mindset, of thinking locally and parochially, generalizing from problems on the local hill to justify and pursue self-interested action wider afield, has also been empowered in Globalton. The information revolution has harmfully enabled and conflated big and global thought and action anywhere, with small and local thought and action somewhere. Burglars in Localton tended to think locally and act locally, breaking in to burgle on a small scale, somewhere near home. Scammers in Globalton think globally and act globally, to deceive and rob anywhere in the world. One of our credit cards was scammed recently and, in a matter of days, thirteen thousand pounds of fraud had been charged to it in a total of some

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15 E. F. Schumacher, *Small Is Beautiful: A Study of Economics as if People Mattered* (London: Abacus, 1973).

twenty places across the country! Social activists also think and act globally on major issues of the day and combine forces through social media to focus and coordinate local action.

Matthew Arnold's (1822–88) book, *Culture and Anarchy*, was a mid-nineteenth-century take on conflicts of culture in human society.<sup>16</sup> I remember reading at school about his take on 'Barbarians' and 'Philistines!' A hundred years on, in the late 1950s, Charles P. Snow (1905–80) divided cultures between the sciences and the arts. The Information Age has spread and amplified cultural division.<sup>17</sup>

Some prophets of change envisage and target a future culture of society, characterized by the 'sweetness and light' that Jonathan Swift (1667–1745) wrote about at the turn of the eighteenth century—a mature sense of beauty combined with alert and active intelligence! The culture of Globalton is an organic one, growing much faster than the Localton culture of my childhood, within times of Whitehead anarchy. Localton culture was grounded and sceptical. Globalton culture seems more beguiled by and susceptible to the promise of magic bullets; these sometimes get blocked and backfire in their rifle turrets.

In their inukbook on the future of the professions in the Information Society, Richard and Daniel Susskind set out what they admitted was a very wordy and legalistic grand bargain governing future professional relationships with citizens.<sup>18</sup> They saw such change as inevitable, with adaptation to the new reality being primarily a challenge of culture, values and expectations. I draw on their ideas in Chapter Eight, in discussion of the shape of health care professions in the future Information Society. There is a similar challenge facing each global villager, in combining their global thinking and action 'anywhere' with local thinking and action 'somewhere'.

These are much the same challenges that Karl Popper (1902–94) addressed in his book *The Open Society and Its Enemies*.<sup>19</sup> There is enduring conflict. Chapters Eight and Nine develop a vision of purpose, goal, method, team and environment for the creation of a care information utility, in the context of the transition from local to global village. Chapter Eight and a Half describes my experience of the past thirty years in working towards that end.

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16 M. Arnold, *Culture and Anarchy: An Essay in Political and Social Criticism* (Cambridge, UK: Cambridge University Press, 1869).

17 C. P. Snow, *The Two Cultures and the Scientific Revolution* (Cambridge, UK: Cambridge University Press, 1959).

18 R. E. Susskind and D. Susskind, *The Future of the Professions: How Technology Will Transform the Work of Human Experts* (Oxford: Oxford University Press, 2015).

19 K. Popper, *The Open Society and Its Enemies: The Spell of Plato* (London: Routledge and Kegan Paul, 1957).

## Instability of the Global Village

What promises to integrate and make whole, can lead to instability and fragmentation. The information landscape can become one of isolated power and influence, orchestrated globally from safe, high-up places. And into the intervening gaps and holes, the less powerful and more exploitable can easily fall, be it by default, lack of care, or incautious and foolish intent. The Internet has connected local villagers and village life into a virtual global village community. Between global villages, today, there are heightened inconsistencies and inequalities of health care. And there is heightened awareness of these, and of the global dimensions of the challenges they pose.

Along my songline, the technologies of telephony and broadcasting, and the superseding digital carriers over land, under sea and relayed by satellites, have evolved into high capacity, superfast broadband. The information highway has channelled rivers of information through every village, flooding out across every plain. Mobile telephony has transformed life on a global scale. It provides a seemingly limitless capacity capillary network of information flow, circulating pervasively in the world. And low-level satellite networks promise yet more. The network is good at delivering information; some is vital and benevolent and some harmful and malevolent. It is poor at clearing up information litter and removing its addictive substance and noxious toxin. It transports secret and criminal content that few know to be there.

Governments were left far behind in adjusting to this revolution. In failing to protect and prepare effectively for new governance, they delegated or abdicated power to eager new information barons of industry, commerce and crime. By default, citizens became clients of global information corporations and monopolies. Governments are now struggling to retrofit vehicle production standards, rules and regulations of the road, and means of navigation, amid information traffic that is fast-moving in all directions. It is a scary and unruly place for citizens to navigate—personal survival favours running for cover!

This revolution has transformed and tested the balance, continuity and governance of services. Human relationships and attitudes are also in rapid transition, challenging belief, culture and values. Facebook is the most wonderful of enablers of social life and the most awesome of Faustian bargains in its misuse and abuse. It is part-motorway and part-car. Unlike these, it has risen virtually unrecognized, hidden in plain sight. Global village citizens and burghers were bewitched by, and welcomed in, what was camouflaged and portrayed as a gift. This gift transformed into a magical power to connect any person with anything. It opened, far and

wide, a Pandora's box of unknowable sequelae. It enabled local eyes to see into the global village and this brought new personal power. Local eyes and ears could be conditioned and manipulated, with image and conspiracy planted from far away, in furtherance of wider and unknown powers.

In the information pandemic that followed, education, research and scholarship, trade and profession all started to operate differently. Cooperation, collaboration and supply lines of trade connected, extended and flattened around the globe. And the politics of the global village polis entered an uncertain evolving order and chaos. Thomas Friedman wrote *The World is Flat* and Francis Fukuyama, *The End of History*, imagining these new bridges to the future and their implications.<sup>20</sup>

There is not yet a discernible centre or law of the land in this global village. There is not yet politics fit for such global polis. There is shared intention and cooperation in building the information network, but little power in finding common ground on which to regulate it. Rather, it has become an instrument and battlefield of conflict and interest. The landscape is then left to the exercise of unbridled and arbitrary power. Attempts to shore up existing frameworks of law and regulation have led to artfully less equitable circumvention of accountability.

The Industrial Revolution was a seedbed of wealth creation and human emancipation, however imperfectly and however unfairly, as it was of empire. From the shocks and after-shocks of conflict and disease, and progressive social emancipation, consensus was created and led towards global institutions of finance, enterprise, health and governance, founded on belief in human rights and strong democratic institutions. They trusted in, and hoped to foster, the better angels of our nature, as Steven Pinker described them.

The Information Age is a comparable leap forward and disruption of *status quo*. It is probing the limits of social cohesion and resilience of the global village life it has led to. This is playing out in the wider context of global disruption and inequalities of climate, economy and politics. These perturbations are of such scale as defies local resolution and such nature that challenges global action. Global viral pandemic, as much as global climate, transcends boundaries and floats under and over drawbridges. Information for health care is pervasive, both global and local utility. It requires adaptable fusion of both global and local architecture, with global and local governance. This is the space that the creation of information utility will populate.

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20 T. L. Friedman, *The World Is Flat: A Brief History of the Twenty-First Century* (New York: Picador/Farrar, Straus and Giroux, 2007); F. Fukuyama, *The End of History and the Last Man* (London: H. Hamilton, 1992).



## Lifespan, Lifestyle and Health Care

In his third chapter of *On the Origin of Species*, Charles Darwin (1809–92) wrote about struggle between species:

It is good thus to try in imagination to give to any one species an advantage over another. Probably in no single instance should we know what to do. This ought to convince us of our ignorance on the mutual relations of all organic beings; a conviction as necessary as it is difficult to acquire [...] When we reflect on this struggle, we may console ourselves with the full belief, that [...] the vigorous, the healthy, and the happy survive and multiply.<sup>21</sup>

This was his observation and reasoning about the natural world. Survival and procreation reflect the biology of life and the behaviour and circumstances of living. In human society, we might simplify these under the headings of lifespan and lifestyle.

One of my more recently added inukbooks is *Lifespan*, by David Sinclair.<sup>22</sup> It gives a biological context to healthy living and ageing, as seen by a life scientist and clinician. It presents a visible prospect of normal human life that could extend over one hundred and twenty years. It describes the author's personal daily prophylaxis for keeping at bay the chronic conditions commonly associated with ill health and ageing. A fortunate life today segregates lifespan approximately within a twenty-five-year period of bodily and educational growth, development and exploration, a forty-year period of work and personal and family development, and an indefinite period of retirement, usually up to twenty-five years, with freer scope for enjoyment and fulfilment, before subsequent, hopefully rapid, decline to end of life.

Lifespan and lifestyle are central preoccupations of the lives we live, in the generally healthier age in which we are lucky to be living. Short and long, healthy and unhealthy, happy and unhappy, they are two sides of a spinning coin. These sides connect, of course, and nowhere more immediately and with greater consequence than through information that flows between them.

One side of the coin, that of lifespan, faces towards health care systems and services, enabling and helping citizens to keep and be kept well, and providing intervention and support where and when needed, from cradle

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21 C. Darwin, *On the Origin of Species by Means of Natural Selection, or, The Preservation of Favoured Races in the Struggle for Life*, (London: John Murray, 1860), p. 58.

22 D. A. Sinclair, *Lifespan: Why We Age—and Why We Don't Have To* (London: Harper Collins, 2019).

to grave. Information that connects citizens with services, is a crucial determinant of their timeliness, effectiveness and efficiency. The other side of the coin, that of lifestyle, faces towards every citizen, individually—towards personal circumstances, activity and behaviour that make for a fulfilled and healthy life. Lifestyle and information about lifestyle cover a wide and open context—nutrition, exercise, housing and personal security, sense of purpose, work and leisure, feelings of enjoyment, caring and being cared for, and trust. Lifestyle reflects environment, personal preference, choice and opportunity.

On both sides of the coin, there are considerations of knowledge, finance, environment, equity and governance. Information and information infrastructure connect within and between the two sides; knowledge as information with causal power to facilitate and deliver care services and self-care, in support of both lifespan and lifestyle. It is an ever-changing and varied scene. Well-customized and accessible information is a prerequisite of improvement in the balance of individual lifespan and lifestyle. Misguided or misused information is a reflector and amplifier of their imbalances and imperfections.

To keep fit and well, some like to puff and pound the streets, cycle or swim, pulsing the endorphins through their body through vigorous exercise. Others walk or stretch and balance the body in Pilates, or practise and create dance. Some read, cook, garden, paint, play, relax and talk. How such a pattern can square throughout a potential future one-hundred-and-twenty-year lifespan, and balance with economy, environment, and personal, community, and wider public health care services, is a puzzle. It is a puzzle faced on differently connected levels—personal, professional and public. As knowledge, capability and capacity change, so does a 3x3 matrix of balances—personal, professional, and public, in rows; knowledge, capability, and capacity, in columns. It is also a matrix of information and information flow.

The Information Age has led to more wide-ranging, and more effective, health care interventions and means to enact them. Capability to deliver the methods entailed and capacity to access the resources required to enact them have become increasingly commoditized, extending their availability and uptake within the personal domain. I can use a pulse oximeter to measure my blood oxygen saturation in a few seconds, with an oximeter that I can buy online. In the professional domain, capability to measure, interpret and intervene has likewise advanced, bringing a new balance of professional skills, roles and team capabilities, and organization of the capacity required to enact them.

Responding to a stroke with the best methods of the day is a logistical puzzle of organizing fast-enough access to treatment within a network of

highly specialized centres. For everyday ailments where the body tends to heal itself over time, the puzzle is a balance of online, over the counter, and professionally delivered products and advice. Responding to a high temperature and sore throat may justify use of thermometer and soothing or more purposeful medicament—but deciding how strong and purposeful a remedy should be pursued is a balance of personal, professional and public choices. A sore throat can be coped with, but a recurrent sore throat is another matter. An antibiotic can fix a problem quite quickly, but over-prescribing risks adaptive resistance of infectious organisms and progressive public harm. In the growing domain of management of chronic illness and disability, the professional domain is increasingly overwhelmed by demand. Means and responsibility for monitoring and management of these conditions is increasingly shared and enacted in the personal domain and within the global village community. Not just my granny weighing her bread and injecting daily insulin to control her diabetes, but easier to take medicines and adoption of a calibrated and supported lifestyle change. Monitoring and reporting of vital signs have become commoditized—blood glucose levels, oxygenation and pressure, heart rhythm and more—with recording, analysis and reporting of measurements, medicaments and outcomes on smart-phones.

Recognizing and responding appropriately to the changing scene is a balance of personal, professional and now computational capability and capacity. Information is central to balance and continuity of health care services. It is central to governance within and among personal, professional and public domains. It is central to equity and trust, on which all these depend.

Information Society health care services of the future will continue to rest on evolving knowledge, capacity, circumstance and choice. Their creation requires renewed purpose, policy and political will, mirroring that of the 1940s. It is a puzzle—better thought of that way than as a problem—that can only be tackled on shared and open ground. It should be tackled in such an environment and in such spirit. To succeed in making the picture whole, it cannot be seen as a contest of capitalism and socialism—it must be a fair and productive partnership of their respective motivations and merits.

Not all needs and expectations can be met; there is no rising tide that can float all boats. There will be necessary, but not necessarily welcome, adaptation on all sides, in roles and responsibilities, trust and expectation, in achieving and sustaining balance matched to the changing society of the Information Age. Lifestyle and lifespan press on the sustainability of many balances: work and leisure; production and consumption; climate and natural environment; personal and public equity and responsibility; private, public and social enterprise. Gains in lifespan and quality of life of the past

century have depended on increasing wealth, impact of advances in science and engineering, shelter and public utilities. We must create and sustain a useful and accessible care information utility that matches and adapts to this changing reality. How we do this will be a crucial determinant of sustainable progress in reinvention and reform of health care, more generally.

There will be new discoveries and developed technologies that continuously change the context, quality and organization of health care services. Automation and robotics are rising tides. They are building at the interface of science and information technology and promise new space and opportunity to meet some human needs more effectively and efficiently, while avoiding some aspects of the associated work that humans do not enjoy. They proffer a double-edged sword in relation to present day lifespans and lifestyles. Working life as drudgery is dire, preferable only when in exchange for no work and sustenance. Purposeful working life is a gift—as gainful or voluntary employment, as enjoyment and fulfilment, or as enabler of fulfilling leisure time. For some, these trends towards automation will be felt and experienced as receding tides, as they drain away and replace work and opportunity that is important to them.

Genomics science and technology promise early identification and awareness of susceptibility to disease. Conditions that might emerge later in life can thereby be anticipated, guarded against and mitigated from early in life. Hitherto opaque and intractable disease may be better understood, characterized, treated and potentially eliminated. Synthetic biology is a rising technology that promises superior and more swiftly and systematically developed pharmaceuticals and cleaner environments. Other rising technologies are targeted towards improved sustainability of the earth's resources and ecosystems, and projection of human life beyond the earth. As ever, earth-wide challenges, such as viral epidemic, and plans to combat and overcome them, rest on common purpose and shared values. Maybe these will not arrive in a humanly good-natured way, waiting on change enforced by conflict or natural disaster, as Houghton feared.

Good, coherent, openly-shared information systems already underpin many domains of science and engineering. Health care, lifestyle and lifespan-related information has been a significant laggard, notwithstanding massive expenditure, and policy peroration. It is unfortunate that information utility for these has become unduly entrained with commercial ambition and monopoly, leading away from integrative utility into fragmented silos of method, infrastructure and data. Fragmentation of health care services has become mirrored in fragmentation of health information systems. Health care system and care information utility must come to a new balance if the current malaise is to be resolved. The rising tide of information pandemic is a pivotal testing ground of opportunity to tackle the many imbalances

it reflects, challenging future lifespan and lifestyle, globally. Can the Information Society both retain and build on the benefits of information technology, and combat the disbenefits that it also engenders, to win through to sustainable new balance?

In Chapter Five, I wrote of information engineering as practical discipline at the interface of science and society. Chapter Six explored the evolution of information as a scientific concept, illuminating understanding of living systems. In this chapter, the perspective has broadened to encompass information as knowledge with causal power to guide and support interventions and behaviours in matters of lifespan and lifestyle. I now embark on a rapid flight along my songline, charting the detailed historical coevolution of health care services with this changing information landscape. It passes over an amazing period of scientific and engineering advance and illustrates how policy and practice of health care services have reflected this. In this respect, it has been an era of excitement in achievement.

There is a parallel landscape reflecting how expectation and experience of health care services have changed, for all involved, and how their organization and governance have adapted. In this respect, it has been a more painfully anarchic era, reflecting and reflected in wider political and economic struggle and social change. In debates about health care information systems, opinions and criticisms are expressed from and aimed in all directions. There is speculative and often unproductive investment in the new. This populates and clutters the stage with many actors talking across one another. Some actors remain there too long, being still powerful and unwilling or unable either to adapt or to leave the stage. Some new ones, with messages worth hearing, find no space and are not heard. The issues faced are divisive. Their resolution digs deep into assumption, interest and belief, and, of course, into pockets as well. Attention to the 3x3 matrix of coherent future information utility—to achieve balance, continuity and governance, across personal, professional and population domains, aligned with purpose, policy and plan of feasible implementation—has been fragmentary. Left substantially and by default to market forces, it has been left adrift and behind.

## Coevolution of Health Care with Information Technology

The information revolution has brought new methods to measurement, analysis, reasoning and action in clinical practice. It has brought new understanding of the nature and scope of health care interventions, and their outcomes. Measurement devices and information systems feature ever

more widely, from small, sometimes now wearable, devices, to systems that capture, represent and integrate data at all levels, from the local and personal to the public and global. Methods of control of devices, data analysis and communication operate over similar range and depth.

Health care services have co-evolved with information technologies for some sixty years. The software in use has been like a tapestry woven over time, with multiple threads drawn from across the public and private sectors. In some areas, the pattern woven has been chaotic and confusing, and in others, more coherent and useful. Radiotherapy and radioisotope methods yielded early gains in medical physics, which also pioneered medical imaging—another success story. Clinical laboratory method was also an early focus. Medical records and clinical decision making have long been a curate's egg of successful and unsuccessful exemplars. Organization and management of service delivery became major concerns, and supporting IT systems came and went, with varying success. Primary care computing, with its stronger emphasis on local clinical autonomy, has perhaps been the greatest success story in the NHS, over time.<sup>23</sup>

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23 To gain an overview of this scene that has played out over many decades, I trawled through multiple sources to construct a timeline of the changes in UK legislation for health care services since 1948 and the creation, abolition and reinvention of organizational structures that were established to run, audit, regulate and promote change in its operations. I charted: eight Acts of Parliament, sixteen major reorganizations, six quality and service improvement agency initiatives, six overarching governance bodies and nine IT restructurings (see Appendix II of the additional resources, available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>). I also mapped the key official summary descriptions of these. I then logged, alongside, my experience of the forty years of what was called information management—the ways in which the many policy documents of those decades were translated into action. I have used some of this narrative to give context to the discussion of the policy documents themselves, later in this chapter. This provides an illuminating context for Part Three of the book, which is about creating the future. The history and battlefield are not pretty, and it is easy to criticize. The actors were placed among many rocks and hard places. They were all the time working upwards towards ministers and downwards towards the front line of services. Policy and investment were, by and large, framed in terms of management perspective and action at scale, from the top down. The need addressed would have been better framed and approached with actions centred more locally, within the professions and from the bottom up. Significant innovation, experience, and learning in the history of the field came from there. In Chapter Eight, at the start of Part Three of the book, I describe some of the great local innovators with global perspective that I have known. It is to such people, teams, and environments, and their stories, that we should look for resolution of recurrent crisis in the field and help their achievements to emerge and grow. In Appendix III of the additional resources, I describe more of my personal experience on the ground through those six decades. It is a subjective and partial perspective and others will have seen things quite differently. I place it in the additional resources as it is not central to my purpose in the book, of

It is in local community contexts and on common ground that a more coherent future information utility can now grow. The secondary and tertiary care domains are more deeply entrenched in silos of data. They will join in with the endeavour as the benefits of doing so grow, and the disbenefits of not doing so, evaporate over time. Policy and investment should reflect this shift of attention from Industrial Age to Information Age medicine.

In well-defined, practical and everyday contexts, machines are beginning to prove adept at learning rules for interpreting data and codifying knowledge, in useful ways. As with their learned strategies for playing the games of Chess and Go, they are increasingly adept in categorizing and interpreting complex patterns and images. That said, clinical histories are revealed, understood and told differently in different contexts, where they may have different meanings. They have social, economic, commercial and political contexts. The patterns they exhibit may be recognized by an experienced human, in ways they cannot fully articulate, as if their human mental process were an opaque machine-learning algorithm. They may become better understood through deliberative and experimental iterative processes of hypothesis, experiment and review, whereby science manages its endeavours; but these are wicked problems and there may never be objectively neutral observers of such experiments.

In all this, a gulf is growing between human and machine expertise in illuminating and tackling tasks central to health care. Giving the machine free rein may prove a Faustian bargain—we do not yet know, and opinions differ. I have drawn on three contrasting sources that have illuminated the complex scene for me, illustrating what is at stake. After their authors, I have named them the Birnbaum beatitude, the Weizenbaum warning and the Illich apocalypse (of iatrogenic disease—I like playing with words!). These are, respectively, descriptive, apprehensive and contrarian in nature.

Birnbaum looked forward, optimistically, to realization of benefit from what he called information appliances and information utilities. Weizenbaum looked on, concerned by the encroaching debasement of health care professionalism. Illich looked back, inveighing against what he saw as the harm done to society by Industrial Age medicine, and arguing for reversal of the progressive medicalization of life.

## The Birnbaum Beattitudes

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helping to illuminate and chart a way forward—I do not wish to stir tired or sleeping dragons, as that will not help!

A useful overview of the evolution of information as a utility was given in a lecture I listened to at the Royal Society in London, in 1999. This was delivered by Joel Birnbaum, an engineer who led research and development activities for the then world-dominant Hewlett-Packard Corporation. I call them beatitudes because they presented as a rather harmonious and logical flow. That is not the way they were experienced, of course.

## Co-evolving hardware and computation - changing workflow over six decades

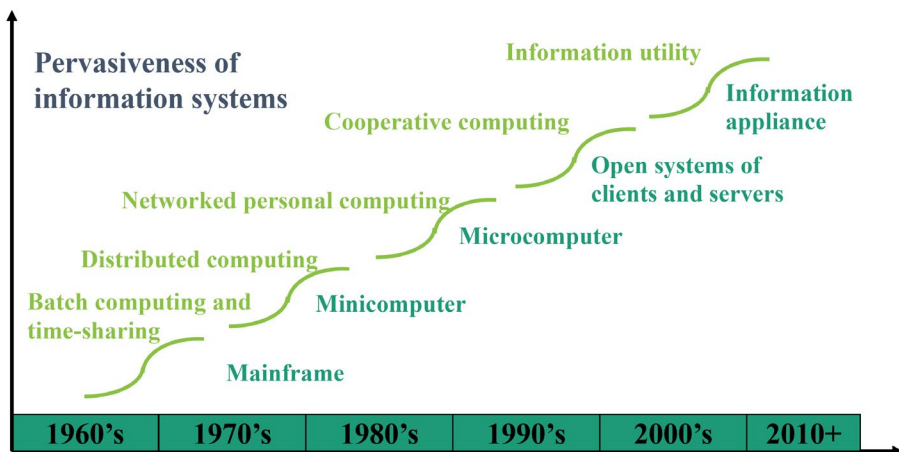


Fig. 7.3 The coevolution of information technology hardware and computation during the Information Age. Image created by David Ingram (2010), CC BY-NC.

Birnbaum described the rise of information technology over five eras, relating patterns of usage of computers with successive generations of infrastructure, during which information systems became a pervasive reality in everyday life (Figure 7.3). I used this chart in my talks of the time, as a template to depict the corresponding evolution of information systems in health care services.

In the 1960s, large mainframe computers predominated and giant companies in Europe and the USA—International Business Machines (IBM), Control Data Corporation (CDC), Universal Automatic Computer (UNIVAC), Honeywell, International Computers and Tabulators (ICT), Bull, Siemens—did battle. Such machines grew in power over two decades. In the UK, Elliott Automation and Ferranti, with their close connection, also, with military systems, built smaller scale machines and had early success in the world of industrial electronics. They were early pioneers



of semiconductor technology, leading to integrated circuit and computer processor components, but were swept past in the marketplace by American giants that took these innovations to a much greater scale. Huge manufacturing plants were placed in poorer countries in the Far East. I visited one in Malaysia when asked to go on an assignment there for the Commonwealth Secretariat, to advise their government.

The large mainframes started by executing program tasks, one at a time, in batches. They progressed to sharing their capacity among multiple simultaneous tasks and users. The software needed to operate these machines was largely devoted to management of attached devices, such as card and tape readers, printers and disc storage devices, a scheduling system controlling program execution, using a variety of language compiler programs to convert the source programs into binary executable form and its final loading into memory, to be executed by the mainframe processor. Remote job entry was possible via subsidiary connected machines that were dedicated to storing and forwarding submitted jobs to the mainframe computer and receiving and printing the output files transmitted back to them.

The next stage was in introducing a time-sharing operating system, slicing the available shared resource among the needs of a variety of simultaneous jobs being edited, compiled and run from instructions typed in by several different users, sitting and connected online, at a teleprinter or visual display unit. This involved allocating a section of the available memory to each user and switching the processor resource among them according to an algorithm designed to smooth out demand over time, as well as keep control of the function of the other attached and shared devices. Over two decades, I worked with IBM 360 series, CDC 7600 series, ICT 1900 series and ICL 2900 series computers. It was Conway Berners-Lee (1921–2019), father of Tim Berners-Lee (the father of the Internet!), who came to our hospital, with Ted Coles, a future head of medical informatics in Cardiff University, as a salesman for the ICT 1900 series.

In the early 1970s, the exponential rise in processor power, combined with the progressive miniaturization of semiconductor devices, meant that medium size computers began to match previous generation mainframe performance, but in a more flexible and customizable configuration. They were still built from large, heat producing panels of electronics. The design was modular and allowed for extension by incorporation of custom-built electronics, to control new prototype devices.

These minicomputer machines had operating software that could likewise be configured more flexibly to acquire and digitize signals at variable rates, from external devices such as body scanners, and drive outputs to generate images on higher resolution display devices. They found

application in the control of laboratory equipment and industrial plant. The operating software required was becoming more complex; the new machine 'users' exhibited different and often time-critical characteristics, which the controller had to adapt to in its sharing algorithm. This had to be able to stop work on one user program and switch almost instantly to deal with a time-critical event for another user program elsewhere, and then revert to the previous program, seamlessly. This brought evolution in both machine design and software architecture, the software necessarily coded in machine language, very closely coupled with the design of the computer processor and its peripheral devices. 'Multitasking' operating systems were designed to meet these new requirements and posed new challenges: machine hardware and operating software evolved synergistically, and sometimes software could not meet the challenge and new hardware was required.

This was a domain that required both physics and engineering expertise, to frame and connect application requirements and system design, to match with viable hardware and software. Applications involving instruments located at a distance from one another, such as in controlling electricity and gas utility supply networks, brought the need for a distributed computing network organizing communication among its nodes. Operating systems able to function across such a network, to control the signalling between and scheduling of activities, stably and sustainably, exercised systems programming further. Messaging systems and telephone and telecommunication systems more generally, evolved into the digital era.

Mainframes and minicomputers were first connected with remote users via analogue signals transmitted over telephone lines. The arrival of digital protocols and standards for telecommunication facilitated direct connection from computer to computer. The bandwidth of these connections grew rapidly, accelerated with fibre optic and microwave links. These computers were then joined in technically standardized networks and the software of operating systems extended within a new architecture enabling jobs to be run on and shared between multiple machines. This process accelerated with the arrival of the World Wide Web, as an architecture for connecting and distributing information resources within an unbounded network. Satellites in geostationary orbit became carriers of broadcast media and the one-way transfer of data. But latency of signal transmission, due to transmission over long distances, made them clunky as nodes in interactive networks. Terrestrial networks enabled single tasks to be shared among communities of users, as well as a single user's task to be shared across multiple computers. Collaboration in the performance of a shared task and multiway communication within teams, became possible.

This was an era in which I studied all rival products in the marketplace, each company jostling for orders. I persuaded the Bart's Medical College to

allow me to purchase the earliest of the DEC PDP-11/45 computers, to install in the new clinical skills teaching laboratory for which I had led the joint medical and nursing college project team.<sup>24</sup> I designed and procured the system and installed, configured and maintained the software, extending out to a college-wide set of clinical department users (the preclinical departments were on a separate campus at Charterhouse Square, half a mile away) through a cabling network. Great attention had to be paid to earthing between buildings, mitigating susceptibility to lightning strikes and David Lloyd (1940–2023) in the Medical Electronics Department helped hugely in all of this. It was very time-consuming work for a year or so until the College took the load from me, allowing me to appoint a dedicated team. It was a draining, full-on but highly educational time, all the same! It equipped me with shop floor experience that was very useful in subsequent roles in which I chaired the UCL Infrastructure Committee overseeing information systems, helped in the procurement and implementation of its new finance system and led the amalgamation of the IT support teams across all the specialist institutes and departments of the UCL Biomedicine Division. Also, in my national roles on oversight boards for eScience and IT infrastructure at the Central Computing Laboratory of the Research Councils (CCLRC), at Harwell, near Oxford.

After an event at the Royal Society of Medicine, where I spoke, I found myself invited by the Chief Executive of the time, John Green,<sup>25</sup> to sit for the ensuing grand dinner at a table he hosted with the then Foreign Secretary,

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24 DEC had its origins at the Massachusetts Institute of Technology (MIT) in the late 1950s and sold its first PDP-1 computer in 1960, for one hundred and twenty thousand dollars, produced in an old wool mill in Maynard, Massachusetts! It became an industrial titan of the era, and in the end it fell mightily. DEC started by concentrating on computers as modular components of laboratory and industrial equipment. The company rose through the 1960s to rule the minicomputer world for two decades, becoming similar in size to IBM. Mainframe technology grew ever hotter in its airconditioned machine rooms. DEC failed to metamorphose to match the business model of the emerging microcomputer world and was outsmarted by rival IBM with its IBM PC. DEC's final demise was to be taken over by Compaq, in 1998, and Compaq by Hewlett-Packard in 2002. This corporation subsequently acquired, and then became embattled with the Cambridge founder of *Autonomy*—the company that accelerated the industry into machine intelligence, based on analysis of unstructured data.

25 John was later appointed to run the Imperial College Medical School, working with Chris Edwards, a consultant endocrinologist and researcher at Bart's, in my early years there. Chris was at the time Head of that Medical School and was subsequently Vice-Chancellor of Newcastle University and a Wellcome Trust Trustee. Years later, he invited me to join in with an interesting initiative, *Planet Earth*, that he was leading, focused on improving utilities of health, shelter, water and environment for Africa. There, I met amazing innovators like Magdi Jacoub, the cardiac surgeon, busy supporting a new research institute in his native, Egypt.

Peter Carrington (1919–2018). I was sat next to a hospitable, quite elderly, but very lively American woman, and opposite to her husband. At the time, I was quite involved with the work creating an electronic museum of tropical medicine for the Wellcome Trust and had recently become a Professor at Bart's. I was quizzed about all this, and the subject turned to satellite networks and what they might offer. I asked her what her interest was, and she told me, in a matter-of-fact way, that she and her husband—sitting opposite, who beamed across at us—owned two satellites and were interested in whether they could contribute by connecting educational resources accessible throughout developing countries in Africa! She told me her name as we parted—Fleur Cowles (1908–2009). I mentioned this to Lesley Rees (1942–2022), my dean at the time, who knew everyone in London, it sometimes seemed. She expressed amazement, explaining that Fleur Cowles was a famous writer, best friends with the Queen Mother, and that she and her husband were icons of US/London social circles! I assume billionaires, too, by the sound of it. Nothing came of it, but it was fun to brush shoulders with 'billionairedom'!

The first computer on a chip had come in 1974, from Intel, and gave birth to early microcomputers from Altair. Similar chips that failed to gain sway, came in England from Ferranti and Inmos. This technological advance heralded the advent of microcomputers—in time, these cost less than the earlier typewriter-like user input/output terminals and were able to process as powerfully and with as much memory as their mainframe and minicomputer predecessors.

Early in the 1980s came the Acorn BBC microcomputer, costing several hundred pounds, hugely configurable by its users for programming multiple applications, and educational in scope. It was designed and manufactured as part of a major BBC Literacy Project, commemorating the nine hundredth anniversary of the Domesday Book. In this, the BBC undertook a snapshot survey of the culture and times of national life, captured in images, descriptions and surveys, involving schools and all mastered onto interactive video disc and played from the BBC micro. It was this sort of profile that led me to spend a good deal of (ultimately wasted!) effort, in getting to grips with using the interactive video disc in medical education.

The Acorn machine was adopted in homes and schools across the country and provided a major fillip to the market, for companies writing new applications. Software became a key driver of standardization and CP/M and MS-DOS were central to this. Many other chip makers and

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The Planet Earth initiative sadly collapsed, due to insurmountable problems with its operations.

microcomputer developers had joined in—Texas Instruments, Intel, Zilog, Advanced Micro Devices (AMD)... Atari, Commodore, Apple. Other players took the stage; computer games became major software products. Word-processing and office administration tasks became new markets for microcomputer-based machines and software.

The minicomputer manufacturers tried to catch up and maintain their upper hand. DEC tried its hand with a machine they called the Rainbow, but there was no gold to be found at its foot, sadly! They ported the PDP-11 minicomputer RSX operating system to run on a microcomputer they grandly called the DEC Professional, and I used one of these for a while to produce the graphical versions of the Mac Series of human physiology simulations. It was an uphill and unrewarding journey, other than to prove it could be done. The company lost out by not following closely enough the newly emerging operating system standards. They probably thought that their pre-eminence would continue to hold, but it did not, and they quite soon disappeared. IBM, which had tracked them through the minicomputer era, cleverly sustaining their markets for which mainframes were no longer technologically competitive, was again clever in falling in line with the de-facto MS-DOS operating system software standard. The IBM PC became the central focus of the expanding microcomputer marketplace. Office applications had expanded the markets of the minicomputer era and many dedicated microcomputer-based word processors achieved a significant market share. The standardizing clout of Microsoft prevailed, and office software became a main plank of its rapidly developing worldwide business.

The maturation of technology was, Birnbaum described, continuing to a point where the information network would become as invisible in everyday use as the networks of pipes delivering water to every home; turned on and off, heated, pumped, filtered, consumed and discarded. It would, he said, be like any common utility, most noticed when malfunctioning and otherwise not registered. In marked contrast to the early eras of computers, or cars for that matter, when the user or driver had, and needed, a high level of awareness of the inner workings of the machine and the requirement to tune and maintain it in everyday use. He believed that this information utility would transform the landscape of commerce as well, with far fewer companies focused on hardware and many more focused on applications delivering value for customers and consumers.

This reality advanced rapidly from over the horizon, as modular microcomputers were built into the ever-larger banks of processors, comprising computational and storage nodes of the Internet. These became the Grid of high-performance computing—the petaflop/petabyte computational platforms of the era of eScience that ensued in the 2000s, which I observed first-hand in many of the sciences, sitting on the national

e-Science Board and the Scientific Advisory Board of the Council for the Central Laboratory of the Research Councils (CCLRC). They started to provide computational resources for large-scale science, supporting data capture and analysis for national laser, synchrotron and neutron source apparatus on the Harwell campus, processing power for data analysis of the Geneva Large Hadron Collider physics community, and coordination of the network of telescopes in use in coupled astronomical observatories located around the world.

The Grid described by Birnbaum has evolved into the Cloud infrastructure of today, hosted by Microsoft, Amazon, Google, Apple and Facebook (see Figure 7.4). The technology standardization paradigms across these communities have come from the World Wide Web Consortium (W3C). They extend the penetration of the Birnbaum-inspired slide of Figure 7.3, into the new and coming era of connected devices and the 'Internet of Things'.

## GRID computing

- towards the information utility

*' the information utility will soon make possible a network of distributed electronic services built on open standards that will irrevocably alter most information-dependant industries...'*

We can expect the huge number of companies today offering essentially the same services to be reduced to just a few, while .. an even greater number.. built upon commodity-like platforms and interconnect middleware will spring into being. '

Joel Birnbaum, Royal Society Lecture, April 1999

Fig. 7.4 Anticipating Grid Computing, the Cloud, and information as a utility—from After the Internet, Royal Society lecture, Joel Birnbaum, 1999. Image created by David Ingram (2003), CC BY-NC.



## Co-evolving health care and informatics - changing focus over six decades

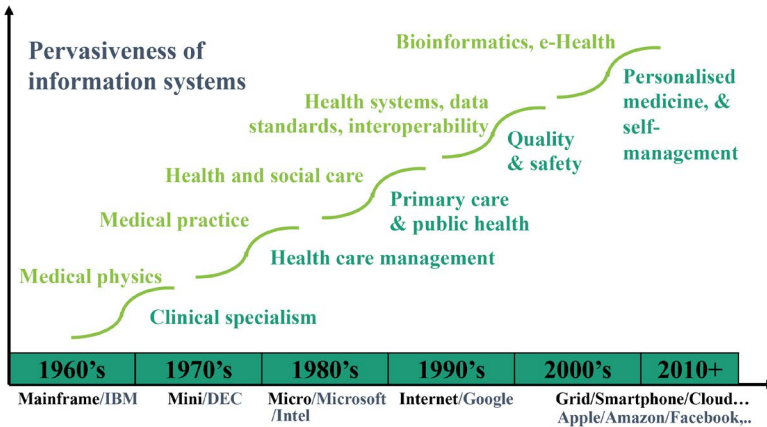


Fig. 7.5 The co-evolving focus of health care services and their supporting information systems during the Information Age. Image created by David Ingram (2010), CC BY-NC.

After listening to the Birnbaum Royal Society lecture, I reflected on the timeline of evolution of computer applications and information systems within medicine and health care. And how health policy focus had correlated with the evolution of technology and systems in the five decades that he described (see Figure 7.5). I have extended this to a sixth decade, which has been aptly described by one of my eight great colleagues from different disciplines (who read and commented at length on the first full manuscript of this book) as being characterized by '[transition in the] functional hierarchy between the patient as an object of care, to the patient being an actor in care, to the patient managing their own condition with the help of clinicians [...] the role of IT is critical and essential'.

Sometimes, ideas experimented with, and knowledge acquired, in each of these eras, persisted fruitfully into subsequent eras, but only when new software methods and tools had emerged to bring them to fruition. Sometimes, knowledge and experience gained was lost, as has been characteristic of the chaotic and explosively innovative Information Age, where focus on the new has buried much learning from past endeavours. It is interesting to reflect on how the tools and infrastructure now available would have alleviated a considerable amount of the legacy and burden of technological obsolescence that now persist in major IT infrastructure, systems and services.

*Era 1: 1960s–1970s—Instrumentation*

In the mid-1960s, there was a combination of large mainframe manufacturers, targeting contracts to provide general purpose computational capacity, and smaller scale machine manufacturers, who worked in specialist markets such as industrial automation. The larger were typified by IBM and UNIVAC, in the USA, and ICT, in the UK; the smaller by DEC and Data General, in the USA, and Elliott Automation, Plessey and Ferranti, in the UK. There were early partnerships between companies active in supplying computers and others focused on a particular area of application, such as the automation of laboratory chemistry tests, performed on samples taken from patients, and analyzed in hospital chemical pathology laboratories. The Technicon company led this field in the USA.

The larger companies had their eye on hospital-wide patient administration systems, to tame the paperwork that tracked and recorded information about inpatients and outpatients, from their hospital appointment or admission to their final discharge from care. Much of the impetus for this came from the companies themselves and they paired with willing and innovative clients within health care. The scale and complexity of such activity gradually became clearer, as systems analysts and programmers, who were brought in to work on the projects, struggled to specify, write and test software and implement systems. The teams of hospital staff that they worked with gradually became more aware of the scale of commitment such planning, design and implementation required from them, and the disruption it brought.

The process of formalizing requirements and brief for what computers were being purchased to do revealed a lack of clarity and consensus, as well as ambiguity and inconsistency in how the current services worked. Humans were used to patching and adapting, to circumvent these weaknesses. Computer programs were less forgiving, and their successive patches accumulated new vulnerabilities. Software entropy came into existence! Custom and practice—ways of working on and working around problems—were intertwined. Design choices made rested on clinical and management authority—on whose word counted and who was in charge.

From this boggy and buggy terrain, there arose a focus on operational research—formal mathematical methods for analyzing and guiding towards efficient organization of services. This invoked statistical models and methods of resource and cost allocation, workflow and queueing of throughput, and the like, used to evaluate alternative patterns of service. It became an area of interest for the already well-established medical physics and emerging bio-engineering communities, who saw the advent of the computer as a natural domain and professional opportunity for them to



develop and improve the range of support services in which they were involved, and as an opportunity to expand their role into information engineering and hospital administration.

Pioneering initiatives emerged on many fronts. Traditional professional rivalries over territory and power extended into this new arena. Each group brought their problems to the table to justify their requirements and priorities. Patient experience was not yet a widely used term. Regarding computers and computerization, it was, inevitably, a country of the blind. I was based in medical physics at University College Hospital (UCH) at that time, and saw and participated in several projects in radiotherapy, medical imaging and intensive care. This was an era where each innovator had to start by purchasing the computer machinery and creating the wider technical infrastructure required to tackle development of the information system in their local health care context. There was no industry standard network protocol—Ethernet networks only slowly emerged and Open Systems Interconnection (OSI) and Transmission Control Protocol/Internet Protocol (TCP/IP) contested for what in the end became *de facto* rather than *de jure* dominance of transmission protocols. Connection was an electrical engineering task to pipe analogue signals along coaxial cables or twisted pair telephone lines. It was an engineering challenge requiring skill and persistence, and a lot of work, but did not have a lot to do with health care.

And the policy makers at local and national level became too involved in the machinery. Assuming that their size gave them power to mandate, they presumed to prescribe and implement change, expecting to bring order by dragooning the NHS to adopt service-wide messaging standards, such as Electronic Data Interchange for Administration, Commerce and Transport (EDIFACT). It was a chaotic world, and most innovators kept their heads down and sought local order, rather than lifting their eyes to see that order was needed much more widely, across domains over and beyond all health care institutions and services, before any of their health care initiatives had a chance to gain traction and scale. This approach is the tail wagging the dog. It persists to this day with machine and management imperative invading into health care imperative. It is an approach of medium becoming message. But clinical communications are about meaning, not message of machine protocol.

These ambivalences and struggles became harbingers of chaotic cultural and professional change in health care services. Leadership through such times was challenging. The challenge was to learn how to use IT effectively by making and doing things experimentally, and to build discipline and capability to extend incrementally. The nature of the experiment was misunderstood; it was an experiment in the domain of understanding the nature of health care and ways of doing things, not one of using well-defined

and suitably configurable computer methods and tools, to perform well-understood and suitably adaptable tasks. Neither of these premises were true. The transition embarked on was not specifiable within known scope, scale, capability and cost of what it would take to realize the hubristic ambitions assumed to be achievable, from helicopters on high.

Many bucked the challenge and others rose to it and were heroic, showing immense humanity, depth, and resilience. It turned into three more decades of work and has still not achieved its goals beyond local and specialized scope and scale. Many who took on the baton of leadership must have regretted doing so—discovering, mid-storm, that there was no end in sight, losing energy, and giving up. Others soldiered on through a succession of groundhog days!

How the task was led and tackled, given its inherent nature as a wicked problem, was as much about character and style of leadership, as it was about what was sought to be made and done. As Fred Brooks would have known and said from the start, this kind of task needed good and trusted architects, able to combine leadership with ability to work with and integrate the needs and perspectives of different sections of the organization to be served. In Chapter Eight, I describe some great pioneers, who I knew and worked with, who rose to that challenge.

Here are two initiatives—one wholly unsuccessful, the other successful in its time.

#### **Example—The King's Hospital Project**

The King's College Hospital project in the early 1970s was the first attempt to computerize patient records for the NHS. The project, under the auspices of a brave and innovative clinician, John Anderson (1921–2002), then the Professor of Medicine at King's College London, was awarded a grant by the NHS to computerize medical records—though not by profession an architect. The project was funded and expected to meet what were likely, at the outset, to have been considered well-understood clinical requirements, using well-established computer technology. It was commissioned by the then NHS Supplies Division. In that era there was almost nothing by way of digital imaging, computer networks or even standardized database methods. A five-megabyte disc cartridge was a bulky item.

The project purchased a batch processing ICT mainframe for the purpose and spent most of the money, paddling hard under the surface, swan like (and inevitably, in time, mirroring the dying swan of Swan Lake), to rewrite the operating system so that it would allow time-sharing on several terminals. In terms of clinical objective, the technology was a total mismatch to the imagined task at hand. The project faltered and the short *Lancet* article burying it was titled, loftily, and with echoes of the still remembered demise of Edward the Sixth, 'The Kings Failure'!

### **Example—The London Hospital Project**

A project focused on hospital patient administration commenced at the London Hospital. The clinical leadership again came from a Professor of Medicine, this time from Robert Cohen (1933–2014), an endocrinologist and a good colleague and friend of John Dickinson, at Bart's. The London Hospital administration was led at the time by Michael Fairey, who went on to lead the NHS national programme and take a seat on the new NHS National Executive, creating a new directorate of information strategy and management. The head of finance, Budd Abbott, a canny street fighter in the politics of NHS organizations, championed it alongside. Theo Brueton was the IT lead who built a large team and computer centre for the project. Barry Barber (1933–2019), a physicist with interest in operational research and confidentiality of health data, provided those areas of expertise.

A dedicated building was created for the computer centre and a monster mainframe, with huge spinning UNIVAC drum data store, ensured the most rapid possible access. This project did indeed computerize the administration of patient flow through clinics, wards, theatres, laboratories, imaging. It captured and communicated data throughout. It stayed clear of the medical record, adding printed copy from the computer to the medical record as the carrier of the 'who did what, when, how and why, with what result', at the heart of the hospital operation and mission. In this era, medical mission had retreated behind the doors of hyper-specialism. General medicine and general physicians divided into twenty or more specialties.

Barber, B., R. D. Cohen and M. Scholes, 'A Review of the London Hospital Computer Project', *Medical Informatics*, 1.1 (1976), 61–72.

Over the following years, others followed a similar pioneering route at hospital level (for example, the redoubtable Howard Bleich (1934–2021), at the Beth Israel Hospital in Boston). Several large mainframe manufacturers attempted to commercialize these patient administration systems (for example IBM with their Patient Care system). Along with other major players in IT, they saw potential and pitched into the flow. Encountering rapids downstream, they mostly bailed out! IT interests earned and lost huge sums in those times; health care was often a loser, too.

Change towards the new era of minicomputer technology made possible a different kind of project, that was owned and operated at departmental level, experimented with and deployed as a component of its professional services and activities. Early into this arena were hospital physics departments, and the radiation physics and imaging services they supported. Alongside, were the laboratory scientists and pathologists. Pioneering clinicians led

the development of record-keeping systems for specialist departments. The focus was very much exploratory, discovering how computers might prove useful in a practical clinical context. One such in London at that time was the nephrologist Hugh de Wardener (1915–2013), a professor of medicine at the Charing Cross Hospital in London, who worked with Mike Gordon on his impressive Clinic 1 system. Mike was a close colleague of our team at UCH in the early 1970s.

Preeminent in the era was the physics department of the Royal Marsden Hospital in London. Jo Milan (1942–2018), working with Roy Bentley (1930–2017), developed there the first computerized radiotherapy treatment plans, using one of the first widely used minicomputers produced by the Digital Equipment Corporation. This was the PDP-8, and the system was called Rad-8. Jo became a master of getting the most from the 4k banks of memory and 32k quanta of disc storage, programmed in the machine and assembler languages of the era. In subsequent decades, Jo also created and led the nationally renowned information infrastructure for tertiary cancer care at the Marsden. This was, by a wide margin, an extremely impressive outlier in terms of clinical acceptance, quality and value for money achieved, as reported in the 2000 national survey of the impact of IT within all ninety-three NHS Trusts. Jo's massive contribution as architect of this era is celebrated among my stories of pioneers, in Chapter Eight, where I focus on clinical information architecture and attempts towards its standardization. It was a superb example of engineering excellence, health care focus and dogged determination, with huge local success—sadly not well understood, valued and duly recognized by the hospital management in the very place in which it grew and prospered, over four decades. Jo was a uniquely talented and committed, wonderful friend.

The database software market became lucrative and competitive and keeping up was tough. Products came and went. Ingres blossomed and went away; Oracle stayed the course and reaped rich rewards. As discussed in Chapter Five, capacity and performance requirements became more demanding as databases spread more widely into industry and commerce. The challenge for programmers centred less on accommodating the limitations of devices and more on meeting the requirements of program applications, that required the rigorous implementation of new and evolving types and extents of data and proved tricky, bordering on impossible, to achieve satisfactorily with the technology of the times.

These requirements were well exemplified in clinical records and the pioneering work of Octo Barnett (1930–2020), Neil Pappalardo and Howard Bleich, in Boston at the Massachusetts General Hospital (MGH) and Beth Israel Hospitals. These teams developed the Massachusetts General Hospital Utility Multi-Programming System (MUMPS) and MEDITECH

Interpretive Information (MIIS) systems with this sort of domain as their focus. The MUMPS global variable concept brought the database down into the software domain, supported by a much simpler software interface to a balanced-tree representation of the data on the disc backing store. Pappalardo founded Meditech and went on, by 2018, to become a demi-billionaire. Barnett's MUMPS legacy persists at the heart of hugely profitable health IT businesses today. I am not sure whether he died wealthy—probably not, and maybe that was not a capability or priority for him—but he did make a huge difference. I celebrate his pioneering contribution in Chapter Eight. Making a dollar and making a difference are two different things—it is the lucky who manage to combine the two!

MUMPS-based systems proved extremely flexible and powerful in clinical contexts and became a mainstay of implementations around the world in coming decades, with many highly successful devotees. As in Jo Milan's systems at the Royal Marsden Hospital, MUMPS language programs were later combined with relational databases, to enjoy the growing power, flexibility and operational rigour these could provide. And, in later times, in the Internet era, non-relational data models emerged, to cope with new requirements posed in accommodating much larger aggregations of less structured data.

The increasing power and flexibility of the minicomputer enabled rapid progress in medical imaging. Pioneers like my colleagues of the time, Christopher Taylor at Manchester, Andrew Todd-Pokropek in London and Stephen Pizer at the University of North Carolina (UNC) Chapel Hill combined mathematics, physics and computer science backgrounds in capturing and digitizing images from microscopes and X-ray and radioisotope-based cameras and scanners. They developed algorithms to enhance and analyze the image, represented as a two-dimensional matrix of digitized elements (pixels), and methods to support and study their clinical interpretation. These methods extended to three-dimensional images, as body scanning technology advanced and to a four-dimensional manifold in time series, to study body function over time. New contrast media enabled information on organ function to be captured and analyzed, giving further insight for the diagnosis and management of dysfunction. Imaging methods also supported treatment, for example enabling more precise targeting of tumours for radiotherapy. Such methods spread throughout the newer technologies of ultrasound and nuclear magnetic resonance imaging, and imaging methods of physical and life science, today.

Godfrey Hounsfield (1919–2004) at Electric and Musical Industries (EMI) in Teddington took his first steps in creating and commercializing computerized axial tomography. In this, a succession of scans of X-ray transmission, taken at different angles in a three hundred and sixty-degree

sweep around the body, was used to model the absorption characteristics represented by a grid of cells within the body, dividing up the cross section imaged. The reconstruction of the image from this set of scans was called an Algebraic Reconstruction Technique (ART). It was a mathematical algorithm and its encroachment into the scientific domain was questioned in a rather pompous commentary entitled 'Is ART Science?'

Minicomputer manufacturers such as DEC and Varian developed bespoke systems for applications in radiotherapy treatment planning and nuclear medicine. In time, the computer became integral to the design and operation of the imaging or treatment device, and these device manufacturers resumed their central place in the market for such systems.

### *Era 2: 1970s–1980s–Medicine*

The growing range of pioneering initiatives in Era 1 engendered wider awareness of the future potential and significance of the unfolding domain of information technology. This spread from science and engineering communities into public and private sector organizations, and national and international policies. In medicine, where did this all fit within traditional ways of working, and professional roles and responsibilities? In the running of hospitals and other organizations, what new roles and skills were required and what changes were needed?

With the increasing range and complexity of services, costs rose. And whereas clinicians and institutions had traditionally worked with some autonomy and limited governmental oversight, often drawing on the perspectives of the great and the good among insiders, there was increased pressure for wider scrutiny and overview at local, regional and national levels. NHS services were reorganized, grouping institutions within districts, areas, regions and national centres. Reorganization became a watchword of the day, the perceived way to tackle the growing and developmental pains of health care in the Information Age.

A new and sharper profession of health care management started to supersede the more gentlemanly world of hospital administration—of course gentlemen were men, but not always gentle! Culture wars ensued. It would seem natural for clinicians who know their profession to progress into health care management. They carefully guard their own citadels. However, managerial professionalism established its own citadels, and non-medical health care managers nailed their colours there, and defended them, too!

I was working at the time in daily contact with the senior staff at the centre of Bart's, a venerable, both loved and disliked, NHS hospital. It was an unusual one, in that it combined eminent and landmark personalities

and ways, with a modern and forward-looking outlook. It had immutable City of London links to money and influence. The Lord Mayor came on a ceremonial visit each year. Thus, the many dimensions of change being played out between medicine and nursing, between clinicians and managers, scientists and clinicians, and between local and district/regional/national politics, influence and power, were present in its life and community. It was a theatre holding a mirror up to health care of those times—it certainly attracted some theatrical personalities onto its staff! Battles over computers bubbled up in academic and clinical service departments, and between hospital and university, over the ownership of the domain. Where should investments be made, by whom and according to whose plans?

In medical education, traditional curriculum wars intensified, over whose priorities would win out, in time and resource devoted to teaching students, and the money that went with it. Computer-assisted learning came into being. Within the professions, almost every specialist Royal College and health care body established a computer group to consult, research and advise policy on these matters. The Royal College of Physicians, prompted by the gastroenterologist Wilfrid Ingram Card (1908–85), established its Computing Committee. This focused its activities on his particular interest in formalizing theory and practice of diagnosis (a discipline that was understood rather differently by different researchers and practitioners across the domain, it emerged), and on exploring statistical methods for analyzing decision making.

As introduced in Chapter Four and rehearsed again, here, for completeness of the chapter, this group became a meeting place for leading figures in medical informatics of the era. Card, who had teamed up with Dennis Lindley (1923–2013) at UCL, proposed a statistically grounded formalism as a theory of medical decision making. He was succeeded by Robin Knill-Jones, who teamed up with the oncoming greatness of David Spiegelhalter, with whom he collaborated on Bayesian methods for diagnosis of acute abdominal pain. Another luminary figure of the era also shone there. This was Timothy de Dombal, who master-minded a simpler Bayesian analysis, bypassing the subtleties of conditional probability distributions, to analyze the same problem area. His work focused on trials extending over many countries and cross-fertilizing with other problem domains.

In the USA, pioneering work, such as that of Edward Shortliffe on the MYCIN system for diagnosing and treating infectious disease, followed a paradigm of rules-based reasoning, building on the LISP and Dendral era at MIT in the late 1950s, as discussed in Chapter Two.

Both statistical and rules-based paradigms for decision making confronted issues of variance and uncertainty. How far was this associated with natural biological variation, or adequacy of measurement and

observation, or adequacy of the conceptual models used to describe and reason about the domain, or other chance factors? How much did clinical context, expertise and experience count? How did clinicians themselves reason in these matters? How much did they differ, and why?

The human-machine interface became a focus of interest, in terms of both the ergonomics of practical methods employed and the psychology of perception and cognition. There was an explosion of research interest in matters of human judgement, more widely, leading to new thinking about clinical skills and their assessment, in formal education and in regulation of professional practice. These matters became of increasing professional concern and wider ethical, regulatory and legal significance, in this and following eras. Human grappling with the performance of tasks by machines led to deeper questioning of previous human understanding and performance of these same tasks—not an uncommon pattern of events as we set out to computerize. These became national preoccupations touched along my songline of the following decades, positioned as I was close to the heartbeat of the associated professional and academic communities.

In medicine, this era saw a major focus on management data, centred in the NHS on the landmark investigation and 1982 report led by Edith Körner (1921–2000), which I discuss in more detail in the section below on fifty years of policy review in connection with coevolution of health care services and IT. This set out what was required for the organization and management of clinical services for a typical community of 250,000 citizens, and their wider oversight and accountability. The separation of concerns of clinical management, responsible for looking after patients, and health care management, responsible for smooth and efficiently integrated services, was notable at this stage. And nowhere better characterized than by Douglas Black (1913–2002), President of the Royal College of Physicians at the time, in a wise leading article reflecting on the report, published in the *British Medical Journal*. He emphasized the important contribution of management information and distinguished it from what he saw as a neglected balance with the information requirements of good patient care. He endorsed a similar critique of the report by the Kings Fund, an institution dedicated to health policy, with a mission in common with the Nuffield Trust and American Commonwealth Fund. The article concluded thus, first quoting the report that: ‘Information technology is only exploited to the full when developments are information led, so that the information requirements must be identified first and only then a choice made from the wide range of technology available’. To which he adds ‘The point could perhaps be made



more simply—"Don't choose a computer until you know what you want to do with it"<sup>26</sup>.

More colloquially, perhaps, the common refrain of our age: 'To err is human, to really mess things up, buy a computer'! This carefully considered article is well worth reading forty years on, from one of the most respected and insightful clinical leaders of his generation.

### *Era 3: 1980s–1990s–Health Care*

Hospitals and specialisms very much cornered the playing field in Era 2. In professional terms, general practice was still very much a poor relation. Academic departments and professors of medicine were not well established in universities in my early years, and it was not until the second half of Era 2 that professors of general practice appeared in numbers on the scene. The differentiation of primary and secondary care was long established, but the expansion and policy influence of primary care rose significantly in the oncoming Information Age, as lifespan increased, lifestyles changed and more was known about, and could increasingly be managed, near to home.

A new culture war intensified over money, power and influence. This played out around Bart's, wedded to the wealthy culture of the City of London and connection with private medicine in Harley Street, but located adjacent to the poorest communities of London's East End. General practice there drew motivated and radical pioneers, some with loud and quarrelsome voices, spoiling for a fight to put things right! General practice patient records became a major preoccupation throughout the country. Many general practitioner (GP) pioneers turned their attention and found a new mission in efforts to computerize these. General practice is a huge domain and commercial activity that has sprung up in many places.

Maturing microcomputers and computer networks gave a new context to these efforts, as costs of purchasing and running systems for practice management fell, and network connection to nationally provided information management services became much easier. Commercially developed systems started to emerge—at one time there were over twenty competing suppliers of practice management systems, all operating on a very similar landscape of clinical practice and data, but with little meaningful connection of data and information models in their systems. National accreditation of systems began to apply a regulatory rudder to their development, to promote convergence. I observed this process playing

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26 D. Black, 'Data for Management: The Körner Report', *BMJ (Clin Res Ed)*, 285 (1982), 1227–28, <https://doi.org/10.1136/bmj.285.6350.1227>

out in evolution of the ParaDoc system, pioneered in the East End system by my close colleagues, Sam Heard and Dipak Kalra, which I describe further in the next chapter.

The attrition imposed by a continuous need to update systems, as experience in their use and changing service requirements evolved, and the mandate introduced that they should fit within a nationally determined set of requirements for accreditation, meant that only the fittest survived. This pattern continued over the coming two decades, with only a handful of survivors and some, by then, rather wealthy company owners, some of whom put their wealth to work, in establishing new centres of research and innovation in the field. Some distinguished careers to this day established their credentials in those times.

#### *Era 4: 1990s–2000s–Health Systems*

The rise of network telecommunication protocols and the pioneering work on a networked information system for the Conseil Européen pour la Recherche Nucléaire (CERN) laboratory in Geneva—the foundations of the Internet and World Wide Web—heralded a new era in the coevolution of health care services and information technology. In earlier pioneering times, there was slow recognition of the need for agreement about and standardization of the requirements to be met by information systems, common ways of defining and describing them, and the roles and tasks they were to serve.

As described in Chapter Two, the College of American Pathologists published a Standard Nomenclature of Pathology. This was the seed of subsequent evolution and international alignment of the SNOMED nomenclature for medicine, subsequently carried forward by the International Health Standards and Terminology Organization (IHTSDO), later renamed as SNOMED International. In the world of librarianship, classification of medical literature led to the establishment of Medical Subject Headings (MeSH) and a Unified Medical Language System (UMLS) was proposed as a language of medicine. The International Classification of Primary Care (ICPC) came and went and the LOINC system for descriptions of laboratory measurements and observations, created and maintained by the Regenstrief Institute in the USA, achieved, and has sustained, worldwide impact in parallel with SNOMED. The WHO had long championed the widely used International Classification of Disease (ICD). Health Level Seven (HL7) emerged in the USA as the mainstream of industry-led standardization of health care IT systems.

The pioneering terminology initiatives started as multiaxial systems, mirroring library classifications of earlier eras. The challenge of refactoring their earlier versions within emergent new disciplines of description logic, also given the scale of sunk cost and legacy content they represented, was daunting. SNOMED has embraced the transition, but ICD has not yet achieved this. A further Generalized Architecture for Language Encyclopaedias and Nomenclature in Medicine (GALEN) project will, no doubt, sometime prove necessary.

The primary motivation for investment in these resources has been the standardization of secondary use of data needed for management of services, population overview and epidemiological research. Where these terminologies fit in underpinning the quality and effectiveness of direct patient care and its records of care, remains contentious. Everyone wants good care, data and records. No one wants the excessive cost and burden of data collection and management that they still currently impose. If there is to be information utility for health, this current transitional burden must somehow recede into the invisible background. This will not arise through managerial fiat. It will require the synthesis of clinical and engineering skills, in a human context. These will be needed to counterbalance the needs of the machine, lest they pull services too far under the control of mechanistic, protocol-driven and money-focused systems.

The impetus for progressive standardization of health systems has been twofold. The first, to help in creating rigorous and sustainable disciplines for the specification and design of interoperable systems. In earlier years, much of this was experimental and pragmatic. It was also untidy and vulnerable to error, inconsistency and inflexibility: in the framing, storage and retrieval of the information contained, in the correction of errors and weaknesses exposed, and in adaptation to changing requirements. This spoke to wider issues of fitness for purpose and safety, and to the burden imposed on users by a legacy of still operational but unwieldy and slowly declining systems. The second was to formalize and regulate marketplaces, making sure that apples were not pretending to be oranges, and bad apples and oranges were not easily confused with good ones. This topic is carried forward in the next chapter.

### *Era 5: 2000s–2010s–e-Health*

The scientific watershed discovery of the double-helix structure of DNA, dates from Francis Crick (1916–2004) and James Watson, at Cambridge in 1953, and the discovery of DNA itself, by the Swiss chemist Friedrich

Miescher (1844–95), nearly a hundred years before.<sup>27</sup> The race to sequence the molecule, pitting the wealth and scientific mission of major funders, such as the Wellcome Trust, with the skill and entrepreneurial drive of the American Craig Venter, took place over the years overlapping between Eras 3 and 4. I knew and worked with the Wellcome leadership and project team that co-funded the sequencing of DNA and the establishment of the Sanger Institute at Cambridge. Fred Sanger's two Nobel Prizes attested to his scientific contribution to methods for unravelling the science of life within every cell.

From this work, intimately connected with Cambridge of that era and since, came foundations of the fifth era of coevolution of information and health care—that of genomics, personalized medicine and e-Health. It emerged alongside changing roles and relationships of patients and professionals, as the scope and scale of primary care and home and community-centred interventions increased, as did the depth and range of information accessible through the Internet. The continuing failure to coordinate health and social care, within their common geographical context but different funding and governance frameworks, became ever more troublesome.

My songline passed alongside great scientific pioneers of those times, such as the physicist Janet Thornton, who worked on protein folding at UCL and went on to establish and lead the European Bioinformatics Institute at Cambridge. The rise of bioinformatics, capitalizing on much cheaper and faster means for tracking genetic markers and sequencing whole genomes, started to transform the focus of life science, throughout its molecular, cellular, organ, whole body and population perspectives. What took years to accomplish, in sequencing the human genome, at a cost of a billion dollars, in the 1990s, led to it taking just days to sequence the SARS virus, twenty years later. New sequencing technology of the past twenty years now reaches towards whole genomes being sequenced in minutes, at a cost of hundreds of dollars. These achieve sequencing speeds one hundred thousand times faster than the earlier methods. Now we have the One Hundred Thousand Genomes Project and Biobank initiatives, tracking the genetic context of population health and guiding interventions and service designs in previously unachievable ways. This will be a central building block of the architecture of future information utility for health care. In a clinical context, it will require a corresponding standardization of the phenotype of care, captured in its records. That is what openEHR has focused on growing, as described in Chapter Eight and a Half. My songline has also passed

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27 L. A. Pray, 'Discovery of DNA Structure and Function: Watson and Crick', *Nature Education*, 1.1 (2008), 100, <https://www.nature.com/scitable/topicpage/discovery-of-dna-structure-and-function-watson-397/>

alongside major European Union (EU) research consortia, such as those led by Norbert Graf, on infrastructure for cancer genomics clinical trials, where I was an external reviewer and then an advisory board member for nearly a decade. I celebrate Norbert's pioneering work in Chapter Eight.

### *Era 6: 2010s–2020s–e-Commons*

The present stage of coevolution of health and information technology into a sixth era, from the 2010s–20s, and extending beyond Birnbaum's original timeline, is of Cloud-based technologies hosting applications software and information services and bringing new opportunities for collaborative work anchored in the e-Commons. I will focus on this in the coming chapters of Part Three. The Cloud now links from the largest to the smallest in the world of the Internet of Things.

### The Weizenbaum Warnings

In 1976, Joseph Weizenbaum (1923–2008), an MIT computer scientist, published his landmark book, *Computer Power and Human Reason: From Judgement to Calculation*<sup>28</sup> It is a fitting counterpoint to the tone of the previous section, set out in successive eras along the Birnbaum timeline. The book contained informed and sombre foreboding about the detriment he feared might impact on human society in the Information Age. It was republished, with a further reinforced sense of peril, in 1984, the timing adding an Orwellian overtone to the warning. The writing of the book was a personal odyssey and he was in good company, acknowledging the support and advice he had received along the way from colleagues, including some who were, or became, luminary figures of the times—Noam Chomsky, known as the father of modern linguistics and founder of cognitive science; Lewis Mumford (1895–1990), philosopher and historian of technology and city life; and Daniel Dennett, cognitive scientist and philosopher of biology, science and mind.

Weizenbaum was the creator of the ELIZA program, which ran on clattering, 1970s, teleprinter hardware and timesharing system software, conducting a conversation with its user. It was a simple box of tricks, asking general questions and using a lexical scan of the program user's responses, to frame and pose more specific follow-up questions. In this way, guided entirely by the terms and phrases adopted by the user and some simple

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28 J. Weizenbaum, *Computer Power and Human Reason: From Judgment to Calculation* (Harmondsworth: Penguin Books, 1993).

heuristics of grammar, ELIZA conducted a ‘conversation’. It was following, slavishly, in the conversation, but gave the user the impression that it was leading, authoritatively.

In Weizenbaum’s eyes, the users testing the program responded to ELIZA and were quickly bamboozled and hooked into a trusting and open counselling session. Knowing the simple program and observing the engagement of its users, he was concerned. Quite apart from whether ELIZA would have passed a more realistic and rigorous Turing test of intelligence, which it certainly would not have, what did ELIZA say about computer power and human reason? His book, written amidst the rise of what he saw as a harmful obsession of children with computer games, reflected a profound cultural pessimism. The current debate about ChatGPT, producing plausible college student essays and news articles to order, drawing on billions of sources across the Internet, echoes the ELIZA dilemma. This software seems closer than ELIZA to Turing test accreditation, albeit perhaps not yet to an alpha grade or Pulitzer Prize!

Weizenbaum has a telling paragraph about the nature and role of tools, for those who use them and those who use their products. I quote at length as to paraphrase would do an injustice:

Tools and machines do not merely signify man’s imaginativeness and his creative reach, and they are certainly not important merely as instruments for the transformation of a malleable earth; they are pregnant symbols in themselves [...] An oar is a tool for rowing, and it represents the skill of rowing in its whole complexity. No one who has not rowed can see an oar as truly an oar. The way someone who has never played one sees the violin is simply not the same, by very far, as the way a violinist sees it. The tool is also a model for its own reproduction and a script for the re-enactment of the skill it symbolises. That is the sense in which it is a pedagogic instrument, a vehicle for instructing men in other times and places in culturally acquired modes of thought and action. The tool as symbol in all these respects thus transcends its role as a practical means toward certain ends: it is a constituent of man’s symbolic recreation of his world. It must therefore inevitably enter into the imaginative calculus that constantly constructs his world. In that sense, then, the tool is much more than a mere device: it is an agent for change. It is even more than a fragment of a blueprint of a world determined for man and bequeathed to him by his forebears—although it is that, too.<sup>29</sup>

His eighth chapter is devoted to artificial intelligence, on which he writes:

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29 Ibid., p. 18.

I had once hoped that it would be possible to prove that there is a limit, an upper bound, on the intelligence machines could achieve, just as Claude Shannon, the founder of modern information theory, proved that there is an upper bound on the amount of information a given information channel can transmit [...] It is now clear to me that, since we can speak of intelligence only in specific domains of thought and action, and since these domains are themselves not measurable, we can have no Shannon like measure of intelligence and therefore no theorem of the kind I had hoped for. In plain words: we may express the wish even the opinion that there is a limit to the intelligence machines can attain, but we have no way of giving it precise meaning and certainly no way of proving it.<sup>30</sup>

The *New Scientist* that dropped through our letter box this morning, as I was writing, has the cover title: 'Have We Got Intelligence All Wrong?'

Weizenbaum poses a question—'What human objectives and purposes may not be appropriately delegated to computers?'—and responds, saying: 'The question is not whether such a thing can be done, but whether it is appropriate to delegate this hitherto human function to a machine'.<sup>31</sup> This was and remains a contentious matter, today even more so. His ninth chapter discusses the danger of incomprehensible programs, and records lively debates at MIT, pitting dismissal of what were perceived as irrelevant philosophical musings against contrary fears that rationality in human affairs would come to be equated with computability and logicity. The Weizenbaum plea is for human reason to be associated with more than application of science and technology, but for these to be placed within clear context of human dignity, authenticity, self-esteem and individual autonomy.<sup>32</sup>

In the 1984-edition of the book, a re-enlivened Weizenbaum added a tenth chapter, which would be a fitting set text to be critiqued by students of courses on artificial intelligence, today. It addresses the imperialism of instrumental reasoning. I highlighted some of this philosophical debate in the context of theory of knowledge in Chapter Two. Referring to the promise and power of science and technology, he highlights the importance of power to choose, saying on: 'Power is nothing if it is not the power to choose. Instrumental reason can make decisions, but there is all the difference between deciding and choosing'.<sup>33</sup>

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30 Ibid., p. 206.

31 Ibid., p. 207.

32 Ibid., p. 255.

33 Ibid., p. 259.

He goes on to discuss the genome sequencing race of the era and biologists' concerns about ethical science and practice. Two major questions arise:

There simply is a responsibility—it cannot be wished away—to decide which problems are more important or interesting or whatever than others. Every specific society must constantly find ways to meet that responsibility. The question here is *how* in an open society, these ways are to be found; are they to be dictated by, say, the military establishment, or they are they to be open to debate among citizens and scientists? If they are to be debated, then why are ethics to be excluded from the discussion? And finally, how can anything sensible emerge unless all first agree that contrary to what John von Neumann asserted, technological possibilities are not irresistible to man? 'Can' does not imply 'ought'. [...] A central question of knowledge, once won, is its validation; but what we now see in almost all fields, especially in the branches of computer science we have been discussing, is that the validation of scientific knowledge has been reduced to the display of technological wonders.<sup>34</sup>

In some of his argumentation, he would probably now, retrospectively, recognize that he was proved somewhat off-beam. Regarding speech and natural language translation understanding, he writes:

Yet we have to remember the problem is so enormous that only the largest possible computers would ever be able to manage it. In other words, even if the desired system was successfully designed, it would probably require a computer so large and therefore so expensive that only the largest and best-endowed hospitals could possibly afford it—but in fact the whole system might be so prohibitively expensive that even they could not afford it. The question then becomes, is this really what medicine needs most of at this time? Would not the talent, not to mention the money and the resources it represents, be better spent on projects that attack more urgent and more fundamental problems of health care?<sup>35</sup>

Without wishing to disavow his conclusion, he clearly could not have imagined a world fifty years later, with the mainframe of his time, collapsed into the smartphone of today.

## The Illich Apocalypse—Iatrogenic Disease

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34 Ibid., p. 265.

35 Ibid., p. 271.



Health and care are deeply personal matters, and human rights and responsibilities are divisive matters in politics. The writings of Ivan Illich provide interesting insight into the extremes of these perennial arguments. One hesitates to call them alt-left wing views as they contain much that might equally be thought of as alt-right perspective of our era, both decidedly authoritarian. They rather confirm the historian Norman Davies's view, that the extreme left and right of the continuum of political perspective are close neighbours at the respective ends of a horseshoe shape. A horseshoe-shaped magnet has strong magnetic field near these north and south poles, but becomes rather weaker towards the centre. Impressionable acolytes are attracted there, but it is a tossup as to which tendency they will adhere to, or maybe they will team up with both!

Illich was born in Vienna, studied theology and philosophy in Rome, and obtained a PhD in history in Salzburg. He moved to New York and was an assistant pastor in an Irish-Puerto Rico parish until 1956, when he moved to become vice-rector of the Catholic University of Puerto Rico, establishing there the widely known and controversial Centre of Intercultural Documentation. He directed seminars on 'Institutional Alternatives in a Technological Society' with focus on Latin-America. Among his well-known radical *cris de coeur* are *Deschooling Society* (1971), and *Limits to Medicine: Medical Nemesis: The Expropriation of Health* (1975).<sup>36</sup>

In *Medical Nemesis*, he pitches in, in his characteristic apocalyptic style:

The medical establishment has become a major threat to health. Dependence on professional health care affects all social relations. In rich countries, medical colonization has reached sickening proportions; poor countries are quickly following suit. This process, which I shall call the 'medicalization of life', deserves articulate political recognition. Medicine is about to become a prime target for political action that aims at an inversion of industrial society. Only people who have recovered the ability for mutual self-care by the application of contemporary technology will be ready to limit the industrial mode of production in other major areas as well.<sup>37</sup>

Information technology as the saviour of society from medical nemesis—interesting how the poles are reversed from Weizenbaum's perspective that therein will arise a deskilled and dehumanized world of health and social care! He signs off towards the end of the book, in similar form:

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36 I. Illich, *Deschooling Society* (London: Calder & Boyars, 1971); I. Illich, *Limits to Medicine: Medical Nemesis: The Expropriation of Health* (London: Boyars, 1995).

37 Illich, *Limits to Medicine: Medical Nemesis*, p. 11.

Medical nemesis is the experience of people who are largely deprived of any autonomous ability to cope with nature, neighbour and dreams, and who are technically maintained within environmental, social and symbolic systems. Medical nemesis cannot be measured, but its experience can be shared. The intensity with which it is experienced will depend on the independence, vitality and relatedness of each individual.<sup>38</sup>

In talking this way, and using the term ‘symbolic systems’, I imagine he was referring to human culture imposed by machines and reflecting an industrial model of medicine. In his analysis, the medicalization of health starts with the language underpinning mechanistic concepts of disease:

The acute problems of manpower, money, access and control which beset hospitals everywhere can be interpreted as symptoms of a new crisis in the concept of disease. This is a true crisis because it admits of two opposing solutions, both of which make present hospitals obsolete. The first solution is a further sickening medicalization of health care, expanding still further the control of the medical profession over healthy people. The second is a critical, scientifically sound, medicalization of the concept of disease.<sup>39</sup>

As befits his political stance more widely, he attributes the failure to recognize iatrogenic disease to professional reluctance to give back the status and power it has acquired:

Just as Galileo’s contemporaries refused to look through the telescope at Jupiter’s moons because they feared that their heliocentric worldview would be shaken, so our contemporaries refuse to face nemesis because they feel incapable of putting the autonomous rather than the industrial mode of production at the centre of their socio-political constructs.<sup>40</sup>

His prescription for new legislation governing health is focused on promoting personal autonomy:

[...] the debate (on health care systems) could be rescued if attention were focused on medical nemesis, if recuperation of personal responsibility for health care were made the central issue, and if limitations on professional monopolies were made the major goal of limiting legislation. Instead of limiting the resources of doctors and of the institutions that employ them, such legislation would proscribe medical technology to professionals until those devices and means that

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38 *Ibid.*, p. 166.

39 *Ibid.*, p. 116.

40 *Ibid.*, p. 161.

can be handled by laymen are truly available to anyone wanting access to them. Instead of multiplying the specialists who can grant any one of the variety of sick roles to people who are made ill by their work and their life, the new legislation would guarantee the right of people to drop out and to organize for a less destructive way of life, in which they would have more control over their environment. Instead of restricting access to addictive, dangerous or useless drugs and procedures, such legislation would shift the full burden of their responsible use to the sick man and his next of kin. Instead of submitting the physical and mental integrity of citizens to more and more wardens, such legislation would recognize each man's right to define his own health—subject only to limitations imposed by respect for his neighbour's rights. Instead of relying on professional expertise to verify such values that will guide them. Instead of strengthening the licencing power of specialized peers and government agencies, new legislation would allow popular choice to entitle elected healers to tax-supported health jobs. Instead of submitting their performance to professional review organizations, new legislation would have them evaluated by the community they serve. Such guarantees against the medical support of a sickening industrial system would set the stage for the practice of health as a virtue.<sup>41</sup>

Here again, there is ambivalence about technology, but the idea of new technological advancements potentially contributing to the wider social agenda he supports remains open. 1984 was still fifteen years away and Orwellian angst did not feature in his perspectives on technology's influence in human society. Working in poorer parts of Latin America, his awareness of information technology was shaped by images of the flashing lights and punched cards of the 1960s mainframe. He writes about respectful technology:

Tekne—the art that produced the first type of tool—was a measured tribute to necessity and not the road to mankind's chosen action.<sup>42</sup>

DNA features nowhere in the book, even nearly twenty years after its discovery—the scientific examples are from the times of the Industrial Revolution:

The loss of a normative human condition not only introduces a newness into the human act but also a newness into the human attitude towards the framework in which a person acts if this action is to remain human after the framework has been deprived of its sacred character. It needs

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41 *Ibid.*, pp. 166–67.

42 *Ibid.*, p. 162.

a recognized ethical foundation within a new type of imperative. This imperative can be summed up only as follows: ‘act so that the effect of your action is compatible with the permanence of genuine human life’; very concretely applied this could mean: ‘do not raise radiation levels unless you know that this action will not be visited on your grandchild’. Such an imperative obviously cannot be formulated as long as ‘genuine human life’ is considered an infinitely elastic concept.<sup>43</sup>

Illich’s prescription is for greater personal autonomy. In his book, *Deschooling Society*, discussed further in the section below on education, he argues for information systems that, when read today, bear strong resemblance to those now characteristic of the World Wide Web. He argues for systems that build a bridge from knowledge and information held and regulated behind a protective barrier of privilege and professionalism, to systems accessible and under the governance of autonomous citizens. He does not make this case in the context of medicine, but the quotations cited seem to indicate his thinking was in that direction.

The perspectives that I have introduced here are contrasting and extreme views of the current trajectories of health care services. Information utility for health care needs to steer between Illich’s fear of disempowerment of citizens at the hands of industrial and commoditized medicine, and a Novacene surrender to machine intelligence. There can be common and open ground between these extremes, and it is this that I seek to alight on in Part Three of the book.

## Genetics and Genomics

When one thinks of ‘information explosion’ in the context of health care today, the data generated by the unfolding story of human genetics and genome science must surely qualify for that moniker. It is hard to give a meaningful overview. So much is changing, and so little time has elapsed in which to gain perspective. The evolution of bioinformatics of the past thirty years has transformed life science and is transforming clinical science, championed from early days in the UK by the immunologist John Irving Bell, Regius Professor of Medicine at Oxford. Many measurements are made, and words written, but it is still early days in relation to the promised benefits for human health and wellbeing that these portend and foretell. It would be interesting to know how Illich would have interpreted the rise of this new science and its impact on his appraisal of medicine and health care. The opportunity it opens for personalized medicine is surely one step

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43 Ibid., p. 163.

towards greater personal autonomy and choice in relationship of patient, professional team and health service.

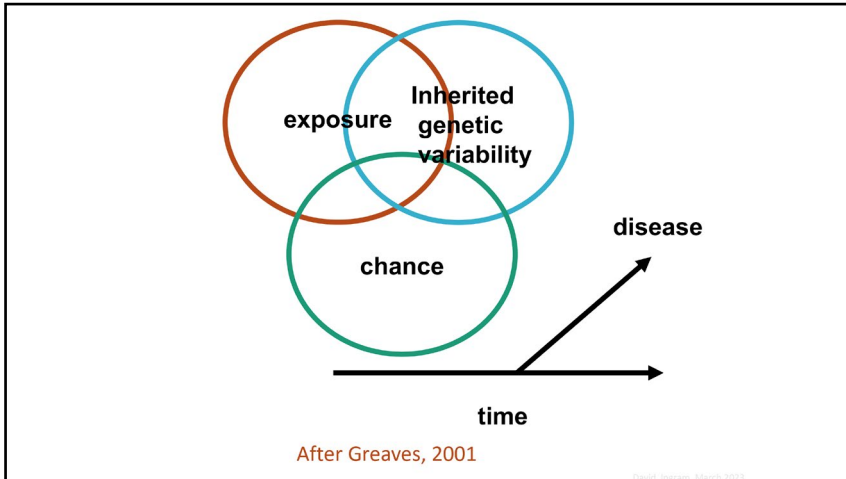


Fig. 7.6 The interaction over time of factors causative of disease—after a lecture of Melvin Greaves, 2001. Image created by David Ingram (2003), CC BY-NC.



Melvin Greaves has been a highly regarded cancer scientist throughout much of my career. Close friends have worked with him. It has been a pleasure to listen to his lectures, to understand the pattern of onset of disease that he describes. I jotted down this simple diagram (see Figure 7.6) that he showed in one of these lectures. It concerns how disease arises, not how it may be treated, and depicts the interaction of variability in the genetic inheritance of DNA, with exposure to harm in the living environment and chance happenings in life. It conveys important truth to counter overly zealous instrumental approaches to health and disease. There are echoes, here, of Jacques Monod (1910–76) and his pre-bioinformatics perspective of chance and necessity in life.<sup>44</sup> There are also echoes of the recurrent ping-pong of perspectives on the interactions of ‘nature’ and ‘nurture’ in the development of living beings, digging deeper into issues of gender, ethnicity, environment and social inequalities, as determinants of health.

<sup>44</sup> J. Monod, *Chance and Necessity: An Essay on the Natural Philosophy of Modern Biology* (New York: Knopf, 1971).

Three basic sciences and their associated technologies have illustrated the advancing power of medical science of the past one hundred and twenty years and its dependence on information technology. These are imaging science, with its origins in physics, mathematics and computer science; pharmaceutical chemistry; and molecular biology. Each has traced a path alongside the evolving capabilities of information technology, into new methods of measurement, analysis and intervention, their translation into everyday use through the industries that support them, and the people and health care organizations that use them. In prospect, today, are two newer technologies, emerging rapidly from their university origins seventy-five years ago and embodying ideas and methods from computer science, mathematic and engineering control systems. These are machine learning and robotics. Overarching these advances is the grand challenge of data integration in the context of ethico-legal records of care.

The discovery of the structure of DNA came from applied physics, and of its cellular mechanisms from applied chemistry. In amassing data from these experiments, a new world of understanding of biological structure and function arose, at the level of cells and signalling between cells, and in microbial systems of gut flora and the natural environment. Emerging from this scientific revolution is a new technology of synthetic chemistry, whereby biologically active molecules are created from building blocks of component chemical structures. This is rather like early electrical circuits being soldered together from discrete component resistors, capacitors, inductors, rectifiers, valves, transistors and the like, and then grouped within integrated circuits for higher level functions such as electrical signal processing.

Nearly to me at UCL, Janet Thornton, herself a traveller from physics into biology and bioinformatics, led the way in formulating new classifications of the folding structures of proteins. She has memorably described bioinformatics as the core discipline of biology. Bernadette Modell, a luminary figure in the WHO context in her study of the burden of inherited disease, and especially thalassaemia, pioneered information systems with our jointly-supervised doctoral student, Matthew Darlison, to bring knowledge of genetics to the affected family and patient communities.

Experimental methods of genetic analysis have enabled study of the propagation of inherited traits across generations of rapidly reproducing living organisms, such as plants, flies and yeast cells, and of patterns of disease in families of human subjects. These now connect through the databases and analytical methods of bioinformatics, to provide frameworks for the characterization of sequences, structures and functions of chromosomes, genes and proteins of living systems. Such databases enable identification and tracking of significant marker sequences within the genome, in determining pattern and progression of disease, and

related personal risk factors, for individuals and their families, and across generations, influenced also by non-genetic inheritance pathways.

The application of this bioinformatics discipline in pharmacology is developing rapidly, to help improve treatments. Related new information services are being created at the population level, to assist study of the aetiology and treatment of disease. Again, the challenge of integration of this data within a coherent care information utility is considerable. The field is prey to exploitation and fragmentation when these methods are adopted and scaled within new industries that operate outside effective governance and regulation frameworks, positioned to protect citizens from exposure to harm and support them when harmed. The Web is increasingly populated with advertisements for pills that are being sold as mitigation for genome-correlated personal risk factors. Scientific trials involving yeast and drosophila can span their short-lived generations in the laboratory, but we are not yet quite ready for clinical trials of such interventions spanning long-lived human generations!

## Education, Competence, Accountability and Risk

Education is the acquisition of the art of the utilization of knowledge.<sup>45</sup>

This Whitehead quotation rings true in highlighting issues of education policy, today, as emphasis shifts from learning facts, to learning how to access, interpret and use facts and methods, within contexts of new, real and virtual worlds of knowledge and experience. The primary schools of our grandchildren are ahead of the older generation in this. It will fall to them to see off 'fake' and 'alternative' facts in the anarchy of today's World Wide Web.

As with health systems, education systems are changing rapidly as the world turns upside-down in its transition into the Information Age. We are healed and kept well by clinicians and carers, and we heal and care for ourselves as well. We are taught by educators and educate ourselves, as lifelong learners. The balance of personal and professional, in education as in health, is a rapidly shifting balance in the Information Age.

Education connects with the philosophy of knowledge and mind. It connects with developmental neuroscience and psychology. We learn as we grow and as we go. Education connects with the assessment of taught disciplines in schools, colleges and universities, and with the assessment of

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45 A. N. Whitehead, *The Aims of Education and Other Essays* (New York: Macmillan, 1929), p. 4.

work performance in profession, craft and trade, where the emphasis is on apprenticeship and learning on the job.

In the first half of the twentieth century, Maria Tecla Artemisia Montessori (1870–1952) and Jean Piaget (1896–1980) focused attention on the developmental autonomy and psychology of the child. Kurt Hahn (1886–1974) and Alexander Neill (1883–1973)—remarkably connected dates for these connected educational pioneers—focused on residential learning communities of secondary education at Summerhill School and Gordonstoun School. In tertiary education, there have been many shapes and sizes of new institution, and networks of institutions. The Adult School movement, and then the Open University, in the UK, brought new educational opportunity in adult life. In retrospect, the World Wide Web seems quite close to Illich's prescription for a 'de-schooled' society. He championed the personal autonomy of learners and hated schools as much as he did hospitals! It would be interesting to hear how he would have reframed his prescription for education, given the concerns about regulation of quality of Internet content and learning resources that have arisen.

Today, we observe and listen to our teachers and consult libraries and other learning resources. We survey, experiment and practise. We learn alone and we learn with colleagues and in groups and communities. Some learning is easy, some is hard—at best enjoyable and motivating, at worst, prosaic and onerous—a mix of inspiration and perspiration. We express and demonstrate our learning through assessments focused on mental and practical articulacy, fluency and capability in the execution of tasks. And much of this through the Covid pandemic has taken place online and in connection with educational software and electronic learning resources.

Albert Einstein (1879–1955) purportedly said that 'It's not that I'm so smart, it's just that I stay with problems longer'. For smartness, read intelligence, and we then enter the realm of what we value and measure when assessing and grading what is demonstrated through learning. Are we intelligent—what does that mean? What intelligence quotients and other quotients of ability and learning, are worth their salt as metrics of assessment—valid, reliable, reproducible and fair? What is emotional intelligence and how does this fit alongside? Should we be seeking more wide-ranging assessments, indicative of how we are capable to connect and contribute, over a lifetime of roles and opportunities? For example, valuing the capacity to negotiate and balance between conflicting viewpoints and imagine creative solutions to complex and contentious problems. This takes us into another set of questions—about judgement, ethics and wisdom.

The human conundrum that is wisdom exercised George Bernard Shaw, in the dialogue of humble waiter and pompous lawyer, in his play *You Never Can Tell* (1897). The waiter's gentle and polite riposte to some of the



lawyer's hubristic posturing—along the lines of 'Well, Sir, if I may say so, if that is wisdom, then so much the worse for wisdom'—rings in my mind from my school days' monthly trips to matinee performances for schools at the Old Vic theatre in Bristol. There seems not much more that can be said about wisdom, than is said in such literature!

Transition into the Information Age has placed these perennial questions and concerns about education and practice under a new microscope and within a wider macro-scope. The education scene is adapting to changing needs, embracing new opportunities and resources for teaching and learning, and challenging the *status quo* for everyone involved—students, teachers, institutions and professions. As with health care services, there has been a wealth of central initiative and local innovation, contained and directed within new approaches to audit and accountability. A few new mirrors have been added to this kaleidoscope, to fragment its images! An NHS University was established in December 2003 and quickly abolished, in 2005!

## Medical and Multiprofessional Education

For successful education there must always be a certain freshness in the knowledge dealt with. It must be either new, in itself, or invested with some novelty of application to the new world of new times.<sup>46</sup>

Medical education has experimented with the division of phases between life science and clinical education, and with parallel and connected flow between the two. It has explored problem-based learning, drawing together different disciplines and ways of thinking, to address a specific clinical problem. It has thereby long recognized the concept of grand challenge, bridging and uniting disciplines in focus on overarching clinical problems, where solutions may embody them all. Such challenges may be intractable, but they are unavoidable.

Information overload in the curriculum, as in everyday clinical practice, has risen steadily alongside the explosion of knowledge and diversification of specialism of health care. In medical education of the 1970s, this had become a significant concern in context of student workload, as the figure based on Anderson and Graham's paper indicates (Figure 7.7).<sup>47</sup>

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46 A. N. Whitehead, 'Universities and their Function', *Bulletin of the American Association of University Professors* (1915–1955), 14.6 (1928), 448–50 (p. 450).

47 J. Anderson and A. Graham, 'A Problem in Medical Education: Is There an Information Overload?', *Medical Education*, 14.1 (1980), 4–7, <https://doi.org/10.1111/j.1365-2923.1980.tb02604.x>

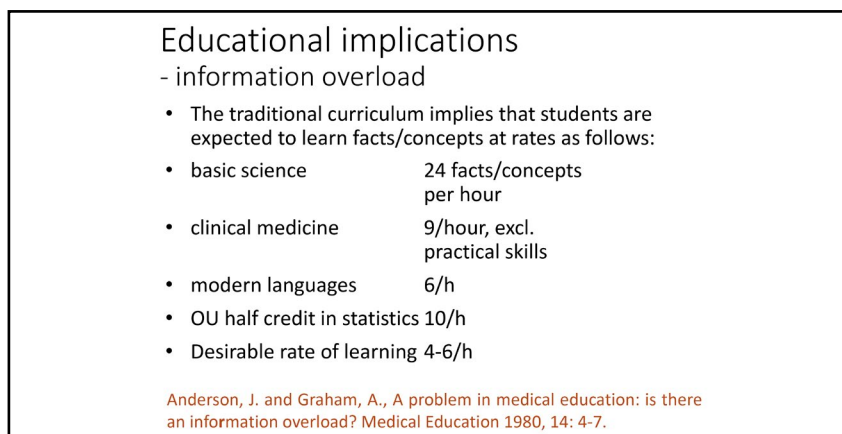


Fig. 7.7 Some early comparative metrics of the scale of factual content in the curricula of different first-degree subjects. Image created by David Ingram (2010), CC BY-NC.



Assessment and regulation of clinical practice has faced wide-ranging challenge and the nature of professionalism is changing, more widely, as discussed in Chapter Eight. The mantra that assessment drives learning became the basis on which to define, constrain and regulate courses of education. Learning objectives for a course of study express what the student will be expected to be able to demonstrate and do. First work out and set out how you will assess, and then use this to define how you will teach and expect students to learn. This approach provided a more explicit focus of educational method in a field progressively overloaded with information, and where intra- and inter-observer variability in the assessments made was known to be high, and thus potentially unfair. Such a framework defines a common learning landscape for student, teacher, employer and regulator. Such clarity and predictability may, of course, come at a price of stifled creativity—an overly regimented factory is an unlikely place to find the freshness and novelty of education that Whitehead deemed essential.

Methods of formal assessment of clinical education and performance in practice have been consuming academic and professional issues throughout my career. Called upon to assess students, the exam boards of clinical medicine—that I watched coming to and fro and heard their chat—were motley assemblies of crusty and talented folk. The top third and the bottom third of students being assessed pretty much defined themselves, but the middle ground was argued over, both vehemently and imprecisely. Opinion

was rife! Assessment in mathematics and science tends to be a bit more precise and reproducible, and rather more dull!<sup>48</sup>

The formal assessment of knowledge and skills features increasingly in medical education and national professional regulation of competent and safe practice. I have been close to three national pioneers and leaders in these areas: Jane Dacre, Lesley Southgate and Charles Vincent. I described the context in which our worlds aligned for twenty, sometimes tumultuous but always creative years—for all of us, in different ways—in Chapter Four, and reflect on this further in Chapter Nine. Here, I revisit the connections which were made then, that shaped my thinking and work, towards the creation of future information utility for health care.

### Skills and Assessment

Jane Dacre worked with me at Bart's to establish the first UK clinical skills centre, established jointly between its medicine and nursing colleges. As medicine has become more accountable, so issues of rigour of assessment have come to the fore. Is it measuring the right thing? Is it measuring accurately? Is it reproducible among examiners, or with the same examiner at different times? Such issues permeate throughout assessment. Assessment has moved into the Information Age with the automation of multiple-choice question banks. The students' answers are analyzed and grouped to provide statistical summaries that guide the setting of student population norms and grading boundaries and help in improving the rigour and usefulness of the tests themselves.

The mantra of assessment driving learning connects with maxims on management from the business world, credited to Peter Drucker (1909–2005), the Austrian modern-day guru of business management. Here are some of the ways he is quoted:

If you can't measure it, you can't improve it.

Management is doing things right; leadership is doing the right things.

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48 Assessments of the quality of craft and profession are inevitably quite subjective. I remember vividly an art class exam in secondary school where we were asked to paint a gloomy, wintry riverside scene, with a wood of trees dangling roots into murky water. I ended with a picture I still have that was, in my eyes, a blurry, wet disaster. Coming to class, feeling trepidation about having the marked work given back, I was shocked to see ninety-eight percent written at the top and hear the genial art teacher hold it up and expound to the class its artistic merits! Art is about conveying meaning and feeling as well as technical mastery, and that involves impact on other people as much as oneself. I still look at the picture and think it was terrible!

The best way to predict the future is to create it.

There is nothing so useless as doing efficiently that which should not be done at all.

These are latched onto in educational contexts, as sound bites, especially in the context of vocational education. Creating the future is the focus of innovators and their leaders. Innovation exists in the Drucker domain of discovery of the right things to do. Management of education is about good and efficient processes and is a gatekeeper role. Support for innovation is a wider role of leadership. Innovation in and management of education and assessment coexist, but embody different passion, perspective and leadership. Innovation operates, importantly and consequentially, to disrupt *status quo*. It is resisted by interests that it challenges, as highlighted in Chapter Five. Doing right things involves letting go of what once might have been thought right, but now no longer is, and recognizing that if we are not doing the right things, measuring them can risk doing more harm than good. Some cans of worms may best be left unopened. Useful disruption without harmful destruction is a difficult balance to strike.

Educational assessment method morphs into management strategy—the model of assessment becoming the model of management of learning. It risks becoming a game—between students and teachers, and between teachers and their institutions and regulators. Marshall McLuhan (1911–80) wrote of the medium becoming the message. The medium of assessment becomes the message whereby we communicate about learning. It is a necessary, but surely not a sufficient message. All this will have to come to terms with ChatGPT!

## Practice and Performance

Innovation in methods of assessment of medical education, such as the clinical skills Objective Structured Clinical Examinations (OSCEs) that Jane Dacre pioneered in the Bart's Clinical Skills Centre, has widened into the regulation of competent clinical professional practice. This trend has been mirrored in more stringent regulation of other professions and services, such as those of plumbers and electricians, and the certification of their competency and work conducted.

Independent audit of quality of care delivered by practitioners has become a matter of judicial determination by professional regulatory bodies, such as the General Medical Council in the UK. These are often difficult and emotive matters to decide within a legal framework, as in the case of a junior doctor colleague, known to one of my children, who mistook the labelling

on a chemotherapy drug package late at night, when tired and alone on duty, and injected a drug by the wrong route, resulting very sadly in the death of the patient.

Lesley Southgate, an East London GP who worked with me in the foundational Good European Health Record (GEHR) research project that led to openEHR, and joined me, along with Jane Dacre, in establishing the Centre for Health Informatics and Multiprofessional Education (CHIME) at UCL, as described in Chapter Nine, became a leading national player in work on behalf of the General Medical Council (GMC). This became the basis of nationally mandated, albeit sometimes hotly contested and resented, procedures for the review of referred individual doctors' clinical competence to practice and the adoption of more formal requirements for every practitioner to keep up to date in their field, by participating in continuing education and training programmes. Lesley was a doughty warrior and political campaigner for East End primary care and medical education. She worked tirelessly to deliver a very difficult and contentious brief, with her team set up within the comparative calm and protection of the CHIME academic department at UCL. She was well recognized by the leadership of the GMC for this work. She and Jane were both elected to lead their respective Royal Colleges and nationally honoured for their immense contributions.

## Risk Management and the Law

The risk of harm being caused to patients because of the clinical interventions they receive, along with the collection of data and presumption of accountability for harm, has become of increasing concern in the transition of health care into the Information Age. This trend was highlighted in John Swales's lecture, when head of research and development for the NHS at the time of its fiftieth anniversary, as described earlier in this Chapter. Medical intervention can, of course, sometimes at best be a palliative measure, or of unlikely success. The death review meetings of my early career were where these matters were handled as part of clinical team culture and practice, within a protected and trusted hospital citadel. They were seriously undertaken, and sometimes uncomfortable, occasions—I lived in that community and heard about them. They sought to learn from experience, improve practice and avoid mistakes—which, again, are inevitable on occasion, with no fairly-accountable responsibility or blame to be attached.

Over time, such culture has translated towards a more adversarial one of cover up and avoidance of blame, within and beyond the clinical community. Medical malpractice and organizational failures in duty

of care became more litigious matters. And these concerns now attract wider public scrutiny and over recent decades there have been notable UK public inquiries into the quality of health care services and the practice of individual clinicians, teams and organizations. Some, such as the Bristol, Shipman and Staffordshire enquiries, became of major national focus and concern. Attention was focused on causes and remedies.

Statisticians combed data provided to the 2000/01 Bristol Inquiry into excess deaths in children's cardiac surgery.<sup>49</sup> They found persuasive evidence that this reality could have been discerned much earlier, given good quality data on surgical outcomes, combined with methods for analyzing such trends that were in routine use in other sectors of the economy, for example in the quality control of manufacturing systems and surveillance for significant trends in drug trials. Cardiac surgeons, nationally, were prompted to lead efforts towards making such surveillance more feasibly a matter of daily routine.

The psychologist Charles Vincent pioneered the study of clinical risk management, working in the Psychology department at UCL, and subsequently at Imperial College, in London. Through his colleague Pippa Bark, I drew this theme within the scope of the health informatics graduate programme I created at UCL from 1995, seeking to connect issues of data and data management with the culture and practice of risk management. As information utility becomes a more coherent, pervasive and connected reality, the aspiration for closer awareness of potential adverse risk and its mitigation will become more tractable. As things stood at the time of the above national enquiries, the political response was to impose greater requirement for central reporting of critical incidents, from within widely disparate and non-coherent information ecosystems. I have mentioned elsewhere the proliferation of burdensome computer-based reporting systems that were created. As in so many areas of sought for quality improvements, coherence of the underlying data models is a *sine qua non* of successful method that can be implemented efficiently and with least possible operational burden.

The invocation to 'do no harm' dates from the time of Hippocrates (c. 460 BCE–375 BCE) and the invention of medicine. A future information utility can support that goal and help to enhance a culture that guides, supports and improves practice, as a shared professional endeavour, rather than simply providing chapter and verse in the reporting of failures, which exacerbates the now prevalent culture of blame and blame avoidance. There is much continuing effort towards improvement. A high proportion of

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49 'Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary', *The Health Foundation* (18 July 2001), <https://navigator.health.org.uk/theme/report-public-inquiry-childrens-heart-surgery-bristol-royal-infirmary>

clinical risk litigations revert to problems of record keeping and continuity of care. Information overload is also implicated.

In the 1980s, research on human decision making was being presented in medical contexts at meetings of the Royal College of Physicians Computer Group. One such talk showed how humans could cope with, refine and improve clinical decisions, drawing on up to seven (the magic number) variables, but thereafter their capacity diminished, and decisions worsened. In the accumulating research literature assembled by Charles Vincent, information overload was demonstrated as a risk factor in acute medical situations such as intensive care unit (ICU) management.<sup>50</sup> Standardization of interventions conducted in situations of heightened risk and uncertainty, such as the Advanced Trauma Life Support (ATLS) protocols for induction of trauma life support in Emergency Departments, have been shown to improve outcomes for the patient.

### Central Roles of a Care Information Utility

The formulation and regulation of personal ethical and legal rights and responsibilities has become increasingly complex in the Information Age. Contending perspectives on privacy, ownership and openness of personal and population data have become contentious issues of debate and the subject of major and evolving legislation. They are put through the wringer and play out more openly in public places, affecting all sectors of the economy and its products and services. Coherent and consistent thinking about these issues matters more as technology advances and interventions become more powerful.

Clinical intervention will always involve potential benefit weighed against risk and cost—not much in life does not. Clinical assessment, whether deployed in health care delivery, academic examination, professional peer review or judicial proceedings, must inevitably weigh evidence and make judgements about probabilities. These judgements need the best possible scientific underpinning, but they also rest on issues of trust—in knowledge, data, expertise and people. How and why patients trust their professionals is also important to understand and appreciate. Trust is vital in clinical practice, and it is a two-way street—the rights of both citizens and their professional carers must coexist fairly alongside their just governance in the public domain.

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<sup>50</sup> C. Vincent, ed., *Clinical Risk Management: Enhancing Patient Safety*, 2nd ed. (London: BMJ, 2001).

Much of medicine is temporal. Much is about giving time and opportunity for the body to recover and heal itself. Much is a balance of risk, trial and error, often characterized by a sense of 'wait and see'. The patient is a key player, over time, in their own maintenance of, or recovery to, good health. Mutual belief and trust in the relationship with their supporting professionals play a key part and require time devoted to them. Regulation of such a personal domain as health care, especially when things go wrong, carries risk of punitive litigation, leading to defensive practice, obscuration, deception and blame. These can extend into cultural miscues, misunderstandings and mistrust.

The current time and capacity constraints on clinical professional practice and working life do not seem consistent with good and feasible solutions to this ongoing and increasing set of interlinked problems. New common ground is needed, on which to adjust and balance the extraordinary and taxing combination of challenges that health care teams face in their everyday lives and careers, in their own struggle to find a sustainable mix of reasonable expectation and achievable reality. This impasse has embroiled both the professional teams and those they serve, in the overloaded health systems of today. Necessary reinvention and reform of services needs to be rooted in education about the changing nature and culture of health care teamwork and professionalism, and of the roles and responsibilities shared. There is much stirring in this direction.

And it is at the centre of the current imbalances that a new kind of information utility is needed, to help towards new fairways and fair ways of working, focused on outcome and value, rather than process and cost that have typified the runaway insolvency of Industrial Age medicine. Ways that balance and interface consistently, continuously, effectively and fairly, and that relieve undue or unnecessary burden on all sides. Health care services must advance alongside individual self-care. Assessment and regulation of professional education and practice must advance, likewise, alongside individual self-assessment and peer-assessment of learning, skills and competencies. This trajectory must join coherently with methods and resources for continuing professional education and quality improvement of services. Taken together, these will help to reshape what has become an unfairly punitive and defensive culture and burden on professional practice. This is reflected in the fragmentation and discontinuity of the current landscape of services. Its infeasibility has been exposed and exacerbated in the transition into the Information Age and must be put right in the Information Society.

These are not new thoughts. Let us look back again, in the wider context of assessment of skills and competences, to an early report of the Congress of the USA Office of Technology Assessment (OTA). This was prepared



jointly with the Association of American Medical Colleges (AAMC) and entitled 'Computer Technology in Medical Education and Assessment'. It contains many interesting observations and highly pertinent, although still largely unmet, expectations of the future role of the computer in connecting a continuum of relationships between education, assessment of professional performance and outcomes for patients.

The use of computers in education and assessment inevitably will be linked to their uses in medical information systems. Such linkages will allow, if not force, the formation of new relationships between segments of medical education and assessment continuum, through accumulation of large databases on student characteristics and performance, on physician and institutional performance in patient care, and on patient outcomes following treatment. These databases could serve as the thread of continuity between portions of the continuum. They could provide more objective and quantitative feedback mechanisms from active practice to education and assessment.<sup>51</sup>

It further emphasized how a focus on standards and standardization could be expected to connect improved medical information systems with medical education of the future.

Currently the best measures of competence in learning do not necessarily predict good performance in practice. Patient care assessments depend on comparison with peers using standards (processes that should be followed) or empirically determined norms (the average care provided). Computer technology could be used to improve the linkage between medical education and patient care through the provision and maintenance of more specific and objective databases for diseases and treatments. In addition to providing better data for generation of standards, computer databases could allow better comparisons of standards and norms of care with actual patient outcomes. These data also could permit the development of computer consultant systems. Feedback from medical information and health data systems could provide continuous updating of the databases.<sup>52</sup>

Fifty years have passed, characterized by failure to show how to turn the promise into a reality. The idea and implementation of the care information

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51 Congress of the United States Office of Technology Assessment, *Computer Technology in Medical Education and Assessment* (Washington, DC: Congress of the United States Office of Technology Assessment, 1979), <https://www.princeton.edu/~ota/disk3/1979/7903/7903.PDF>, p. 5.

52 *Ibid.*, pp. 5–6.

utility, as set out in Part Three of this book, is, in significant part, about the practical realization of these now tractable and achievable goals.

## Research

As we have seen, the role of the computer is still at a transitional stage in the pedagogy and assessment of learning in medicine and health care. By contrast, it has more rapidly transformed the scope, methods, scale and infrastructure of research, but not without difficulties specific to the health care domain. My songline has travelled widely across this changing landscape, over five decades.<sup>53</sup> In keeping with the increasing scale of data capture and broadening scientific and geographical connectivity of clinical research of those years, I was close to many teams working to design, install, program and operate ever faster and more extensive computational facilities, link them across networks and enable them to handle and process ever larger data stores and computational loads.

The UK CCLRC was established to draw together and support such research endeavours across disciplines. Its home base is the inspiring national science campus at Harwell, near Oxford, and there are similar and closely connected computational science communities in many countries. The USA has the Oak Ridge National Laboratory, which is dedicated to ‘solving big problems’ and describes its ‘greatest strength’ as the people from sixty countries working there. I describe my connection with CCLRC and its great teams of scientists, in the science and computation section of Chapter Three, on observation and measurement.

Through these integrative scientific endeavours, built around shared computational methods and resources, scientists have joined forces to the mutual benefit of their respective communities, enhancing the kinds of research they are thus enabled to pursue. In medicine and health care, with their special responsibilities for handling personal and confidential data, activities have tended to remain fragmented within non-communicating

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53 My involvement in creating and running research computing environments and infrastructures extended over many disciplines. I was for several years given the responsibility to lead and coordinate the IT professionals working in separate computer support teams on the three main medical school campuses and the separate biomedicine research institutes of UCL in London. These comprise some fifty percent of the volume of academic work of UCL, as is typical of world-ranking Universities. I also chaired the university IT infrastructure committee and was a member of its information strategy and finance committees, and of the biomedical executive committee of the University. Further afield, I was at different times a member of boards overseeing research and library computing for the MRC, EPSRC, EESRC, CCLRC and for the British Library and Wellcome Trust.

silos of data. Considerable, both technical and organizational, difficulty was experienced in safely connecting the IT systems used for the academic and clinical service roles of clinical researchers, who sometimes ended up working with several personal computers connected on different firewalled networks.

The challenge of integrating data from these disparate silos is well illustrated by this slide of my clinician colleague, Richard Begent, which he used to illustrate the wide-ranging requirements of his cancer research (Figure 7.8).

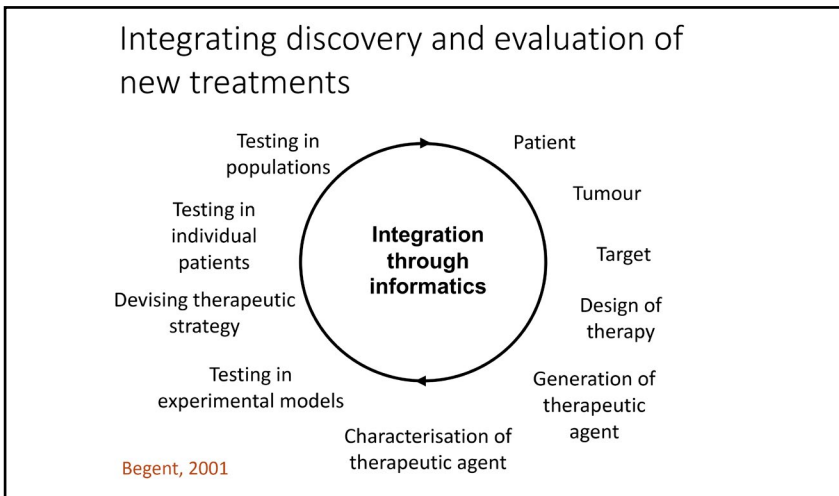


Fig. 7.8 Integration of research and practice through informatics—after a lecture of Richard Begent, 2001. Image created by David Ingram (2010), CC BY-NC.



In such situations, there was much scope for research teams that had enjoyed, and preferred, an independent working life, and were reluctant to spend time in pooling their efforts for the common good, to shelter under different organizational firewalls, and making claims of exceptionalism! One way or another, a more cost-effective and scalable approach was increasingly necessary, and achieving it was a human as much as a technological challenge. I relate several of the local stories, here, to illustrate how local and wider national research issues enmeshed, and organizational development became a central focus and concern.

One of my tasks as a member of the biomedicine executive group of UCL was to create and populate a more cohesive, resilient and efficient

common ground of IT support services, drawing together members of some ten long-established separate small teams. This involved gaining their trust and commitment, and permission from the senior academic leaders they worked for, some fearing loss of autonomy and the funding for IT that they enjoyed within their separate domains. They had different needs for connection with clinical services in their different local NHS Trusts. My task also involved building a good relationship with the corporate IT support services of the university, that already provided a wide range of computing services pursuant to the University's central information strategy. I was a broker among highly intelligent, experienced and successful teams and leaders, where mutual trust was not always the order of the day! The different team members identified with and felt protected within the different local departments, faculties and institutes that they worked for. We met over two years to articulate and create a shared mission and common approach to the IT support services.

In parallel, we discovered that within the largest of the UCL-linked NHS Trusts, UCLH (University College London Hospitals), there were some three hundred separate small computer systems in operation, funded locally and often running software that was idiosyncratic, poorly documented and sometimes of unknown design. I discovered this through the dissertation project of one of my Master of Science (MSc) students in health informatics, who went on to lead cancer information services in a national research institute. This situation was common to other major medical schools where I enquired. The NHS side of the research challenge we faced was clearly, in itself, a highly fragmented IT domain.

A few years before embarking on the IT support services initiative described here, a similar effort was devoted to creating a network of the many clinical research investigators and their teams, based in the eight constituent NHS Trusts linked to UCL, later called UCL Partners. The UCL Chief of Medicine of those times, Leon Fine, and the Director of Research and Development at the Institute of Child Health, Great Ormond Street, Al Aynsley-Green, asked me to join them in establishing a Clinical Research Network Board to oversee this project.<sup>54</sup> The Trusts involved were sometimes quite fiercely independent institutions! The Royal Free Hospital in Hampstead; the UCL Hospitals in Bloomsbury; the Whittington Hospital in Archway; the Institute of Neurology at the National Hospital for Nervous Diseases site in Queens Square; the Institute of Child Health

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54 This initiative was mentioned in Chapter Five, in the context of a meeting to discuss a consultant's report on the anarchic disorganization of some government databases, that Al had asked me to attend with him, in his later capacity of national Children's Commissioner.

at the Great Ormond Street Hospital site; the Institute of Ophthalmology at the Moorfields Eye Hospital site; the National Centre for Orthopaedics at Stanmore; the Eastman Hospital Dental Institute in Gray's Inn Road. All told, an annual turnover now in excess of five billion pounds. It naturally fell to me and one of my IT support team colleagues to create a searchable database of investigators and projects. Another taxing human exercise! Much of organizational development these days is driven by and revolves around innovation in information systems. That involving health care is no exception, but it is typically a harder task because of its multiple interconnections across academic and health care service domains and constituencies!<sup>55</sup>

Extending from these local roles at UCL, I was drawn into efforts to tame the wider computational challenges posed by large-scale scientific research of the Information Age, as a member of the Medical Research Council's informatics board and then representing it on the national e-Science Programme Board. This drew together representatives from the Biotechnology and Biological Sciences (BBSRC), Engineering and Physical Sciences (EPSRC), Central Laboratory of the Research Councils (CCLRC) and Economics, Environment, and Social Sciences (EESRC) research councils and connected also with the Wellcome Trust and the NHS Information Centre. Some of the eScience 'moonshot' initiatives, to use the UCL economist Mariana Mazzucato's term, spread over five or more years and progressed very well. Alongside worldwide efforts, they pioneered a new generation of networks and grids of computers, leading over the next decade to the technology underpinning the commercial Cloud data centres and computational resources of today, including those of global corporations such as Microsoft, Amazon, Google, Apple and Alibaba.

This research computing community grew to span disciplines and continents. In contrast with the medical, health care and social sciences, other sciences did not face the challenge of coherent and confidential linkage with data obtained from operational health care systems. Such clinically linked research lagged behind as a result but has been investing

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55 Under its then new leader, Robert Naylor, the UCLH Trust recruited Paul Bate from Chris Ham's department of health care management in Birmingham, who specialized in organizational change and came to run the Organizational Development programme of the UCLH Trust. This Trust was itself engaged in pulling together several other local NHS Trusts under the one UCLH umbrella. Paul and his colleague, Glenn Roberts, joined our department and conducted several research projects across the NHS and internationally, including one studying the organizational impact of IT innovations. I arranged for Paul to teach what became a very much appreciated module on this topic for our very successful health informatics graduate programme, led at that time by Paul Taylor.

to catch up in recent years. At the same time, there were other differences and rivalries in play. For example, the wider eScience research community sometimes envied and somewhat resented the virtuosity of its physics community membership, which could always be relied on to have the most demanding computational challenges to put forward, and the best worked up and coordinated bids for national funds, to create and run the computer infrastructure their science required, and for these to be adopted as a top national priority!

Now, everyone has the equivalent of what was the largest mainframe research machine at the start of my academic career, in their laptop, connected via the Internet to the massively more powerful computational resources and data warehouses of today. And the software that runs within this infrastructure has matured beyond recognition. In similar virtual proximity are the electronic libraries and archives of research and publication, also worldwide.

Realization of the undoubted research potential of the NHS has also been hampered by the lack of a semantically coherent information architecture, of the kind that initiatives such as openEHR have been experimenting with, specifying and disseminating. Moreover, the wider health care IT domain is a very substantial commercial marketplace which has, unsurprisingly, long been kept under the watchful eyes of many powerful industry interests. Companies retain control through contracts, Trust by Trust, covering the use of the proprietary information infrastructures that underpin their health care products and services. The operational clinical data arising in everyday health care delivery is thereby managed by the health care services concerned in a proprietary manner. And this inevitably leads them to have a close dependency on the particular companies they contract with, and the hardware and software technologies employed in their systems. This is not a good position from which to sustain lifelong records of care.

The governance and management of personal health care data, which are seen much more, nowadays, as owned by the citizens they concern, and of the related software applications, of both public and private provenance, that create, store and process that data, are slowly becoming seen as separate and separable concerns. The separation of these concerns, sustained on the basis of global and public domain standardization and governance of care records, is central to the future care information utility that this book foresees.

## Information Policy as a Wicked Problem

Gladstone [...] spent his declining years trying to guess the answer to the Irish Question; unfortunately, whenever he was getting warm, the Irish secretly changed the Question.<sup>56</sup>

Joking apart, we're all a bit like that! Neither we, nor the Irish, for that matter, are, or would like to think we are, particularly wicked! But this joke is funny because it reveals the human side of many a difficult, seemingly intractable, human dilemma. These have been called 'wicked problems'. In the next sections of this chapter, I focus on the framing and history of national policy for information systems and technology that support health care services. This has been termed a 'wicked problem' and this section is about wicked problems in general, and how health care policy fits the bill. Horst Rittel (1930–90) and Melvin Webber (1920–2006) used the term to characterize socio-technical problems that arise in social policy formulation.<sup>57</sup> Policy for health care IT ticks all their boxes of wickedness.

In the paper, they compare these wicked problems with the 'tame' problems of science—a bit of special pleading, perhaps! They characterize the wicked problem as one lacking definitive description, and for which the public good to be addressed by solving the problem is always disputable within a pluralistic society. Likewise, they argue, there can be no objective principles of equity involved in weighing solutions. There can be no correct or false answers, and only by imposing 'severe qualifications' on the definition of the problem can solutions be considered in any sense optimal.

But how far would such a characterization be out of place in describing the riddles that physics wrestles with in delving the depths of the 'What is reality?' question? Leaving aside this piece of, no doubt eclectic, special pleading on my own part, if science is seen as posing 'tame' problems and social problems are 'wicked' ones, health and care, being problems of science and society, and the engineering that joins them, combined with the anarchy of transition to a knowledge and information-based economy of global reach, must qualify at the super-fiendish end of the Sudoku spectrum of wicked problems! Quoting from another context entirely, a wicked problem might be described as 'a riddle wrapped in a mystery inside an enigma'—I leave that uncited, not wishing to stir unwarranted association! But I smile to note the association, here, of Rittel and riddle!

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56 W. C. Sellar and R. J. Yeatman, *1066 and All That. A Memorable History of England Comprising, All the Parts You Can Remember Including One Hundred and One Good Things, Five Bad Kings, and Two Genuine Dates* (London: Methuen, 1930), p. 116.

57 H. W. J. Rittel and M. M. Webber, 'Dilemmas in a General Theory of Planning', *Policy Sciences*, 4.2 (1973), 155–69, <https://www.jstor.org/stable/4531523>

Rittel and Webber go on to argue that only by pursuing and reviewing alternative solutions can the nature of a wicked problem be understood, and a solution refined over time. Such problems are never completely solved, and solutions adopted require adaptation in the behaviour of the community addressed. In such connected worlds of policy and practice, it is unsurprising that the wicked problem lacks clear ownership and leadership. Any party aspiring, conspiring and perspiring to take control must not fail, and the way in which they tackle the problem is as important as how it is tackled.

This seems the right place in the book to emphasize a crucial connection that runs throughout. This is the inextricable interconnection of the approach taken to the resolution of wicked problems and the methods, teams and environments whereby they are evolved and implemented. In the next two chapters, the principal focus is on issues of implementation. Elsewhere in the book I have several times connected how, in both science and society, the challenge and uncertainty of such enigmas are approached, both in tackling them (as in science) and reacting and adjusting to them (as in society at large). These concerns are different in kind, and therefore in approach, but there are commonalities, too. Bifurcation and emergent transition, complementarity and dualism, polarization and dichotomy, crop up in several chapters. They cropped up in the Introduction, illustrated from a luminary scientist's perspective, in Robert Oppenheimer's Reith Lectures. Writing at the dawn of the Information Age, he introduced the riddle of quantum theory, and the idea of complementarity, as an analogy from which to reflect on riddles of society and human values. His lectures resonate today, as we live through the Whitehead anarchy of scientific and societal transition that has ensued from those times. Similar concerns, from a societal perspective, were reflected in the quotations from Primo Levi and Voltaire, in the Introduction and Chapter Eight.

Leaders of science and engineering reacting to and pursuing solutions to their enigmatic problems, and leaders and citizens of society at large doing likewise, when faced with theirs, may well have to behave and choose differently. But not necessarily always so! Choices made on all sides will reflect beliefs and temperaments, as much as a more strictly evidential weighing of ideas. Those shaping ideas for how new approaches to the enigmas of social policy should be 'led' might find it illuminating to study Oppenheimer's seminal lectures, reflecting his experience of how ideas and leadership play out in science and engineering, and reflect in society.

The history of the digital care record, exemplifying that of health care information policy more widely, might be fairly described as one of riddles, mystery and enigma! My maxim that the three top priorities of openEHR are 'implementation, implementation, implementation' rested



on my implementation-focused approach to this wicked problem. As Rittel and Webber wrote, it is fundamental to the taming of wicked problems in social policy, although I demur, as above, from how they contrast them so emphatically with those of science. That feels like an unhelpful dichotomy. I prefer to think in terms of trifecta (as in 'a situation in which you achieve three things'). I will expand on this idea in the following chapters. For now, the triple of the implementation maxim is emphasis of its priority, rather as the then UK Prime Minister once highlighted and stressed the importance of 'education, education, education'.

Policy for an information utility conflates divergent interests and understandings of the purposes served by its information content and who is responsible for it, both as supplier and regulator, and of the scope, specification, supply and operation of its related information infrastructure. An example from health care is critical incident reports, whereby awareness and response to incidents of exposure of patients to clinical risk are monitored. These flow from the medical directorate of the local Trust where the incident occurs to the office of the Chief Medical Officer, nationally, and sadly, sometimes, into the judicial system, too. I remember this topic coming up in discussion with a UK Chief Medical Officer of the time, at a joint USA/UK conference on health care quality where I was invited to contribute. They told me of the thirty different structures and formats in which these were compiled and reported, from different computer systems across the NHS. The aggregated information carries risk of inaccuracy and bias because of divergence in the ways it is collected, collated and summarized. Perhaps this situation is now better standardized. This critical incident scenario has been mirrored in stories of Covid pandemic data being collated centrally, by cut and paste from very many submitted documents into a central spreadsheet.

Information about patient allergies is of potential relevance in many contexts, within and beyond the health service—in social care, education, ambulance, police and hospitality services, for example. A common definition of this information and a service providing and maintaining it as a common national resource, accessible wherever relevant to be shared, is a candidate standardized information utility. Known drug interactions form another dataset best kept consistent, up-to-date and easily accessible and integrable with other systems, wherever this knowledge needs to be used.

The challenge of achieving this level of coherent and useful standardization is considerable in the current diverse landscape of health care information systems. Some ten years ago, I was asked to chair a national board that oversaw efforts to standardize information about prescribing practice, seeking a common semantic framework throughout the NHS, accessible across different sectors of health care. The project started with a focus on primary care systems and brought together academic experts

in prescribing practice, the suppliers of practice management information systems in use and the NHS team charged with managing the project. This mandate required some six suppliers of systems to adapt their software to comply with a relatively straightforward common data model. It took two years of extremely slow, tortuous and expensive work—a major headache for all concerned. Given a well-formulated service information architecture, there would again be good reasons and capability to make this a national utility, drawn on by all suppliers of systems. This process would much more easily enact and consume updates required over time, just as Apple or Microsoft update their operating systems online, for all their users.

We might compare this sought for information utility with a water supply utility—they both impact greatly on public health. Infrastructure for capture, purification and distribution of water supply, and drainage and disposal of rainwater and sewerage waste, created a healthier environment that contributed to the elimination of typhoid, cholera and other infectious diseases. The infrastructure is tangible and the water itself, chemically the same everywhere, whether in overwhelming or short supply, clean or contaminated, and collected from aquifer, reservoir, or river, or through desalination. H<sub>2</sub>O says what it is. It does not say how pure it is, reveal why it feels wet, or explain its surface tension. In its different forms, as liquid, ice and steam, it is always water.

Digitized information is all the same bits (or qubits), but its meanings are infinitely diverse. Data are captured in different types—integers, text strings, logical variables. They are grouped and annotated to convey further meaning and context. Knowledge bases, likewise, generate and communicate information that guides and supports decision and action. The purposes served by this information, the contexts of its use and the formalisms in which they are represented, interact within and between systems, and need to be accommodated consistently and coherently, throughout, when connecting and computing.

The nature of the information and the representational methods adopted for storing, interrogating and retrieving it, need to be consistent, clear and understood, whether engineered for use within a single system or shared among systems, more widely. Well-ordered or not, whether generically or locally applicable, the basis on which these representations are specified and constructed needs to be clear. And changes made over time, to remedy error and extend or revise functionality, need similarly clear provenance and governance. Where multiple architects design multiple systems, the specifications that they develop, and which the information engineers build from—syntax and semantics of the data and how it is being processed, using data models, information models and knowledge bases—all need to be

consistent, coherent and declared. And formal terminology used needs to have its provenance and formal description, similarly declared.

All of this oscillates between the impossible and the very difficult, as my colleague Alan Rector notably described the domain of medical terminology. We grapple between the formalized and formalizable, with fragmentary or rudimentary formal method to underpin our efforts. This is a principal reason why much medical communication has persisted in narrative, written and diagrammatically illustrated forms, and word of mouth. It is why medicine is sometimes said to be the most fruitful domain in which to position and grow exemplars of innovations in computational methods, and the hardest in which to bring them to fruition. The complexity of meanings conveyed in health care systems and the understanding of the nature of health care that is assumed and embodied in the ways in which the systems are designed and constructed, is too great for capture within a mandated framework of policy—democratic or otherwise. It is an organic entity that is seeded, grows, emerges and evolves in theory and practice. Software production was once commonly described using the analogy of a waterfall, flowing from systems analysis and design to coding and product. But like the apparent upward flow of water in the Maurits Escher lithograph *Waterfall* (1961), this is an illusory process.<sup>58</sup>

Software cannot emerge along a series of waterfalls. Software standards, likewise, cannot emerge in declarative form, ahead of agile iterations and consensus process based on experience in use. Information engineering and information flow require a different approach. What we do at present is often, with some justification, called out as ‘imagineering’ more than engineering.

Consistency in these enterprises matters, but when we seek, or impose it, by taming the complexity of the wicked problem through narrowing the scope of enquiry or constraining the analysis of data collected, the meaning and relevance of results is inevitably diminished. It is a messy domain that defies narrow consistency. As Ralph Waldo Emerson (1803–82) famously wrote in *Self-Reliance* (1841), ‘A foolish consistency is the hobgoblin of little minds, adored by little statesmen and philosophers and *divines*. With consistency a great soul has simply nothing’. And as Erwin Schrödinger (1887–1961) translates in quoting a remark of a Spanish colleague, Miguel de Unamuno, ‘If a man never contradicts himself, the reason must be that he virtually never says anything at all’.<sup>59</sup> There is also risk in moving too far in the other direction: by adopting a looser but more true-to-life scope for a

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58 M. C. Escher, ‘Waterfall’, *Digital Commonwealth*, <https://ark.digitalcommonwealth.org/ark:/50959/3r076s93c>

59 E. Schrödinger, *What Is Life?* (Cambridge, UK: University Press, 1948), p. 76.

project, it becomes progressively harder to fund and pursue, as it will likely not be considered ‘appropriate’, as a manageable goal or subject of enquiry.

In tackling wicked problems, the rationale of what was done, how and why, and how it turned out in time, is all important to document and learn from. It is lost all too quickly. Seeking to adapt from an unsatisfactory and unsustainable *status quo*, policy makers tend to commission backward-looking and self-justifying reports and proposals. These largely comprise lofty rationales of times past, airy pontifications about times future and hubristic policies and proposals for time now. They set in train successive, likely equally unsuccessful, eras, with new heroic figures to take them forward, through a new iteration of high-budget megaprojects, costly reorganizations and general resulting mayhem. This costs too much and is, too often, largely ephemeral.

And resulting code and databases too often appear like this:

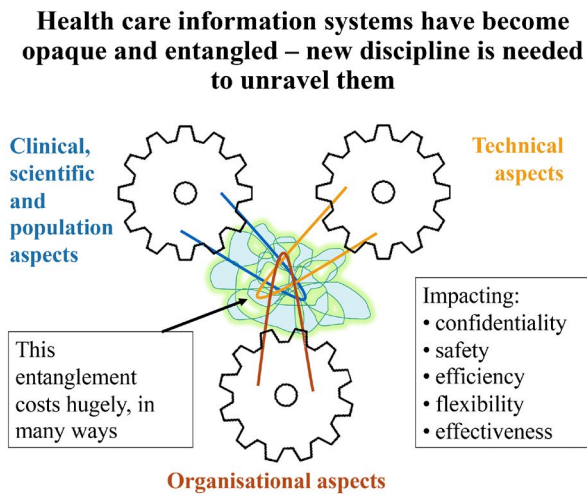


Fig. 7.9 An image of scrambled and non-coherent clinical data. Image created by David Ingram (2010), CC BY-NC.

Public policy makers who control purse strings have proven ill-equipped to manage this anarchic domain. There is hubris and lack of knowledge about the nature and complexity of computational methods and the precision and rigidity of computer systems and the underlying information architecture of clinical practice. They have been all too ready to place trust in commercial suitors eager for government money for their businesses, offering magical thinking to persuade funders that magical outcomes, of interest to these

policy makers, will be delivered, but sadly, too often, not well placed to deliver value for money.

A lurid example from another field illustrates this reality. The planned UK West Coast main line railway modernization was at one stage reduced to a mandated budget by adopting an engineering solution that existed only in the minds of the bidding main contractor. This proposed to remove the very costly element of wired signaling circuits by adopting a non-existent, yet to be designed and implemented, wireless-based approach.<sup>60</sup> The model of region-wide, single consortium, standardized hospital information systems, on which the National Programme for IT in the NHS was based, proved a similarly costly triumph of hope over experience.<sup>61</sup> The Covid-19 Test and Trace service has been a more recent example, costing many billions, involving an interplay of technical, organizational and clinical factors, and demonstrating a limited capability to design and implement ambitious, unproven systems.

Overly ambitious, hubristic, ill-informed or just unlucky, policy makers become emperors with scant clothes, left throwing the dice of infrastructure decisions, and watching them roll to lucky or unlucky outcomes over time, perceived in retrospect as wise or foolish. Sometimes, small unforeseen and overlooked weaknesses magnify into dramatic emergencies, as with the Challenger Space Shuttle Disaster (1986).<sup>62</sup> Sometimes, situations change so rapidly that the original objective and commitment becomes outdated, in timescale, resource and technology, before the envisaged infrastructure has come into use. The time constants of science, engineering, business and politics are often considerably out of sync.

The resulting confusion can lead to stasis or deadly embrace, with separate initiatives moving in different directions, combatting one another, and producing a vector sum of outcomes, near zero. Spending on infrastructure is an easy tap to turn off in times of financial imbalance, and a convenient tap to turn on when financial management prudence takes second place to the need to spend, in mitigation of economic decline and loss of employment. One often observes that in the abstract reality of money supply, spending is as much a matter of who wants and has the power to spend or not spend, as it is about availability of ready cash, or, in times

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60 D. Shirres, 'Digital Delusion: A Lesson from Not-so-long Ago', *Rail Engineer* (3 September 2018), <https://www.railengineer.co.uk/digital-delusion-a-lesson-from-not-so-long-ago>

61 T. Justina, 'The UK's National Programme for IT: Why Was It Dismantled?', *Health Services Management Research*, 30.1 (2017), 2–9.

62 In *What Do You Care What Other People Think?* (New York: Bantam, 1989), Richard Feynman (1918–88) unravelled the sequence of decision making that led to the inappropriate rocket seals that caused the explosion on take-off.

of old, gold in the ruler's bank vault! As Paul Krugman, the American economist, now declares, debt is not what it used to be—a bit like nostalgia!

Subsumed within the health care field is an abundance of examples of the wicked problem described by Rittel and Webber and the multidisciplinary and multiprofessional challenges encountered in tackling them. These are real dilemmas and I do not wish or intend to discount or disparage the pressures in play. In the next chapter, I describe the work of five pioneers I have known and worked with, who tackled this reality, head on, in widely different health care contexts, and with considerable success and acclaim. What was special about them? In Chapter Five, I made an analogy with the character of the innovators and innovations that drove steam power and powered industry in England of the eighteenth century. They had head, heart, hand and skin in the game. And they saw and grasped their opportunities. We need to encourage and better enable such people with the opportunity to engage more realistically with wicked problems.

The balance of life between work and leisure is changing. And in today's world, scope and motivation for innovation resides in powerhouses of industry and commerce and the voluntary sector, as much as in universities and the public sector. The importance of volunteers has been shown in a new light during the pandemic. A great deal of what will make a difference in achieving better balance of health care for the future will reside in framing and responding to need much more flexibly and recognizing and harnessing those sectors, and the human motivations that drive them.

The banner and battle of Creative Commons is crucial in this regard. Traditional commercial processes have often proved too costly, and time consuming, and new web-based infrastructure is proving qualitatively and quantitatively more efficient and effective for creating systems that are both agile and scalable. This theme is developed in Chapter Nine. It is, for me, a lodestone in the quest for a care information utility fit for these divided and divisive times. Lodestones are natural magnets; they naturally align to attract, and, otherwise aligned, they can repel. So it is with Creative Commons; we need to understand the polarities and forces in play.

## Information Policy for Health Care

Whosoever, in writing a modern history, shall follow truth too near the heels, it may happily strike out his teeth.<sup>63</sup>

The story now enters more sensitive and febrile territory, where politics, policy, and money reign—hence the quotation from Walter Raleigh

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63 W. Raleigh, *The Works of Sir Walter Raleigh* (New York: Burt Franklin, 1966), p. lxiii.

(1552–1618).<sup>64</sup> Some call government kitchen politics. A UK Prime Minister of the 1960s, Harold Wilson, advised people to stay clear of the kitchen, if they could not stand the heat. Raleigh’s quotation captures the ambivalent feelings about politics of many who are attracted to statecraft, while others appear relatively unaffected by kitchen heat. It is best not to set frying pans on fire, though, and when they are on fire, to clear the fat and put out the flames. Information and information systems have moved centre stage in the policy and politics of health care. A lot of money has flowed, and a lot of anarchy has reigned. Many initiatives flamed, fizzled and burnt out.<sup>65</sup>

**Transition - information technology can facilitate a more patient-centred health care**

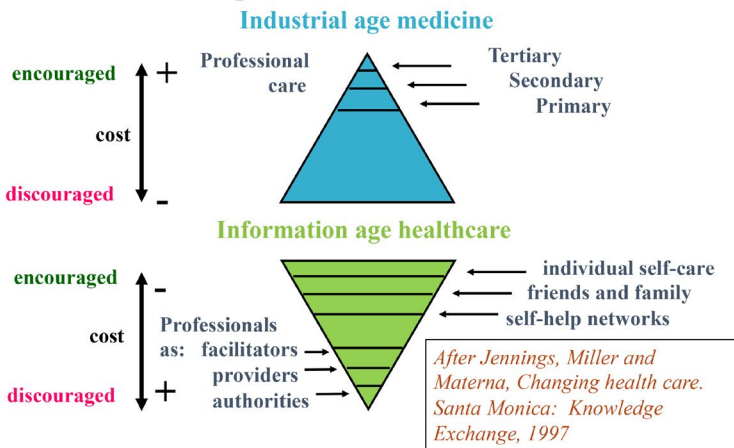


Fig. 7.10 The inverted triangles depicting the transition from Industrial Age to Information Age medicine. The original image was used by Richard Smith in his 1997 *BMJ* Editorial discussed in this chapter. The version here was created by David Ingram (2010), CC BY-NC.

Richard Smith was a pioneering editor of the *British Medical Journal (BMJ)* in the 1980s and 1990s, and the first to focus on information as a key policy

64 Raleigh was an on-off favourite of Elizabeth I and, subsequently, an inconvenient bête noire of James I.

65 This section of the book was written in what seems, as I finalize it, a rather outspokenly critical and direct manner. It perhaps reflects a time when a highly emotional personal struggle with mitigation of the lack of connected and accessible health care records of my wife, in a critical care context, was still deeply infused in my mind. I have chosen to leave it expressed in this vein as it is authentic of how the failure of information policy to achieve coherently connected care records can deeply affect us all. It is offered with constructive intent and without recrimination or rancour.

issue for medicine. In a notable editorial around the time of the NHS fiftieth anniversary, he set the scene for the transition of health care delivery in the Information Age.<sup>66</sup> It is a complicated story with multiple interests and perspectives in play, each tending to require others to bite on bullets. The imagery of the inverted triangles (Figure 7.10), a version of which Smith used in his editorial, has echoes of Paul Tillich's book, *The Shaking of the Foundations*, describing the upheaval in religious doctrine over the centuries since the Reformation,<sup>67</sup> and the phrase 'world turned upside down', describing the era of Oliver Cromwell and transition from the divine right of kings to parliamentary government in the seventeenth century.

Regarding the biting of bullets, I recall the words of the memorable media celebrity Anthony Clare (1942–2007), who came to Bart's as Professor of Psychiatry in the 1980s, in a discussion about service organization and budget with the august College Committee at Bart's. He described the problems his department faced and made the case for more money. A senior and influential medic, defending the fiscal *status quo*, countered, saying soft but firm words to the effect that it is tough, but there is no money, and we must all 'bite the bullet'! To which, in his mellifluous Dublin tones, Clare responded: 'I recognize, in the clarion call of Dr ..., that we should bite the bullet, the voice of one whose teeth will not be doing the biting'. Done so well that all sides of the Medical Committee broke into laughter, including said influential medic! It requires a particular strength of mind and timbre of tongue to speak truth to power like that, survive and stay on good terms—not an easy feat or common phenomenon!

Public sector policy makers who control purse strings have proven ill-equipped to manage the information policy domain and are left firing bullets to be bitten, in multiple directions. They have harboured often quite naive misconceptions about the nature and complexity of computational methods and the quality and robustness of computer systems. They have been too ready to place trust in commercial suitors eager for government money. Information services for health care were wrongly thought of, from the beginning, as a technical and routine commodity. They were seen primarily in terms of management and communication, not as an information utility and integrative ecosystem of wide reach: representing and communicating meaning and purpose among all concerned; facilitating their reasoning and enabling and justifying their choices, decisions and actions; capturing and recording data and workflow in all contexts of health care; supporting

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66 R. Smith, 'The Future of Healthcare Systems', *BMJ*, 24:314 (1997), 1495–96, <https://doi.org/10.1136/bmj.314.7093>

67 P. Tillich, *The Shaking of the Foundations* (New York: Charles Scribner's Sons, 1953).



education and research; and managing personnel, materials, facilities, queues and money.

This change to an integrative perception of the information system as a utility, is as profound as William Harvey's (1578–1657) *de Motu Cordis* (1628), where he postulated the circulation of blood in the body. It is as ground-breaking as Sherrington's conceptualization of an integrative nervous system in the body, the foundation of neuroscience of today. What we are concerned with, here, is, by analogy, the integrative information utility of the body and mind of health care systems and services.

As previous chapters have demonstrated, established thinking has often been biased and protective in its metrics and judgement of innovation, perhaps especially so in areas of wicked problems, where stakes are high.

For example:

New systems are cumbersome to install and make use of. This is nothing new. The TIMES wrote in 1834 that it was unlikely that the medical profession would ever start to use the stethoscope, 'because its beneficial use requires much time and gives rise to a fair amount of difficulties'.<sup>68</sup>

This is understandable as an expression of human limitation in predicting the future. The information policy response needs to be refocused away from controlling and regulating today, towards *how* to create a desired and sought for tomorrow. The perceived wisdom about failings in health care, when observed from high up, has been of poor or deficient management. This has been addressed by adding management. No one has pieced together the timeline of actions, monitored the changes, and remembered and learned from the outcomes. In politics, five years is the event horizon, although a week is also sometimes a long time. In science and engineering, implementation horizons can stretch three times that far ahead. In business and everyday life, the eyes are focused in the days, weeks and months ahead. Failed corporate memory and incommensurate timescales of ambition contribute to the wicked nature of the policy challenge, where problems can neither be fully understood nor fully owned.

Whitehead's term 'anarchy of transition' headlined this second part of the book, and the transition, here, is the information revolution of our times. The information pandemic is a chaos, imposing additional burden on services and sucking away resources that they need to cope. Local IT services operate, in Francesca Wilson's (1888–1981) phrase, 'in the margins of chaos'.<sup>69</sup> They are the ones having to bite the bullet and cope, because

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<sup>68</sup> *The Economist*, 28 February 1998.

<sup>69</sup> F. M. Wilson, *In the Margins of Chaos: Recollections of Relief Work in and between Three Wars* (New York: Macmillan, 1945).

their life, generally, is hard! In her case—that of military conflict—it was especially true.

It is harder, though, to accept administrative chaos as being as inevitable as the chaos of war. In twentieth-century health care, it is not. It is the cloaking and denial of repeated failure. Few people, partly mindful of Raleigh's caution at the head of this chapter, and partly out of genuine bemusement and confusion, choose to speak out, dare to speak out or can speak out. And those who do speak, often do so loudly, making assumptions and diagnosing the issues to serve narrow personal, professional and commercial leanings and interests. Political discourse at the top of health care services, and in its ramifications into education, law, commerce, finance and governance, has become a fierce and controversial domain, of local, national and international rivalries and interests, and contest for resources. Much of this now plays out in policies and markets for information systems and infrastructure.

Chaotic and unstable discourse, playing out in limit cycles of policy change, has resulted, time and again, in implementation failure, patched over with bureaucratic and political justification, obfuscation and amnesia. As an organization that prides itself on learning, the almost non-existent organizational memory of our NHS on information policy and implementation through these times, or even recognition of its lack, is woeful. People prefer talking to bullet points rather than biting bullets. They wring their hands, and cash registers ring. And still the 'imagineering' and throwing of billion-dollar dice persist and charge ahead. My songline has travelled through many of the connected worlds I have cited, here, and some may think I have misrepresented and traduced them. It is said and written without rancour and with good will. Personally, and thankfully, I have come out the other side, but many good people have not been as fortunate. Having expressed these feelings of dismay, here, in Part Three I will stop looking back and looking on, and start looking forward to what can and needs to be done differently in the future.

At this point, I will trawl through public policy and reports linking health care and information technology of the past fifty years and then revisit Illich's perspective of fifty years ago, to draw conclusions about where health care services now are, and the direction of travel that future information systems and services should chart, in support of their reinvention, enablement and support.

## Connecting Policy with Practice—A Fifty-year Timeline

If there were to be an informative poll of the costliest and most enduringly significant failures of public policy, internationally, of all time, my guess is that failure in health care information policy would rank quite highly. It might even prove an outlier. In recent years, Barack Obama was persuaded to invest heavily into improving standards of electronic medical records in the USA. He expressed the limited progress achieved as the greatest disappointment of the health reforms prioritized in his term of office as US President.<sup>70</sup> The UK Parliament's Public Accounts Committee has regularly called in the NHS hierarchy for a drubbing about IT, whenever they felt in need of some action with this all too easy target. It is regrettable that their spotlight is not also turned on the hubris and pretence exhibited in the political drivers of the anarchy.

Policy makers have sought to defend by distancing themselves from the arena. One tactic has been to relegate information policy to a lower level. In the UK of the 1970s, it was a matter for the supplies division of the Department of Health and Social Security (DHSS). Finding the issue coming back to the top of the pile, another has been to delegate or subordinate it—making it primarily a technical matter or a local responsibility, or a matter to be resolved within commercial markets. Repeating the exercise under new management and leadership, a third approach has been to call on independent review and advice, within or outside government, from a mix of disciplines and professions.

Some such consultants and reporters have their personal axes to grind or wear blinkers. They put a periscope above the water and peer ahead, beyond the waves to a new order—a brave new world of science and society, health and care. This is usually a twenty-year perspective, clothed in the buzzwords of the day—an intoxicating mix of opportunities and the changes implied in getting there for patients, professionals and managers. A parcel of recommendations is tied with ribbons of new information-led institutions and services, to be relied on to square circles, ensuring that expectations are met, quality ensured and efficiency achieved. Beyond the blue skies, sustained ownership and leadership of planning and implementation have been severely challenged and found wanting, in all phases of the

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70 S. Kliff, 'Obama's Surprising Answer on Which Part of Obamacare Has Disappointed Him the Most', *Vox* (9 January 2017), <https://www.vox.com/2017/1/9/14211778/obama-electronic-medical-records>; S. Pipes, 'Electronic Health Records Are Broken', *Forbes* (28 May 2019), <https://www.forbes.com/sites/sallypipes/2019/05/28/electronic-health-records-are-broken/?sh=14ad868d546a>

implementation and review of such vision. 2020 vision should be better than this.

As Rittel and Webber's characterization of the wicked problems of social policy has illuminated, health care information policy is a nightmare of changing and evolving, ungripped risks and complexities. Its implications extend throughout health care and in all their scientific, technical, social and economic contexts. A twenty-year timeline of radical change cannot be managed over an electoral cycle, within a domain and marketplace that can spin on a (Covid!) coin in three months. We are living through multiple spins of coins—politics and choices are 50:50 toss-ups and black swans are flying in from all directions.

A strategy for navigating this domain might best be seen through the guiding tenets of Sun Tzu's two-thousand-five-hundred-year-old *Art of War!* In his almost poetic encapsulation of the nature and imperatives of battle, lie human objectives and insights, set out within the context of plans, strategies, methods, energies and the leadership, choice and adaptation of decision and action, through the unfolding engagement. I do this for fun and light relief, in Chapter Nine!

There are battles over information all around the circle of knowledge, and throughout the communities of health care practice—as academics, professionals, industrialists and citizens. Rational policy becomes intractable in the changing landscape of science and society, and of industries and professions. Alternating bullish hubris and air-brushed failure has been disabling at the coalface of health care services. But this anarchic situation will play out, one way or another, and good new approaches can take root and emerge from the confusion.

In thinking about how to describe the policy position we find ourselves in, one way to start is by observing how the landscape and its challenges have been framed in policy documents and legislation, historically. One way of recognizing, gauging and learning from failure is to search back into archives of past policy initiatives, to see what was achieved and learned. In policy for medical information systems, there is a fifty-year track that I will follow here. I have lived through it in both personal and professional contexts. Stacked around me as I write are what seemed key reports in their times, and the more recent ones are a few clicks away online.<sup>71</sup>

The following review tracks these documents and their contexts of health care IT since the 1970s, when such documents first came on the scene. A striking observation is that these have changed remarkably little over the

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71 I am quoting, here, from paper documents in my archive and some have now proved impossible to trace online. These thus lack accessible source citations, but are, nevertheless, important to include as illustrative of the fifty-year timeline.

intervening years. The descriptions of current realities, and what should be aimed for, when adjusted, and normalized for the language and context of the day, are recognizably the same. The implications and costs of failure are today more acutely characterized and impactful. They have evolved into a central crisis of health care services of the age. In the additional resources for the book, Appendix II,<sup>72</sup> I have catalogued the key legislation, policy and organizational changes in the NHS since 1948, and this has helped to provide contextual orientation and trigger of my memory.

### 1967–The Flow of Medical Information in Hospitals–Nuffield Provincial Hospitals Trust

This short and succinct report described the flow of information within and between all departments of an acute hospital.<sup>73</sup> It is the earliest such publication in my archive, from the time I entered the field and started collecting them. The Nuffield Provincial Hospitals Trust, subsequently the Nuffield Foundation, has taken a strong philanthropic interest in health care since earliest days. William Richard Morris (1877–1963), the first Viscount Nuffield, was the English Henry Ford of his era, as a pioneer of the UK motor car industry.

The report took the form of flow charts, which were seen as an essential first step in planning for automatic data processing in any part of the hospital's information system, 'so as to record the precise content of each item of communication and the responsibility for its origin'.<sup>74</sup> The study was conducted in partnership with the English Electric Leo Marconi Group, prominent in early computer hardware design and manufacture, which was spreading its wings at the time into industrial automation and business data processing. It made a strong case for systematic study of information in its real-world context, as a basis for improving existing procedures or introducing new techniques.

### 1977–Policy Implications of Medical Information Systems–Congressional Technology Assessment Board of the US Senate

On 28 October 1977, Senator Edward Kennedy wrote to the Committee on Human Resources of the US Senate, submitting a report from the Office

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72 Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

73 Nuffield Provincial Hospitals Trust, *The Flow of Medical Information in Hospitals* (London: Oxford University Press, 1967).

74 *Ibid.*, p. 5.

of Technology Assessment. The commissioned report was entitled ‘Policy Implications of Medical Information Systems’.<sup>75</sup> The Office of Technology Assessment (OTA) was created in 1972 as an advisory arm of Congress, to provide wide-ranging reviews of policy issues. Its brief was well framed:

[...] OTA’s basic function is to help legislative policymakers anticipate and plan for the consequences of technological changes and to examine the many ways, expected and unexpected, in which technology affects people’s lives. The assessment of technology calls for exploration of the physical, biological, economic, social, and political impacts which can result from applications of scientific knowledge. OTA provides Congress with independent and timely information about the potential effects—both beneficial and harmful—of technological applications.<sup>76</sup>

This was the first governmental strategic review of the field that I encountered. I have emboldened the key issues it highlighted, which remain central concerns to this day, approaching fifty years on:

1. **The benefits and limitations of medical information systems;**
2. **The factors influencing their adoption; and**
3. **Policy alternatives for the Federal Government with regard to such systems.**<sup>77</sup>

The team assembled to conduct the study came from across health care, academia and industry. Octo Barnett (1930–2020), the luminary director of the Laboratory of Computer Science at Massachusetts General Hospital and Harvard Medical School, was a notable member—alphabetically and in terms of his eminence, first among equals on the list. His name must feature in the top level of those whose practical and intellectual insights and endeavours defined and shaped the field over the coming decades.

A medical information system was defined thus:

A medical information system is defined as a computer-based system that receives data normally recorded about patients, creates and maintains from these data a computerized medical record for every patient, and makes the data available for the following uses: patient care,

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75 Congress of the United States Office of Technology Assessment, *Policy Implications of Medical Information Systems* (Washington, DC: Congress of the United States Office of Technology Assessment, 1977), <https://www.princeton.edu/~ota/disk3/1977/7708/7708.PDF>

76 Congress of the United States Office of Technology Assessment, *Coastal Effects of Offshore Energy Systems* (Washington, DC: Congress of the United States Office of Technology Assessment, 1976), p. 4.

77 Congress of US OTA, *Policy Implications*, p. v.

administrative and business management, monitoring and evaluating medical care services, epidemiological and clinical research, and planning of medical care resources.<sup>78</sup>

Acknowledging the fledgling status of exemplars from the field and the pace of evolution of systems and technologies, which made assessment of benefits and limitations difficult, the report cautioned that without a federal policy towards these systems,

[...] their diffusion may well proceed indiscriminately, and standardization will not be possible. If so, the full potential of medical information systems is not likely to be achieved.<sup>79</sup>

The eighty-page report was commendably informed, succinct and wide-ranging. Its findings regarding benefits and limitations covered the following: institutional delivery of care, support of clinical decision making and physician education, assessment of the quality and utilization of medical care services, malpractice litigation, roles of medical care professionals, health data systems (by which was meant a clinical data repository for study of population health and health services), planning and research, and confidentiality of patient records. Factors influencing adoption covered: acceptability to medical care providers, technical transferability, cost and wider contexts of technology development and federal policy and incentivization.

Regarding technical transferability, the report noted:

Prototype medical information systems have been proven technically feasible, but most have not yet been made adaptable to the various conditions of different institutions. In order to realize the benefits of a standardized database and to market systems economically on a large scale, flexible systems are required.<sup>80</sup>

The study was focused on direct patient care, saying:

The capability to accumulate and retrieve data for each patient is critical for both the process of patient care and research.<sup>81</sup>

Attention was thus paid to individual patients' medical records, while acknowledging that:

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78 Ibid., p. 4.

79 Ibid., p. 4.

80 Ibid., p. 5.

81 Ibid., p. 7.

[An important capability is to provide necessary data for] administrative and business offices.<sup>82</sup>

Successful federal support, from the mid-1960s, for the development and adoption of systems addressing business needs, was noted.<sup>83</sup>

The report also noted that early attempts in the 1960s to install integrated information systems in hospitals had proved costly failures. The common themes characterizing accounts of those failures were seen to be:

Inadequate understanding of the complexity and variations in medical care, inadequate computer hardware and software, and inadequate commitment of capital for long term development.<sup>84</sup>

The report described three prominent prototypical systems to illustrate potential implications for patient care and the whole health system. These were: the Technicon Medical Information System at Al Camino Hospital in Mount View, California; the COSTAR system developed at Barnett's Laboratory of Computer Science at Massachusetts General Hospital, in use by the Harvard Community Health Plan, and the PROMIS system (Problem-Oriented Medical Records Information System, based on the original ideas of Larry Weed (1923–2017) for structuring medical records according to problems identified and tackled) in use at the University of Vermont Medical Centre. No attempt was made to survey the field and categorize systems by design and capacity. Attention was restricted to integrated systems rather than those dedicated to particular specialties or departments.

In their review, the team focused on:

- Capture of data;
- Provision to providers of care and administrative and business offices;
- Administrative and communication functions: messaging among departments, scheduling of appointments, charging and billing;
- Provision of database for investigators: quality of care assessment, clinical decision making, epidemiology, health services research and planning and evaluation of care.

They noted that, although now technically possible, no systems currently incorporated all four functions. They highlighted how the speed of access

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82 Ibid.

83 Ibid., p.12.

84 Ibid., p. 14.



online and the ability to manipulate and analyze data requires careful structuring and definition of the database, as well as aggregation of 'massive amounts of data on large populations for long periods of time'.<sup>85</sup>

In a section considering the variability of medical care, the report highlights variability of style, format and language of records—between institutions, and clinicians within institutions. The importance and additional complexity of handling free text was noted:

At present, lack of standardized nomenclature or established protocols in medical care continues to constrain the development of a generalised database.<sup>86</sup>

Another problem seen to be significant was that:

Because medical information systems have been developed through the independent efforts of many investigators, today's systems reflect diversity of philosophies and technical approaches.<sup>87</sup>

The section on policy alternatives adduces a compelling rationale:

The federal government could continue current policies and allow adoption of medical information systems to be determined in the open marketplace. However, this policy could result in medical information systems being marketed and adopted without additional investment in research to improve certain capabilities. Because capabilities to improve and monitor the quality of medical care and to facilitate research and planning are the least developed and require standardization, these potential benefits for patients and the medical care system might be lost. Computer systems limited to administrative and financial functions could continue to dominate the market. Medical information systems that might be used could also lack high standards of quality or provide inadequate protection for the confidentiality of patient data.<sup>88</sup>

In arguing for Federal action influencing development, standardization and eventual use of medical information systems, a range of policy options was proposed:

- Central clearinghouse to coordinate developmental projects and provide public information;
- Funding for cost-benefit evaluation;

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85 Ibid., p. 12.

86 Ibid., p. 14.

87 Ibid., p. 12.

88 Ibid., p. 6.

- Contracts for design and development of systems with specified capabilities;
- Incentives for adoption of systems that improve quality of care and support research and planning;
- Central organization to develop, validate and maintain the knowledge content of medical information systems;
- Standardized databases, to include nomenclature, terms, definitions, classifications and codes for use in systems;
- Guidelines for precise standards to protect the confidentiality of patient data.

I've quoted this report at length because its early policy pointers, as highlighted here, have remained relevant and impactful to the present day. Failure to understand and take due notice, at all levels and in all sectors of health care services, has cost society hugely, in waste, burden and lost opportunity. If Barnett's successors at Harvard Partners, led by Blackford Middleton, were anywhere near the mark in their assessment of the economic cost of this failure, it has amounted to a direct accumulating cost of eighty billion dollars per annum for the USA alone.<sup>89</sup> That was a midpoint estimate, between 1977 and around the year 2000. Let us be extremely conservative and say forty years at that level, in present day money—not adjusting for inflation, that is. This is an eye-watering amount of several trillion dollars—an explosively combinatorial hit on just one economy. Slow adopters have been quite fortunate! It is hard not to suspect some meaningful correlation between this underlying cost and the outlying high costs of health care in America, as a proportion of GDP, connected with its commercial computerization.

### 1982—The Körner Report—UK Department of Health

Edith Körner came alone to England as a schoolgirl, in 1939. Her relatives that she left behind died in wartime extermination camps. She learned English and earned a living in monitoring wartime intelligence, using her fluency in Russian, German, Italian and French, and at the same time studying economics at the London School of Economics. She was, by all

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89 J. Walker, E. Pan, D. Johnston, J. Adler-Milstein, S. W. Bates and B. Middleton, 'The Value of Health Care Information Exchange and Interoperability: There Is a Business Case to Be Made for Spending Money on a Fully Standardized Nationwide System', *Health Affairs*, 24.Supp1 (2005), W5-10-W5-18, <https://doi.org/10.1377/hlthaff.W5.10>

accounts, a formidable person in public life in Bristol and the Southwest of England. I've known people like her.

In 1980, she was asked to chair a review of health service information required to manage a district of two hundred and fifty thousand people. The Körner committee worked for four years and produced six reports. This was the first review of how the NHS collected and used data and set the scene for the coming decade of NHS Information Strategy. The scope was comprehensive and made recommendations for changes in information collected about hospital clinical activities and their patients, community health services, paramedical services, patient transport services and information about manpower and finance.

The goal they adopted was to devise a series of 'minimum datasets', providing basic statistics that every health service authority should have, to manage its health services effectively, to be collected economically, quickly and accurately.

The Terms of Reference were:

- (1) To agree, implement, and keep under review principles and procedures to guide the future development of health services information systems;
- (2) to identify and resolve health services information issues requiring a coordinated approach;
- (3) to review existing health services information systems; and
- (4) to consider proposals for changes to, or developments in, health services information systems arising elsewhere and, if acceptable, to assess priorities for their development and implementation.

Many of the recommendations concerned data about individual patients but patients' names were not included in the datasets, with the argument made that management use required the data in aggregated form. Improvement of methods for collecting, processing and analyzing the data, at local levels of care, was a major concern of the times.

### 1986–The National Strategic Framework for Information Management in the Hospital and Community Health Services–UK NHS

The scale and cost of the NHS had risen continuously over the previous four decades. Health and Social Security policy, legislation and resource were focused centrally within a London-based ministry—the Department of Health and Social Security (DHSS). Operational management was overseen and directed from the centre but devolved within five regions of the country, which were, in turn, subdivided into areas and districts. This was a massive brief and management challenge, awareness of its detailed context heightened through Körner's intelligent, determined and trusted eyes.

A central NHS Management Board was established, reporting to a Health Services Supervisory Board operating within the Whitehall ministry. In subsequent decades, this was recast as the NHS Executive and numbers of separate and autonomous health-related agencies, with different coordinating focus, were established by statute—NHS Improvement, Care Quality Commission (CQC), and Monitor, among others. Responsibility for the education, training and regulation of the health professions resided with the separate General Medical Council and professional bodies, such as the Royal Colleges. These, in turn, had umbrella organizations for coordinating policy and practice. Other government agencies with generic responsibilities for oversight roles, such as the Audit Commission, retained their interest and power to act in investigating the health service.

It was a struggle to keep any head steady around the complexity that was unleashed. The power to set policy, legislate and control money was the only stabilizer of this unwieldy ship of NHS state, a super complicated supertanker. The idea that IT would help solve anything at that level was ambitious, but maybe just seen as bold and decisive! There were brave souls who saw this as their mission and chance, and first to the top of the tree was Mike Fairey, a hospital manager at the London Hospital, in Whitechapel, whose pioneering hospital patient administration system project had set the scene for what was to come in the wider NHS, as introduced earlier in this chapter.

He became Director of Planning and Information Technology, and set about the task of creating a National Strategic Framework to ‘make sure that people control IT rather than the other way around [...] to collect data wisely and to apply information skilfully’.<sup>90</sup> In four pages, seven annexes over a further ten pages, and a one-page action plan, the management vision was set out as follows:

Key issues:

- Integration of information management within health care as a ‘business’;
- Developing better systems;
- Being more efficient;
- Making health care more effective.

Framework:

- Central policy and control constraining local implementation strategies, supported, and enacted through common technical standards and management information requirements.

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<sup>90</sup> M. Fairey, *A National Strategic Framework for Information Management in Hospital and Community Health Services* (London: DHSS, 1986), foreword (n.p.).

The Annexes are a blur of clipped management speak and generality:

- Annex One—the range of information;
- Annex Two—deriving information requirements from service plans;
- Annex Three—delivering information systems;
- Annex Four—managing the key resources;
- Annex Five—research, development and applications;
- Annex Six—the use and supply of information;
- Annex Seven—information management at the centre.

The document concludes with a one-page summary and timetable of seventeen actions for implementation, delegated to the five branches of a newly created Information Management Group, populated by NHS and Department of Health appointed staff. Politics of the era features heavily in these structures. The separation of family practitioner services (FPS) and hospital and community health services (HCHS) within the existing DHSS structures, led to some juggling of who controlled and did what.

The policy-related responsibilities and roles of the DHSS required that control and monitoring of NHS performance indicators, statistics and research should remain with the DHSS in Whitehall. Responsibility for what was now being identified and defined as corporate data management and, more specifically, custodianship of the Körner data definitions and creation of an NHS Data Model, came under a new grouping called NHS Corporate Data Administration. Development and implementation of common technical standards and systems throughout the NHS came under a new grouping called NHS Centre for Information Technology. Both these latter new groupings were established at a new home in Birmingham. Primary Care strategy and implementation remained in Whitehall, associated with the FPS, and pursued as a largely separate agenda.

The now acutely problematic separation of social care policy, practice and management from NHS services was reflected in this National Strategic Framework, from the start. I get a headache, still, today, when reading it. The authors must have been quite convinced by it as the timescales set for implementation were precipitate. Fifteen of the actions would lead to the final product within two years. Action 2 on common data standards was described as ongoing and Action 7, to produce a Common Basic Specification for NHS IT systems development was given three years. Given what subsequently transpired, the similarly set and similarly defaulted on timetables for implementation of the Information for Health policy, ten

years later, and the NHS National Programme for IT, fifteen years later, are sobering.

Such documents are intoxicating to the heads that commission and write them and head-aching to those at the sharp end of what ensues in implementation and practice. The tone is magisterial and coolly declarative. Much about process management and cost, nothing much about content, leadership, outcome and value. They come across as written by ascending stars, struck by the magnificence and authority of what they were about to make happen in the world. These mostly burnt out as shooting stars, in the atmospheric friction of everyday health care delivery realities. Seen from the top down it must have come as a relief to ministers that this burgeoning problem was under such firm and decisive control. It was a Herculean vision and Hercules quickly looked around and passed the stone to Sisyphus.

The Roman Poet, Horace (65 BCE–8 BCE), put it quite well in his *Ars Poetica* (l. 138): *Parturient montes, nascetur ridiculus mus* [the mountains will go into labour, and a tiny little mouse will be born].

### 1988—The Common Basic Specification—UK NHS

And so was born the Common Basic Specification. In 1984, the NHS had made a fateful decision—to build a common data model that would be mandated for use by all its Health Authorities across the country. A first version was published in 1986–87 and was not received with any enthusiasm by those charged with maintaining management data in local health communities. Data modelling was already reasonably well-established practice in the industry, but the groundwork required for defining and validating a common and generic standard that would be useful in practice, however attractive as a concept, was lacking.

But the mood of the times was top-down control, and the failure to connect with data at a local level was attributed to incompleteness of the data model rather than that the plan itself was deficient. It was resolved to develop the model further by incorporating it within a generic model of health care processes, to which all local systems would be required to map. This was decided by the NHS Management Board in 1988 and made a main plank of the mission of the new Information Management Group.

Substantial resources and protected spaces were given to this group over subsequent years. Its main mission was seen to be the creation of a process model and mandating it into practice, rather than working iteratively, with feedback from practical implementations. It published hundreds of pages of detail, with the generic model mapped to different subsystems of health care management information. There was completely inadequate ongoing

connection with health care delivery, to ground the work and establish whether the idea was feasible in practice and was useful in solving local problems faced in managing information.

To quote:

[The CBS is]

- A powerful extension to the NHS Data Model, of use to information systems specialists and to anyone planning and managing any part of the NHS.
- It makes available in one source all the basic material required by anyone specifying information requirements in the NHS. It will give precise definitions of all NHS activities and the data they require.
- The activities are shown in a logical structure which is of potential use to any manager or clinician. Starting from any particular activity such as 'diagnose', the CBS traces the logic up through, for example, 'plan service delivery' to 'maintain and improve the health of the population'.
- The CBS will always need to evolve, as the service which it describes evolves. At this stage, three volumes are being published: a core summary, the first detailed volume, and the first guidance volume, on how to use it.<sup>91</sup>

I was asked to be a member of a team established to review the work of hospital-based projects funded to implement the CBS. As far as I could observe and elicit information, there was no discernible link between the code they produced and the CBS models. It proved a task beyond them. Oracle received funds to implement it within their database technology, which I imagine they gratefully accepted, but also came up with blank connection of this work with practical health care systems.

There are some good bits in the CBS documents—the cartoons were quite amusing, but the jokes turned out to be on the CBS rather than on the clunky health care systems they depicted: NHS as a chariot with triangular wheels, CBS as the brain of the NHS, CBS as a pulley manipulating users into systems, CBS as a racing horse and NHS as a sickly camel. A doctor standing in the 1980s and peering through a telescope into the 1990s. Talk about 'Imagineering'!

There followed many such attempts to shoehorn NHS operational data into manageable groupings with varying success at the coalface. Proposed

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91 NHS Information Management Centre, *Introduction to the Common Basic Specification* (Birmingham, UK: NHS Information Management Centre, 1990), p. 1.

groupings were sought, as idealized simplifications of real-life that could be used to compare the scale and level of service being delivered in different settings, such that resources could be allocated and managed on the basis of this 'Casemix', and performance assessed. Coding and classification of episodes of care, diagnostic and health related groupings became focal issues, and this area of work became embedded in routine reporting and central aggregation of data for the NHS.

The untidy nature of patient care, across different sectors and institutions, militated against tidy and useful data definitions. Those adopted became instruments of managerial mandate. Finished Consultant Episode (FCE), Health Resource Grouping (HRG) and Diagnosis Related Group (DRG) became axioms of how health care worked and how its management data should be aggregated. This added considerable back-office burdens, and unknown benefits to the health of the nation.

### 1991—The Health of the Nation—UK Department of Health

Years of preoccupation with management of the NHS were seen to have become detached from strategic focus on the NHS's primary purpose, to maintain and improve the health of citizens. It was also seen to have added a burden to local service managers and clinicians, to the detriment of the services themselves. Thus was born the government's magisterially titled publication, 'The Health of the Nation'.<sup>92</sup>

The emphasis switched to public health and balance of prevention, treatment and rehabilitation, following the differentiation employed by Beveridge in the early post-war years. It placed the lifestyle of the citizen centre stage and, likewise, the importance of education and information to guide the choices they make. It kept faith with the importance of good management but refocused its mission towards setting objectives and targets for improvements in health. For example, on page 13, there was an obesity target! How these targets should be prioritized, set, and monitored, to be effective, was a major part of the consultation set in motion.

Recognizing the wide range of influences in play, the report acknowledged the need for widely shared 'ownership' (the report's quotation marks) of plans and implementations, at all levels. The need for 'better ways of monitoring and assessing health and measuring the effectiveness of interventions and monitoring their achievement' was emphasized.<sup>93</sup> The need was recognized for the NHS to function better as a 'head office' and

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<sup>92</sup> Secretary of State for Health, *The Health of the Nation: A Consultative Document for Health in England* (London: HMSO, 1991).

<sup>93</sup> *Ibid.*, p. 7.



for the Department of Health to work with the NHS and bridge to other Government ministries with key roles in this wider strategic framework. All very top down, as ever.

### 1993–Tomorrow’s Doctors–UK General Medical Council

This document presented findings of a wide-ranging national review of medical education.<sup>94</sup> This had long been divided into a basic science component and a clinical component organized through attachment to clinical teams in different specialities.

The undergraduate, postgraduate and continuing education and training of doctors, nurses and paramedical professionals has profound implication for NHS workforce planning. The accreditation, registration and regulation of doctors for professional practice lies with the General Medical Council and Medical Royal Colleges. Different levels of registration occur after several years in professional employment, after undergraduate study, and medical schools have close links with hospital Trusts where graduating students move to complete these preregistration years of practice. Seeking to balance the supply of graduating students with the availability of supervised preregistration positions, and a flow from these into more senior positions within the NHS, numbers of medical students and thus of medical schools are nationally overseen and mandated.

This influential review took a new look at the knowledge, skills and attitudes required of a practising doctor in the late twentieth century. The curriculum had become more and more densely populated with science and specialism, and a fresh approach was sought, to achieve better integration between the scientific and clinical practice components and the assessment of both knowledge and skills in the examination system. There had been several decades of increasing specialization in the treatment of disease, in which each new and expanding field was eager to have its contributions recognized in the formal curriculum, and, of course, receive the associated student fees. The changing balance of physician, surgeon and imaging and laboratory specialisms was a part of this evolution, and general practice was gaining status, as the health service increased its focus on the role of primary care. Costs were extremely high, reflecting the extended seven-year curriculum through to first GMC registration to practice.

Implicitly, wider issues of competence and accountability in clinical practice were surfacing, questioning the extent to which these were

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94 General Medical Council, *Tomorrow’s Doctors: Recommendations on Undergraduate Medical Education* (London: GMC, 1993).

rightly the sole preserve of clinical professional organizations and their judgements. The curriculum was widening its coverage of ethics and law, but the GMC document mentions 'information', only in passing. The impact of information technology was perceived mainly in the context of clinical skill in managing the knowledge base of medicine and computer-based learning. This was worrying evidence of a general failure of insight about the central importance of coherent electronic care records, for clinical method and practice. Regulatory bodies must play a more central role in their design and implementation and adjust their focus to be cognisant of the crucial roles they can and must play in the future, in education and training, and review of competent practice.

### 1994—Peering into 2010—A Survey of the Future of Medicine— *The Economist*

In March 1994, the widely read and influential weekly journal, *The Economist*, published 'A Survey of the Future of Medicine: Peering into 2010'.<sup>95</sup> The message was optimistic that 'new technologies are set to transform medicine, eradicate most disease, and hugely improve people's health'.<sup>96</sup>

I interpose it here as it lies halfway in time between the US OTA Report of 1977 and the Eric Topol Review of 2019, which is the last of the UK government reports I review in this section. The image of the then current reality of the mid-1990s that it depicted was a close match to the image of the mid-1970s presented in the OTA Report. The image of the prospective reality, looking twenty and more years ahead, as seen through *The Economist's* telescope of 1994, bears striking resemblance to that seen in the Topol telescope in 2019. It would be a bit depressing for astronomers if their images of the universe were as unchanging as that!

Taken together, the three reports are close in the way they highlight the key challenges posed by poor quality and coherence of care records and population-based information systems, and the potential to be realized with digital records. Each survey recognized, up front, that improvement in this area was a *sine qua non* of achieving the wider improvements and benefits they expected to see. They agreed, very largely, on why this was important and the difficulties it posed. None had anything substantial to offer by way of *how* it was to be achieved. Arguably, Barnett's team was more

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95 A. Wyke, 'Peering into 2010: A Survey of the Future of Medicine', *The Economist* (19 March 1994), 1–20.

96 *Ibid.*, p. 2.

clear-sighted—he was both clinician and engineer and a Harvard Professor in both domains.<sup>97</sup>

Running to twenty pages, *The Economist* report took apart the efficiency, effectiveness and professional domination of ever more costly contemporary medicine in the USA, piece by piece. One page is devoted to the perennially and pervasively ‘poor medical record’, giving a passing plug for the ‘ongoing work of Advanced Informatics in Medicine Initiative (AIM) in Europe’ where the GEHR project team had just published its first health record information architecture. In its place, it assembled an edifice of automated systems and customer-focused, managed care, integrated in an all-embracing information network, capturing data, both little and large.<sup>98</sup>

Prototypes surveyed ranged over tele-presently operated, image-guided interventions and robotic surgery, working less invasively, and more precisely and safely, and gene therapy. Cystic fibrosis and other single gene defects would, it expected, have been cured, twenty years hence, by 2015, and longevity gene drugs would be licensed by 2020. Jumping to 2050, cancer, heart disease and other serious diseases would have been cured by 2040, and most serious disease by 2050.

The survey was also cautious to some degree, but optimistic: ‘There will be upheavals along the way; there may be resistance from medics or others with an interest in stopping change. But the concomitant health gains will be so great that such obstacles are bound to be overcome’.<sup>99</sup>

An industrial model of health care delivery pervaded, exuberantly and overpoweringly, throughout the report, as it does in in many places still,

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97 It is hard not to descend somewhat into ranting in appraising this situation in retrospect, here. Given the extent of clear failure to achieve goal after goal, plan after plan, billion after billion of resource, decade after decade of effort, litigation after litigation of medical error, the ‘how’ of digitizing health and care records has been an Emperor’s clothes disaster of confabulation, collusion, justification and shame! Rather than blushing in the face of clear evidence, and attending to the repair of modesty, Emperors of today continue with a mixture of hubris, denial and obfuscation. Why has all this failed, repetitively, for so long? What have we learned from this failure? How should that learning reflect in how we proceed from here? I have, for thirty years, since 1990, helped build and lead an international community, across health care, academia and industry, which has devised, worked on, implemented, demonstrated and made openly and freely accessible, in the Creative Commons, a radically different methodology for tackling the how question. This is the subject of Chapters Eight and Eight and a Half. End of rant! No judgemental or malign intent towards anyone, but this has been hugely consequential systemic failure.

98 Little and Large were a comedy double act some years ago—one rather little and one rather large. Little was the sharper brain of the duo and large the brawnier—there are echoes of little and large (Big!) data, here!

99 Wyke, ‘Peering into 2010’, p. 17.

today. Thus, we read that 'If health care systems are to be made more efficient there must be some way of measuring their input (sick patients) and output (cured ones). To gather this sort of information, a patient's welfare has to be tracked from medical records, data must be pooled and processed, and the outcome of any treatments must be monitored'.<sup>100</sup> Touching on issues of privacy, it quotes a Stanford professor's judgement that the 'level of security provided by electronics is now ten times better than by hospital manual records today'.<sup>101</sup> The recent experience of extensive and sustained hacking of US Federal Government data via the SolarWinds Orion software used to monitor networks counsels continued vigilance on that score.

On the downside, slow social adaptation to the pace of technological change and the potential for harmful genetic mishaps, through germline gene modifications, were cited. The report concluded, thoughtfully, as follows:

Putting concerns about privacy and the ethics of human genetic engineering aside, the biggest worry may be 'Humanities inescapable triumphalism'. This says John Maddox, editor of *Nature*, is what accompanies a rush of discoveries that leave the impression that scientists know much more than they really do. New technologies are adopted with wild enthusiasm, even when they need a lot of further work. This time, though, science is being cautious. New regulatory bodies have been set up to oversee genetic engineering. New medical products cannot come to market without undergoing rigorous testing—though there may be a case for broadening the tests' criteria [...] Although many new technologies raised tricky medical, ethical, and social problems, they can be managed with legislation and with the right regulatory constraints [...] Given this, it is hard to see why anyone should reject the opportunities that new medical technologies are likely to offer. The reward, after all, could be a guaranteed hale and hearty future for all.<sup>102</sup>

One looks forward to *The Economist's* retrospective view of its telescopic predictions from twenty-five years ago!

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100 Ibid., p. 18.

101 Ibid., p. 18.

102 Ibid., p. 18.

## 1995–Setting the Records Straight–A Study of Hospital Medical Records–UK Audit Commission

The NHS, at a senior level, was becoming more aware of the central role played by medical records, in relation to ensuring the quality and efficiency of care and in keeping track of methods adopted, resources employed and outcomes achieved. The Data Protection Act of 1984 (another eery Orwellian 1984 coincidence), the Access to Medical Reports Act of 1988 and the Access to Health Records Act of 1990 defined new legal rights and obligations in relation to access to and safekeeping of patient records. The changing social context of health care services and professional accountability were given a new context by the Patients' Charter setting out what patients should have a right to expect from the NHS, which was promulgated by the Government in 1991 and revised in 1995 and 1997. It was supplemented by the NHS Plan of 2000 and replaced by the NHS Constitution for England, in 2013.

The extent to which clinical services required the management of information, in one form or another, was realized to account for a significant proportion of health care expenditure—variously estimated to be between a quarter and a third. Medical notes had for years been perceived as outside the scope of management information systems for health care, connecting with them principally through secondary use extracts of their coded clinical data. But greater detail of what was being done, by whom, where, how and why, and with what outcome, was increasingly seen to be of primary importance for management, in both its clinical care and business-related aspects. Medical notes were still typically paper-based and carried around in huge piles by busy team members, with dictaphone in hand, reeling off cassettes of letters to family doctors, dictated after outpatient clinics or when in-patients were discharged home or to convalescence and social care services, sometimes to be typed up weeks later, in typing pools overseas.

The transition from paper-based to digital records was rising in importance for improvement on all these fronts, as well as support for population health and research. The report<sup>103</sup> sought to balance issues of ownership, duty of care and access by patients, guided by emerging principles of personal information confidentiality, framed from the Organization for Economic Co-operation and Development (OECD) published guidelines. The recommendations were brief and generic: sort out immediate problems before attempting digital methods; experiment with patient-held records; research new technologies; NHS Executive to establish advisory service covering research outcomes and best practice. Not exactly

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103 Audit Commission, *Setting the Records Straight: A Study of Hospital Medical Records* (London: HMSO, 1995).

SMART objectives—Specific and Stretching, Measurable, Achievable and Agreed, Relevant and Time-bounded. But SMART methods are not smart for tackling wicked problems like this, as we come on to in Chapter Eight.

### 1996—Seeing the Wood, Sparing the Trees. Efficiency Scrutiny into the Burdens of Paperwork in NHS Trusts and Health Authorities—UK NHS

A new word was surfacing in the management lexicon of health service management, that of burden. This report, commissioned at ministerial level, set out to balance the value of paperwork, as expressed by the parties involved, against the effort involved in creating, collating and handling it.<sup>104</sup> Records and communications integral with patient care, information about the NHS as a whole and information that assisted management of the effective use of public funds were seen as more valuable. Unnecessary bureaucracy was seen to be often associated with poor relationships between organizations, poor quality of information and disputes. It noted marked variation across the services in these regards, with much good practice evident in organizations that were working well together.

Ways to make immediate improvements were foreseen, as were longer-term improvements that could be tackled through promoting a better quality of relationships and the use of information technology. Structural changes instituting new contracting arrangements for provision of care services had been introduced five years earlier and, in 1996, the five NHS Regional Health Authorities were disbanded, and new area-based Health Authorities created, with wider responsibilities for integrating health services across their communities. Formerly distinct Family Health Services and District Health Authorities were merged, giving opportunity for streamlining of management information flow across the NHS and in its relations with the Department of Health.

The report concluded that unnecessary bureaucracy was a systemic and cultural ill and the responsibility of all parties to work on and improve. The overlapping of communications from the NHS Executive and the Department of Health was criticized. There was an urgent need to simplify and reduce amounts, duplications and complexities of management reporting, and make greater use of operational data, rather than add additional information gathering tasks. Each new policy proposal should be assessed for its likely impact on the administrative burden on the NHS. Greater investment in

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<sup>104</sup> NHS Executive, *Seeing the Wood, Sparing the Trees. Efficiency Scrutiny into the Burdens of Paperwork in NHS Trusts and Health Authorities* (London: HMSO, 1996).

IT and prioritization and streamlining of IT procurement and the twenty-five central Information Management Group development projects were recommended. NHS-wide networking was identified as the highest priority.

The review team recorded:

What has influenced us most is the compelling evidence that, where the various parts of the NHS have developed more mature relationships, rooted in trust and openness, where sensible judgements and decisions are made in partnership and cooperation, paperwork can be kept to a minimum.<sup>105</sup>

One reflects that disjointed goals and objectives, mutual rivalry and distrust, and narrow self-interest create unhelpful and unfruitful burdens both operationally and in legal matters within health care services and at their interfaces with the communities they serve and the industries they draw on. This, in turn, reflects an anarchic culture of social transition into the Information Age. It is ever more urgent to focus, in the way this report did, on longer-term efforts to overcome the fragmentation of information within non-communicating silos, which adds directly to information overload and burden.

### 1997–The Future of Healthcare Systems–Information Technology and Consumerism will Transform Healthcare Worldwide–*BMJ* Editorial, Richard Smith

This editorial of 24 May 1997 was a tour-de-force of radical journalism.<sup>106</sup> The topic of the day was inspired by a US thinktank organized by Andersen Consulting, where twenty-five people from across the world, including the *BMJ* editor, had debated how the world's health care systems might develop. The urgency brought on by unsustainable current models and unpredictable futures convinced all that major change was imminent and would proceed for decades. Issues of cost, complexity, pace of change and changing consumer focus, as well as issues of choice and personal responsibility, and advancing science and technology, were voiced in the different experience of participants from all over the world. The model of Singapore reflected personal responsibility of citizens, mandatory saving for health and co-payment of costs, resulting in only three percent of GDP devoted to health. The model of the USA, a mix of private high-quality care at the top, social insurance-based managed care plans in the middle

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<sup>105</sup> *Ibid.*, para. 223.

<sup>106</sup> Smith, 'Future of Healthcare Systems', 1495–96.

and lower quality, government-funded care at the base was costing nearer to twenty percent of GDP. The NHS and Sweden represented ‘socialized medicine’ and insurance-based systems from other countries.

The group was challenged by ideas forecasting the overturning of traditional models and relationships in the Information Age, achieving a government regulated, ‘anywhere, anytime’ network of providers, suppliers, funders, insurers and consumers, with consumers playing a more central role. The methods evolved to monitor and manage quality, mix and cost of care, within managed care plans, and the information utility available to inform, guide and be shared among consumers were seen as likely to be applicable within all services, whatever the model for funding. The message of the final paragraph was change is coming, ‘you ain’t seen nothing yet!’<sup>107</sup>

### 1998–Information for Health—An Information Strategy for the Modern NHS 1998–2005—UK NHS

Next along the line of policy statements came the most encouraging that I encountered, sadly including some that turned into the greatest disappointments as they played out, dissolving or running into the ground. They networked, booked, scheduled and summarized, but did not integrate services and care records in the way they set out to achieve. On numerous occasions, I put the then crystallizing openEHR vision to the leaders and teams, from top to bottom, but we had little to demonstrate of implementation at the time. I suggested from the start where the Achilles’ heel of method for standardization of systems risked crippling the flow of information. Maybe they did not understand, or did not believe, or listened to and were reassured by more powerful voices who told them that they had the problems taped. Not so, it turned out.

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107 As an aside, I see that on p. 1559 of the same issue was a personal column by Trish Greenhalgh, a kindred radical spirit of the Editor, reflecting on corporate speak about health care services and their management, and the rather simpler and more important things that matter to patients—being listened to, having problems sorted out and receiving continuity of care. I got to know her when she brought her team onto the same floor as CHIME, at UCL; we respected and valued her courage and energy. With self-effacing humour, she touted her new image accompanying the piece—new hairstyle and airbrushed detail to distract and conceal *anno domini*, she said! She used this as a clever and wickedly rebellious, as ever, allusion to the corporate speak that she observed in contemporary times, which she described as buffing a self-image of general practice that was unrecognizable in the experience of many such practitioners, who are, nonetheless, she observed, rather good at meeting the simple basic needs of their patients.



With the change of government in May 1997, the NHS, and its progress in employing information technology, came under renewed scrutiny. A commitment to modernize and improve health care was expressed in a December 1997 White Paper publication, *The New NHS: Modern, Dependable*, and a Green Paper, *Our Healthier Nation*.<sup>108</sup> These set out a ten-year programme to rebuild the NHS as a modernized service that is:

- a national service;
- fast and convenient;
- of a uniformly high standard;
- designed around the needs of patients, not institutions;
- efficient, so that every pound is spent to maximize the care for patients;
- making good use of modern technology, and know-how;
- tackling the causes of ill health as well as treating it.

Associated with these, a further White Paper, *A First-Class Service: Quality in the New NHS*, was published in 1998, setting out a ten-year plan for securing quality improvement in the health care system.<sup>109</sup> Here were announced: NICE (National Institute of Clinical Excellence), Commission for Health Improvement, National Service Frameworks, Primary Care Groups and the concept of Clinical Governance. In professional terms, much of this reconsideration and innovation did bed in successfully and effectively.

The heady wider ambition was followed up in September 1998 by the publication of *Information for Health, An Information Strategy for the Modern NHS 1998–2005*, written by a new Head of NHS Information Management and Technology (IM&T), Frank Burns.<sup>110</sup> He had run IT at the Burton NHS Trust and knew what he was talking about. The central goal was that of supporting integrated care through NHS-wide standards and infrastructure. The document rehearsed the change of emphasis, from a strategy centred on management of care through an internal market, embodied in contracts between purchasing and providing organizations, to one centred on partnerships and performance. National benchmarks would be set for the quality and efficiency of services, in supporting individual patient care,

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108 Department of Health, *The New NHS: Modern, Dependable* (London: The Stationery Office, 1997); Department of Health, *Our Healthier Nation: A Contract for Health* (London: The Stationery Office, 1998).

109 Department of Health, *A First Class Service: Quality in the New NHS* (London: The Stationery Office, 1998).

110 F. Burns, *Information for Health, An Information Strategy for the Modern NHS 1998–2005* (London: NHS Executive, 1998).

enabling of public health improvement and provision of information to meet the needs of patients and the public. It was a refreshing and persuasive shift of emphasis.

Modernization of the NHS became a buzz-phrase, more widely, and a national Modernization Agency was established, mirrored in boards established at the regional level, to encourage and foster the adoption of redesigned service delivery, adjusting to changing needs. My Medical School Dean at UCL nominated me to serve for an interesting period on the London Modernization Board, chaired by the dynamic Professor of Surgery and pioneer of robotic surgery at Imperial College, Ara Darzi, meeting there a wide range of committed people and teams across the capital.

The Information for Health (IfH) strategy announced it was committed to:

- lifelong electronic health records for every person in the country
- round-the-clock online access to patient records and information about best clinical practise, for all NHS clinicians
- genuinely seamless care for patients through GPs, hospitals and community services, sharing information across the NHS information highway
- fast and convenient public access to information and care through online information services and telemedicine
- the effective use of NHS resources by providing health planners and managers with the information they need.<sup>111</sup>

It affirmed that:

The principles on which this strategy is based are:

- information will be person-based
- systems will be integrated
- management information will be derived from operational systems
- information will be secure and confidential
- information will be shared across the NHS.<sup>112</sup>

The author had come to the fore in his leadership of a Trust where progress had been towards clinically-focused and integrated systems. The document set out his ideas for how this new national strategy could be implemented

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<sup>111</sup> Ibid., p. 9.

<sup>112</sup> Ibid., p. 15.

at local level. It set out two-, four- and seven-year targets up until 2005. He approached the challenge, as others had before him, emboldened by the certainty that his prior experience gained in what he had led locally, provided an implementable global blueprint. Sadly, and ever more expensively, such confidence proved once again to be unfounded.

The first chapter of the publication considered support for direct patient care. It argued for two distinct but mutually integrated kinds of record. The Electronic Patient Record (EPR) would record 'periodic care provided mainly by one institution'<sup>113</sup>—typically an acute hospital but also specialist units and mental health NHS Trusts. The Electronic Health Record (EHR) would provide 'a longitudinal record of patient's health and health care—from cradle to grave'.<sup>114</sup> Given the defining mission of the NHS, as a universal service, free at the point of delivery, this was an extremely high level of ambition, and so it proved. It was captured in the publication's Figure 3, which shows hospital, social care, community service and mental health services records all feeding into a 'Primary Care Electronic Health Record'.<sup>115</sup>

The chapter rehearsed gaps that currently limited and inhibited progress towards this goal, starting with Primary Care records:

It is essential that health care professions agree the nature and content of the component datasets so that a consistent model of EHRs can be constructed.<sup>116</sup>

Currently there is no agreement on either the content, structure or potential use for patients, clinicians, public health specialists and planners of individual personal summary health records. The NHS must consider these issues in the context of developing integrated electronic records in Primary Care.<sup>117</sup>

The importance of protection of privacy was highlighted.

Moving on to consideration of the EPR and its role in provision of integrated care:

It is essential to create and maintain accurate, complete, relevant, up to date and accessible EPRs.<sup>118</sup>

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113 *Ibid.*, p. 25.

114 *Ibid.*.

115 *Ibid.*.

116 *Ibid.*, p. 26.

117 *Ibid.*, p. 27.

118 *Ibid.*, p. 28.

As a minimum, coordination of care must improve across the following organizational boundaries: within the full primary care team, between hospitals and general practice, between health and social care.<sup>119</sup>

The report acknowledged the trailing-edge state of information technology in ‘most of the NHS’ and the partnerships, teamwork and funding needed to match the ambition of the strategy. It identified the ‘lack of a common primary care record structure’ and that GP, community and mental health systems were ‘proprietary systems with hardware and software which is incapable of coping with sophisticated EPR functionality’.<sup>120</sup>

Regarding EPR systems, the report concluded that ‘The NHS simply cannot sustain the present disparity in the level of information systems support to clinicians and must set a minimum level of development across the acute sector’.<sup>121</sup> A six-level model was proposed, with functionality of increasing breadth and sophistication.<sup>122</sup> The action target was for level three functionality (supporting clinical activity such as placing clinical orders, results reporting, prescribing and multiprofessional care pathways). For this work to progress, a consensus was required ‘on the content, structure and use of EHRs, with the health professional and managerial community, involving the views of patients, carers, and the public whom they serve’.<sup>123</sup>

Several new bodies were established to oversee the programme, including a Clinical Data Standards Board. This was led with great determination and skill by my clinical colleague, Martin Severs. Section 3.6 summarized current issues and problems in the support of integrated care—it may sound like a stuck gramophone needle, here, but the echoes back to the OTA Report in 1977 are so strong that they need emphasizing like this:

[These were]

- The lack of common record structures and terminology (with some notable exceptions) being used within and between primary and secondary care
- the absence of comprehensive nationally agreed standards and protocols for the capture and communication of clinical information

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119 Ibid., p. 29.

120 Ibid., p. 32.

121 Ibid., p. 36.

122 Ibid., p. 38.

123 Ibid., p. 39.

- professional and public concerns over the security of information in EPR's and EHRs and the transmission of identified personal records over electronic networks
- the uncoordinated approach to developing condition-specific clinical minimum data sets without ensuring there is a common core
- practical difficulties in providing mutual access to patient/client records between health and social care
- the lack of a universal coded drug dictionary
- uncertainty surrounding mandatory use of Clinical Terms Version 3 (Read Codes)
- Confusion over the development of operational information systems to support community health workers.<sup>124</sup>

Staff from across NHS centres, including for coding and classification and Casemix, were deployed to implement a clinically led Clinical Information Management Programme:

[... inheriting] existing work programmes covering:

- clinical headings and definitions
- clinical terms and coding classification
- Casemix development
- clinical messaging standards
- condition-specific clinical data sets (e.g., for the cancer information strategy)
- standard clinical record structures.<sup>125</sup>

The strategy set out national goals, identified central players and allocated resources, responsibilities and timescales. It focused on matters of who, when, where and why, but passed on the most fundamental question that subsequently bedevilled its implementation in real life, at the coalface of health care services, clinically, technically and organizationally. A simple question, unanswered: how? *How* concerns method—in this context, rigorous, clinically owned, implementable and trusted method, supporting design, development, procurement, operation and sustainability.

It waved its hands over the central importance of standards: but which standards, and how they are created, sustained and applied? It waved its

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<sup>124</sup> Ibid., pp. 46–47.

<sup>125</sup> Ibid., p. 48.

hands over confidentiality: but how is this regulated and enforced through design and operation of networks and systems? It waved its hands over public information. All no doubt considered as just matters of technical detail, within the grand scheme of things—at these heights, devils were elsewhere than in the detail!

There was a lack of realism about the scale of the problem and the challenges involved in transitioning to scale from prototype to a nationally integrated and trusted system. There was a lack of understanding of the accelerating evolution and growth of the Internet and World Wide Web, making the issues facing health care progressively global issues in global marketplaces. There was a lack of hands-on sense of the complexity and vulnerability of existing legacy systems, where simply maintaining them in day-to-day use was often a full-on challenge for local teams and suppliers, let alone revamping or replacing this legacy, to meet new requirements for integration within a common national framework and infrastructure.

This situation played out in a mismatch of the goals and capabilities of the NHS Information Authority in Birmingham, which was charged with making the strategy implementation concrete and coherent, and the local IM&T teams and software suppliers, who were tasked with keeping things running as they were, and integrating the necessary changes to align with the national steps towards the modernized national infrastructure. The service at all levels faced conflicting and complex pressures and demands, from all directions—from top down, bottom up and in the compressed middle: in Trust boards accountable for local services and answerable to local communities; in higher-levels of NHS management responsible to ministers; in local IM&T teams answerable to Trust Boards for maintaining local systems and managing relationships with suppliers.

Symptoms and breakdowns abounded. At the local level, a glimpse under the bonnet of the churning computer software revealed and reflected the intractability of the *How* question—string and sealing wax patches to creaking byzantine code deployed on ageing and incompatible technologies; inability or slowness in making any changes to respond to local or changing needs; IT professionals struggling to survive the stresses and strains. I knew and worked alongside the good and dedicated people struggling and coping at all these levels.

At the national level, the lack of provenly implementable technical and clinical standards on which to base the integration of systems proved its Achilles' heel. Standards governing the terminology and structure of records, and electronic messages passing information between systems, were aspirations and works in progress, internationally, not at all rigorous methods that could be relied on to exist and be fit for purpose, as the handwaving of the strategy had rather assumed.

Computerization relentlessly exposes weak assumptions, at all levels, where unproven methods—assumed and sometimes promised by the industry to be straightforward, in turn reflecting the struggles *they* experience—are invoked as solutions to unsolved and intractable problems. The achievement of consensus around a core method for defining implementable clinical data standards and the safeguarding of confidential personal data also proved long and exploratory processes. Faced with unachievable target dates and expanding workloads, the first three years of implementation of IfH implementation came to a crisis.

Thus was born the National Programme for IT (NPfIT), launched in 2002, at what was supposed to be the weigh-point of the second two-year phase of the original seven-year IfH implementation. This programme, subsequently renamed Connecting for Health, marked a new stage in learning about standardization and implementation within varied local legacy contexts. Political agreement was sought and agreed, at Cabinet level, for additional investment of central government funds, on the condition that the goals of Information for Health should be achieved within the coming three years. It was a guessing game, once again. With the Treasury more fully engaged, money flows were multiplied into billions, conditional on the acceptance of a centrally mandated strategy of regionally aligned procurements of systems.

Advised by leaders of the industry and commerce of the time, the story changed to one of central command and control of a limited set of systems implemented to operate right across the NHS, their performance enforced by legally binding and tightly managed contracts with suppliers. A new leader was appointed—from management consultancy, this time—to bring proven skills in large-scale IT contract management. This was Richard Granger. His leadership style was north country direct and south country rough and self-assured; I did not see much of him, but he was different, and I quite liked him. There were many hopeful industry participants—some of them heavyweight newcomers attracted by the money potential. Existing suppliers formed consortia along with new suppliers and consultancies, to bid for huge contracts. Major primary care system suppliers managed to face down the contract terms and stay out of these sorts of arrangements—apparently rather heavy-handed attempted coercion, notwithstanding. A well-regarded and capable consultancy company was appointed to create a central Design Authority to underpin the programme.<sup>126</sup>

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<sup>126</sup> I met Alan Duncan McNeil, who had headed the NHS NPfIT Design Authority, some years after, when he was running the IHTSDO and Martin Severs and I were seeking to align openEHR and SNOMED, conceptually and organizationally. He was impressed and in favour of this, I understood, but the quest succumbed in

In these contracts, the money was certainly big, but the supposedly legally binding nature of the accompanying commitments on performance proved a mirage. There was a lack of grounded sense of the capability and experience of the supplier community. The order of the day seemed to be: make the contracts ‘water-tight’ and all will be well. They may have seemed water-tight but lawyerly adversaries, loyal to their clients, delight and drown in words and loopholes. They were certainly not ‘costly hot-air-tight’, either! At one stage in the ensuing chaos, I heard it said that if current suppliers could not match the moment, the NHS would specify and commission its own, wholly new system and have it developed in India! Bravado, delusion and folly, all in one!

This era was distinctly pricey and decidedly dicey! Leaders of the hospital systems industry were, however, delighted, and magnanimous in their lucrative victory. I met one of the leaders of HL7 at a party in London launching one of the major projects. The belief that the HL7 v3 standard was up to the challenge of integration of these systems was the orthodoxy of the day. He sipped from his glass of red wine and murmured, ‘If I were a British citizen, I’d be very worried about all this!’

New infrastructure—including the NHS-wide network and Spine for message communication between systems, e-prescribing, the booking system for appointments and summaries of care records (as a small first step towards the aimed for EHR)—made slow but steady progress. Integration more widely within the five regional consortium contracts for secondary care systems, proved a major disappointment and failure, bringing numbers of Trust operations close to collapse, and the NHS to costly settlement in battles with suppliers that they lost. Proudly characterized at the outset as the largest public IT infrastructure project ever attempted, it ended its days, as characterized after a subsequent Parliamentary enquiry, as the greatest computer procurement disaster of all time. The programme did, however, establish a baseline infrastructure that has endured and improved communication of data between different health care services and institutions. From a public perspective, the value for money achieved and all the surrounding disruption, were not good.

The gap and mismatch of the consortium capabilities and products, with the problems and needs they were intended to address, and their implementation, were terminally too great. Smooth and highly paid

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an international cauldron of ‘argee-bargee’, like that which boiled the waters of IfH/NPfiT/CfH care record integration, nationally. The latter quest has continued to bubble in subsequent NHS-X, and now NHS England, waters. The structures have changed again, twice, during the writing of this book! And the new industry saviour in favour looks to be Palantir. Zobaczmy [we will see]!



consultants with next to no grounding in health care, meeting battle-worn IT team members in Trusts to put them straight and bring them into line, was not a comfortable scene. I saw this first-hand when attending board meetings, representing UCL and local Trusts, in local and regional meetings. The saga played out with bombast and threat over five years, and continuing failure, recovery and litigation over another five years. It was a noisy scene, protected from bullets for the usual five- to seven-year cycle of politically driven projects, and its leadership ultimately assured only its own self-destruction. There were big fights over blame and compensation, of course, and the NHS came off badly. There is forewarning, in this experience, of how the trading of NHS data in return for commercialized artificial intelligence might play out into the future.

Politics after this latter period became enmeshed with the global collapse of financial markets, consequential on instability introduced into the management and mismanagement of money in the world economy of the Information Age. The NPfIT and CfH initiatives were roundly derided as having proved unfit and disconnecting for health. More truthfully, they exposed and reflected weaknesses of method and capability in providing and integrating useful electronic health care records. The priorities set by Barnett's team in 1977, thirty years before, remained a grand challenge. In another time, Fred Brooks could have had no more consequential an example and case study for his book *The Mythical Man-Month* about the prime importance of architecture and architects.<sup>127</sup>

And as AI raises its head, new partnerships bring premonition of Faustian pacts, with the NHS as Faust, surrendering health care data in return for knowledge and power over its use, which Mephistophelian big industry promises in return. No doubt overly dramatic, but there is good reason to be clear and cautious.

## 2002—Securing our Future Health—Taking a Long-term View— The Wanless Report, UK Treasury

After Prime Minister Tony Blair initiated NPfIT, from 10 Downing Street, Chancellor Gordon Brown, across the road at the Treasury, decided to commission a long-term review of health care. There was much tense jostling of these personalities and their teams, at Cabinet level! The review was conducted by Derek Wanless, a former banking chief executive.<sup>128</sup> His

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127 F. P. Brooks Jr., *The Mythical Man-Month: Essays on Software Engineering* (New Delhi: Pearson Education, 1995).

128 D. Wanless, *Securing Our Future Health: Taking a Long-Term View* (London: HM Treasury, 2002).

impressive command of detail heralded a substantial report, which he presented with clarity and authority. As a Treasury report, the focus was on financial implications for the service as a whole. In this regard, it highlighted low historic focus and investment in health care information and communication technology (ICT) as a major issue for government.

It was a hopeful breath of fresh air and projected a twenty-year forward view, as many such reports have done. That is now, for this report! I quote here extensively from figures given in the report as these are likely to have been best estimates.

An Interim report outlined the Review's three-stage approach:

- Stage 1: to understand what patients and the public are likely to expect from a comprehensive, high-quality service available on the basis of clinical need and not ability to pay, in 20 years' time;
- Stage 2: to map the likely changes in health care needs, technology, and medical advance, workforce, pay and productivity; and
- Stage 3: to assess how these changes will affect the resources required to meet patient and public expectations.<sup>129</sup>

From Section 4.3:

The health and social care asset base is huge: there are over 1600 NHS hospitals in the UK. There are around 10,500 primary care premises. The combined value of this asset base in England is estimated to be over £25 billion; the value of the social care asset base in England is estimated to be around £13.3 billion.<sup>130</sup>

From Section 2.5:

The interim report outlined what the review believed patients and the public will expect from the NHS in 2022: safe high-quality treatment; fast access and integrated, joined up system; comfortable accommodation services; and patient centred service.<sup>131</sup>

Looking to 2022, this would mean:

Modern and integrated information and communication technology (ICT) is being used to full effect, joining up all levels of health and social care and in doing so delivering significant gains in efficiency. Repetitive requests for information are a thing of the past as health care

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129 Ibid., p. 4.

130 Ibid., p. 67.

131 Ibid., p. 14.

professionals can readily access patient's details through their Electronic Health Record. Electronic prescribing of drugs has improved efficiency and safety. Patients book appointments at a time that suits them and not the service.<sup>132</sup>

Section 2.15 describes 'a new "whole systems" relationship between self-care, primary, secondary, tertiary, and social care',<sup>133</sup> while Section 2.24 examines the then reality:

The health service makes very poor use of ICT. There are examples of successful use of ICT at local level, but systems have typically been developed and installed in a piecemeal fashion. This prevents the effective integration and sharing of information across a wide range of health care providers.<sup>134</sup>

From Section 2.27:

A safe system is an integrated system where there are effective links and good communications between different parts of the service and beyond. This was highlighted by many respondents in consultation, who especially pointed to problems in social care impacting on the effectiveness of the NHS.<sup>135</sup>

And from Section 2.32:

At the heart of the 2000 NHS Plan's quality strategy is the development of National Service Frameworks [NSFs] which set out national standards for catching up to a high quality, integrated service in key areas, initially coronary heart disease, cancer, renal disease, mental health, diabetes, older people, and children.<sup>136</sup>

From Section 2.35:

The NSFs [National Service Frameworks] aim to reduce health inequality by improving access to care for those most in need and currently least likely to receive it. A range of sources suggest that, although need for treatment often increases with the level of deprivation, chances of receiving treatment decrease. This so-called inverse care law is likely to be the result of people from lower socio-economic groups having less

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132 *Ibid.*, p. 15.

133 *Ibid.*, p. 16.

134 *Ibid.*, p. 18.

135 *Ibid.*, p. 19.

136 *Ibid.*, p. 21.

access to care facilities, presenting at a later stage of disease development and being less demanding of medical professionals.<sup>137</sup>

The report presented three scenarios of implementation of change, characterized as: solid progress, slow uptake, fully engaged. With regard to self-care, it says:

Increased self-care, and the more aware and engaged public associated with it, could result in useful cost-benefits for the health service both in terms of levels and effectiveness of resources, arising from more appropriate use of health and social care services.<sup>138</sup>

With regard to genetics, it considers the impact very uncertain and concludes it is unlikely to be large by 2022.<sup>139</sup>

With regard to ICT, it remarks that expenditure per employee is the lowest of any sector of the economy. It expects expenditure on infrastructure, electronic patient records (EPR), telecare for chronic conditions, clinical governance support, and training to double—quoting US projects projecting savings in other costs.<sup>140</sup>

In Section 3.74, there is a massive and fateful caveat:

How effective this investment proves in delivering a higher quality, more responsive health service and in reducing costs will depend on the **quality of implementation** [my emboldening]. In particular, it will depend on the extent to which the investment takes place in an integrated manner with consistent standards across the whole service.<sup>141</sup>

The report's fifth chapter considers resource implications in three scenarios: 'solid progress', 'slow uptake' and 'fully engaged'. It expected health expenditure to rise from 7.7 percent of GDP to 10.6 percent, 12.5 percent and 11.1 percent respectively in the three scenarios (solid progress, slow uptake, fully engaged). This represented the NHS budget rising from sixty-eight billion pounds to one hundred and fifty-four billion, one hundred and eighty-four billion and one hundred and sixty-one billion pounds, front-loaded for change over 2002–08.<sup>142</sup> The report notes that historically

137 Ibid., section 2.35.

138 Ibid., p. 50.

139 Ibid., p. 53.

140 Ibid., pp. 55–56.

141 Ibid., p. 56.

142 The Office of National Statistics reported total current health care expenditure in 2020 as two hundred and sixty-nine billion pounds, representing 12.8 percent of GDP. J. Cooper, 'Healthcare Expenditure, UK Health Accounts Provisional Estimates: 2020', ONS (1 June 2021), <https://www.ons.gov.uk/>

the current figures have been 1–1.5 percent lower than the EU average since 1972. In Box 5.1, it warns that spending does not guarantee outcome, quoting comparative figures from Sweden and the USA in relation to life expectancy.<sup>143</sup> In relation to ICT budgets, it expects these to double to 1.2 billion pounds per annum. In relation to social care (Sections 1.2–2.1, 2.5, 2.0–2.7, 2.9, 3.4 and Chart 5.8), it shows costs doubling between 2002–22 from 6.4 billion pounds to 11 billion pounds. This does not include cost implications of their quality improvement. In Section 5.58, it makes a strong statement about health and social care, as follows:

**Health and social care are inextricably linked** [my emboldening]. There are many interactions between the two sectors. For example, recent increases in the number of older people being admitted to hospital in an emergency partly reflect reductions in the availability of appropriate social care. In planning the delivery of care, health and social care must be considered together in order to ensure that both provide high quality services for the individuals receiving care and make efficient use of resources.<sup>144</sup>

And in Section 5.59:

this demonstrates the need for a greater focus in future on whole systems modelling to help provide a better understanding of the interactions between health and social care and the implications for the level of resources required.<sup>145</sup>

The sixth chapter of the report focuses on the effective use of resources. The first area identified is: '**Setting national standards for clinical care and an integrated ICT system** [my emboldening]'.<sup>146</sup> It ranges widely over balances that need to be struck in improving health: incentives and targets, national and local standards, health and social care, primary and secondary care, treatment and prevention, health gain maximized and care delivery setting made the most appropriate and efficient, audit and public engagement.

Box 6.1 focuses on standards, processes and delivery.<sup>147</sup> The report says that ICT standards must be set centrally but does not go further. In Section

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peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/healthcareexpenditureukhealthaccountsprovisionalestimates/2020

143 Wanless, *Securing Our Future*, p. 78.

144 *Ibid.*, p. 92.

145 *Ibid.*, p. 93.

146 *Ibid.*, p. 97.

147 *Ibid.*, p. 98.

6.18 it concludes that poor performance in ICT reflects inadequate budget and lack of standards.<sup>148</sup>

Section 6.21—brings the report to a crucial conclusion:

If these issues can be addressed, the review believes that national, integrated ICT systems across the health service can lay the basis for the delivery of significant quality improvements and cost savings over the next 20 years. Without a major advance in the effective use of ICT (and this is a clear risk given the scale of such an undertaking), the health service will find it increasingly difficult to deliver the efficient, high-quality service which the public will demand. This is a major priority which will have a crucial impact on the health service over future years.<sup>149</sup>

Other sections are also of significant note: Section 6.36 on collaboration with the private sector; Section 6.40 on balance of health and social care—which it believes to be wrong, where acute bed costs are three hundred pounds per day (Section 6.46).<sup>150</sup> It sees Primary Care Trust's (PCTs) control of fifty percent of NHS budget in 2002 rising to seventy-five percent in 2004. Box 6.3 focuses on new balance of diabetes care;<sup>151</sup> Section 6.81 on partnership rights and responsibilities and better ways of keeping the public informed;<sup>152</sup> Section 6.91 on ownership of health status.<sup>153</sup> The report looks further at demographic trends for 2020–40 that are likely to adversely impact on health care services.

In relation to the Summary Recommendations in Section 7.6, the report recommends unifying health and social information resources (A.4) and improving modelling with better ICT (A.9).<sup>154</sup> In its forward look, it brings together two contributory trends: population health (dependent on age structure, genetics, lifestyle, effectiveness of health service; C. 29); and tomorrow's patient (who will be better informed, educated and affluent but who will have less time and be less deferential to professionals, and who will be able to compare the service against alternatives, wanting more control and choice; C.38).<sup>155</sup>

On reflection, as I review and write this now, it is difficult to imagine a more thoroughly executed and thoughtfully appraised policy review on health and social care. Wanless was extremely impressive as a presenter and

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148 *Ibid.*, p. 101.

149 *Ibid.*, p. 102.

150 *Ibid.*, pp. 105–08.

151 *Ibid.*, p. 110.

152 *Ibid.*, p. 115.

153 *Ibid.*, p. 117.

154 *Ibid.*, pp. 123, 127–28.

155 *Ibid.*, pp. 145, 148.

I have no doubt he was listened to, despite the much-telegraphed Number 10 versus Number 11 (Prime Minister versus Chancellor) Downing Street politics of the era. One can only conclude that the central political culture of the NHS within government had no means to translate it into action. It lacked traction in *how* to move forward on the central issues, although powerfully and persuasively highlighted, about effective use of ICT and integrated health and social care, especially.

### 2002–National Specification for Integrated Care Records Service–UK Department of Health

This was almost the last throw of the dice for the NHS Information Authority, before the NPfIT juggernaut rolled in.<sup>156</sup> It lumped together a huge set of existing data sources and services currently operational within the NHS, directly and indirectly supporting patient care, that needed to be brought into an integrated infrastructure. It offered no architectural or design solutions and was more a voluminous statement of requirements.

I was subsequently asked to take part in a review of some seven hundred proposals from across the NHS, seeking funds from a pot of money allocated to projects showing how they would integrate their patient records along these lines. It was a salutary exercise. I saw almost no proposals that extended much further than a bolting together of existing data sources and their presentation to users through a Web integration engine. An openEHR-coordinated proposal, from Bill Aylward and me, linking OpenEyes and other open-source patient records onto a platform we called Orsini–Open Records Standardization INitiative–was put together. Basically, what in due course came to life in the EtherCIS and then EHRBase platforms, as described in Chapter Eight and a Half. We were advised that the Treasury had diverted some of the allocated funds to cover an NHS overspend that year, and the project, although shortlisted, did not secure support.

### 2003–The Quest for Quality in the NHS–A Mid-term Evaluation of the Ten-year Quality Agenda–Nuffield Trust

Improvement in the quality of care was a major concern addressed in a set of consultation documents and White Papers in the years following 1997. At

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<sup>156</sup> Department of Health, *Delivering 21st Century IT Support for the NHS: National Specification for Integrated Care Records Service* (London: Department of Health, 2002).

the mid-point of the NHS ten-year quality improvement programme, the Nuffield Trust published an evaluation of progress.<sup>157</sup> It set four objectives:

- a review of the vision, strategy and structural changes that underpin the quality agenda;
- a synthesis and presentation of data to evaluate quality in multiple dimensions;
- an in-depth analysis of key components of the quality agenda, including the role and contribution of organizational culture, primary care, patient engagement initiatives, information technology and public reporting for accountability;
- summary analysis and recommendations.

It was useful in drawing together the welter of new initiatives and acronyms, which it described as ‘numbing’. By 2004, these had included:

- National Institute for Clinical Excellence (NICE): created in 1999 to publish cost-benefit analyses for technologies and pharmaceuticals;
- Commission for Health Improvement (CHI) and later Commission for Healthcare Audit and Inspection (CHAI): established as an independent regulator of NHS Performance;
- Modernization Agency: established in 2000, to help local clinicians and managers redesign local services around the needs and convenience of patients;
- National Patient Safety Agency (NPSA): established in 2001, to coordinate efforts to learn from and prevent adverse incidents after the scale of these had been revealed in a 2000 report of a team led by the CMO [Chief Medical Officer of the Department of Health]—eighty-five thousand per annum with one out of five incidents leading to disability or death;
- National Clinical Assessment Authority (NCAA): established in 2001, to provide support to Trusts and Health Authorities faced with concerns over the performance of individual doctors;
- Commission for Patient and Public Involvement in Health (CPPPIH): established in 2003, as an independent body to champion greater public involvement in health-related policy and decisions.

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<sup>157</sup> S. Leatherman and K. Sutherland, *The Quest for Quality in the NHS: A Mid-term Evaluation of the Ten-year Quality Agenda* (London: The Stationery Office, 2003).



The report talked of the need for 'development of routine data collection, analysis and reporting capability to monitor quality'. It listed a set of critical tasks covering standards setting, development of quality measures, data collection and analysis, leading to the design, based on evidence, of 'interventions to predictably improve patient care'.<sup>158</sup>

The recommendations were couched, predictably, in the language of further new initiatives!

Recommendation 1: Establish a National Quality Information Centre. [...] England's Quality Agenda simply cannot thrive in an environment that is deficient in access to valid, reliable data, and in the necessary analytic and interpretive skills for expert performance evaluation and credible reporting [...] Rectification of these problems calls for a comprehensive strategy that encompasses an information systems infrastructure, electronic patient records, and expert informatics. [...] The NHS is deficient in well-organized data that produces coherent, defensible, credible, and actionable analyses of system performance and clinical quality. The lack of a shared robust information base that provides a common understanding of the NHS's strengths and weaknesses jeopardises the quality agenda and prevents the various organizations and initiatives from living up to their potential.<sup>159</sup>

There is little if any discussion about how quality improvement might better be rooted in support for self-assessment conducted among clinical practice teams at the coalface of care.

Two authoritative books were published by the US Institute of Medicine (IoM). A great colleague of the times, Donald Detmer, played prominent roles, both at the IoM and in the UK, on sabbatical in Cambridge at the Judge Institute of Management and on the board of the Nuffield Trust. Two inukbooks of the times, published by the IoM, were: *Crossing the Quality Chasm* and *Computer-Based Patient Record*.<sup>160</sup>

## 2004–Diagnostic Audit 2003–04–UK Audit Commission

The Audit Commission investigated the state of information systems across the ninety-three NHS Acute Trusts. I discuss this report in the section of

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158 Ibid., p. 44.

159 Ibid., p. 267.

160 Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, DC: The National Academies Press, 2001); Institute of Medicine, *Computer-Based Patient Record: An Essential Technology for Health Care* (Washington, DC: The National Academies Press, 1991).

Chapter Eight devoted to the work and contribution of my colleague, Jo Milan, in the context of the Trust that was, by far and away in the report, the outstanding exemplar of high quality, clinically valued, paperless and cost-effective information services. He was the physicist, engineer and IT architect and lead who made it so. More could have been learned in studying the design and understanding the success of this exemplar at the Royal Marsden Hospital in London, than from the writing and reading of all the other Whitehall and NHS reports of the era, put together.

A health minister of the times, Helene Hayman, asked me where the IfH Programme of 1997 might be suitably launched, and I recommended The Marsden. It was a great day and the Secretary of State, Frank Dobson, The NHS Chief, Alan Langlands and the IfH author, Frank Burns, gave strongly supportive talks. Jo's team's work was presented to the press. For whatever reason, NPfIT subsequently ignored it completely. Jo contributed hugely to the early days of the GEHR project and openEHR, as I record in Chapters Eight and Eight and a Half.

### 2005–World View Reports–UK Department of Health, Denis Protti

Another good colleague of the era was Denis Protti, who, like Donald Detmer, came to the UK on a sabbatical visit and was commissioned by the Department of Health to write a set of reports summarizing health informatics research and development of the era.<sup>161</sup> It was an interesting and informative collection, summarizing initiatives across a wide range of activities.

### 2007–e-Health for Safety–Impact of ICT on Patient Safety and Risk Management–UK NHS

This document came from the NHS team dedicated to patient communications and safety.<sup>162</sup> It summarized well-established work on clinical risk and suggested how ICT might fill the gaps in information that lead to harm. I heard the clinical lead for the work present on this theme at the Royal College of Physicians. I asked them about risk arising when ICT systems fail or are intrinsically incapable, through design, of

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161 D. Protti, *World View Reports* (London: NHS CFH Press, 2005).

162 V. Stroetmann, J.-P. Thierry, K. Stroetmann and A. Dobrev, *eHealth for Safety: Impact of ICT on Patient Safety and Risk Management* (Luxembourg: Office for Official Publications of the European Communities, 2007).

communicating with one another correctly, fully, or in meaningful context. It seemed a thought that had either not occurred to them, or was deemed of minor, esoteric significance.

I had a similar experience at a USA/UK intergovernmental conference on care quality, where geographical information systems were under discussion, in relation to public health services. I found myself in conversation with a national legal ombudsman from a prominent Commonwealth country and the Head of the UK Care Quality Commission, at a coffee break. The preceding talk had demonstrated drilling down through public health datasets, to identify geographic proximity of the homes of unidentified people presenting with communicable disease. I asked them how they saw the legal data protection framework interacting with such information utility, where it would be straightforward to identify individuals from supposedly anonymized datasets. They saw no difficulty, saying it was surely a simple matter of process, to safeguard against such deidentification of the data!

### 2016–Making IT Work: Harnessing the Power of Health Information Technology to Improve Health Care in England—The Wachter Review, UK Department of Health

The early years of the twenty-first century were marked by political turmoil, war and financial crisis. Understandably, the eyes of government were not on the progress of health reforms. Politicians had set major programmes in motion and their eyes turned elsewhere. It was a good while before the reality of continuing and growing turmoil in health care services rose back up the political agenda, and thus a prudent time for new wide-ranging review!

Here from the terms Terms of Reference of the 2016 Wachter Review—*déjà déjà vu!*

The review will inform the English health and care systems approach to the further implementation of IT in health care, in particular the use of electronic health records and other digital systems in the acute sector, to achieve the ambition of a paper-free health and care system by 2020. It will have a particular focus on issues around successful clinical engagement with implementation.<sup>163</sup>

Here, from the conclusions:

We believe that the NHS is poised to launch a successful national strategy to digitize the secondary care sector, and to create a digital

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163 R. Wachter, *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England* (London: Department of Health, 2016), p. 58.

and interoperable health care system. By using national incentives strategically, balancing limited centralization with an emphasis on local and regional control, building and empowering the appropriate workforce, creating a timeline that stages implementation based on organizational readiness, and learning from past successes and failures as well as from real time experience, this effort will create the infrastructure and culture to allow the NHS to provide high quality, safe, satisfying, accessible, and affordable health care.<sup>164</sup>

And:

The experience of industry after industry has demonstrated that just installing computers without altering the work and workforce does not allow the system and its people to reach this potential; in fact, technology can sometimes get in the way. Getting it right requires a new approach, one that may appear paradoxical yet is ultimately obvious: digitizing effectively is not simply about the technology, it is mostly about the people. To those who wonder whether the NHS can afford an ambitious effort to digitize in today's environment of austerity and a myriad of ongoing challenges, we believe the answer is clear: the one thing that NHS *cannot* afford to do is to remain a largely non-digital system. It's time to get on with IT.<sup>165</sup>

The *what* is the same. The *how* is two words—standards and interoperability. The invocation, as ever, is to bite more bullets, albeit sadly now with long broken teeth. The question that politicians might better have asked is *why*, given the history, are these things being said pretty much as they were said twenty and fifty years ago. And what does this mean for health care services moving forward. Health care IT has been on a long runway and runways do end. Some planes do not, or cannot, take off. We must cast our eyes more widely over passengers and crew, destinations, modes of transport, kinds of machines and means of navigation. Wachter pointed to people not technology. The next major review focused there.

### 2019—Preparing the Health Care Workforce to Deliver the Digital Future—The Topol Review, UK Department of Health

This review was led by another eminent US clinician and professor of medicine. He comes from a long line of eminent US academics who have stood high over medicine and IT, back to Barnett at Massachusetts General

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<sup>164</sup> Ibid., p. 6.

<sup>165</sup> Ibid.

Hospital (MGH), whose contributions featured at the start of my archive. They have lived in a wealthy environment where health care expenditure is the highest, both *per capita* and in proportion to GDP, and in total amount, in the world, where private medicine predominates and where research and industry are well-funded and organized. It is a country that has long featured strongly politicized and polarized debate about population health and individual health care—the individual has access to the best in the world, and the population overall fares poorly. Individualism and socialism are the ‘isms of political tribes.

In my experience, such leaders value and admire the NHS for its mission and culture but believe, and live their lives, in the resource rich environment of a different mission. They seek the cohesion of an NHS and wish to add to it the science and product they create and use in their mutually supportive settings of academia, health care, and commerce. The business of health care is its central focus. Such inequalities that prevail are down to the individual to put right on their own account.

One comment stood out as I read the report, which reiterated the NHS focus of many years on objectives for management, not for clinical care. I recalled a precisely similar comment by Douglas Black, President of the Royal College of Physicians, in a leading article in the prominent *British Medical Journal* (also discussed above), commenting on the Körner Report in 1982, where he also said that good management of health care services is important and so is good management of patient care. They are not the same thing, but they are not separate things—they connect. Black quoted a Kings Fund paper, as follows: ‘Information technology is only exploited to the full when developments are information led, so that the information requirements must be identified first and only then a choice made from the wide range of technology available’. He adds that ‘the point could perhaps be made more simply—“Don’t choose a computer until you know what you want to do with it”’.<sup>166</sup> This much has long been known and has long exercised government.

In the Topol Review conclusions we find a welcome strong emphasis on people, implementation and learning:

This is an exciting time for the NHS to benefit and capitalise on technological advances. However, we must learn from previous change projects. Successful implementation will require investment in people as well as technology. To engage and support the health care workforce in a rapidly changing and highly technological workplace, NHS organizations will need to develop a learning environment in which the workforce

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<sup>166</sup> Black, ‘Data for Management’, 1227–28.

is given every encouragement to learn continuously. We must better understand the enablers of change and create a culture of innovation, prioritizing people, developing an agile and empowered workforce, as well as digitally capable leadership, and effective governance processes to facilitate the introduction of the new technologies, supported by long term investment.<sup>167</sup>

Here is the scope of the report, from its Table of Contents:

4. Introduction
5. Ethical considerations
6. The top ten digital health care technologies impacting the workforce
7. Genomics
8. Digital Medicine
9. AI and robotics
10. Health care economics, productivity and the gift of time
11. Organizational development
12. Providing a learning environment for education and training<sup>168</sup>

And, in case you thought I would not mention it, yet again, Section 6.2 notes as its first priority that ‘For data-driven and autonomous technologies to flourish the following are required: the digitisation and integration of health and care records; [...]’.<sup>169</sup> But only a ‘what’ and, as ever, with no sign of a ‘how’, or any evidence of learning from past efforts. No USA Presidential seeing of the world ‘as it never was and wondering why not’.

## 2010 and 2020—The Marmot Reviews

This 2010 review, and its update in 2020, revisited the social disadvantages that were surveyed in the Beveridge Report of 1942, but with a now more specific demographic and epidemiological focus on health inequalities in the very different society of today.<sup>170</sup> The trend over the past decade is

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167 E. Topol, *The Topol Review: Preparing the Healthcare Workforce to Deliver the Digital Future* (London: National Health Service, 2019), p. 12, <https://topol.hee.nhs.uk/wp-content/uploads/HEE-Topol-Review-2019.pdf>

168 *Ibid.*, pp. 3–5.

169 *Ibid.*, p. 54.

170 M. Marmot, *Fair Society, Healthy Lives: The Marmot Review: Strategic Review of Health Inequalities in England Post-2010* (London: Marmot Review, 2010); M. Marmot,

correlated with the pattern of reductions in government expenditure after the financial collapse of 2008.

It is focused on the factors that impact as social determinants of health—how disadvantage due to poverty and disability are associated with declining health and lower life expectancy. It shows how health outcomes have stalled over the past decade, and policy measures have exacerbated decline by disproportionate withdrawal of support from those most in need.

The recommendations are hard-hitting and focus on advocacy of health policy as the foremost responsibility of government. The recommendations prioritize a national focus on the needs of children and support for families in poverty. They place considerable emphasis on the need for a holistic approach, coherent at local and government policy levels, working to ensure good local work opportunities for all citizens, combined with a safety net of state benefits centred on a guaranteed minimum wage. The report does not cover the design and operation of health care services, although there are clearly substantial dependencies between these and the wider issues of poverty and inequity in society, which the report charts with great clarity.

## 1970–2020—Fifty Groundhog Years

*Parturient montes, nascetur ridiculus mus* [the mountains will go into labour, and a tiny little mouse will be born]<sup>171</sup>

I see a double message here, no doubt unintended by Horace! The obvious one is that largescale endeavours can lead to incommensurately small-scale outcomes. That certainly applies in relation to the mountains of money that have been spent on IT systems, overall, often yielding relatively small benefits in the delivery of health care. More idiosyncratically—and remembering that muscle comes from Latin for ‘little mouse’—is a message that the little things can emerge as powerhouses of the big things in life. Little Data, as I have discussed elsewhere, is what Big Data is built from. Little things can operate below the radar of the big. Simple things can provide keys to unlock the intractable complexities of bigger things.

In his book that I drew from in Chapter Six, Ian Stewart described a simple mathematical insight that unlocked understanding of the configuration of viruses of increasing size.<sup>172</sup> As also discussed in that

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‘Health Equity in England: The Marmot Review 10 Years On’, *BMJ*, 368 (2020), m693, <https://doi.org/10.1136/bmj.m693>

171 Horace (65 BCE–8 BCE), *Ars Poetica*, l. 138.

172 I. Stewart, *Life’s Other Secret: The New Mathematics of the Living World* (New York: John Wiley and Sons, 1998).

chapter, John Wheeler surmised, in setting out his ‘it from bit’ ideas, that the key to unravelling many contemporary unknowns of fundamental physics may prove much simpler than current complexities might indicate.<sup>173</sup> Quite simply stated positions can unlock complexity and also focus action. The key to their success is that they align purpose, goal and method with traction in enabling, making and sustaining effective action. For example, a single newspaper article sixty years ago coining the term, ‘Prisoner of Conscience’—individuals imprisoned for opposing powerful governments—led to the simple and apolitical action of writing letters on the behalf of these individuals and sending food and clothing to support them and their impoverished families. It was simple to get involved and it led to the worldwide movement of Amnesty International.

In my review of key documents along the timeline surveyed in the preceding section, the Marmot Reviews seemed fitting final documents to place in apposition to the first OTA Report of 1977, on medical information systems. Technology has changed beyond recognition since that long-ago report, but core issues it identified, affecting successful implementation, remain substantially unchanged—not so much perennial as ‘per-multi-decennial’! Health care has likewise changed beyond recognition since those times, but Marmot charts inequalities of health that are, in his estimation, stalled or getting worse, with uncomfortable comparators to those highlighted in the 1942 Beveridge Report. How has society’s transition into the Information Age been implicated in these stark realities, I wonder? I reflect, now, on the fifty Groundhog Years of health information policy.

On reading again, the Wachter and Topol reviews of 2016 and 2019, and thinking about what has changed since the mid-1970s, when I started my first academic post at Bart’s in medical computing, my reflections focused on what has not changed. Remedies are prescribed and swallowed, repetitively, as the problems repeat. A bit like an inappropriate drug treating recurrent indigestion. Here, again, are the presciently expressed mid-1970s concerns about future policy for medical information systems, as expressed then by the great Octo Barnett and the team assembled with him. I’ve labelled, numbered and emboldened them, to correlate with my following comments on how the intervening years have played out.

1. Policy: **‘Without a federal policy towards these systems, their diffusion may well proceed indiscriminately, and**

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173 J. A. Wheeler, ‘Information, Physics, Quantum: The Search for Links’, in *Feynman and Computation*, ed. by A. Hey (Boca Raton, FL: CRC Press, 2018), pp. 309–36, <https://doi.org/10.1201/9780429500459-19>



- standardization will not be possible. If so, the full potential of medical information systems is not likely to be achieved’.**
2. **Adaptability/Agility: ‘Prototype medical information systems have been proven technically feasible, but most have not yet been made adaptable to the various conditions of different institutions. In order to realize the benefits of a standardized database and to market systems economically on a large scale, flexible systems are required’.**
  3. **Granularity: ‘The capability to accumulate and retrieve data for each patient is critical for both the process of patient care and research’.**
  4. **Combined clinical and business/administration needs: ‘An important capability [...] is to provide necessary data for administrative and business needs’.**
  5. **Mutual understanding of clinical and engineering domains and need for long-term investment: ‘[Common reasons accounting for early failures in the 1960s were seen to be] inadequate understanding of the complexity and variations in medical care, inadequate computer hardware and software, and inadequate commitment of capital for long term development’.**
  6. **Clinical standardization: ‘At present, lack of standardized nomenclature or established protocols in medical care continues to constrain the development of a generalised database’.**
  7. **Diversity of non-communicating architectures and technology dependence: ‘Because medical information systems have been developed through the independent efforts of many investigators, today’s systems reflect diversity of philosophies and technical approaches’.<sup>174</sup>**

They looked at two paths ahead in the wood. The first is a free market, which they considered too risky.

- a. Option to allow a free market to develop:
  - **‘The federal government could continue current policies and allow adoption of medical information systems to be determined in the open marketplace. However, this policy could result in medical information systems being marketed and adopted without additional investment in research to improve certain**

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<sup>174</sup> Congress of US OTA, *Policy Implications*, pp. 4, 5, 7, 12, 14.

**capabilities. Because capabilities to improve and monitor the quality of medical care and to facilitate research and planning are the least developed and require standardization, these potential benefits for patients and the medical care system might be lost. Computer systems limited to administrative and financial functions could continue to dominate the market. Medical information systems that might be used could also lack high standards of quality or provide inadequate protection for the confidentiality of patient data’.**<sup>175</sup>

They proposed a second approach: the central shaping of the market with investment incentives to encourage coherence in knowledge bases and databases, encompassing language and workflow.

- b. Proposal for a national authority to coordinate systems design, common datasets and protection of confidentiality of patient records:
  - Central organization to develop, validate, and maintain the knowledge content of medical information systems.
  - Standardized databases, to include nomenclature, terms, definitions, classifications, and codes for use in systems.
  - Guidelines for precise standards to protect the confidentiality of patient data.<sup>176</sup>

Reflecting on the intervening decades from the mid-1970s until today, numerous issues have emerged, mirroring the concerns highlighted in the 1977 OTA Report. There has been progress mixed with regret and disappointment in relation to national programmes, internationally. These have encountered issues that cannot be resolved by any amount of government spending and a new approach is needed.

Expression of clinical and health system requirements and capable and proven technology to meet them have typically been, or quickly became, a poor match, failing to synchronize and keep pace with one another. ‘Imagineering’ is the application of imagined method to meet poorly framed requirement; it results from failures of discipline, profession, industry and working environment. It is akin to building bridges with little understanding and experience of stresses and strains in mechanical structures under load, and the context of their use. Expensive wobbly bridges have been writ large within health care software systems of our age. We have seen them fail but have not understand or learned the nature of the wobbles and collapses.

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<sup>175</sup> Ibid., p. 6.

<sup>176</sup> Ibid., p. 7.

## 1. Policy

The OTA foreboding has been borne out by events. Health care IT has been a huge and consequential policy and market failure; it costs too much for delivering too little—in terms of both money and burden on frontline care. I do not think one needs to read more than the Beveridge report, the OTA Report, the Wanless Report, the Topol Review and the Marmot Reviews to get answers to almost every question, save one, that policy must address. This is the most important one—*how*? These are issues central to health care, in terms of professional practice, education, research, management and governance. How is it that the NHS has always looked to senior and experienced clinicians from the USA to guide its policy, given how US foundations, commentators and presidents have appraised achievements there. And why have they looked to almost every discipline and profession, save two, to lead its plan? It has handed the mantle of leadership to a succession of appointees who all went twist and bust. An NHS manager, a physicist, a computer scientist, a hospital IT manager, a management consultant, a journalist, a civil servant and a diplomat. But never to a professionally trained and experienced clinician, versed and trusted in the complex realities of coalface clinical care, and never to an experienced engineer, trained and versed in the architecture and implementation of complex engineering systems. That says a lot about the repeating failure of traction and the competence to construct and execute a realistic policy and plan. It says a lot about the clinical professions, too, that they did not use their power and influence to insist otherwise, other than in the wise and unheeded advice of Douglas Black at the time of the Körner report, when hyper-and top-down managerialism took a much stronger hold at the centre. It says a lot, too, about the elitism of politics and the derogation of the importance and contribution of engineering in making things happen. The leaders of professional bodies have a lot to do. I suspect they, along with most hospital managers, have been fearful of career suicide by becoming too involved.

Of course, health care was not alone in these kinds of failure within the public sector. Many such failures have common origins and distinguishing features as well. At the heart of the policy failure has been one of ownership of the domain. Health care information systems are instantiated within a community of three communities—of citizens, services and businesses. It is a domain where each of the three has a characteristic interest, all fundamental and in need of one another. Each needed to change, and each needed to learn from the others, and thereby learn about itself. The intersection of these evolving interests is the wider community interest they all serve—that

is the proper focus of policy, and where governance and trust must be earned. Each of the three has a different perspective on the issues they face as a group—about implementations that interface at the coalface of care, and the secondary interfaces of education, research and management that are integral with the health system, and with the processes, technologies and governance they entail. The conflicts of interest that inevitably arise can only be resolved in the context of overarching community interest, common ground and joint implementation endeavour.

This is where the future care information utility, serving a coming era of Information Society health care, must be owned, and positioned as an evolving reality, seeking towards better balance, continuity and governance of services and efficiency and effectiveness of the methods they employ and their validation. Today, clinicians, managers and technologists sit around a circle, and blame circulates clockwise and counterclockwise. The patient sits in the centre and feels bemused, and everyone blames the politicians, watching from a circulating helicopter and throwing the occasional bags of confetti money and defending themselves to one another.

## **2. Adaptability/agility**

There has been a deficit of sustained, coherent, clinically-informed and -led policy, and appropriately targeted resources. Design, implementation and practice have proceeded piecemeal. This has, in large part, reflected barriers that practising clinicians have experienced, or by default imposed, limiting their practical engagement with an area so fundamental to their work. Good development and prototyping tools were not available to help them in this.

A 1970s mindset of IT has permeated throughout, conditioned by the waterfall model of system development and implementation, as essentially a sequential process. Systems today are designed and implemented using more agile methods, which recognize the chameleon-like qualities of the problem addressed. System architects need to be able to rescope and redesign their work as its practical implementation and use evolve. We have learned a great deal about the stacks of software that integrate from the local user interface to server farms and data stores distributed in the Cloud. We have learned new discipline, and accessible technology now spans these dimensions.

## **3. Granularity**

We have also started to turn the world upside down and work from the patient outwards in the methods for structuring and persisting data, so

that it can be searched and analyzed with generic methods and software tools. Architecture can now embrace a hierarchy of granular and structured detail about patient care combined with less structured data. The OTA recommendation is that systems must be able, as a priority, to answer all questions about individual patients and their care, and as a secondary purpose also provide valid data at organization and population levels, with no further data collection burden imposed on frontline staff. This is simple to state but extends deep into issues of architecture and design, where these can only be arrived at iteratively over time, testing ideas at each stage in a real-life context. This scarcely ever happens in top-down driven implementation. We need the tools and teams to enable it to be approached from the coalface of care, outwards and upwards. This has been the unifying focus of the pioneers I describe in Chapter Eight.

#### **4. Combined clinical and business/administration needs**

Health services require a wise mix and capacity of health care professional expertise, combined with efficient administrative, managerial and governance arrangements. It is teamwork and it is trusted team culture that holds it together at all levels, as the demands are intense. The efficiency and effectiveness depend on coherent, accessible and unburdening information systems. Repetitive capture of data and incoherence of its forms and applications are costly. The work of the organization is coalface care, and the information systems require an architecture that supports the coherence and continuity of care, at all levels, where it is most effectively delivered.

#### **5. Mutual understanding of clinical and engineering domains and need for long-term investment in innovation**

There is a need for a workforce skilled and experienced in both the technical and clinical domains of information technology and informatics. The NHS once grew such a cadre of staff and proceeded to weed it out or demote it to an administrative role, principally devoted to management of outsourced service contracts. This occurred when unknowledgeable managers perceived this wider home-grown experience and expertise as inessential for the procurement and implementation of IT systems that were needed, and that it could be left to suppliers of systems to provide them, as necessary. This resulted in the service effectively outsourcing a crucial area of expertise central to its ongoing knowledge and development. The marketplace did not, and could not, grow that breadth of on-the-ground capability. Its staff were focused on selling and installing their own bespoke technology, minimally adjusted to the bespoke needs of client organizations. That is a pathway towards a market dominated by very undesirable monopoly.

It also serves to constrain innovation within a product-, specialism- and organization-focussed ecosystem that is ill adapted to foster and lead radical innovation. Such innovation should draw on and harness the potential of new device technology, information systems and networks to invent new methods of measurement, review and intervention, in support of safe and effective health care services that can now be delivered in, or much nearer to, citizens' homes, and which can be operated and overseen there by themselves, their carers and their community-based professionals.

We tend to think of these trends in the context of affluent country requirements and their costly health systems. Such radical reinvention of care service delivery would be of equal, if not greater, applicability in developing world contexts where workforce scarcity and remoteness of communities from the nearest clinics and hospitals is of a different order, and yet where access to low-level satellite mediated broadband at one hundred and twenty megabits per second, backed up by unflinching, battery-stored solar energy, currently continuously reaches the most remote Aboriginal communities situated many hundreds of kilometres from Alice Springs. I was talking to this service's medical director, my openEHR co-founder Sam Heard, and discussing this reality, only this morning, in one of our regular weekly chats that brighten both our lives.

## 6. **Clinical Standardization**

The clinical importance of standardization of data has been a rallying call from the start, with a great deal of learning required, and underestimated, as to how to achieve this. Clinical practice has had a lot to learn about itself in its encounter with the computer. Marrying of the disparate worlds of clinical and technical standardization has been erratic. It has not been a well-conceived and thus well-owned process. Efforts towards standardized frameworks for computer-based methods and systems, as integral components of clinical methods and service delivery, have struggled to align within the total health system that supports the maintenance of health and the diagnosis and treatment of disease.

Some of what has been attempted was akin to taking software that implements the TCP/IP standard (Transmission Control Protocol and Interchange Protocol) that underpins data network communication and expecting to use it as a basis for standards defining the meaning and content of the messages themselves. More absurdly, to emphasize the point, it has been somewhat as if the librarian profession was being charged with defining a unified field theory of physics, when deciding a basis for cataloguing the physics literature!

Efforts towards standardization of clinical nomenclatures and knowledge bases sprang from the efforts of academic departments and professional bodies, seeking coherence and discipline in these endeavours. Within well-bounded domains, such as imaging, laboratory services and instrumentation for patient monitoring, interfaces have been sufficiently clear that standardized approaches for data capture and management could be evolved from within those communities of practice, be taken up safely within devices in use, and used to share their data more widely within health care records.

Other than in the domains of medical language and terminology, and of relatively well-defined and encapsulated domains of computerization, such as imaging and laboratory systems, the standardization of clinical data has been predominantly conducted as an exercise in technical standardization, pursued in a mixture of industry and government, and inter-governmental bodies, in a consensus building process more than an experimental one. These processes have lacked recognition of the fundamental message that surfaced in discussion of formal logic and knowledge bases in Chapter Two, that much of medical knowledge and data, including that relevant to individual patient care, is highly context dependent. Chapter Two rehearsed the defeasible and indefeasible components of knowledge bases. Records of care must capture that relevant context if they are to convey meaning and be capable of reliable grouping and analysis over time. The formalizing of clinical data standards is a huge area of interface with the onward development of information systems, and closely related also to data protection principles and measures, that require to be standardized, too.

The OTA Report exposed this issue, long ago, and it has reverberated through the decades, at all levels of endeavour, resulting in new datasets, new governance and new law. There is very little continuity of practice in the systems in use, between different institutions and levels of health care. Only when clinicians are enabled to step up, engage and participate as equal partners in system development, with tools that mirror their interests and concerns, can properly experimentally-based ecosystems of standardized clinical data, within standardized technical infrastructure, become a tractable and sustainable proposition.

Lacking the synergy of a common and shared methodology that provides a provenly implementable answer to the *how?* question, products arising will continue predicably to prove inadequate, inflexible and constraining of choice within the marketplace. The products, in turn, are then unduly costly and burdensome for fulfilling the tasks they are expected to support. Frustrated efforts towards standardization of data and methods have impeded efforts to move from prototype to product, and integrate, locally and at scale. By default, standardization of health IT systems

sprang from the industry players' need for their products to communicate digitally with one another. It did not arise from the users' need for them to communicate clinical meaning between different clinical record-keeping systems. Transparent sharing of methods employed for representing clinical content within and between systems was seen as a concerning threat to a proprietary product's commercial viability. Its lack became an even more impactful threat to its clinical and organizational viability.

### **7. Diversity of non-communicating architectures and technology dependence**

The truth of this observation, the final concern raised in the OTA Report, has become ever more present and impactful over the intervening years. It has resulted in an unhealthy monopolistic tendency of markets, as purchasers despair of a more flexible and adaptable ecosystem of information systems and commit to a product that ties them and their data tightly to a single supplier of systems. Computer science and computational method have evolved continuously, rendering architecture, design, and implementation, and the skills they embody, quickly obsolete. Clinical science and the computational methods and systems required by health care services have also evolved, in parallel, along with clinical governance and the requirements for the certification of products. Part Three of the book offers a way out of this dilemma, that has been shown to be implementable and scalable. It has been achieved with a miniscule fraction of the resource spent elsewhere seeking solution to the challenge set out in the OTA Report from the 1970s.

#### **a. Option to allow a free market to develop**

The OTA Report feared that an unregulated market would divert attention from innovation and improvement of the process and quality of care, towards a focus on the business of supplying systems, to the disbenefit of patients and lack of protection of their data. It made early suggestions for areas of federal intervention, and all over the world, governments have adopted a middle way in leaving systems architecture in the purview of the industry and regulatory requirements at national level. The problems that have become more evident over time relate to how to set a generic framework of regulation which can be implemented safely and efficiently in a plethora of architectures. This goes beyond agreement on datasets into how the data are persisted and processed within systems and communicated from one architecture to another across the different disciplines and levels of the care system.



**b. Proposal for a national authority to coordinate systems design, common datasets and protection of confidentiality of patient records**

The OTA argued for a national body to hold the centre of the stage and many countries have followed that route. The problem is that the markets for systems are international, and the records of patients need to travel meaningfully between countries. To achieve this, greater discipline and rigour is required, which is openly and freely available and shared between countries. Standardized methods for handling and communicating meaning and context of care remains a requirement over and above what is decided to meet the needs of any one jurisdiction. This has been a difficult and contentious socio-technical and political challenge and other than in the areas of terminology that have been highlighted in Chapter Two, rather limited progress has been achieved in relation to whole records.

It should, all the same, be acknowledged that the NHS did in its early initiatives follow something of the OTA alternative blueprint to a free market. It created an Information Authority, it invested into clinical domain terminology and classification, it instituted wide-ranging data protection regulation. The problems that arose reflected misunderstanding and miscalculation of the nature and scale of the task, the environment and leadership required for tackling it, and the achievability, and resource and time required for realizing its ambitions, in changing clinical, technical and managerial contexts.

Over and above the prescient OTA appraisal of the unfolding domain, several other observations might now be added:

**Corporate engagement:**

Large corporations have serially dropped in and out of engagement with the challenges set out in the earliest reviews. Governments, likewise, have looked in detail and then looked elsewhere. Focus on methods and quality of clinical care and management of services, have lacked synergy of approach with data and record management. The marketplace has often appeared as a Wild West kaleidoscope of money, power, circumstance, technology and obsolescence. Either that or as an orchestra of untuned instruments and frantic conductors with ineffectual waving arms.

**People and environment:**

There has been a dearth of good and appropriate multi-disciplinary and multiprofessional environments in which committed teams could learn from and inform one another, to make and sustain progress in designing,

implementing and operating sustainable and integrated information systems, working on this from the coalface of care.

**Developmental tooling and infrastructure:**

Pioneers work with head, hand and heart, and while their head and heart have been able to engage, their hands often have not. Some have built tools and infrastructures with which to make progress, but few of these have survived, scaled and matured as products, infrastructures and services. A much more coherently tooled ecosystem is required to enable active and effective clinical engagement with the domain.

**Failure to learn:**

Putting all these domains together in the context of a computerized individual patient record, sharable among systems and technologies, as envisaged from the earliest reports, remains contested territory, populated by opposing ideas and ambitions.

Efforts towards computerization frequently expose new questions about the foundations of discipline and practice, as illustrated many times in the preceding chapters. The pursuit of quality improvement in health care practice has become entwined with disparate challenges that need to come together as one: the reform of health care services; information utility supporting balance, continuity and governance of care services; team building to provide the range of skills and competences of health care professionals, engineers and scientists that can be trusted and relied on at the coalface of care.

**Legacy:**

There has resulted a patchwork of underperforming, redundant and unsustainable, ever more costly legacy of information systems. Surely the time has come to address, more deeply, why this situation has been such a hugely more difficult and consequential problem and ambition for medicine and health care services, in comparison with other sciences, professions and sectors of the economy and their supporting industries. I hope this book may be a useful contribution to this important quest. At heart, for me it is a problem of language, logic and reasoning in the context of the clinical and care domain. The efforts to 'computerize' have exposed a mismatch between what science, management and technology can contribute to health care, and what are deemed good practice and outcomes that citizens need, and increasingly expect from their health care professionals and services.

Joseph Weizenbaum placed the fault-line differently, arguing that computer science was a spurious knowledge domain, imputing value in the coding more than in the practical method and content it enabled. That does sound a bit like saying that mathematics is a spurious knowledge domain, and we should rather value its applications! Pushed from many sides, about where reform and breakthrough in health care practice will come from in the coming decades, there is, all the same, a heightened sense of imbalance and unfairness, of rights and responsibilities, and of patterns of inequality in health, tracing back to those identified in Beveridge's five giants of 1942 and reiterated in the Marmot Reviews of the past decade. Since these have persisted over those many decades, notwithstanding the revolutions of computer science and technology and now genomics science, one must wonder whether AI is destined to help, and whether they ought not to be the greater focus of our attention. There is greater awareness of imbalance, but little sense, still, of how to seek and promote redress. New balance can only be achieved with movement on all sides, supported, I believe, by reinvention of health information systems as a citizen-focused care information utility—common ground that all share in need of, and have a role in creating and sustaining, at the heart of the mission for a healthier and better cared for future Information Society.

## Ivan Illich Revisited, Fifty Years On

To complete this long chapter, it is interesting to revisit Illich's *Medical Nemesis*,<sup>177</sup> to consider how the landscape has changed and adapted to the issues his books identified in the 1970s. Some key developments that appear to line up with the direction of travel he favoured are:

- Genomics has arrived and, with it, personalized medicine in the shape of treatment customized to individual genomics profile and phenotype. The production line analogy with hospital care crumbles a bit when each thing 'produced' is unique. The pace of advance in genomics has greatly exceeded Wanless's cautious twenty-year predictions from eighteen years ago;
- Primary care combined with embryonic and feasible means to combine it with effective and efficient self-care, has started to emerge;

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<sup>177</sup> I. Illich, *Limits to Medicine: Medical Nemesis: The Expropriation of Health* (London: Boyars, 1995).

- Medical risk and harm caused have been recognized and embodied within regulation of professional practice and law;
- Data protection laws have recognized ownership of personal data and codes of conduct have evolved to protect them in information systems.

A further trend that supports Illich's line of argument has been the escalating and increasingly unportable cost of hospital medicine and the burden that the application of advanced technology has placed on health care services. This has reflected new methods of acute medicine and care of the elderly and chronically ill in society, associated with increased human lifespan. The trend is well-recognized, and self-care and community delivered services are identified aims towards their resolution. Machine learning has assumed more concrete form. Advances in artificial intelligence and the novels of Ian McEwan and Kazuo Ishiguro have brought the prospect of humans living with artificial friends into a more plausibly realizable form.<sup>178</sup> From the Illich perspective, such innovation would remain doom-laden for humankind.

Illich's challenge was for society to redefine the disease focus of industrialized medicine into a focus on autonomous individual health care. That virtuous circle could perhaps be squared in a society where healthy lifespan and healthy lifestyle coexist, both locally and globally. No one can be protected from viral pandemic until all are protected. This still looks a long way off. An encouraging and more optimistic vision is that research and discovery, can now happen locally and propagate globally, as rapidly as news travelled in the local village. Within recent decades, the sequencing of DNA has evolved from a billion-dollar multi-year, multi-laboratory global effort into a single device that achieves much the same ends within hours or minutes. Candidate pharmaceuticals can be rapidly adduced, targeting visualized and quantum theory characterized receptors on cell surfaces. Epidemics can be tracked, albeit that the social, political and economic implications of control of pandemic remain intractable. And Honeywell's quantum computer prototypes can now be accessed from the Cloud and bring promise of collapse of computer processing time on complex computational problems, from mega-millennia to hours.

This chapter has addressed fifty years of coevolution of health care with information technology and the *status quo* of today, where early fundamental goals have not yet been achieved. In what way should we re-imagine information for health care and reset our goals, and how should we gain

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178 I. McEwan, *Machines like Me* (Toronto: Knopf Canada, 2019); K. Ishiguro, *Klara and the Sun* (New York: Knopf, 2021).

traction in realizing them? That is where Part Three kicks off. To close, here, I reflect on another westward rush for gold!

## Parenthesis–Goldrush

As with the ‘alchemy’ of money, vividly characterized as such in the modern age by Mervyn King, the alchemy of information has made and destroyed livelihoods and fortunes.<sup>179</sup> It has created and nurtured emergent oligopoly and confused democracy. It has engendered a new goldrush to that same territory out west. Gold was searched for at the end of rainbows and magic bullets filled the air, missing their targets and exploding in nearby neighbourhoods. Information in the Information Age has assumed ever more strongly political and commercial guises and vestments. Data has been mined for money, power and influence, in basements, backstreets and penthouses, all over the world. It has been an information wars zone. There was triumph and disaster, redemption and retribution. There was once a dustbowl created on fertile land. Will bitcoin bite the dust? Is information mirage reverting to data sand? Will quantum circuits blow up a new sandstorm?

This is, no doubt, rather naff hyperbole, but it seeks to dramatize an unwanted future and an urgent need to find new and fertile common ground of information on which to help reinvent the future of health care services. Hype of each era, of whatever kind, on whatever topic, is naturally expressed in articles and histories focused on survivors and their successes. The Gartner consultancy even trades on ‘hype’, characterizing information technologies along a ‘hype cycle’—that is where the money is. In health care, it is money traded within a marketplace of products and services geared to the eyes of investors and purchasing power of organizations. It is a market structure that has led to multiple manifolds of non-coherent health care data about individual citizens, persisted in multiple ecosystems of inconsistent, mutually redundant, proprietary databases, focused on ‘what is in it’ for the investors, companies and organizations concerned. It is a market of costly and inflexible products, lacking an architecture of personal data and record that relates, first and foremost, to ‘what is in it’ for individual citizens in their relationships with multiple organizations of health care, and increasingly in using home-based devices and services that support them in meeting their individual health care needs, including for self-care, and of those they care for.

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179 M. King, *The End of Alchemy: Money, Banking and the Future of the Global Economy* (New York: W. W. Norton and Company, 2016).

The reinvention of health care will require reinvention of the architecture and marketplace for health care information systems and services. The drivers for this must be individual citizens, health care professionals, and the provider organizations delivering health care. They alone have the experience, capacity and indeed the right and responsibility, to insist on a different architecture and marketplace, and set a different course.

The saying that those who do not learn from history are destined to repeat its failures is maybe not really true—we tend rather to make new mistakes, in new times, conditioned by new contingencies! We tend to shape our own conclusions from what we want or choose to see in the pattern of past successes and failures. But the impact of our actions can spread with extra force in times of information alchemy and great change, and we should observe and reflect on them carefully. It might also be argued that much detail of the past is redundant, insignificant, and best forgotten. The highly articulate presenters of the ‘The Rest Is History’ podcast series pondered the topic of whether we can learn lessons from history, in an early episode.<sup>180</sup> Amusingly, they quoted a very early historian, Gregory of Tours, writing in the sixth century, who, they say, had the best book opening lines ever, throwing up his hands to express a minimalist overview of history: ‘A great many things keep happening—some of them good, some of them bad!’ That sounds a bit like the opener of *The Tale of Two Cities*!

Many decision makers, and even many practitioners, have not really experienced, let alone learned from, their failures. Failure can signal a personal negative, but the greater negatives are from organizations that do not learn or do not try to. Perhaps we should not dwell too much on the past, but we surely need to learn better in the present. Each era builds on foundations that it comes to take for granted. Troubles arrive when ground shifts too quickly under foot, foundations subside, and we have forgotten where we came from. Information pandemic is subsidence of a kind, in the foundations of society today. It highlights what we can and cannot currently understand, and safely do. Most experiments are conducted in local contexts and the impacts of failure remain local. It is a characteristic feature of global infrastructure that good and bad things can grow and spread quickly. Software viruses and bugs can turn up almost instantly on machines across the world, and experiments that fail can have wider significance and impact, too.

At a wild guess, perhaps ninety-nine percent, or even more, of the methods used to design and implement information systems over the past five decades are already obsolete. Sadly, a significant proportion of the

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180 D. Sandbrook and T. Holland, *The Rest is History* (2020–), <https://www.goalhangerpodcasts.com/lineker-and-baker-copy>

systems they were used to build are still slogging on, with current work in some way still dependent on them. Knowledge about their design and the tools used in their development may no longer be extant. There is an experienced, but largely unseen, legacy of incompatibility and lost, now obsolete, art lying beneath the surface of software systems still in everyday use. There is a mirage of code, as seen from outside or from afar. What might look easy may have been very hard to achieve; what might look hard may have proved easy. Skilful programmers can find elegant and simple solutions to problems that others find complex and laborious to solve. And AI, too, can now write code!

Society has paid a very high price in creating, sustaining and living in this anarchic landscape. The sunk costs have been huge but have created rather less future value. New costs, both in shoring up the hole into which this legacy has dug us and in building out of it more sustainably for the future, are prospectively also considerable. How well are we learning as we go from this experience, by way of insight about how to do better in the future?

In the West, the locus of invention and creation has moved away from public sectors onto much wealthier, cash-rich commercial landscapes that can operate autonomously and often with power greater than governments. Only in relatively few environments—like the Harwell science campus, Daresbury, Culham or CERN (Conseil Européen pour la Recherche Nucléaire), or the science campuses from Massachusetts, through Oak Ridge in Tennessee, to California, for example—is comparable capacity and capability brought together and set free to spearhead major innovation today, where science, engineering and practical application can focus and advance in tandem.

Achieving a creative balance of support for public innovation and private industry, tuned to emerging new markets, is a well-recognized concern of our times. The power of global tech-based corporations, in their home and offshore bases, has risen markedly in the age of the Internet. The assumptions and rules governing these industries looks to be changing, with anti-trust legislation that regulates monopoly moving beyond law focused on avoidance of consumer detriment towards law based on utility and equity across countries.

The need for standardization, independent of vendor products and suppliers, has long been recognized in key areas of physical infrastructure. It is becoming a more insistent concern for software, too. Incompatible and proprietary products can entrench unhealthy monopoly, by making change away from them intractable, or the cost of doing so too high to be afforded from current budgets. Switching software and system often entails high cost for semantically safe and accurate migration of historic records, sometimes prohibitively so. Such migration was attempted unsuccessfully in several

hospital system procurements I have observed. This matters, increasingly, for coherent lifelong records of care.

We can and must now raise our sights to do much better. Part Three of the book, to which the storyline now moves, is optimistically forward-looking. It moves the focus to *who, what, when, where, how and why* questions. It is time to put away the ‘retrospectoscope’ and take out, not telescope or ‘predictorscope’, but ‘prospectorscope’ and ‘cocreatorscope’, to seek out and fulfil the Dreaming<sup>181</sup> of a future common ground for a coherent, citizen-centred care information utility.

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181 On the Aboriginal concept of the Dreaming, see Preface.





# PART THREE—PROGRAMME FOR REFORM

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*Human nature is so complex that paper plans for society are to the statesmen not worth even the price of the defaced paper. Successful progress creeps from point to point, testing each step.*

—Alfred North Whitehead (1861–1947)<sup>1</sup>

This book as a whole is akin to a songline and its three parts to a Dreamtime-like continuum of past, present and future. Part Three might thus be thought of as a Dreaming about the creation of a care information utility that is central to the reform and reinvention of health care for the future Information Society, anchored locally, nationally and internationally in the public domain. Reinvention requires bold imagination, linked with creative and carefully calibrated implementation and learning by doing.

This Dreaming is not yet close to a technical specification. It is a vision focused on future health care needs, a rehearsal of values and principles that such a utility should embody, and the imaginative implementation required to evolve and sustain it. The reflection in parenthesis of Chapter Five of Part One has set out context and motivation of this endeavour.

Such dreams are difficult to connect meaningfully with the concrete language of a dreamless machine and how it gets involved in health care. The openEHR and OpenEyes initiatives described in Chapter Eight and a Half were once similar dreams and are now substantially implemented and gaining traction in everyday use, spreading around the world. They and the stories of their creation might be seen as signposts and halfway houses towards the care information utility which remains to be created.

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<sup>1</sup> *Adventures of Ideas* (New York: Macmillan, 1933), p. 27.



## 8. Care Information as a Utility— What Is Needed and Why?

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This chapter is in three parts. The first explores what we have learned during the anarchy of transition of health care in the Information Age and why new ideas are needed. It emphasizes the organic nature of a care information utility, distinguishing it from a technical infrastructure. Organic, that is, in the sense of ‘relating to, or derived from living organisms’ and being adaptable, evolving and humanly-centred, to serve the needs of individual citizens for supportive health care services. In this regard, it draws an analogy with the forest ecosystem of the natural organic world, which was termed a ‘Wood Wide Web’ in a 1997 issue of *Nature*. It makes a parallel analogy with monetary ecosystems, discussing the relevance for health care information policy of the lessons drawn by Mervyn King, when writing about the world monetary system crisis of 2007–08.

The second part of the chapter celebrates pioneers I have known and worked with, who have made notable contributions in framing and implementing new ideas for information systems, achieving iterative and incremental advances towards meeting longstanding policy goals. The third part draws together future-facing perspectives of the changing patterns of knowledge and discipline, professional practice, education, research and global village community, which will form the landscape on which the care information utility evolves. It discusses the values and principles that should guide the development of the utility, the importance of a viable means for its standardization and the difficulties faced in achieving this.

The chapter concludes with a parenthetical reflection on what matters at the heart of the interconnected and currently fragmented domains of care information services, and the dilemmas they pose. This has been characterized in other contexts of public services as the need for a unifying change of perspective, from a focus on ‘What is the matter with you?’ to one of ‘What matters to you?’

Adventure is necessary to prevent withering through repetition—learning and learned taste replacing ardour of adventure.

—Alfred North Whitehead (1861–1947)<sup>1</sup>

This is where we are today: patients exist in a world of insufficient data, insufficient time, insufficient context, and insufficient presence. Or, as I say, a world of shallow Medicine.

—Eric Topol<sup>2</sup>

The framing of government policies for Information Age health care has become somewhat witheringly repetitive, and replete with ‘learning and learned taste’! Perhaps, the lengthy chapter just past felt like that to read! I am seeking to be more adventurous, now. The above quotation from a luminary doctor and scientist with a special interest in information technology, Eric Topol, gives a vivid context for the scale and significance of the challenges to be faced.

In this, I am not comparing or criticizing any particular technologies that might be adopted to underpin implementation of future information policy for health care. Such debate is sterile; these technologies should, and inevitably will, evolve experimentally over time, albeit some more expensively and wastefully than others. I am, rather, drawing on experience and example from along my personal songline, to give personal perspective and paint a picture of the values and principles that should underpin future policy in this field. I am, thereby, principally seeking to help clarify what future endeavours should embrace and comprise, and what their purposes, communities and environments might look like. This envisioning is by no means complete.

The storyline of the book has reached a tipping point. Thus far its approach has been one of description, with focus on drawing together and connecting diverse contexts of two millennia of medicine, centuries of science and engineering and seventy-five years of the Information Age. At the end of each chapter, I have reflected, in parenthesis, on general issues and challenges faced in introducing information technology to the domain on which the chapter has focused. In Chapter Two, this was about traction in getting to grips with the application of knowledge—connecting ‘what is true with what to do’, as it is sometimes expressed. In Chapter Three, the theme was about manifold and balance, in getting to grips with new measurements and methods, as tools of science and society in the Information Age, and

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1 *Adventures of Ideas* (New York: Macmillan, 1933), p. 246.

2 E. Topol, *Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again* (London: Hachette, 2019), p. 31.

their impact on the balance of health care. In Chapter Four, there was reflection on purpose, as central to why and how we build and apply abstract models of the appearances of reality. In the parenthesis of Chapter Five, there was consideration of the engineer's inventive spirit of making and doing, and how this relates to the challenges faced in reforming and reinventing health care, through the present-day anarchy of the Information Age and leading into the future Information Society. At the start of Part Two, in Chapter Six, there was reflection on how transition in knowledge about the nature and science of life and information has paralleled changing ideas about health care services, and information policy supporting them. In the parenthesis of Chapter Seven, the theme was goldrush, reflecting on serial endeavours to commercialize health care information systems during the Information Age.

In this and the next chapter, the approach switches from one of description to what might be termed a prescription—a forward-looking perspective of the nature, design, implementation and operation of a future care information utility, adaptable to the emerging and evolving needs of tomorrow. It is a Dreaming<sup>3</sup> about something yet to be created—difficult to conceptualize since the specific purposes and goals of such a utility remain to be discovered in detail, based on experience gained during iterative exploration and incremental implementation. Its creation will thus require an agility of approach, and implementation in manageable incremental stages. The chapter ventures off-piste, to sample experience in other fields that have encountered similar challenges in the Information Age, to look for their common ground with the changing face of health care. A bit like the dog one sees racing around and exploring, connected with and on a walk with its owner, attached by a spring-loaded expanding and contracting lead!

It is easy to spend much time talking and reading about seemingly intractable problems, hunting illusory perfection of potential solutions. There must also be traction in the way such problems are tackled at scale, otherwise the law of unintended consequences may bite hard. Traction may require a mixture and balance of methods of implementation. And each method will have its own characteristic qualities—helpfully expressive of the problem domain, in some respects, and unhelpfully limiting of the applicability of what can be achieved with it, in others. Horses for courses, as it were. A good engineer guides and melds these choices, combining an artist's aesthetic eye, a mathematician's grip on shape and form, a practitioner's experience of useful things and a scientist's knowledge of materials and methods under consideration.

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3 On the Aboriginal concept of the Dreaming, see Preface.

Chapter Seven traced a changing pattern of health care services, alongside information systems, in their transition into the Information Age—albeit a pattern still primarily determined by and focused on health care providers and their supporting suppliers of products and services. With a touch of hyperbole, the parenthetical reflection characterized this as goldrush—panning for glinting advance in science, technology, profession and industry! This has treated the data subject as a resource for serving those ends, rather more than as a person to be supported in relation to their wishes and needs for intervention and support. A new balance is needed that supports and enables people to cope better in what matters to them, as active and responsible citizens, and partners in their own health care. This chapter charts this ambition—one of an information utility centred on the needs of individual citizens, and the professional and public services they directly engage with. It explores the perspective of what this utility should look like, and why. It profiles some key pioneers encountered along my songline and their pioneering endeavours to build better information systems.

Past problems have resulted from a combination of failed traction, exacerbated by rapidly obsolescent technology, proprietary enclosure of both data and method, and failure to learn. Chapter Nine will make a case for the pooling of knowledge and a better balance of local initiative and community-led governance with national policy that concentrates on enabling and supporting methods and services which can and need to be shared, nationally and internationally. The foremost of these requirements is for a platform for capturing coherent, mutually consistent and sustainable care records, specified independently of technology or supplier of technology. It seeks thereby to chart a realistic and affordable path away from the burdensome accumulated legacy of non-coherent, unmaintainable, unduly expensive and progressively unsustainable information systems and their supporting infrastructures and services.

As tracked in Chapter Seven, the digital care record has been serially reidentified as the principal challenge of the field, since the 1970s—the *sine qua non* of progress. The reasons why it has serially disappointed are manyfold. The challenge, as so often in the quest for computerization, is not essentially technological. It goes to the heart of how to express, enable and support, in a computable form, what medicine and health care are, and what they do. It is then a challenge of how this reality is managed and governed. The problems thus ramify throughout the personal, professional, scientific, social, managerial and industrial domains of health care. They probably could only have been gripped successfully, centrally, at the professional level, and this has never happened or, indeed, been seriously attempted. The 1990s UK General Medical Council perspective of *Tomorrow's Doctors*,

that I introduced in Chapter Seven, which was considered a landmark of policy of the time, scarcely touched this issue.<sup>4</sup> Almost by default, it has fallen to be picked up and picked over by a mix of industry, academia, national government and international bodies; very often by people who are working at a distance from the everyday realities of health care services, science and technology.

The professions of health care must recognize a greater sense and measure of responsibility to chart and lead implementation in, and learning from, this central field of endeavour, and failure, hitherto, to do so, effectively. And policy makers, more widely, must likewise recognize the failure to understand and manage the unruly and ruinously expensive, burdensome and wasteful aspects of the scene that has unfolded. Rather than a cutting to the chase, it became something of a wild golden-goose chase leading and following into Topol's Shallow Medicine.

Here is a slide I used at a Medical Research Council (MRC) conference some fifteen years ago, seeking to flesh out strategy for tackling the challenge of implementation of digital care records:

The slide is titled "What should we do?" in a dark red font. It features a blue vertical bar on the left and a yellow horizontal bar on the right. The content is as follows:

- Re-adopt an experimental approach, rooted in the needs of individual patient care
- Negotiate a shared mission, as the basis for strategy
- Clearly differentiate what we know and know how to do, from what we need to know but don't yet know how to do
- Work to bridge the gap, in terms of:
  - Capacity
  - Partnership – across sectors, international
  - R&D
  - Infrastructure

Fig. 8.1 A slide from a Medical Research Council conference presentation on health informatics. Image created by David Ingram (2010), CC BY-NC.



4 General Medical Council, *Tomorrow's Doctors: Recommendations on Undergraduate Medical Education* (London: GMC, 1993).



I also used Maurits Escher's (1898–1972) lithograph, *Ascending and Descending* (1960), which, on this occasion, I interpreted as depicting zero sum, disjoint endeavours.<sup>5</sup> Problems arise when central and locally driven policies and approaches, top down and bottom up, run contrary to one another, and become out of kilter and out of step. The ascenders and descenders in the optical illusion keep passing one another by and go round in circles! I described optimistic and now widely implemented, but then still highly experimental and exploratory, ideas for creating and pioneering a new way forward—that of openEHR. These are delineated in Chapter Eight and a Half. The ideas have evolved, improved and gained traction over thirty years, and now demonstrate global community and uptake. They have combined iterative and incremental clinical engagement and grounding in both mission and method, technical rigour in specification of implementations, and a culture of open sharing and demonstrated sustainability and affordability. They have not been created top down, they have evolved from and on newly created common ground, predominantly as an expression of wide-ranging health care related community motivation, effort and commitment. They are parables of what money and power cannot create or buy, and yet society needs and will depend on for its future health care.

Such initiatives show how it is possible, now, to restore ownership and stewardship of care records to where they belong, close to the people and communities they describe and to which they belong. They aim to position the uses of the data, such that it can accumulate value for all people and in all services, and rather does not isolate and fragment them. These initiatives have created a template example for future creativity in building a coherent and connected open ecosystem of care information as a utility–applications and data built on a technology and vendor neutral platform, that can be freely adopted, implemented, evolved and sustained, over time. This is particularly crucial in the health care domain, a quintessential example of a field for which lifelong coherence of personal data matters, as its lack can cause great harm as well as avoidable cost.

For health care, the ecosystem of information appliances and information utility that Joel Birnbaum envisaged, as discussed in Chapter Seven, might be described in simplest terms as an enabler of the best achievable and affordable health care services, for all concerned. In this, it must connect methods, devices and systems that function efficiently and effectively together, with outcomes that are useful and affordable, for individuals and for society, and with participation, oversight and regulation that is fair and

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5 M. C. Escher, 'Ascending and Descending', *Digital Commonwealth*, <https://ark.digitalcommonwealth.org/ark:/50959/3r076s51v>

appropriate. The success of this information utility will depend on the values and principles that it embodies and the manner in which it approaches its implementation and governance.

The present-day landscape of health care information systems comprises a legacy of disjoint and bespoke systems, closely integrated with complex and still current workflows of health care services that are becoming increasingly cumbersome and unsustainable. This is costly, wasteful and inefficient, and it clutters and distorts the scene. It is a pattern that has accumulated widely across society, well beyond the health care domain. We can achieve systems supporting health care services that are, by far, more effective, affordable and adaptable than have been achieved, to date. There are now technologies and tools available to be deployed to this end, that are considerably more powerful, flexible and accessible than was imaginable at the start of my songline. This chapter focuses on what this future utility should look like. The half chapter gives examples to illustrate progress in how it can be created—iteratively, incrementally and sustainably.

It remains an open question as to whether society can and will succeed in such an adventurous mission—to create a coherent and citizen-centred information utility that supports current and new services and ways of working, where technology now enables us to make and do better, while not damaging what was well made and done before. It is an open question because information technology has both transformed society and exposed and exacerbated its weaknesses and vulnerabilities. It has been explored and exploited, and society has adjusted to life like that. *Zobaczmy [we will see]!*<sup>6</sup>

But along with the political scientist, Robert Putnam, and knowing well the oncoming generation of our own nine grandchildren, I am decidedly optimistic on this score. In his book, *Upswing*, published in 2020, Putnam characterized the past sixty years in the United States as social downswing, which he described as a movement from ‘we to I’.<sup>7</sup> This era coincided with the arrival of the Information Age. In those decades, information technology transformed institutions and their working methods and exposed them to destabilizing and destructive forces. What was promised by IT-toting canvassers at the front door, to enable better ways of connecting, working and integrating, has, when let in through the back door, created a new mess and destabilized the household. And some canny operators called at the front door to divert our attention, while their accomplices crept in at the back door to rob us!

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6 On this Polish expression, see Preface.

7 R. D. Putnam, *The Upswing: How America Came Together a Century Ago and How We Can Do It Again* (London: Simon and Schuster, 2020).

For many, life has indeed evolved for the better, but many have encountered new burdens, fragmentation and isolation in their lives. Putnam's extensive research and collation of national and international trends and data charts that sixty years of upswing ('I to we') from the turn of the twentieth century, which was followed by sixty years of downswing. Countries do not move in phase with one another, but one might reflect that, in his perspective, we may be at another social tipping point, where transition from today could, as he believes it will in the USA, coincide with a new era of upswing. In this era, a care information utility can be a powerful tool and motivator of a future healthy and caring society, helping to put right the health inequalities that have become entrenched and exacerbated—in the United Kingdom, as characterized, from William Beveridge (1879–1963) to Michael Marmot, in the past sixty years of Information Age downswing.

We need, now, to think ahead, and differently, about the environment in which the envisaged information utility will grow and operate. First, we must differentiate infrastructure from utility. The quality of the utility will depend on the quality of the environment of which it is a part. This includes, but is much more than, its infrastructure. The meanings and values ascribed to the information utility for health care are human and social in nature. The present-day divided and overburdened environment of health and social care has not been a good or easy environment in which to engage in radical information engineering.

In this and the following chapter, I imagine in more detail what an information utility and environment in which patients and professionals are partners, co-creators, owners and sharers of knowledge and capability, that can gain traction in creating a pathway into practice, would look like. We are, perhaps, halfway towards making this a reality, as I conclude in Chapter Ten.

In my Dreaming, I think first of care information utility as a forest ecosystem. Forest ecosystems illustrate many aspects of mutual creation, sharing and enhancement of common resources. Both are integral with life and living and evolve organically. In our times, the realization of a new forest ecosystem and utility has depended heavily on the motivation and mobilization of volunteers. Like forests, information utilities have communities—those that create, nurture and sustain them, and those that search, discover and consume them. They have an architecture of structure, function and connection.<sup>8</sup>

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8 Having first written this chapter in autumn 2020, I later discovered and read Suzanne Simard's wonderful book, published in May 2021, entitled *Finding the Mother Tree: Uncovering the Wisdom and Intelligence of the Forest* (London: Penguin Books, 2021). This is a story about the forest ecosystem, based on her experience

In my second dream, I think of information as a currency, exploring the human ecosystem of money. Here I discuss Mervyn King's analysis of the reasons for the near collapse of the world monetary system in 2008, and his urging of the need for new ideas to guide its recovery. My purpose here is to see what light this history may throw on the ecosystem of information, and the need for new ideas, there.

These two dreams are quite lengthy detours in the storyline of the book, drawn together in the succeeding sections, which provide fresh perspective on the recurring problems and failures in the health care information ecosystem. Here, and in Appendix III,<sup>9</sup> I describe how fragmented policy of the past fifty years has been framed and implemented by government, how this has played out in practice and the impediments faced. I draw on examples of great pioneers of the field and what they achieved, the environments in which they worked and how they approached their work.

The chapter then looks ahead to the factors now shaping requirements for a health care information utility, focused on the needs of citizens in their global village lives and in the rapidly evolving landscape of knowledge and discipline, professional practice and education, more widely. I highlight Richard and Daniel Susskind's advocacy of shared practical expertise as the common ground of professional-client relationship in the future, 'where our collective knowledge and experience, insofar as is feasible, is nurtured and shared without commercial gain'.<sup>10</sup> I also connect with Ivan Illich's (1926–2002) 1970s, pre-World Wide Web, vision of a web of shared resources for education in a 'deschooled' society. The chapter closes by suggesting the pattern of culture, principles and approach that will be needed to underpin the creation of this utility, and the common ground on which its ecosystem can grow and be sustained—open and common ground, on which its success will depend. The challenges of standards and standardization of this common ground are discussed, and the chapter concludes with a reflection on how information utility connects with changing balance in health care and society today, from 'What is the matter with?' to 'What matters to?' its citizens.

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and foundational research of several decades, from childhood in a family and community of foresters in British Columbia to her status now as a world authority on forestry. I describe it further in the section below. I, too, grew up in remote countryside, amidst woods and trees.

9 Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

10 R. E. Susskind and D. Susskind, *The Future of the Professions: How Technology Will Transform the Work of Human Experts* (Oxford: Oxford University Press, 2015), p. 307.

## Infrastructure and Utility

The term infrastructure embraces a wide range of facilities that support everyday life. We call the services they deliver 'utilities', as they are widely used and useful. We hear the term used in many contexts: local roads, national railways, national electricity grids and gas pipelines and satellite communications networks. With the pervasive spread and flow of information systems and services, linked through the Internet, information itself has become a utility. Such utilities extend into every home and engage us all in the way we live our lives. As such, they are much more than the physical infrastructures through which they reach us and affect our lives.

It is important to differentiate the utility from its associated infrastructure. The distinction parallels that of structure and function of systems, more generally. Computer programs have often mixed the two in a disorderly manner—such overlaps bedevil their clarity, coherence and sustainability.

Utilitarianism is a school of philosophy that focuses attention on usefulness, in terms of the achievement of as much good as possible for as many people as possible. The movement was pioneered by Jeremy Bentham (1748–1832). In reaching decisions among multiple options, policies must come to terms with differences people have: about what is good to achieve, who creates and who benefits. Statistical methods in decision theory use the term utility as a measure of achieved outcomes, combining the value each possible outcome would deliver and the probability that it will occur in practice.

In simplistic terms, utility might be thought of as about meaning—what it means to have shelter, security, clean water, reliable communication systems and good health care services. And infrastructure is, likewise, about method—how we create and operate the utility. The principles that determine the goals and framing of a utility underpin the requirements for and operation of its associated infrastructure. These principles cannot be described in the language of infrastructure. Specification of infrastructure is subsidiary to the purposes it serves and the requirements it must meet. Information utility and infrastructure for health care function and connect within contexts of discipline, profession, community and governance. They must mesh smoothly as they are connected at the hip (in the Health Information Platform, that is!).

It is in the language of health care purposes, values, meanings and choices that we must express the requirements that the infrastructure is designed to meet. There has been a plethora of competing orchestrations of these requirements and their associated roles, responsibilities and accountabilities. As a result, the design and performance of the information infrastructure has embodied a motley, and ever-changing, collection

of skills, instruments and tunes—a centre-stage, out-of-tune and often wrongly blamed orchestra, lacking conductor and lacking score. It has not scored well!

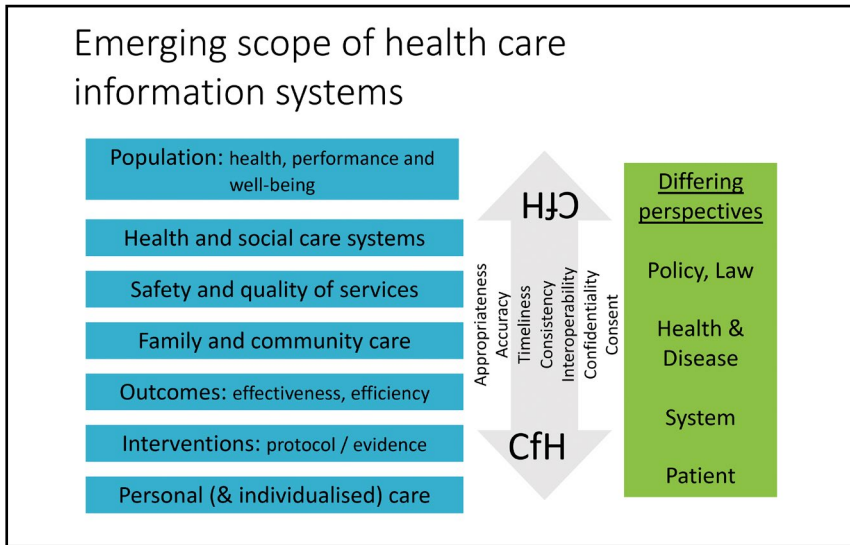


Fig. 8.2 The scope of health care information systems—domains served, regulatory perspectives and expectations of the quality of data encompassed. Image created by David Ingram (2010), CC BY-NC.



The left of this slide (Figure 8.2) depicts the scope envisaged for IT infrastructure seeking 'connection for health' in health care. The different perspectives in play are depicted on the right. And the expectations of their combined orchestration are featured along the arrow. Nowhere was there evidence of a coherent, rigorous, engaged, resilient and dependable plan and design for data and information flow—encompassing how, when, where and why it is used and governed, and by whom.

Infrastructure is difficult to create and manage. It is historical and circumstantial, not all about gleaming new and fast railways. I used to use this amusing story to illustrate its legacy (see Figure 8.3).

## Infrastructure has historical context!

The historian, Norman Davies, in his book *Heart of Europe - a short history of Poland*, discusses the post-war task of integrating the people, institutions, and traditions of Poland's disparate elements: five autonomous regions, 4 languages of command in the army, three legal codes, two incompatible railway gauges.

He recounts the apocryphal tale of an ex-Austrian officer who had to consult his French army manual before telling his ex-Russian infantry men how to load their ex-English ammunition into their ex-German rifles!

This is legacy health care data and IT infrastructure writ large!

Fig. 8.3 A military analogy for the challenges faced in harmonizing and integrating disparate infrastructures. Image created by David Ingram (2002), CC BY-NC.



The challenge of creating coherent information infrastructure for health care systems is all there! This kind of challenge has faced us all in our everyday battle to keep our domestic IT functioning and up to date. We throw a lot away and bear our losses, but this is not an affordable or manageable option for health care services, in what we buy and implement there, lacking coherent requirement, scope and definition.

Whole industries engage in providing and maintaining infrastructures. Some are owned and operated in the private sector, subject to legal regulation where quality and availability are matters of legitimate public concern. Some are owned and operated in the public sector and others involve partnership between the two. There are choices and consequences implicit in each model chosen, depending on social, technical and economic context, political culture and need.

As Birnbaum remarked in his lecture at the Royal Society, when discussing the concept of information utility, infrastructure is most successful when least noticeable. The nervous system is in a way an information infrastructure and it, too, pulses away largely unnoticed, unless alerting us by design (that

frying pan is hot!) or in malfunction (a sectioned nerve has paralyzed an arm). Physical infrastructure declines, visibly, with age and use. Poorly or inadequately functioning infrastructure becomes obsolete and burdensome, and this is widely noticeable by its users. Disjoint implementations impose scalar sum burdens on services and vector sum benefits for health care. Two scalars of equal size, sum to one scalar of twice the size. Two vectors of equal size, lined up and facing in opposite directions, sum to zero.

Birnbaum argued for the benefits to users of switching to a focus on information utility and information appliance, as I used to summarize with this slide:

## Benefits for users of an information utility

- pay by usage
- controlled obsolescence
- simpler, better collaboration
- applications by composition
- large scale distributed experiments
- families of communicating appliances for almost all aspects of how we learn, work and play

Joel Birnbaum, Royal Society Lecture, April 1999

Fig. 8.4 Advocacy for information as a utility—adapted from Royal Society lecture, Joel Birnbaum, 1999. Image created by David Ingram (2010), CC BY-NC.



Pervasive information utilities have enabled considerable social and economic gains: in education and research, delivery of products and services, access to knowledge, opportunity for personal enrichment and group participation, collaboration and cooperation. On the flip side, they have become easy targets of manipulation and corruption, channelled through rampant social media, with their owners and operators pervasively powerful and their brands profiteering. New challenge to equity has been described as a ‘digital divide’, separating those able or unable to use and benefit from information technology. It is a paradox of our times, that being more connected, digitally, has become associated with becoming more divided, socially.



As reflected in the anarchy that has reigned, and the inequalities and inequities that persist, the Information Age is shaking the foundations of the ways we live, as Whitehead said major transitions always do. There is a blizzard of alternative choices, meanings and ideas of goodness, and even 'alternative facts' have made an appearance. Bertrand Russell (1872–1970) believed the basis of knowledge to be truth and believed in facts. As a mathematician and logician, he had a precise reasoning mind when discussing these matters. In health care, personal meanings and contexts matter and influence strongly. And as ever, 'what is true' and 'what to do' are inextricable, but not so much Russell's area of expertise. As recorded along the timeline of Chapter Seven, the context and balance of personally and professionally managed care has shifted in the Information Age, with burden of disease more chronic. Once quickly terminal or intractable diseases are now more manageable and survival times longer.

Observing the credulous 'e-counselling' interactions of colleagues at the Massachusetts Institute of Technology (MIT) who were using his ELIZA program, Joseph Weizenbaum (1923–2008) became fearful of human gullibility and error in relation to machine intelligence and personal communication. There was, he said, a hidden context that deceived and misled them. He wrote as follows:

Claude Shannon showed that even in abstract information theory, the 'information content' of a message is not a function of the message alone but depends crucially on the state of knowledge, on the expectations, of the receiver. The message 'am arriving on 7:00 o'clock plane, love, Bill' has a different information content for Bill's wife, who knew he was coming home, but not on precisely what aeroplane, than for a girl who wasn't expecting Bill at all and who is surprised by his declaration of love.<sup>11</sup>

Just as human communication depends on understanding human context, computer representation and reasoning with knowledge depends on appropriate and relevant machine capture of human context and meaning. This is of considerable impact in the socially connected, biologically and clinically diverse knowledge and actions of health care. For those in need of support, the boundaries between different fragmented agencies can easily become automated barricades and bureaucratic filters, disabling rather than enabling and supporting lives.

The management of publicly provided infrastructure and utility requires cooperation across many levels of organization and governance. Government spending involves choices: about method, distribution and money. In turn, it

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11 J. Weizenbaum, *Computer Power and Human Reason: From Judgment to Calculation* (Harmondsworth: Penguin Books, 1993), p. 209.

involves choices about the capability and capacity of those who provide and receive services. Constrained within finite time and resource, information for health care exhibits considerable complexity. Taming that complexity is technically and organizationally essential, while remaining clinically and socially unpredictable and potentially harmful. This intrinsic uncertainty is a principal reason why information utility and infrastructure for health care have proved so difficult to scope, design, build, operate and sustain.

And in this anarchic situation, politics, both local and national, as the art of the possible, is stretched to its limits. Those at the top of the political ladder sometimes express themselves as feeling powerless to lead and influence how policy aspirations and goals are implemented and play out in real life. It seems appropriate, here, to think more widely about the information ecosystem. First emphasizing its organic nature, through analogy with the forest ecosystem, and then as an impersonal data stream, through analogy with the monetary system. I build from these parallel Dreamings, to prescribe core elements of a future information utility and infrastructure centred on care records. The analogies are not perfect—none such are—but their comparisons throw light on the ecosystem of information utility. When one looks at the fractal structures of data persisted in care records, and their intrinsic variability from case to case, as they grow over time, and from time to time, one sees a mirror of the basic and repeating patterns of plant growth. It is a difficult challenge to build faithful and tractably useful computer software representations of this dynamic form and complexity. I am in no way suggesting that such software is itself some kind of mystical organic entity. I am using the analogy to emphasize that the information it processes is mirroring whole living beings. We must choose carefully how we seek to implement this reality in a machine.

## Information Utility as Organism—A Connected Forest Ecosystem

The forest is not a collection of entities [...] it is a place entirely made from strands of relationship.<sup>12</sup>

The connection of information utility with forest ecosystems lodged in my mind over the past decade, as the largest new forest in the UK was being

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12 D. G. Haskell, quoted in M. Popova, 'The Songs of Trees: A Biologist's Lyrical Ode to How Relationships Weave the Fabric of Life', *The Marginalian*, <https://www.themarginalian.org/2017/12/08/the-songs-of-trees-david-haskell/>; see further D. G. Haskell, *The Songs of Trees: Stories from Nature's Great Connectors* (London: Penguin Books, 2018).

planted, just five kilometres from our house. Heartwood Forest, as it is called, is an initiative of the national Woodland Trust charity and tens of thousands of volunteers of all ages have planted hundreds of thousands of saplings, which have now grown up to five metres tall. The volunteers were inspired to contribute to a global need for replanting of forest resource, which has been disappearing at the rate of a country the size of Denmark, every year.

Today, as I am tidying the book's first full draft (7 May 2021), I have discovered Suzanne Simard and her ground-breaking work on the ecology of the forest. Her passion for forestry was nurtured from childhood as the daughter of foresters in British Columbia, then focused in her 1997 PhD, debunked for years by the learned in concert with their interested industry parties; she doggedly pursued this work throughout her career, and is now Professor in the Faculty of Forestry at the University of British Columbia and a recognized world authority. Her findings about the declining health of trees and their implications for forestry practice are now mainstream. The practices needed to recover the damage of years of industrial forestry and global deforestation are in their infancy. Her research established the idea of the forest as an organic information ecosystem. The echoes between her story and idea, and the story of breakdown of Industrial Age health care and idea of care information utility as an organic ecosystem, felt compelling and worthwhile to explore further, here.

Imbued with a love of trees and forest environment and the ancient Aboriginal communities that inhabited and depended on them, Simard developed an instinctive understanding of the complex and integrated web of communication and mutual support that different trees and forests embody, and the biological pathways and organisms that constitute this resilient, adaptable and productive network—over time, above and below ground. The journal *Nature* published her original paper and featured it on the issue cover, under the moniker of 'Wood Wide Web'.<sup>13</sup>

Heartwood Forest is located on common land and abuts an area that was once, according to St Albans folklore, the haunt of a notorious highwaywoman, who was seeking to repair her aristocrat family finances by robbing the occupants of passing horse-drawn carriages, hastening north and south, to and from London. She was known as the Wicked Lady and we used to park our car at the Wicked Lady pub that commemorates her exploits, while walking our regimented many thousands of steps a day, in the forest and through the Spring, Summer and Autumn of our Covid year.

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13 S. Simard, D. Perry, M. Jones, D. Myrold, D. Durall and R. Molina, 'Net Transfer of Carbon between Ectomycorrhizal Tree Species in the Field', *Nature*, 388 (1997), 579–82, <https://doi.org/10.1038/41557>. See also Simard, *Finding the Mother Tree*.

It is now halfway to becoming a forest environment, full of trees, vegetation, wildlife, walkers and their dogs, cyclists and horse riders. It includes a newly planted arboretum of all the trees native to the UK and envelops one of the oldest ancient bluebell woods in the country. It has provided afternoon exercise and relaxation to balance the morning writing of this book.

In Chapter Five, I made connections from steam engines to information engines. Here I am making connections from forest ecosystem to information utility for health care. We use metaphors of wood and trees to describe knowledge and meaning hidden in detail-branching data structures, a forest of data and not seeing the wood for the trees. We create and consult maps of the pathways through the forest. Forests, like information systems, have uses and users. They draw together the animal and insect kingdoms and the natural world of fungi, sharing moisture and nutrition across a connected network, embodying both animate and inanimate worlds. We talk of the tree of life and pulp paper from wood.

The trees grow by drawing and sharing resources—water and nutrients from roots and fungal networks below ground, and photosynthesis from sunlight in the leaf canopy overhead, channeled through top-down and bottom-up highways of sap. And likewise integrated are the insects, animals, plants and fungi that co-create the forest and live there, and the humans who are its stewards and users who visit. This is an ecosystem of forest life, with water and nutrients as its currency and the sun's energy as its source. Health care information ecosystems are similarly organic—the information content is akin to water and nutrients, and information flow is akin to a traded currency. In this imagined information forest, we grow trees of knowledge, integrating, sharing and communicating through roots and leaves of electronic interface, energized in computers by electrons of electric current rather than the photons of the sun.

The information utility is a virtual forest, guarded and sustained by information foresters who are its co-creators, sustainers and users. Its role is to provide useful and meaningful connections of trees of knowledge and data. Information is the currency of these connections. Trees grow from and propagate through seeds. Trees of knowledge and data are members of a virtual forest grown from a multitude of seeds, as are the trees, plants and other organisms of the living forest.

In the natural world, forests have grown and evolved, from the ground up. Trees of different kinds and scales have been created, propagated and planted. They have evolved, conditioned by use, time and circumstance. A community of foresters and ecologists, inhabitants and users has emerged, nurturing the forest, and feeding from it. In the virtual forest, we encounter hierarchical trees of knowledge and data, describe their different roots, trunks, branches and leaves, and their mutual affinities and antipathies

towards other inhabitants of the forest—of discipline, function, content and use.

Trees grow from seeds planted in, and drawing nutrition from, the ground. Forests develop as flourishing habitats and engines of photosynthesis and propagation, decaying over time to fallen trees, no longer functional or useful, blocking the way, and decaying back into the ground. Information systems support life cycles of usefulness of information and have life cycles of their own.

Trees and forests that survive centuries, are organic ecosystems held together by mother trees that nurture the young and provide continuity and reliance. Forests are beautiful places. They exist above ground, in ground and below ground. They coexist with the animal and insect kingdoms and their human users. Trees differ—their canopies intersect and cooperate, and roots enmesh and communicate. New trees and old, healthy and diseased, grow, live and decline. All need water and nutrients, share common information at a cellular level and participate in global respiration and energy balance. There is a dynamic balance of sustenance and use. Information systems mesh with ways of living and working, just as patterns of mathematics and information play out in life itself. In the knowledge of their evolving balances and imbalances lies understanding of health and disease, life and death, and ways of enabling, protecting and enjoying life.

In our times, a plan to create forests will acquire and prepare the ground, in collaboration with specialists and volunteers, to choose, seed and plant the trees. It will learn about forestry from foresters, forest ecology from ecologists. And needs, priorities, purposes and feasibility—energy, construction, vegetation, recreation—must be weighed. National and commercial ambition have sometimes confabulated, looked to an imagined future of beautiful forest ecosystem, and attempted to short circuit organic growth. They have brought bulldozers to clear and prepare the ground, killed presumed competing and unwanted trees, destroying the fertile and synergistic habitat of the mature forest that has evolved over millennia. Factory-farmed saplings and full-grown trees outside of their natural ground and community have been craned into place and lowered into holes bored in the prepared ground. Fertilizer spurts early growth and then a weaker kind of forest ecosystem leads to disease and decline. I have seen lines of oak trees alongside airport motorways and in city squares in the Middle East and the water they consume. Many die quickly, unsuited to either location or use. They fail to integrate through canopy, subsoil and roots, and do not become a balanced ecosystem. Expectations, timescales, materials and methods, capability, discipline and the driving sponsorship and management of the enterprise are all found wanting.

The health information utility of today has been driven, in large part, by commercial and managerial goals, arriving akin to the bulldozers and boring machines of the artificial forest. New information utility must be grown foursquare as an ecosystem integral with health care communities of practice, drawing on the connections of people, disciplines, professions and ancillary services, including the supporting industries, that come together to enable them to function as needed and desired. A sound ecosystem can be replenished and supported efficiently. An artificial ecosystem costs hugely, initially and over time, is not resilient and often does not fulfil what was hoped for from it and depended upon. I have seen pedigree herds of cattle producing the most amazing milk, feeding on alfalfa grass at an oasis deep within a life-threatening desert of Saudi Arabia, and hydroponics greenhouses producing useful salad crops, there, too. Careful engineering to match ecosystem with environment and community pays dividends. I will write below of people I have known who have achieved this in information systems.

Simard's story, with its experimental underpinning that fills out her concept of a Wood Wide Web characterizing forest ecology, is transformative in its implication for care information utility. In the patterns of material, energy and information flow that she has lovingly revealed lies an important message for the Information Society. And in her description of the destructive impact on forest ecology of forest management of many recent decades is an analogy of the problems that the machine imperatives of the Information Age have brought in care of the individual and the communities and practices through which it is sustained. In this analogy, the trend of Globalton life might be seen, apprehensively, as a deforested Localton, stripped of its mother trees and the communication and nurturing that sustain health and resilience.<sup>14</sup>

Two further threads illuminate the way ahead towards creation of the care information utility; the first about values and choices, and the second about focus and creation of options.

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14 On Globalton and Localton, see Chapter Seven.

## Paths through the Forest

In 1915, the poet, Robert Frost (1874–1963), wrote a poem entitled ‘The Road Not Taken’. It was for his poet friend, Edward Thomas (1878–1917). They used to walk together. It starts like this:

Two roads diverged in a yellow wood,  
 And sorry I could not travel both  
 And be one traveler, long I stood  
 And looked down one as far as I could  
 To where it bent in the undergrowth [...]<sup>15</sup>

As the story goes, Frost claimed subsequently that it was written in jest, to chide his indecisive companion, who often could not make up his mind about the route they should take and, after the walk, talked with regret about how the route they did not take would have been better. Talking the talk and not walking the walk, as it were! Too much talking and too little walking, or too much walking with too little talking. It is not easy to balance the two. The poem has been multiply-dissected, verse by verse, to cut out meanings perceived by its readers—as with mine, here, as an allegory of choices made when walking through life. Apparently, Frost was taken by surprise by this depth of study of his joke, but he also purportedly said ‘I’m never more serious than when joking’, so, who knows? Literary clowning is sometimes used to camouflage serious intent.

In the case of a walk through some wood, sometimes there is a single bifurcation of the route ahead and sometimes there are more options, all looking feasible to be followed, one at a time, adding to experience in successive visits over time. If we think of the forest as a wicked problem domain, and each walk as an attempt to resolve the problem, each walk changes the available paths, so it may not be possible to retrace or repeat steps. A choice is made, implicitly or explicitly—it is one way or another. Choices are often cast in the light of bifurcation, and decisions line up fifty-fifty, indicating either ‘don’t know’, or, in a style as described by Primo Levi (1919–87), one half convinced of one and the other half of the other, repelling one another to greater extremes of divergent opinion.<sup>16</sup>

These choices are not like the double-slit experiment that pervades descriptions of quantum theory, where the electrons, in some sense, follow a path through both, like a wave of water, and producing a similar interference pattern when observed on the other side. That is hard to reconcile with appearances in other experiments, of the electron as a particle. If the observer

15 R. Frost, ‘The Road Not Taken’, ll. 1–5.

16 P. Levi, *Other People’s Trades* (London: Sphere Books, 1990).

sets out to observe which slit each electron goes through, the interference pattern disappears. The electron as particle view of reality and the electron as wave view, each seem to make sense as interpretations of some experimental set ups and not others. How can theory that is so astonishingly successful in predicting outcomes observed, be so unfathomable as to what it means in terms of the nature of the underlying reality itself? As discussed in more detail in Chapter One, when introducing Robert Oppenheimer's (1904–67) 1954 Reith Lectures, science has to live with that complementarity, about different ways of looking at and reasoning about appearances and choosing between them.<sup>17</sup>

Even poets cannot actually walk along both paths through the wood, simultaneously, to weigh them up. But from a different viewpoint and perspective, maybe from a helicopter, for example, they could experience a pattern emerging from the two, together. Maybe the two taken together in this way would prove a better option than either taken alone. As attributed to the author, F. Scott Fitzgerald (1896–1940), in 'The Crack-Up', published in the *New Yorker Magazine* (1936), 'The test of a first-rate intelligence is the ability to hold two opposed ideas in the mind at the same time, and still retain the ability to function'.

There are choices to be made about the path we take to shape the future information utility, that cannot be avoided. Only by exploring the possibilities in a full and principled manner, can we weigh their merits. We must engage first at the level of principle, express it as simply as we can, and go from there. The following, from the concluding page of Richard and Daniel Susskind's inukbook, which is discussed further below, is about two paths in the road ahead for professional culture in the Information Society. It is about matters of principle. I cannot say it better:

Beyond the professions, there will lie a fork in the road, with two possible routes stretching out. One leads to a society in which practical expertise is a shared online resource, freely available and maintained in a collaborative spirit. The other route leads to a society in which this knowledge and experience may be available online, but is owned and controlled by providers, so that recipients will generally pay for access to this resource and our collective practical experience is enclosed and traded, most likely by new gatekeepers.<sup>18</sup>

Thus far, we have largely been shepherded along route two. The information utility for health care is so intimately bound up with human society that

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17 J. R. Oppenheimer, *Science and the Common Understanding* (Oxford: Oxford University Press, 1954).

18 Susskind and Susskind, *Future of the Professions*, p. 307.



route one should be given a better chance. Here are the Susskinds, again, in their final chapter, talking about living and evolving treasure troves of knowledge, empowering citizens to live healthier and happier lives—my forest ecosystem of information utility:

We feel a great sense excitement in imagining human beings across the board—rich and poor—having direct access to living, evolving treasure troves of help, guidance, learning, and insight that will empower them to live healthier and happier lives. But this shift will not come about spontaneously. It is a goal to which we must actively strive. We must remember that inaction, as well as action, is a choice [...] the potential sins of omission here are too profound to ignore. We now have the means to share expertise much more widely across our world. We should also have the will.<sup>19</sup>

We use the expression ‘my way or the highway’ to express our convictions about paths ahead of us. Highway One encircles Australia. People in retirement sell their houses, buy motorcaravans and live on the road, encircling this route. Božena and I chatted to some of these peaceful and contented folks who we met on one of our holidays there. For them, Highway One seemed a safe and enveloping circle for their lives. I do not know where Highway Two goes to in Australia, but hopefully somewhere safe!

### Hedgehogs and Foxes

Around 1953, the philosopher Isaiah Berlin (1909–97) published a scholarly essay entitled *The Hedgehog and the Fox*, drawing on a classical poem of Archilochus (680–645 BCE), in which he says *Multa novit vulpes, verum echinus unum magnum* [A fox knows many things, but a hedgehog knows one big thing].<sup>20</sup> Berlin used the hedgehog/fox classification to categorize great writers. His readers took it much more broadly, to be allegory of meaning and truth. Matthew Syed, writing in the *Sunday Times*, has Berlin’s hedgehogs reducing everything to one idea and filtering out everything else. His foxes, by contrast, run with lots of ideas in different contexts, seeing how the pieces fit together. He takes Berlin to imply that:

It is psychologically easier to be a hedgehog, but to understand a complex world, it pays to be a fox. And that neither meaning nor truth is contained in bare facts, assertions, datapoints, viral clips and simplistic headlines:

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<sup>19</sup> Ibid., p. 308.

<sup>20</sup> I. Berlin, *The Hedgehog and the Fox* (London: Weidenfeld and Nicolson, 1953).

rather, truth is contained within a context—how one thing relates to many other things, and how parts fit into more complex wholes.<sup>21</sup>

This idea echoes with David Haskell's idea of forests as made from strands of relationship, and to Carlo Rovelli's idea that physical reality is best expressed through relationships. Berlin, himself, commented 'I never meant it very seriously. I meant it as a kind of enjoyable intellectual game, but it was taken seriously. Every classification throws light on something'.<sup>22</sup> So, who knows? I tend to agree with Syed, though.

We all classify when seeking to simplify, make tractable and cast light on complex phenomena. On their walks, Frost and Thomas might have encountered hedgehogs and foxes. I am not suggesting hedgehogs populate one route and foxes another, by the way! Maybe Frost and Thomas are fox and hedgehog, or hedgehog and fox, for that matter. In life, the hedgehog does move slowly and rolls into a bristly protective ball, and the fox does move faster and range wider, some silver and some sly. We have both hedgehogs and foxes in our garden—the hedgehogs live there and sleep at this time of year. The foxes make a lot of noise and visit, sometimes attacking hedgehogs that venture out in winter, as happened last month, sadly.

Where have we got to, though, with these poets and philosophers engaging through jokes? At one rather serious evening gathering, I tried joking about the perceived dualisms and dichotomies of health informatics standards: digitized messages passing between information systems; information models that define those systems; controlled terminologies to capture the content of records. As Berlin said of his fox and hedgehog classification, these informatics classifications do throw light on something, but they are not meaningfully battled as dualisms or dichotomies. They are mixed realities, in need of investigation by hedgehogs and piecing together in context, by foxes.

Health informatics discipline has, perhaps, taken itself a bit too seriously and assumed precision of language and classification beyond what is real in the world of health care. It has become skewered on matters of ontology in description of health and disease, and 'polychotomy' in classifications and kinds of classification of these. Such may throw useful light on, and help organize, the appearance of the scene but are often of less help in navigating the real world of health care needs. More data, of however high quality, does not necessarily equate with better health care outcomes.

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21 M. Syed, 'Piers Morgan's Idiotic rants Reduce Subtle Arguments to Soundbites', *The Times* (24 January 2021), <https://www.thetimes.co.uk/article/piers-morgans-idiotic-rants-reduce-subtle-arguments-to-soundbites-d2zpchbjv>

22 Quoted in R. Jahanbegloo, *Conversations with Isaiah Berlin* (London: Peter Halban, 1992), pp. 188–89.

If we want to reach a tractable consensus between foxes and hedgehogs, we have two choices. Just allow time to pass, hoping to know them better by their fruits, and live with them for now, warts and all. Or seek better understanding of their differences, now, and find common ground between them, on which to chart the path to be followed ahead. Making time the arbiter is not a good idea with wicked problems. These mutate, and evidence elicited to guide choices becomes either irrelevant or remains disputed in its usefulness. We have sometimes made bad choices and reacted like hedgehogs, burrowing into the undergrowth, and digging deeper. Some wily foxes have claimed to be, and camouflaged themselves as, hedgehogs, and vice-versa, which has not helped, either. It has all been very expensive and very burdensome.

A colleague and friend, illustrious in health informatics, who has had a serious illness to contend with in his retirement, commented to me in a recent letter about his observation on the ward, while a patient, of the struggles the clinical teams had with the IT systems in use there. He expressed his sense of disappointment, shared, he said, by other colleagues, that this situation should have pervaded so far and persisted so long, as an outcome of so much effort over his career to build IT systems that would assist in the management of care. He has been mostly hedgehog in his career, and I have been mostly fox. The combination of both, and the common ground they create, is crucial for information utility to become a practical reality.

## Information Pandemic—Parallels with Recurring Crises of the World Monetary System

In his book, *The End of Alchemy*, Mervyn King travelled along the timeline of his career as an economist and banker, latterly as Governor of the Bank of England.<sup>23</sup> He reflected on the origins of recurrent financial crises in world economies. These he described as ‘a long series of financial crises since our present system of commerce became the cornerstone of modern capitalism’.<sup>24</sup> They culminated most dramatically in the near collapse of the world’s banking system in 2008. He diagnosed this failure as primarily a ‘crisis of ideas’, rather than as a technical crisis or policymaking failure and mistake.

His book describes the foundations on which the monetary systems of the world now rest, following the crises of twentieth-century World Wars.

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23 M. King, *The End of Alchemy: Money, Banking and the Future of the Global Economy* (New York: W. W. Norton and Company, 2016).

24 *Ibid.*, blurb.

It is an eyewitness participant's account of how these foundations were shaking, with the banking edifices constructed on them and the actions of those shoring them up, no longer fit for purpose. The tools available and being deployed were, he believed, an alchemy born of a mixture of hubris and pretence of knowledge. He quoted Edward Gibbon on the invention of money in classical times and would surely have appreciated Robin Lane Fox's recent book, also today at my side, in relation to the invention of medicine and the elixir of life in ancient and classical times.<sup>25</sup>

These stories of medicine and money form an interesting conjunction of narratives—about their origins and evolution, and how they are playing out in the Information Age. In our present-day context, they juxtapose the Marmot Reviews' critique of failures of the health system with King's critique of monetary system failures. Today, the admixture of cryptocurrency, blockchain and quantum computation is a new alchemy, challenging and testing the foundations of value, principle and trust on which the systems of money and health care depend. And threading through both these narratives is the story of information.

King's book came out in 2016, eighty years after Whitehead had written *Adventures of Ideas*. When thinking of ideas, it is good to reread the latter's book. Here, we find that: '[Great ideas] start as speculative suggestions in the minds of a small, gifted group' and 'Great ideas enter into reality with evil associates and with disgusting alliances. But the greatness remains, nerving the race in its slow ascent'.<sup>26</sup> Great ideas, speculation, dangerous associates and alliances all connect and resonate with money. What, then, went wrong with the idea of money that had powered society's slow ascent, but then tipped it into 'crisis of ideas' and fast descent? What were the evil associates that overwhelmed the great idea?

Money arose from local trade and barter. It had trusted form, ownership and value in this context. It provided a currency, both to facilitate flow and lubricate trade, and to be distinctive, beyond counterfeit. It opened the way to standardization of prices—everything had a price. It opened the way to markets and exchanges, for commodities, products and services and for money itself. Buyers and sellers shook hands and money, goods and services changed hands, and that is what mattered to their owners and users. Trade and money markets spread, within and between countries, transacted in multiple currencies.

Gold as currency had trusted value and was a natural, cautious choice to underpin money when trust in different currencies and their tokens of value

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25 R. Lane Fox, *The Invention of Medicine: From Homer to Hippocrates* (London: Penguin Books, 2020).

26 Whitehead, *Adventures of Ideas*, p. 25.

came under threat. Money, as King says, is 'stuff'. But stuff happens and in waxing and waning times and situations, the exchange value of money floats up and down, too. Money itself was traded. It was lent and borrowed, at a price, by money brokers. Rather than keeping money under the bed, it was entrusted to banks, banks became brokers in the economy of money, and the economy of trade and the economy of money linked and floated in sometimes tight and sometimes loose equilibrium. Governments anchored these markets and central banks stabilized these equilibria, within and between currencies and underpinned by a bedrock of gold held in vaults.

The citizen carried coin and paper—the paper itself carried a written guarantee of its value in the currency. An ever more intricate ecosystem evolved. In city financial districts, it was transacted on foot between offices and buildings with paper as the trail. Elsewhere, the central bankers lugged gold bullion between stacks labelled for their different owners and held in fortress vaults, to balance the accounts. Profit secured on foot depended on how fast you could run and whether your door knock was answered at your destination. Were you trusted in the transaction?

The computer arrived as a new money broker's runner, with lots of new 'stuff' up its sleeve, poised and positioned to happen in the markets. Over time, profit by computer transaction came to depend on microsecond differences in how fast you could execute trades. Insider trading came to mean inside track in speed of access to the central database recording transactions. I knew some people who designed and coded these systems. They were seeing opportunity and doing a job, but it was coding for an accelerating flux of unknowable futures emerging from Pandora's box.

A global ecosystem of trading has evolved, dealing in money and commodities, debts and surpluses, profits and losses. This system is enacted by quick-witted, unseen, possibly heard shouting traders, who may not always be considered the most trusted or trustworthy actors. This new style of brokerage brought a new scale of breakage. Local bubbles, even those on a South Sea scale, can burst and have global ramifications, much like the rapid spread of Covid-19 infection. The alchemy of chemically immutable gold metamorphosed to alchemy of computationally immutable bitcoin, alongside other strange non fungible tokens of value (NFT).

Money was the utility; the banking system was the infrastructure. It ruled over a complex balance and equilibrium, increasingly fragile, easily disturbed and perturbed. The prices for exchange of food and other commodities went up and down, daily, according to the weather and season. Brokers of insurance mitigated and traded the risks that the traders of money and commodities incurred with these fluctuations. Traders in the exchange of goods and services became ever more adept at buying things cheaply and selling them at a profit, and then in making artificial purchases

and sales, for immediate and future closure of contracts at a net profit. They gambled to buy now, with the expectation of selling later at a profit, as traders always had. They entered into contracts to sell things they did not possess, or had borrowed from someone else, at a price, with a promise to deliver them at some future date. In this set of transactions, they had the expectation that when the time came to make the promised delivery, and thereby close the contract, they would be able to buy what they had already promised to sell, but at a lower price than that at which they had already agreed to sell it, thus securing a net profit.

Bulls and bears of trading markets became adept at exploiting loose equilibria, to push, pull and nudge prices up and down, to their advantage rather than that of the commodity producer and consumer. Multiple markets enmeshed: markets trading shares in company ownership, markets trading the commodities, products and services in which those companies themselves traded, markets trading risk and markets trading money. The alchemy of money transacted on paper and in database records underpinned these brokerages and breakages. The central banks were lenders of last resort, but their gold of last resort was sold, and its role evaporated away, increasingly leaving debt recorded in ledgers and then in databases as the foundation of their trade. King suggested that ‘pawnbroker of last resort’ might provide a better description of the central banker’s role!

Trust became subjugated to global power, brand, and clout, a trade guild tending towards a gilded money mafia. Agile, hard-working, hard-pressed and predominantly honest wits propped up the edifice, as its foundations in trade, trust and equity were washed away beneath. Equilibrium likewise disappeared and was propped up with ever more desperate artifice. It is a large system and has inertia. It is like an oil tanker that cannot be shifted quickly in its course, but it also encounters rocks of stuff that happen and quickly sink it, polluting the economy with the spilling of money. Oil and money, too, have been closely linked! And as I write, now, armies of social media-coordinated small-scale traders tweak the tail of reptilian hedge fund operators, to squeeze their massive, short trades. An army of Davids, slinging billions of ping-pong balls to cause pain and discomfort to well-healed Goliaths, both calling Foul! and Unfair!

King explains the nature of financial alchemy as a product of disequilibrium, radical uncertainty (that maybe translates as anarchy) and the Prisoner’s Dilemma of trust. He proposes policy to raise productivity, rebalance economies and reform money and banking—he calls this ‘audacious pessimism’ and says that if not adopted, rational pessimism will prevail. Weighty reviewers have applauded. Lawrence Summers, who held similar high office in the USA, said ‘Mervyn King may well have written the most important book to come out of the financial crisis’. King argues

that: '[although money and banks] have provided the wherewithal to accumulate capital—vital to economic growth—they have done so through financial alchemy, by turning illiquid real assets into liquid financial assets'. And that 'because they are man-made institutions, they can be reshaped and redesigned to support a successful and more stable form of capitalism'<sup>27</sup>

I am not persuaded by Marxist critique, either, as it does not seem to balance well with crucibles of enterprise and new ideas. But he had a point about the exploitative potential of capital and capitalism. Ownership of money has disproportionately further enriched the richest, spread and sustained more widely and thinly through the middle classes, and impoverished and further disadvantaged the poorest. The landscape of health inequalities mapped in the Marmot Reviews is strikingly parallel. These parallel trends have come together in crisis of the Information Age.

In one respect—probably the most important one—there is a complete parallel. Brokerage in all domains, at all levels, depends, one way or another, on trust. And breakage of brokerage is breakage of the trust that underpins it. Stuff falls apart and the central bank cannot hold. And William Butler Yeats's (1865–1939) gloomy foreboding is that then 'mere anarchy is loosed upon the world'.<sup>28</sup> It is as simple (and complicated) as that! That is where 'rational pessimism' sets in. That is why reform must be 'audacious'.

What would be a good metaphor of crisis of information for the modern mariner, I wonder? Maybe something like T. S. Eliot's words, as quoted on the front page of King's book:

The endless cycle of idea and action,  
Endless invention, endless experiment,  
Brings knowledge of motion, but not of stillness;  
Knowledge of speech, but not of silence [...]  
Where is the wisdom we have lost in knowledge?  
Where is the knowledge we have lost in information?<sup>29</sup>

Why all this diversion and panegyric? What is the connection between money as currency, in the way it has evolved to underpin an ecosystem and equilibrium of trade and exchange, and the ecosystem of health care information—apart from both being associated with sickness of some kind? King called for new ideas about the financial system. What can we see in his story about information as currency in the Information Age? What is the alchemy of information? How is it traded and brokered? What is its role as currency of health care systems and services? How does it differ—what are

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<sup>27</sup> King, *End of Alchemy*, p. 367.

<sup>28</sup> 'The Second Coming' (1919), l. 4.

<sup>29</sup> 'The Rock' (1934), ll. 6–9, 15–17.

the reasons for alchemy of information, and what are the policy levers to enact change?

Health care systems today are both adventure and crisis—clinical and technical adventure, organizational and socioeconomic crisis. Both adventure and crisis have accelerated in the transition into the Information Age. Care information utility is an important key for unlocking the wicked problems arising in this adventure and crisis of ideas in health care. And as with the collapsing bank infrastructure, the infrastructure of information in the health care system is ever more pressed. Health professionals are the runners on foot, and patients and citizens are awash with Weimar Republic wheelbarrow loads of devalued information currency, disgorged, not from bankomats, but from ‘informat’ machines. And everyone else is somewhere in the clouds, devising new ‘informats’, pulling policy levers that connect reliably with expense but less reliably with desired and enduring health outcomes, seeking to regiment the flow.

In ancient times there was little by way of information or knowledge on which to envisage and base an ecosystem of care information utility. Bodies as systems and diseases as disorders were not recognized, and what was seen was believed to be evidence of the actions of mystical deities. Doctors emerged as actors in folk medicine, as Lane Fox well describes,<sup>30</sup> with his delightful whiff of classical pedantry and hauteur! His is the story of the invention of medicine, from the times from Homer (c. eighth century BCE) to Hippocrates (c. 460 BCE–375 BCE) and the classical texts of the *Epidemics* associated with him. These are stories about individual patients and evolving knowledge, clinical methods and record. His account pegs information in matters of health care to its earliest origins. Citizens fell ill and needed care. Their health care was not a matter of barter and trade. Healers treated conditions; it was a service and had a value. The words that went between patient and healer were an exchange and the story of how this translated into a currency of monetary exchange, in ancient and classical times, is told in scholarly detail in Lane Fox’s book. It is an interesting and closely contextualized story.

To describe information in terms of exchange and record, within a complex ecosystem of health care services, and to compare with exchange of money, is an abstract analogy, not to be pushed too far. There are many more dimensions in play. The equilibria that health care systems depend on are multifaceted, complex and subtle. In their origins, though, there was motivation of barter and exchange, albeit sometimes with deities—a good

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30 Lane Fox, *Invention of Medicine*.



sought and a sacrifice made. Over time, doctors stepped on to the pedestal of gods and money changed hands.

Barter and exchange depend on mutual trust and understanding of value. There are many kinds of transactions and relationships in play in health care, dependent on these. They are created and sustained on both sides. The services that exist around us, our knowledge of them, and belief and trust in them, reflect our needs, abilities and desires to either handle tasks ourselves or depend on and commission others to assist us in accomplishing them. These many relationships play out in the context of family and friends and draw on both personal and impersonal services available and affordable to us. This is where information disequilibrium easily takes root. The information experienced in the personal world, and that experienced in the professional world of health care, have separated too far apart. The exchange has lost trust and meaning, and the information system, like the banking system, has become an agent for containing and propping up the disequilibrium. If there is to be greater trust, these worlds must connect better.

It is disequilibrium of the information, not of the transaction itself. At its heart, it is not an exchange of money; money as currency does not capture the value of the exchange to the patient. But of course, it does govern access to and management of services. The industrial age of medicine has created a huge money-based market and economy of health. The result is that approaching towards twenty percent of GDP can be expended in exchange for outcomes achieved that are not correlated well with their cost. The highest in cost among the world rankings of health systems, comes quite far down the rankings in terms of outcomes achieved. Professionals have become entrained as traders in this progressively unequal and unsustainable market. And the recipients of care greatly value the care and support of friends, family and volunteers, which do not appear in the economic appraisals of health systems and the policies adopted for them.

King's book was published in 2016 and the 'stuff' that has happened since—notably, political mayhem, increasing climate concern, viral pandemic and war—can only have compounded his concerns. He articulated his sense of radical disequilibrium in the world economy and the need to move from an economics of 'stuff', born of a time of expectation and trust in achievable equity and stability, to one of 'stuff happens', in an era of disequilibrium and Prisoners' Dilemma, where capacity to cope is as important as capacity to manage. He is powerful in his analysis of the dynamic processes in play, reflecting within structures of economies and markets. He sees information technology and bioscience as positive contributors to new means for rebalancing these structures, in terms of productivity. He does not seek to make any of the connections with health and wellbeing that I have made,

here. To paraphrase King and echo Ivan Illich (albeit I acknowledge, that they would have been rather unlikely bedfellows!), we might describe information pandemic and recurrent failure of national programmes for health care information technology as ‘a long series of information crises since our present system of industrial medicine became the cornerstone of modern health care’. Crisis in health care is, as he diagnosed of finance, increasingly a crisis of ideas that do not gel, reflecting in current alchemy of practice. They are exposed and exacerbated in the burden experienced by professionals and the persisting social inequalities of health catalogued in the Marmot Reviews. Both need deeper overhaul and reform than that of policy and technology.

To what extent is the crisis of ideas that King diagnoses as the alchemy of money one and the same as that in a parallel alchemy of information in health care? Is it crisis at a deeper level, enveloping both money and information, manifested and let rip in our societies from the Pandora’s box of transition into the Information Age? Polemic, again, just to emphasize the urgency of the question, but worth pondering!

King cites four areas in which, he suggests, we require audacity of pessimism, to combat the rational pessimism which he sees as underlying the imbalances at present. He sees rational pessimism reflected in how citizens respond to the economic forces they battle in their daily lives. His focus is on productivity, trade, national flexibility, and is optimistic that a sustainable equilibrium of money and economy can be achieved because of the new potential of technology to improve life for everyone. His four areas are his prescription for restoring value and ecosystem of economy and money. He discusses the paradox of policy, in which, too often, policy focused on short-term gain does long-term harm. Simard’s demolition of forestry policy showed how it resulted in short term profit from timber and long-term decline of timber quality and forest health. King sees much policy as focused on false belief about the nature of the system as a whole. He has clear ideas for the top-down priorities for stabilizing money in the short term but sees these only achieving their ends if there is radical change in life, as seen and experienced from below.

Policy currently aspires, but struggles, to be SMART in its objectives—i.e., specific, measurable, achievable, realistic and time-bound. Those engaged and experienced in its exercise, swing, he says, between youthful, hubristic optimism and aged, tired fatalism. King is in favour of new thinking and strategy based on coping rather than shaping—listening and responding to narrative rather than analyzing and predicting what we do not and cannot know.

Whitehead described ideas as adventures within sociological (human and humanitarian ideals), cosmological (encompassing laws of nature) and

philosophical contexts. His concept of civilization is as a reflection of ideas, expressed in terms of truth, beauty, adventure and peace. How we pursue ideas is as influential as the ideas themselves. We all have our own, different ideas and pursue them differently. He wrote that 'The history of ideas is a history of mistakes. But through all mistakes it is also the history of the gradual purification of conduct'.<sup>31</sup> In life, we talk of costly mistakes and the cost of mistakes in the information era of today are ever greater, because they connect faster and more widely. The mistakes of the financial crisis of 2008 were immensely costly in monetary terms, as are the direct and opportunity costs of information systems that impose burden and legacy, while not delivering comparable benefit.

Reading, once more, King's reflections on money and Lane Fox's account of the invention of medicine, it seems a good point to reflect on reasons why there has been serial failure of policy for health information infrastructure and utility; why these have been so difficult to frame, design, implement and sustain.

Symptoms of these failures are revealed in plans that falter, repetitively, and at different levels of process and delivery, adding a new burden of cost and legacy to already overloaded service capabilities, failing to meet targets, deadlines and budgets. They are, more tellingly, revealed in failure to learn from failure—in repetitive mismatch of aims and aspirations with investments made, teams appointed and approaches adopted. They reflect in the observations in the 2002 Wanless Report, as discussed in Chapter Seven, showing health care far adrift in its use of information technology that is now a *sine qua non* of so much academic and commercial work, and of everyday life.

Continuing this thread, I review what has happened to date and set out priorities for care information utility and infrastructure in the future. I consider how each might connect with life in the evolving global village. The story of serial failure of increasing national investments in information infrastructure and utility for health care in the UK, is set against the timeline of changes in National Health Service (NHS) organization, through some eight acts of Parliament, along my timeline, since 1945. I present examples of leaders I have known, in both medicine and information technology (IT), who have demonstrated and clarified the domain. I link changes to evolving international standardization. To illustrate this thread in the book, I describe examples of integrative approaches to care information platforms and methods, that are starting to emerge widely across the world. I describe the pioneering endeavours on which these approaches have built. This then

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31 Whitehead, *Adventures of Ideas*, p. 25.

leads into Chapter Nine, which addresses how, where and by whom a future care information utility can and must be created and sustained.

## Recurring Troubles of Health Care Information Policy

Health care information policy is an international challenge that transcends geography, language and markets. Its troubles have reflected, and reflected in, increasing imbalance of health care services. They signify what King termed radical uncertainty. There are, today, 2020s 20-20 costs—up to twenty percent of GDP is spent on health care services and up to twenty percent of health care professional staff time is devoted to gathering, managing, using and sharing information, and, as mentioned in Chapter Seven, the Deloitte Consultancy has estimated that over twenty percent of expenditure on health care in the USA is wasted. At a Royal College of Physicians meeting in the mid-1990s, at which we both spoke, my colleague Jan van Bommel estimated the worldwide market for health IT products and services, mainly centred in developed economies with advanced health care systems, at in the region of one hundred billion dollars per annum. This is now estimated to reach four hundred and fifty billion dollars by 2025.

It is not that the problems have lacked priority. Renowned figures in academic medicine have chaired government enquiries around the world. In 2004, President George Bush established the Office of the National Coordinator for Health Information Technology. One of his clinical advisors came to talk to me several times and sent me the very ornate White House Christmas card, which I keep, to impress the grandchildren—though I doubt they are! President Barack Obama commissioned a national effort to improve clinical records. Asked to describe the greatest health care policy disappointment of his eight years at the White House, he said it was the failure of this multi-billion-dollar programme to make progress. Some of the largest and most successful computer companies and consultancies have entered government-created markets for national health IT systems and infrastructure. They come and go, as money taps are turned on and off and the Gartner technology consultancy hype-cycles of new technologies play out.

New computer-based devices and systems to support well-defined activities—radiotherapy, medical imaging, laboratory analysis, patient monitoring and drug infusion systems, robotic surgery—have become enduring success stories. And where these successful devices need to share data, standards have evolved across competing companies, governed by industry standards boards. Successful portable information appliances are scaling to world-wide markets.

Going up a level to the computer systems that integrate clinical work within specialisms, the problems faced are of a different order. In a perhaps extreme example, but used here to illustrate the situation more generally, one might track information for a patient brought by ambulance to an Emergency Department, admitted along with information recorded by the ambulance paramedical staff, *en route*. While the patient is cared for there, procedures are enacted and data is captured and recorded in a departmental record system. These activities may involve data acquired from the patient and those accompanying them. It may be acquired from, or supplied to, other hospital departmental systems, and searched for from further afield. Entries are likely to be registered in hospital-wide patient administration and management information systems. And then the patient is moved to another ward for onward care, and these processes repeat there.

According to one of my long-standing and pioneering consultant colleagues in Emergency Medicine, from the time of their admission to the Emergency Department, to transfer to the next ward, a patient's data has, typically, already passed through some thirty different IT systems. Here, and elsewhere in similar specialist hospitals, there are typically of the order of five hundred different computer systems connecting with patient care in one way or another.

Consider then, that many of these five hundred systems are technically archaic, still ticking and operated by staff knowledgeable about how to use them, but now obsolete. Out of date in meeting present day requirements, lacking in formal specification, based on hardware and software tools, programs and expertise that are no longer available should problems arise—all increasingly difficult and expensive to service and maintain, or replace when they ultimately fail.

Consider another patient visiting London from their home in St Albans, who falls and breaks an arm, is taken to an Emergency Department. Images are acquired, the fracture is set and they and their partner are accommodated overnight as a precaution, then discharged home next day, with an appointment made for follow-up care in the fracture clinic at a district general hospital nearer to their home, to ensure continuity of care. Attending for the appointment several days later, none of the record from the acute event has been transferred to the new clinical team. Consequently, lacking that information, they conduct fresh imaging as a precaution and rebook the appointment for another time. And to get the information into the patient's general practice record, once this episode is resolved, requires further letter-writing, to patient and general practitioner (GP). All this has probably at least doubled the time, cost and inconvenience incurred within the ecosystem, for want of a connected information utility. And it has further exacerbated, commensurately, the information explosion, heating the water

surrounding the cloud data centres placed on ocean floors to dissipate their heat. And the Cloud is accelerating an approaching electrical energy crisis.

These issues also affect private sector services and their interconnections with public sector services—internationally and not just locally or nationally. Due to pressure in meeting demand, there is inevitably a growing mixed economy across all public and private sectors. This reinforces the imperative to build towards a utility focused on the needs and wishes of citizens and their records, and not one centred on providers of services and their needs and interests.

Alongside imbalance and discontinuity of delivery of care has evolved parallel lack of coherence of the information held about care. These mutually reinforce and amplify one another and the burden on health care resource increases. A large amount of money is wasted through inefficiency and duplication of processes, and their knock-on consequences throughout society. At a national level, the picture is of diverse health care providers and workforces struggling to maintain services at a local level, and central services struggling to curate and operate compatible national information resources, seeking to support local services and guide central policy. And the management of all these processes is tied up within financial and legal process and regulation—a similarly ramifying administrative burden ordained to ensure efficient and accountable use of money, that also adds to costs.

There then easily ensues institutional paralysis. Efforts to improve and adapt services have been described by ministers as pulling ‘levers of jelly’, when referring to the edicts issued in managing the current Covid crisis. The Test and Trace service allocated billions to centrally contracted national logistics organizations. It did not work as expected. The quickly exemplary vaccination programme has built on local collaboration—facilities, professionals and volunteers, GP practice by GP practice, district by district, combining local and national logistics and expertise. It has progressed remarkably smoothly, and many can justly claim credit. One thing that I was told had failed, according to the cheerful GP who first vaccinated me, was the central IT records system placed there in support. This had crashed through overload, necessitating paper backup and subsequent keying in of data, and unreliable national statistics about its progress, day by day.

The changing pattern of requirements for health care services exacerbates these problems. New initiatives attract funding and promise benefit. Meetings, conferences and publications about these, very many of which are not pursued beyond prototype, further escalate burden and information explosion across the service. The complexity and scale of the challenges to information policy is easy to describe in stories like this, and hard to deny. In many respects, they are impossible to rationalize and resolve, other than

in an evolving, locally-centred environment and context. This is where the information utility of the future must be created and grown.

A key goal of the examples I set out in Chapter Eight and a Half is that they should exhibit public domain methods and solutions which are of international application and relevance, to engage worldwide communities and assist national developments. They are doing this by creating an international currency of care information, thus enabling local initiatives to build compatible, home-grown systems, or mix and match from commercial markets for products that do not tie their data to technology choice or commercial supplier.

The aim is to seed a new balance of public and private cooperation and collaboration—a diminution of proprietary enclosures of data and an opening of new common ground. There will, I believe, be much greater rigour, engagement and trust in an open ecosystem, and much greater benefit, value and safety in its adoption. I have characterized this as a 10:10:10 ambition—ten times the benefit at a tenth of the cost, and ten times more agility in adapting to change. It is an audacious idea and has long been an unpopular one, at the top and the centre of today's health systems, where big stuff converges. But its implementation has been shown to be tractable and can be and is being made to happen. Its dissemination has started at little and local scale, in small ways, in small jurisdictions, albeit some now involving large-scale industries and whole health economies. Big ideas for little locations—little downside risk and big upside potential.

## Realization of Information Policy Goals

The universal computer of Alan Turing (1912–54) and the lambda calculus of and Alonzo Church (1903–95) established strong mathematical foundations for computer science that have been extended and clarified but not supplanted. The technologies of machines and their handling of data and algorithms have been in continuous and exploratory coevolution over many decades—new devices, new applications, trial and error, compromise and optimization. Very much an art of the possible. Theory into practice and practice into theory. Information systems today reflect organic pathophysiology. Software systems have been characterized as following a progressive downward spiral of entropy accumulation and disorder, only revivable by periodic 'binning' and reinvention. There is all manner of systemic computational disorder lurking inside polished and admired machine-rooms and Cloud data centres, And the cyber mafia know it and exploit it! The e-passport gates in UK airports all broke down for twenty-four hours, three days ago as I write.

Substantial information systems have been constructed on what proved to be rapidly shifting sands of user requirements and available technologies. Over time, many have just about been kept operational and generating revenue, being firmly ensconced in place, and difficult to displace. They have struggled to accommodate ever-changing aspirations and expectations of their users, comprised as they were with inflexible and increasingly obsolete and unsustainable devices and software, held together over time by software patches. Their minders have had little choice but to palliate the malady, which is mostly incurable, for reasons of cost, complexity and logistics of cure. The skills and resources used by the programmers who wrote the original code may no longer have been around. To the outside world, the accumulating incapacity of such systems to perform is obvious, but it evidences an unrevealed pathology. The user has little option but to bear the burden imposed.

Set within these multiple contexts, the serially repetitive boom and bust of five decades of centrally mandated health care information policy, as tracked in Chapter Seven, is a sorry but understandable story. Figure 8.5 shows a diagram I constructed as part of my effort of those times, to give a more positive and helpful perspective on how to promote progress, contain and manage the inevitable impediments encountered along the way, and learn how to do things better.



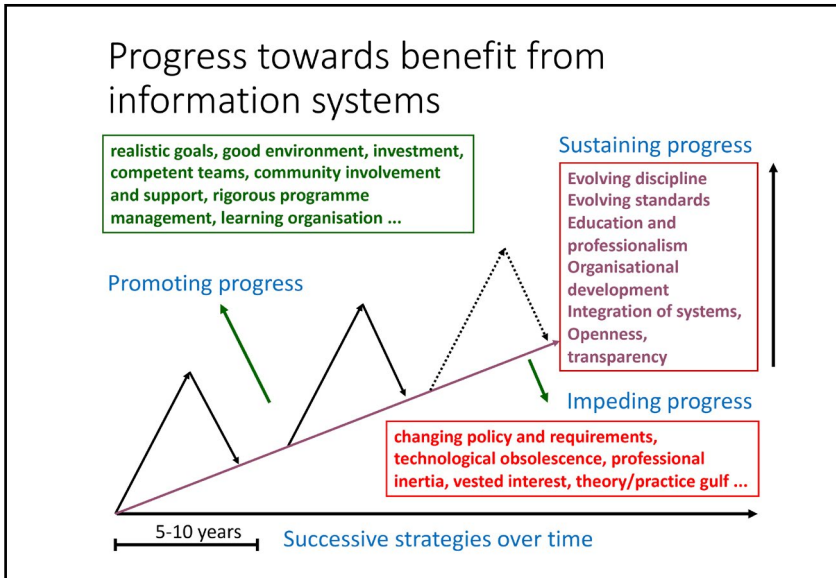


Fig. 8.5 Factors impacting on progress with health care information systems. The sawtooth progression of implementation of information policy—the gradient of improvement, overall, a matter of perspective and debate. Image created by David Ingram (2003), CC BY-NC.



Attendance and participation in many, both local and national activities and events, over many years, confirmed a dearth of motivated and supported communities and environments, near to the ground, in which coherent and useful and sustainable information infrastructure and utility could germinate and grow. The sawtooth of policy initiatives cut through services in those decades and was, at times, brutal, wasteful, costly and largely ineffective. The song about the Grand Old Duke of York and his ten thousand men comes to mind—marching his troops up and down the hill, the top being the summit of central policy aspiration and the bottom the ground level reality of local implementation, often leaving the troops half way in between, experiencing neither one nor the other!

The Portbou railway station process, extending or contracting the separation of wheels on carriage axles and attaching a new locomotive, to enable trains to operate between French and Spanish gauge railway systems, is played out for every train and every elaborately constructed axle, suspension and carriage. We observed it from our friend’s flat, which

overlooked the railway, one way, and the sea, the other. This sort of process plays out, analogously, in standards conversion of information flow within and between information systems. The railway gauge conversion is rather exact—otherwise the train will not work. The information conversion is less sure and potentially riskier, when translating language and mapping information that is modelled differently throughout the system on either side.

The integration of data that preserves semantic integrity between different specialist domains of use has been a continuing problem in succeeding eras of IT systems for health care. It results in uncommunicating silos of data, limiting their utility and magnifying their cost and associated operational burden. It leads to lock-in between buyers and sellers of systems, with intended market competition tending towards monopoly. It limits meaningful dialogue between user and supplier domains. Health care professionals and other users of systems struggle to engage with developers and suppliers of the systems needed for their everyday work. Integration of systems, which require communication between different sectors and specialisms of health care, is impeded when they embody incompatible methods and technologies.

The original innovators of hospital information systems fifty years ago had to build locally bespoke infrastructure before they could create clinical applications, and such applications were, thus, typically limited to working within this local framework. Local application developers today must match their work to local definitions of data and workflows that are specified in terms of locally adopted and implemented infrastructure. Folding new scientific methods—for example involving genomics data or machine intelligence—into these databases and software workflows becomes a very laborious and time-consuming task—often prohibitively so. Aligning to a common, semantically attuned methodology that guarantees implementation within a common platform technology of infrastructure will multiply market opportunity and efficiency for the supplier of systems and increase the flexibility and choice of the user. And information utility all around will benefit and multiply. That is the necessary direction in which we must now shape care information utility. It is not, of itself, sufficient—other aspects of environment, leadership and governance will be central to success, as further discussed in Chapter Nine.

Designers of algorithms and users who capture and use data are now, increasingly, co-creators of programs. The World Wide Web has transformed the computational environment in which these programs are hosted and can connect. We have moved from an era where most of new project money was spent in creating local infrastructures. These progressed from central mainframe set ups to local area networks (LANs) and dial-in

external telephone connections, linking users, machines and applications, and running in bespoke fashion on bespoke systems. We now have hugely more powerful machines, more extensive data stores and more connected networks. This enables architects, designers and programmers of systems to plug and play within network utility, processor and data store utility, and applications platform utility, drawing on substantially evolved software coding stacks and system development platforms. These all contribute towards enabling and causing what was previously complex and difficult to engage with infrastructure to disappear from view, subsumed within everyday information utility.

But much of health care data, today, still does not move through algorithms in ways that respect and reflect their semantics, standardized in ways that signify what they mean and how they can and should be safely and reliably used. In this arena of standardization, the focus of information utility will move to the frontline of health care services—to integrate with the wholeness of needs and attributes of citizens and the professionals and services they draw on and interact with. We have not yet envisioned and enabled a landscape in which that kind of utility can emerge and integrate—locally and globally, and safely—as it needs to do. But we have the tools to help us, and we have examples—used, improved, scaled and internationally adopted and standardized, in practice, showing that we are perhaps already halfway there.

Individual academics are used to defining their information system needs and methods. In their research, they capture and analyze data, build mathematical and computational models, communicate within teams and communities, and access libraries. They customize a personal information utility and infrastructure from shared resources, accessible wherever they are situated. In education, teachers and students interact through the learning resources and platforms used for their teaching and assessment. Some unique to each teacher and student and some shared within wider communities. Both teacher and student can customize and share.

The widely ramifying landscape of health care practice encompasses service, education and research. It extends more widely across the public domain in many kinds of professional and operational connections with management, governance, regulation and law. Health care professionals share this environment within their own and co-working teams, and with those they care for. All parties contribute to and use the underpinning information utility thus constituted. What data means is crucial to these connections and dialogues. And no one has time or inclination to work within multiple different infrastructures and multiple expressions of the same information within different information utilities.

Organizations everywhere have struggled with increasing information entropy, as the many hundreds of progressively obsolete, disjoint systems operating in individual centres of excellence attests. Here, it is the cost and effort of keeping workflow and records in good order that is the worry. Blackford Middleton's team's estimate, many years ago, of eighty billion dollars per annum of consequential cost arising from the disorder in health care information in the USA, even if only very approximate, was indicative of the scale of problem this presents. The addition of personal genomics data to care records, rendering them intrinsically beyond anonymization, adds new technical, logistical, legal and ethical complexity to the challenge. Integrating the burgeoning range of home-based information appliances, to underpin the effectiveness and safety of self-care and hospital-at-home, presents further challenges.

As the world has faced choices in moving to standardization of technology, it faces choices about the semantics of data, not just at the level of terminology and description, but in its clinical context and meaning. This has moved standardization of care records into the realm pioneered by openEHR, in creating and exploring common ground on which to build sound and sustainable semantic interoperability and integration of care records. This has been an uphill quest of thirty years, to develop and implement capability for expressing and communicating the requirements of this coming era of care records, and innovate—clinically, technically and organizationally—to experiment with their implementation as a common ground of care information utility.

We need a utility that captures and communicates the semantics of the data, connects the algorithms that process the data, and makes all the information safely accessible and available for patients and professionals, anywhere, anytime, in their consultations and interactions. We need a utility that does not embody monopoly and respects ethical and legal rights and responsibilities of all participants. We need a trusted utility tuned to continuous, effective, efficient and safe updates and changes, engaging innovation within worldwide community of users and providers of systems—from industry, academia, public and voluntary sectors alike, under trusted governance. The information utility we need will be operable across Cloud and wristwatch, meeting the needs of all its users and organizations. It will provide a common method for integration of the detail and context of health care information, but not be a sole or exclusive engine in implementing these. There will be specialized engines of integration and innovation for research and education. There will be algorithms that are shared, just as physicists unravelling symmetries of particle physics share computational methods.

Governments have focused on painting a picture of what a more smoothly functioning and effective health care information world might look like. As preceding chapters have shown, the grand challenges of data and records remain stated very much as they were fifty years ago, although hundreds of billions of dollars are spent annually on systems that do not yet rise to the challenges then set. Of course, they can show the shiny car bonnets and souped-up engines of today's giants, but these are not on a path to the information utility that is needed, because many commercial interests fear loss of power and revenue if their markets become vendor neutral, and publicly owned and governed information utility and tooling come into contention. New players would, they quite reasonably fear, then more readily and reliably innovate to compete with the well-established, because the new ecosystem of common ground, on which all systems could be based, would enable them to bypass much of the current prohibitive cost of market entry. They would, moreover, have the benefit of a clean slate in adopting the more efficient and agile development tools of today.

But without this common ground, there can be no commonality or community of practice in future care information utility. If achieved, it will simplify systems and enable much more affordable, efficient, effective, safe and useful information resources. Mathematicians support one another by sharing their methods and insights, and thereby mathematics benefits, and indirectly so does society through the science and practice that mathematics underpins and enables. Information utility will likewise rest on commonality and open sharing of method, governance and community of practice. I have given the information utility for health care an acronym, CIU. I invented openEHR as a name and brand that caught on, but who knows whether this might too. CIU and uic, perhaps. Care Information Utility (CIU) with you in charge (uic), placed, owned and governed in the commons of the public domain.

We now need a new community of information architects to bring all this to life, in the spirit of Fred Brooks's advice about systems needing architects. Architects to imagine and lead the building of the CIU. Charles Moore (1925–93), the American architect credited as the founder of postmodernism in architecture, emphasized architecture as an instrument of connection, as a medium to reflect human experience, where occupants must be able to imprint their lives on a building. Norman Foster, the English architect, described architecture as an expression of values, saying the way we build is a reflection of how we live. Information architects are needed to illuminate and lead the way in support of human, not machine, reinvention of health care for the Information Society.

This is certainly an audacious idea and maybe a bit too hopeful! But if pessimists doubt its realism, the default fragmented alternative is far less

hopeful to contemplate. Its purpose and goal is a better and sustainable CIU. It requires grounding in new ideas—about co-creation and custodianship of records, citizen and professional relationships, software architecture and ecosystem standardization, and governance. It must be built on common ground that instills hope and belief in local communities on the ground, where there is, today, much pessimism. Hubristic pretention toned down into a more capable, realistic and humble approach. Hope and pessimism finding common ground in shared creative endeavours, of the kind and quality shown by the outstanding pioneers celebrated in the next section.

## Pioneers of Health Information Systems

My songline has seen some seven eras of NHS national strategies to bring health care services into the Information Age: each replaying a common theme saying why it was needed and promising what would be achieved; each conditioned by prevailing socio-technical attractions and distractions of the times; each dependent on new national proponents and leadership; and all too quickly, mostly running into sand. It would be a task of Sisyphus to catalogue in detail the many pioneering efforts to do these things better that I have observed and participated in during my career. It would be too long and much of it would now be uninteresting and irrelevant. There are other places to dip into this history. The *IMIA Yearbook of Medical Informatics* journal, edited by Jan van Bommel, kept pace for many years, as do the MedInfo publications (conference proceedings from the World Congress on Medical and Health Informatics) and HIMSS (Healthcare Information and Management Systems Society) publications of today, and specialist journals.

My aim, here, is to introduce several amazing pioneers who have been inspirational for me, and whose ideas and contributions have been foundational to how I have come to envisage the nature of the future care information utility, and work collaboratively and internationally, in the public domain, to create the methodology, communities and governance this will require. I describe how they have connected with me along my songline, some very close, and some far away, and the wide impacts they have had. They are contrasting stories of struggle to create the future, seeking to make and do things that will count, and each illustrating different facets of grand challenge and wicked problem, in what they undertook and accomplished.

## Octo Barnett–Massachusetts General Hospital and the MUMPS Language

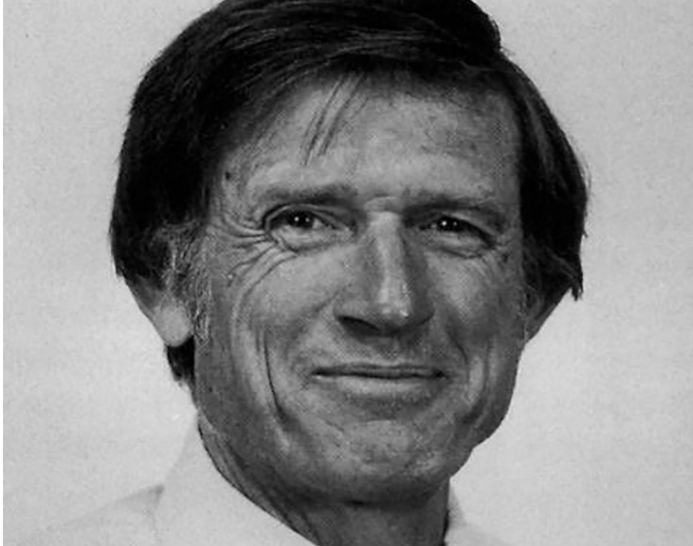


Fig. 8.6 Octo Barnett—clinical and computer science pioneer of medical informatics at the Massachusetts General Hospital and Harvard University. CC BY-NC.

I met Octo Barnett (1930–2020) in his office at Massachusetts General Hospital in the early 1980s and spent the day with him. He was a foremost and celebrated pioneer of his times.<sup>32</sup> It was an honour to spend time with him at that still formative stage of my career in health informatics, much as it had been with Arthur Guyton, a decade before, at his laboratory in Jackson, Mississippi, as recounted in Chapter Four.

Octo knew of my work at St Bartholomew’s Hospital (Bart’s) with John Dickinson and asked to receive a copy of the Mac Series MacMan model of cardiovascular dynamics. He was already a legendary figure in medical informatics and was also active in curriculum change in medical education, linking informatics with the New Pathways Programme at Harvard University. He had been following the graduate entry programme and curriculum innovation at McMaster University, a few hundred miles north of Boston, and I flew there from Toronto to meet him.

Octo immediately impressed with his energy and enthusiasm; his work was an all-consuming passion. Harvard made him a professor in both

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32 ‘Celebrating G. Octo Barnett, MD’, *Journal of the American Medical Informatics Association*, 27.8 (2020), 1187–89 <https://doi.org/10.1093/jamia/ocaa170>

medicine and computer science, in recognition of these twin motivations and driving forces. Along with Homer Warner (1911–2012), at Salt Lake City in Utah, he was a polymath who took the fledgling computer by the scruff of the neck to do his bidding. In the DxPlain system, he and Edward Hoffer took medicine by the scruff of the neck, to shoehorn diagnosis into a paradigm of decision support, mapping from the symptoms, signs and measurements of clinical practice to a guided pathway for diagnosis.<sup>33</sup> In his earlier work centred on computerizing medical records, he learned the practical implications of implementing the requirements for assembling a clinical record, incrementally over time and accommodating the sparse, dynamically changing structure and occupancy of the data collected. These proved extremely difficult to represent and manage efficiently and effectively, using the database paradigms of the era.

Faced with this reality, and displaying great imagination, he worked with Neil Pappalardo and others to create the Massachusetts General Hospital Utility Multi-Programming System (MUMPS) language, with its groundbreaking innovation in data storage and retrieval, integrated seamlessly and efficiently with computation. The MUMPS language was a key that opened doors to practical applications that have persisted to this day, in leading medical record and patient administration systems and, more widely, in financial transaction processing systems. The functionality that their innovation squeezed from the minicomputers and operating systems of the times, was astonishing. The MUMPS language became an international standard. It was a pragmatic and interpretive language, well suited to both its clinical and early technical contexts, and it performed extremely well.

Through the decades from the 1970s, computer science struggled with formal database architecture, going through a long circle dominated by the mathematical formalism of relational database theory, and then gradually back towards simpler, MUMPS-like key-value stores. This evolution tracked transition into the Internet era of networked systems and the need for datastores to accommodate a greater variety of datatypes, of different shapes and sizes, at much greater scale, increasingly less suited to implementations of the relational model.

Programming languages evolved along two principal lines of formalism. A culture war developed between adherents of object-orientation, centred on rigorous representation of data structure, and adherents of functional programming, centred on rigorous representation of algorithm. In the object-oriented scenario, processing of data was incorporated through

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33 E. P. Hoffer, M. J. Feldman, R. J. Kim, K. T. Famiglietti and G. O. Barnett, 'DXplain: Patterns of Use of a Mature Expert System', *AMIA Annual Symposium Proceedings* (2005), 321–24.



methods attached to descriptions of the data on which they operated. Functional programming was the idyl of computer scientists concerned with specification of rigorous and provably correct programs. In this scenario, description of data was integral with the scope of the program language. Each paradigm struggled with the other's principal concerns. Niklaus Wirth's pithy description that 'Algorithms + Data Structures = Programs' held in both domains of formalism, of course. Over time, functional programming languages improved their capabilities with respect to diverse datatypes. The pragmatic world of FORTRAN continued to hold sway in scientific programming, where datasets were more orderly and there was less concern about theory of computation! Greater formality and problem domain specificity arose in languages like ALGOL, PL/1, APL and Simula.

At our meeting, Octo promised to send me the source code in MUMPS of some of the decision support and educational software he had devised with Edward Hoffer, including one that related to my own work in modelling clinical physiology. This guided doctors in managing fluid and electrolyte balance for acutely ill patients.<sup>34</sup> I wanted to see how this might fit within the computer-based learning software platform that John Dickinson, Khursheed Ahmed (our colleague and friend at McMaster) and I were developing (MacAid).<sup>35</sup>

MUMPS code is dense and parsimonious. One of its principal goals was to use data storage efficiently, in handling the very sparsely populated arrays of data which are characteristic of the clinical domain. Another was to fit the program into the smallest possible amount of main memory of the minicomputer on which it ran, so that the programs of more users could be accommodated, simultaneously. The logic embodied in voluminous and rambling code can be hard to understand, and so, too, can be that of parsimonious code, but for different reasons. Algorithms can be artfully subtle, rather as mathematical proof can be. And where descriptors of program variables and processing operations are kept brief, and thereby the length and number of lines of code kept as small as possible, they can be difficult to read and understand.

Octo and his team became past masters of this parsimonious art and, as with many geniuses, had little regard for the reader of lesser brain, seeking to understand their code! To my eyes, it combined all manner of detailed

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34 E. P. Hoffer, G. O. Barnett, B. B. Farquhar and P. A. Prather, 'Computer-Aided Instruction in Medicine', *Annual Review of Biophysics and Bioengineering*, 4.1 (1975), 103–18.

35 K. Ahmed, D. Ingram and C. J. Dickinson, *Software for Educational Computing: A General-Purpose Driver for Computer-Assisted Instruction, Interrogation and System Simulation* ('MACAID') (Lancaster: MTP, 1980).

medical knowledge and data, with program logic reasoning about them, in a rather haphazard way. The program that I analyzed was both a database and knowledge base of the specific domain of fluid therapy. To update this program with changing clinical understanding and practice, would have required understanding not just of the logic, but also of the knowledge and data it was based on at the time, and how it reasoned with them. This looked to be of doubtful sustainability, and so it was proved.

Here, in about 1980, I saw the growing need to separate concerns of data, algorithm, knowledge and reasoning, if software for the field was to prove sustainable beyond the insights and expertise of its pioneers. Another difficulty that started to emerge was a loss of access to the skills and knowledge underpinning the software. Attrition of effort—because of rapid obsolescence of clinical domain knowledge and requirement, available technology and knowledge and skills possessed by program developers—became a significant factor limiting progress in this era of transition.

COBOL (Common Business-Oriented Language) was a hugely successful development for business data processing of those times. Many applications written in COBOL cost many millions of dollars and required much time and effort, to create. They continued to perform essential roles, but, over time, it became increasingly impractical to assemble the machine environment and technical skills needed to adapt them further. They continued as historical artefacts, deployed within newer software ecosystems as binary modules that did what they said on the tin, but could not be changed. This reality may not have been apparent to purchasers, who then receive a painful awakening should their needs not be met in practice, requiring the module to be changed. This occurred, for example, when software was purchased for a major NHS IT project, where a demographics module managing patient details needed to be changed to match UK practice. These considerations arise more widely where obsolete tools and methods render impractical the incremental development of software over long periods of time.

The evolution of methods whereby systems can, more easily and sustainably, be integrated one with another—customized and localized to suit different practice in the user communities served, and updated as science and practical requirements change—is a considerable challenge. One that my involvement with care record architecture has continued to face, since those times.

## Jo Milan—Royal Marsden Hospital and Tertiary Cancer Care



Fig. 8.7 Jo Milan—architect, designer and implementer of the innovative hospital information and care records ecosystem of the Royal Marsden Hospital, London. CC BY-NC.

If ever there was a person who most completely and powerfully epitomized Denis de Rougemont's characterization of the necessary synthesis of head, hand and heart, in his 1936 book *Penser avec les mains* [To think with the hands], that person, for me, would be Jo Milan (1942–2018).<sup>36</sup> Sadly, Jo died from sepsis in late 2018, just as my wife was battling for her own life in intensive care. Jo was my hugely talented and committed friend. He is greatly missed. In temperament and pragmatic mien, he, as physicist computer scientist, and Octo, as clinician computer scientist, were quite alike.

I met Jo in the early 1970s, when we were both appointed to the relatively new Computer Topic Group of the UK Hospital Physicists' Association. Also there, I first met Christopher Taylor. Chris was using the computer to analyze shapes of cells in microscope images of pathology specimens, to complement the trained eye of the pathology laboratory team. Jo was completing his PhD based on pioneering work to computerize the collection and display of ultrasound images, having created the early Rad-8 radiotherapy treatment planning software some years before. I have written

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36 D. de Rougemont, *Penser avec les Mains* (Paris: A. Michel, 1936).

of his pioneering work in medical physics of the era, in Chapter Seven. Here I focus on his contribution as architect of the hospital information systems for the Royal Marsden Trust specialist cancer hospital in London. There is a chapter devoted to this story in the medical oncologist Eve Wiltshaw's history of the Royal Marsden.<sup>37</sup> She was one of his close clinical supporters there.

The Marsden has long been preeminent in science and cancer research, with its connected Institute of Cancer Research. Its information systems enabled and underpinned synergism between clinical service and research. It is, I think, no exaggeration to say that Jo was a cornerstone contributor to the Marsden's pre-eminence, nationally and internationally, as Wiltshaw's book affirms. His massive achievements exemplified good information utility—at the Marsden it worked and flowed and was, in Birnbaum style, substantially invisible. That is, to all but those, like his team and some, like me, among their wider admirers, who knew from whom it came, how it was achieved and the effort it involved.

Jo and I kept in close touch as we progressed through our respective careers. In the mid-1970s, Jo was taking first steps in computerizing the Marsden's information systems. His work on this was conceived, designed, implemented and operated in-house, serving the two sites of the Marsden—one in Sutton, twenty miles from the centre of London, and one on Fulham Road, in central London. Jo worked at the Marsden for the rest of his professional career. He built a loyal and respectful team around him, led them, and supported them. He met and married Sarah, there, and they became family together, and work colleagues, for life—an impressive achievement in itself!

Jo was the most practical of physicists and engineers, whose intellectual life was everyday spent exploring ideas, devices, methods and systems. In later years he was busy making and flying autonomous model airplanes and machining novel kinds of engine, which he discussed with me at length in evening phone calls. Mine are personal reflections on someone who was the most authentic, motivated, diligent and talented of people and friends. He was not at all a saintly figure—he was crusty, emotional, dogged and straight as a die. He argued and disagreed a lot, but only in pursuit of his truth and goals. In the proper sense of the words, Jo collaborated and cooperated. In the words of one of his long-term colleagues, who told me of Jo's untimely death, when we met at an openEHR Foundation meeting in London: he was a boss respected because everyone in the team knew there was no task that he asked them to tackle that Jo himself was not equipped to tackle better!

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37 Wiltshaw, E., *A History of the Royal Marsden Hospital* (Middlesex: Altman, 1998).

Jo started to think about the design of an integrated information system for the Trust, in the multiple contexts of operational management, clinical service and research. At a leading institution like the Marsden, clinical service and research are closely aligned. Clinicians at the Marsden were focused on exploring and describing the time course of innovative treatments and their everyday practice was on the frontiers of research. Cancer was a cause of death at all ages, and experiment in its treatment was essential, albeit carrying risks of its own. In cancer treatment of that era, efforts were devoted to novel methods of surgical excision, radiotherapy and many new compounds and combinations of compounds, that might slow, reverse and eliminate tumour growth.

In a sense, every patient was to an extent being treated experimentally, and was thus a candidate, if consent was given, for inclusion in clinical trials. These are scientific experiments to test the safety and efficacy of new drugs and drug combinations. They are the gold standard whereby new interventions are permitted and regulated for widescale use in clinical services. Clinical trial data and its analysis formed a key plank of medical statistics discipline. Clear protocol for conduct of a trial, definition of the data collected, and analysis of results, was required for ethical approval of experiments involving tests in animals, human volunteers and patients.

Clinical research has long relied on separate information infrastructure from that provided for clinical practice because of the need to record structured, longitudinal data on interventions and outcomes. The hospital focus was mainly on its clinical records and management information system, but a separate clinical research management system was needed to enable clinicians to collect and analyze structured clinical research and trials data for their particular specialties. From the outset, Jo was anxious to avoid duplication of effort by ensuring that, wherever possible, routinely collected clinical data should be made available to the clinical research databases. He envisaged the hospital information system throughout as in need of a coherent and common unifying thread of information. Living every working day as a citizen of that community, he knew this requirement intimately. As a physicist and engineer, he possessed a mind trained and supremely competent in formulating a coherent and consistent model of that information, and the interrelationships of roles and activities represented in all its components—about wards, outpatient departments, diagnostic and therapeutic support services, pharmacy and so on—and in workflow and management, at department and Trust levels, bringing it all together.

Jo knew this world better than any external agency ever could, given whatever resources and deploying whatever skills. He tolerated no blandishments to the contrary. That often meant that ninety percent of the wider world was already against him! Fortunately, under the umbrella of

hospital physics discipline, itself used to adopting a defensive encirclement of its right and need to exist in practical everyday hospital context, he was sponsored and supported to explore and discover where his interest and insight might take him. He and his team created and sustained a unified information system. Jo was its Fred Brooks-style architect. My colleague Steve Pizer was a colleague of Brooks at University of North Carolina (UNC) at Chapel Hill. He and Jo introduced me to the insights of Brooks's book, *The Mythical Man-Month*.<sup>38</sup> In the early days of MUMPS, Jo became expert in framing his ideas within MUMPS code, and in design and procurement of the computer system, network and user devices.

The team sustained and evolved an operational system for the Trust, through successive, roughly seven-year cycles of new generations of design and implementation, while hardware and software technologies and standards underwent a Moore's law pattern of rapid change and extension.<sup>39</sup> They explored a combination of MUMPS and relational database formalisms for persisting their data model and confronted the major issues impacting system performance that were becoming clearer in those times, where optimization of speed and depth of access into complex and diverse individual patient data structures conflicted with performance in searches across all patients and activities. They introduced, in parallel, a database containing just a time-sequenced index of all activities, which, in combination with the full database, solved this performance problem and transformed the system's capabilities. They combined data and programming code in a dictionary of data objects, mirroring the rising object-oriented paradigm of the era. This transformed the functionality and flexibility of the system and reduced the development time and maintenance burden it imposed.

Jo thought through the place of standard terminology, first in relation to the classifications offered by the Systematized Nomenclature of Pathology (SNOP) and the Systematized Nomenclature of Medicine (SNOMED) for pathology of tumours. He used them when he had a use and positioned them where they were useful. He became an early master of the spreadsheet and integrated a spreadsheet module within the analytical functions required for management reporting purposes. His system dealt with almost all aspects of the activities and costs of the Trust, save for the accounts, payroll, estates and personnel functions.

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38 F. P. Brooks Jr., *The Mythical Man-Month: Essays on Software Engineering* (New Delhi: Pearson Education, 1995).

39 J. Milan, C. E. Munt and M. W. Dawson, 'A Model Based Approach to the Evolutionary Development of a High Performance Hospital Information System', in *Medical Informatics Europe '90*, ed. by R. O'Moore, S. Bengtsson, J. R. Bryant and J. S. Bryden, Lecture Notes in Medical Informatics (Berlin: Springer-Verlag, 1990), pp. 457–61.

I wrote in Chapter Five of one striking example where the coherent design methodology of the Marsden system shone. This was in the vetting of the system for Year 2000 vulnerability—a central edict of the NHS at the time was that such a detailed review be conducted. Jo shrugged his shoulders, saying he knew the answer before looking but had to go through the hoops and write a report. What the design of the Marsden system enabled him to verify in seconds—because time computation was carried out throughout by just one tiny, shared object module—required many months of team effort in assessing other less-ordered spaghetti heaps of code, where time computation and other common functions were coded, repetitively, in a multitude of long forgotten places within the programs. A situation sadly typical of many information infrastructures, still, today, and a key reason for the repeating heavy cost and burden on services, of the efforts to improve health information infrastructure more widely.

When I switched from the domain of mathematical modelling of body systems and computer-assisted learning into that of health information architecture, in 1990, Jo and I developed closer working links. Jo was a great mentor and support to me. When he struggled with sustaining and extending his pioneering work at the Marsden, against the management predilection of the times to buy in or outsource IT systems and services (and thereby seeking to avoid the pains experienced in devising and growing local solutions), I helped him through some tough months.

I was working at that time, on getting the GEHR (Good European Health Record) project team into good shape, with Sam Heard commuting several months a year from Australia and me establishing my first academic group, linking clinical skills and informatics at Bart's. In his work, Jo recognized, pragmatically, that patient notes were so widely varied and idiosyncratic, and in many aspects necessarily so, as to defy the sort of information model that was state of the art in those times. He came alongside in the GEHR project and was a great litmus test and mentor of its evolving ideas and progress. In these debates, the separation of information model and data model came into clearer focus. I remember with pleasure him attending the founding dinner of the project where the GEHR partners and the leadership of Bart's sat down together in Dean Lesley Rees's (1942–2022) elegant dining room at Charterhouse Square. Jo was opposite Sam Heard and I gave a speech, sitting with Dean and health authority chairs and Alain Maskens, who, with Sam, had been a leading light in drawing together the GEHR Consortium bid and inviting me in to take the lead. Remembering the powerfully argued debates between Sam and Jo about clinical requirements and relational modelling of data in the form of tables, one the dominant clinician, one the dominant engineer, and both versed in the domain of practice that joined them, I had a good 'in joke' to tell, celebrating their

close relationship across a table! I can still see my mind's image of them high-fiving across the table!

Through Jo, I first met Thomas Beale, a young Australian IT consultant living in England at the time, in 1992. Thomas was developing his skills in using the evolving World Wide Web and building a career in software design and object-oriented programming, well versed in the object-orientation mission of Bertrand Meyer. Jo had employed him as a consultant at the Marsden and these two great minds had already engaged one another, to their mutual enlightenment, I think. Jo, ever the pragmatist, believed that his highly innovative ETHOS higher order software brainchild, running on the two sites of the Marsden, gave the best of object-orientation, flexibility of MUMPS programming and rigour of relational database persistence of data.

At that time, I needed to establish a new paradigm for the GEHR project, for how it conceived and expressed its mission to create a formal architecture for electronic health records, as discussed more fully in Chapter Eight and a Half. This was to be central to how we would subsequently enact the exploratory work and build teamwork and environment around it. It was a formidable consortium, comprising different expertise and interests from clinical professional, technical and organizational management backgrounds, working in academia, small and large industries, and health care organizations. I recruited Thomas as a disrupter, to help with new ways of thinking. I wanted him to bring his knowledge of object-orientation into the mix of methods under consideration. I did not appreciate at the time quite how good and well-adapted he would prove in that role! If I were doing the same today, I would bring a functional programming disrupter to the table—I know just the one!

It was a risky but necessary strategy and felt quite threatening to some, challenging already established teams and relationships within the consortium membership. As described further in Chapter Eight and a Half, I managed to create and sustain a cohesive and committed team through some very difficult years, initially anchored by our physical presence with Sam's colleagues, Mel Salkind and then Lesley Southgate, and the Primary Care Department she led, and my newly conferred professorial status in the Medical School. Also, supported by a superb administrative assistant, Marcia Jacks, who had built her career first as a secretary to the head of Primary Care, then as a departmental manager for me when we later moved to establish the (CHIME) at UCL, and finally as divisional manager for Ian Jacobs's Institute for Women's Health within UCL Biomedicine.

On the completion of the GEHR project, we were facing key issues of how to progress from the GEHR information model to a new care record architecture based on what we started to call two-level modelling. The term



described a methodology yet to be realized. The first level was focused on creating clinician-defined and governed ecosystems of care records, containing all kinds and varieties of clinical data, composed from and conformant with a single generic pattern of clinical data model, customizable according to both clinical discipline and local organizational requirements. The next level was focused on the design of a common and openly specified software platform infrastructure, to host and enable free flow of the content of care records structured in this way, within and between systems designed to generate, store, communicate, process and interrogate these records, to support bespoke and specialist health care domains and purposes. The purposes served and the manner they were addressed were thus to be wholly in pursuit and support of the needs of clinical services, including those to be operated by patients and citizens, themselves, and, likewise, the needs of clinical professionals and their health care organizations. The care record ecosystem needed to be configurable according to local needs, with data structures standardized according to clinically determined patterns, and the specification of the platform for hosting these data kept neutral with respect to its underpinning implementation technologies and suppliers.

This was the new endeavour on which we set to work—Sam and Thomas pursuing a commercial pathway in Australia, setting up Ocean Informatics (now Ocean Health Systems), and me, with Jo and Dipak Kalra, joining forces in the mid-1990s, with Jane Grimson and Bill Grimson, in Dublin, and other partners, to collaborate on the Synapses project. Jo and I devised and wrote the work package that captured this new architecture, expressed through the concept of a clinical object dictionary. Sam and Thomas, in parallel, evolved a very similar idea and christened it an archetype repository. In the subsequent years, these worlds recombined and the rest, as they say, is history—the history of GEHR and openEHR that I tell in Chapter Eight and a Half.

I turn, here, to highlight another highly significant period some twenty years after I first met Jo, and to the report prepared by the National Audit Commission in 2003–04, appraising progress of information infrastructure for the country's ninety-three Acute Hospital Trusts. Jo provided me with the content relating to the Royal Marsden Hospital, which I draw from here. The report focused on the contribution of information systems to the clinical work of these Trusts. It explored: extent of use; clinical value derived, as assessed by working clinicians; progress towards paperless operation; and value for money achieved. I have an original copy—it counts as an inukbook—its message is clear.

## Health IT in all NHS acute hospital trusts c. 2000 - % of information items obtained by paper only

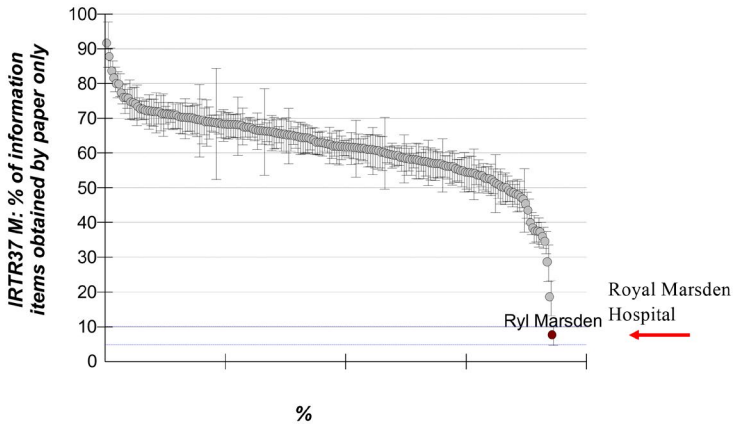


Fig. 8.8 Progress in going paperless: a figure illustrating the outstanding achievements of Jo Milan and his team at the Royal Marsden Hospital. Adapted from the 2003–04 Diagnostic Audit of NHS Acute Hospital Trust IT, The UK Audit Commission. Image created by David Ingram (2010), CC BY-NC.

A widely touted objective of the era was ‘going paperless’. It still is. The report chart from which Figure 8.8 is adapted shows the percentage of information collected only on paper on the ordinate and lays out the amount, Trust by Trust, from the one with the highest to the one with the lowest along the abscissa. Information gathered only on paper comprised less than ten percent of the total at the Royal Marsden. The next most paperless Trust had double this amount of paper-only information. The sigmoid curve is strikingly revealing. The median level of information collected on paper only was around sixty percent and the flat central region showed a range of thirty-five to seventy-five percent in almost all Trusts. The highest paper-only pile was over ninety percent. The Marsden is highlighted in red in the figure, as number ninety-three in the sequence of ninety-three Trusts. As an example of how a picture can be worth a thousand words, this one could not be bettered!

Figure 8.9, also adapted from the report, shows relative value for money obtained—how well the Trusts were doing in obtaining value from their expenditure on information systems, in terms of the amount of information they gathered. Again, the ninety-three Trusts are charted, but in a new sequence, along the abscissa, and the score allocated to each, based on data from the Trusts, is shown on the ordinate, from the Trust achieving greatest

value for money on the far left, towards those achieving progressively less value for money, Trust by Trust, along the abscissa. The red line is used to pinpoint the Marsden's score—it is an extreme outlier in terms of value for money in eliciting information. The data are arranged with a score of zero at the median performing Trust.

## Health IT in all NHS acute hospital trusts c. 2000 - total expenditure and obtaining information

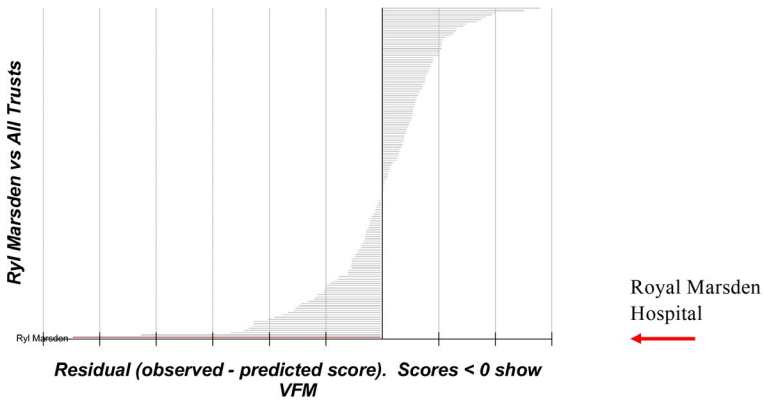


Fig. 8.9 Cost-benefit expressed as information acquired in relation to investment made, further illustrating the outstanding performance of the systems developed at the Royal Marsden Hospital. Adapted from the 2003–04 Diagnostic Audit of NHS Trust IT, The UK Audit Commission. Image created by David Ingram (2010), CC BY-NC.

Figure 8.10, also adapted from the report, is based on attitude surveys of staff in the Trusts about their use of the local information systems. Here, value for money is judged in terms of the ratings provided by Trust users, about their use of the systems and their assessment of the quality and relevance of the information for their work. Once again, a red line is drawn to position the Marsden. Once again, literally outstanding—that is extreme outlier.

## Health IT in all NHS acute hospital trusts c. 2000 - clinical approval and value for money

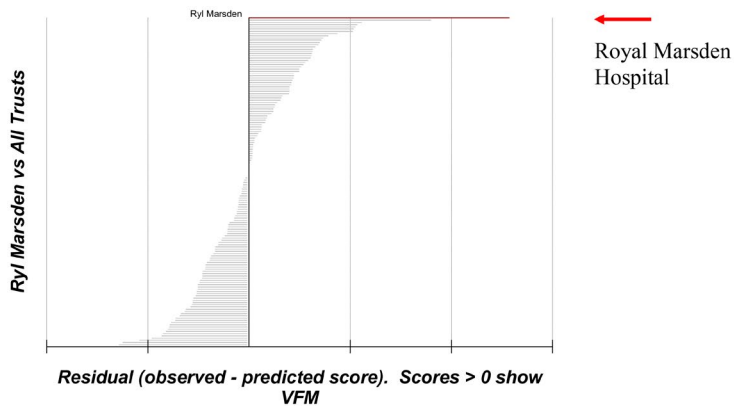


Fig. 8.10 Cost benefit expressed as clinical value perceived in relation to investment made. Illustrating how clinicians at the coal face of care rated the systems developed at the Royal Marsden. Adapted from the 2003–04 Diagnostic Audit of NHS Trust IT, The UK Audit Commission. Image created by David Ingram (2010), CC BY-NC.

Positioning individual cases within such distributions is a good way to express and learn from individual performance. It is useful and effective for good and bad performers alike, in their self-assessment, to take pride in achievement and motivate remedy and improvement of practice. There are important messages here for the wider community. They have largely gone unseen and unheard—not willfully but certainly neglectfully—which is, itself, significant. For me, these messages start and end with Jo Milan as a person—who he was, how he was perceived, how he achieved what he did, how the Marsden systems were designed, implemented and evolved, how they were managed, and how Jo himself was received and treated. He was a tough, highly-skilled and focused innovator—I found a lot of Jo in what I read of the engineers discussed by Samuel Smiles (1812–1904), who I wrote about in Chapter Five.

In a noisy world, a quietly pursued mission and modestly spoken words easily go undetected and unrecognized. It sometimes seems that experimental evidence of an outcome is required before the experiment is seen as credible or to be supported. In the commercial world of technology, innovation follows a cycle of hype—characterized by the Technology Foresight arm of the Gartner consultancy in the rise, fall and levelling off of

the hype cycle. The hype diagrams sometimes look akin to a lightly damped and oscillating, controlled system, with changing target level and feedback signal! In a dazzling world, less visually lustrous images than those capturing Jo's and his team's achievements at the Marsden easily go unseen and unrecognized. And yet these are the hallmarks of the Birnbaum–best when least visible–information utility! In a competitive and argumentative world, some wish neither to hear, see or think about what they do not want to hear, see or think about. Jo's achievement was monumental and heroic. At the Marsden, it was felt but not well recognized by its management team, probably focused more on key performance indicators directed upwards than to what was being achieved locally on the ground. Clinician support, as shown in the above graphs, was more understanding and supportive, as warmly evoked in Martin Gore's (1951–2019) funeral oration for Jo, I gather, which was fulsome in praise and acknowledged that Jo's contribution had not been duly recognized there. His fame spread abroad, but in the national NHS context he was largely overlooked. In Chapter Five, I gave examples of similar patterns in innovators and innovations of past centuries. Jo's story ranks alongside them.

### Stanley Huff–Intermountain Healthcare and Clinical Element Modelling



Fig. 8.11 Stanley Huff–career-long Chief Medical Informatics Officer at Intermountain Healthcare in Utah and architect of its innovative information systems based on clinical element models. CC BY-NC.

I mentioned Homer Warner, the doyen of medical informatics based at Salt Lake City in Utah, in my above profile of the pioneering contributions of Octo Barnett at the Massachusetts General Hospital and Harvard University in Boston, USA. Some of his early work from the 1970s that used a computer-based Bayesian statistical model for teaching clinical diagnosis, caught my eye. One of Warner's academic progenies of the early 1980s was Stanley Huff, who worked over the following decades at Intermountain Healthcare, where he played a notably practical and clinically focused pioneering role in the evolution of its information systems, just as Octo did in Boston. Stan graduated in basic science before switching to medicine, in which he specialized in pathology. In the early 1980s, he worked for a while at Bell Labs before joining Intermountain for the next thirty-five years. An amazing pedigree of synergistic connections of science, IT and medicine!

The team and environment Stan created at Intermountain, and the information system it gave birth to, looked to bear some resemblance to those which Jo Milan created at the Royal Marsden Hospital, in and from the 1970s. Intermountain being a very considerably larger and more wide-ranging health care community, and Stan's initiative being based on close industry partnership for the implementation of systems, they also differed considerably. At the heart of both their systems was a novel approach to rigorous separation of clinical data models from programs, in modelling and implementing a coherent and modular system architecture. The Royal Marsden advances were developed in the public domain. At Intermountain, the methods devised were developed in partnership with the corporate IT private sector.

As with Octo's pioneering work in the creation of MUMPS, Stan's foundational contribution in creating and shaping the Intermountain systems, as both clinician, architect and implementer, was iconic. I do not know how the relationships and associated intellectual property rights were handled in the commercial partnerships, but the general approach in such cases has necessarily been to anchor the IP protection under proprietary lock and key, integral with the contracts between the health care and industry partners. Wider generalization and dissemination of the Marsden systems was constrained by it not having the benefits that derive from a strong and synergistic industrial partnership. This proved impossible for Jo to secure within the UK health care IT markets of the times, and in the context of the subsequent tumultuous management of the contractual framework for procurement of systems for the NHS National Programme for IT.

I have known little of the inside story of Intermountain Healthcare, having had quite limited working contact with the North American scene, but have read and heard accounts of its focus on quality of care. Stan and I met only a few times, in the context of his Clinical Information Modelling

Initiative (CIMI) and discussion about openEHR with one of his industry partners, fifteen years ago. In recent years, my stalwart GEHR and openEHR colleague, Thomas Beale, has developed close working and professional links with him.<sup>40</sup> From what I gathered, it seemed that, in contrast with Jo's situation, an opposite constraint impacted the generalization and dissemination of Stan's work of those times, with industrial partnership in the work limiting options for open sharing of the methodology developed, within the wider health care world. This was not for lack of Stan's personal efforts in the field. He worked hard to shape international agreement and alignment in the realm of standards for health record systems architecture, within the HL7 organization and the CIMI initiative, and in the realm of health care terminology, within the SNOMED organization.

Indeed, one thing that seemed largely to unite commercial interests through those decades was that open anything (especially openEHR, perhaps!) was seen as undesirable for health care record systems, except in support of a niche and non-competing, open-source medical records project focused on adoption in the developing world (openEMR). For year after year, from the time that I was running the website for openEHR from UCL, by far the greatest flow of traffic to the site came from the USA, and this correlated with a parallel and almost complete lack of USA-centred interest in engagement with its open and public domain-focused core mission. This was understandable and justifiable as home patch, market-protecting commercial strategy, of course. It did not bode well, though, for the creation and sustaining of more clinically focused, citizen-centred, mutually coherent, affordable and continuously evolving information systems that became increasingly necessary in support of high-quality health care more generally.

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40 As I completed the book manuscript in March 2023, Thomas told me that he and Stan have joined together in a not-for-profit company called Graphite, which is backed by the US health care providers: Kaiser Permanente, Intermountain Healthcare, Presbyterian and SSM Health. It will build on the Intermountain Clinical Element Models (CEM) as the basis of a trusted and open lingua franca of health care systems. The mission sounds to have much in common with that of openEHR and I hope that may prove the case. The CEM idea is closely analogous to that of the Marsden/GEHR/Synapses/openEHR clinical data object dictionary and openEHR archetype ideas that evolved from the 1980s. Thomas's stellar contributions to this history, now to be pursued within Graphite, places him in a pivotal position to help further anchor the coherence of the health informatics domain, as a global public good and moving forward as a community interest endeavour, under international governance. As an interesting aside, I noticed the carbon ring hexagon of graphite used in the Graphite company logo. The 1992 GEHR project motif, as I created and used it in presentations and brochures of those times, was also hexagonal and emotive of the hexagonal ring of six carbon atoms in graphite (see Chapter Eight and a Half).

Unfortunately, and almost by default, commercial considerations of products, more than health care requirements, have tended to dominate the airwaves of this complex domain. And much time and money have been expended on avowedly collaborative international efforts that get bogged down when contrary national and commercial interests are in play, as they usually are. At the current stage of its evolution, a critical need is for a more inclusive, credible and trusted leadership and governance of the domain, which stems from, anchors and connects the coalface of health care, locally, with government health care and industrial policy and markets for health care IT products, globally. Health care professionals and care provider organizations need to advance their competencies and step up their contributions to this end. Failure in this regard has been a significant factor in the anarchic scene that has emerged in and pervaded health care of the Information Age.

In this quest, it remains a work in progress to discover how best to reconcile currently constrained business models for proprietary products and services in the health care IT marketplace, with governance and funding of collaborative endeavours that seek to create and sustain an evolving and dependable common ground of open specifications, clinical data models, software platforms and tooling, education and training, to enable a trusted and citizen-centred care information utility. Moreover, a shared resource that anyone, in any country and in any native language, is enabled and free to build on in the context of their personal, organizational or commercial health care related needs and ambitions. My collaborations with Jo Milan and Sam Heard were instrumental for me in creating and travelling the foundational years of such an endeavour, in the iterative and incremental creation and development of the vendor- and technology-neutral specifications, clinical models and tooling of openEHR and their international community interest governance. This I envisioned as a necessary enablement of a future information utility for health care, that could grow and prosper, as a global public good.

None of this is achievable by talking, writing and voting. It is achieved by implementing and learning thereby how to implement. openEHR has been an experiment exploring what could be achieved in a comparatively inexpensive and community-driven endeavour directed along these lines, deriving energy and motivation focused on enabling bottom-up 'coopetition' (eliding cooperation and competition). To have any chance of succeeding, it needed to discover ways to embed a culture and mission to collaborate and share methodology, to help the world of health care achieve and sustain greater value from the resources it does spend on IT, in meeting health care need. And to do so more flexibly and faster. Unsurprisingly, holding together the teams, environments and staying power required to remain steadfast in



this ambition and to make progress, has, many times, been touch and go, over three decades! This a theme that I reflect on and take further in Chapter Eight and a Half and Chapter Nine. From the early decades, none of this would have happened without Sam Heard, who I profile next.

### Sam Heard—East London Primary Care and the ParaDoc Practice Management Software

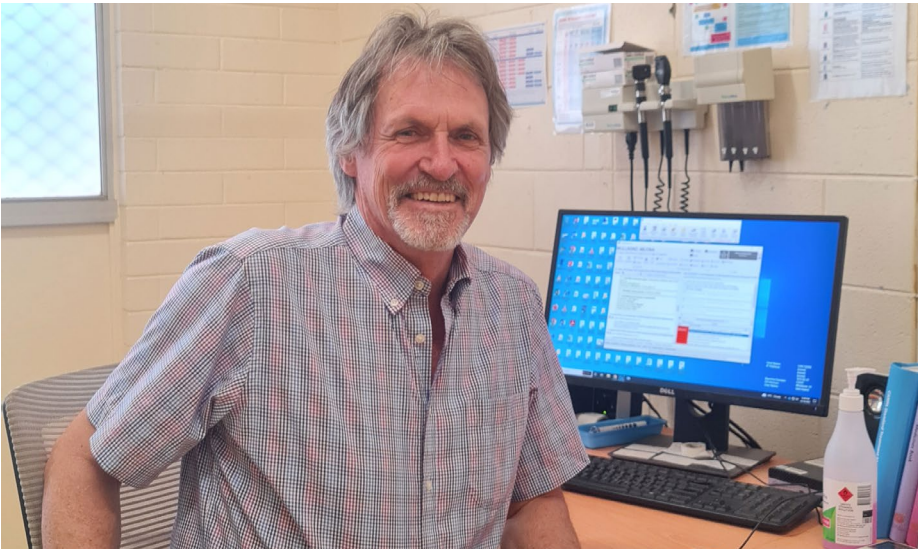


Fig. 8.12 Sam Heard—East London GP and co-founder of openEHR at Bart's, UCL and Ocean Informatics. Now medical director for Aboriginal community health care services in Alice Springs, Australia. CC BY-NC.

Sam and I first met in the early 1980s when he was working as a GP in a newly established practice in Hackney within London's East End. I was in the early years of my academic career in the Department of Medicine of St Bartholomew's Medical College, a principal East London Medical School.

Hackney in those early days was a poor relation of the hugely affluent City Square Mile, situated close by. Its health care services faced many challenges that required bold and imaginative advocacy, resilient and charismatic leadership, and selfless devotion of its champions to the community they served. It attracted highly motivated doctors such as Sam, who built their practice there in the face of sometimes dismissive attitudes towards primary care among the powerful local establishments of secondary and tertiary care. These pioneers required strength of character and staying power of a high order. Sam was always upbeat and determined and became highly

respected and loved among his peers and within the wider community. He participated fully in the medical education curriculum of the Medical College and in the professional training of GPs. His career demonstrates a very admirable pattern of devotion to the needs of depressed and deprived communities, which extends from these early days to his leadership today in the Aboriginal community health services in Australia.

The first example, that I observed first-hand, was when he taught himself the rudiments of a database technology of the era, called Paradox, and single-handedly wrote the prototype of a practice management and patient record keeping system for primary care. Drawing from his clinical experience and insight, this stood out for its focus on the clinical requirements and time constraints of everyday practice. He implemented the software within his own practice and demonstrated it to colleagues further afield, thereby persuading a consortium of East End general practitioners, among them our subsequent long-term colleague Dipak Kalra, to join in and fund professional programmers to continue the development and provide operational support services over the coming ten years. The ParaDoc system, as it was first named, and the associated GP consortium, became a national, rigorously accredited software product and provider. This substantial accomplishment owed its success to Sam's innovative capability, drive and leadership. Dipak later took on this mantle and pursued with his mastery of administrative procedure, alongside Paul Julian, the senior partner in another East End practice, who was also closely connected with the Bart's academic department. All the while, these people were full-time GPs working in a demanding clinical setting and fulfilling wider professional roles. It was a major voluntary contribution that stood out in its ambitious scope and challenging context.

The achievement evidenced in this example led on to and brought impetus to the development and subsequent worldwide dissemination of the openEHR methodology for standardizing electronic health records, as described in Chapter Eight and a Half. Sam has contributed massively to the openEHR mission, demonstrating exceptional commitment, and staying power. He has been a steadfast leader and colleague throughout testing times, sensitive to the values and needs of the openEHR Foundation and contributing much time and expertise.

I have known many key innovators in health informatics throughout the world during my career from the late 1960s. Staying power is a quality that has marked out the most successful among them, whose contributions have endured and grown. Recognizing Sam by conferment of the Order of Australia for the distinctive and distinguished, both practical and professional contributions he has made, was a powerful expression also of the importance of outstanding staying power, against often very formidable

odds. Achieving and sustaining progress on such difficult challenges requires engagement at the centre of innovation and change, socially, scientifically and technically. Important causes Sam has served have not carried immediate prestige and have often been contentious. Progress has depended very considerably on the power of his insight and example.

### Bill Aylward–Moorfields Eye Hospital and the OpenEyes Care Record



Fig. 8.13 Bill Aylward—ophthalmic surgeon, formerly Medical Director at Moorfields Eye Hospital in London, and founder of OpenEyes. Now an ocean sailor navigating the world with his wife in their catamaran, *Double Vision*, and pictured here on Antigua (2023).

Bill Aylward had a stellar career as an eye surgeon at the prestigious Moorfields Eye Hospital in London, linked with the Institute of Ophthalmology at UCL. He became its Medical Director and, on completing that term of office, devoted his considerable talents to sorting out the problems he had encountered first-hand, professionally and managerially, with digital eye care records. This led to the OpenEyes initiative, and our paths crossed in the first phase of the endeavour, as he assembled a team around him and launched into the work, on all fronts. He asked me to join his OpenEyes project board and he became a board member of the openEHR Foundation.<sup>41</sup>

<sup>41</sup> Bill read Natural Sciences at the University of Cambridge and then Medicine. Before moving to Moorfields, he had worked at Bart's, although our paths did not

The context in which we got to know one another was one of great change at UCL and its associated NHS Trusts. The UCL Institute of Ophthalmology, closely linked with Moorfields, is a key part of the UCL Biomedicine academic mission and a global leader in research. Each of UCL's specialist biomedical research institute or hospital-based campuses has an important, close relationship with clinical services in its connected NHS Trust. UCL Biomedicine links with Great Ormond Street Children's Hospital, Moorfields Eye Hospital, The National Institute of Neurological Disorders and Strokes, The Eastman Dental Hospital and The National Orthopaedic Hospital, as well as the Royal Free Hospital, UCL Hospitals and Whittington Hospital campuses.

In my time working as a head of department at UCL, from the mid-1990s, biomedicine activities had increased to constitute about fifty percent of UCL's one billion pound per annum financial turnover. In those times, many UCL academic research institutes and departments, situated widely across north central London, ran independent IT systems and services, supporting their local activities. They wished to retain local autonomy in managing these, and to be funded for operating them, while still, and increasingly, drawing on and acting as rightful customers of the university's central services, of course! And when Bill and I first met, around 2005, I had been given the role of leading an important aspect of institutional change, in persuading, encouraging and pulling together these separate teams into a coherent and integrated group and service, destined in time to become a large part of the central UCL-wide Information Services division. With each component team's strong historic and everyday working ties to their local academic communities and related clinical service organizations, this was quite an ask in terms of harmonious and trusted change management!

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cross there. I well remember one of our lunch time meetings at the Senior Staff Common Room of UCL, where he took out his diary and showed me an entry: 'Today is the day I was due to retire', said this young and vigorous person, looking not a day over fifty! He told me that, on leaving Cambridge, he had written the date in his forward diary, anticipating sailing adventures to follow, very well ahead of time! He clearly planned life in great and practical detail! To my relief, he went on to say that he had decided to postpone this plan because our collaboration on OpenEyes was proving such fun and other things could wait. In the event, after some years of intensive involvement, the Moorfields Trust management became uncertain about OpenEyes and recruited some IT consultants, who succeeded only in rocking the boat further. This disturbed even Bill's sturdy sea legs. He jumped ship and his and his wife's long planned-for life on the ocean wave came back on track, on a huge catamaran that they bought and christened Double Vision. This is their current odyssey of incremental voyages and explorations in circumnavigating the globe, to be completed before grandparent ties take hold. Judging by Bill's podcasts, it has involved some of the same mixture of adventure and danger that Odysseus experienced!

I draw on this experience in Chapter Nine, as an example of the creation of a new environment—a key challenge facing plans for realization of the care information utility.

There were, throughout, two further continuing tensions in play—between non-clinical and clinical departments of the university, and between the university and health care organizations with which the academic medical education and research missions closely connected. The latter extended nationally throughout relationships between the university sector and the NHS, covering wide-ranging technical issues of interface and compatibility of information systems, notably for maintaining security and confidentiality of personal data, while enabling clinically based teams to work efficiently in both their academic and clinical service roles and activities. This highly fragmented environment was a fertile ground for IT-related impasse and error! Helping to chart a trusted and achievable path forward was a wicked problem territory!<sup>42</sup>

But a tremendous bonus from this work was the opportunity it offered to me for building supportive alliances across the many parts of UCL and its related NHS Trusts that were touched by these issues. In anarchic times of transition, such alliances, and the trust and mutual dependencies developed through them, are invaluable. Many may feel safer in keeping their heads down and creating and living in a protected, siloed domain and environment. The nature of my academic mission precluded that as an option. I could achieve nothing of value if not seeking always to build alliances, to help me connect across such boundaries and barriers.

One such hugely creative alliance was with Bill, who was the driving force and innovator of OpenEyes. His reputation brought resources to his

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42 As further described in Chapter Nine, it had been part of the expectation implicit in my recruitment to UCL that I would engage with change in all these dimensions, and this took much time and energy, alongside the work of building and supporting the team for my new Centre's academic mission. It was not my responsibility to run the related disparate services, but I was given authority to engage with them and help chart a way forward. Being seen as a flag carrier for such contentious, and often fought over and disruptive, domains as information services and health informatics placed me in the front line of many personal and institutional rivalries, both within the University and in its relationships with local and national NHS organizations and communities. I must have done quite well because several years later I was given a considerable promotion by the Provost and Dean. One eminent but still quite young head of a major clinical division that I had to negotiate with, told me that were it any other colleague coming with the request to join in with a collaborative approach to biomedicine IT support services, he would have distrusted the motivation and feared the consequences for his own research mission, and would therefore have likely stood out against the plan. There are advantages in being an outsider and not engaged in the usual battle ground for status and resource that tend to characterize university communities!

side and the Moorfields institution had capacity and was persuaded to invest. The software has evolved into a leading open-source medical record, now in use in approaching fifty percent of eye consultations across the UK, including at the heart of the national ophthalmology services for Wales and Scotland. Bill was hands-on in the design and prototyping of the software application, in the team and project management at Moorfields and in wider professional advocacy and fundraising from national and international organizations populating the world of ophthalmology. We co-supervised the work of a PhD student, Seref Arikan, who used the Moorfields clinical record repository as a testing ground for his research project, in which he built a formal framework of decision support and Bayesian predictive analysis on top of the openEHR specifications.

Bill had a talent for rapid engagement in partnerships and rapid decision and disengagement, as needed, when difficulties arose. The personality of a surgeon, you might say—he was an exceptionally capable one. He engaged in racing dinghies as a hobby and cooking cordon-bleu quality food, in everyday life. The range of clinical and organizational partnerships he drew together in the cause of OpenEyes, including the Royal College of Ophthalmology in London and international charities, such as Orbis, was astonishing.

The development team Bill created drew strength from him, but the going was tough, and it was his sparkling talents and capabilities that held things together and drove the project forward and into use. It was early prototype software, and institutions hosting prototypes have a tough time, too. In the subsequent years, OpenEyes consolidated into a commercially viable mission, but the first ten operational sites are usually as demanding and difficult to establish as the following one hundred, following my interpretation of the Penrose law of squares that I describe in Chapter Nine.

In his roles as clinician and Medical Director, Bill had experienced the difficulty of providing and sustaining clinically focused and useful software for use at the coalface of care services. He had seen the progressive disconnection between software systems and the evolving functional and operational requirements for their close integration with clinical practice, leading to the problems that accumulate in efforts to sustain such systems, as requirements and technologies evolve. OpenEyes was born of his close observation and engagement with the difficulties he had faced with the then current electronic records system at Moorfields. This had grown, topsy-like, as a proprietary commercial software, gradually leading to a tangled web of data relationships, confounding the clinical management of patients and operational management of the institution.

Bill saw national clinical community involvement in oversight of the design and development of OpenEyes as of paramount importance. To

encourage this wide professional engagement, his vision was of a clinically focused and led open-source care record to support practice at the coalface of care. It was to be tuned to the needs of both clinicians and health care organizations and their IT support services. Bill brought to this mission all his many talents as a highly intelligent, practically accomplished, energetic and streetwise soul. He understood and knew from training and experience what and how the clinician needed to capture and use entries in the care record, throughout the life cycle of the presenting eye condition and its treatment. Combined with his polymath skills, this gave him special insight and capacity to innovate. Like Tony Shannon at Leeds, who worked with my team at UCL on the first stages of creating an open-source openEHR platform, as described in Chapter Eight and a Half, he was a strong advocate of open-source software and clinical community-led governance of its design. He was publicly very critical of the NHS National Programme for IT (NPFIT). He used to take an NPFIT labelled coffee mug to brandish at his talks, saying it was just about the only thing the programme had given him, as a practising clinician! Others might say they had also been given a lot of headaches!

The OpenEyes software was envisioned and brought to life from the inside of the wider ophthalmology clinical community that Bill engaged. Like John Dickinson, Octo Barnett and Sam Heard, Bill saw no impediment or reason not to write his own code, to explore and enact his vision of what he and the wider community needed, in realizing his dream. As I saw with Octo's, John's and Sam's code, there were deficiencies and vulnerabilities that needed to be ironed out in making their ideas and products long-term coherent, performant and sustainable, but their unique insights and capabilities to work across disciplines was what made them and their contributions special and significant. Bill devised and implemented a program that enables clinicians to record efficiently the problems encountered in clinic sessions. It embodied a flexible interface through which essential features were recorded on a graphical template diagram. This was the EyeDraw software that he developed, which was contributed to and used to great effect by his PhD student, Maria Cross, working on the depiction of family trees.

As time went by and step by step, the requirements of the multiple ophthalmology sub-specialties were attended to, adding further modules to the OpenEyes software. The team devised the means to integrate this record with the specialized instruments used in assessing and measuring eye performance and health—such as intraocular pressure and visual acuity measurement, visual field defect mapping and other imaging methods. They understood how data needed to be aggregated and integrated with other computer systems, within and between departments and institutions,

and the standardization of method and recording needed for these data to be reliably accurate. A growing group of clinicians and adopting NHS Trust IT service leaders met as a board, to advise on requirements and design. These early adopter NHS Trusts provided significant development funds and their commissioned software companies provided software development and installation support. The resulting, increasingly performant and impressive OpenEyes product was introduced to professional meetings and succeeded in tenders for new installations around the country.

Alongside Bill, from the start, was another formidable clinical and polymath talent—James Morgan, Professor of Ophthalmology, and general all-rounder star at Cardiff, who later took on the project leadership role, as Bill withdrew. Also close by was Peng Khaw, the luminary pioneer of glaucoma care at Moorfields. With Peter Coates at the Apperta Foundation, David Haider from Bolton, and Andy Barker from East Kent—the latter two having been early adopting Trusts in the NHS—the ongoing updating and development of the software settled into a gradually more sustainable product ecosystem, working with software development partners, Jason Brown and Clayton Blake of the ABEHR and ToukanLabs companies. Carole Jones and Michelle Teo later joined the Board—Michelle still a trainee ophthalmologist but with the distinction of having already won a Google entrepreneurship competition.

The OpenEyes project went through several phases of evolution—detaching from some people that Bill had employed, who proved ill-equipped to consolidate the progress, and from the Moorfields Trust management that was going through its own difficulties and felt unable to continue support. The mission was helped in this transition to a new structure, independent of Moorfields, by my colleague and friend Sarah Hamilton-Fairley, who I had worked with for many years on her StartHere Project. I return to this connection in Chapter Nine. There was some debate about the software IP relationships with Moorfields and potential business models for expanding the project, internationally. Bill's focus was always towards making OpenEyes an international exemplar of doing better, as an open-source initiative. This was organized first, in-house, at Moorfields, then as an independent charity owning the OpenEyes IP, and finally under the aegis of the Apperta Foundation. Through these stages, we experimented with different ideas for consolidating and sustaining the mission, and then extending it, through fledgling commercial partnerships. It has been a long runway, but the project has taken wing, and is climbing—the crucial importance of grounded mission and staying power, once again fully in evidence.

Bruised by the internal strife at Moorfields, which consumed time and energy and wasted much money, Bill's long-ago expressed ocean sailing



ambition reasserted itself, and he and his wife started to prepare. At this vulnerable moment in time, project leadership of OpenEyes passed to James Morgan, with his 'can do and does' character, like that of Bill. He and David Haider held together the, by then, some twenty-strong, clinical advisory group. And as adoption further widened, the entrepreneurial elan of Peter Coates at the Apperta Foundation and the company partners helped to consolidate and chart an increasingly confident dissemination pathway for the product, to the point where OpenEyes is regularly winning tenders for NHS hospital and community systems. As mentioned above, it is now the national platform for eye care records in Scotland and Wales and adopted in some ten large NHS Trusts in England, combining to provide the records for fifty percent of national eye care consultations. OpenEyes has been an amazing story of survival through thick and thin, to become the software it is today. It is easily and quickly spun up as a tool, on Cloud platforms across the world, and a trail blazer of new approaches to care information utility, as I discuss in Chapter Eight and a Half.

Thanks to its outstanding pioneers and their clinical vision and staying power, the OpenEyes initiative has proved its metal in delivering high-quality software that provides value for money. Its goals are humble and humane, dependent on its strong and wholehearted, clinically active leadership, pitched beyond the commercial and industry-led focus that has characterized much of the big tech era in health care IT.

My personal focus within OpenEyes, apart from as a founding management board member and trustee, is in exploring its usefulness in support of busy and overburdened services in developing countries, and in helping meet wider needs of patients throughout their history of eye-care. We see a viable pathway opening for it to become a global utility, safely and sustainably. As young and developing eyes are increasingly focused on mobile phone and other close-by screens, a pattern of increased prevalence of early eye problems is being seen.<sup>43</sup>

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43 Over the past year, I have been working with a local optician in my global village life, who has pioneered an innovative technology called StyleEyes, for producing and customizing prescription spectacles at very low cost. The technology can be used to fit spectacles for users anywhere in the world, by a technician trained to test eyesight and customize the spectacles, in a single visit. This week as I write, my lifelong friend Chris Mullard is discussing with governments and investors in Africa, during one of his regular visits there as a UK business ambassador, to explore how StyleEyes might now be brought to life by investors there.

## Bernadette Modell—UCL and the WHO Collaborating Centre for the Community Control of Hereditary Diseases



Fig. 8.14 Bernadette Modell—epidemiologist at UCL and Director of the WHO Collaborating Centre for the Community Control of Hereditary Diseases. CC BY-NC.

One day, out of the blue, the genetic epidemiologist Bernadette Modell, a world authority on the genetics of hereditary diseases, came to visit me. She worked in collaboration with a clinical team in the Haematology Department at the Whittington, led by Beatrix Wonke, which provided leading care for the many thalassaemia patients living in the local community. She came to discuss her interest in creating information systems accessible to the affected communities she worked with, and to explore potential for collaboration with my department, CHIME.

North Central London is home to ethnic communities that originate from countries where genetic variants of the haemoglobin protein are prevalent. These variants are associated with abnormal structure of the red blood cells that distribute oxygen and carbon dioxide around the body, in respiratory gas exchange. One such disorder is thalassaemia, a complex and life-threatening disease requiring regular mitigating clinical interventions and lifelong care. The disease is endemic in countries where malaria, transmitted by mosquitos, is an everyday threat. The haemoglobin gene variant has persisted, it is suggested, because it provides some protective advantage to the population, in resisting malaria.

The mathematics of the affinity of the haemoglobin molecule to capture oxygen and carbon dioxide within its structure, in different prevailing acid-base balance conditions of the blood circulating in the body, was something I knew well from my mathematical modelling days with John Dickinson. I had optimized models of this changing dynamic to analyse respiratory gas exchange in critically ill patients at Bart's, as described in Chapter Four. In that situation, the haemoglobin molecule was typically in good shape, but the gas transport and exchange, through lungs, circulation of blood and tissues, was under abnormal stress.

One of Bernadette's principal goals, which I felt fitted well with CHIME's wider mission, was to focus national and international attention on creating an information system supportive of consistent and contextually appropriate advice for the thalassaemia patients and their families. This had echoes for me from my time years before, working with Bob Jones, Ilora Finlay and the Marie Curie Foundation, developing a videodisc-based educational resource to support multiprofessional care for cancer patients and their families at home. It was that connection that had led me to my involvement in the project creating a tropical medicine education resource for the Wellcome Trust.

Bernadette brought the World Health Organization (WHO) Collaborating Centre for the Community Control of Hereditary Diseases, of which she was the Director, into CHIME, to align with the informatics interests of our Centre. She became a much-valued, inspiring and supportive colleague of those times. She was a wonderful supervisor of research students and her international network of collaborators brought connection with inspiring leaders like Arnold Christianson in South Africa, adding lustrous global context to our local academic community.

Bernadette and I co-supervised Matthew Darlison in his PhD project to design and create the APoGI (Accessible Publishing of Genetic Information) resource. In this, Matthew formed close personal links with both the local thalassaemia clinical team and their patients. It was a difficult endeavour, both in its design and implementation, because of the complexity inherent in the manner of its expression, relevant to the needs of individual patients and others seeking guidance. A further context was that of population screening for the disorder, and counselling services communicating about the risk of its transmission to following generations. The lead clinician for the national thalassaemia services in Iran, also became a PhD student of Bernadette in CHIME, visiting as often as she was able.

Through Bernadette, the care environment that I discovered and was privileged to be welcomed into and become involved with was exemplary in many respects relevant to this book. It connected global scope of the clinical problem addressed, with how it was coped with and tackled locally.

It embodied clarity of purpose and goal, centred on listening to members of the affected local community and learning about its needs—what mattered to them—and helping and supporting them. It had a balance of motivation, mutual support and dynamism on all sides—the patients and their community, the NHS clinical community and the academic epidemiology community. There was powerful motivation for these groups to work together to tackle the multi-faceted challenges they faced, and this showed in their mutual trust and respect. It was a holistic environment and there was supportive synergy in all their efforts.

The clinical disorder and dysfunction of haemoglobin is deeply consequential for the everyday lives of affected patients and their families in the community. The clinical science and practice that strives for improved treatment connects with a rigorous timetable of hospital visits, and stays. The genetic epidemiology connects local understanding and communication about the disease and its consequences, with experience of the impact of the disease on the provision of services in other countries and cultures. Each group would have been much less effective in achieving its goals, had they not been drawn together and worked collaboratively in this way.

Bernadette's work in the WHO Centre was impactful in raising awareness of the global burden of non-communicable diseases. In terms of wider advocacy for the work, we succeeded in interesting the City of London Livery Company for the IT industry, in running a national walk to raise money for its support. We also tried, but failed, to engage national policy support for the APoGI approach to providing context-sensitive information for patients in national screening programmes for genetic disorders. Funding of its further development was difficult to secure as it was seen to fall awkwardly between the two stools of research and practice. Policy makers were attuned to top-down more than bottom-up perspectives of how screening programmes should operate, and there was a melee of such ambitions in play. Bernadette and Matthew were focused on creating information utility tuned to local community needs and synergy with local clinical practice, building outwards from this in wider advocacy and community engagement, both nationally and internationally. The need to ground such services in local knowledge accords with the reality that the needs for preventative care are typically found to be greater within poorer and more deprived communities, where personal options are more limited, and that such communities, as in North London, sit cheek by jowl, locally, in a chequered landscape, alongside much more affluent ones.

National service development initiatives, each jostling for attention and funding, came and went with great rapidity in those years. The resulting regularly disrupted pattern had the effect of blocking rather than enabling sustained innovation in services, which require a long-term focus, well

beyond the few years of each electoral cycle. This too rapid turnover of initiatives risks poorly configured services beset by noise and bias of data.

## Trends Shaping Future Care Information Utility

The purpose in creating a coherent and connected care information utility is not to cure the problems of the past, but to learn from them in helping to shape and create a better future. It is not about reforming health care; rather it is about helping to reformulate and reinvent it to serve the future Information Society. The pioneers I have highlighted in the preceding section are some of many I have encountered and learned from along my songline. Each in their own way has responded to that need in their commitments and actions. It is, of course, an ever-changing mission, as the Information Age moves on. The story now switches from microscope looking back to telescope looking forward to what may lie there. There is no Hubble or James Webb telescope equivalent able to help us probe back in time, to illuminate our understanding of where we are now, and project forward to what the future may hold. We must invent and create our imagined and desired future of health care.

The WHO has defined health as '[...] a state of complete physical, mental, and social wellbeing and not merely the absence of disease or infirmity'.<sup>44</sup> It is clearly the case that information technology has led to astonishing and transformative new scientific insight and capability to combat disease, resulting in both greater lifespan and correspondingly greater proportion of chronic disease and disability. It is clearly not the case that society of Globalton yet enjoys a state of 'complete' wellbeing; life there for many is more challenged, anxious and uncertain than was Localton life.

Human actions, as well as natural disasters, perturb both local and global ecosystems and communities, with consequent adaptations over indeterminate time. Short-term gain can turn to long-term pain. Long-term action can be required to rectify short-term inaction. Health care interventions that may appear attractive and strengthening, in the short term, may lead to longer-term harm—the over-prescribing of antibiotics comes to mind. Human resilience is hard won and easily lost. The *milieu intérieur* of Claude Bernard (1813–78) is hard-won bodily defence—that defence, evolved and tested over millennia, may be weakened, and overwhelmed, over millennia, too. Medicine has rightly been a conservative profession. As we promote conservation of environment, so we must promote conservation of health. Information utility must serve that end.

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44 'Constitution', WHO, <https://www.who.int/about/governance/constitution>

The two inverted triangles of Richard Smith's editorial characterize the era of Whitehead transition of health care services, from what is described as Industrial Age medicine to Information Age medicine (see Figure 7.10). They focus on the relative volumes and costs of services, from costlier, low-volume acute hospital care to cheaper and more extensive home and community-based care and self-care. The horizontal width at each vertical level of the triangles represents volume of services provided at that level, and the side bars indicate relative focus and cost. They do not attempt to reflect utility–value that derives from the efficiency and effectiveness of services. Let us think of the lower triangle as also representing my Localton experience, in terms of the reality of how things were then in village life. As I recounted in Chapter Seven, mutual care and self-reliance were, of necessity, more the order of the day.

Information technology deployed in this era of transition has been focused in broadly three directions: improvement in methods powered by advances in science and engineering, to achieve greater insight and effective intervention (imaging, genomics, pharmaceuticals, machine intelligence, robotics); improvement in service delivery, powered by new possibilities for both specialist and self- and community-based care, surveillance, prevention and early intervention; improvement in governance, driven by changing population-based data, ethical and legal concerns and social and cultural change.

Suppose we think now about IT investment within the two triangles and how it encourages and facilitates the transition from the top to the bottom triangle. The greater investment focus, by far, has been into the costly hospital care settings of the top triangle. The lesser by far into community and self-care settings of the bottom triangle. The new money in the Information Age has followed the old money, into further support of Industrial Age medicine and at the expense of enabling and supporting Information Age health care to come of age. Investments come from different sources and push in different directions, and thus in some cases cancel one another—investments sum as scalars, directions of travel sum as vectors. Costs add up, progress is a Brownian movement.

The UK Poet Laureate Simon Armitage wrote a beautiful poem for the 2020 National Poetry Day (4 October).<sup>45</sup> It gives an optimistic vision from his own village in the North Country, of Globalton experience in the Covid crisis. It is an evocation of how global village life might be experienced, from beyond the transition to the Information Society. An optimistic vision of

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45 The poem is entitled 'Something Clicked'. See BT, 'Something Clicked by Simon Armitage, in Partnership with BT', online video recording, *YouTube* (1 Oct 2020), <https://www.youtube.com/watch?v=kQS3k3yBxAk>

connectedness and cohesion, stretching and empowering human potential and challenging the individual citizen to take charge and not fall victim to dystopian vision of disconnectedness and fragmentation. In health care, this sense of personal control and self-reliance is not widely experienced today. How can the culture of self-reliance, mutual support and cooperation, essential in Localton life, translate to Globalton life, which interacts and impinges globally as well as locally?

For health care services that support the WHO vision, balance and continuity of a coherent and comprehensive information utility must be a clear and trusted goal of the bottom triangle. It must as well be an enabler of the transition from top to bottom, centred on care of the individual citizen rather than, as now, on the management of services. The design and development of such a utility must respect and reflect the citizen's capacity to understand, learn and grow, and their need to know about and be involved in their care. Citizens, for their part, must understand and acknowledge that there will often only be good and bad, better and worse, ways of acting, not right and wrong ways, and they are party to their enactment, for others as well as for themselves. This balance will require local governance and community leadership, exercised from below rather than by fiat from above, in the Taoist tradition of leadership. Such a utility, supportive of lifespan and lifestyle, consonant with economy and environment, realizable with capable and trusted professional services, leadership and governance, will be a considerable test of human ingenuity, commitment and staying power.

This qualitatively different, citizen and professionally focused care information utility, can only be centred on data and record that integrates and connects health and care. There will be many evolutionary changes and adjustments required in the framing and sharing of knowledge and discipline, in professional practice and in education and governance. The information revolution and its impact on health care, as discipline and as practice, has presented everyone involved with a great deal of change, to be coped with and adapted to. It has surfaced and highlighted issues of understanding, choices and values, which go to the heart of how services reason, decide, act and record what they make and do. It has imprinted Internet time onto these changes, that need more time for learning how. It has comprised a giant black swan era—lasting fifty years, but black swan, nonetheless. Realistically, we are only halfway through this anarchic transitional era and its challenges for coping, as we all do our bit to shape and create a very different world. It is a vulnerable and manipulable era.

## Knowledge and Discipline

Discipline is an assertion of rules of knowledge, belief, and behaviour. It operates to keep order within the boundaries of a defined domain, and defend against usurper and interloper, coming from outside.

This is implicit in the term. I can still recall my feisty first Latin teacher starting each class with *salve discipulos* [Hello, (or Be well) pupils], said loudly, to wake us up! And we pupils noisily responded, *salve magister* [Hello, teacher]! I cannot imagine that anywhere in the school culture of Globalton, today! Discipline connects pupil and teacher, citizen and sage. And academic discipline has changed at an incredible pace in the Information Age and continues to do so, connecting many domains of knowledge. Whitehead made an observation about scholarly caution in the face of this trend, that still resonates today:

Your thoroughgoing scholar resents the airy speculation which connects his own patch of knowledge with that of his neighbour. He finds his fundamental concepts interpreted, twisted, modified. He has ceased to be king of his own castle, by reasons of uncomfortable generality, violating the very grammar of his thoughts.<sup>46</sup>

The culture and practice of medicine has strong foundations in craft, apprenticeship and accepted procedure. Professional skills, honed over a lifetime of practice, are not always easily formalized within boundaries of discipline. A radiologist looks at thousands of images, over time, and learns how to interpret them in their clinical practice and context. A GP draws on the experience of observing and listening to the narrative of many patients' lives, when discerning the clinical issues in play for a particular patient, at a particular time and place, and how best they may be approached and understood.

Imbalance and disconnection of knowledge and experience are weaknesses easily amplified in the Information Age, through bias, corruption and overload of information. These dangers were anticipated in different ways by Albert Einstein (1879–1955) and Whitehead:

All knowledge of reality starts from experience and ends in it.<sup>47</sup>

The consequences of a plethora of half-digested theoretical knowledge are deplorable.<sup>48</sup>

46 A. N. Whitehead, *Adventures of Ideas* (New York: Macmillan, 1933), p. 108.

47 A. Einstein, *Ideas and Opinions* (New York: Crown Publishers, 1954), p. 271.

48 A. N. Whitehead, *The Aims of Education and Other Essays* (New York: Macmillan, 1929), p. 4.



One remedy for disconnection lies in focus on reconnection, revisiting boundaries of discipline and profession and connecting their sources of knowledge and experience. Information as we have seen connects knowledge and action. It also connects knowledge with experience.

Some twenty years ago, I worked on summarizing the interdisciplinary connections of health informatics across UCL. This was initiated by the then UCL Vice-Provost for Research, my medical physics colleague of years before, Dave Delpy, who went on to become Fellow of the Royal Society and Chief Executive of the Engineering and Physical Sciences Research Council of the UK, and Anne Warner (1940–2012), a biologist and head of an interdisciplinary centre established at UCL to foster connection between the mathematical, physical sciences and life science and experimental medicine, arranged to give the name CoMPLX. These are two diagrams we constructed to capture the issues (Figures 8.15 and 8.16).

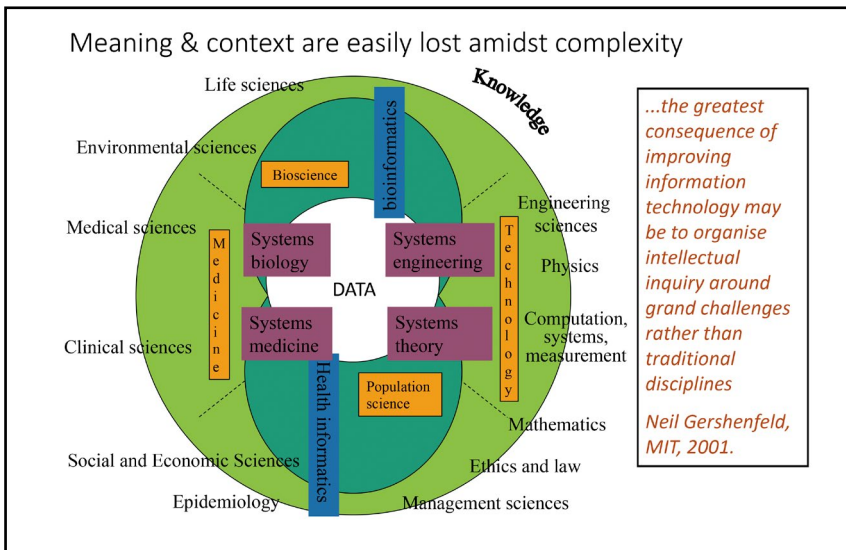


Fig. 8.15 The interdisciplinary science of medicine, connected around Ranganathan’s circle of knowledge. Image created by David Ingram (2010), CC BY-NC.



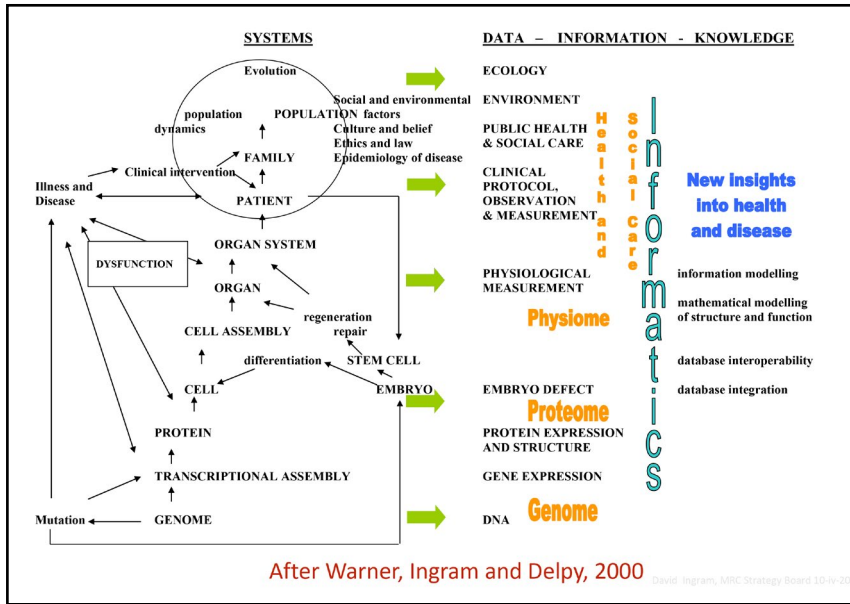


Fig. 8.16 The connected information landscape of human biology and medicine. Image created by David Ingram, Anne Warner and Dave Delpy (2000), CC BY-NC



The focus and governance of interdisciplinary science was the subject of much debate and prediction, suggesting growing connections grouped around what were called ‘grand challenges’, as explored by Neil Gershenfeld, at Massachusetts Institute of Technology (MIT).

The greatest consequence of improving information technology may be to organize intellectual inquiry around grand challenges rather than traditional disciplines. If this turns out to be so, then a title like the physics of information technology may eventually become triply redundant the truth is that none of those words can properly understand without all of them.<sup>49</sup>

This approach was being championed by the Provost of UCL, Derek Roberts, at the time I re-joined the University in 1995. He came to meetings that he organized to encourage partnerships among disciplines, equipped

49 N. Gershenfeld, ‘Bits and Chips’, *New Scientist*, 169 (2001), 55.

only with his formidable personality and a single overhead slide, depicting an unlabelled set of overlapping ellipses. This he used as his sole visual aid, ascribing the ellipses to different departments, and faculties, as he spoke, according to the occasion! His aim was to encourage innovations stemming from common endeavour shared across disciplines. He wanted these to become vectors of advance, coordinated within and across existing disciplines, not as supplementary and separate islands of new discipline.

In the following years at UCL, this became a continuing goal of Vice-Provosts for Research. After Dave Delpy, David Price proposed a wide-ranging set of interdisciplinary grand challenges, chosen to bring together disciplines from all around the Ranganathan circle of knowledge (see Figure 2.2). These were global health, sustainable cities, cultural understanding, human wellbeing, justice and equality and transformative technology. They echoed the saying of Einstein that 'All religions, arts and sciences are branches of the same tree'.<sup>50</sup>

As I have already mentioned, in a footnote above and in Chapter Seven, a complementary practical challenge for the university involved designing and implementing corporate research computing facilities and associated training courses, and integrating many and diverse existing IT support teams, whose loyalties were to the department in which they were situated. It was an exercise in finding common ground and creating an environment supportive of the dual goals of local and global community. It was a challenge of maintaining the local environment that was an important and valued home for its staff, while engaging everyone in creating a strategy for transition towards alignment within an evolving and standardized, university-wide framework of information services. It was a human challenge of helping people put aside their fears and anxieties and step safely from one comfort zone to create a new one, working together in maintaining geographical ties to their local communities while evolving new working relationships more widely.

The same issues existed in the context of local NHS Trusts and the connection of academic research and education between the NHS and the university. This is a slide I used, highlighting the different perspectives in play, in building these bridges:

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50 A. Einstein, *The Einstein Reader* (New York: Citadel, 2006), p. 7.

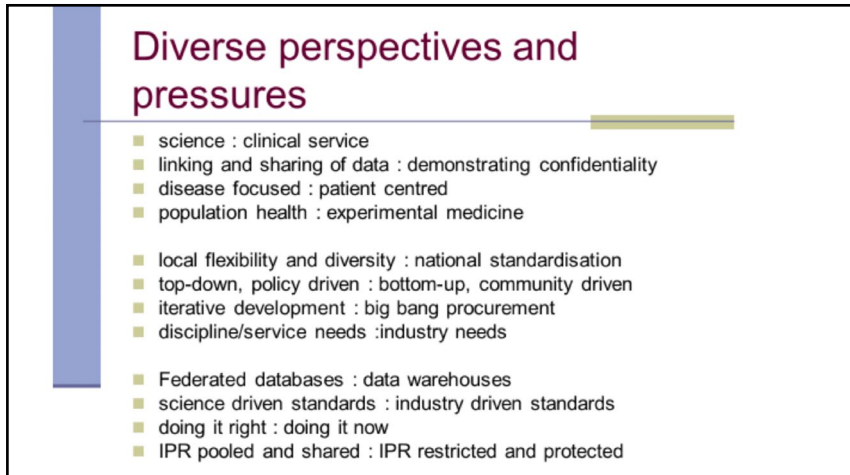


Fig. 8.17 Diverse perspectives in play when seeking to bridge academic, clinical service and industry domains of health care information. Image created by David Ingram (2010), CC BY-NC.



The central role of information infrastructure in enhancing research capability and capacity is illustrated in this morning's (7 October) announcement of the award of the Physics 2020 Nobel Prize to Roger Penrose, Reinhard Genzel and Andrea Ghez.<sup>51</sup> This synergistic interrelationship is as true, now, in the life sciences. And improved information utility is a prerequisite of health care services becoming part of a virtuous circle of progress and

<sup>51</sup> Penrose devised new mathematical methods that enabled him to show the black hole as a firm prediction of the Einstein equations of general relativity. His theory was published in a paper from Oxford, in early 1965, when I can attest there were no computers in sight, anywhere. Genzel and Ghez are astrophysicists, in Germany and the USA, who spent many years from the early 1990s in mapping the movements of stars in Sagittarius A\*, at the centre of the Milky Way galaxy, in which we sit. With progressive refinement of both instruments and correction for distortions of images, they demonstrated the presence there of a massive black hole. The mathematics was the product of a brilliant and inventive mathematical brain, with pencil and paper. The astrophysicists' observations were only made possible by the much later advances in instrument engineering and computational infrastructure. The evidence demonstrating the correctness of Penrose's prediction, without which it would have remained interesting theory, was also evidence of the central role of this computational infrastructure in the creative interaction of mathematics, science and engineering.

improvement in health care, enabled by advances in biomedical science and engineering.

Research priorities have driven academic investment in the research computing services that have powered transition into the Information Age, creating and benefiting from shared computational methods and resources, implemented and operated through funded collaborations between universities and industries, internationally. Where requirements are specific to one discipline or group of disciplines, that community creates its own bespoke services. Astronomy, physics, bioinformatics, natural environment, social science—all created specialized national centres. Clinical research was a special case, where individual projects and programmes had requirements for gathering and integrating data from outside the academic domain, from health care institutions that do not share common basic infrastructure, and where operational data were substantially incompatible, from one institution to another.

The Medical Research Council faced this issue with multiple long-term population studies, each with its own needs, each having created its own bespoke information systems. The multi-year European Union Advancing Clinico-Genomics Trials on Cancer project encountered similar difficulties in integrating diverse cancer treatment datasets. The situation became increasingly onerous, expensive and intractable. The Royal Marsden Hospital experience described above showed the clear benefit, to both local institution and global domain, of coherent data management. A 2022 report from the health IT industry body, HIMSS in the USA, charts the number of medical record systems of different companies that individual health providers are using.<sup>52</sup> On average, each hospital is running sixteen different electronic health record platforms, and each vendor of hospital systems is connecting with eighty-two other vendors' records, with no common information model to underpin their clinically meaningful interoperability.<sup>53</sup> Coherence is of equal significance, and yet more complex to achieve, between institutions and across national boundaries. openEHR has pioneered openly specified and standardized clinical data modelling for care records, translated across languages, and an open platform for implementing them. This is steadily disseminating to provide common ground for institutions and sectors of health care, globally, as described in Chapter Eight and a Half.

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52 HIMSS, '2022: Future of Healthcare Report' (2022), <https://pages.himss.org/rs/420-YNA-292/images/PDF-FOH%20Report-2022-08.pdf>

53 T. Sullivan, 'Why EHR Data Interoperability Is Such a Mess in 3 Charts', *Healthcare IT News* (16 May 2018), <https://www.healthcareitnews.com/news/why-ehr-data-interoperability-such-mess-3-charts>

As requirements to be met by standardized systems become more extensive and complex, connecting multiple domains of knowledge and discipline—for example, in health care, embodying phenotype, genotype, environmental and social science data—human capability and capacity issues assume ever greater significance. How will the nature of professions and educational needs change in the transition to the future Information Society? These are issues that connect with every citizen and are thus, inevitably, disruptive and contentious matters.

### Professional Practice—How Information Technology Will Change It

How and why professional people specialize and practise their skills and trades is highly personal. Interest, challenge and satisfaction in work, wealth, prestige and power in position, all factor in. Assessment and regulation of professional practices centre on issues of trust—in knowledge, expertise, behaviour and ethics. How and why their clients need, trust and engage with them is also personal.

In thinking about this section, I have been reading, again, *The Future of the Professions*, by father and son, Richard and Daniel Susskind. It is a great book—comprehensive, detailed and reflective, but also pressing and passionate—a delightful mix of father and son. Richard is eminent in IT and law and Daniel in economics, with experience of work in central government policy circles. Together, they bring a wide range of ideas and examples. The book is authoritative and contains important commentary. It identifies implicit imbalances of knowledge between the professions and the public they serve, that synchronize them in a *status quo* of relationship and trust. It describes the trends in information and technology that challenge this *status quo*, pushing and pulling fundamental change.

They summarize what they call the Grand Bargain between professions and society:

In acknowledgement of and in return for their expertise, experience, and judgement, which they are expected to apply in delivering affordable, accessible, up-to-date, reassuring, and reliable services, and on the understanding that they will curate and update their knowledge and methods, train their members, set and enforce standards for the quality of their work, and that they will only admit appropriately qualified individuals into their ranks, and that they will always act honestly, in good faith, putting the interests of clients ahead of their own, we (society) place our trust in the professions in granting them exclusivity over a wide range of socially significant services and activities, by paying

them a fair wage, by conferring upon them independence, autonomy, rights of self-determination, and by according them respect and status.<sup>54</sup>

They admit this is a trifle legalistic—as my paediatrician wife, a believer, would say—as she sometimes does, understandably, of wordy things written by the agnostic me—Amen!

Before confronting the challenges to their Grand Bargain in the Information Age, the Susskinds detour, as I have, frequently, in this book, into its history and context—George Bernard Shaw (1856–1950) and his description, in *The Doctor's Dilemma*, of the professions as ‘conspiracies against the laity’; the happy hunting ground enjoyed by sociologists in exposing and unpicking the bargain; and its Marxist framing within the language of the struggle of capitalism and the proletariat.

The central focus of their book is embodied in its strapline: ‘how technology will transform the work of human experts’. They explore alternative ways of organizing professional work and consider to what extent human beings are indispensable in delivering this and whether professionals are to be trusted in making such judgements. All this within incisive questioning of the extent to which the Grand Bargain remains fit for purpose in the Information Age—is it serving society well?

The first of three broad sections surveys professionalism and change in health, education, divinity, law, journalism, management consulting, tax and audit and architecture. It surveys patterns of transformation in skills and competencies, configuration of work, workforce structure, customer choice and the preoccupations of professional firms as their trade becomes demystified in the Information Age. The second broad section surveys the onward march of information and technology and the production and distribution of knowledge. The third section looks forward to the implications of change in professionalism, in more human terms—trust, morality, empathy, personal identity with craft, work, trade and human interaction, and where these are leading, and choices to be made in shaping them. They are almost universally cautious of exclusivity (an enclosure of knowledge and knowhow) and prefer to focus on a decades-long evolution towards open commons as a means for democratization of knowledge.

They ask the question ‘To what problem is professional work the solution?’ They propose ‘access to knowledge’ as the ‘hole in the wall’ or need that professional work drills and fulfils.<sup>55</sup> Knowledge and the imbalance in human knowledge are at the heart of professional work, and this imbalance underpins the Grand Bargain. It is a changing landscape in

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<sup>54</sup> Susskind and Susskind, *Future of the Professions*, p. 22.

<sup>55</sup> *Ibid.*, pp. 37–38.

human social evolution, and as machines progressively take on aspects of professional work (for example, book-keeping substituted by accounting software) and become more 'knowledge-full', the balance and the power it confers, also change. In considering implications for professionalism in the Information Age, it is on this changing balance that they believe the focus should lie. The trust, reassurance, quality, status, training and regulation components of the Grand Bargain are, they suggest, secondary matters.<sup>56</sup>

In the context of health care services, access to knowledge has been transformed out of all recognition along my songline, for professionals and public alike. Knowledge has flowed over, washed away and tunnelled through and under barriers and boundaries between disciplines, professions and services, and those they serve. The nature and organization of the health care professions, the education and training programmes and assessments that aspiring entrants pass through, the regulatory frameworks that govern them along the way, all combine to shore up professional barriers under siege. Access to knowledge is a battering ram that knocks them down; like Venice, defended with flood barriers to ward off the inevitable. They create new points of contention and vulnerability that also come under siege, to allow the rising tide to flow through.

The Susskinds conclude with questions about what we should do, and first ask, what future should we want? In the context of health care, this echoes in my mind back to Douglas Black (1913–2002) and his *BMJ* leading article in 1982.<sup>57</sup> Do not set out to computerize without thinking first about the requirement you are addressing. Their book discusses two broad paths ahead in the Information Age—more efficient ways of working based on what we do today, or gradual replacement of professional work by increasingly capable information systems—two paths in the Robert Frost wood. The path most travelled is the former. The AI fallacy they write of—as Richard Feynman (1918–88) did, more generally, long before—is that such systems

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56 I should note at this point that my knowledge and experience of the practical skills and professions of surgery and invasive procedures, more widely, are very limited, although I have observed them at close quarters and worked alongside their practitioners. These are domains where unfolding information technology and engineering—image guidance and robotics, for example—have been transforming practice and likewise education and training. I will not delve into the separate considerations in play in investment, assessment and regulation of these professional skills, and how they may evolve and impact the health care professions as such tools and devices acquire greater scope and usability in the years ahead. They will be an important aspect of the transition towards more citizen-centred health care.

57 D. Black, 'Data for Management: The Körner Report', *BMJ (Clin Res Ed)*, 285 (1982), 1227–28, <https://doi.org/10.1136/bmj.285.6350.1227>



will be based on how professionals create and distribute knowledge, today. They argue that:

In an era of increasingly capable systems, the professions, or elements of them, should survive and prosper because they bring value and benefits that no system or tool can; not because we regulate competitors out of the market, nor because we cannot imagine a world without the professionals, nor again out of nostalgic impulse for a fading way of life.<sup>58</sup>

Their view, captured in the book's flyleaf, is that 'In an Internet society, we will neither need nor want doctors, teachers, accountants, architects, the clergy, consultants, lawyers, and many others, to work as they did in the 20th century'. In conclusion, they place liberation of knowledge and enclosure of knowledge in counterpoint. They estimate human society will favour the former, and place their personal marker on this, saying finally, 'We now have the means to share expertise much more widely across our world. We should also have the will'.<sup>59</sup>

The bifurcation of choices that the book highlights feels close to that which I focus on in Chapter Nine, in the search for common ground based on Open Society and Creative Commons. I came to this, though, after two decades in which I had focused on information technology for medical education. The future of education in the Information Age is as disruptive a prospect as that for the professions it prepares for. This is where the storyline now moves on to.

The activities I initiated and led at Bart's from 1990–95, to create a joint medicine and nursing clinical skill teaching centre—combined with leadership of multidisciplinary, multiprofessional and multi-sector EU projects on health record architecture—brought our group to the notice of the leadership of UCL and the Whittington NHS Trust. As a result, I was invited in 1995 to establish the UCL Centre for Health Informatics and Multiprofessional Education, which I led for the next fifteen years up until my retirement. This placed us at the centre of the development of the newly merged UCL and Royal Free Medical Schools and Postgraduate Institutes. It positioned us to explore academic connections of health informatics with clinical education, research and practice. This was a local grand challenge, leaving aside the wider implicit pursuit of new academic community and discipline of health informatics in its connections with the wider health economy, nationally and internationally. This mission involved a great deal of trust and a great deal of challenge. In microcosm it connected with and

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58 Susskind and Susskind, *Future of the Professions*, p. 45.

59 *Ibid.*, p. 412.

embodied, in practical everyday terms, the wider dilemmas faced by health care in transition to the Information Society. I reflect on this environment, its successes and failures, the exhilarating freedoms, and unnerving challenges of creating and leading it, and its legacy, in Chapter Nine.

### Education—Environment for Learning

The transition from Industrial Age to Information Age medicine, highlighted by Richard Smith's two triangles (see Figure 7.10), is paralleled in education—learner focus mirrors patient focus, self-directed learning mirrors self-care. Roles, costs, performance and accountability of services and institutions, and equity of access to them, face increasing scrutiny and challenge in education, as they do in health care.

Questioning of the rationale of education services is not new, but information technology has fundamentally changed the playing field. Transformed access to knowledge, teaching and learning resources, and related assessment methods, have thrown new light on lifelong learning and the interface of education and practice, in formal study and apprenticeship. This has been accompanied by a changing perspective, and 'radical uncertainty', in Mervyn King's phrase, about the permanence of work, ways of working and lifelong careers. The ways in which different educational institutions have adapted to the risks of Covid-19, to work in different ways and embrace a different mix of technology and access, have added contemporary impetus and opportunity for constructive change.

Whitehead was questioning the role of universities a hundred years ago.

The universities are schools of education, and schools of research. But the primary reason for their existence is not to be found either in the mere knowledge conveyed to the students or in the mere opportunities for research afforded to the members of the faculty. Both these functions could be performed at a cheaper rate, apart from these very expensive institutions. Books are cheap, and the system of apprenticeship is well understood. So far as the mere imparting of information is concerned, no university has had any justification for existence since the popularization of printing in the fifteenth century. Yet the chief impetus to the foundation of universities came after that date, and in more recent times has even increased. The justification for a university is that it preserves the connection between knowledge and the zest of life, by uniting the young and the old in the imaginative consideration of learning.<sup>60</sup>

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60 Whitehead, *Aims of Education*, p. 97.

Illich was questioning the nature of schooling, more widely, fifty years ago. As shown in the discussion of *Medical Nemesis*, in Chapter Seven, he was a political radical. As the *Guardian* newspaper wrote in a review of one of his books '[...] his radicalism goes out beyond Left and Right'. I've just been reading a short book, *Math without Numbers*, by Milo Beckman, and it prompts me to wonder whether, as he muses, this manifold extends infinitely along a line, or whether political cultural affiliation is more horseshoe shape than line spectrum.<sup>61</sup> Norman Davies avers the latter, that its Left and Right extremes are close human companions, as extremes of a common radicalism. Illich's radicalism is akin to that of Paul Tillich (1886–1965) in his description of the shaking foundations of religious belief. He was both priest and philosopher after all. His gender language is all *his* and *he*; of *his* age and *his* culture, always.

Regarding education, Illich set out his stall emphatically in *Deschooling Society*:

Universal education through schooling is not feasible. It would be no more feasible if it were attempted by means of alternative institutions built on the style of present schools. Neither new attitudes of teachers towards their pupils nor the proliferation of educational hardware or software (in classroom or bedroom), nor finally the attempt to expand the pedagogue's responsibility until it engulfs his pupils' lifetimes will deliver universal education. The current search for new educational *funnels* must be reversed into the search for their institutional inverse: educational *webs* which heighten the opportunity for each one to transform each moment of his living into one of learning, sharing, and caring.<sup>62</sup>

As with his book *Medical Nemesis*, which I used in Chapter Seven, I have used this book as a framework, here, because it is a perspective that challenges, not because I think it is right or wrong. Some of it rings true, some seems off-beam—on the wrong track, that is. He was an eyewitness and commentator of his times. His eleventh chapter, which I have been rediscovering, with my margin notes from that time, is about learning webs—this was from long before the World Wide Web, of course. It starts from a question he says should dominate over all others when planning educational institutions: 'What kinds of things and people might learners want to be in contact with, in order to learn?' He goes on to describe four kinds of educational resource. I quote here, in detail, how he introduces them:

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61 M. Beckman, *Math without Numbers* (New York: Penguin Books, 2022).

62 I. Illich, *Deschooling Society* (London: Calder & Boyars, 1971), p. viii.

Educational resources are usually labelled according to educators' curricular goals. I proposed to do the contrary, to label four different approaches which enable the student to gain access to any educational resource which may help him to define and achieve his own goals:

1. Reference services to educational objects—which facilitate access to things or processes used for formal learning. Some of these things can be reserved for this purpose, stored in libraries, rental agencies, the laboratories and showrooms like museums and theatres; others can be in daily use in factories, airports or on farms, but made available to students as apprentices or on off-hours.
2. Skill exchanges—which permit persons to list their skills, the conditions under which they are willing to serve as models for others who want to learn these skills, and the addresses at which they can be reached.
3. Peer-matching—a communications network which permits persons to describe the learning activity in which they wish to engage, in the hope of finding a partner for the inquiry.
4. Reference services to educators-at-large—who can be listed in the directory giving the addresses and self-descriptions of professionals, paraprofessionals, and freelancers, along with conditions of access to their services. Such educators, as we will see, could be chosen by polling or consulting their former clients.<sup>63</sup>

What strikes one first, in this list, is its foresight of the paradigm and evolving culture of the Internet and the World Wide Web. Tim Berners-Lee had yet to start his undergraduate physics course at Oxford, five years after I had finished mine. This was the era of Arpanet and my first introduction to computer science and technology, from Peter Kirstein (1933–2020) at the London Institute of Computer Science and the first Master of Science (MSc) course in Computer Science in the University of London. The second impact of the list is more personal, in its connection with the first half of my ensuing academic career, where computer-assisted learning and self-directed learning enriched by computer-based learning resources, were key areas of experiment. What strikes me as missing—but is perhaps anticipated in the final chapter, in his recounting of the story of Pandora and Prometheus in Greek mythology and the Greek state of Plato's Republic—is a reflection on the extent and dynamic of social change accompanying transition of formal education to a more learner directed focus; how it might unfold

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<sup>63</sup> Ibid., p. 113.

and be encouraged to unfold. There is no foresight of the weaknesses and vulnerabilities that might emerge within that paradigm. For example, the downside of learning in virtual classrooms—of what is lost there. He was not re-imagining education within a virtual reality, I think.

As characterizes his polemical style, Illich is strong on all that is wrong, and the need to fight for change. It is a not uncommon spirit in people fired to put right the imperfections of health care services. Such drive is a vital force in overcoming inertia. It tends to slam doors noisily and knock them off their hinges as well, sometimes! For Illich, efforts and opportunities for change are seen through a lens focused on deprivation, disadvantage and the forces that conspire to deny or limit access to education, save to those possessing wealth and power; to which one might now add luck and access to the Internet!

For Illich, modern day city life was akin to the Hell of classical mythology. For him, the story of Prometheus and the fire was a parable of how schooling had become a conditioning, creating a world in which there is great sense of expectation and little sense of hope.<sup>64</sup> He saw the computer as amplifying that hell, saying:

The Pythia of Delphi [the Oracle] has now been replaced by a computer which hovers above panels and punch cards. The hexameters of the oracle have given way to 16-bit codes of instructions. Man the helmsman has turned the reader over to the cybernetic machine. The ultimate machine emerges to direct our destinies.<sup>65</sup>

Notwithstanding his florid apprehension of George Orwell's *1984*, and a Novacene era, it is interesting to note that fulfilment of his four wishes has been substantially enabled by the computer technology he parodied!

In wishing for something better, he wrote of education as an agent of decline in the ideal state characterized in Plato's *Republic*, in which:

Man assumed responsibility for the laws under which he wanted to live and for the casting of the environment into his own image. Primitive initiation by Mother Earth into mythical life was transformed into the

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64 According to legend, Prometheus stole fire from the gods and gave it to humanity, interpreted as a gift in the form of technology, knowledge and civilization, aiming to cure human ills but betimes leading to overreach and unintended consequence. There are several stories about how Zeus, the king of the gods, took vengeance by condemning Prometheus to eternal torment and presenting Pandora to Prometheus's brother Epimetheus. Pandora opened a jar (or box, as it became known) left in her care and out of it came sickness, death and other evils that spread into the world. Only hope, or in a pessimistic translation of the Greek, 'deceptive expectation', remained when she hurriedly closed the jar.

65 Illich, *Deschooling Society*, p. 115.

education (paedia) of the citizen who would feel at home in the forum. To the primitive, the world was governed by fate, fact, and necessity. By stealing fire from the gods, Prometheus turned facts into problems, called necessity into question and defied fate.<sup>66</sup>

He described modern day institutions built in this tradition as creating ‘needs faster than they can create satisfaction, and in the process of trying to meet the needs they generate, they consume the earth’, and ‘surreptitiously, reliance on institutional process has replaced dependence on personal goodwill’.<sup>67</sup> Drawing conclusions from these Greek myths, the final paragraphs of the book are a plea for humanity to rediscover purpose, freed from the dictates and chains of *status quo*, and collaborating for the common good.

At this point, the Greek myth turns into hopeful prophecy because it tells us that the son of Prometheus was Deucalion, the Helmsman of the Ark who like Noah outrode the flood to become the father of a new mankind which he made from the earth with Pyrrha, the daughter of Epimetheus and Pandora. We are gaining insight into the meaning of the Pythos which Pandora brought from the gods as being the inverse of the Box: our Vessel and Ark.

We need a name for those who collaborate with their Promethean brother in the lighting of the fire and the shaping of iron, but who do so to enhance their ability to tend and care and wait upon the other.<sup>68</sup>

On reading this again, I was reminded of the altogether more satirical and subversive rewriting of stories of the Noah’s Ark, in Julian Barnes’ *A History of the World in 10½ Chapters*. In the first chapter, Noah is a questionable character focused on self-preservation rather than a new mankind, and the animals an exploited means to that end, rather than as citizens of a new earth.<sup>69</sup> Barnes reveals the identity of the narrator of this story as a woodworm on board, only in the chapter’s final sentence—like a death sentence! Myth, rhetoric and satire are close bedfellows and feed from one another!

Coming back to earth, I move now to the late 1970s, when the future impact of information technology on medical education and assessment came under critical scrutiny. As with Octo Barnett’s foundational 1977 report on policy implications of medical information systems, as discussed in Chapter Seven, an early overview came from the US Congress Office of

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66 Ibid., p. 107.

67 Ibid., p. 111.

68 Ibid., p. 115.

69 J. Barnes, *A History of the World in 10½ Chapters* (New York: Knopf, 1989).

Technology Assessment. This 1979 report entitled *Computer Technology in Medical Education and Assessment*, which I also quoted from in Chapter Seven, brought together leaders from across acute medicine, community medicine, sociology, economics, social security, statistics, consumer affairs, health care providers and research foundations. The scope set was again a wide one, covering education and assessment and its interaction with computer-based materials. It looked at undergraduate and postgraduate training and their both formal and informal connections with patient care and life-long learning. It set these alongside changing regulatory requirements for validation and revalidation of clinical skills, considered in the context of quality of care provided—structure, process and outcome.

A key paragraph in the conclusions is as follows:

The use of computers in education assessment inevitably will be linked to their uses in medical information systems. Such linkage will allow, if not force, the formation of new relationships between segments of the medical education and assessment continuum, through the accumulation of large databases on student characteristics and performance, on physician and institutional performance in patient care, and on patient outcomes following treatment. These databases could serve as the thread of continuity between portions of the continuum. They could provide more objective and quantitative feedback mechanisms from active practice to education.<sup>70</sup>

This future-facing perspective was my rationale when seeking to connect clinical skills and informatics, as parallel themes of my first department at Bart's, after conferment of my professorial position there. Clinical education is preparation for clinical profession, and its future thus connects directly with the previous section of the book and its focus on the future of the professions in the Information Age. I reflect on how this ambition has played out, in Chapter Nine.

The story now moves on to think about the pathway ahead for creating a care information utility, in the context of global village citizenship and evolving health care services and professional communities of practice of the future. Guided by the foregoing perspectives on the transition of knowledge and discipline, professional practice and education, how can we establish a common mission—or, at least, a common ground of mission—that evolves forward in the context and spirit of these transitions, engaging fully

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70 Congress of the United States Office of Technology Assessment, *Computer Technology in Medical Education and Assessment* (Washington, DC: Congress of the United States Office of Technology Assessment, 1979), p. 5, <https://www.princeton.edu/~ota/disk3/1979/7903/7903.PDF>

with future health care professionals and services, and the individuals and communities they serve?

As I describe in Chapter Nine, this landscape is already starting to assemble, through co-creation and sharing of common intellectual property, standardization of platform infrastructure and the transforming potential of personalized medicine and self-care in home and local community environments. Also, in the light of a transforming public health and societal focus that balances better between the curative, preventative and caring aspects of health care. On this new landscape, and only there, can and will crystallize care information utility of the kind that is needed—supporting better balance, continuity and governance of ways of working, on all sides. Creative commons, open platform, Globalton governance of the information infrastructure and standards and Localton governance of the information utility itself, with inclusive community ownership, participation in and leadership of the enterprise. That has been the inspiration and innovation of openEHR—it was an idea, is an experiment and is halfway to becoming a reality. Its exploratory and incremental implementation and adoption in health care organizations and communities, worldwide, is described in Chapter Eight and a Half, which gives context and evidence of progress.

## Artificial Intelligence

As introduced briefly in Chapter Two, in 2019 the renowned American cardiologist, Eric Topol, published *Deep Medicine*.<sup>71</sup> Microsoft Word interprets my dictation of his name as ‘Eric top hole’, and the book certainly is that! I intend no disrespect in also characterizing it as a topology of future medicine. It is an admirably articulate and thoughtful book—an extensively contextualized and deeply felt *cri de coeur*, grounded in both personal experience of health care and a luminary career in clinical practice and medical research, in America over the past forty years. I unfold his thinking, here. In Chapter Ten, I step back and reflect on the 2023 crescendo of concern about the impact of rapidly evolving artificial intelligence (AI) on human society, especially in the context of health care governance. Many of these fears have been imagined long ago and before the Information Age, in the writings of E. M. Forster (*The Machine Stops*), Aldous Huxley (*Brave New World*), George Orwell (1984) and in the recent novels of Ian McEwan (*Machines Like Me*) and Kazuo Ishiguro (*Klara and the Sun*). These have already surfaced at several points in the storyline of this book.

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<sup>71</sup> Topol, *Deep Medicine*.



In Topol's introduction to the book, he lays out his stall with impactful simplicity:

Now, the highest ever proportion of doctors and nurses are experiencing burnout and depression owing to their inability to provide real care to patients, which was their basis for pursuing a medical career. What's wrong in healthcare today is that it's missing care. That is, we generally, as doctors, don't get to really care for patients enough. And patients don't feel they are cared for.<sup>72</sup>

I often hear this story, and the word 'broken', from the front line of UK medicine, too, where my children and their friends and partners work, and from retired colleagues experiencing that world, now as patients. They have experience, and words, too, about breakdown on the patient's side of the relationship.

Topol's starting point for his book is bleak:

This is where we are today: patients exist in a world of insufficient data, insufficient time, insufficient context, and insufficient presence. Or as I say a world of shallow medicine.<sup>73</sup>

He nowhere minces words. Anyone thinking about the future of health care should read them and reflect. In relation to 'Shallow Medicine', Topol's word cloud is both sobering and sad,<sup>74</sup> in its panorama of patients' two-word characterizations of their doctors. I make no comment about this; it is better to leave this to admirable doctors, like Topol.

In his Introduction, Topol characterizes his book as being '[...] all about finding the right balance of the patients, doctors, and machines. If we can do that—if we can exploit machines' unique strengths to foster an improved bond between humans—we'll have found a vital remedy for what profoundly ails medicine of today'.<sup>75</sup> He concludes that section of the book, emphatically, saying that 'The rise of machines has to be accompanied by heightened humaneness—with more time together, compassion, and tenderness—to make the care in health care real. To restore and promote care. Period'.<sup>76</sup>

The themes developed and examples provided throughout the book are compelling reading, placing personal experience as a patient alongside insightful professional commentary as a doctor. His story, too, conveys much personal songline. In contextualizing the advent of AI and its interaction

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72 Ibid., p. 18.

73 Ibid., p. 31.

74 See *ibid.*, p. 29.

75 Ibid., p. 20.

76 Ibid., p. 21.

with the nature and practice of medicine, he contrasts ‘Shallow Medicine’ with a ‘Deep Medicine’, informed by and realizing the benefits that AI already does and can, in future, increasingly bring. This he sees as improving insight that guides diagnosis, choice and effectiveness of interventions and workflow, thereby substantially relieving much of the waste and inefficiency, errors and inconsistencies, and time and money pressures that have grown to a breaking point in the Information Age. With his uniquely informed patient and clinician eye, and as a doyen of medicine’s coevolution with AI, he gives chapter by chapter examples, throughout health care, placing advances made in AI in the context of what is done today and can and could be done better with machines.

He devotes his fifth chapter to highlight new liabilities that arise in these contexts, as authority and responsibility are delegated to machines. He explores how the traditional arts of medicine, in building a trusted and attentive relationship with patients, hearing their individual stories and concerns, can be enhanced within the context of algorithms that can be more adept at discovering patterns that clarify diagnosis and guide treatment options and their effectiveness. His forthright views on the failings of Industrial Age systems and services and their wider context and cost in society are breathtakingly frank! The book is avowedly a call to arms for clinical professionals to stand up against the forces in society he sees as destroying them. He sees huge potential and imperative for reinvention of this landscape, such as in mental health, which gets a whole chapter, as does discovery science, informed by AI, which can in turn throw new light on ‘Deep Diet’ and lifestyle choices, and the way in which this knowledge can be brought directly to individual citizens.

In discussing the IBM Watson system that seeks to improve diagnostic acumen across medical practice, he is cautious and adds an impactful comment that:

There is certainly potential for computing to make a major difference, so far there has been minimal delivery on the promise. The difficulties in assembly and aggregation of the data have been underestimated, not just by Watson but all tech companies getting involved with healthcare.<sup>77</sup>

This very much mirrors my own experience of the health IT industry forays into the health care world over the past fifty years. It has provided key context and motivation of my own work in building initiatives such as openEHR and OpenEyes, and now, I hope and intend, openCare. Topol’s book is forthright in its comments about much of that industry—for example,

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<sup>77</sup> Ibid., p. 56.

in a punchy aside, relating a restrictive contract requiring that clinicians in institutions adopting a particular market-leading product should make no public commentary criticizing its use! Jose Collados is approvingly quoted for what Topol says is a sharp critique of lack of transparent and understandable explanation and verification of AI methods and 'growing (often self-interested) misinformation and mystification of the field'.<sup>78</sup>

With regard to the still early days of AI, Topol quotes François Chollet, a Google deep learning specialist, saying 'There's no practical path from superhuman performance in thousands of narrow vertical tasks to the general intelligence and common sense of a toddler'.<sup>79</sup> He comments that 'It's the combination of AI learning with key human specific features like common sense that is alluring for medicine', and cautions that:

Progress made should not bypass the time accepted validation of the expert peer review process. Further, the majority of medical studies published to date are retrospective, performed *in silico*, yet to be prospectively validated in a real-world clinical setting.<sup>80</sup>

In relation to malpractice avoidance, he highlights failures of documentation and casts a critical eye over the failings of the industry's electronic health record products.<sup>81</sup> He is sceptical of Web-based diagnosis-noting that symptoms and signs are not binary (0-1) entities, and that ways of expressing them, and the associated body language, are important indicants not achievable in such systems.<sup>82</sup>

The book, overall, is a threefold story of Deep Medicine as a triad (Topol uses the word triad where I, as an engineer, prefer tripod, perhaps also preferring to keep feet stably on the ground and not be associated in the mind with secret society involved in organized crime!) of machine-enhanced understanding of Deep Phenotype, Deep Learning about life science and medicine and Deep Empathy in relationship of doctor and patient. Topol sees this synergy as the basis for recovery from the multiple present-day failings he describes throughout the book, which have degraded time and presence of doctors in their connection with the unique life stories and needs of their patients and achieved much less by way of successful outcomes in relation to money spent. Reading his brief mentions of the DeepMind company, I wondered what cross-fertilization there might have been, there, connecting with his evident passion for the 'Deep'.

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78 *Ibid.*, p. 94.

79 *Ibid.*, p. 92.

80 *Ibid.*, p. 94.

81 *Ibid.*, p. 50.

82 *Ibid.*, p. 52.

The final chapter of the book is entitled Deep Empathy and is headed by a quotation from my dad's much read and pondered Aldous Huxley—as I recounted in the tour of the horizons of my bookshelves in the Introduction!

By these means we may hope to achieve not indeed a brave new world, no sort of perfectionist utopia, but the more modest and much more desirable objective- a genuinely human society.<sup>83</sup>

This chapter is once again a *cri de coeur* about the decline of empathy and what Deep Empathy might look like in a world where the interface of machine and AI with everyday life, and everyday medical practice, is evolving into the new era he envisages. He quotes Anatole Broyard in saying that 'In learning to talk to his patients, the doctor may talk himself back into loving his work. He has little to lose and much to gain by letting the sick man into his heart'.<sup>84</sup> He explores what it is to be human in this age, and what will be gained by recapturing the gifts of time and presence in the encounter with patients. His 'Shallow Medicine' has, he says, hugely truncated time for individual consultation, and likewise impoverished listening to patients, with clinicians finding themselves spending excessive amounts of time facing computer screens. I reflected on reading all this that his book does not address more widely the broader issue of young eyes connecting more to screens than to other eyes and minds. It is a huge topic of conversation and concern in our families. Excessive screen use in developmental years appears now to hasten myopic eyesight. We do not know what change may emerge in 'mindsight'.

For Topol, reinvention of clinicians' practice requires that they recover a sense of physical presence within the domain that they serve. I reflected that nursing and paramedical professions may have kept this presence more successfully than doctors, although, in my experience, they are also too often unduly beset by screens. He reflects on the changing relationship between doctor and patient in this new world and the changing priorities of medical education, matched to a culture centred more on care and less on cure.

He ends with this most heartfelt of paragraphs, once again elevating medicine as mission of care:

But it's hard to beat the boost from a doctor or clinician you trust who can bolster your confidence that it will pass, that he or she will be with you no matter what. That you'll be okay. That's the human caring we desperately seek when we are sick. That's what AI can help restore. We may never have another shot like this one. Let's take it.<sup>85</sup>

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83 Quoted in *ibid.*, p. 82.

84 Quoted in *ibid.*, p. 82.

85 *Ibid.*, p. 310.

That is why, in my world of health informatics, I have worked to help imagine, focus and create a care information utility, and openCare.

## Human Connection in the Global Village

If the care information utility is to take root in a local community context, what will that community look like in the future. We are midway in transition from the Localton context of my childhood to the Globalton context of tomorrow. It is a soul-searching era—what do we want it to look like?

Important human connections have been broken and are being remade differently. ‘Company’ as a term, as Gillian Tett reminds us, derives from the Italian for the sharing of bread.<sup>86</sup> Good company characterizes human connection. The commercial company embodied a different orientation based on money and markets, but this is also in transition, with today’s corporate identity reorientating from one centred on shareholder ownership and value, to one embracing stakeholder interest and value. Enterprise that can embrace and be co-created by a mix of citizen, community, profession, organization, industry and political stakeholders is drawn together, and balanced within the new UK legal model of the asset-locked community interest company.<sup>87</sup>

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86 G. Tett, *Anthro-Vision: A New Way to See in Business and Life* (New York: Simon and Schuster, 2021).

87 The lawyer who led the preparation of the legal framework of the Community Interest Company (CIC) in the UK, Stephen Lloyd, was a fellow trustee of mine in the charity, StartHere. This pioneered an information system and kiosks where citizens could readily access information about local and global support services available to them, to provide help and support when they did not know where to turn. This was, essentially, an example of a prototype citizen-centred information utility. It struggled to gain traction, in large part, it seemed, because of the fears of existing groups and interests that did not wish to have their perceived ownership of individual channels of communication usurped or destabilized, and others who saw themselves as the rightful owners of responsibility to integrate them, in different contexts. Like the APoGI project of CHIME at UCL, discussed above in context of Bernadette Modell’s pioneering vision, it sought to provide a single point of access and a manageable balance and continuity of information provided, configured to suit different audiences. I describe StartHere and its founders and motivational leaders, Sarah Hamilton-Fairley and Richard Crofton in Chapter Nine. I tried, and failed, to gain traction between this kind of information service and the openly standardized care records approach I was helping to pioneer in the openEHR care records platform and OpenEyes, as featured in Chapter Eight and a Half. The industries and services of the day fought to preserve their fragmented identities and associated silo information environments, albeit often to the detriment of the communities served, that became easily overwhelmed by the complexity involved in navigating the non-coherent information environments

Working in the office is moving to a new balance with working at home. Health care services are also transitioning into new balance, continuity and governance, centred on the citizen and this wider and more inclusive concept and sense of community interest. We think of 2020 vision as a metaphor of balance. We are still only halfway there towards finding balance in support for the health care needs of the global village. We are unbalanced regarding lifespan and lifestyle. Not so much, now, in what we know, but rather in knowing how to use our knowledge, and deciding and being responsible for what we wish for, and what we do.

The start of my songline was as a villager in Woolton Hill, in rural Hampshire. In the 2020s, I am a retired global villager in Fleetville, on the edge of the ancient city of St Albans. This global village has shops and services way beyond those of my childhood village. In greenbelt-protected countryside just to the north is the ancient and newly planted Heartwood Forest, connected along cycle routes from Fleetville, where most of daily needs can be met within walking distance. The city centre is a mile away and a trading estate is a mile in the other direction. It is one of the busiest communities of London commuters, with trains every few minutes to London, and a partly monorail connection to Luton Airport, to the north. Covid-19 has significantly changed the scale of commuter travel to the office, with a newfound emphasis on remote work and increased activity and engagement in local community life and liveliness.

During the pandemic, local support groups have sprung up along our street and along others everywhere. Friends and family are near and far away—hundreds of miles in the UK and thousands of miles across Europe, the Americas and Africa. Some are nearby in the virtual world, and far away in the real world. Letters by post are mostly a bygone practice, almost unknown to a younger generation more familiar with communication through gifs, emojis and video-hosting platforms such as TikTok. Christmas parcels and letters have taken six weeks to cross the globe, this year. Virtual connectedness relies on an information infrastructure that we depend on and notice most in its failings or absence. Signalling failures delaying trains for hours, power cuts, gas leaks and water pipe bursts are quite rare, disorientating and disabling events. When broadband fails, it can bring life to an almost immediate halt. The electricity appetite of the Cloud is way too ravenous!

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that prevailed. Lloyd's law firm, Bates Wells & Braithwaite, helped me hugely, in later years, in steering the transition of the globally expanding operations of the openEHR Foundation, into the framework of the self-governing openEHR International Community Interest Company (CIC).

Despite the advancing media of communication and practice in the virtual world, there remain countervailing feelings of social isolation in the real world, mitigated by pets, and some say, in future, robots. It might be tempting to put this down to people getting older, but the travails of the young through the past year of pandemic that I have felt and engaged with as a grandparent, indicate that this isolation spans generations. It is interesting to see how strongly Globaltons have sought new local virtual connection during their Covid physical isolation. Isolation and polarization go hand in hand as fear gives way to anger. The adversarial, bordering on hostile, half and half, 50:50 politics of our age reflects this. Infectious and manipulable social instabilities, such as those that arose five hundred years ago, stoked by fixations with satanic practices and unleashed by the invention of the printing press, are coming into view again, today, with similar fixations, unleashed and amplified by the Internet.

Living through the uncertainty of disequilibrium is polarizing. Mervyn King describes it as radical uncertainty. Uncertainty does not preclude clarity, but lack of clarity fuels uncertainty. As Levi wrote, in *Other People's Trades*, having lived through the stark inhumanity of the 1930s and wartime in Europe, humankind often reacts to uncertainty by dividing into polarized opposite groupings. Voltaire (1694–1778) wrote that uncertainty is uncomfortable, but certainty is absurd. And William Butler Yeats wrote of how in such times, 'things fall apart; the centre cannot hold'.<sup>88</sup> Societal polarization is about falling apart. A polarizing filter passes light according to the orientation of its component electromagnetic field. Information systems filter human knowledge and experience, according to the orientations of their creators and users, both enhancing and countering enlightenment.

And social media as an information utility is increasingly anarchic. In the sense that knowledge is information with causal power, its causal nature, both positive and negative, becomes more apparent, and its balance is brought into question. Francis Bacon (1561–1626) wrote that knowledge, itself, is power. Power is an energy and capacity; acquiring and expressing power and control in life is a vital instinct. Powerful human instinct seeks to control knowledge. Anarchy and chaos mean without form. For some, anarchy feels attractive as a rebellion and a counter against perceived arbitrary power. Other mindsets exploit and manipulate anarchy to gain and sustain arbitrary power.

But complexity does not imply chaos; the simplest of mathematical equations can exhibit chaotic solutions—some beautiful, such as the fractal Mandelbrot patterns. Living organisms are complex but life is not inherently

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88 'The Second Coming' (1919), l. 3.

chaotic. A living organism can and does progress through states of chaos in well-marked transitions—cell division has been described as chaotic transition. But it cannot be reverse engineered back to a previous ordered state—the two cells, reemerging as one. The biochemical and physiological chaotic imbalance of sepsis can be arrested, controlled and placed in a new environment, consistent with progress towards recovery, normal function and future growth and development, allowing the imbalances to settle and be put right.

Learning is the assimilation of knowledge into the way that we do things. Learning can be a painful process. Many lives go through periods that might be described as chaotic. Some gain strength and security in surviving and coping with this adversity, and in facing and learning from the experience of personal vulnerability and insecurity that they entail. Many more cannot manage and become ill. T. S. Eliot describes April, the month of Spring and new growth, as ‘the cruellest month’.<sup>89</sup> My dad—who throughout his ninety-four years of life battled feelings of personal inadequacy, which he attributed to both childhood poverty and lack of formal education—introduced me to that thought. His was cruel learning. He did not learn to be cruel, except a bit, perhaps, to himself, but many do.

In the Information Age, we are exploring and experiencing change and transition on every scale, from the smallest to the largest. We have acquired immense new knowledge, through observation and experiment. This knowledge holds causative power on the scale of atomic warfare, pandemic diseases and irreversible climate change. But it can be a well-marked transition, as Whitehead characterized, and our responsibility, halfway through, is to take time to understand, characterize, cope with and mark and shape it as best we can. When we are called upon to make choices, we have many options on which to place our X.

We should not trust or rely on prediction of the future as if it were a historical narrative. We must create our future in a Popperian Open Society blessed with an infinity of possible futures. The imaginative dualism of theory and experiment ties together and makes science. The practical dualism of design and implementation ties together and makes and sustains innovation. Both we describe as creative, and, as Marcus du Sautoy writes in *The Creativity Code*, the creativity of art and science may at some stage be exceeded by machine intelligence.<sup>90</sup> As Weizenbaum cautioned, humane behaviour and the experience of community are at risk in the transition.<sup>91</sup>

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89 T. S. Eliot, ‘The Waste Land’, l. 1.

90 M. du Sautoy, *The Creativity Code: How AI Is Learning to Write, Paint and Think* (Cambridge, MA: Harvard University Press, 2019).

91 Weizenbaum, *Computer Power*.



How we guard against that is a challenge for another balance on which stable society will increasingly depend—that of private ownership and sharing of knowledge.

We need a bridge across these troubled waters of transition. Returning to etymologies, the term *pontiff* derives from the Latin for bridge. In contemporary connotation, it sometimes implies the hubris and bravado of pontification, positing knowledge of an uncertain, unfolding future. Building bridges combines purpose and belief, encompassing questions of *where, how* and *why*; of the science of materials and methods, design and leadership. It involves determining the optimal location for the bridge, and possessing the determination and resources to construct it and successfully cross it. And in creating the Information Society, the *who* is everyone—we are all bridge builders.

It is a great challenge of leadership in times of great uncertainty, to imagine, learn how to and build bridges, and lead across them. Trust in leadership is crucial and clarity and honesty are key foundations of trust. It may or may not require greatness, which is, in any case, neither born to, acquired or bestowed. It is earned and shown, not told. As Norman Davies said, for every person wanting to tell, there are twenty who do not want to hear!

To assert humanity and exhibit humility, civilized life needs three things: safe and dependable home ground and means of navigation beyond, common ground for inspiring and sharing improvement, and equitable governance whereby both local and global village citizens are participators in, and not just consumers of, the estate. This reality extends to private and corporate balance. The corporate world needs new regulation, extending beyond legal articulations of consumer interest and detriment. Democracy needs a fresh perspective and balance of rights and responsibilities. Of course, there is a lot of wreckage to stabilize in the global village and make sustainable through a new sense of ecology and ecosystem, as and when the storms and chaos of anarchic transition subside, which will take as long as it takes.

At the heart of all this for health care will be new care information utility and infrastructure—both social and technical. We need a practical sense of the form it can now start to take and how it will be created. This is the hitherto elusive ‘how’ imperative of care information utility. Information with causal power must be underpinned, justified and trusted, with clarity about method showing how it operates. It will either be democratic and led by democrats or it will be autocratic and led by autocrats and oligarchs, sometimes criminal ones! The 50:50 balance of so much political discord of the day reflects that we do not yet know where to head or whether to turn tail; we are effectively flipping a coin to decide. Policy for such an uncertain

domain is almost intractably hard. In the Appendix III of the book's additional resources, I describe what I saw of governmental implementation of the policy framework I traced in Chapter Seven, addressing the wicked problem of health care information.<sup>92</sup> I offer this material in an Appendix because I do not wish to reflect on and critique this challenging era at this point in the story; instead, my focus here is on a different reality, of how we can now progress from where we are, towards the creation of an information utility fit for the future.

### Characterization of the Care Information Utility— Perspective, Approach and Implementation

Since the early 1990s, a principal focus of my work has been directed towards realizing a coherent ecosystem of care records. Characterization of this endeavour boiled down to three interacting elements—perspective, approach and implementation. In embryonic terms, these might be termed conception, description and inscription—the framing and germination of ideas, their further elaboration and the enactment of their iterative and incremental realization in practice. Somewhat fuzzy and abstract triangulations of concerns, like this one, helped in understanding, communicating and keeping abreast of the complex balances in play. The wider context of the endeavour concerned matters of subscription—about resources, finance and governance. Who plays, who pays, and the means, rules and understandings whereby they do so. This chapter focuses mainly on perspective and approach; the next one on approach and implementation.

I summarized the *status quo* some years ago like this (see Figure 8.18). Much has remained essentially the same for fifty years.

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92 Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

## The current scene

- Biomedical science is being transformed
  - 'bioinformatics is core discipline of biology' – Royal Society 2005
- Health care and research are increasingly technology and information intensive
  - 'information is the heart of medicine' – BMA 1994
- Multiple legacy information systems are in use
  - supporting and linking health care, research and industry
- Governments want pervasive and standardised (open-source) ICT infrastructure for health care
- Other initiatives, commercial and public domain, are creating relevant infrastructures and de facto standards

Fig. 8.18 The current scene of health care computing, spanning fifty years. Image created by David Ingram (2010), CC BY-NC.



In terms of clinical effectiveness, the picture presented in the UK NHS Priorities and Planning Guidance (1996/97) is as follows:<sup>93</sup>

93 NHS Executive, *Priorities and Planning: Guidance for the NHS 1996/97* (Leeds: HMSO, 1996).

## Promoting clinical effectiveness

- UK NHS priorities and planning guidance, 1996/97

- Show sources of information used to judge effectiveness of services
- use evidence of outcomes and results of audit to secure changes in effectiveness of services
- use information to help patients have better understanding of treatments
- make significant changes to investment in interventions on basis of evidence

Fig. 8.19 The NHS clinical effectiveness drive from twenty-five years ago. Image created by David Ingram (2010), CC BY-NC.




This feels like a perspective as viewed from high up, in a helicopter; more concerned about the secondary uses of data than on its primary purposes and provenance, supportive of and building from the everyday needs of citizens and professionals, in care services on the ground. The patient feels here to be more data source than data owner—a cash cow of data serving other parties' needs and interests. This perspective does little to help build a sense of a community that is able, enabled and trusting to use information as a utility for conducting and improving services, or to enable patients to own their personal data and participate more fully, with greater oversight should they desire it, in their encounters with the professional teams working on their behalf.

The focus of recent decades has certainly moved towards a more citizen-centred perspective and approach, as illustrated in successive policies adopted in the EU Framework Programme objectives for health care (see Figure 8.20), but with too little of the investments in national programmes directed to involving and enabling citizens to manage their health care issues more effectively, from their local and home-based environments. In this evolution, there will be much to be learned about the recording and sharing of personal data, and its governance within records of care and more widely. Transparency within this domain should not, though, be approached as a universal good. Sharing uncertain, distressing or potentially contentious health-related matters involves both personal and professional balances that must be approached sensitively on all sides, negotiated and learned.

## EU Framework Programme

- objectives for health care, 1989

- Unify European activities by providing the means for efficient communication of medical records and knowledge so that these may be understood and compatible, thereby permitting the integration of health information systems
- Strengthen competitiveness ... , Improve the quality of life ...
- AIM Framework 4, The GEHR Project, 1991-1994; to research and prototype the foundations of electronic health record architecture
- FW5, Services for Citizens
- FW6, Knowledge Centres and the GRID
- FW7, Integrated projects, Networks of Excellence



*Niels Rossing, DG of AIM*

Fig. 8.20 The contrasting perspectives of the AIM Third and Fifth Framework Programme objectives for health care—from patient as data source for systems to systems serving the needs of citizens. Image created by David Ingram (2010), CC BY-NC.



In the mid-1990s I worked closely with an innovative young hospital manager, Flemming Rosleff, who was busy transforming health care services in the Vejle Municipality in Denmark. He had read about the work I was doing for the Marie Curie Foundation with Bob Jones and Ilora Finlay, and invited Bob and me to give a talk at his hospital, about the *Cancer Patients and their Families at Home* videodisc educational resource we had developed together.<sup>94</sup> Flemming subsequently worked as a management consultant for Coopers and Lybrand in London. He wrote an influential report on managed care systems in Europe, in which he identified the need for a new generation of information systems to support services.<sup>95</sup> This is the scope he set out there (see Figure 8.21). This, too, has the flavour of a helicopter perspective. We might now think of the challenge also from a perspective of self-management of care.

94 D. Ingram, R. V. H. Jones, I. Finlay and A. Lant, 'An Interactive Videodisc "Cancer Patients and Their Families at Home"', Designed for Education in Primary Health Care', *Journal of Audiovisual Media in Medicine*, 15.2 (1992), 73–76.

95 F. Rosleff, *European Healthcare Trends: Towards Managed Care in Europe* (London: Coopers and Lybrand, 1995).

## A definition of managed care

- To maximise health gain of a community
  - within limited resources
  - by appropriate range and level of services
  - by monitoring on a case-by-case basis
- To continuously improve care
- To meet national targets for health and individual health needs

requires redesign of information systems

*Rosleff, [European Healthcare Trends, Towards Managed Care in Europe, 1995](#)*

Fig. 8.21 Flemming Rosleff's definition of managed care. Image created by David Ingram (2010), CC BY-NC.



The following sections are about the values and principles framing the information systems that this would require and the mode of their standardization. They need to be based on common ground that provides scope to accommodate diversity of individual need, preference and choice, and foster innovation, as opportunities arise, and times change. The more simply the choices facing citizens are identified, the more likely they are to be communicated, weighed and acted on effectively. At the centre of this common ground is the care record. Its principal stakeholders are patients and their families, and the professional teams they connect with in their care. Other records and resources, centred in many associated institutions and industries, will connect with this common ground, both to supply data captured in the record, and make wider use of it.

## Values

Our culture and the human values we subscribe to say who we are and are central to our human connections and what matters to us. The governance of the care information utility must reflect and be inclusive of all who create, operate and depend on it—this is the only way to grow and maintain mutual trust, which is what matters most. Communities that realize and sustain the utility will need to see themselves as being locally centred and globally integrated. They will share methods globally and customize and deploy them in line with local needs. Their culture should be one that thinks for itself and has self-belief. The utility will have fractal connectivity in two directions—from the individual citizen connecting within health care systems and services, locally and globally, and from each global component of these systems, ramifying to each individual citizen, locally. These twin perspectives are anchored within common ground of shared knowledge, method, environment and community.

It is in the relationship of the two perspectives that we struggle to achieve balance, continuity and governance of services, and make them mutually coherent. Where they are not coherent, their computational counterparts—the artefacts separately implemented in many parts of the information ecosystem, to address needs perceived there—will reflect this incoherence and amplify its confusions. In the Information Age, actors in different businesses, institutions, professions, voluntary services and local and national governments, have all, individually, invented and propagated information appliances and systems according to their own take on the semantics of the domain they connect with and the purposes to be served. Taken together, they are assembling, albeit largely unwittingly, a non-coherent and tottering data and computational tower of Babel. A new culture of community enterprise must start to deconstruct and reconstruct this reality and build towards an information utility based on common ground of human meaning and computational semantics, whereby people can communicate safely and effectively, with and through the computational web.

Three quotations characterize the energy and approach required within such community if it is to succeed. They resonate with culture and values more generally.

The ultimate hidden truth of the world is that it is something we make and could just as easily make differently.<sup>96</sup>

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96 D. Graeber, *The Utopia of Rules: On Technology, Stupidity, and the Secret Joys of Bureaucracy* (New York: Melville House, 2015), p. 89.

This is about self-belief and self-reliance. We all make health care—looking after ourselves and those we care for, and in relationship with those who care for us: family, friends, community and professions. We own our personal health care needs. People given trusted and shared means and methods to connect with one another, in meeting their own and other peoples' needs, are every day inspired with energy to do so productively.

We may become the makers of our fate when we have ceased to pose as its prophets.<sup>97</sup>

This is about realism in the here and now and avoidance of hubris and pretence of knowledge in prediction of the future. We should attend to making and doing what needs making and doing now and prepare, as best we can, for a future that is unknown and unpredictable.

In the end, therefore, intellectual definitions raise more questions than they answer. It is the same with European history. As with a camel the practical approach is not to try and define it but to describe it.<sup>98</sup>

This is caution against burrowing too deeply, hedgehog-like, into the fractal complexity of current anarchic realities, but to stay more straightforwardly focused on the simpler elements that can provide traction in meeting health care needs. We should accept that the present transition into the Information Society is complex and anarchic—we should observe and describe it and not attempt, too much, to define it. Describing and defining go hand in hand in theory and experiment of science. In social matters, we learn to cope with, as well as describe, the here and now, before we can reasonably know how to rationalize, shape and manage the unfolding future. The quotation is in tune with Mervyn King's reflection that managing complexity of the world financial system should focus on telling stories that assist in coping with it, as much as in predicting and shaping it. They are both arguing for a more human balance of hand and head. Norman Davies also wrote *Heart of Europe: A Short History of Poland*, alluding to heart as culture and soul, as well as central location.<sup>99</sup>

It would be interesting to have heard the thoughts of Illich about the culture of transition of society in the Information Age. In the prospectus for *Medical Nemesis*, he argued that the principal challenge in health care is a human challenge of recovering and reinstating human autonomy and

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97 K. Popper, *The Open Society and Its Enemies: The Spell of Plato* (London: Routledge and Kegan Paul, 1957), p. xxxvii.

98 N. Davies, *Europe: A History* (Oxford: Oxford University Press, 1996), p. 46.

99 N. Davies, *Heart of Europe: A Short History of Poland* (Oxford: Oxford University Press, 1984).



pursuing health as a human task and virtue. He described it as a 'rediscovery' that effective health care depends on self-care. Concerned by what he saw as 'iatrogenic disease' arising from the practice of medicine, his diagnosis was that an over-dependence on medical oversight was ultimately disabling, turning humankind into lifelong patients. He proposed legislation that would rebalance society towards autonomy and self-care, and away from an industrial culture built on the medicalization of life. He even proposed to outlaw all technology that could not be operated in the hands of lay people—a trifle exuberant, perhaps—truly, a folk medicine of the Information Age!

Leaving the more ideological aside, one might observe that in the changed scientific and technological landscape of the Information Age, the evolving pattern of health care services has recognized and adjusted to much of the reality that underlay Illich's observation and perspective of fifty years ago. He was a Tillich-like figure, seeking to shake the foundations of orthodoxy in medical practice, in the way that Tillich described the shaking foundations of religious belief—a nice conjunction of names and missions! Likewise, in *Deschooling Society*, his perspective of education was built on autonomy of the life-long learner. His advocacy was for technology-driven learning webs, within which learners and their teachers could communicate and be informed, beyond the constraints and manipulations he identified with schooling institutions and their governance. Although richly polemical, it succeeded in anticipating and addressing contemporary concerns of today, as such technology and method reveal themselves, and their benefits and limitations unfold more widely, including in the health care of our changing times.

Coping is an essential frontline strategy for anarchic times. Coping is frontline in health care. If autonomous citizens are to be co-creators with professionals of their health care, and participate in maintaining its balance and continuity, under a co-created governance arrangement, they must have the option and wherewithal to manage their health care as much as they are able, prepared and wish to do so, and to be supported, as far as possible, when in need.

To envisage information systems with all this in mind is not to say that health care services could or would be organized and enacted in a spirit of 'you're on your own, Jack'. It will, rather, reflect the requirements of community wherein patients and their advocates can connect with professionals and services, protecting personal autonomy and sharing roles and resources in ways that are negotiated and agreed as balanced and equitable on both sides, and embodied in clear and stable governance arrangements. It will require ways of working that embody fairness in the balance of rights and responsibilities—of both givers and receivers.

Where we fail adequately to cope with the changing cultural dimensions of balance, continuity and governance of health care, computerization will further exacerbate difficulties. Load the rifles with computer-enabled silver bullets, and use them to kill disease, but do not expect this to clear the fog (elision of fox and hedgehog, remember!) of confusion caused by computerization of the imbalance, discontinuity and governance mayhem of unequal and inequitable health care services. They will evaporate some of it and add to it elsewhere, as they explode!

## Principles

Principles are the basis on which we start to implement on a blank canvas and martial our ideas. Mine start from experience and observation that information systems of today are costing too much, delivering too little of the value they could, and are too slow in adapting to changing needs and opportunities. With the evolution of technology over the past thirty years, and alignment of software methods and standards to the emergence of the Internet, there is, for the first time, a sound and sustainable basis for transition to an information utility for health care, that will work and deliver value for citizens and assist in improving the working life of professionals. There is, however, a considerable legacy of software and systems that will not survive the transition and is impeding it.

The challenge is now of working incrementally to supplant this legacy with a sustainable and future-facing resource. The community that comes together around this mission should think big but start small, focusing on demonstrably achievable, safe and incrementally implementable goals, with iterative review. It is a huge endeavour but there is a huge human resource to engage with in this, including very capable and motivated computer science students eager to participate in work that they see to be of transforming value. Catalyzing this engagement requires a coherent platform and method available for all to learn about and work with, and a mature and joined up community of practice to join in with.<sup>100</sup> Big Data encourages and excites big ego. The information utility should be built stepwise from Little Data,

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100 IXN is a network of university computer science departments, collaborating on project assignments for students, as part of their taught course. Created and led by my UCL colleagues Dean Mohamedally and Graham Roberts, it has proven mutually beneficial for health care research and development teams and the many thousands of undergraduate and postgraduate students studying computer science. They are collaborating on ambitious projects involving novel new clinical applications. One such has been to bring AI software into assessment of eye disease, linking with clinicians and system developers of the OpenEyes ophthalmology medical record system.

the term I alighted on, many years ago, for the ‘omniscles’ of clinical data of Chapter Three. A *Sunday Times* review of data technology that I read yesterday (February 2022) highlighted the risk in applying AI methods to poor quality data.

The principles that should govern future care information utility are gradually clarifying along the following lines:

- An information utility placing the citizen and the data and resources they command at the centre of architecture and design, with open governance that protects their ownership and autonomy;
- This utility should be run as a public enterprise with commercial partnership enabling innovation within a common framework, built on top of the World Wide Web Consortium (W3C). Public enterprise across countries should combine their efforts to fund this platform. Revenue from use and exploitation should be invested back into its ongoing development and support;
- The platform specification should maintain vendor and technology neutrality and be owned in the public domain, designed to prevent antitrust outgunning trust, through monopoly and appropriation of intellectual property;
- Data used in commercial context should protect the IP of the owner of the data and require that revenue be shared equitably to provide resource for the support of the utility;
- Choice and shaping of content should emphasize support for balance, continuity and governance of health care services more broadly. The following linked tripods of concerns are central to these:
  - Citizen, professional and organizational requirements;
  - Service delivery, education and research needs;
  - Technical rigour of implementation, engagement and participation of users, and public trust;
  - Patient autonomy, professional peer review and external audit and review;
- Implementation of systems and services should emphasize coherence, efficiency, and simplicity:
  - Generic methods and standards supporting design, implementation and sustainability of systems;

- Interoperability of data and algorithm, enabling balance of knowledge and reasoning, observation and measurement, modelling, mathematical and logic-based analysis and information engineering;
- Scalability of data capture, storage and computation, from personal information appliances and local networks to grids of processors and storage devices;
- Efficiency of storage and retrieval from sparse, changing, and accumulating arrays of data, in the different contexts of personal, professional and population level usage;
- Unified and secure user interface with balance of client-side and server-side processing and high bandwidth connectivity throughout.

Whatever the principles adopted, there must be contracts and there will be consequences, accordingly. These will be social contracts as much as commercial contracts. Often the following of more than one path, in parallel, can be a sensible risk management as well as leading to a symbiosis that proves more useful than following just one.

Culture, values and principles must cohere within an approach to creating an integrated and sustainable information utility. Following the wisdom of Fred Brooks, computer systems need architects who oversee their design and implementation. This is a creative role and needs something to start from, against which to test principles and ideas about ways to go forward. My first attempt to capture the architecture of health records was in 1991, when formulating the GEHR project that was commissioned by the EU to propose a common architecture for health records. This story is told in Chapter Eight and a Half, and in Chapter Nine the story moves on to consider a similar exercise in the context of the wider care information utility.

Now, thirty years on, the original GEHR architecture has substantially evolved. In continued fulfilment of its founding principles, it is openly specified, instantiated and widely implemented, in different software technologies and by different vendors of systems, under the aegis, now, of the openEHR Foundation and the self-governing openEHR International Community Interest Company. The need is for a similarly cohesive and concise, principled framing of an architecture of care information utility, centred on common ground of the care record.

A note of caution seems appropriate at this point. As recounted in the context of Illich and his book *Deschooling Society*, sickness and death were Zeus's vengeful legacy, willed to the world. In the myth, sickness and

death betoken all manner of evils that the gods bestowed. They have come to dominate health care systems and, in Illich's perspective, led to over medicalization of society and its expectations. The computer as Pandora's box and information as that released from it into the world, is tempting analogy or parable for our times! The legend of Epimetheus (whose name translates, Illich says, as afterthought) reflects the need to be careful about what we wish for. Rescue services have a hard job. It is a hard job when we are left to contain and reverse floods and put out fires. It is a hard job to rescue information when it has spread into the environment, as a sickness rather than as a utility. The legend foretold trouble, and that we certainly have. It has picked up a redemptive flavour of wisdom arising from folly. Erasmus used it to illustrate a Latin proverb, *Malo accepto stultus sapit* [from experiencing trouble a fool is made wise].

Are we yet wiser? The Information Age has had its grand follies and a lot of money has been parted from foolish owners along the way. Taken to extremes, information, everywhere, and not a pearl of wisdom in sight! A bit like King's pithy advance on Samuel Taylor Coleridge (1732–1834) and *The Rime of the Ancient Mariner*, saying of the alchemy of money: 'debtors, debtors everywhere, and not a loss in sight'.<sup>101</sup> The goal of care information utility is to provide a connective and integrative role, at one with human wishes and wisdom, and to guard against fragmenting influences that unleash new troubles to beset future generations who live on into the Information Society.

## Standards and Standardization

Communication of any kind of information involves considerations of trust. How far can we trust that measurements of weight, length, time or anything else we choose to measure, that arise from different devices, in different locations and contexts, that are declared to be comparable, are in fact comparable and not subject to what might prove significantly different bias and noise?

One way to feel sure might be to place the devices used, side by side, and trust one's own sense that they are recording the same measurement of a common object, as one makes the measurements. That may once have sufficed, but to most intents and purposes, today, it is not a practical solution. Another is to calibrate the different devices and methods that are used to make the measurements in the different locations, against a special status device or object that is declared to be the faithful representation or

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<sup>101</sup> King, *End of Alchemy*, p. 343.

measurer of the quality being observed and measured. Then, if each of the other devices is shown in this calibration process to measure identically with the special status device, or within a prescribed narrow range of agreement, we may satisfy ourselves that they can each be trusted, independently, in different locations but otherwise reliably similar contexts, to be making acceptably correct and comparable measurements.

That special status device or object is the 'standard'—a standard object of weight (e.g., one kilogram) or length (e.g., one metre), or a standard device for recording time in seconds, for example. It might be called a reference standard as all objects or devices used in measurement are calibrated and referenced to this one, when justifying and stating their credentials as a trusted means of measurement. Clinical chemistry measurement was an early field where improved standardization of devices and methods was imperative, to ensure dependable accuracy and reproducibility of blood and other clinical test results obtained in different laboratories, using different methods and machines. Standardization became central to their quality assurance programmes.

Systems of standardization pervade throughout science. They vary according to geography and discipline, and within discipline. Converting measurements between different standardized units was mental arithmetic exercise in my primary school maths classes and tests (weights in stones, pounds and ounces to grams, and lengths in inches, feet, yards, chains, furlongs and miles to metres). Standards now permeate and prevail more widely, into ways of doing things as well as ways of measuring them—a standard glucose tolerance test procedure, for example, defining the fasting protocol, administration of the bolus of glucose and collection of subsequent blood samples and measurement of their glucose levels. They permeate into standard ways of recording and communicating information. People train in their use and their skills are assessed and accredited accordingly.

In the early days of my encounter with computer systems, device manufacturers set their own standards for the electrical signals and data formats employed in devices connected to the computer. Analogue and then digital signals communicated between device and computer, making the connections. Computer manufacturers wrote software to manage these transfers and called them 'device handlers'. The scientists and engineers who were developing their own devices and interfacing them to computers, were on their own. The computer manufacturer gave instructions on what the computer needed to see, both in terms of hardware plugged directly into its internal data highways, and hardware connected via manufacturer-provided generic modules connected to that highway, that received or generated analogue and digital streams of data through which device and computer were to interact. The developers created these bridging electronic

circuits, adjusting device and software to make the transfer work correctly and efficiently.

In my early work in medical physics, our team designed electronic circuits and wrote machine code software to transfer and process data from imaging devices, to and fro, across these electronic bridges between device and computer. In time, their design and manufacture took advantage of commoditized electronic components one could buy off the shelf—integrated circuits and modules such as analogue to digital and digital to analogue signal converters. These interface circuits and algorithms developed to process the signals and data generated by them, became integrated within commoditized specialized hardware and software modules. Devices took on some of the work previously handled by the computer, and vice versa. The physics and electrical engineering discipline involved in working with these devices became standard working practice for their users, but the standards defining the operation of the devices—what went into them and what came out of them—were specifications determined and supported by their manufacturers. The user selected the product device that worked best in their situation, and that was all that was possible and mattered.

For connections at a distance and between different users of the computer systems, there were limited options—twisted-pair cables enabled signals to get there and be disentangled from noise picked up along the way. Coaxial cables transmitted the signal along a central wire and provided encircling shielding. There were horses for courses, and you had to know about electrical circuits, amplifiers, filters and earthing differences between buildings, that might cause potentially disrupting electrical current flow, and the like. There was common ground with the then current technology of analogue telephony and its connecting lines were used to piggy-back the signals from devices to computers and then across the public telephone network. Binary Morse code had long been transmitted by hand-operated switching of analogue signal levels along telegraph lines, but this was no way to transfer rapidly alternating signals of the bit streams of digital data! Neither could one route the data automatically, through a manually operated telephone switchboard. Automatic switching arrived, with new issues for enabling and ensuring smooth connection of a continuous signal through exchanges, like keeping trains running smoothly on railway lines routed through railway networks.

The problem then became that of the Portbou rail interchange between France and Spain. Different telephony companies were not in a position to call the shots over their competitors. Even conquering armies, as recorded by Norman Davies, had trouble in coordinating standards of munitions and firearms, as vanquished armies were shotgun-wedded with their victorious counterparts! Industries had to cooperate to enable signals to flow between

their respective domains of sovereignty. Circuits could be arranged to convert electrical signals between proprietary standards, but at a cost of extra equipment and degradation of the signal—less signal, more noise. The industries had to cooperate, in order both to create and evolve their markets and to compete. If they could agree on a common standard for the transmission of signal between their respective domains, additional cost and loss of quality could be avoided. Conformance to a standard was an advantage for them—of course they fought over what that standard should be! Oftentimes, unsurprisingly, corporate muscle and preservation of *status quo*, would vie with objective appraisal of technical superiority and experience in use of competing putative standards. More powerful customers and users wanted better and cheaper services and began to insist on standards, too, as these started to impinge on aspects of their own operations and viability.

The problem of standardization mutated and moved on. Not just the electrical engineering of the route but managing the traffic. Trains on railways are controlled by signal boxes and procedures that avoid collisions. I can still remember steam train drivers passing a huge metal token between them, as one completed transit along a single-track section of line in one direction and the other waited to be allowed to enter that track in the opposite direction. The driver in possession of the token was the only one allowed to take their train along the line. Putting more and faster trains on a network of lines brings risk of accident—breakdown of trains and breakage of lines, blockages disrupting flow, and collisions of trains. In digital networks, data traffic management arrived—embodied in protocols for detecting and recovering from collisions and errors and accidents that crept in along the route. These provided ways of grouping bit streams together within blocks of data, and blocks within messages, all electronically tagged and labelled, such that the structure was intelligible all along the line. These were matters of the technical framing and transmission of messages. The meaning of the message was immaterial to its transmission—it could be a birthday greeting or an urgently needed clinical laboratory measurement, everything went along the same lines and conformed to the same underlying standard pattern.

And by this stage, there was a hierarchy of different levels of connection involved in the communication, all of which were potential circuit breakers, combined and described in the language of performance: efficiency, effectiveness, cost and risk. Mathematics, physics, electrical engineering, computer science and human experience and skill were all in this loop, all adapting to one another in providing utility of the communication. And their component contributions were interdependent—broken or heat-buckled rails, snow or leaves on the railway line, absent signal box operators, broken levers and wires, company bankruptcy. There was need for a protocol of



mitigations to minimize their impact. Complex socio-technical systems emerged, where the whole was no longer simply the sum of its parts but developed its own behaviours and was embedded with the purpose and meaning of the information being communicated. Human communication interwove with technical characteristics of the communication system.

And so, in health care and medical computing, our eyes focused on standards. Signal protocols led on into network protocols, message protocols, document markup methods, health care messages, clinical terminologies and classifications, protocols of health care processes, audit and management, regional and global information standards and the top to the bottom of the World Wide Web. The terminology and acronyms of this world buzzed with feedback resonance of loops of communication: (in no particular order!) Ethernet, TCP/IP, OSI, HTTP, EDIFACT, SGML, XML, HL7v2, HL7v3, HL7 FHIR, IHE, ICD, Read Codes, GALEN, SNOMED, ICPC, LOINC, Casemix, HRG, DRG, CBS, GEHR, Riche, LRA, openEHR, CEN/ISO 13606, W3C, OMG...

OMG (Object Management Group) is an amusingly apt acronym and emoticon to complete the Topsy-like proliferation and complexity of these standards! 'Twitter' is apt as a characterization of the messaging and communication about them! These domains of standardization did not necessarily work well, or at all, together. Conversions diminish signal and aggravate noise. The Portbou interchange slows transport flow and aggravates noisy passengers! Families of standards linked arms and repelled invaders. *De jure* battled *de facto*. There was accommodation to the impasse. Neither France nor Spain was going to completely re-lay its railway network and change all its trains.

As users, most people are mainly concerned with the performance of the systems they use. Could my wife's ninety-six-year-old dad hear her across the mobile and landline telephony network connecting between her mouth and his ear, in England and Poland? Some users may be consumed by dislike of the colour of the telecom maintenance engineer's company van, and judge his service accordingly, but, hopefully, only a few! In communication about health care—and Bożena and her dad were talking doctor to doctor, as well as daughter to father, and they trained and practised in different eras, in different specialties—communication of meaning is of a different order, and technical and data-driven standards at that level still have a long way to go. They will be central to care information utility.

The story of information in the context of telecommunications of the Information Age is an interesting allegory of the story of information in the context of living systems that I sketched out in Chapter Six. That story traversed from the machinery of life to the function of the integrative nervous system, information networks of living cells, organs, bodies, conscious

thought and meaning. The science of life has tunnelled down to the bioenergetics of electrons and protons acting across membranes and the free energy donations from the sun. The science and engineering of information has evolved from statistical physics of gases and electromagnetism, through the engineering of circuits, the capture and communication of signals and messages, to the exchange of records within health care systems and information utility.

The purpose of a railway system has definable technological, personal, social, economic and political contexts. The purpose and form of the health care systems has been turned upside down in all these contexts in the Information Age. I am not, here, doing a Horst Rittel (1930–90) and Melvin Webber (1920–2006)-like categorization of ‘tame’ and ‘wicked’ problems, morphing into them being labelled as ‘easy’ and ‘hard’. I am highlighting meaning and context as being more tangible and tractable matters to judge and decide on for a railway, than they are for a health care system.

Health care information infrastructure has, however, grown like a railway or telephony system, emphasizing the purposes most suited to machine and management and relegating those aspects more dependent on human meaning, skill and judgement. As our focus necessarily now moves above the machinery of the infrastructure to its purpose and performance in achieving desired outcomes, we move up a level, from data model to information and knowledge model, and how they support connections of meaning, context, workflow and reasoning. The quest for care information utility is challenging boundaries of connection and communication—in research, education, professional practice and in personal identity and autonomy. The nature of signal source, message, route, and destination, within the infrastructure, then assumes a place within meanings and contexts of information utility. That utility is intrinsically much harder to standardize and reengineer than a telephony or railway system, in large part because it is abstract and cannot be seen. Health System Standardization is HS<sup>2</sup> as opposed to HS2—the current project for a high-speed railway joining London and the North of England!

The standardization of data and computer systems that work and can be sustained through periods of rapid clinical and technological change, over time, is, for all these foregoing reasons, a very considerable challenge. The quest for this standardization has been both the albatross and Achilles’ heel of NHS IT programmes, throughout my five decades of involvement. It has been labelled, but gone unrecognized in nature and form, for too long. This is especially important because, in many circles, a health care standard is seen as an enforced technical conformity of systems, as opposed to its primary purpose, which is as a *lingua franca* enabling and facilitating communication about meaning. This, like any language, evolves over time,

as clinical practice, science and technology move forward. But therein lies the rub. For some, control of such standards is an important insurance policy guaranteeing marketability of products and services. Standards are fought over and defended, becoming like tablets of stone, because software costs money and changes in underlying standards can rapidly render systems unmarketable, unsustainable and obsolete. That is a bit like the Académie Française enforcing rules of usage to tell the French people how to speak proper French!

In recent decades, the difficulty of keeping pace with changing technology, both hardware and software, at scale, within large health systems has proved unmanageable and unaffordable within the parameters set for them. So much so that the field has, in the main, been characterized by local successes—local, that is, to a particular technology, domain or institution delivering services—and costly global failures—global, that is, in terms of sharing records across domains in which the data about a particular patient needs to be communicated and worked on, wherever, whenever and by whoever they are cared for, locally, nationally or, increasingly, internationally. This is in the context of capture, processing and communication of data where patients, themselves, are more closely involved, or need to be able to be so involved, when at home, out and about or travelling abroad.

New approaches and experiments are needed to meet the challenge of defining a practical and deliverable scope for standardization of health care information as a utility. These need to focus on working more effectively and practically, with patients, professionals, health care providers, education, research and industry, to learn, through practical implementation experience, about standards that work. The evidence and experience of past endeavour is that the need and urgency of this goal is recognized but the means of framing and implementing it has proved beyond the joined-up capabilities of the teams and environments in which it has been pursued.

As a result, our options when buying IT are too often locked down in inflexible designs, which cannot be changed because their technological underpinnings are already effectively obsolete, or where there has been so great a past investment committed in them, that it is deemed impossible to consider experimenting and replacing them with new methods and approaches. That is why innovation and implementation to get past this impasse is best and most achievably envisaged at smaller scales of endeavour, with agile and incremental integration, outwards and upwards, from there.

Some levels of standardization matter greatly as means for underpinning coherent, efficient, safe and effective information systems, and creating stable and transparent markets for those that develop and trade in them. They reflect cooperation that underpins and makes possible competition, while leaving opportunity for commercial gain where value is added through

private investment. There are issues of equity and regulation, ethics and law, and human roles and responsibilities, that favour basing standardization of the specifications, methods and tooling required to underpin and support a coherent care information utility, on common ground and under Creative Commons and open-source licensing. I address these issues in Chapter Nine.

Standards presenting as open commons are, inevitably, sometimes manipulated behind the scenes, to facilitate new enclosure, through undercover relationship with vested interests that are pitching to take special advantage. Standardization processes are, as ever, high politics and hard grind. I have observed international standards processes at close quarters but not engaged much in the circus they often seem to bring. They are greatly needed but come at a price. They would be better and more authentically handled from a more experimental and evolutionary perspective, based on implementations as well as designs. Standards upholding quality of health care and the engineering of its care information utility cannot be justified on the basis of political compromise—such standards are Emperors' clothes.

Many areas of the technology and software of health information systems have achieved official or *de facto* status of standards over my songline. Standards help to stabilize and consolidate markets, and, as I have said, they are also managed and manipulated to the advantage of different competing interest groups. Apple operates an ecosystem for its products and an associated App market that aligns with its proprietorial rights in iOS. Google has adopted Android as an open-source platform for hosting Apps. In health care, free market monopolist tails must not be allowed to wag dogs and create fogs obscuring what should be coherent community wide interest. Once again, balance, continuity and governance are important litmus tests of how such evolution of platform and utility is to be regulated.

## Parenthesis—What Matters and Why

If we are not satisfied with the continuation of the Chapter Seven rush to find gold at the end of a rainbow in the Information Society, and do not wish to solely rely on chance to determine the outcome, we need to be clear about what we want to create, and why. What are the key considerations guiding our approach to making the care information utility fit for purpose in the Information Society, and why are these the key considerations? What cultures, values and principles, missions, goals, methods, teams, communities and governance do we seek? All of these will be inherent in charting a path and we need them to be, so far as possible, mutually coherent and sustainable. Because otherwise, the computer will do for us what it is

has shown itself good at doing—exposing and further burdening us with the inadequacy and incoherence of our ideas and actions. And we must not delay this work. Lacking coherently implementable and implemented policy, each year we generate new, disjointed legacies that become ever harder and costlier to dislodge. These are two good reasons *why*.

Chapter Seven surveyed fifty years of policy perambulation. Chapter Eight has suggested a new policy focus—the Care Information Utility. Chapter Eight and a Half now describes movements dedicated to iterative and incremental exploratory steps in this direction, designing and implementing standardized clinician- and user-governed clinical data models and a related information platform architecture, supporting coherent care records. It shows how it can and is being done. Chapter Nine is about how to learn and evolve from this work to implement and sustain a wider care information utility, and create the environments, teams, leadership and governance required to that end.

As I first made notes for this section, the Covid-19 pandemic had been evolving for a year and was currently declining from a precipitate third wave peak after Christmas celebrations, into early 2021. My reflections on this chapter reflect the dramatic community context of that time. What was seeded mainly in the South-East and spread north westwards, bounced back, with upsurge in the North-West spreading in a south-easterly direction. Pandemics flow like waves and jump long distances, like tsunamis and grasshoppers. And viruses mutate, posing new challenges of detection, measurement, prediction, containment and treatment of infection. A more highly infectious mutant form emerged in Kent and rapidly dominated a third wave of infections, spreading northwards again. And successful vaccine trials led to a national mobilization of vaccination, centred in local communities, and resulting in half the adult population being vaccinated within three months. Further resistant strains were spreading from South Africa and Brazil and causing increasing alarm, with calls for heightened restrictions on travel, just as summer holidays to warmer climes had started to look feasible, once again.

Our Globalton village had seen relatively few cases, thus far, but the pattern of infection was complex. It changed rapidly, within and between adjacent areas of the country. As everywhere, our community was greatly affected by the restrictions, evoking many daily acts of kindness and support for those shielding at home, orchestrated through social media groups and in the Street, City, County and Country. The challenges, responses and impacts varied greatly across the country and across the world. There was a Pandora's box of uncertain unfolding outcomes.

For those of us who knew and remembered it, this felt like a resurgence of Localton community connection and sense of belonging—not starry

eyed but with a stability and certainty no longer so widely felt. It has been an encouraging and optimistic revelation and experience of what, in my childhood and early decades, people remembered nostalgically as wartime spirit. It is often called team spirit—successful teams, in work and sport, or anything else, share a common sense of occasion and purpose that overrides common seeds of fragmentation and distrust. It is an emergent phenomenon—spirit engenders success and success engenders spirit. It is a dynamic of head, hand and heart and people care about those in their teams and are cared for by them.

This care is a local phenomenon, but it spreads outwards and upwards. Neighbourhood relationships, so often busily constrained behind front doors and morning rushes to schools, cars and trains, opened into neighbourly care and concern, along streets and within communities. It has been in evidence when industry and academia have applied hands to ploughs, with rapid cooperative and collaborative effort to create new vaccines and ventilators, moving from prototype towards production and testing, with unheard of combinations of twenty-four-hour skill, diligence and speed. And it has been on show in the military mobilization to create huge fallback hospital capacity and in organization of the vaccination programme. Above all, it has been in evidence in extraordinarily demanding commitment of frontline staff, who are the most exposed to infection in the epidemic.

We must not get carried away with euphoric relief that some anxious early forebodings of worst outcomes were forestalled in this way. The capacity to rework hospital care patterns to absorb a huge influx of seriously ill patients, where the disease presenting was a largely unknown quantity, has impressed, as seen from the outside, and exhausted those working on the inside of those services. Reading the very moving diaries written, by their attending nurses, for patients near to death and in induced coma, one can feel the presence of dedication and care. Moving accounts of care for residents of care homes abound, as do accounts of families coping with the abrupt upending of their lives, with loved ones suddenly stricken and in prolonged intensive care and dying.

But the Covid-19 pandemic challenge to health care, nationally, has also highlighted crisis in care services, locally. It might be characterized in terms of how priorities were set for testing for the disease and availability of safe working contexts for staff, including protective clothing. The unmonitored spread of asymptomatic infection in the community and into the care sector was disabling and created a surge of deaths of people who should not have died at that time. The movement of infected but untested patients from highly infected hospitals to then uninfected care homes, also created high risk of outbreaks there. There was a bifurcation of attitudes. Those who were unaffected and perceived themselves as having minimal risk wished

to plough on. Those who were affected and at highest risk, and those in the front line of services struggling to cope, sought caution. The balance struck was political and chaotic, and the cost has carried forward and been prolonged, in the country's account. John Houghton (1931–2020) spoke of present disaster as the only driver of change in society. Global pandemic, like irreversible climate change, is a shock and call to action, where we are confronted to find common ground on questions about what matters and why.

The Covid pandemic is a partial metaphor for information pandemic, which has been accelerating, chaotically and expensively, through the information revolution of the past seventy-five years, starting from the time of foundation of the NHS. This pandemic has co-evolved alongside changing science and technology but remains substantially unbalanced and uncontained. If you doubt that, look again at the perspectives and policy goals of the 1970s and those of today, in the sequence of documents I reviewed in Chapter Seven. Couching these in new language does not alter their essence.

The experience of going through the Covid pandemic gives pause for thought about lessons learned from the information pandemic, and how creating a more coherent information utility could in some sense vaccinate us against its harmful effects. There are three key issues which stem from an understanding of the nature of information utility. It is an organic entity: a tree that needs to be seeded and nurtured, as much as produced and sold. It cannot be created and imposed, it needs to take root and grow. The value it represents derives from its existence and how it is created, sustained and trusted, as much as from what it is. It has no meaning standing alone; it needs consensus, effort, business model and incentive to integrate coherently with citizens and their health care in everyday life.

Thus far in the book, I have explored numbers of 'What is' questions, starting from basics like 'What is reality?' and 'What is life?'; to this list we have now added 'What is the information utility for health care?' There then follow all-important 'How?', 'Who?', 'Where?' and 'When?' questions. *How* is the care information utility to be imagined, designed, created and sustained? And *who* will do this work and *where*? *When* is easier—best to start now! Different approaches to governance of such endeavour have reflected differences of culture and belief. Leaving aside coercion, they mirror the classical advice of Confucius (551 BCE–479 BCE), that to govern there must be trust, food and weapons and the greatest of these is trust. By analogy, we might equate them as follows to a successful campaign against Covid-19:

- Trust = fairness, openness and humility;
- Food = treatments, vaccines and information;
- Weapons = people, resource, infrastructure and method.

In tackling the challenge of information utility, the food is information and the trust and weapons are much the same. As the Susskinds summarized at the end of their book about transforming the professions to be fit for the Information Society, the question is whether there is the will to do it. 'Where there is a will, there is a way', is not so true of the Information Age. The nature of government and the weapons at its disposal have changed or are at least changing. To govern is to enable good governance and a weapon is a means to an end. Where there is seen to be a way, it is more possible to summon the will to do it—there is little will for an untrusted or untested way. The way is about *how*, and that is about method—and it is to this question that the story now moves in the first half of Chapter Nine. Before that, Chapter Eight and a Half, mirroring that of Barnes's *A History of the World in 10½ Chapters*, is a parenthetical trip along the timeline of my work of thirty years discovering care information utility. This then naturally raises two further questions: 'Who?' and 'Where?' The next sections of Chapter Nine are about people who take up the challenge of creating and sustaining care information utility, and their leadership in the environments created for this work. The story concludes in Chapter Ten, with a discussion of what remains only half done, and the Postscript forms a preface to the second half, in whatever comes next.





# 8½. Halfway Houses towards openCare–Stories of GEHR, openEHR and OpenEyes

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This half chapter introduces missions and movements that have evolved from adventure of ideas, through anarchy of transition, into central components of programmes for reform of health care services, now extending across the world, at scale. It is not a pitch for their adoption or a comparison with other endeavours. It is an eyewitness account of how they came to be, and a perspective that has unfolded alongside of what the future might be created to look like. It is these aspects that seem important to record, so that progress can continue to be made.

The principal story told is of a mission to help bring coherence to electronic care records. This is the story of GEHR and openEHR—persisting along a thirty-year stretch of my songline. Its survival and continuity have rested on the enduring commitment of its pioneers and a growing, vibrant, humanly variegated (and sometimes quarrelsome!) community of creative and determined participants. It has had stalwart friends and supporters but, until quite recently, enjoyed almost negligible public funding. It is an iterative and incremental story of implementation that has embraced new perspective, approach and delivery of digital care records. I have described the three top priorities of openEHR as implementation, implementation and implementation. Only by enacting such vision can one learn how to do it. As Robert Oppenheimer wrote in his immediate post-war Reith Lectures, which I referenced in the book's Introduction, in attempting such a mission we discover who we are. The second story, told in less detail and combining with the profile of its founding pioneer, Bill Aylward, in Chapter Eight, is of OpenEyes. This initiative has evolved and disseminated a state-of-the-art open-source eye care record, now supporting around fifty percent of ophthalmology services in the UK. It has been made possible by a public sector-led collaboration of clinicians, NHS Trusts and companies.

Care records are concerned with capturing the 'Who did what, when, where, how and why?' in support of the health care of individual citizens. This half chapter seeks to encompass these same attributes. It is a story of the creation of halfway houses that have been instantiated today, along

a path creating common ground on which the future care information utility can grow in the coming decades. The mission to imagine, create and sustain this coherent, citizen-centred, well-governed and trusted resource will be central to future health care, as the world turns upside down in transition from Industrial Age to Information Society.

If trillion-dollar funding streams had been utilized differently, the kinds of mission described here might have saved the world much money, heartache and lost opportunity. Enacted faithfully and well, positioned at the centre of the care information utility that they can now help to create and sustain, such missions will contribute shared common ground that enables the world of health care to become a more caring, equitable and sustainable place.

This book has attempted a novel history, its structure inspired by Julian Barnes's novel, *The History of the World in 10½ Chapters*, hence its ten chapters and this half chapter.<sup>1</sup> Each chapter brings new and complementary account and perspective. The whole might well be described as a history in ten-and-a-half books! They are woven together along both historical timeline and personal songline.

Barnes's book starts with a stowaway woodworm's story of Noah's Ark and builds further stories in successive chapters, each based on events and interpretations that cast a different light on the history of the voyage, and therein on the ambiguity of all histories. It is a very entertaining mix of complementary stories—some fantasy, some historically sourced with precision, presented and interpreted with a delicious mix of intelligent and insightful commentary, understated ridicule and amusement. I knew Julian as an undergraduate at Magdalen College, University of Oxford, and was thus drawn to and loved reading his books. His writing feels perfectly in tune with the person I met there; a penetrating thread of acerbic discord runs throughout. He probably likes people like that—I think I recognized a clinician of similarly dynamic and penetrating personality, who I also knew a while ago, acknowledged in a cameo role in the book.

Barnes entitled his half chapter 'Parenthesis'—it is a personal and touching story of the ambiguity of love. That is how I read it—he did not say it as such. My half chapter, also numbered Eight and a Half, is a personal story of adventure, anarchy and reform, played out in two movements building towards common ground on which to base a future care information utility. These are the openEHR care record platform and its associated clinical information models, and the OpenEyes clinical ophthalmology electronic

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1 J. Barnes, *A History of the World in 10½ Chapters* (New York: Knopf, 1989).

medical record application. They are building on the legacies of other pioneering initiatives that the book has connected with and drawn together. Legacy is fundamental to reform.

I have framed my half chapter like this, in part to emphasize that it is my story, and that others will, rightly and appropriately, have theirs, as players also closely involved in or observant of the events it describes. Stories of eyewitnesses bring historical perspective to the playing out of anarchies of transition and the unfolding of programmes for reform. How did the story I relate come about and unfold? The world will give different answers. This account represents my own experience, as someone who has been involved, from the beginning, with varying degrees of direct involvement: capturing ideas and designs; building and leading core teams and implementations; creating and sustaining interdisciplinary and multiprofessional environments, partnerships and alliances needed for the work; navigating storms and resolving conflicts; and establishing and managing the legal frameworks required for wider dissemination, governance and growth of the missions described, within worldwide context.

In terms of the credit and intellectual property embodied in these now very wide-ranging endeavours, they truly are the work and accomplishment of all the brave and committed souls who have participated in creating and sustaining them. They are heroes. Those closest to me feature and are acknowledged widely throughout the book and in its archive of additional resources.<sup>2</sup> Many hundreds of others now populate the websites of openEHR and OpenEyes.<sup>3</sup> Perhaps the most important aspect of each generation's successes is demonstrated in the strength and staying power of the succeeding generation of heroes that it, in turn, enables and inspires. This half chapter is, in part, also an acknowledgement that the missions it describes are, as yet, still halfway houses along the road to an information utility that supports the reinvented and recreated health care services of the future.

## Legacy and Reform

The term legacy has negative connotations in the context of information technology (IT), where it is often associated with incompatible and out-of-date systems that impede progress. Let us be more positive, here. Legacy is what we create and re-form from what we inherit, and then pass on, to be built on with new ideas and in context of new requirements—what

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2 Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

3 *openEHR*, <https://openehr.org/>; *OpenEyes*, <https://openeyes.apperta.org/>

speaks for us when we do not, or no longer speak. A good legacy shows a way forward and helps create community and environment to carry the continuing burden of reform. Where there is a good way to follow, the will to follow it will grow. A bad legacy gets in the way. In the Information Age, we have become aware of legacy information systems that sink costs, fail to or no longer work well enough, and block future reform.

Legacy and programme for reform appear and connect in many guises. Their histories embody ambiguity, just like Barnes's stories of Noah's Ark. They are inherited as preface and passed on as postscript. As we play with words, they evolve, enriched by new conceptions, descriptions and inscription of ideas, informed by iterative and incremental experimentation and the experience we gain. They extend and connect over time: through prescription, by way of future standards of theory and practice; through subscription, by way of resources invested and governance applied; and through trust, by way of nurturing of community. The formative stages of reform depend especially on trust, which must be grown and sustained. Trust connects and cascades throughout programmes for reform.

Legacy also connects with law, by way of legates and legality—good and not so good people, good and not so good law. Reform connects with rebirth—reformation with renaissance. In the world of health care IT, our legacy is what we have helped to implement and sustain—good bits and not so good bits. Health care connects all around the circle of knowledge and throughout individual lifetimes of experience. It is in the accumulating common ground of this knowledge and experience that such wisdom as any may possess, resides, and holds its value and meaning.

Legacy and reform encircle past, present and future Dreamtime-like realities. They convolve with **songline**, **landmark**, **environment** and **trust**. These all feature, constructively and destructively, in the connections made. Those emboldened letters contrive **solvent**; legacy as solvent, ideas as solute and reform as solution, perhaps! Legacy as medium that enables and sustains people and ideas to grow and support future life; like water—the image of its molecules being the cover image of this book. Solute dissolves in solvent to make solution. Solutions arise in the mixing of solvents and solutes.

New solutions become new legacies, passed on and enduring, beyond personal songlines into new and different environments and to participants in these new worlds. Legacy encompasses not only traditional forms like money and property, but also information in the form of useful knowledge, method, histories and stories—stories of people and lives, the causes they have served and carried forward. Legacy is about luck as well as intention, both good and bad. Times of transition encounter many sliding doors, and lives are cascades of many transitions. A mixture of goals is tackled

with a mixture of motives, and with a blend of methods, resources and understanding. Legacy, like information, has multiple connections over time; it conditions and is conditioned by events.

Much of what we struggle to achieve and put in place dies quickly when we are no longer there to keep it alive. Not because it was wrong or misguided, although that may be the case, but often because it is no longer in tune with the times or has become obsolete or no longer relevant. How can we best make our endeavours connect and pass on a useful and sustainable legacy? We owe this to the future generations; we have been extraordinarily lucky to live through our age. What each of us, individually, contributes to legacy and reform is for us to justify to ourselves and for others to work out and decide on.

I have much enjoyed and appreciated my part in the stories of openEHR and OpenEyes, one in large part and one in much smaller part. I have been with them from their origins, planting and helping them to grow, making connections, staying the course within their growing communities of endeavour. This half chapter draws together the story of the seeds of openEHR, the seeds of OpenEyes to which they connected, the ground in which they germinated, sprouted and grew from flimsy saplings to sturdy trees, and how they are seeding, cross-fertilizing and expanding into forests, in what are now world-spanning movements. They are mutually complementary and reflect two co-dependent concerns—one of platform infrastructure and one of application utility. I hope and expect these will, before long, be connected in one much wider story.

## Opportunity Knocks

In Chapter Four, I described three sliding doors through which I stepped after my twenty years in the Department of Medicine and then my own small Department, at St Bartholomew's Hospital (Bart's), from 1975 to 1995, where I had focused on the mathematical modelling of clinical physiology and its application to intensive care medicine and the creation of computing resources for medical and pharmacy education. In that chapter, I outlined the formative context of these three transitions, and what followed from them, first at Bart's and then at University College London (UCL). In this half chapter, I draw together the events that unfolded through the second sliding door, as I took on leadership of the European Union Good European Health Record (GEHR) Project and its pioneering focus on the standardization of care record architecture. This project and my previous work with Jane Dacre and Maggie Nicol, in creating the Bart's innovative joint medical and nursing Clinical Skills Centre (the first of the three sliding door transitions), led us

to the third sliding door, several years later. Through this door we moved together, as a combined health informatics, medical education and health services research group, to the Whittington Hospital campus of the UCL Medical School. There, the second half of my career in health informatics and multiprofessional education unfolded from 1995, as further described in Chapter Nine. It was at UCL that the mission of openEHR crystallized and came into being over the following decade.

In 1990, Sam Heard, my colleague at the Bart's Medical College, approached me to lead a new research-based consortium and bid for funds to develop a common generic architecture for electronic health care records, within the extensive EU Advanced Informatics in Medicine Initiative (AIM). Together with Alain Maskens, an oncologist who had left his clinical practice to establish a small company in Belgium and develop a health care record product called HealthOne, Sam was instrumental in drawing together a group of industry, health care and academic partners for this bid. I had recently become the first professor in the United Kingdom in the emerging field of medical informatics, and between us we established the research workplan and were successful in a highly competitive bidding process for funds to take the project forward. How was this architecture going to be imagined, created, developed and sustained? I describe here the historic legacy of the AIM GEHR Project and connect it with the evolution of openEHR. Additional detail is provided in Annexes hosted in the book's archive of additional resources. It is an ongoing story.<sup>4</sup>

What we started in 1991–94, in GEHR, led over the following decade to a succession of EU research and development projects and commercial implementations led by Sam and Thomas Beale at the newly created Ocean Informatics company in Australia. Successive phases of an evolving clinical and technical architecture for the digital health care record were piloted and reviewed. They came to be known as the openEHR specifications. The section of these that deals with the generic models of clinical data structures, from which individual care records are constructed, now

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4 To supplement the material in this half chapter, further details of people and ideas involved in the creation of the GEHR architecture and subsequent evolution of the openEHR methodology and mission are included as Annexes lodged in the book's archive of additional resources (available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>), as well as on the openEHR website. I aim to include in the book's archive, an updating storyline that corrects errors and omissions and provides an opportunity for others, too, to give an ongoing account of newly formative contributions. Further detailed lists of contributors can also be tracked on the openEHR website, mirroring the wider pattern of acknowledgement, these days, in some publications from large-scale projects, such as the Large Hadron Collider experiments at CERN in Geneva, where sometimes hundreds of participants are every day essentially involved in the work.

known as openEHR archetype models, has been incorporated within both the Comité Européen de Normalisation (CEN) and International Standards Organization (ISO) 13606 standard for electronic health record communication. The specifications governing associated openEHR platform software implementations, on which to host clinical applications software are freely accessible, used, and now form the basis of care record system implementations, worldwide. Their scope extends over care records, medicines management, clinical decision support tools, patient reported outcome measures, clinical workflow management and regional public health systems, such as for infection control. In addition, generic software tools support the lifecycle of the associated clinical models.

The openEHR specifications are model-based and can be used directly to generate code for openEHR-based platforms, applications and services. They seek to contribute to and underpin a coherent common ground of patient-centred care records. One that facilitates the semantic interoperability of digital care records, such that their meaning and context, as specified and vouched for by frontline care professionals, can be well captured, shared and communicated within and between different communities and levels of health care services, and their diverse specialisms, native languages, geographies and jurisdictions. Moreover, one that also contributes to, and underpins, rigorous technical interoperability of openEHR-compliant software products, such that they function together reliably and sustainably, within and between different technology implementations and vendor products.

The public domain openEHR specifications and associated internationally governed corpus of openEHR archetypes are foundational to the re-formed architecture of digital care records proposed in this book, which envisions a shared common ground on which to base a future ecosystem of coherent care information. Crucially, this must enable and facilitate a sustainable and citizen-centred information utility, evolving to meet the changing requirements of individual health care in tomorrow's Information Society. What I have called 'Care Information Utility with you in charge' or openCare.<sup>5</sup>

Going back to 1991, Sam caused me quite a jolt when he came to see me soon after we had been awarded the GEHR project grant, to tell me that he and his family would be moving back to Australia! He promised to maintain his commitment to the project, including through regular extended visits

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5 CIU with uic: the palindrome appealed to me! Something like working both ways, from citizen to professional and professional to citizen. I have imagined a logo for this, rather as I imagined the name openEHR (=open air). Now, perhaps we might talk of the care information utility as openCare!



to London to work within the team we created and led, there and across Europe. He was good to his word and our close and trusted friendship has grown and endured in regular contact and exchange for now over thirty years. The GEHR project team at Bart's included: Lesley Southgate, a close colleague of Sam in East London Primary Care and subsequently the Professor of General Practice at Bart's; Dipak Kalra, another East End general practitioner (GP), who was, thereafter, instrumental in connecting the evolving work with standards bodies in Europe and internationally; David Lloyd (1940–2023), an early pioneer of medical electronics and electrophysiology signal processing at Bart's; and Marcia Jacks, who started her career as a medical secretary at Bart's and became our team administrator. Introduced to us by Jane Dacre, Sian Griffiths, a trainee rheumatologist, took a sabbatical year from her professional training programme and joined the clinical team. Introduced to us by Jo Milan, Thomas Beale, an Australian engineer and computer scientist based in London, joined a year later, as did Stanley Shepherd, who had originally represented a GP system supplier, Update Computing, that was a member of the initial GEHR Consortium but then quickly withdrew from the project. Its elderly owner invited me for dinner at the London Savoy Hotel, to weigh me up, and decided not to commit the company to the GEHR mission.

Some years later, Sam and Thomas joined forces with others, including Peter Schloeffel (who I had met at conferences in Australia, when a visiting professor there), to establish the Ocean Informatics company (recently renamed as Ocean Health Systems). Ocean thereby formed a commercial test bed for the developing ideas, focused on implementation within the health IT industry and product marketplace. The company became an influential early bridge with many other companies, helping them to understand the ideas, see their way to adopting them within their own products and services, and become central players in the dissemination of what became known as the openEHR methodology.

The die was cast in those formative years, in those formative environments, by those formative teams—a die to press new perspective, approach and delivery of a shared common ground of clinically focused and rigorous conceptual coherence of digital care record structure, and to lay foundations for the future evolution of citizen-centred care information utility.

As described above and in Chapter Four, as the third of three sliding door moments in my career of the early 1990s, in 1995 I was invited by the UCL Provost, Derek Roberts, and Chair of its associated NHS Trust at the Whittington Hospital in North London, Helene Hayman, to move there, along with some nine of my Bart's team colleagues of that time, to establish and lead a new academic Centre that connected health informatics, medical

and multiprofessional health care education and health services research. The story of this new centre, christened CHIME (Centre for Health Informatics and Multiprofessional Education), is told in detail in Chapter Nine, as an example of the creation of an innovative new environment. The opportunity was created and orchestrated by the Vice-Dean of the medical school based at the Whittington hospital, David Patterson, and the Dean of the Medical School, John Pattison (1943–2020), advised by my long-term colleague at UCL, Mark Leaning, who was based there in the Clinical Operational Research Unit (CORU) Unit that I described in Chapter Four. Sam, Thomas and another colleague who later became central to the openEHR mission, Ian McNicoll, were appointed as honorary members of this academic department, until my retirement from academic life in 2011. As was Justin Whatling, who went on to key appointments in the Cerner and, more recently, Palantir companies. Don Detmer, Peter Singleton, Tony Shannon, Mark Leaning and Tim Benson were closely involved with us in those times.

The not-for-profit openEHR Foundation was established at UCL in 2003, to take the work forward in the public domain. The now very extensive related intellectual property is made freely available under Creative Commons license. The openEHR methodology has since then connected progressively with electronic health care record systems, products and services throughout the world, guided by iterative and incremental implementation experience. Its operations have now transferred to an independent Community Interest Company with directors elected from the communities of individual subscribing members, and industry and health care organizational partners. In all the steps towards establishing a sound legal footing for the openEHR Foundation, we had outstanding support from the UCL Business department and its chief executive, Cengiz Tarhan, his staff member, Renata Tarnowska, and our first employee as manager of the new openEHR International community interest company, Jill Riley. We also benefitted from substantially *pro-bono* support from major London law practices specializing in Intellectual Property law and Charity and Community Interest Company law (Reynolds Porter Chamberlain, Oliver Bray; Bates Wells & Braithwaite, Stephen Lloyd and Abbie Rumbold). When establishing the Community Interest Company, we had invaluable support from a Swedish colleague, Gunnar Klein, and the Apperta Foundation, chaired by my OpenEyes colleague, Bill Aylward, and its Chief Executive, Peter Coates.

Throughout these early endeavours, seeking to capture and articulate what became the openEHR mission, Sam and Dipak were principal articulators of clinical requirement, and Sam a key innovator as well, able to break new and emerging concepts through into working software

prototypes which could then be learned from, refined and extended by the technical experts who joined in, from their academic, health care and company bases in many countries. Thomas anchored the technical side of this evolution, to provide a rigorous and effectively coordinated ecosystem of specifications and tooling. Sam's colleagues at Ocean, notably Sebastian Garde, Chunlan Ma and Heather Leslie, made the massive contribution of the Clinical Knowledge Manager developed and used for the curation of the clinical models. There was wonderful and essential complementarity of approaches to, and synergistic endeavours in support of, the openEHR vision and movement—there was a core group, and now there are many more, of leadership roles and leaders joining efforts under this umbrella.

Both Sam and Thomas have put astonishing amounts of sustained personal commitment and life work into the mission. I characterized the qualities required as a combination of technical rigour, clinical engagement and trust. Of us three enduring founders of openEHR, Thomas has been the pillar supporting technical rigour, Sam that of clinical engagement, and I have sought to provide strategic vision and an inclusive home base and environment, to hold things together in a spirit of trust that has—at times precariously—prevailed through thick and thin! I consulted on and set out terms of reference for wider review boards to anchor the architecture technical specifications (ARB) and clinical models (CRB). The former took root and evolved well. The latter has had a trickier and more troubled pathway over the years—reflecting a world where frontline clinical collaboration and governance have proved harder to anchor successfully for the domain, than have the more technical aspects. Notwithstanding such reflection, those who stuck with and anchored all parts of the mission can be justly proud of what they have achieved. Even those who were hostile to, or unpersuaded by, the openEHR mission, have noticeably paid a good deal of attention to its detail and evolution. We could see details of the growing traffic to the hosted website as evidence of this! All told, not an easy mission to lead, especially when one's principal employment responsibilities were much wider and mainly focused elsewhere, nearer to home, as exemplified in Chapter Nine!

### Germination of Mission

It is no accident that the pioneers of health information systems whose contributions I celebrated earlier in this chapter were at one in their presence at the coalface of health care professional practice, and all but one clinically qualified. This reflects that I had chosen to base my career in health informatics in a medical school clinical department and hospital

setting, as a non-clinical academic. There were opportunities at that time to work as an IT professional, developing and delivering a support service in a health care setting. These opportunities were, in the main, line managed not by clinicians but by hospital managers. There was also opportunity to work in an industry or consulting setting but there the focus was more narrowly on product development and overview at a distance from frontline care. Many followed an academic route in medical physics or computer science departments, again with narrower research focus on collaboration with clinicians working elsewhere. My choice was to work in the middle of a community comprising all the disciplines and professions that come together in academic medicine and hospital care and build from there. To follow this exploratory approach, my need was for alliance with colleague clinicians within the medical school, where my skills could align with their everyday concerns in education, research and practice.

From my early Bart's days, I set about building such personal alliances to help and support me in pursuit of my exploratory academic mission. This required much time spent and attention paid to listening and responding to a wide range of clinical colleagues, about their individual perspectives, interests and needs. Highly intelligent people and each with an angle on what informatics might have to offer them! I looked for win-wins, aligning my area of skill and interest with theirs. The scope for informatics innovation spanned medical education, clinical research and development, and more straightforward IT support for everyday work. No amount of words would help in connecting our missions in practical terms—the sole unifying paradigm was one of practical implementation. Taking on and making and doing things that were perceived as interesting and useful, and thereby learning more about them and how to use the computer in novel ways to explore and improve practice.

Many of my activities in the Bart's Department of Medicine, working with junior doctors intent on gaining their professional doctorates, had been of this kind, such as I have described in Chapter Four. Writing software to enact Huw Llewellyn's ideas about the diagnostic decision making process, based on mathematical set manipulations; creating a novel database to store and process Andrew Gorsuch's complex and extensive time-series data tracking genetic and immunological concomitants of diabetes; creating non-linear optimization methods to match the Mac Series respiratory model with intensive care unit (ICU) data, with Charles Hinds, and innovative problem-solving exercises for medical students and postgraduate trainees, using this model; extension and refinement of the Mac Series drug metabolism model for use in pharmacy education and research, with Giles Saunders at the London School of Pharmacy; development with Giles and Steve Jackson at Bart's, of a new simulation model of drug prescribing. Of course, few of

these proved of lasting significance, but as a means for me to experience and get to know these communities and worldviews, it was a good environment.

I reflected in Chapter Four on how this stage of my career came to a conclusion in 1989 and a new one opened up, in combining clinical skills training and informatics concerns in a new joint initiative and taking on leadership of the GEHR project. As Bridget Ogilvie, the wise head of the Wellcome Trust of that time, had advised me, when I told her about winning the EU GEHR project funding in 1991, I was faced with a choice between talking and writing about it and doing it. She smiled, saying that the breadth of ambition was so great that, if I took the 'make and do' route, no one with power to back it would wish or find themselves able to do so, but if we were successful, they would always, secretly, have been our friends! Rather typical of the reception of attempts to tackle 'wicked problems', in general, one might say! But it is pointless to be critical of such reality—not everyone is cut out to be a pioneer, and we would not get far if they were! We need educators, commentators and managers to keep pioneers honest, as well! More problems arise from those who imagine they can pioneer meaningfully in a particular health care setting, while living in a different and otherwise focused setting, and thus not sensitively connected with and experiencing the impact over time of the implementation of their ideas.

In the context of the new world that I moved into with the GEHR project, my general approach was much the same as in my earlier period at Bart's. It focused on iterative and incremental implementation as the basis of building and sustaining new alliances—in this case much more extensive and international ones—to gain understanding of the domain, to enable and guide the formulation of new approaches. My principal role became one of creating and leading an inclusive working environment, drawn widely from across complementary disciplines, professions, organizations and industries. This pattern followed on into the new centre we went on to create at UCL. It was a pattern where leaders from multiple complementary domains had a home base from which to lead a wide variety of initiatives, and new team members could develop to become leaders in their own fields of endeavour.

To emphasize the point about learning by doing, I recall commenting sometime later, to a group of visitors from the European Federation for Medical Informatics, that the three most important priorities of the openEHR Foundation were implementation, implementation, implementation—it stuck! Implementation comprising new approach and method, environment and team, and governance—a trifecta I explore in Chapter Nine. In such a historically perilous domain as the grand challenge of the electronic health record, it was, admittedly, a riskily adventurous approach, but it was the only way to engage constructively and significantly with this

implicitly interdisciplinary and multiprofessional domain. It could easily have heralded a downswing towards disaster, but, fortunately, openEHR survived along an upswing towards success. This path, however, was not without turbulence and personal cost and disappointment to some, along the way.

Before describing the adventure of ideas that started with GEHR and are now central to openEHR, I will nail some more personal colours to the mast. These have underpinned my vision of what the mission has been about, how I set it up, prioritize, and balanced the complementarity of contributions to its methodology, and led it during my time at the helm. It was from the outset an inclusive mission, growing from the coalface of clinical, technical and organizational requirements for care records, and embracing perspectives and participants from throughout health care communities, professions, academia and industry. This breadth of vision and community has served us well, even if sometimes portrayed as naively academic and esoteric! It now has considerable track record of impact, albeit with an inconsiderable record of words written about it in journals and books. It is sometimes criticised for that failing, being thus considered insufficiently academic. It was, thus, both too academic and not academic enough! That resonates with the way the world views efforts to resolve wicked problems, as rehearsed in Chapter Seven! One cannot please everyone!

It cannot all be wrong, though—I am somewhat in agreement with the Thomas Lincoln (1929–2016) school of thought in that regard (that more clinical data sometimes betokens less clinical effectiveness). But I do recognize that it might have been better for me to have said and written more along the way. From some perspectives, yes, but with perspective focused on creation of the nuts and bolts of a practically grounded and sustainable contribution to the grand challenge of the electronic health care record, I remain unsure. I couldn't do both, as Bridget Ogilvie had wisely advised. And given the challenge and uncertainty of the times, and the above-described imperatives of implementation, my adding to the noisy anarchy of the times might not have helped much. In the wider history of the health informatics field, flourished staking and advocacy of ideas, as yet unimplemented, has too often led in short order to a busted flush of cards then played. I was never much good at poker! Joining in might have hindered the unique opportunity I had been given, to anchor a vision, create and shelter a base camp and staging posts from which to pursue it, assemble and hold together a team of doughty mountaineering volunteers, and collaborate widely across the world with them and others who joined in the quest, in the incremental discovery and implementation of the openEHR mission. We had to learn how as we climbed, and it has proved an Everest-scale ascent! Climbing a difficult mountain has to be step by step, from

below; there is no way to think, talk or otherwise project oneself straight to the summit! And as introduced in Chapter One and further discussed in Chapter Nine, where it is described as 'leading from below', insider mediation is best led and conducted under the radar, and I often had that kind of role during my career.

During Covid restrictions, while shielding and since, I have put sometimes six hours a day and more, up to six days a week, for almost three years of my retirement, into this book. I hope this might be seen as some measure of atonement for having written too little before! I have never taken the step frequently taken by academic chiefs in my time, of placing their name on the publications arising from their teams. I suspect I might now be thought to be writing too much—such is the phenotype of advancing years!

### GEHR—Perspective, Approach and Delivery

The GEHR team's first attempt to capture the scope and architecture of electronic health records was in 1991. The objectives were simply expressed on page one of the project brochure published through CEC DGXIII–C4 Health Telematics (AIM).<sup>6</sup>

A common electronic health care record architecture for Europe—evolving through cooperative development:

- the development should be based on an experimental methodology, starting from clinical needs and ethical and legal requirements
- the architecture should be in the public domain

A good first step in any such quest is to focus first on the requirements and these were expressed and reported in terms of:

- Requirements for clinical comprehensiveness, Deliverable 4 (144pages)
- Requirements for portability, Deliverable 5 (141 pages)
- Requirements for communication, Deliverable 6 (139 pages)
- Specification of functional requirements for clinical use, Deliverable 7 (85 pages)

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<sup>6</sup> I have digitized this brochure and included it as an additional resource of the book. My brief history of GEHR, written at the time, is also included in the Annexes to this half chapter posted there (available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>)

- Ethical and legal requirements of GEHR architecture and systems, Deliverable 8 (69 pages)
- Educational requirements of GEHR architecture and systems, Deliverable 9 (62 pages)

I have the slides for these presentations in front of me as I write, here, which express their essence succinctly. Here is the simple diagram I invented to crystallize the mission, which formed the basis of the expression of requirements for clinical comprehensiveness:

## An overview of requirements for the digital care record

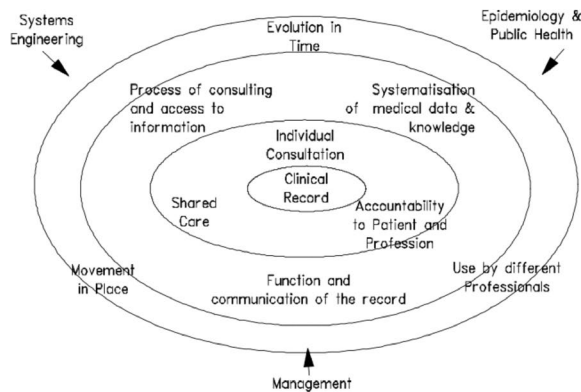


Fig. 8.22 The comprehensiveness of the electronic care record ecosystem, as expressed in the requirements for the GEHR architecture and mission. Image created by David Ingram (1992), CC BY-NC.



It focuses on ‘tripods’ or ‘trifectas’ of complementary concerns, in concentric ellipses, centred on the perspective of the citizen at the centre. This ‘thinking in triangles’ became embedded in my conceptualization and expression of the domain. In this perspective, a patient is present both as an autonomous individual and with their family and carers, in personal relationship with a clinical team, surrounded with information that is personal, shared with professionals and professionally accountable.



The next enveloping ellipse leads to formalization of information elicited and used within individual care episodes, combining with relevant knowledge of the domain, and set within an organizational ecosystem of health care services. And one step further outwards it connects with the evolution of care records kept, over time, in different places, and in interaction with different people and services. All this information is sustained and pieced together within the context of health system management, population health and technical infrastructure. The architecture we sought to characterize and specify was of the record of care produced and used within this whole ecosystem.

The diagram proved a good foundation on which to create, coordinate and lead the project. It was a quite simple framework that all could see and own—in the partner organizations of the project consortium and the Coordinating Partner project team that I built and led. It opened into a principled framing of the requirements that would underpin the architecture, ranging across the ecosystem described. This framework of requirements was taken up, almost entirely, in subsequent European and then International Standards Organization statements of requirements for electronic health care records of the era.

Here is what we drew together into the final description of the project, from which the following quotations are taken.<sup>7</sup>

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7 *The Good European Health Record (GEHR) Project A2014, CEC DGXIII—C4 Health Telematics (AIM)* (Brussels: European Commission, 1994), pp. 1–16. My geometrically tutored mind often connects and visualizes issues in threes and triangles. Diagrams where I picture the tripod or trirecta of clinical, technical and organizational dimensions of coherence of clinical data populated many slides that I used to explain the GEHR project and successor openEHR missions, from the early 1990s. My initials being DI, these, and other geometrically inspired designs I frequently used, including one for challenging and inspiring my doctoral students to capture their contribution and its disciplinary context in a single image, became known by them as DI-agrams! In my mathematician days, I loved learning and taming geometry; for me it is a wonderful synthesis of the mathematical and the visual, and their connections with the natural and human world. There are other dimensionalities than threes, of course. Triangles tessellate, as do rectangles and hexagons. I started also to use hexagons to give visual impact to the network connectivity of the GEHR project's architecture of the digital care record. In Chapter Nine, I reflect on monisms as principles, dualisms and dichotomies as complementarities and choices, and tripods and trirectas as stable building blocks of the systems and processes required for imagining, implementing and sustaining a viable ('livable') organic and evolving care information utility.



Fig. 8.23 Front sheet of the GEHR Project Brochure, 1994. Image created by the GEHR project team (1994), CC BY-NC.

The GEHR project was established to develop a comprehensive and widely applicable common data structure (architecture) for using and sharing electronic health care records in Europe. The information environment in which such an architecture would be applied includes all sites capable of creating and maintaining medical and related data. It encompasses many different system types, networks, database types and vendors, and also many levels of software engineering capability. The user organizations range in size from large health regions and hospital groups with dedicated computing departments to single handed practitioners with a PC and a modem.

Clinicians are becoming increasingly aware of the opportunities the computer could offer to support their clinical practice. The management of complex diseases, clinical audit, and the automatic generation of reports are examples. The growing complexity of health care provision means that resource managers need greater access to aggregate information about the processes of clinical care. Unfortunately, the computer systems currently used in most hospitals and general practice surgeries, and more importantly the data modelling concepts which underlie them, are ill equipped to cope with these new challenges. The Good European Health Record architecture provides a framework which supports the full diversity of clinical data storage and communication required by clinicians. It is formulated to encompass the different disciplines of primary and secondary health care, for doctors, nurses,

and other professionals and in all European countries. Ready access to a wide range of datatypes is of increasing clinical importance, and the work of the project has included these multimedia aspects of the record architecture. Examples specifically addressed include X-ray and photographic images, bio-signals, technical drawings and most importantly textual information, for example clinical observations and laboratory data in the form of coded terms and free text.

The architecture has been derived on the basis of a full analysis of the requirements for an electronic health care record to support ethically and legally acceptable individual patient care. The GEHR project has employed iterative prototyping by clinicians to explore and test evolving ideas in practical situations. The project has consulted widely and has sought to establish and maintain close working relationships with other projects and teams. The project has members on CEN TC251/WG1/PT011 and the GEHR work, and deliverables have contributed the early standardization work being coordinated there.

On completion, GEHR will offer:

- architecture description
  - formal object model
  - exchange format
- multilingual dictionary of health record items
- library of anatomical drawings
- specifications for data access and integration tools
- a follow-on initiative to support future development

These results will be made available in the public domain.

GEHR is an architecture with supporting data sets, specifications, and recommendations for the implementation of compliant systems. GEHR is not a medical records software system.

### **Requirements for clinical comprehensiveness**

The foundation of the development of the GEHR architecture was a thorough review of the clinical requirements for recording and processing patient information. This work involved literature reviews, questionnaire surveys, and group discussions, and was supported by the evaluation of successive prototypes. This preparatory phase covered the first year of the three-year project. The priorities of the GEHR project have reflected the belief that the clinical record is most necessary, and should be most available, when a clinician is offering care in a consultation. Thus, any compromise should always be directed towards offering quickly

accessible, accurate, and complete information to an authorized carer when attending a patient. The clinical record will be used by staff trained in different disciplines, working in different settings, on different sites and in different languages. The architecture must facilitate record storage on different sites and provide a common interchange format between heterogeneous systems. It must accommodate evolving needs for coding and classification standards and for the use of clinical guidelines in the management of care. The clinical record must accept these three areas of change: in time, place, and clinical perspective. A health care record evolves gradually over a person's lifetime, and family records over generations. A person's health care needs will change and evolve in time, as does the practice of medicine, and the economic and social framework within which medicine is practised.

### **Ethical and legal requirements**

Ethical issues are fundamentally important because the use of electronic health care records (EHCRs) brings a risk of serious harm to patients or clinicians. However, the risk can be minimized without compromising the usefulness of the record, and regulation is both technically feasible and morally appropriate.

As understanding of many of the ethical issues depends on understanding of the purposes of the EHCR, these have been made explicit. These purposes have been assigned to a hierarchy which will itself aid the resolution between competing ethical imperatives. The primary purpose of the EHCR is to benefit the patient by providing a record of care which supports present and future care by the same or other clinicians. The secondary purpose is to provide a medico-legal record of the care provided and hence to demonstrate the level of competence of the clinicians involved. Tertiary purposes must be legitimate (involve consent) and can never be allowed to compromise the primary or secondary purpose. Examples of tertiary purposes are the generation of data for health service management or public health programmes.

Two important foundations of the relationship between a clinician and a patient are the delivery of clinical care to the highest standard and respect for patient autonomy. The latter inevitably leads to a proposal that the right to informed consent and the right to confidentiality are also moral principles of the highest importance underlying implementation of a 'good' EHCR. Patients should exercise as much choice over the content and movement of their medical records as is consistent with good clinical care and lack of serious harm to others. Records should be created, processed, and managed in ways that optimally guarantee the

confidentiality of their contents and the legitimate control by patients over them. The record must be secure yet accessible to patients.

The project has also considered the legal principles which have a bearing on the EHCR in terms of confidentiality, ownership and copyright, liability and accountability, identification, durability, processing of personal data, and transparency. The present diversity of legalisation on these issues is uncoordinated. There will be a need to harmonise legislation if movement of medical records is to be sanctioned by clinicians and patients.

Ethical and legal acceptability:

- preserve patient confidentiality
- respect patient autonomy
- faithfully record clinical actions
- only allow appropriate user access
- facilitate adequate audit trails and backup

### **Requirements for education**

All health care students will need to be familiar with operating electronic health care records and with the ethico-legal framework in which they must be operated. It is therefore proposed that a portion of the electronic health care record is dedicated for student use. This would enable students to gain experience in making records, but this portion would be excluded from service functions. The record must also support teaching of students and aggregation of data for educational purposes.

### **Requirements for portability**

Portability independent of:

- Hardware
- operating system
- software application
  - database, network, programming language
- national language
  - coding system

The GEHR architecture seeks to support clinical records which are independent of hardware, operating system, software application and the language used to record the clinical information. Language independence includes not only national language but also medical language and coding systems for medical language. Language independence clearly requires

the translation of the contents of clinical records. But there is widespread agreement that the electronic health care record must be structured and that the meaning of the data may depend on their context. GEHR clearly should not favour any one national language, nomenclature or coding system over another. The original language must be identified with the health care data in the EHCR itself.

### **Requirements for communication**

The GEHR project has reviewed emerging clinical and technical standards for the communication of health care data. The project has developed a consistent approach to deal with the functionality and capacity issues encountered when incorporating 'bulky objects' and other externally held data into the health care record, covering the following communication requirements:

- standard representations for data types (images, ECGs)
- standard data sets (laboratory data, drug prescriptions, minimum data sets)
- Standard messages and data transmission protocols
  - standard EDI and ODA protocols
  - confidentiality of data transfer

### **Technical functional specification**

#### **Preservation of meaning**

Clinicians value the facility for individual expression and creativity within the EHCR; however, this may make it more difficult to share. In order to ensure that meaning is preserved when the record is transferred from one computer to another, information should be recorded within its context. The original language and terms set should be identified, and original views of the data should be retained to maintain the grouping of specific pieces of information.

#### **The boundary of the record**

The clinical record must be clearly defined, and information should not form part of the record until a clinician has taken responsibility for that information and placed it into the record. Information within the computer system must be held in something like an electronic mailbox, and only considered part of the record when it has been committed to the record by an authorized person.

### **The transaction**

In order that electronic health care record may grow logically in a way that preserves its integrity, and complies with ethical and legal requirements, it is proposed that the transaction should form the basic unit of the clinical record. In fact, the clinical record may be considered as a set of such transactions. Within the GEHR project, a transaction is defined as 'the information recorded about a patient by a single author in one institution at one point in time'.

### **Description of the GEHR architecture**

The results from the foregoing requirements deliverables provided the basis of a first attempt to define a formal data architecture, in largely clinical terms: the Interim GEHR Architecture. This had the objective of providing sufficient flexibility to accommodate all the potential individual styles of record and define a set of constructs with which to model the data and concepts used in clinical practice. The fundamental architectural components evolved by GEHR for specifying what is contained in the record may be summarized as:

1. The *Transaction*
2. The *Health Record Item*
3. The *HRI Collection*

Each of these is further defined in terms of attributes which address aspects of identification, content, and context.

Every effort has been made to derive the most generic, flexible, and prescriptive structure possible. But where conditions have identified the need to be prescriptive (for example in situations where medico-legal security must be maintained) the model incorporates features which may be utilized for this purpose. The EHCR is the top-level containment structure and would be composed of many transactions, together with some data enabling the record to be identified.

A key specification of the clinicians within GEHR has been to treat the clinical encounter as a special grouping of data items for medical legal reasons. This grouping, termed transaction, has been fully documented in the functional specification. It reflects the data entered in one interactive session with a patient record—either a consultation or perhaps the 'filing' of a test result or letter. Common transaction identifiers might also form part of the context characteristic and allow a complete consultation to be identified and processed as one unit of the computer system. This would be used, for example, during the transfer of information to another institution.

The *Transaction* is a containment structure for collections and/or items which are committed to the record by an authorized person at a particular time and place. Transactions do not contain other transactions.

The *Health Record Item* has been proposed (and has been adopted by CEN PT011) as the basic unit of health information within the record. This represents the finest granularity by which an individual piece of information may remain meaningful if viewed in isolation (although complete interpretation may require it to be seen in perspective of other health related items—the clinical context). In essence, the Health Record Item is composed of an item name, its primary content value, and other associated identifiers, properties, and attributes. ‘Weight–76 Kg’ and ‘Family history–Hypertension’ are simple examples.

*Health Record Item Collections* allow for the construction of more complex aggregations of data. Examples are the decomposition of ‘blood pressure’ into ‘systolic’ and ‘diastolic’ components, or the breakdown of an antenatal examination into several sections. The recursive structure of the collection allows the health record items to be assembled into completely flexible but valid structures, of which the largest collection would be the entire patient record itself. The overall item and content values within it can each be further elaborated. The *Content properties* are used to further define the content value, such as units. The *Context characteristics* are features which relate to the whole item (its name, content, and properties) such as date and time of recording, author identification, language used in the recording.

The focus of work of the project moved to concentrate on developing from the Interim GEHR Architecture towards defining a comprehensive and rigorous information model appropriate to the content of a multi professional, multimedia health record. One particular application of this model is in deriving a formal view which can constitute an exchange format whereby safe and rigorous exchange of clinical data may be undertaken. The end objective is a formal model of the data defined in terms of object classes and structures which capture the full semantic richness of the clinical and ethical legal requirements. This is likely to be an important requirement for a formalism to anchor the future common health record architecture for Europe, with capability for monitoring of compliance to specified standards.

GEHR thus embraces an architecture which can be used to define the progressive adherence to standards for the clinical content of records and for compliance with requirements for ethical legal practice.

### **Object model and exchange format**

The GEHR project has developed two formal definitions in support of its proposals for a common electronic health record architecture. The GEHR



object model defines the structure and content of information at a site. The GEHR exchange format defines the information exchange between sites.

It is recognized that what needs to be standardized is not how people practise medicine, but some useful minimum semantics of the information recorded in the process of care. Thus, the most basic aim of the information model is to enable efficient and effective computerization of existing and new medical information, not to suggest or prescribe how practitioners should do their work. At the technical level, the model of the information held at a site is most importantly a model of 'standard' underlying information structures and not a model of any particular view of such information as seen for example on a screen, on printouts, or as grouped within particular database methodologies. This is because in the heterogeneous European health context there are a multitude of users using different applications electric reflecting many views and usages of information.

The model must also facilitate implementation by hundreds or even thousands of diverse system implementers. This is a significantly different situation for most IT system developments. To achieve these goals, a model is required with the following characteristics:

- It must be a formal expression of the entities identified in medical information. A formal model can be validated, is implementable, and enables conformance testing (for example, do our databases and applications conform to GEHR version xx)
- It must facilitate evolution (rather than revolution) in existing system implementations and data as well as the construction of new implementations. It is important that any proposed model and exchange format adopted does not leave large numbers of existing systems 'out in the cold', unable to develop towards compliance with the proposed standard EHCR architecture.

To satisfy these requirements (and many others) a pure object-oriented modelling formalism has been chosen. Some of the advantages include:

- An OO formalism has a superset of the semantics found in other formalisms, such as encapsulation of data and behaviour, modelling of incomplete concepts, and inheritance; it is therefore capable of expressing existing concepts as well as more powerful ones;
- Since the primary construct is the class, which can address the model of real- world entities, it is directly comprehensible to human beings. It is also of course comprehensible to a computer

by means of expression in an OO programming language and the use of programming tools;

- Rigorously defined ‘views’ of the model can be created for less semantically powerful but extremely important non-OO technologies such as relational databases, and exchange mechanisms such as ASN.1

Inheritance is a major feature of an Object-Oriented formalism and can be used in very powerful ways to formally define and enforce relationships between different levels of the model, and between the model and OO implementation. For instance, an implementer can directly create a subclass of the ‘EHCR’ class found in the model and guarantee conformance (enforced by the compiler) while being free to expand the idea of EHCR to fit that existing at the site. Furthermore, it facilitates the creation, understanding and maintenance of non-OO views such as relational database table definitions.

It should be re-emphasized that use by the GEHR project of this formalism does not imply that GEHR compliant record systems would be required to implement all its features. Neither does it imply recommendation for use of object-oriented database methods. The GEHR object model is intended to capture the full set of GEHR care requirements which affect data structure and communication. Good ethico-legal practice must be supported by the medical record, but its accomplishment also rests on sound procedures beyond the remit of GEHR. Legislation in this area may influence clinical procedures and may imply constraints on the data structures and organization within the record.

### **The GEHR Object Model (GEHR OM)**

Presented here is an abridged part of the GEHR OM expressed in the Rumbaugh notation [see Figure 8.24]; the diagram is derived formally (and in future, automatically) from the equivalent formal textual definition expressed wholly in the Eiffel language. GEHR is not wedded to a particular modelling notation, but to the use of a formalism for which a public domain definition and tools exist.

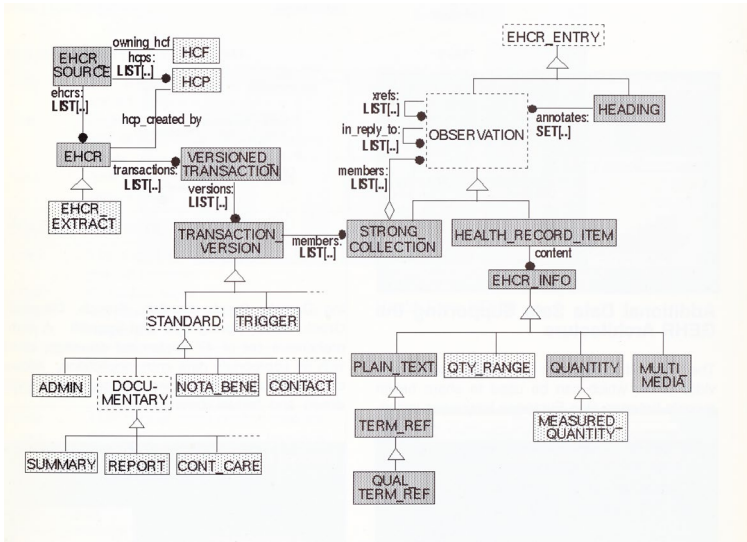


Fig. 8.24 The earliest formulation of the GEHR Object Model in 1994. In subsequent years, it was separated into the Synex reference and clinical data object model and aligned with the Ocean reference and clinical data archetype model, to provide the foundational openEHR architecture, in 2002. Image created by the GEHR project team (1994), CC BY-NC.

While there are many modelling ‘formalisms’ available, only a few have true formal definitions and are powerful enough to model abstract concepts. Many popular OO diagramming notations in use today have no formal definition, and therefore no reliable way of creating implementations and other views of the model without a lot of specialist human effort.

The formulas used by GEHR (currently the Eiffel language) avoids these problems, while providing powerful modelling and implementation capabilities, as well as tools.

### The GEHR Exchange Format (GEF)

When exchanging EHCR data between sites, it is essential to preserve the structure and meaning of the data, while recognizing that different platforms, databases, and languages may be in use at each site.

A GEHR Exchange Format (GEF) has been developed which is independent of these site-specific aspects [see Figure 8.25]. It is designed to work if the two sides can represent their EHCR data in a way which conforms to the GEHR object model.

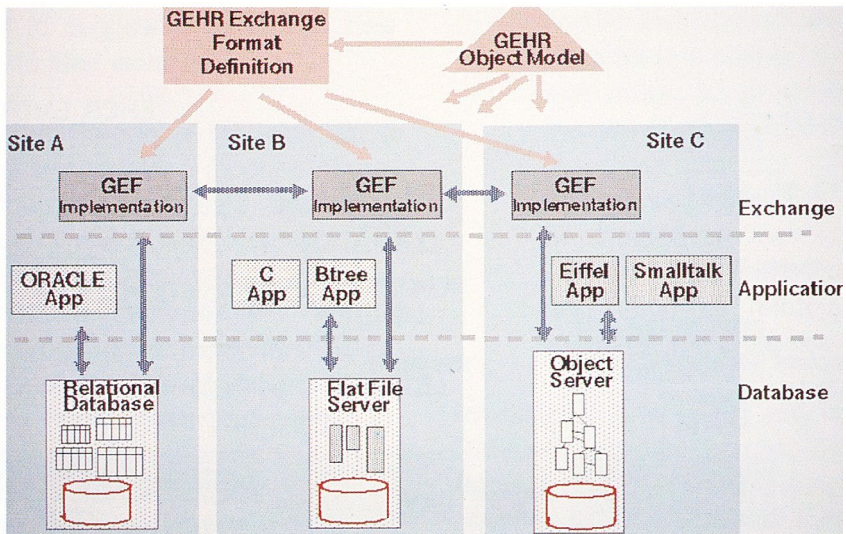


Fig. 8.25 Early ideas for a technology and vendor neutral care record exchange between systems. Image created by the GEHR project team (1994), CC BY-NC.

The Abstract Syntax Notation (ASN.1) has been chosen for the GEF since it is able to describe complex data objects which are all derived from a set of elementary types formally defined in the official ASN.1 recommendation CCITT X.208 / ISO 8824. The basic encoding rules of ASN.1 can directly be used as described in CCITT X.209 / ISO 8825 to produce a formal transfer syntax.

ASN.1 can express and encode the fact that Health Record Items (and HRI Collections) are *contained* in Collections, themselves contained in Transactions, according to some original structure.

The basic ASN.1 rules provide a simple mechanism using 'tags' for encoding all the various structural components of the EHCR. Tags have specific coding rules, so that any EHCR structure will be clearly identified in the exchange format.

### Additional data sets supporting the GEHR architecture

The termset, comprising over 2000 entries, provides terms which can be used to share health records between nine European languages including Danish, Dutch, English, French, German, Greek, Italian, Portuguese, and Spanish. A comprehensive set of 47 anatomical drawings, used with an appropriate data entry application, allows clinicians to annotate outlined sites on the body with drawn and textual observations.

### **Specifications for GEHR data access and integration tools**

The project has also built and provides specifications for tools to interface and integrate the GEHR architectural formalism (exchange format and object model) with the emerging range of standard messages and architectures from specialized domains and systems. For example, laboratory data (OPEN-LABS), images (DICOM), ECG (SCPECG), prescribing (OPADE), systems (HELIOS), and such generic messages as HL7 and communication standards such as EDI.

### **Some GEHR-compliant health care records software products and prototypes**

These prototypes were implemented at test sites in Belgium, France, Luxembourg, Portugal, London, and Hull/Sheffield.

### **The immediate future objectives of the GEHR Consortium**

Raise awareness of GEHR as providing a coherent basis for the kernel of a common architecture for the contents of a comprehensive multimedia health record.

- Further develop the architecture, with an associated object dictionary towards an umbrella architecture for medical information across projects and clinical domains.
- Disseminate the Deliverables of GEHR in the public domain and participate in the future work of AIM and CEN towards a common architecture and standard for the EHCR.
- Disseminate GEHR object model, exchange format and tools specification in the public domain.
- Explore models of the EHCR created in specialist clinical domains and map these to GEHR object model, query, and exchange format.
- Explore interface of knowledge-based systems frameworks with GEHR object model, query and exchange format
- Explore emerging health care guidelines and map these to GEHR object model, query and exchange format.
- Establish mechanisms for generation, evaluation, and standardization, in appropriate domains of the fundamental GEHR record constructs: transactions, items, collections, context attributes.

- Work collaboratively with other clinical and technical groups and projects to establish a set of user test sites/demonstrators where common architecture compliance is specified, implemented, and evaluated.

### **Deliverables**

4. GEHR requirements for clinical comprehensiveness
5. GEHR requirements for portability
6. GEHR requirements for communication
7. Specification of functional requirements for clinical use
8. Ethical and legal requirements of GEHR architecture and systems
9. Education requirements of GEHR architecture and systems
10. GEHR general syntax and semantics - interim report
11. GEHR implementation software tools - interim specification
12. Final systems report with evaluation of architecture and tools
13. Final clinical report with evaluation of architecture and tools
14. Final architecture report: details of specification and maintenance
18. GEHR software tools: final specification
19. GEHR final description
23. Documentation and maintenance procedures
24. GEHR users' manual

Preservation of meaning and clear delineation of the boundary of the record, in terms of authorship, access and accountability, were central to the GEHR architecture clinical functional specification. The technical architecture and its associated information model are further discussed below in the more detailed context of development of the work over the next ten years, leading to the creation and delivery of the methodology of openEHR.

Now, thirty years on, the original GEHR architecture has very substantially evolved. In continued fulfilment of its founding principles, it is openly specified, instantiated and widely implemented, in different software technologies and by different vendors of systems, under the aegis, now, of the openEHR Foundation and the openEHR International self-governing Community Interest Company (CIC). The need now is for a similarly cohesive and concise principled framing of an architecture for a care information utility, centred on this architecture of the care record.

## openEHR

At the time we were creating the openEHR Foundation, I was working closely with UCL Medical School deans and heads of departments, to pull together the wide-ranging community of clinical researchers, creating a database of all investigators and their projects. I was also responsible for coordinating the merger of disparate IT support teams right across the clinical and life science faculties of UCL and its merging medical schools and research institutes. I was doing all this as a member of the UCL Biomedicine management executive, and thus closely in daily contact with its leaders and with the wider university management, also as a member of its Information Strategy Committee and later as a member of its Finance Committee. These were important integrative academic roles, strongly dependent on IT, and thus the sorts of things I was appointed for and expected to take on. They gave me a wider position of status and trust, and thereby some shelter for the highly vulnerable nature of a pioneering mission like health informatics within a medical school. I was asked to chair the UCL-wide Infrastructure Committee, overseeing the changing relationship of corporate academic services and academic departments across all faculties. In the context of the clinical mission, I represented the University in its research linkages with and handling of clinical data arising in the everyday health care services of its partner NHS trusts, and on the groups drawing together the IT teams of each trust, through local mergers and implementation of the NHS National Programme for IT. I was also asked by the NHS to create and lead a national academic forum for health informatics, bringing together people from all UK universities.

My UCL academic department thus became a hub and hive of connections across academic and professional, technical, clinical, organizational and public and private sector bodies. It connected with students in many faculties and in the wider NHS, on many levels. Leading all this was a complex, multi-faceted and busy enterprise! My staff were resilient folk and took on the challenge of finding their way through what was often a jungle in those anarchic years of transition in health care and information technology, much as I had done in my early years at Bart's. As it had been for me at Bart's, this was a tough ask, especially so being positioned in a medical school environment. Such environments can often feel a bit like the Wild West, but they come with the compensating reward of independence and freedom to explore, which are essential in all creative endeavours.

It was around this protected, both interdisciplinary and multiprofessional base, that the mission of openEHR was created and evolved. It did so with members and external colleagues of the department who already had, or went on to achieve, eminent positions of academic and professional

leadership elsewhere in the country and the world. All drew on and contributed immeasurably to the rich and complementary connections of different perspectives and endeavours made possible within this unique environment, as I further discuss in Chapter Nine.

From the foundations of the GEHR project, the progression to the openEHR architecture and its associated curated archive of clinical data models of today has been a lengthy, challenging and often perilously insecure story of iterative and incremental implementation and adoption. It has involved navigating changing scope and requirements, architectural refinement, implementation and testing, team and organizational development and, most crucially, growing industry, health care organization and governmental adoption and partnership.

From the original GEHR object model has evolved the openEHR reference model of today, which includes well-tested and stable classes of data descriptive of the who did what, when, where, how and why, of digital care records. And from it and subsequent projects and products have come iterated versions of the archetype constraint model that overarches the models of clinical data captured, searched and communicated, in and through these records. A new scope of decision support and work-planning has been pioneered, notably by Rong Chen at Cambio Healthcare Systems and Thomas Beale at Ocean Informatics, Ars Semantica and now Graphite Health.

Open-source specifications, tooling and other shared code have been contributed by partners in the growing international openEHR community. The openEHR website is the gold standard of recognition of these. Those with which I have more closely connected include: Ocean Health Systems (Archetype 1.4 Designer, Clinical Knowledge Manager), Cambio Healthcare Systems (early openEHR Reference Model classes, open-source) Better Healthcare (Archetype 2.0 Designer), Thomas Beale (openEHR Eiffel workbench, lead curator with Sebastian Iancu (Code24) of the openEHR specifications and their technical governance, basic metamodel and expression language), NEDAP (Archie 2.0 reference model classes, open-source), Seref Arikan, UCL/David Ingram (Opereffa openEHR platform, open-source), Pablo Pazos/Cabolabs (EHRServer openEHR platform, open-source), Tony Shannon and Christian Chevalier/Ripple Foundation (EtherCIS openEHR platform), Rob Tweed/M/Gateway Developments (QEWD openEHR platform tooling, open-source), Vita Group (EHRBase openEHR platform, open-source). Pablo Pazos and Vita Group are likewise working on a software framework to test and accredit software products for their practical operational conformance with the openEHR specifications.

Through the foundational work and collaboration of Heather Leslie, Silje Ljosland Bakke and Ian McNicoll, and many others, now being led by Paul



Miller, Joost Holslag and Vanessa Pereira, the body of clinical models has grown to contain the largest curated set of datapoints of any such resource in the world. This has been a phenomenal achievement and the translations of these archetypes into multiple languages, with their different alphabets is, in itself, a highly significant offering that is openly licensed to the whole world. Again, the openEHR website is the gold standard of recognition of these contributions. Hanna Pohjonen and Heather Grain are likewise bringing new focus to openEHR educational resources and accreditation of course providers. And a first cohort of openEHR ambassadors and openEHR affiliate organizations has evolved to represent openEHR mission and localize its adoption in different national jurisdictional contexts. This again has entailed learning by doing: we have usually imagined these entities and allowed time to pass before formalizing them legally, in their scope and relationship to the main openEHR International board.<sup>8</sup>

This pathway has been long and meandering, all the while seeking to steer a straight course along crooked lines. Rather than rewrite more detail of the history, here, and risk unintended errors of omission and commission, I have assembled key documents that I have written over time and include them as a set of Annexes to this half chapter, in the online archive of additional resources of the book.<sup>9</sup> These trace the origins and development of the openEHR mission, alongside documents recording and acknowledging foundational contributions and contributors. They provide an important record, and I will aim to continue to update these to ensure they remain consistent, inclusive and supported statements. The online and freely accessible archives of the openEHR specifications and related clinical models acknowledge their multiple contributors very carefully, from a worldwide community that crosses disciplines and professions.

Annex I, written in 1999, ten years after the commencement of the GEHR project, expresses the mission and rationale of openEHR. Annex II describes the origins of openEHR up until the establishment of the openEHR Foundation, in 2002. Annex III is a transcript of my lecture at Medinfo 2007 in Brisbane, which is also on *YouTube* and accessible from the openEHR website. The history of the movement from 2002 until the creation of the Community Interest Company, openEHR International, in 2018, is

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8 As I finalize this book's manuscript, after its copy-editing by Open Book Publishers, Sam Heard has just taken on the chairmanship of the openEHR Foundation from me, and Rachel Dunscombe has been appointed to be the first Chief Executive Officer of openEHR International. It is a wonderful time of transition in openEHR mission, hugely enabled by the openEHR International Board.

9 Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

recorded in Annex IV, and the updated 2020 vision and mission, written with Thomas Beale, is at Annex V. An updating account of the current status of the movement will be added to, from time to time, which I will ask new leaders of the mission to help create, and perhaps then take over.

openEHR is now a proven vendor and technology neutral architecture for digital health care records. Through its decades-long evolution and stabilization, it has acquired much new structure and form which is best not paraphrased here but taken up through study of the website. It now embodies clinician-defined models of record content (the models with ISO-standardized generic structure, known as openEHR archetypes) linked with internationally standardized clinical terminologies and translated into many languages. The reference model of generic building blocks and associated software tools enable non-technically literate health care users to design and specify a care record. By design, this record can then be hosted as an application on an openEHR standardized and generic technical platform for health computing. This is akin to an Android platform for health care with the health record running as an Android App. There can be many such applications, supporting the many specializations, workflows and connections of health care services, but they share a common semantic core, embodied in the reference model and archetype model.

The foundational ideas about record architecture embodied in GEHR through classes of Health Record Item, Collection and Transaction, have iterated, metamorphosed and extended to element, composition, cluster, entry and folder, all strictly version-controlled, and connected into a model of recorded observation, evaluation, instruction and action, and their combination in workflows and timeseries of events. The archetype model and expression language have widened in scope to enable close alignment and binding with evolving clinical coding, classification and messaging systems, such as SNOMED (Systematized Nomenclature of Medicine), ICD (International Classification of Diseases), Logical Observation, Identifiers, Names and Codes (LOINC) and Fast Healthcare Interoperability Resources (FHIR). These have, perhaps, reached tractable limits of relevant elaboration for general purposes, and Occam's razor looms. They will likely continue to evolve through simplification of essence and refined granularity of description. The Ocean Health Systems Clinical Knowledge Manager (CKM) tooling has advanced and now hosts substantial libraries of both nationally and internationally curated clinical data models. The Better Care and Ocean company tooling for openEHR archetype design are used widely around the world, as is the Vita Group EHRBase open-source openEHR platform implementation.

Conformance to this open platform specification ensures that data can (with due and informed care!) be reliably queried across all component

software applications in a standardized manner. It holds the promise of loosening the harmful hold of proprietary data formats, that currently prevail in health IT systems. By adopting the openEHR platform approach, users can build a local set of inter-compatible systems, choosing from the products and services of a growing community of both large and small providers, or developing their own. Most importantly, the transparent clinical and technical discipline of openEHR provides robust ethico-legal foundations on which to satisfy growing international concerns and expectations for confidential handling of personal data, as exemplified in the general data protection regulation (GDPR) in Europe, for example. Huge sums are spent in health informatics, but very much greater value will be achievable when shared methods and resources prevail, as they do elsewhere in science and engineering.

A key focus of new learning is about implementation reaching towards the vision of a citizen-centred care information utility. Leadership in this quest will be centred on pioneering openEHR adoption in various care sites, involving whole health care organizations and regions and their supporting industries, in new partnerships. A most encouraging development has been the adoption of openEHR as a standard for care record repositories in substantial clinical initiatives of health care providers, such as cancer services around The Christie Hospital in the Wirral in England, the care record ecosystem of the Karolinska University Hospital in Stockholm, and the health care system of the state of Catalonia, in Spain. Better's OneLondon project has been another and widely acclaimed advance along these lines. There is also growing confidence demonstrated by pioneers in India, and in the activities of openEHR ambassadors, national affiliate organizations, and the now more formally established clinical and educational programmes, which are all starting to gel in a complementary fashion, under the increasingly securely-established CIC board, ably co-chaired by Tomaž Gornik and Rachel Dunscombe. Jordi Piera-Jiménez, leading for the trail-blazing adoption of openEHR in Catalonia, has provided notable leadership and advocacy in world fora. Details of all this can be found on the openEHR website.

**Health care information systems have become opaque and entangled – new discipline is needed to unravel them**

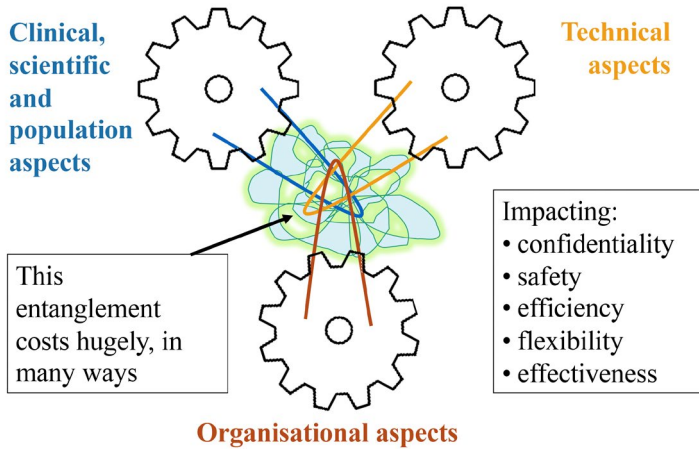


Fig. 8.26 The entanglement of non-coherent information systems. Image created by David Ingram (2010), CC BY-NC.

***openEHR* was created to help disentangle clinical systems, so they can interoperate rigorously and meaningfully**



Fig. 8.27 Interoperability achieved through the common ground of a coherent semantic framework. Image created by David Ingram (2010), CC BY-NC.

I often used these two slides (see Figure 8.26 and Figure 8.27) to illustrate the entanglements of clinical data that can arise when they are interchanged between systems, devoid of a unifying semantic framework of meanings, and then illustrate how we are working to untangle the knots, using the common ground of openEHR. The cogs are pictured properly, here, reflecting the engineering rigour we have prioritized in openEHR, and they are revolving in synchrony, in contrast with Figure 5.1 and its imagineered depiction, which is actually of a non-functional, broken machine! I focused most on providing and sustaining an overarching vision and inclusive team environment, to hold and keep mission and people together. I was fortunate beyond imagination to have been a leader among a team of great leaders and have their commitment, support and trust.

### From Opereffa to EHRBase—Towards a Standardized openEHR Open-source Platform

As wider interest in openEHR started to grow from the early 2000s, our previously closely knit team, centred on UCL, spread and expanded along different paths. Ocean and Cambio were early pioneers, and Rong Chen at Cambio created a set of Java classes to implement the openEHR reference model and make these available open-source, to help others experiment with the creation of openEHR-based systems. In parallel, my colleagues, Dipak Kalra and David Lloyd, working at UCL, switched their focus to leadership of a CEN project team established under a Working Group chaired by Gerard Frericks, to work on a standard architecture for electronic health record communication. This involved them in several years of intensive work, subsequently adopted in CEN and ISO as the 13606 standards. In its two releases, this incorporated the openEHR archetype model as a public domain standard for the clinical content models used to specify content of the care record shared between systems.

In 2008, Seref Arikan came to London as my doctoral student, to build on his extensive experience, both as an economist and computer software developer for hospital systems in Turkey. This connection evolved into a most fruitful and consequential professional partnership, supported jointly between CHIME and Ocean, and from it have come new insights that have strongly influenced implementation. In his PhD dissertation, Seref explored how Bayesian networks could be integrated with the architecture of openEHR. He invented a new software paradigm and model for implementation of queries into structured care record data, unravelling and resolving ambiguities that had arisen in the overlap of terminology used to

describe clinical knowledge and the information model used to structure and organize it within a clinical record database.

In those early years, I was concerned about the legal integrity of openEHR intellectual property rights. Through my involvement in the StartHere community and with the invaluable help of its leader, Sarah Hamilton-Fairley, and the chief executive of UCL Business, Cengiz Tarhan, I was introduced to and commissioned Oliver Bray, a partner specializing in intellectual property rights at the leading London law firm, Reynolds Porter Chamberlain, to draft documents formally assigning the openEHR intellectual property rights (IPR) to the by then established openEHR Foundation, from its founding member organizations, UCL and Ocean Informatics.

I was further concerned that we make a reference implementation of openEHR available, as an open-source platform (akin to an Android or Unix of healthcare), to facilitate dissemination and uptake. This was tricky territory as early pioneering companies partnering us were, very understandably, anxious to maintain their advantage as early adopters of the openEHR methodology, in their products and businesses. These conflicting interests required careful and sensitive balancing, in the interests of sustaining our partnerships and finding common ground on which to pursue the purposes and goals to which we and the openEHR Foundation were jointly committed and dedicated.

With Seref, I funded and pursued an early project to create such an implementation. He christened it Opereffa. Tony Shannon was likewise a committed advocate for open-source health care software and contributed his time generously to our project. Here is the diagram (see Figure 8.28) that set its scope and context. It was published on GitHub and the Opereffa software was downloaded and referenced in projects in many countries. It invited but attracted no more widely contributed code. This was a salutary lesson that open-source can be seen as a useful bootstrap by others—a free good—but not one they are always committed to or able to advance. The Opereffa initiative and its pioneering first steps towards an open-source platform implementation of openEHR, now being realized in the EHRBase project in Germany and the Cabolabs EHRServer project in Uruguay are described in a 2013 paper by Ingram and Arikan.<sup>10</sup>

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10 D. Ingram and S. S. Arikan, 'The Evolving Role of Open Source Software in Medicine and Health Services', *Technology Innovation Management Review*, 3.1 (2013), 32–39, [https://timreview.ca/sites/default/files/article\\_PDF/IngramArikan\\_TIMReview\\_January2013.pdf](https://timreview.ca/sites/default/files/article_PDF/IngramArikan_TIMReview_January2013.pdf)

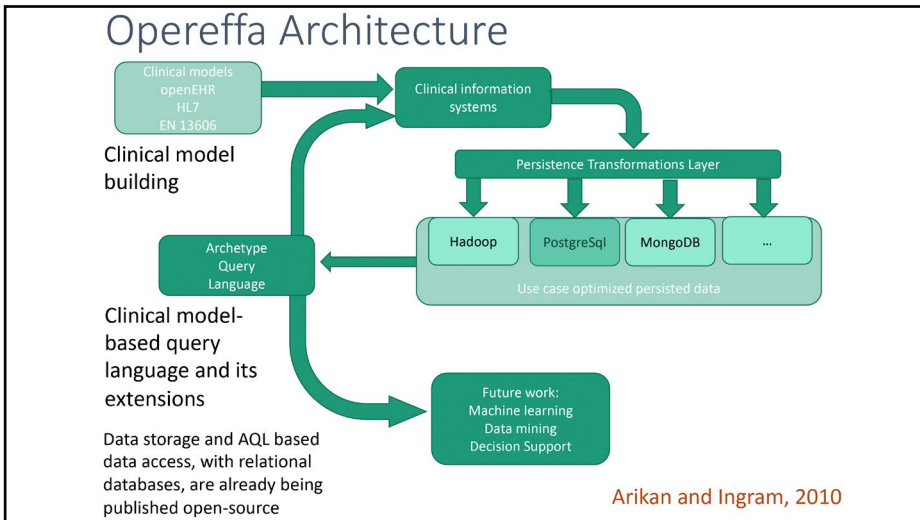


Fig. 8.28 The scope of the first open-source openEHR platform, Opereffa. Image created by Seref Arikan and David Ingram (2010), CC BY-NC.



Following from his engagement with Opereffa, Tony Shannon joined forces with Christian Chevalier, from Cambodia, who had previously visited me at UCL, along with a French clinical colleague interested in making a professional and commercial link with openEHR. Together they pioneered the EtherCIS platform, later joining up with Jo Milan's former colleague, Rob Tweed, who added his invaluable Marsden background in the Massachusetts General Hospital Utility Multi-Programming System (MUMPS) language. Rob capitalized on this to write a developer toolkit (QEWD) for openEHR compatible implementations under the Ubuntu operating system, including on the cheapest of microcomputers, the Raspberry Pi. The team had local successes in implementing a prototype shared care record in Leeds, but the battle to secure longer-term funding defeated them, despite Tony's Herculean and very public-spirited efforts over more than a decade. He eventually moved back to Dublin and took on a key clinical role overseeing policy for health care IT in Ireland.

In about 2015, Vita Group, a German company connected, I gathered, with the group that developed the worldwide success story of a prominent business software suite, entered the arena. Tony organized a meeting with them in London, in 2018 and, over time, the EtherCIS project metamorphosed into a solidly anchored new development activity, to

bring an Apache open-source-licensed openEHR platform to the level of a rigorous and dependable product. This has drawn on the already wide-ranging expertise of Vita Group and brought Christian Chevalier and Pablo Pazos into their development team, alongside Birger Haarbrandt and Stefan Schraps. Pump-priming resource was received from the German government in the HiGHmed project, tasked to connect clinical data and records from principal German academic medical centres onto an openEHR platform, linked with additional tooling to enable integration with HL7 FHIR messages communicated between systems.

This open-source initiative was christened EHRBase. It is the long-sought realization of an openEHR reference implementation, some fifteen years after my early championing of the importance of such an implementation, in growing and disseminating openEHR methodology and community. It is a stepping-stone that enables new entrants to the field to implement innovative clinical projects and applications, quickly, agilely, credibly and scalably. (Microsoft Word doesn't like 'scalably', suggesting I mean 'saleably'—I'm sure that is true, too!) Much to my pleasure, this is starting to happen widely across the developing world.

For many decades, such innovation has been impeded and prevented by the start-up cost and effort involved in getting a new, closed source and proprietary platform up and running. The USA Veterans Health Information Systems Technology and Architecture (VISTA) initiative, with its considerable backing, struggled to sustain and update such an infrastructure, focused on health-system-wide application. Such endeavour typically requires many years of effort, building and sustaining a substantial software team and guided by only a small fraction of the international clinical community input that openEHR has mobilized. openEHR clinical models now constitute the world's largest corpus of tried and tested, formally assured, openly licensed care record content models. These models are developed and live within their local domain of clinical requirement, service and governance, while able, as required, to interoperate within the widening range of health care systems that have adopted the standardized openEHR care record platform architecture. The Ocean Health Systems Clinical Knowledge Manager software is coming into its own as a tool for curating these knowledge models in context of local community needs.

The incremental emergence and backing for EHRBase, is transforming the market alongside the now powerful openEHR-based products of early closed source offerings of companies like DIPS in Norway, Better Care in Slovenia, Cambio in Sweden and Ocean Health Systems in Australia, with other well-established companies now starting to join in.



## openEHR and OpenEyes

OpenEyes has a shorter pedigree than openEHR and arose as a mission and preoccupation for me after meeting Bill Aylward, its founder. I introduced him as one of the pioneers whose contributions were described and celebrated earlier in Chapter Eight. I have described there and elsewhere in the book how these two missions connected along my songline.

I met Bill and connected with OpenEyes in the early stages of its prototype development at Moorfields Eye Hospital. Bill had clout and credibility there and it underwrote his team. He had free rein and ability, personally, to link and oversee both the clinical purposes to be served and technical prototyping of the software. We worked together closely from its early days. He joined the openEHR Foundation Board and I the board of OpenEyes. Had openEHR then existed in the form of what is now the EHRBase platform, OpenEyes would have been built on that platform from the start. Bill, Seref Arikan, Ian McNicoll, Mark Leaning and I secured funding and worked on building bridges between the two—for example, in designing an archetype for recording visual acuity and creating a software interface with high street ophthalmology services, working with the Black Pear software company.

To inform his PhD project, Seref and I worked alongside Bill to study and extract data from the legacy patient record database at Moorfields and take first steps to harmonize it within the framework of openEHR methodology. The tangle revealed in the underlying structure of the database of clinical records of this justly world-renowned institution was a shock. The local Trust IT team must necessarily have been substantially engaged in sustaining arcane methods for reliably feeding and interrogating it. Bill's motivation for creating OpenEyes, to improve on this underlying costly and unsustainable disorder, was well justified.

One great personal regret, that it is important to record, here, is that in mid-2013, Bill and I tried very hard to interest the National Health Service (NHS) in helping us integrate OpenEyes onto the evolving platform of openEHR. Sadly, this came to nothing. Our detailed proposal to bring together key initiatives in open-source clinical applications software of the time onto an openEHR integrated care record platform, that we worked on with Ian, Seref, Mark, Tony, Thomas and several other groups fell afoul of funding gremlins, somewhere. I saw several hundred proposals adjudicated under this NHS Integrated Care Records initiative, and, under the bonnet, few were much more than a Web-based patching together of separate applications.

Our ORSINI (Open Record Standards INitiative) vision, as we christened it, remains on the 'to-do list' for OpenEyes, as soon as possible, when we can

find a funder. This will, hopefully, soon succeed, as we gain implementation experience in the OpenEyes national programmes for Wales and Scotland, and alongside the groundswell of international usage and interest in the open platform approach. The Apperta Foundation has pioneered a new business model for open platform-based health applications. This has thus far proved viable, against the doubts and concerted opposition of some. It remains to be seen whether it can prove viable for attracting the level of new investment needed to align the current OpenEyes software onto an openEHR standardized platform, such as EHRBase.

In my new retirement roles at a distance from the more onerous fray, I see a pathway opening for our long-ago ORSINI platform to become a global utility, safely and sustainably, in a way that achieves much more, much faster and more cheaply. That has been my provocative ten-ten-ten mantra (ten times in each of these aspects) of recent years, along with the buzzphrase of 'Small' or 'Little Data', which I alighted on to focus attention on the ground-level data captured using the 'omniscles' (see Chapter Three) of openEHR archetypes, as a necessary foundation of less noisy Big Data.

openEHR and OpenEyes are both landmark initiatives that started from ones, twos and threes of participants, grew to tens and hundreds, and are now, in a similar leap, moving towards the tens of thousands. Such transitions are similar in terms of the energy, staying power and persistence they require. This kind of experience has informed my approach in leading disruptive endeavour, holding together teamwork, culture and environment at the centre of connected mission. As activities in my legacy portfolio, they are chicken and egg-like, now coming increasingly into focus as a unifying thread of initiatives at national levels. In terms of their specifications and implementations, they demonstrate a modular architecture of clinical record applications, and a modular platform architecture to house and interconnect families of such applications. OpenEyes is now (albeit very slowly because of resource constraint) on a pathway of migration to fully align its data with the archetype model standard of openEHR, following on from our initial foray in capturing visual acuity data in this way, some years back. It is disappointing that health informatics policy in the home country of openEHR and OpenEyes has somewhat lacked acuity of vision and been somewhat short-sighted in its goals. Perhaps this an inevitable reflection of its huge size. Scotland and Wales have established teams to work on a national openEHR platform and ecosystem of open-source clinical applications.

In parallel, OPENeP for medicines management (a significant missed opportunity for the NHS in not heeding Apperta's attempt to secure this, too, in the public domain, I gathered) has been developed and marketed by Better Care and is largely already constructed and operating within its

openEHR-based platform framework. New applications to support routine clinical ward level observations of vital signs, linking with new integrated instrumentation for their capture (open-eObs), and patient reported outcome measures (openOutcomes), using internationally standardized questionnaires, are advancing rapidly within the Apperta Foundation, and creating considerable worldwide interest. These are all building blocks of future care information utility.

Why has all this failed for so long to crystallize in policy circles? My former student and colleague, Dipak Kalra, who now works as a consultant at senior industry and government levels across Europe, told me in a March 2023 e-mail that the message is at last beginning to take root at those levels. As purpose and goal, the concepts and their early implementations were articulated and visible, twenty years ago, and presented at the highest intergovernmental levels, as many stories in the book describe and bear out. The legacy of frequent new initiatives and poorly interoperable systems and applications *in situ*, that health care IT teams have had to adapt to, choose from, and keep running, have kept them distracted by short-term issues, with few able and equipped to take a longer-term view.

More detailed history, spanning now thirty years of openEHR and twenty years of OpenEyes, can readily be traced online. I retain the most detailed personal archive of those decades, charting there the progress along my songline. I do not wish to paraphrase or rewrite them. Stuff happens and things change but it is not for me to revise the history of something I was so closely connected with. Others must now traverse their own songlines, tell their own stories, and write their own histories.

Through this reflective half chapter, I hope the reader will find anthro-vision—Gillian Tett’s new term<sup>11</sup>—and insight into the human side of openEHR and OpenEyes, as this is where their sustained success had its origins and retains its staying power. It is a hard story to tell as it has been very hard to achieve, and hard to survive, for many people. Of course, there has at times been contentious, manipulative and angry dispute and disappointment. I have not written about these instances, to preserve confidentiality about hard times that many have been through, and still do, and will likely prefer not to be reminded of! Learning from experience of this human dimension is where important lessons for the future of care information utility will lie. Environment is all important—a place and setting where people are enabled to connect, work and be valued, both collectively and independently. Teams, and their complementary perspectives, goals, roles and motivations, are all important. Connecting with and capturing opportunity, and using it flexibly

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11 G. Tett, *Anthro-Vision: A New Way to See in Business and Life* (New York: Simon and Schuster, 2021).

and well, are paramount. Above all, what have mattered most have been trust and staying power. What matters in anarchic transitions is to cope and get on with the work, see it through and preserve important values and meanings. Otherwise, much more can and will be lost.

Bill and I have both stepped aside from our central roles in OpenEyes and openEHR. Me to dance with my wife, look after our health, enjoy family, freedom, fun and opportunity to branch out in new directions, and write this book! And Bill, a decade or so younger than me, to sail and enjoy the world with his wife. Stepping down is as important as stepping up. Innovation does not happen unless people step up to carry the load. It is not sustained unless they step down, too. That is the way in which current postscript is translated into future preface, and a new generation inherits and uses the useful legacy landmarks and stepping-stones left to them, and learns from the less advantageous ones, as well, as health care continues to evolve and move forward. Bill stepped down and James Morgan, Peter Coates and David Haider have powered his vision of OpenEyes forward. As the openEHR founders have gradually stepped down, a new board and team of complementary leaders, brimming with energy and commitment and reaching to wider horizons, is powering their vision forward, too. As a seasoned grandfather, like myself, a principal reward in life is to have confidence and pride in your family. openEHR and OpenEyes are also great families and I do in them, too—with head still, just about, and heart, always warm, but not so much with hand, other than to clap!

## Parenthesis—And So?

This half chapter has described long-term work dedicated to imagining, developing and implementing tested solutions for a central component of the care information utility—a globally standardized, openly specified and freely accessible methodology supporting a locally governed, citizen-centred platform ecosystem of digital records of care for whole health economies. In parallel, and in connection with the profile of its founder, Bill Aylward, in Chapter Eight, it has connected with his ambitious and highly successful quest to create a clinical community motivated and led, widely adopted and sustainable, open-source medical record for eye care. These interdisciplinary, multiprofessional and multi-sectoral initiatives have explored practical issues of implementation, in detail and at scale, and the creation of new community and legal organization to lead and coordinate their further evolution, as viable and cost-effective community interest endeavours. And so, where next? That is for others to envision and lead. It will be what they now create from the legacy that they inherit. How they do it will matter as much as what they do.



# 9. Creating and Sustaining the Care Information Utility—How, Where and by Whom?

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We come now to the most challenging questions concerning the care information utility: how, where and by whom will it be created and sustained, and under what governance arrangements? This chapter looks to the wider and future scene, to consider how the work described in Chapters Eight and Eight and a Half can be extended and sustained, in the context of greater opportunity and need for individual self-management of care and supportive services that move from a fragmenting culture of ‘What is the matter with you?’ to an integrative culture of ‘What matters to you?’ We must embrace an iterative and incremental approach here, where we learn by doing. The chapter is thus not prescriptive; it rather reflects on the nature of the challenges faced and what we should have in mind in framing our policy and practice in tackling them.

Central to this will be the approach and method adopted for implementation of a coherent and trusted information utility that every citizen can feel part of and contribute to, which helps and supports them along the way as they seek health and wellbeing in their own lives, and the lives of those they care for. The chapter highlights the importance of the Creative Commons and public domain governance that bridges with and preserves the non-exclusive relationship with private enterprise. The story of common land and its appropriation to private interests through the eighteenth-century Enclosure Acts in the UK, is visited as a parable of common ground in the Information Age. It discusses the harm that restriction of intellectual property does in blocking innovation that tackles intractable ‘wicked problems’, which require connection and collaboration on common ground, within diversely connected communities of practice.

The chapter then focuses on the work of implementing and sustaining the care information utility and the environments, teams and communities whereby it is enabled and supported. It looks at the different qualities of leadership that such pioneering endeavours require and exemplify, and playfully compares them with the principles outlined in *The Art of War*, the classic text of Sun Tzu, which is much used in

elite management courses on leadership. With its focus on people and environments, this part of the chapter draws a great deal on people I have known and worked with, and environments we worked in and created together, and is thus especially personal and autobiographical.

Trust in and recognition of individual and communal roles and responsibilities must unite citizens with the multiple professions and communities of health care practice, around shared goals for the care information utility. Governance arrangements will thus constitute a third major component of implementation of a utility that is coherent, effective, efficient, equitable, stable and life-enhancing, in support of health care services for the Information Society of tomorrow.

These threefold challenges of implementation will require strong alliances—the theme I reflect on, in parenthesis, at the end of the chapter.

Bolder adventure is needed—the adventure of ideas, and the advantage of practice conforming itself to ideas. The best service that ideas can render is gradually to lift into the mental poles the ideal of another type of perfection which becomes a programme for reform.

—Alfred North Whitehead (1861–1947)<sup>1</sup>

When spontaneity is at its lowest, in practice negligible, the final trace of its operation is found in alternations backwards and forwards between alternate modes. This is the reason for the predominant importance of wave transmission in physical nature.

—Alfred North Whitehead<sup>2</sup>

I repeat this first quotation to re-emphasize that care information utility is an adventurous idea and a central focus in the reform and reinvention of health care. It is a shared resource, created, owned, operated and sustained locally. It is not a directed flow from a source to a recipient of information. It is a resource that faces and informs both ways. Governance and rules of the road must reflect this mutuality and be understood, trusted and supported accordingly.

Chapter Eight has addressed questions of *what* is needed and *why*. This chapter connects them with the practical question of *how*. It is about the approach to and method of implementation, and the endeavour and governance that will be required to create, bring to fruition and sustain an evolving care information utility. At the centre of the utility is record, and at the centre of record is the individual citizen. How will this utility be

1 *Adventures of Ideas* (New York: Macmillan, 1933), p. 248.

2 *Ibid.*, p. 247.

created, based on what approach and method? How will it build on and supplant current fragmented legacy information systems? Why, what and how form a tripod of implementation that frames endeavours—they are about approach and method. They must be learned, not prescribed. I call this tripod Implementation One.

Where, who and when form a further tripod for endeavours. I call it Implementation Two. *Where* is about environment—the setting in which to tackle the creative and ongoing challenges. *Who* is about people—teamwork and leadership. *When* is continuously—the imperative is to keep moving upstream and sustain efforts through staying power. This chapter is thus also, crucially, about the people, teams and wider connected communities needed to co-create, own, operate and sustain the utility, the environments where they collaborate and the common ground they create, occupy and share. These are the good environments that Richard Wollheim (1923–2003) described as not a luxury but a necessity, that are needed for nurturing the utility from sapling tree into forest ecosystem.

Those first two tripods of implementation need a third to balance and stabilize approach, method and endeavour. This is the tripod of head, heart and hand of citizens and communities, expressed through systems of governance. I call it Implementation Three. Good governance, too, must be learned.

In my geometrically and visually configured mind, implementation is thus depicted as a triangle of the three complementary tripods of approach and method, endeavour and governance. It is enacted by people in settings and contexts, imbued by the culture and values they develop and exhibit in their work and behaviour. I have thus cast implementation as a triangle of tripods (implementation, implementation, implementation!) to emphasize its importance—a trifecta of complementary tripods! Making and doing these things, iteratively and incrementally, is all-important. And drawing everything together, at the apex of a tetrahedral implementation pyramid, is indivisible trust. Implementation comes together within a safe and trusted framework of making and doing. Figures 9.1 and 9.2 provide a pictorial representation of this esoteric geometry in my mind!



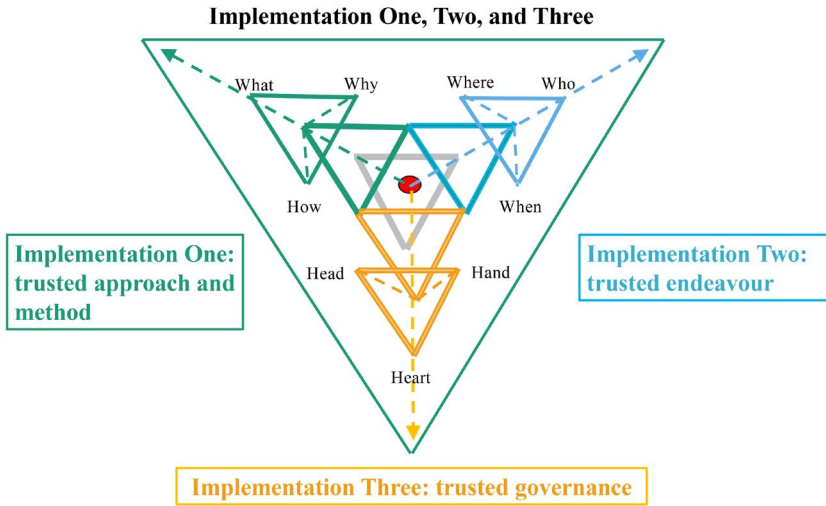


Fig. 9.1 Looking down from the red trust apex of the threefold implementation pyramid. Image created by David Ingram (2022), CC BY-NC.

The Polish mathematician Waclaw Sierpiński (1882–1969) was a pioneer of set and number theory and topology. His work has inspired model builders and artists. Images of the fractal decomposition of the Sierpiński tetrahedron have inspired my characterization and illustration of the threefold dimensions of implementation of the care information utility in this chapter.

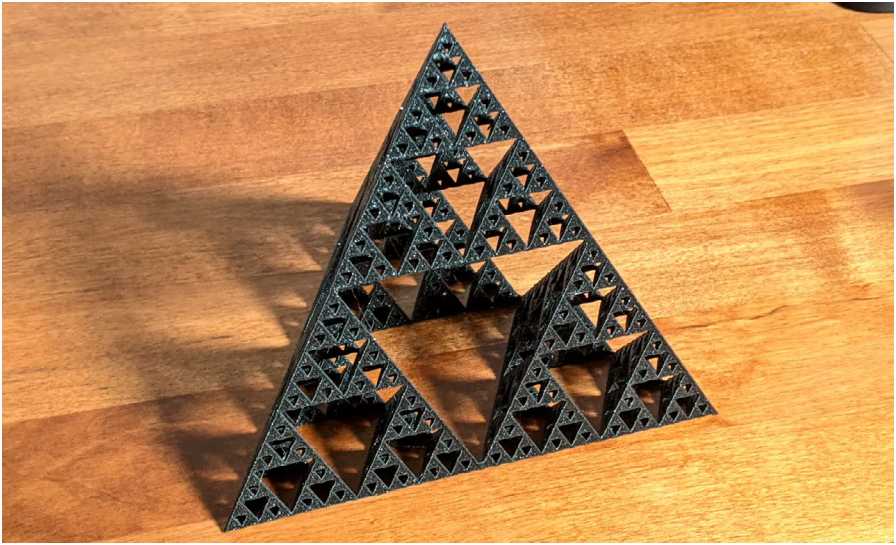


Fig. 9.2 A fractal three-dimensional printed model of the *Sierpiński* tetrahedron–tetrahedron enfolded within tetrahedron, illustrating the fractal nature of implementations. Based on a design by Josef Prusa (2021), CC BY-NC, <https://www.printables.com/en/model/67531-sierpinski-tetrahedron>

Enough abstract geometrical analogy! Implementation cannot just be analyzed, planned and managed. It is organic and must be nurtured, grown, led, and sustained, and learned about through example.

We might similarly characterize three dimensions of reinvention and reform of health care services, as matters of approach and method, endeavour and governance. There is continuous interplay along and between these dimensions, that defies prescription and requires resilience to cope with events and adapt as they unfold uncertainly over time. This chapter draws from personal experience of this interplay along my songline, in several different contexts. It compares the ‘horses for courses’ observed and experienced, seeking to highlight patterns relevant for the future. Notwithstanding the pretence of electoral cycles and manifestos, none of this can ever be created with magic bullets or in rapid progress. Controlled nuclear fusion-based power stations have long been fifty years away, and care information utility is a still forming vision and long-term goal!

The quotations from Whitehead that headline this chapter, written a hundred years ago, are still to the point. In the first, he is suggesting that bolder adventure of ideas is needed to guide reform. This complements Mervyn King’s call for new ideas that are approached with audacious

pessimism.<sup>3</sup> He must have pondered that term—preferable to risk-averse pessimism or audacious optimism, which abound in uncertain times! The second quotation reflects the price we pay when lacking adventure of ideas, common purpose and energy in what we make and do—our actions oscillate to and fro, like waves in a water tank. The politics and policy of health care has oscillated between central and devolved focus, public and private provision and different models of delivery. Expensive reorganizations of associated services have gone through recurrent limit cycles of boom and bust.

King described the recurring crisis of the money and banking systems as a crisis of ideas. In banking, huge sums of money were spent on new information infrastructure and yet the instability of the monetary system persisted and worsened. The lack of ideas that King regretted was not about ways to spend money shoring up infrastructure. It was about lack of ideas for reform of the purposes, principles and goals underpinning the monetary system, as the global economy headed through the Information Age, with the computer exposing and amplifying its vulnerabilities. Care information utility is not about ways to spend money on infrastructure, either. Governments have spent very considerable amounts on computers and consultancy, mistakenly expecting thereby to change and shore up a fragmenting landscape of health care services.<sup>4</sup>

Some of these fragments have been prioritized and benefited hugely and function much better as a result—general practice IT systems in the UK being one good example. There have also been pre-eminent scientific, technological and clinical advances in imaging systems, genomics and pharmaceuticals. Confidence in what artificial intelligence (AI) might contribute is both exploding and imploding, as I write—valiant AlphaFold meets its shifty

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3 M. King, *The End of Alchemy: Money, Banking and the Future of the Global Economy* (New York: W. W. Norton and Company, 2016).

4 As I finalize this section in the weeks ahead of my self-imposed publisher deadline, the *Times* newspaper has an article by the economists, Mariana Mazzucato and Rosie Collington, presaging their new book, *The Big Con: How the Consulting Industry Weakens Our Businesses, Infantilizes Our Governments and Warps Our Economies* (London: Allen Lane, 2023). The article title is more explicit still—'Trillion-dollar Con Trick: Advice that Makes Things Worse' (*The Times* (10 February 2023), <https://www.thetimes.co.uk/article/trillion-dollar-con-trick-advice-that-makes-things-worse-pgrs5jc5j>). Confidence tricks take us down—be they by sleight of hand, deceit, hubris or pretence of knowledge. Intentionally or otherwise, they break faith and trust. We must not mix up our cons and contras, though. Con- is about togetherness. We need new confidence and conviction to conjoin and connect in ways that help us back up and help keep us there in matters of health care. The idea of care information utility, as developed in this book, is as a common ground of implementation of information utility, towards that (convivial!) human end.

alter ego, ChatGPT, as it were! Perhaps the Neocene will never be seen, or perhaps it will be us that no longer see. Implementation Three and confident governance resembles St George squaring up to this unpredictable dragon, hopefully equipped with effective armour and a sharp sword!

Leaving such speculative conjecture aside, in terms of what health care information systems could now be, with the individual citizen the central focus, the reality still falls far short of requirement and expectation. Ever more money spent in falling short, makes long-term reform ever harder. Confidence is at a low ebb.

Through the course of the preceding chapters, I have highlighted what I have seen and experienced as historic overemphasis of policy on *what* is needed and expected from health care information systems, and *why*, and lack of focus and critical examination of *how* its vision can be created, governed and sustained. Lacking a practical sense of *how* desired reform can occur and be sustained, the outcomes sought and invested in are not achieved, and undesired outcomes grow in their place. Implementation of policy has swung like a pendulum, between central fiat and local autonomy; it has been scattered and inconsistent in focus, oblivious to harm done in places struggling to cope and care. It is hard not to feel appalled by and ashamed of the cost, waste and harm it has engendered in many out of sight, out of date and increasingly decrepit environments in which our health care services, and their teams must operate.

Information policy is central to all the professions of health care and those they serve, the ways they work together and are organized, and the information systems and technologies they employ. Approaches to policy focused on prediction and management of goals and targets that have not often been met—as Chapter Seven addressed in detail—and pursued largely devoid of methods for achieving traction, have repeatedly failed to gain traction. This has made successive policy initiatives increasingly hard to implement, being increasingly encumbered and impeded by changing requirements, new science and technology, and a burgeoning legacy of incompatible information models and systems brought into being along the way. This failure has led to poorly contained explosion of noisy information—much as the Octo Barnett-led report to the Office of US Congress Technology Assessment Board feared and foretold, fifty years ago.<sup>5</sup>

All that said, Richard and Daniel Susskind counselled against what they called ‘technological myopia’, by which they meant the tendency to discount

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5 Congress of the United States Office of Technology Assessment, *Policy Implications of Medical Information Systems* (Washington, DC: Congress of the United States Office of Technology Assessment, 1977), <https://www.princeton.edu/~ota/disk3/1977/7708/7708.PDF>

future potential of technology to assist and improve, by emphasizing too greatly its current perceived failings.<sup>6</sup> Whitehead described mistakes and failure as normal parts of improvement and growth. All this is true, but simply repeating an ever more expensive and complex failure, revisiting the same ground that has characterized much of the past fifty Groundhog Years, is not acceptable. New ideas are needed, as is deeper and more openly shared reflection on the reasons for successive failures of policy and strategy, and failure to learn from experience, that have characterized policy in the field.

This chapter proposes how we might, and now can, bypass and progressively clean up the costly and accumulating legacy of unconnected and incompatible information systems, to create a care information utility that is much more cost-effective and better positioned along a sustainable pathway for the future, more in tune with the changing times, as we evolve into the Information Society. It proposes an effective, affordable and agile way to approach, create, replenish and sustain this utility, drawing on thirty years of personal experience and effort along the runway. This may, no doubt, be seen by some as a silly, unworldly and naively optimistic vision, perhaps also fearing that it is a destabilizing and threatening one. It has certainly been treated in those ways, but it is still alive and developing, as Chapter Eight and a Half has shown, after those many years of growing pains. I have taken heart from King and Erwin Schrödinger (1887–1961) in expressing it here. New ideas are needed, and we should not shrink from appearing or being cast as foolish in expressing our ideas, especially when we have real-life examples of these ideas being implemented and working coherently in practice and at scale, with connectivity and continuity that has eluded much, and far more expensively unsustainable, practice to date.

Implementation experiences of the architectural blueprints outlined in Chapter Eight and a Half are well advanced along new runways all over the world. And through dint of hard-won and multiprofessional team culture, practical industrial and organizational skill and effort, and staying power, these are amassing achievements that are helping shift the balance to a more open and inclusive way of thinking and acting. If these small efforts, many of the early ones substantially voluntary and unfunded, continue to bear fruit, they will have been very worthwhile. They have been, and probably will still be countered by giga-amounts of money and influence spent on powerful politically and commercially coordinated and focused efforts, with deep pockets and a mix of ambitions for enclosure and control of services and markets. At worst, if they ultimately fail, our now worldwide

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6 R. E. Susskind and D. Susskind, *The Future of the Professions: How Technology Will Transform the Work of Human Experts* (Oxford: Oxford University Press, 2015), p. 46.

teams and community will have reset the dial for other communities to think differently and generate their own new ideas, that build and improve on what has been made and done to date. This will be useful learning to have documented, alongside that of the Broad System of Ordering and GALEN Project of Chapter Two. Great movements do fail—the Chartist movement, for example, with its story of community empowerment before universal suffrage. Samuel Smiles (1812–1904), my Chapter Five guide to the transforming power of innovation, as exemplified in the Industrial Revolution, was one of its champions. But, in failing, that movement also moved the dial.

In the parenthesis of Chapter Four, the topic reflected on was purpose. In Chapter Five, it was making and doing things differently. There is little point in having a purpose, unless pursued with commitment, and little point in setting a goal, unless accompanied by a realistic sense of how to achieve it. How, in practical terms, will the care information utility be created? How, likewise, will it work and be maintained and sustained? Implementation is about setting achievable goals and building the communities and environments needed for achieving them. It is about values and principles guiding the approach taken and method adopted, whereby success can be nurtured, and approach and method adapted, in context and over time, to remain focused on the purposes served.

Wicked problems of policy are real and the complexities and difficulties they present must be coped with, as much as predicted and managed. This coping centres on honest communication and competent listening, responsive to needs and recognizing limitations, and creating and building on common ground. It is very much a domain in need of what Gillian Tett, the anthropologist and financial journalist, described in her 2021 book, *Anthro-Vision*.<sup>7</sup> She argues for a different AI–anthropology intelligence not artificial intelligence. She describes new attention being drawn globally to corporate governance focused around ESG (Environment, Social and Governance) principles of sustainability. This is seen as a modern-day imperative, when coping with the VUCA era (Volatility, Uncertainty, Complexity, Ambiguity) which has intensified through the Information Age.

This chapter suggests an audacious idea of care information utility, built on a tripod of co-created and shared intellectual property, community interest and enterprise, and an inclusive balance of global, national and local governance, drawn from these communities. As ever, in a spirit of ‘audacious pessimism’, this must prove its credentials, iteratively and incrementally, and be seen to be realistic, in actions and outcomes, not

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7 G. Tett, *Anthro-Vision: A New Way to See in Business and Life* (New York: Simon and Schuster, 2021).

words. It must prove an agile and flexible approach, adaptable to changing context and need, as science, engineering, health and care, all experience, live through, learn from and emerge from the transition of the Information Age. It must accommodate new balances: of human head, hand and heart, with technology; of professional and personal roles and autonomy; of public and private enterprise; of global and local society and culture.

This is an open and inclusive perspective that seeks to help repair and reunite the prevailing fragmentation of sectors and professions of health care services, and of the organizations, communities and individuals they serve, and those that support them. The policy for several health economies well known to me—usually smaller ones, each serving no more than several million citizens—is aligning and further fostering creation of care information utility along this pathway. As I write, highly innovative tenders for openEHR-based community-wide health care information ecosystems have just been adjudicated for Catalunya, attracting considerable interest among policy makers in other places. Also as I write, a similar tender is being publicized by the Östergötland region of Sweden, potentially spreading more widely across the four or five principal health regions of the country.

I draw on several and disparate sources, in making the case for creating common ground and pursuing openness and collaboration in these endeavours. These reflect social, economic and political circumstances, and thinking that is not new. Such concerns have arisen in much the same way, both in history and in present-day deliberations about other major policy challenges. The first comes from the history of common land and its enclosure in early nineteenth-century England. The second from Karl Popper's (1902–94) *magnum opus* of 1945, making his case for Open Society where creativity and democracy can thrive. The third from six thought leaders of today, illuminating themes of global crisis, social change and reform. Their perspectives (of economist, lawyer, financier, social historian and philosopher) align on the need for new thinking and new foundations of endeavour anchored in the Creative Commons of intellectual property. I also draw on the history of open-source software, supplementary to the discussion of the World Wide Web in Chapter Five.

I then circle back to the care information utility and where it should be pitched in the ecosystem of health care services, alongside the information systems of today. One goal must be to enable the still depended-upon legacy system functions to migrate safely, with the least disruption, into the new organic ecosystem that the information utility will nurture, incrementally, over time. In Chapter Eight and a Half, I described progress towards a central component of the utility, which bridges between knowledge, practice and community. This is the citizen-centred digital care record—its

serial non-delivery being the fifty-year-old elephant in the room—perhaps not so old, for elephants!

So how can and should the care information utility be created, maintained and sustained? What is required for implementing and nudging change towards realization of a functioning information utility for health care?

## Implementation One—Approach and Method—Learning and Showing How

Implementation is where we *learn* about wicked problems and *how* to tackle them. We learn how to do things by doing them—there is no other way. We must be engineers, keeping a close eye on what we are trying to achieve and aware of how the computer may be helping or hindering us in this.<sup>8</sup>

In science, theory and practice are grounded in hypothesis, experiment and evidence. Creation and innovation arise from left and right field—substantially independently from commentary and prediction. They proceed, like the steam engine, under their own steam and ahead of evidence. My anthropologist colleague in Centre for Health Informatics and Multiprofessional Education (CHIME) at the University College London (UCL), Paul Bate, specialized in the organizational development of health

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8 Computers tend to work or not to work. Their designs have limitations, exhibit behaviours and develop faults. Mine is five years old and suffering from ailing silicon joints, and slow performance on the increasingly demanding machine racecourse that Microsoft sets programs to run on. No doubt this reflects the greater complexity of the computer and increased attack from data highway robbers in the global environment of computers, today. If all else fails, I can buy a new machine and be assisted for my purposes by this more athletic and less accident-prone young device. I can revert to handwriting, but even paper and ink can run out and pens and fingers fail. I balance the costs and benefits and make a choice. Health care is not like this. The body can be measured and imaged to the limits of the capability and capacity of the Information Age, but if we look for dysfunction, we will surely find it somewhere, but so what? Back pain may be investigated with imaging devices and an MRI will find ageing joints. The significance of findings and the choice of remedial action are wide-ranging in context and efficacy. The reporting and interpretation of the pain will likewise reflect the human subject in pain—some more Stoic and able to cope than others. Treatment may involve analgesia, acupuncture, physiotherapy, surgery—it can give some help and cause some harm. Unlike with the machine, a new back is not (yet!) an option—we must cope and be helped to cope with the reality as best possible. Machine virtual realities may usefully complement and enhance human realities and they may conflict or prioritize differently. My back is not a machine that can be conjured back to life. But both machine and back have patterns of behaviour and trade-offs in how we chose and accommodate them. In how we mix the two and how we use them—individually and in combination.



services. He emphasized the need to work from experience of practice into theory of practice, as well as vice-versa, with new ideas—the latter, the traditionally construed ‘bench to bedside’ paradigm of translational medicine. As discussed further, below, this has been called Ostrom’s Law—that is, ‘things that can work in practice, can work in theory as well’!

When formulating and implementing new ideas for tackling wicked problems, what seems often to engender success and sustainable impact is the way in which perceived needs and deficits are tackled. Bate highlighted this in his studies of health care innovations. The way we act can be as important as what we do. We should focus less on theory that predicts, or second-guesses, how the uncertain future emerging from Pandora’s box will play out. We can now predict the weather ahead more accurately and adjust accordingly. But even this knowledge remains couched with increasing uncertainty, the further ahead we look, in days and weeks.

Unfortunately, but inevitably in highly charged realms of politics, innovation as a focus for reinvention and reform is openly or covertly opposed, at times and places where it is most necessary for exposing and helping to clarify problems being faced. With wicked problems, it seems often to be required that anyone seeking a solution be able to demonstrate how to solve the problem before being helped and supported to discover how to do so. As the very wise former head of the Wellcome Trust advised me, thirty years ago, you cannot succeed with this kind of problem by talking and writing about it, you can only succeed by showing how. Until you succeed, no one wielding power will feel able to support you, and when you succeed, everyone will all always, secretly, have been your friend, she said, smiling encouragingly!

Such innovation is about creating and learning by making and doing. It is where head, hand and heart must align. It is mission, insight and alliance. It is not a place where money is easily, if at all, made, other than by the already wealthy, clever or lucky gamblers about the future. Some grab, pre-empt or gamble the future, and some opt out and manage, or prefer, just to gambol into it! Innovative mission is about staying power.

Politicians and civil servants have a hard job in presiding over dreamers, apparatchiks, gamblers and those who gambol. Managers must draw on evidence to focus and lead. But faced with complexity, reasonable concern for evidence can easily segue into treating ‘lack of evidence’ as ‘evidence of lack’. When there is a lack of evidence confirming something, it is often mistakenly treated as untrue. This is a cardinal error in clinical practice as well as a potential Achilles’ heel of ‘closed-world’ logic, as was discussed in Chapter Two. It may not do the health of the nation much good, either. We set standards that evidence must meet and use them as instruments for regulating innovation in areas not yet well-understood, but where there is

pressure to frame and manage them, nonetheless. This is more defensible when managing well-established discipline, but of questionable value when charting the unknown. We need to create and experience futures before we can evaluate them sensibly with evidence. Disruptive futures are feared and shot down, for lack of evidence, before they can, or are allowed, to prove themselves. Remember the debunking of Charles Babbage (1791–1871) by George Airy (1801–81), as recounted in Chapter Five! Disruptive innovation was the focus of the economist Clayton Christensen (1952–2020).<sup>9</sup>

In Chapter Five and elsewhere in the book are numerous stories of obstruction of what ultimately proved successful and important insights and innovations, from centuries ago in the Industrial Revolution and in modern times—James Lighthill’s (1924–98) take-down of AI, for example. Funny from afar but not so funny up close, in similar machinations of the information revolution of today. Failure to marry necessary but inevitably disruptive innovation with enforcement of *status quo* often betokens hidden or unrecognized issues of understanding and capacity—what Whitehead and King saw as poverty of ideas and pretence of knowledge. King wanted more focus on narrative and storytelling, and my Chapter Eight and a Half tells a story.

Endeavour that sets out to create the care information utility will, inevitably, bring to the fore undecidable aspects of ‘wickedness’ in the problems addressed. Is human society capable of, and up for, the shouldering of the personal responsibilities that are entailed in realizing the personal expectations of health care services in the Information Society? Our expectations of and about other people in our community are easy to express and readily communicated widely in the Information Age—this is a distal connection. Our individual trust and participation in that community will depend on ways available to each of us, to help us feel part of and valued in achieving shared goals—this is a proximal connection. Enhanced distal connection and diminished proximal connection do not fit well together. Will the creation of the care information utility in Globalton<sup>10</sup> community run aground, and rougher justice and injustice prevail in health care, by default? *Zobaczymy* [we will see]!<sup>11</sup> The future will be created, one way or another.

There is no logical way to argue such matters of belief, one way or the other—we do not know the answer, or even if there is one, but we do have responsibility and opportunity to work for the creation of the future we

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9 C. Christensen, M. E. Raynor and R. McDonald, *Disruptive Innovation* (Boston, MA: Harvard Business Review, 2013).

10 On Globalton and Localton, see Chapter Seven.

11 On this Polish expression, see Preface.

want to see. Horses backed and decisions taken, and the outcomes they lead to, one way or another, will matter. These are new times and today's answers do not lie in retrospective view. Stubborn and obsessed innovators and their innovations look forward and reveal paths ahead of us in the wood. Social movements start in threes and tens and rise to hundreds and tens of thousands. The statistician Lionel Penrose (1898–1972) proposed a square root law to characterize the power of social influence, after studying the voting behaviour of groups.<sup>12</sup> I have found this insight helpful in thinking about the strategic growth of openEHR. In seeking to influence a group of people of size  $n$ , a cohesive sub-group numbering the square root of  $n$  can prevail. Ten committed and coordinated people can influence one hundred—in good and bad directions, of course! You can think of this another way—if you face a problem of scale  $n$ , first focus on a goal of scale square root of  $n$ —or  $\sqrt{n}$ —etc. to a scale that is tractable—and then work and seek to scale up from there.

The flip side of audacious hope is the resigned pessimism that can easily prevail in the face of the extent of wasted investment and opportunity that has been sunk in and now holds back progress. Much of the current legacy of health information technology (IT) systems is in a slow extinction phase, as indeed is that from much else of the historic investments to date in all IT systems. Globalizing monopolies are hoovering up some of the remains. I have seen and heard trusted reports of what lies under polished 'car bonnets', in too many places, not to know this. Many suppliers of systems know it, too, and are in survival or safe exit mode.<sup>13</sup>

We must not disregard or deny extinction events, including extinction of software technologies or patterns of health care; it is too costly. As with changing a house, there comes a point where modification is too costly and disruptive, and knocking down and starting again is the best and most cost-effective way forward to achieve the new house desired. The in-between stage is hard. We have neighbours two doors up from us, who, for eighteen months, have been creating a new house over the foundations of an old one—the family is living there as it metamorphoses. They have been caught by a

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12 L. S. Penrose, 'The Elementary Statistics of Majority Voting', *Journal of the Royal Statistical Society*, 109.1 (1946), 53–57.

13 Nearly twenty years ago, I attended a lavish party celebrating one of the first awards of major contracts under the ill-fated NHS Programme for IT. This was for a hospital-wide patient administration system. The successful company surged in value on the news. Its owners quickly sold out. The 'bonnet' of the system purchased was lifted by the hospital team. I was told that much of the engineering was ancient, key aspects of the product a poor fit, and the necessary reengineering to make them fit, costly and time-consuming. Tens of millions of pounds of direct and indirect cost and disruption ensued. The system has since been replaced.

delayed timescale, consequential on having started the building work just a couple of months before the Covid-19 virus struck! Shortage of materials, subsequent discovery of weak foundations, woodworm and more, have doubled the estimated construction time to eighteen months and still going. And they work from home and have teenage children! Other neighbours, at the end of the road, with four younger children, decamped to a fortuitously vacant close-by house while their builders moved in, ripped the house apart and rebuilt it. It has all been done in six months.

But we cannot move out of health care information systems and services while we rebuild them! We must work *in situ*, and this multiplies the complexity immensely. Bringing new imaging systems to a radiology department is almost straightforward, when contrasted with a project for creating and maintaining the integrity and continuity of part-paper, part-electronic health care records. These records cannot continue to be lost, in the ways that they have been multiple times during my career, due to organizations migrating them onto new systems that are not backwardly compatible. Data migration has been so complex that there has often been little choice but to throw up the hands and decide not to try. Data migration between systems lacking shared semantic and syntactic information models is a risky, noise-generating undertaking, if not intractable and unsafe. It makes no sense to continue to pile resources into pretending otherwise or believing new hype, that a new method can magically achieve it, where repeating history has indicated otherwise. This is a good example of one of the Susskind book's short-term expedients that do long-term harm. Neither should we countenance placing all eggs in one or a few, monopolistic baskets—what one might provocatively describe as a 'basket case' strategy!

So, what of implementation of care information utility?

- Align under a simple monicker: A citizen-centred care information utility, perhaps called openCare;
- Tackle tractable goals in support of well-delineated groups of citizens and their supporting professionals, that integrate at home, in hospital and care settings, and on the move within and between countries, in their daily lives;
- Be clear about and pursue purpose and goal in improving the balance, continuity and governance of services;
- Focus on what matters to citizens in their health care services, and to the professionals who serve them;
- Focus on and engage carers and volunteers;
- Focus on services that bridge disciplines and professions across sectors of care;

- Focus on common ground;
- Think and act both locally and globally;
- Adopt an open platform;
- Build and support collaborative teams, environments and communities;
- Build iteratively and incrementally, in individually manageable and beneficial stages;
- Build in parallel and integrate;
- Prioritize Little Data and let the Big Data take care of itself. As Michelle Obama writes in her book *The Light We Carry*, we must go small before we can think big.<sup>14</sup> We should focus on small and completable tasks—that is how we develop and grow.

## Approach—the Culture of Care Information Utility

The approach proposed, here, is a natural and logical progression from the fifty-year halfway stage we have reached, as we now look forward to the next fifty years. In parallel with the opening of new vistas of prevention, detection, treatment and management of illness, the utility will reflect the greater capability and personal autonomy of the citizen in understanding and managing their personal health care needs, as an active participant who shares more fully in what is decided and what is done and is owner and sharer of their personal data. This contrasts with past approaches to information systems and their governance that have painted the subjects of care as passive actors, treated implicitly as a source of data to be harvested in pursuit of stuff that is done to and for them. We are at a bifurcation of paths forward in the use of information technology—one on a downhill and increasingly fragmented pathway, patching up inevitably always overburdened services, and one on an uphill and increasingly integrative pathway, building outwards from the individual citizen and their health care needs as a global villager, from their home.

This integrative goal is implicit in the image of the inverted triangles, based on Richard Smith's landmark *BMJ* editorial of 1997 (see Figure 7.10) and depicting the transition from Industrial Age medicine to Information Age health care. In this perspective, services will focus and be based much closer to citizens at home. They will own their personal data and have greater

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14 M. Obama, *The Light We Carry: Overcoming in Uncertain Times* (London: Penguin Books, 2022).

personal autonomy and associated rights and responsibilities for taking care of their health. Services supporting them in these matters will focus more locally and around them. It has been a failure of vision of the intervening quarter century that too much attention has focused on advancing and shoring up struggling institutions and the data silos of fragmenting and overloaded Industrial Age medicine and social care, and too little on creating new, both real and virtual, environments for the delivery of health care services, in keeping with changing science and society.

This change of approach to care information systems will reflect and represent a transition of values and principles, extending throughout many communities of interest concerned with health and wellness in society. The lesson of experience of wicked problems like this is that it is impractical to orchestrate such a transition and inadvisable to leave matters to individual sectors or free markets to organize. It requires inclusive enablement of communities of interest, environments and endeavours. The multiplicity of potential connections embraced by such wide-ranging communities of interest is immense and realizing the vision can but be tackled collaboratively. There are many and diverse resources that the care information utility can draw on and contribute to. Again, incremental development and prioritization are inevitable. As with the Good European Health Record (GEHR) project described in Chapter Eight and a Half, the mission to imagine and create an architecture of this information utility is once more an iterative and experimental process that should be conducted in the public domain. What are the requirements and how can these be expressed in terms of an information architecture? This work is at the same early stage that I described in Chapter Eight and a Half, when writing about the workplan and drawing together of the GEHR project requirements. GEHR started from an existing prototype architecture and incremented from this in successive stages of modelling, implementation, testing and scaling. openCare can build from where openEHR has reached, and engage community-wide teams and organizations, aligned around shared goals, methods and governance. It can create and test prototypes and evolve iteratively and incrementally from there.

In tackling the wider integration of health and wellness services, the Nordic Countries stand out as pioneers in the formulation and implementation of their plans for the health and social care domain, with individual populations of Finland, Norway and Denmark, of around five million citizens, Sweden around ten million and the other smaller countries bringing the total to around twenty-eight million.<sup>15</sup> The initiatives for

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15 The Nordic countries include the sovereign states of Denmark, Finland, Iceland, Norway and Sweden as well as the autonomous territories of the Faroe Islands

Finland provide an instructive example, where the openEHR industry partner Tietoevry is playing a coordinating role in the creation of supporting information systems.

In 2022, the country has embarked on a complete reorientation of the organization of health care, social welfare and rescue services. In February 2022, presentations were given to a Nordic Countries meeting to consider collaboration in openEHR implementation. The aim of the proposed reform was to offer the population more equal access to services, to reduce disparities in health and wellbeing and restrain costs. In the IT dimension, focus was placed on service coordination, integrated health care and social welfare services and well-managed care paths, digital services and digitalization of processes. There will be considerable organizational transformation over the coming year, to create a national network of twenty-one Wellbeing Counties plus Helsinki and Åland, for organizing health care, social welfare and rescue services. Funding of the counties will principally be based on central government funding. This is a shift from services based on one hundred and sixty primary health care centres and twenty-one central hospitals, five of which are university hospitals; and from a previous configuration of two hundred and ninety social care units and twenty-two rescue departments managed by municipalities. Some two hundred thousand people will have a new employer.

This is not a scope as revolutionary as that implied by the Richard Smith diagram, but it is an important stepping-stone in that direction, tackling the re-integration of 'health care and social welfare' services, drawn together around a common methodology for standardizing care records. To my way of thinking about the implementation challenge of an information utility architecture that builds outwards from the citizen, there will be a requirement for wider integration with all manner of other products, activities and services that help promote individual wellness. Help in coping with and monitoring chronic disease; exercise and nutrition; social prescribing—for counselling and support of mental wellbeing, for example; personal advocacy and support services; citizen-based networks reporting on experience of, and coping with, disease. These all connect within the citizen's purview of what is involved in keeping well and coping with illness. There is a huge network of home-based carers, hospice and other voluntary-sector support services, and local and national charities that contribute. Although not all within the scope of national government funding, they may attract large amounts of local government funding and public donations. This is where a locally framed and governed utility

could be highly beneficial, by encouraging and facilitating local community ownership of needs and coordinating collaborative endeavours in concert with taxation-funded services.

I draw, below, on ideas gained in working for many years to support the StartHere charity, founded by Sarah Hamilton-Fairley and her husband Richard Crofton. This was inspirational and influential work, lauded and successful in multiple pilot projects, but ultimately not something that disparate community interests were prepared to risk their separate interests and identities to sustain. It lacked the care records dimension and my thoughts on integrating these under a common framework of global and local governance led to the conception of the care information utility I propose here.

All this will come to the fore in tackling health inequalities and shifting the focus of care onto a worldview of the citizen in need, not the organization providing services. It needs fresh thinking inclusive of this wider community of interest. It needs reinvention and redefinition of scope of service and articulation of requirements addressed. It needs new focus on wellness and the citizen at home. Citizen and service focus are complementary. We will need to overlay wider and complementary perspectives onto the ellipses of the GEHR requirements for comprehensiveness of care record architecture depicted in Chapter Eight and a Half (see Figure 8.21): wellness and illness; patient and professional; citizen and community; local and global standards and governance; citizen and academic science; computer science student and professional system developer.

At this point and time, as described at the beginning of Chapter Eight, we appear to be at a Robert Frost moment of choice between bifurcating pathways in the wood. Up-down and down-up paths beckon. Along the down-up route there must be vision and principle for connection of people, community, environment, architecture, design, resource, organization and governance. There must be a trusted and shared purpose and goal, forming the basis of cooperation. There must also be a process or roadmap that connects and creates from the here and now and its legacy, to a new and more sustainable future legacy. There must be incremental steps, and learning along the way, spreading out and integrating, horizontally across landscape of disciplines, professions, services and countries, and vertically within governance and government. As is being more widely spoken of, now, this is reinvention more than reform of health care. The care information utility will be one thread in the braid of that reinvention.

The technical dimensions of the reinvention will require authority within political, professional, commercial and institutional circles; the social dimensions will require authority within personal and community circles. Authority is not conferred—it is acquired. None of this can be mandated or



imposed—it must be seeded, nurtured and helped to grow. There must be practical credibility, of head, hand and heart, throughout. These are the dimensions of the challenge for health care services to come through their anarchic Information Age transition, facing up to current fragmentation and inequitable unravelling of service, infrastructure, discipline and profession, and the need for their reinvention, reform and reassembly, supported by an inclusive, integrated and whole care information utility.

This rather ethereal vision of the implementation challenges posed by the utility is, admittedly, an abstract and symbolic one, and it sits alongside other symbols whereby people and communities gain strength and trust, to cope and cooperate. As Robert Axelrod wrote in *The Evolution of Cooperation*, based on his influential research in the early 1980s, trust is the foundation of human cooperation.<sup>16</sup> Whitehead's warning that I have quoted in the book's Introduction, and again in the Postscript, also resonates—society must learn how to sustain its symbols or risk its own destruction by the anarchic forces of fundamental change. The Information Age is a transitional era of fundamental change in society. To borrow, and possibly misuse, a phrase from Benjamin Franklin (1706–90), 'We must all hang together, or assuredly we shall all hang separately'.<sup>17</sup>

The practical things needed to achieve the specific goals we set out towards creating the care information utility can all be made and done incrementally, over time. In development of human life, the embryo evolves a very long way towards wholeness, from single cell to body, before it is born into the world outside. Care information utility already has a living body, personality and community. It is directly relevant to the here and now of policy and practice for health care information. And crucially, it has examples that support and evidence it, and growing influence at a global scale: in Australia, Brazil, China, England, Finland, Germany, India, Italy, Jamaica, Japan, Netherlands, Norway, Pakistan, Portugal, Russia, Scotland, Slovenia, South Africa, South America, Spain, Sweden, Uruguay, Wales and many more, too extensive to list or possibly not yet known about.

When I first met Xudong Lu from Zhejiang University in China, while representing openEHR in Sao Paulo at the 2015 Medinfo world conference of Medical Informatics, he presented an astonishing paper about implementation of an openEHR-based health record system at his nearby two-thousand-bed hospital. He had built a team and created this system solely from the Creative Commons specifications of the openEHR architecture of electronic health records and the then existing, and now hugely more comprehensive and refined, body of clinically curated

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16 R. M. Axelrod, *The Evolution of Cooperation* (London: Penguin Books, 1990).

17 Benjamin Franklin at the signing of the Declaration of Independence, July 4, 1776.

openEHR models of clinical data—the largest such repository in the world and in large part a product of cooperating professional volunteers, across disciplines, professions, organizations and industries.

And today, people all over the world can download and spin into life a functioning open-source OpenEyes ophthalmology record keeping system, the same as that now servicing approaching fifty percent of eye consultation records across the UK. And openEHR and OpenEyes are incrementally being harmonized, for national platforms of care record services, in whole national jurisdictions. The achievement of incremental goals, contributing towards the realization of Care Information Utility (CIU) is happening, now, North and South in the world. It started, as most seeds do, with a very small chance of success—it is now a 50:50. We are halfway there—the theme of the Postscript—echoes of Bon Jovi!

Having gone on at length about the importance of practical implementation, as is my wont, I now look back into history, as is also my wont, to the origins of two phrases—the Creative Commons and the Open Society.

## The Commons

The word ‘common’ is semantically rich. It is the common land on which we can all walk, and maybe graze our horse. It is common sense, which is, paradoxically, both easy to talk and argue about and nigh-on impossible to define from an algorithmic and data-driven perspective, or have AI acquire! It is social and intellectual rank—House of Commons and House of Lords in the UK Parliament; scholars, exhibitioners and commoners in the archaic Oxbridge student parlance of my days there.

Common land was an interest of the historian Richard Tawney (1880–1962). After graduating from the University of Oxford in 1903, he and his friend William Beveridge (1879–1963) lived at Toynbee Hall, then the home of the recently formed Workers’ Educational Association. Tawney is a hero of the widely read and listened to Harvard University philosopher, Michael Sandel, who recently published his own critique of contemporary society, entitled *Tyranny of Merit*.<sup>18</sup> In medieval England, there was a balance of land divided into strips, where villagers looked to their own needs for cultivation, and common land that was shared. This was an expression of the public and the personal, of owning and sharing. And in this environment, there was trust and continuity, independence and mutuality in life. This spirit is also

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18 M. J. Sandel, *The Tyranny of Merit: What’s Become of the Common Good?* (London: Penguin Books, 2020).

expressed and illustrated today in the concept of Creative Commons. One must not get too starry eyed—there is always unfairness, poverty, criminality and exploitation, as well. But common ground was a valued and valuable resource. And in the Enclosure Acts of early nineteenth-century England, common land was enclosed and privatized, thereby destroying habitat, life and an enduring culture of community and countryside. John Clare (1793–1864) described ‘Enclosure like a Bonaparte let not a thing remain’.<sup>19</sup> His poetry, nurtured in the rural idyll of his daily life, conveys sensitivity to the importance of this balance of personal and shared, private and public. He expressed this through everyday scenes and features of the landscape—an iconic elm tree—and the history and meaning they embodied.

Some have written of the ‘tragedy of the commons’, others of its ‘comedy’. In the tragedy, individual self-interest exploits the commons and triumphs over collective interest in sustaining and preserving it. In this scenario, as described by Garrett Hardin (1915–2003) in 1968, a group of shepherds graze sheep on common-land pasture; one shepherd places more than their equitable number of sheep, to their own benefit but to the disbenefit of their community of colleagues who keep to their quota. The value of the common pasture becomes impoverished for all, save for the miscreant, for whom default pays off. That is, until the members of the community, one by one, lose heart and the common pasture is no more. The ‘comedy of the commons’ describes how people contribute property and value accrues from its wider sharing. In the Information Age, what is contributed is knowledge and content—not for personal gain but for the good of the community. Examples often cited of this are free and open-source resources such as Wikipedia, and the many open-source projects made public through GitHub, parented by Microsoft, rather as UCL parented openEHR and the Apperta Foundation now parents OpenEyes.

The modern-day Creative Commons is an important and adventurous idea, being played out on common ground. Its legal foundations are tuned to different ways allowed for sharing and building on this common property, in balance with privately enclosed property. It is concerned with protecting and sustaining intellectual property for the common good, and preserving and sharing its value and meaning, for everyone. It is both lodestone and stepping-stone in the quest for social equity. Creative Commons is finding ways to protect and share intellectual property, that do not involve enclosure and defence against access. Lodestones are natural magnets; they naturally align to attract and cohere, and, otherwise aligned, they repel. Stepping-stones show a path across a stream. Thus it is with Creative Commons; we

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19 ‘Remembrances’, l. 67.

need to explore and understand the opportunities, polarities and forces in play, in shaping and sharing common ground, for the common good.

Common sense comes into play as much through perception of its absence in human thoughts and behaviours, as its presence. Maurits Escher (1898–1972) tackled the challenge of making sense and nonsense from incompatible, inconsistent or intractable ideas, in his collection of iconic lithograph designs, that I have pointed to in several parts of the book. To be valuable as common ground, there must be discipline in the intellectual commons, and a transparent and open balance of theory and practice. Where this balance is attempted on enclosed and opaque ground, it fosters division, exclusivity, inequality and extremity. Information Age infrastructure and services have evolved and migrated onto considerable mutual common ground, as I explore further later in the chapter. Next, I will briefly trace historical ideas about ‘openness’. This is a different trajectory, but the two come together in the context of future information utility.

## The Open Society

The word ‘open’ is also semantically rich. Open, ajar and closed doors; open and closed minds; open and shut cases in law, where legal principle and precedent brook no argument as to the outcome; open sesame where anything goes. Open books are transparent—what lies inside is seen. Black boxes hide what lies inside. Black holes presented an information paradox—was information conserved or lost, and how? I gather that there are seven theories at least that seek to resolve this matter! Zobaczmy—or maybe we will not see!

It feels appropriate to mention Popper’s epic book, *The Open Society*.<sup>20</sup> It is a heartfelt account, written while living in New Zealand. The country’s geographical isolation helped it to avoid the spread of world wars from Europe, in the decades in which Popper developed the philosophical ideas set out in the book. Popper went there as an exile from the Anschluss annexation of Austria, in 1938, and the book first appeared in 1945, the year of my birth. New Zealand was a relatively isolated enclave from Covid-19, avoiding the first waves of the pandemic.

The book is long (seven hundred and fifty-five pages) and outspoken. Maybe that is why Bertrand Russell (1872–1970) liked it so much! In my editions, Russell pips Popper in page count—eight hundred and forty-two pages of his *History of Western Philosophy*, but Popper out-pips Russell with

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20 K. Popper, *The Open Society and Its Enemies: The Spell of Plato* (London: Routledge and Kegan Paul, 1957).

rhetorical invective, decrying culture of deference and centralism leading to totalitarianism. Popper's highly influential book is an often-florid expression and interpretation of culture, history and belief, born of powerful personal experience. He recognized this in prefacing a later edition, saying it had not been a time to mince words.

Popper had an affinity with Communism after the First World War but in time espoused liberal democracy. He railed against the mirror phenotypes of fascism and totalitarianism exhibited in his growing years. His analysis traced these cultural trends to pillars of Greek philosophy and onward into the twentieth century, sparking fiery debate and accusations of misunderstanding and misrepresentation. A bit like contemporary debates about ontology! His portrayal of the philosophy of Socrates (470 BCE–399 BCE), Plato (c. 428 BCE–348 BCE) and Aristotle (384 BCE–322 BCE) in support of his arguments was criticized, as was his critique of twentieth-century Marxist interpretations of history. He attracted warm support from radical philosophers of the time, such as Ernst Gombrich (1909–2001) and Gilbert Ryle (1900–76), as well as Russell.

Popper also railed against historicism–teleology in historical narrative—maintaining that history was influenced by growth in knowledge, which was inevitably unpredictable. His writings on conjecture and refutation became a key plank in the philosophy of science. I will leave the philosophical debate to others who know how to argue about such matters. My only reason for detouring through this history is to make a parallel with the meaning of 'open' in contemporary debate about Information Society, where information technology has become a stepping-stone on pathways both to enlightenment and to monopoly and extremism. The landscape of health care IT is an archaeological record, bestrewn with the remnants of ideas pursued with unsustainable methods, by unsuited and poorly led people, in the wrong place at the wrong time. We need a sense of what constitute open alternatives with better chances for success. A utility centred on proprietary knowledge and intellectual property, placed in control of citizens' personal data, is most unlikely to prove a sustainable or acceptable model for a care information utility, although both public and private components assuredly will and should feature.

### Threads in a Braid

Many threads are being woven together in discussions of major challenges the world faces at the outset of the twenty-first century. Braiding hair can help it to grow faster and provide a more stable structure. Unravelling of braids can lead to a tousled tangle. Transition in society is the disheveled

unravelling of braids and the purposeful weaving of new ones. It is also the cycle of downswing and upswing in social cohesion, described by Robert Putnam in his 2020 book *Upswing*,<sup>21</sup> and the similar optimism of Thomas Piketty in his equally magisterial 2022 book *A Brief History of Equality*.<sup>22</sup> The six threads I describe, here, come under headings of economics of property, nature of professionalism, global community, global crisis, pendulum of change and social equality. They have profound implications for creation of care information utility.

### *Elinor Ostrom on the Economics of the Commons and Property Law*

The Nobel Laureate Elinor Ostrom (1933–2012) challenged the assumptions about property that underpin economic theory, especially that which is held in the commons. She analyzed alternative ways of looking at examples of functioning common property, showing how they worked in practice and arguing that if they worked in practice, there must be a common theory to account for their success. This became known as Ostrom’s Law, which Lee Anne Fennell summarized as: ‘A resource arrangement that works in practice can work in theory’.<sup>23</sup> I think of the development of openEHR and OpenEyes, with their emphasis on the primary importance of implementation experience, a bit like that!

We hear a great deal about intellectual property and its protection and appropriation for commercial benefit. We hear that the Amazon Company is valued at trillions of dollars while the Amazon rain forest is registered nowhere as a financial asset. For many house owners in South East England, personal property has for many years been accumulating more value in a year than is earned in full-time employment.

### *Richard and Daniel Susskind on Professional and Personal Sharing of Knowledge*

In their book that I discussed in Chapter Eight, Richard and Daniel Susskind concluded that the societal contract—they called it a Grand

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21 R. D. Putnam, *The Upswing: How America Came Together a Century Ago and How We Can Do It Again* (London: Simon and Schuster, 2020).

22 T. Piketty, *A Brief History of Equality* (Cambridge, MA: Harvard University Press, 2022).

23 L. A. Fennell, ‘Ostrom’s Law: Property Rights in the Commons’ (John M. Olin Program in Law and Economics Working Paper No. 584, 2011), p. 10, [https://chicagounbound.uchicago.edu/cgi/viewcontent.cgi?article=1356&context=law\\_and\\_economics](https://chicagounbound.uchicago.edu/cgi/viewcontent.cgi?article=1356&context=law_and_economics)

Bargain–underpinning the relationship of trust between professional and citizen could only come into balance in the changing dynamic of the Internet age if communities and partnerships between communities shared their knowledge. In their seventh chapter, entitled ‘After the Professions’, they dissected the arguments both in favour of and in opposition to the idea of this operating as a Creative Commons, in terms of motivation, incentive, and sustainability. Citing the example of the success of Wikipedia, they highlighted that as a cost-free, supporter-funded initiative, it overcame problems of exclusivity.<sup>24</sup> In their envisaged ecosystem, with the sharing of knowledge transacted and governed in the commons, they argued that a new, more equitable and beneficial professional relationship would emerge, trusted on all sides—a Wikipedia of professional practice.

They were not focused exclusively on the professions of health care, but their wider review of many professions provides a useful context for thinking about health care professionalism. It is a mistake to think along the lines often encountered, that because something is different, it is completely different. It seldom is, and such thinking says more about protectionism than the potential for collaboration around common purpose. Health and care have much common ground, with one another and with other professions.

*Cass Sunstein on Aggregation of Knowledge and Markets, Deliberation of the Crowd and the Nudging of Behaviour*

Cass Sunstein is a Harvard Law Professor who has made extensive studies of group dynamics in the Internet and social media age. In his 2006 book, *Infotopia*, and others of his works, he reflects on the many new contexts and communities in which we now accumulate and share knowledge and reach decisions, both individually and in groups debating with one another.<sup>25</sup> The rise of the Internet has changed market mechanisms and Sunstein explores the new ways in which these can be predicted and gamed, and how they interact to cajole and persuade, through new forms of targeted advertising and manipulative manoeuvres that seek to influence and exploit behaviour.

He considers emerging Internet resources and tools, such as open-source software, wikis and Wikipedia, and revisits citizen rights in this context,

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24 Susskind and Susskind, *Future of the Professions*. One should note, however, that according to its founder, Jimmy Wales, typically only two percent of its users respond to a request to donate in support of the work it involves. This is not enough and Lionel Penrose’s ‘square root law’ might suggest that ten percent will be needed for it to be sustained and prosper.

25 C. R. Sunstein, *Infotopia: How Many Minds Produce Knowledge* (Oxford: Oxford University Press, 2006).

settling around traditional areas of education, shelter and health, and with new focus on protection against monopolistic practices. He is concerned by the potential for the weakening of democracy through retreat into echo chambers of views and experiences that play out online, and isolated from direct human contact and ideas that might challenge their beliefs—a process called ‘cyberbalkanization’.

In 2021, Sunstein teamed up with Daniel Kahneman and Olivier Sibony, to publish *Noise*.<sup>26</sup> This book draws on Kahneman’s ideas about behavioural economics, set out in his celebrated book, *Thinking, Fast and Slow*, showing how we are all influenced in our decision making.<sup>27</sup> It presents a new and more forensic appraisal of how human judgements exhibit different kinds of noise and bias, including, for example, in sentencing practice of judges and clinical judgement of doctors.

### *Mark Carney on Global Crisis of Money, Climate and Pandemic*

In December 2020, the annual BBC Reith Lectures were delivered over the Internet by King’s successor as Governor of the Bank of England, Mark Carney. Anticipating his new role as United Nations (UN) Coordinator of Policy on global climate change, he drew parallels from three crises of our age, and common problems of economics and society that run through them. These were the near collapse of the world monetary system in 2007–08, the escalating climate crisis and the 2020 viral pandemic. The lectures reminded me of John Houghton’s (1931–2020) much quoted remark, in relation to his time working on the UN International Panel on Climate Change initiative, decades ago, that humankind only takes issues seriously when in crisis.

Carney identified three areas of focus for change: engineering, politics and finance (new opportunity in innovation). His focus was on barriers to change, and he noted that the Gates Foundation emphasized the significance of speed and scale in their initiatives; policy must be driven quickly to scale, if it is to succeed.<sup>28</sup> Agreeing a common approach and making it a reality

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26 D. Kahneman, O. Sibony and C. R. Sunstein, *Noise: A Flaw in Human Judgment* (New York: Little, Brown Spark, 2021).

27 D. Kahneman, *Thinking, Fast and Slow* (New York: Macmillan, 2011).

28 Whitehead was more incremental in his thinking than this, as the quotation heading Part Three of this book indicates. I suspect few if any wicked problems will succumb to being driven rapidly to scale. Of course, the larger and more diverse the entity wherein we seek to engender change, the harder moving quickly to scale becomes. The greater success of smaller jurisdictions in successful implementation of health care information policy is significant. Anecdotally, an upper limit of around fifteen million in the target population seems to have proved a tipping point, from achievable to unachievable success. However, I have



should be as high a priority as dotting i's and crossing t's in selecting the particular policy to be implemented.<sup>29</sup>

In his lectures, Carney highlighted Cass Sunstein's above discussed work on how social movements gain traction. He set out some principles of implementation of change, based on feedback and self-reinforcement cycles, with 'values driving values'. Nothing succeeds like success, as it were. His emphasis was first on 'reporting', citing the maxim that what gets measured gets managed. His second focus was on risk management—all sectors must align around risk. His final emphasis was on what he called 'returns'—making innovation for sustainability a business and making investors hold company policies and plans to account around specific values that their work embodied. This idea aligns closely with what Tett described in *Anthro-Vision*, as mentioned above, as the changing emphasis towards goals of sustainability which she had noted at the Davos conferences of world corporate leaders she had attended and reported on.

Carney's take-home message in his Reith Lectures was the need to tie policy to what he called the leverage of social coalitions, with fairness, and income and welfare reflecting values. Again, this seems much in tune with Tett's anthropological perspective, as well as with the ideas set out by Mariana Mazzucato in *The Entrepreneurial State*, when discussing reformulation of economic relationships in the world economy, in response to the crisis of VUCA.<sup>30</sup> These ideas are much in keeping with the purpose and goals of care information utility, as proposed in this book. Carney's central idea of values driving values is also descriptive of practitioner peer group review and reinforcement, on the ground. This bottom-up perspective and approach needs equal status alongside a managerial approach that takes a top-down view—both are seeking to 'drive' improvement of quality of services, and both are needed if a care information utility is to be created and sustained.

### Robert Putnam on Upswing

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observed representatives of such smaller and successful countries bristle at the suggestion that they might be more successful because smaller!

- 29 I recalled noting in my talk for a UK/USA intergovernmental conference of 2004, on the role of informatics in improving the quality of health care, that failure of attempts to drive innovation successfully to scale had bedevilled health care information policy from the beginning. This was picked up on later, and wise heads from right across governments nodded, but it was not seen as anyone there's problem.
- 30 M. Mazzucato, *The Entrepreneurial State: Debunking Public vs. Private Myths in Innovation*, rev. ed. (London: Anthem Press, 2014).

As referred to several times in the context of previous chapters, this is a forensically researched and well-illustrated account of the half century or so ‘upswing’ of society from 1900 in the USA—from ‘I’ to ‘we’, as Putnam characterizes the era—with its emphasis on concern for the common good supplanting a culture of individualism and social divisiveness. The following half-century or so of ‘downswing’, from the 1960s onwards, he characterizes as ‘we’ back to ‘I’, with emphasis on assertion of individual rights and cumulative pressure on countering social and group norms that had come to frustrate individual freedoms. Putnam is four years older than me and has lived through downswing. His copious and wide-ranging socio-economic data analyses, notably including those on gender and race, are authoritative in tracking the century of American history, through which my parents lived, here in the UK.

Graph after graph of Putnam’s social and demographic analysis exhibits a similar inverted U-shaped curve of upswing and downswing over the century. One cannot help noting that the Information Age has emerged alongside these fifty years of downswing. Putnam does not connect the two, but it is tempting to postulate a causative and not purely associative relationship with the local social disconnects and global virtual connects of those times—one wonders!

In thinking of the prospects for the coming decades of the twenty-first century as we emerge towards the Information Society, with the experience of VUCA and related ESG priorities and calls for new focus, it is interesting to note Putnam’s optimism. He writes that the historical perspective laid out in the book leaves him more optimistic than he has ever been about the future trajectory of American society. Let us hope so—for other countries, too.

### *Thomas Piketty on Equality*

As I completed my second draft of this book, around April 2022, Piketty’s *Brief History of Equality* appeared. It is itself a woven braid of decades of his treatises on the theme of equality in society, written in French and translated to English in this inspiring book. To do it justice briefly, here, is well beyond my ability, but I have collected a set of quotations from the introductory and concluding sections, where he sets out his stall. I have abbreviated them to exclude their particular contexts, simply to highlight their general relevance and connection to themes of this book.

From the book cover:

We need to resist historical amnesia and the temptations of cultural separatism and intellectual compartmentalization. At stake is the quality

of life for billions of people. We know we can do better. The past shows us how. The future is up to us.

Regarding knowledge and learning, Picketty writes:

The process of collective learning about [...] is often weakened by historical amnesia, intellectual nationalism, and the compartmentalization of knowledge. In order to continue the advance [...], we must return to the lessons of history and transcend national and disciplinary borders.<sup>31</sup>

Regarding transition:

[...] economic and financial crises often serve as turning points where social conflicts are crystallised and power relationships are redefined.<sup>32</sup>

Regarding instability and iteration:

However, each of these arrangements, far from having reached a complete and consensual form, is connected with a precarious, unstable, and temporary compromise, in perpetual redefinition and emerging from specific social conflicts and mobilizations, interrupted bifurcations, and particular historical moments. They all suffer from multiple insufficiencies and must be constantly rethought, supplemented, and replaced by others.<sup>33</sup>

Regarding social and organizational change:

The social sciences naturally have a role to play in this, a significant role, but one that must not be exaggerated: the processes of social adaptation are the most important. This adaptation also involves collective organisations, whose forms themselves remain to be reinvented.<sup>34</sup>

Regarding pitfalls between theory and practice:

Two symmetrical pitfalls must be avoided: one consists in neglecting the role of struggles and power relationships [...]. The other consists, on the contrary, in sanctifying and neglecting the importance of political and institutional outcomes along with the role of ideas and ideologies in their elaboration. Resistance by elites is an ineluctable reality today, in a world in which transnational billionaires are richer than states.<sup>35</sup>

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31 Picketty, *Brief History*, p. 2.

32 *Ibid.*, p. 10.

33 *Ibid.*, p. 12.

34 *Ibid.*, p. 13.

35 *Ibid.*

Regarding the process of reform:

Questions regarding the organisation of the welfare state, [...] are both complex and technical and can be overcome only through a recourse to history, the diffusion of knowledge, deliberation, and confrontation among differing viewpoints.<sup>36</sup>

Regarding a balance of politics and ideas:

It is not always easy to find a balanced position between these two points: if we over emphasize power relationships and struggles, we can be accused of [...] neglecting the question of ideas and content; conversely, by focusing attention on the [theoretical and programmatic weaknesses of ideas and content] we can be suspected of further weakening [them] and underestimating the dominant classes' ability to resist and their short-sighted egoism (which is however often patent).<sup>37</sup>

Regarding the importance of an empowered citizenry:

[such] questions are too important to be left to a small class of specialists and managers. Citizens' reappropriation of this knowledge is an essential stage in the transformation of [...] relationships.<sup>38</sup>

And finally, in his conclusion, Picketty advocates for the reframing and reorganizing of common ground:

We must also describe precisely the transnational assemblies that would ideally be entrusted with global public goods and common policies [...] Economic questions are too important to be left to others. Citizens' reappropriation of this knowledge is an essential stage in the battle for equality.<sup>39</sup>

There is much of the culture and values of care information utility woven into Picketty's vision, as extracted, and summarized here.

### Co-Creation of Common Ground

This book is about the co-creation of common ground on which to base a care information utility, and discusses achievements to date as stepping-stones to that end. It is about what we grow there, and how we live and work

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36 Ibid.

37 Ibid., p. 15.

38 Ibid., p. viii.

39 Ibid., p. 244.

there. The previous section drew together diverse perspectives on what implementation on common ground entails and how these complement one another. It is where those seeking to fulfil and achieve shared purposes and goals, combining diverse threads and methods of implementation, come together to complement, collaborate and co-create, thereby braiding and strengthening their endeavours. It is another organic analogy. Braiding occurs naturally in plants. The urgent new shoots of honeysuckle and wisteria outside my study window flail independently as they grow, seeking traction. They find one another, intertwine as a braid, and grow upward, stronger. In relation to the braiding of the many threads and methods of care information utility, in what contexts, according to what principles and governance, can they be created, extend to scale and be sustained?

In tackling grand challenges with wide-reaching impacts, from the local to the global, the balance and alliance of public and private sector endeavour is crucial. Where such alliance is scarce and balance questionable, their impact can be harmful. Reinvention of the balance and alliance of the two sectors requires new ideas, as Mazzucato has explored.<sup>40</sup> For care information utility, these ideas must reflect and respect a shared common ground of values, principles, goals and methods. Fred Sanger (1918–2013) worked always in the public domain. James Black (1924–2010), John Vane (1927–2004) and Salvador Moncada, whose paths crossed with mine at various times, worked in partnerships of public and private endeavour. Great scientists such as these created, underpinned and led molecular biology and pharmaceutical science for several decades. Global money and industry organized, scaled, monetized and further developed its products and markets. In like manner, academic research created, underpinned and led methods for coping with large-scale unstructured data, and these foundations have been built on in the global tech companies of today.

Modern-day pharmaceutical industries have grown from intellectual property created and shared in academic and health care environments. Government, philanthropy, industrial partnership and individual voluntary and charitable endeavours have co-created and sustained those environments. AI, automation and robotics have been similar in provenance. No parties acting alone could have made this progress. Google and Facebook have grown from and traded on knowledge created on common ground, appropriated into private enclosure, aided by passive data volunteers. Wikipedia builds in the public domain, on the contributions of an active community of volunteers who offer their knowledge; it is a utility that can grow, enhance and share their knowledge and resource. In the

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40 Mazzucato, *Entrepreneurial State*.

Information Age, models of public interest have faced powerful competition with business models of enclosure. The Creative Commons is powering a reversal of that trend and enabling new and more open business models to prosper.

The word open has found a new niche in the Information Age—open-source software, open data, open knowledge—even openEHR and OpenEyes! Being ‘open’ does not in itself solve any wicked problem and it raises new problems of viability and governance of its own. As an expression of human aspiration and commitment, it is a bugle call and flag to rally under, about culture and practice of the Information Age. It is interesting that in the connected contexts of the previous section, several of the cited authors make connections with the advance of the open-source software movement, and with Wikipedia, as pioneering initiatives in creating common ground.

### *Open-source Software*

A good starting point, here, is the story of Unix. Quite early along my software songline, I became aware that manufacturers’ operating systems for their computers were an eclectic mix, difficult to get to grips with and work with, and consuming a good deal of time, effort and resource on the part of their users. And this was ephemeral knowhow—one got better at it as one tackled essentially the same challenges for successive machines that one used. But it tended to ensconce tribal loyalty to particular manufacturers and their ways of doing things, as the devil one knew. People built their careers around International Business Machines (IBM), Honeywell, International Computers and Tabulators (ICT), Digital Equipment Corporation (DEC), Data General, Hewlett-Packard... and so on.

The idea of the AT&T Unix operating system emerged in the Bell Labs research centre. It was to be portable across different computers and provide a common programmer and user experience of a multitasking, multiuser operating system. Ken Thompson and Dennis Ritchie were its originators at Bell Labs, and the system was licensed from there, not originally as open source (i.e., providing all the code to its users), but addressing many of the needs for a common research computing environment. It spread under its own momentum across the world. From this beginning in the 1970s, arose a Unix family of implementations on different machines.

In 1991, the Finnish Computer Scientist Linus Torvalds published the first version of an open-source Unix-like operating system, which was named Linux—a bit of Linus and a bit of Unix! The license chosen was a cautious one, to preclude downstream meddling that might corrupt the free dissemination and functional integrity of the standard version. Torvalds

was and remains the Fred Brooks style of architect-in charge, capable and motivated. New business models emerged for companies providing installation, training and consultancy services based on Linux, which remained free to download and unrestricted in use.

In the following decade, the Android open-source project drew together a community of developers to create an operating system that spanned smartphones and notepads. From 2005, it was taken in and run by Google, which set and maintained a high standard for cost and performance, with the software freely downloadable under the liberally permissive Apache 2 open-source license. The viability of this software ecosystem depends on Android remaining state of the art, such that there is no functional or cost incentive for forked versions of the code to emerge, although these are technically permitted under the license. Google, itself, mixes proprietary code with Android open-source code in its own products, presumably to maintain some exclusivity. Other suppliers can do likewise.

In the openEHR world, as described in Chapter Eight and a Half, open-source versions of the openEHR platform have germinated and grown. The first seedling was the Opereffa initiative, a collaborative effort between my student Seref Arikan and myself, for which we further teamed up with Tony Shannon, then a Leeds-based clinician in the UK and now a health IT leader in Ireland. Tony, in turn, pioneered his EtherCIS initiative and, in parallel, Pablo Pazos, a computer scientist in Uruguay, pioneered his EHRServer open platform. These pioneers and threads have now braided together in the EHRBase platform initiative, spearheaded by the strong and resilient Vita Group company in Germany, which is attracting national funding there and worldwide interest and adoption.

As with Unix, Linux and Android, this progressive commoditization of an open-source and standardized platform for openEHR is creating new common ground. This is enabling greater mutual understanding and alliance among clinical, technical and organizational users and developers of openEHR-based systems, and lowering the bar, economically and timewise, for development of new, mutually coherent and innovative applications. What would, many years ago, have consumed a large part of any project budget, for creating a machine operating environment for the planned new application, is now available as common ground, downloadable to a local machine or operable on globally networked infrastructures and services, such as Microsoft Azure, Amazon Web Services, Google Cloud and IBM Cloud Resources.

The software of applications is now configured in layers of a program stack. These layers integrate with one another and may bring in products and services from different software suppliers. They intercommunicate through standardized interfaces between each stack layer, to build the complete

platform required for the application to run. Programmers specialize in different stack architectures that support different kinds of application—a web service, a database service, a geographical information system and so on. Wikipedia lists some thirty such available generic software stacks.

Bench chemistry evolved in a similar fashion, connecting resources and processes in a chain of chemical reactions, increasingly operating and connecting them automatically. Chemists and life scientists evolved the different stages of the underlying chemical analysis and standardized their interfaces. This incremental process is now mirrored by a series of robotic devices positioned along an automated production line. Each robot collects the product thus far assembled by its predecessors and additional materials required for the assembly tasks that it, in turn, is delegated to perform. It completes this next stage of subassembly and passes the incrementally assembling product as input to the following stage of robotic assembly along the line, and so on until the final product has been made.

What, though, if people like Sydney Brenner (1927–2019), Fred Sanger (1918–2013), Max Perutz (1914–2002), Francis Crick (1916–2004), John Sulston (1942–2018), Paul Nurse and many others had patented the interconnecting life science knowledge and knowhow they had ‘assembled’, on which the industrial automation of genomic medicine has been built? There would be no biotech industry—just entrenched biotech monopoly and probably one of considerably less sustainable utility for the world. IT system suppliers have, carefully and selectively, set out to enclose and protect the methods and interfaces that make them special and able to control their proprietary platforms. Let us hope that the tech giants of today find other planetary and interplanetary ambitions on which to compete and choose to adopt a more collaborative approach in their interface with a care information utility.

The story of my encounter with the open-source platform, DOSBox, in reviving legacy work on the Mac Series of Physiological Models, which I tackled alongside writing Chapter Four of this book, and recorded there, is another example of open-source community development encountered along my songline. I have come across others—sharing methods of image processing for example. We are still learning, experimentally, where open-source principles and practice will fit in the co-creation of care information utility. From my perspective, what constitutes common ground of this collaboration must, by definition, be transparently owned, shared and governed in that spirit. That is not to say that proprietary property and methodology cannot and will not play crucial roles. It does, though, say that success in achieving balance, continuity and governance of care services will depend on what is held in common within the care information utility.



## Method—Discovering the Form and Function of the Care Information Utility

‘Just the place for a Snark!’ the Bellman cried,  
As he landed his crew with care;  
Supporting each man on the top of the tide  
By a finger entwined in his hair.

‘Just the place for a Snark! I have said it twice:  
That alone should encourage the crew.  
Just the place for a Snark! I have said it thrice:  
What I tell you three times is true’.<sup>41</sup>

I have placed emphasis on the importance of ‘implementation, implementation, implementation’ three times in Part One of the book. It must be triply true! We can only discover the form and function of the care information utility by imagining and implementing it. It was my mum who introduced us children to this whimsical and insightful poem. It often seems to be our streetwise mothers who best combine those essential attributes of whimsy and insight in our lives!

Lewis Carroll’s (1832–98) Snark poem is sometimes described as an allegory of the pursuit of happiness. According to the poem, elusive comforting and benign Snarks sometimes turn out to be malign or harmful Boojums. In context of this book, the poem might be an allegory of the pursuit of AI in furtherance of Eric Topol’s ‘Deep Medicine’.<sup>42</sup> Will AI prove Snark or Boojum, there? Or it might be that the hunt for the care information utility, as Snark, leads to a noisy and biased Boojum, not much better than the disjoint silos of knowledge and data today—we must track both these Snarks carefully!

I made my first attempt to picture the care information utility (see Figure 9.3) ten years ago, when closely involved in the StartHere initiative that I describe later in the chapter. It is a concept still in embryo.

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41 L. Carroll, ‘The Hunting of the Snark’, ll. 1–8.

42 E. Topol, *Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again* (London: Hachette, 2019).

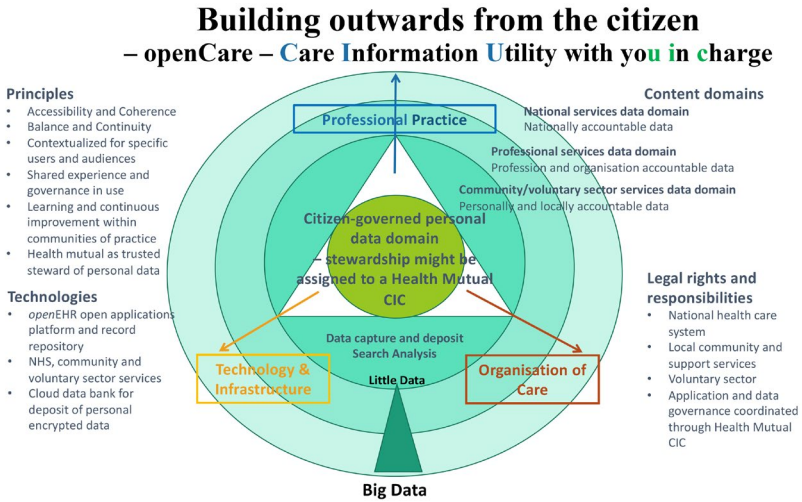


Fig. 9.3 A first step towards framing a scope and architecture of requirements for a Care Information Utility, with you in charge—CIU with uic! Image created by David Ingram (2012), CC BY-NC.



In thinking about the multiple facets shaping and reflecting form and function of this care information utility, my geometrically inclined (and maybe also annoyingly alliterative!) mind constructed tables of what I loosely, and probably somewhat inconsistently, described as monads, dualisms or dichotomies and tripods or trifactas. The monads are seen as values and principles—things on which we need to find agreement. The dualisms are sometimes seen as alternative realities but often as usefully complementary ideas—things that we need to balance and broker between. In the Introduction, I discussed Robert Oppenheimer’s 1953 BBC Reith Lectures, in which he used particle and wave duality in physics to illustrate general points about the importance of dualisms, or complementarities, in shaping our ideas. The dichotomies are sharp cuts or divisions, seen as contrasting, competing or opposite perspectives. False dichotomy is sometimes used as a device to divide and control, for purposes other than clarification of truth.<sup>43</sup> The tripods are groupings that mutually reinforce and

<sup>43</sup> Much of the advocacy of FHIR and openEHR as alternatives (it used to be GEHR and HL7—Version 3!) in argumentation about digital care record interoperability has invoked false dichotomy, in my view. They have addressed different

cohere, stably, in defining and building an architecture—the term draws an analogy with stable physical structures. The trifactas relate to matters where all three components are needed and mutually complement one another (for example ‘the trifacta of life’: self, work and relationships). It originated in discussions of gambling outcomes (as a term for a horse-racing bet in which the first, second and third place finishers are chosen in the correct order), but has since broadened in meaning to refer to a group of three.

Figure 9.3 and the following two Tables are not intended as in any way polished—they build on and give another take on the values and principles that guide and frame implementation, as set out at the end of Chapter Eight. I introduce them to be rebutted, replaced or improved, to illustrate what first steps might look like in formulating the form and content of the care information utility. Just as my GEHR ellipses diagram and subsequent original openEHR manifesto were in framing those embryonic ideas. To make it rhyme, I am calling this idea openCare!

The monad column is descriptive of values and principles on which we need unity if the scope of the co-created utility is to be coherent, clear and trusted. The dualism and dichotomy column represent complementary and contrasting choices and requirements that we must debate and seek to balance, staying true to the values adopted. The tripod and trifacta column groups perspectives and methods whereby coherence and stability of endeavour is achieved and sustained, within a dynamic equilibrium of a functioning citizen-centred care information utility and the related health care services that it supports. Again, these are not intended as clear-cut categorizations, but as a way to help describe, achieve unity in, and hold trust together in mission, method and community of endeavour, when seeking to implement the idea. They are not yet good enough and I have not discussed them widely. They are presented here in part as provocation, risking accusations of foolishness and woolly thinking (probably both still true) for others to improve, dismantle or replace with something

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requirements—one of communication of information between systems and the other of architecture and persistence of care record systems, themselves. In those respects, the one cannot subsume the other’s design, although they will, of course, interrelate. They can both be good and succeed, or be bad and fail. Their balance is not about information technology alone—it is a matter of the purposes they serve and their sustainability over time—in other words about implementation. Better by far, to implement, balance and broker them in the sense of dualism, and find common ground. I have not had the time or energy to engage in false dichotomy and others are better than me at debating the dualisms. I have had the privilege and preference to create and lead an environment where we implemented meaningful concepts for practical use and debate, rather than merely confabulating ideas about what might be possible but never quite materialized!

different—hopefully drawing on practical experience of implementation. These are vertical lists, more than horizontal rows.

Table 9.1 is focused on terms characterizing information that is the currency of the care information utility.

<b>Monad</b>	<b>Dichotomy and Dualism</b>	<b>Tripod and Trifecta</b>
care	preventive and curative home based and institution based	knowledge, phenotype, empathy
confidentiality	derogation and consent	personal privacy, co-ownership, sharing of data
equity	ethics and law	liability, accountability, responsibility
identity	autonomy and dependency	family, kinship group, community
coherence of meaning (also implying clarity and consistency)	top-down and bottom-up	education, research, practice
common ground	public and proprietary	clinical, technical, organizational
comprehensiveness	self-directed and professionally determined	interdisciplinary, multiprofessional, multiagency
choice	protocol and judgement	risk, exposure, compliance
continuity	global and local	time, place, person
governance	free enterprise and regulation	public, private, community interest
collaboration	specialization and integration	community, secondary, tertiary
trust	personal meaning and professional meaning	head, hand, heart

Table 9.1 Towards characterizing the information content of the Care Information Utility. Table created by David Ingram (2022), CC BY-NC.

Table 9.2 is focused on terms characterizing implementation that creates, develops and maintains the care information utility.

Monad	Dichotomy and Dualism	Tripod and Trifecta
requirement	global and local general and particular	personal, professional, social commissioner, provider, user
architecture	centralized and distributed	system, service, ecosystem
design	simplicity and expressiveness	agility, adaptability, acceptability
sustainability	cost and benefit	resource, method, team
performance	effectiveness and efficiency	capability, capacity, opportunity
resilience	risk and safety	knowledge, omniscience, model
affordability	service and user	current, medium term, long term
standardization	<i>de jure</i> and <i>de facto</i>	global, national, local
implementation	public domain and proprietary	rigour, engagement, trust

Table 9.2 Towards characterizing the implementation challenges in creating and sustaining the Care Information Utility. Table created by David Ingram (2022), CC BY-NC.

Topping the first table is care; key to this, at the bottom, is trust—in what the information means and why it matters. Topping the second table is requirement; key to this, at the bottom, is implementation. We learn what to do and how to do it by doing it—iteratively and incrementally. The two tables share a connection through their concern for method—how to link information that supports care and trust with requirements and implementation of the associated information utility. Key to good care services and a trusted care information utility are guiding values and principles that frame the balance, continuity and governance of those services and the requirements and implementation of the coherent, citizen-centred care information utility that both reflects and supports them.

Care information utility is an idea and product of head, heart and hand. In such matters, actions and outcomes speak louder than words. Reinvention of health care services requires imaginative listening and response between the communities served and the professionals who co-create with them

the environments that are needed and valued. Care information utility will grow on common ground created ‘somewhere’ that underpins the creation and sustaining of this reinvented reality. That is a David Goodhart ‘somewhere’, anchored in head, hand and heart.<sup>44</sup> We cannot avoid carrying the load that is necessary for creating the ‘somewhere’ that we seek. Science has learned where and how to use information technology to keep a handle on its ‘somewhere’ signal and noise. It shares understanding of how to secure, standardize and trust its meaning. Society at large has not yet come to terms with care information in this way. Information created without meaning that is anchored somewhere and somehow can quickly degenerate into noise, anywhere, anyhow. Not very useful and not very trustworthy!

Utility is about values, principles and meanings. A good water supply means an adequate flow of clean water, delivered at a satisfactory temperature and pressure, and an acceptable price. A good electricity supply means a reliable and affordable source of electric power, safely and stably arriving at the point of use at a standard voltage and alternating current frequency, delivering adequate power for the task at hand, with electric current tripping off quickly if adverse events expose danger. A good heating utility means being fueled cleanly and safely, permeating the house, quickly switched on and off and from room to room. Coherent care information utility means support for safe, citizen-centred, effective, orderly, equitable and affordable health care. A picture of health is also a picture of care.

In the human body, the nervous system integrates and balances. If it goes wrong, balance goes wrong, too. Bodily balances are mostly not matters of conscious choice, although imbalances may of course arise that way. But information utility in health care is closely connected with choice and lack of choice in how health care is practised and made accessible. We must add choice to the issues of value, principle and meaning in play. Information in all these contexts cannot be metered by volume. But who is to judge information’s utility, in all these multi-faceted contexts?

Those best placed to judge meaning and value are those at the coalface of care, who experience it in their lives and work, pay the price and pay the bills. We need patients and those cared for to join in co-creating and sustaining information utility, side by side with the professionals, family and community carers and volunteers who serve them. Of course, we will need new tools and systems to enable and support them in this. Patient reported outcome measures is one good step along that pathway; they must be made accessible, consistent and mutually coherent. Many other parties will have more distant roles, making wider connections, and they, too, will

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44 D. Goodhart, *Head Hand Heart: The Struggle for Dignity and Status in the 21st Century* (London: Penguin Books, 2020).

have important parts to play in the creation and enactment of this new ecosystem—each qualified by the value flowing from what they can bring, make and do in the process of reinvention and reform of health care services.

In his 2020 Reith lectures, Carney connected the three global crises of money, climate and pandemic, and the learning from these, suggesting how this might impact in his new UN role. All three have common ground in imbalance of information and environment. They have escaped Pandora's box and their rescue, according to Carney, requires new focus on values. Values are imbued by both nature and nurture. In the lectures, he left values on one side (perhaps inevitably and wisely), to focus on leadership of change. His prescription for change was top down, focused on engineering, politics and finance (new opportunity in innovation). In terms of method, he focused on measurement, risk management and returns—the latter meaning a focus on making socially desired interventions worthwhile and profitable to enact.

For a care information utility, values, principles, meanings and choice are all central and cannot be left on one side. Repeated prescription of things that have not worked, from the top down (a continuing prescription of the same interventions), should be paused, to allow greater space and resource for innovation in method, team and community, working from the ground up. This is where new trusted fulcrums of balance, continuity and governance of services can come from, to help cure 'Shallow Medicine', the term Topol used to characterize the uncaring predicament of medical practices, today.<sup>45</sup> Carney's risk management and returns are needed, and these can best be addressed within the wider governance of information utility. Vested interest conspires with *status quo* to minimize returns on innovation it does not want. It has little exposure to and awareness of poor quality of service and management of risk at the coalface of care. It has only indirect levers for influencing them, anyway. Money and management of infrastructure and workforce become their surrogates in pursuit of value.

My 1991 exploration of the topic of information explosion and its impact on clinical medicine, combined with confirmation by wise friends of the huge scale of the new challenge that I was about to engage with, confirmed my inclination to focus on practical implementation of digital health care records within the communities and environments that I had just started to join, in leading the European Union GEHR project.<sup>46</sup> It was a new adventure

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45 Topol, *Deep Medicine*.

46 This was when I was preparing the 1991 Royal Society of Medicine talk on this theme, that I was asked to give at the halfway point of my career. The notes prepared for this talk are available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

of ideas: discovering, exploring and demonstrating the *how*, of how to achieve information utility for health care. Catch-22 has abounded when making such choices in the Information Age. We are at fault if we make and do, and at another kind of fault if we write and cite. A chimera of fox and hedgehog<sup>47</sup> might be a fog or a ho(a)x! Theoretical fog or practical hoax—plenty of both of those around! Catch-22 has become catch 20-20. Above all, we need imagination around which to build a vision of the future that we wish for.

### An Imagined Tomorrow

It always seems impossible until it is done.<sup>48</sup>

Costly burdens, waste, incompatibilities and obsolescence pervades the current health care IT legacy; intractable problems reflecting information systems not turning out as they were hoped and envisaged to. Five decades of effort have battled to alternately reinvent and contain this reality. As with climate change, it is a combined challenge of discovering new methods that can help make things clear and clean, and ways of working clearly and cleanly to implement them. How should we approach this challenge in pursuit of creating the care information utility? Not without a common ground of semantically rich platform architecture, I think. And not by adopting and imposing proprietary architecture, either. We must think from both global and local perspectives about how we choose, remembering at all times that we are envisioning something that is organic in nature, in the sense of ‘relating to, or derived from living organisms’ and being adaptable, evolving and humanly centred, to serve the different and changing needs of individual citizens for supportive health care services.

The case for reinvention and reform of health care services, and the practical realization of a citizen-centred information utility that supports it, aligns with a wider case for reform of public services. There is growing recognition that the assumptions that underlay implementation of the Beveridge vision of the 1940s, in the way that the National Health Service (NHS) was constituted, are no longer sustainable, on all sides—patients, professionals, providers and politicians. Failure of affordability, feasibility and effectiveness of this model of services, albeit multiply reorganized over time, has been laid bare in the anarchic, fragmenting and continually inequitable transition of health care services into and through the Information Age. Efforts to cope with ever-rising demand, set against

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47 On the hedgehog/fox classification, see Chapter Eight.

48 Quote attributed to Nelson Mandela (2001).



limited resources and workforce, have focused on efficient management of demand and supply, aimed principally at dealing with and coping with acute episodes of need. These have consumed ever increasing resource and energy. In consequence, there has been insufficient attention paid to understanding the many and important causes underlying these needs and focusing priorities to support and promote personal and community capability and resilience in preventing and coping with illness and ill health and providing supportive care.

Local and community strengths that existed in Localton have not survived into Globalton and its ever-increasing and fragmented silos of needs, discontinuity of services and non-coherent data. People experience, feel and suffer from this reality. The Information Age opened multiple Pandora boxes of fragmentary ideas relating to questions that asked, 'What is the matter with you?' and drowned in non-coherent data conveying the fragmented answers. This has overwhelmed inclination or opportunity to pose and reflect on answers to the question 'What matters to you?' 'Never mind' is not a good answer when hearing about what matters! We need an information utility to guide and support services and actions that get closer to the heart of the underlying causes implicit in the answers we hear and prevent as many as we can of them from happening. We may then gain greater capability to act promptly, effectively and humanely in matters requiring urgent care, rather than become increasingly overburdened in coping with their unmitigated consequences. The information utility must therefore be very much citizen-centred and focused on preventing, anticipating, coping and caring. To be citizen-centred is to be rooted in local context and contingency, not in an imagined helicopter view.

Thinking and exploring along these lines, experiments in local UK Government (Wigan and Barking) have pooled budgets of fragmented services and explored unified service models, under common ownership and governance of solutions that are tried. They have saved money and improved citizens' experience of their services. Bob Jones's Continuing Care at Home (ConCaH) story of thirty years ago and the family receiving twenty-seven unconnected visits from 'support' services in one week (as described in the section on continuity of care in Chapter Seven), is paralleled in similar stories, today. Yesterday, I heard described a situation of twenty uncoordinated visits and visitors similarly arriving at the door of an elderly patient discharged from hospital, to provide care, but unaware of and unconnected with the network of family and neighbours already there and primed to support.<sup>49</sup> We cannot continue to have one episode of discharge

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49 C. Naylor, 'The Case for Public Service Reform', *BBC Radio 4* (6 March 2022), <https://www.bbc.co.uk/programmes/m0014x7v>

from hospital ramifying into and through the Cloud data stores of twenty non-coherent care records.

Maybe we should start by taking note again of a comment attributed to F. Scott Fitzgerald (1896–1940) in ‘The Crack-Up’, published in the *New Yorker Magazine* (1936), that ‘The test of a first-rate intelligence is the ability to hold two opposed ideas in the mind at the same time, and still retain the ability to function’. We should not funnel all our efforts along single paths through the wood or devote all energy to prophecy, debate and conflict about their merits and demerits. We should raise our sights to the level of purpose, goal and method—to making and doing things on incremental scales and learning as we go. We really should stop inventing large-scale, nationally ‘imagineered’ initiatives, that swing all concerned dizzily from one scramble for resources to another, and repeatedly disrupt all in their path. We should focus more on imagining the coherent common ground required for any approach to succeed, and collaborate as engineers of all disciplines and callings, to create, evolve and sustain it.

The openCare endeavour will be of moonshot dimensions and duration and will exercise the best of the best. But approached collaboratively, across countries and institutions, it can be made tractable and affordable, if tackled as a well-articulated vision, and in the right spirit, better-expressed and contextualized than I have managed to frame it here. Somewhere, somehow, in whatever increments, we need to give it a go. I believe it will be, for many key people, a career-defining goal, just as openEHR was mine. It can only succeed when locally connected, implemented and governed within a coherent global context. History and experience suggest that it cannot be achieved in the world of governments or industries, and neither can it happen without them. It requires community-led enterprise and continuity of method, throughout: rigorous design and associated tooling shared in the Creative Commons; engagement with health care professionals and citizens at the coalface of care; inclusive participation of public, private and voluntary sector; connection within international community that shares common cause. These are all necessary in setting the scope of an approach to implementation of a care information utility. But they are not sufficient for gaining traction in *how* it is achieved. For that we need a shared vision of what we are aiming for.

So here goes with one such organic envisioning (Figure 9.4). Everything must start somewhere! Again, this is not intended as being a technical specification or health care reality. It is a purely imaginary picture inspired by Maurits Escher’s (1898–1972) *Circle Limit III* woodcut.<sup>50</sup> The diagram is

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50 M. C. Escher, ‘Circle Limit III’, *Wikimedia Commons* (3 February 2015), [https://en.wikipedia.org/wiki/Circle\\_Limit\\_III#/media/File:Escher\\_Circle\\_Limit\\_III.jpg](https://en.wikipedia.org/wiki/Circle_Limit_III#/media/File:Escher_Circle_Limit_III.jpg).

an Aunt Sally, to focus debate and be improved on, just as my GEHR ellipses and openEHR manifesto were.

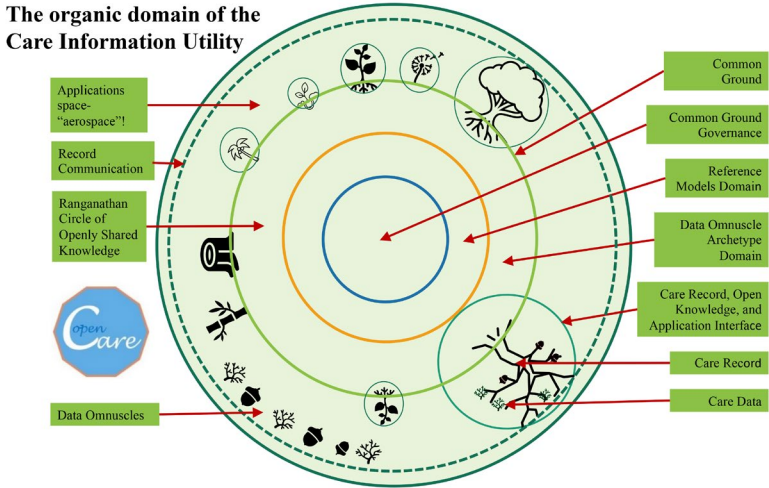


Fig. 9.4 An imagined organic ecosystem of the Care Information Utility, inspired by Escher’s *Circle Limit III* woodcut and the journal *Nature*’s characterization of Suzanne Simard’s vision of forest ecology as a ‘Wood Wide Web’. Image created by David Ingram (2022), CC BY-NC.



In Escher’s organically inspired woodcut, the infinite and fractal patterns at the periphery of the circle grow into central, swimming, fish-like forms and structures, and dissolve back outwards again, into an infinite variety of manifestations. For me this mirrors the fractal nature of the health care knowledge and data domain, thus characterized by my clinical colleague, Tony Shannon, who pioneered theEtherCIS open-source openEHR platform initiative, as described in Chapter Eight and a Half. My picture here is inspired by the forest-like information ecosystem described in Chapter Eight. It depicts this ecosystem, above and below ground, with zones labelled as components of information utility fitting in with this metaphor:

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This woodcut was inspired by the work of the French mathematician Jules Henri Poincaré, bounding the whole of an infinite flat plain within a finite circle. Escher was inspired by the marvelous designs of nature and mathematics and an artistic approach to infinity.

data and connecting data formalisms; circle of knowledge and connecting knowledge formalisms; care records and connected record formalisms. The common ground is where coherence of clinical data models, reference models of the patterns of data drawn on, and where the governance that aligns these within systems and services, locally and globally, is anchored and resides.

The records and data are shown with diverse tree and plant like omniscular shapes and forms, omniscule being the term I invented in Chapter Three, to characterize clinical data elements and compositions. They are rooted, communicate and propagate within the forest, above and below ground, and are transferred through the air above ground. The green circle is ground level and encircles the common ground around which the utility revolves and evolves, in an imagined (fanciful) applications EHRospace! The governance of this citizen-centred utility operates from the centre of this common ground.

The diversity of message formats in the EHRospace is not the issue (do not shoot the messenger!). What matters is the coherence of the semantics and contingency of the data collected, according to the formalisms of data and knowledge residing within this common ground, that conveys (or fails to convey) the coherence of their meaning for the individual subject (person) of care. We need global design combined with local customization and governance of a shared common ground of information systems to underpin an information utility fit for purpose in supporting the balance, continuity and governance of health care services.

The transition to an 'organic perspective' (organic here carrying the same sense as Whitehead's application of the term to his process philosophy, as mentioned in Chapter Two and further elaborated on in Chapter Eight) of care information utility, is inherently uncertain and will continue to be so. But the transition is nonetheless very necessary for conveying meaning in the highly contingent world of health care. It will take us into a new world of requirements and methods for formulating, accessing and managing information. Diverse, ill-formed and loosely connected information systems have amplified difficulty and uncertainty in coping, loosely, with these sorts of requirements. But the progress captured along the timeline traversed in this book has brought considerably greater clarity and certainty into ways of tackling these challenges in the future. We are halfway there in devising means to approach the clarification and cleanup required. There remains the considerable problem, though, of how, iteratively and incrementally, to supplant the burdensome legacy of creaking and maladapted software and systems from the past fifty years, that is still relied on to support increasingly costly and overburdened services. I am not thinking here of hospital systems or vaccination systems, general practice systems or any

clinical management systems. I am thinking of the individual citizen and what involves, and matters to, them, in all these multiple contexts, as well as their common ground and grounding.

Putting the data together, and putting the records and services drawing on the data together, are two different concerns—both important and mutually dependent, but different. Modelling and reasoning with knowledge, modelling information in its roles in support of actions, and modelling related data through their evolving and declining life cycles, are different but closely related domains (knowledge model, information model and data model, as discussed in Chapter Five), each requiring different methods and governance. The history of these domains has not easily coped with and come to terms with these wide-ranging connections, buffeted by ever-changing technology and requirements for survival in service, professional, academic and commercial contexts. It has dealt with them in isolation, writing and pontificating copiously, but comparatively less emphasis has been placed on implementing, learning and connecting at scale.

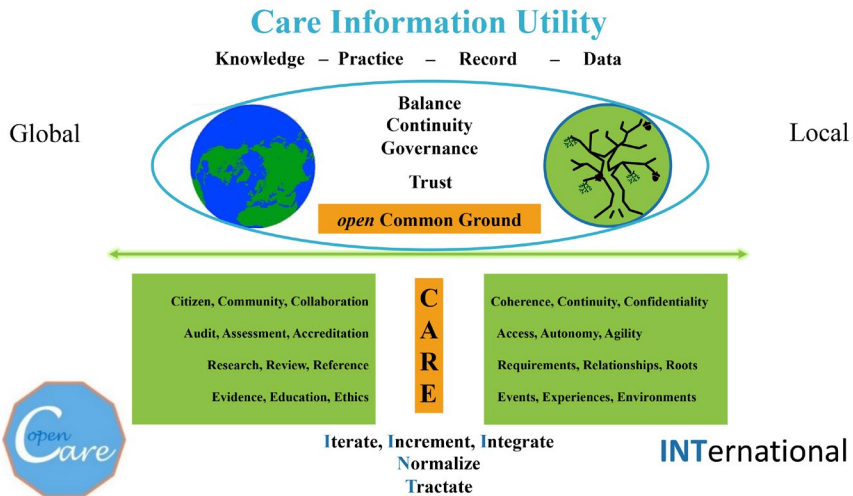


Fig. 9.5 Creating coherent common ground on which to base the openCare Care Information Utility. Image created by David Ingram (2022), CC BY-NC.

Mervyn King characterized our era as one of radical uncertainty. This is notably true of health care. I have attempted to express in one diagram (Figure 9.5), again rather contrived and ethereal at this stage, what seem today to be suitable inuksuk concerns—defining and guiding landmarks—signalling a path towards greater certainty in health care, with their

initial letters spelling out CARE, expressing the pervasive scope of a care information utility.

Throughout, a balance of global and local perspective and governance is depicted, with concerns of knowledge merging into practice on the left, and of data accumulating and aggregating within record on the right. Balance, continuity and governance characterize and anchor the trusted common ground between them. Coherent common ground is where greater clarity and certainty must obtain if co-evolving knowledge and record are to cohere within an overarching and trusted care information utility, supporting a caring service.

And, in addition, the words with initial letters INT spell out how its implementation should be approached. It is a play on both letters and words, intended to stimulate controversy as much as anything. I hope it gels well enough in that regard. Taken together CARE and INT conveniently spell CERTAIN! The elements shown depict the broad scope that this greater *certainty* must embody. How it can now be achieved, joining values, principles, methods, implementation, people, services and environments, is the challenge we face. It is a challenge we have to meet but we can only do this iteratively and incrementally. There is no helicopter-viewed solution that short circuits that path.

### **Citizen, Community, Collaboration: Coherence, Continuity, Confidentiality**

The care information utility is a bridge between the autonomous **citizen**, in the context of their local **community**, and **cooperation** among the professions and services of health care, and with concern for **coherence**, **continuity** and **confidentiality** of data and record. It has two modes—one facing towards the professional teams and the other towards the citizens they serve. Its central rationale is the communication of meaning. It democratizes knowledge, enables quality and continuity of professional practice, and empowers and supports citizen and local community autonomy. It is both a global and local integrator, under both global and local governance. It must be free at the point of use.

### **Audit, Assessment, Accreditation: Access, Autonomy, Agility**

The data and records of the care information utility focus on providing **agile** configuration of its content and **access** for **autonomous** citizen and professional users. It anchors wider purposes of **audit**, **assessment** and **accreditation**, for personal use, and community and professional governance.

**Research, Review, Reference: Requirements, Relationships, Roots**

The care information utility is a **reference** library and knowledge base—joining **research** and **review** of the professions and what matters to them, with the **requirements** and interests of citizens and what matters to them. It is a resource in support of citizen science which will greatly enhance the scope and validity of achievable epidemiology and health care services research. It will support and integrate research alongside education, training and practice. It formalizes record-keeping and its connecting **relationships** with and **rootedness** in knowledge and methods of data capture, analysis, reasoning, explanation, decision and action.

**Evidence, Education, Ethics: Events, Experiences, Environments**

The care information utility is a bridge between data and record that captures the **events**, **experiences** and **environments** of personal health care, with aggregation and accumulation of **evidence** within an **ethical** environment of health care systems and services, providing information resources that underpin and enable formal **education** and lifelong learning.

**Iterate, Increment, Integrate**

The care information utility is an **integrator**—it bridges from the **iterative integration** of data and record to the **incremental** advance and **integrity** of knowledge sources, alongside personal and professional, accountable action. Figure 9.6, along with Figure 7.8, illustrates the breadth of integration of information involved in dual support of knowledge and practice.

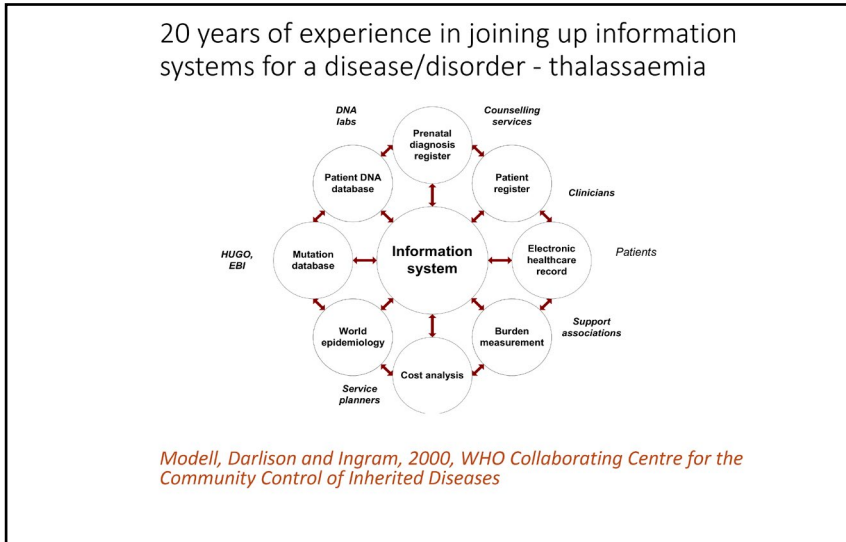


Fig. 9.6 The integration of information sources drawn on in formulating the APoGI (Accessible Publication of Genetic Information) utility developed at CHIME in UCL for patients affected by thalassaemia.<sup>51</sup> Image created by Bernadette Modell, Matthew Darlison and David Ingram (2000), CC BY-NC.



## Normalize

The care information utility is a bridge between domains of standardization—**norms** of health care practice and **normalization** of data, record and knowledge-based systems used in the delivery of services. Common ground of standardization underpins ways of working and the architecture, design, operation and governance of information systems.

## Trust and Traction

**Trust** is central to cooperation and collaboration; **traction** is central to effective action. Data and record must have traction. Traction in working incrementally at appropriate level and sustainable scale. The growth and preservation of trust involves head, hand and heart—expressed in education, experience, commitment, action and belief. It grows along all these axes through actions that speak louder than words. Robert Axelrod’s insights, as expressed in his book *The Evolution of Cooperation*, on the building of trust,

<sup>51</sup> See Chapter Eight.



are central to the values and mission of the information utility, expressed in its methods, practice and governance.<sup>52</sup>

Some of this daunting range of topics will be more amenable to consensus and others more prone to contention. The diagram serves to complement Topol's declaration that reinvention of health care, from 'Shallow' to 'Deep', must be focused on reinvention and rediscovery of the capacity to care—period, he says, emphatically, to which I would add open care, period! The utility must be approached as a global public good, much as openEHR and OpenEyes have been and are increasingly seen.

These letters (CARE and INT) also conveniently line up in expression of openCare as an international mission or as openCare International! As with openEHR International, the world will tend either to love or hate openCare International. Zobaczmy!

### *Incremental Goals—Promoting Trusted Balance, Continuity and Governance of Care*

All knowledge of reality starts from experience and ends in it.<sup>53</sup>

A journey of a thousand *li* [miles] begins under your feet.<sup>54</sup>

The accumulation of knowledge is intimately connected with the capture of experience. It is a difficult, long and winding road to the creation of a viable citizen-centred care information utility, but we must not be afraid of and avoid travelling it, thereby making things harder. We should approach it purposefully, a step at a time, by framing of specific goals on which we set our sights, towards which we then navigate. I suggest some candidates later in the chapter.

The amount of data routinely collected in health and social care settings has increased massively in the Information Age, whether strictly exponentially, or not. We know that data capture costs time and money and adds burden to health care services, with more data not necessarily correlating with or guaranteeing better outcomes, and overload of information risking poor decision making. We know that fear of legal blame may lead to defensive, repetitive and over-investigatory professional practice, whether for reasons of caution or financial gain. The resulting segregated silos of data and record

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52 Axelrod, *Evolution of Cooperation*.

53 A. Einstein, *Ideas and Opinions* (New York: Crown Publishers, 1954), p. 271.

54 Lao Tzu (sixth century BC), *Tao Te Ching*, trans. C. Q. Wu, *Thus Spoke Laozi: A New Translation with Commentaries of Daodejing* (Honolulu: University of Hawaii Press, 2016), p. 137.

lead to poor continuity of care. These multiple factors can easily combine towards redundantly expensive, time consuming, inconvenient, inefficient, ineffective and potentially harmful practice.

We know that citizens have access to knowledge as never before and this changes the balance of citizen and professional relationships, where patients as individuals, groups of patients with similar conditions, and local and national charitable and voluntary sector organizations engage more knowledgeably in matters of practice, support and advocacy. We know that concern for protection of the confidentiality of personal data has increasingly been expressed in law that places a high burden of responsibility for compliant practice with people and systems, responsible as custodians and handlers of these data.

We know that obsolete software becomes increasingly difficult, and then impossible to maintain and use. And that the cost and disruption caused in switching between systems places a brake on change required to keep pace with increasing medical knowledge and changing nature and organization of services. We know that standardization is a precondition of coherent information systems in support of continuity of care and the communication of content, context and meaning of care records. And we know that these are complex and contested matters and interests, set within the context of competitive markets for products.

In all these aspects, there is a balance of individual, community, professional, commercial and wider public interest. A balance of rights and responsibilities as expressed in law. A balance of the art of the possible in framing implementation and operation. A balance of fairness in access to health care services and support. These balances are essentially those that I set out in Chapter Eight, when framing the scope of a care information utility.

In seeking to cope with all this complexity, we need always to remember that there are only individual citizens, patients and professionals who are being cared for and caring. They are not fragmented human instances in these separate and fragmented domains of service activity: a resident of a care home; a GP; a community nurse; an occupational therapist; a social benefits claimant; a cardiology or cancer patient being treated by organizations based in a nearby or faraway city, that deliver their services through a network of district hospital outreach clinics; and so on. The ways in which the identities of people and their human interests become fragmented instances within databases, to serve the needs of the fragmented information systems operating in these separated and differently governed and regulated domains, impact us all—those treating and caring, those they serve and everyone who picks up the tab and pays the price.

The records attached to these fragmented identities can easily become noisily, inconveniently, inefficiently, expensively, ineffectively and unsafely inconsistent and inaccurate. Conflation and discontinuity of values, principles, purposes, goals, methods and outcomes can become deeply engrained within information systems, placing aggravated strain on the tripods of implementation that I have described above, whereby the struggle to maintain stability plays out. Tripods fall over, squares are better, but a circular foundation is the most stable. The common ground is a circle of knowledge, data and information utility, with services encircling the citizen, rather than citizens encircling each service.

There is an expanding and evolving landscape of information, adding to this fragmentation of identity: genomics data; the internet of things with devices everywhere monitoring, reporting and guiding management of chronic disease; the alerts and advice of AI based on Big Data. Such machine-based representations and their data explosions can come to disorientate and condition human sense and sensibility.

I am exaggerating, of course, but things do not have to, and should not, go this way. We must signal, steer and nudge in a different direction, where we do not just pay lip services to patient-centredness and then align all the data and records around multiple different centres of health care services, devices, organizations and IT systems that splinter the individual subject into multiple proprietary and secret representations. There are, and should remain, markets, and they will do their work in incentivizing innovation and investment for change, and there must be associated recognition and reward. But we should remember that we cannot do science without sharing systems of measurement and models of reality. We may use different ones—standardization does not necessarily imply uniformity. But it does imply openness, sharing and trusted governance. Only in this way can we learn and act to do things well, and improve and replace our systems safely, without unnecessary encumbrance of legacy, over time. These considerations have not arisen uniquely in the Information Age, but it has amplified and highlighted their impact. We need common ground of language, method, community, governance and trust, to hold our endeavours together—otherwise we will continue building Escher's unstable Tower of Babel—a biblical construction seeking to reach towards God, but arrested by God, who created confusion of language such that the builders were unable to understand one another!<sup>55</sup>

In the early information era, spending on systems was perhaps eighty percent on hardware and machine environment and twenty percent on software. This is just an 80-20 guess, the precise number would be variable

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55 M. C. Escher, 'Tower of Babel', *Digital Commonwealth*, <https://www.digitalcommonwealth.org/search/commonwealth:3r076t25f>

in place, time and context, anyway. The hardware was the utility. Over decades, this balance inverted, and software became the eighty percent utility and hardware a twenty percent commodity. Now software, too, along with hardware, is increasingly a commodity, and the costs incurred are moving up another level, into the user domain, building towards information as a utility—with adaptation and replacement of health care services, accordingly. It is a semantically tuned utility, capturing, reflecting and integrating with social and professional goals of health care, and moving beyond the machine and software constraints that have dominated and beset them for fifty years.

We could never envisage a project to realize this new stage of evolution by approaching the care information utility as a software stack, any more than we could envisage ideas of life and consciousness constructed from the biophysics of cell membranes and the magnetic resonance imaging (MRI) brain scans of neuroscience. These insights help significantly to illuminate and systematize our knowledge, but they do not in themselves integrate. Understanding of life and consciousness exists at a higher level of information and meaning, and thus it is with information utility for health care. Care information utility embodies an ensemble of values, principles, meanings and choices, along with purposes, goals, methods and actions, and the governance of this enterprise must reside where those meanings play out in society.

But we do, at the same time, need to understand and control the technical, professional and organizational architecture of the utility, and adopt policies that can start to be implemented, incrementally and rapidly, at scale. We need to pick pieces that can be configured and connected, and then, as with a jigsaw puzzle, assembled, piece by piece and section by section, into the evolving structure of the utility. We need purposes, goals and methods that persist, throughout. We need team and environment. We need resources and governance. We need commitment, ownership and trust.

A common ground of method, owned and freely accessible in the Commons, will enable and empower the valuable resource of students, volunteers, companies, countries, charities and funding bodies, to participate in and, importantly, feel valued as a part of the endeavour. The governance of infrastructure and method should be global, clear and concise, as small as possible, and characterized by a light touch. The harder the challenge, the simpler its framing needs to be. The governance on the ground at the coalface should be locally contextualized and owned and built with the local community and within the Creative Commons—extending upwards in terms of sharing of method and outwards in alliances and sharing of endeavour.

All should have interface and connection with the organic information utility, which should be allowed to grow, as trees planted and nurtured, not as a grand design imposed and erected far off. It should exist and scale through the building and sustaining of alliances, because it works for them, not because someone says it should work. It should supplement, enrich and enable health care of today, under its own momentum, consuming resource commensurately as it proves itself in practice and scales. This is about design, organizational development and campaign—about the people who are motivated and can make it happen, because it creates a better world for them in what they need and wish to achieve. Where commercial enterprise ticks these boxes, it can and should take root within an information utility, as well, just as a voluntary agency, charity, public enterprise or other community interest can and should do so. There are huge resources available to be drawn on and the utility can join up and spread nationally and internationally.

The care information utility is an evolving ecosystem:

- Its methods are a shared common ground;
- Its values and principles are expressed in the monads;
- Its **balance** reflects the dualisms and dichotomies;
- Its **continuity** rests on the tripods;
- Its **governance** works to articulate and promote community interest and engender safety and trust.

Returning to the perhaps overly poetic forest symbolism of Chapter Eight, it is an organic network and should be seeded as a new forest on common land—alongside legacy forest. Like the Heartwood Forest we often walk through, governed by the Woodland Trust, bringing together the human and natural world, as users as well as professionals and volunteers, onto new common ground and forging new connections, from ancient woodland to newly planted trees. The ground occupied should be the common ground of all health care communities, where they will plant new seeds that can germinate, grow, connect and communicate more straightforwardly, on new ground. These will connect with, and over time supplant or enable, the reinvention of the legacy of siloed data and record. Some citizens will choose to engage under the canopy of the information utility, and some not, with consequences that flow.

Some areas ripe for such incremental reforestation goals might be:

- Chronic conditions—monitoring, treatment and progression;
- Patient Reported Outcome Measures (PROMS) and vital signs;

- Component data descriptive of patient state—allergies, for example;
- Dashboards of community services and specialisms, summarizing activity, health status and quality of services;
- Continuity and logistics of care—shared care records;
- Platforms that integrate cognate services at all levels—for example, continuity of eye care, from High Street opticians providing spectacles to tertiary treatment of eye injury and disease;
- Perinatal care;
- End of life wishes;
- Hospital at home—community care, teleconference, telemetry of vital signs;
- Keeping fit and well—approach, interest and opportunity;
- Medicines management;
- Infection control;
- Screening and vaccination.

## Implementation Two—Endeavour— Where, Who and When

We now come on to the *where*, *who* and *when* questions. Through whom—in terms of people, teams and leadership—and in what kinds of environment should the pursuit of purposes and goals of the care information utility be taken forward? When and over what time? These are big asks in the destabilized world of health care that we are living and learning through. Each fragmented component of the health care system has an interest that it defends—none can make progress in isolation, and no one can own and lead the whole endeavour. Successful formulation of such a complex endeavour is the second implementation challenge of the care information utility. Rival stakeholders doggedly lock claws on battlefields and contrive something akin to the lobster quadrille of Charles Dodgson (1832–98) (a mathematician and author, better known as Lewis Carroll, whose Snark hunting headlined the previous section), emanating downstream in a computer-software-like deadly embrace!

Admittedly these are huge challenges, but scale of challenge does not always necessitate, or benefit from, scale of endeavour and enterprise—it may

be a Fred Brooks mythical man month challenge,<sup>56</sup> requiring the seeding, nurturing and growth of new ideas, and their exploration in implemented prototypes, by new people in new environments, where scale attempted too early may prove counterproductive. It may require Suzanne Simard's level of dogged and persistent individual courage and insight, whereby endeavours like hers have prevailed in resetting understanding of the ecosystem of the forest and its health.<sup>57</sup>

Endeavour is anthropology writ large—Tett, in her book *Anthro-Vision*, describes how she sees anthropology contributing to the understanding of human endeavour.<sup>58</sup> Without delving too deeply into belief and philosophy, a human endeavour might be described as a creative circle that connects what, why and how with with who, when and where, aligning people and environment with adventure of ideas. As Whitehead said, adventure of ideas lays the foundations of programme for reform. Creative endeavour is an iteratively and incrementally connected set of solutions to problems encountered. Progress can involve a good deal of costly endeavour, failure and lost time. Seventy years and counting in health informatics and care information utility!

Record of endeavour, like record of care, starts with questions: about who and what. It captures facts about people and what happened. These questions broaden: Who participated where, when, how and why? Where, when, how and why also pertain to the factual record—about environment and time, and method and purpose. Questions about people, method, environment and time capture issues of capacity, capability, appropriateness and timeliness. Creation of care information utility needs capable people, in conducive environments, with necessary connections and resources, and suitable governance, doing appropriate things, in a good way, at the right time. A challenge, at which it would be easy to throw up one's hands!

Two inukbooks have provided a useful guide and perspective about the human dimensions of doing better things in better ways, among communities of sometimes uncooperative and disagreeing participants

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56 F. P. Brooks Jr., *The Mythical Man-Month: Essays on Software Engineering* (New Delhi: Pearson Education, 1995).

57 S. Simard, *Finding the Mother Tree: Uncovering the Wisdom and Intelligence of the Forest* (London: Penguin Books, 2021).

58 In my UCL/CHIME years, from 1995–2012, two anthropologists worked with us and nearby. Paul Bate specialized in organizational development of health services and Cecil Helman (1944–2009), working in our neighbouring, closely allied Primary Care Department. Paul made a much-valued contribution to our graduate health informatics programme, and Cecil, world-renowned for his book *Culture, Health and Illness*, 4th ed. (Oxford: Butterworth/Heinemann, 2000), which went to five editions, was an interesting and educative person to talk to at lunch times in the canteen. It was a richly creative environment in its time.

(especially the clever ones, possessed of the conviction that they know best—which they sometimes do, of course, but not always!). These are *The Evolution of Cooperation* by Robert Axelrod, in its analogies with games theory, and *Getting to Yes*, by Roger Fisher (1922–2012) and William Ury, with their insights on the principles of negotiation.<sup>59</sup>

Co-creation and use of the care information utility are inseparable, just as health and care are inseparable. Balance, continuity and governance of the utility created, are essential. So, too, are its community and working environment of implementers and users. The interaction of different people and perspectives, assembled over time and in close propinquity, was central to the utilitarian philosopher Jeremy Bentham's (1748–1832) felicific calculus—a calculus of happiness. Human community and environment are the essence of that happiness and sense of wellness. The quality of community and environment in which care information utility is created and sustained will reflect in the values and meanings attached to it. It will be a co-creation by developers and users—there is no waterfall from creation into use. Implementation of the utility involves the joining of its people, environment and use, and is an intrinsically organic and local concern, where it is used. Coherent purpose, goal and method adopted for the creation of the utility will underpin its continuity; these aspects are intrinsically global in nature. A fragmented utility that lacks global coherence will not promote balance and continuity in the local purposes it serves. Global and local governance must maintain balance of global and local perspectives.

Such 'we' not 'I' thinking is on the upswing in our grandchildren's generation. It was equally partitioned over time in my parents' lives—first on the upswing and then on the downswing. The Information Age has been created on the downswing, and it shows. The Information Society must now be created on a tide of upswing. Putnam, the author of *The Upswing*, as described above, predicted that society today is at a nadir, poised for a reversal from downswing into upswing. Let us hope the nadir is not too noisy!

Diverse and overlapping mechanisms make for resilient and fault-tolerant bodily health. They are likewise intrinsic to strength of endeavour. Health care needs are diverse, as are the services that support them. Diversity is not the same as fragmentation—diversity encompasses while fragmentation breaks apart. We need an information utility that encompasses the whole of health care and enables inclusive and holistic, rather than fragmented, endeavour. Policy must reflect diversity, but a fragmented diversity of policies directed towards a common goal is a recipe for inconsistency,

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59 Axelrod, *Evolution of Cooperation*; R. Fisher and W. Ury, *Getting to Yes: Negotiating Agreement without Giving In.*, 2nd ed. (New York: Penguin Books, 1991).



waste and ineffectiveness. The nature of wicked problems is that they lend themselves to this sort of policy fragmentation—everyone and no one owns them, every approach and none is applicable, and political estimation tends to trump policy implementation at every turn. And when we computerize, we are dealing with a technology that does not naturally embody diversity and stokes fragmentation—we are best not to code a diversity of sampling and analysis algorithms to collect a common dataset, such as the NHS had to cope with when instigating central reporting of critical incidents, as discussed in Chapter Seven. Where such inconsistency prevails, official statistics exhibit computer generated noise and bias as a result. But it does not need to be that way.

## Environment

Good environment (to repeat Richard Wollheim, yet again!) is a necessity. An organic information utility can only grow from the ground—it cannot descend from the information forest canopy. Creating the environments in which it grows is about bringing together the complementary teams and expertise required, on the ground, and supporting them and meeting their needs, too, over time. Environments where iterative and incremental adaptation and change can be harmoniously embodied as the utility permeates and disseminates, organically, in its development and growth. Environments where complementary teams, leadership and governance seek to cohere, whereby circles of users, communities, professions, organizations, industries, regions and countries, can draw together and cohere in pursuit of shared vision and common goals. Environments that are at one within the information utility they create, sustain and participate in, anchored on the common ground that they share.

We participate in and experience multiple environments in our lives and endeavours, catering to different interests and responding to different needs. We make of them what we wish to, while we can or must. They shape us and we shape them. Environment, teamwork and leadership of innovative endeavours are complex interactions. First impressions count—one learns a lot about an environment when first setting foot inside: about leaders when first meeting them; about team and mission when first sitting with them.

## A Songline of Environments

In this section, I describe and compare a diversity of creative environments and complementary endeavours that I have experienced first-hand. I start in care, travel through education, medicine and health care, in public, private,

charitable, commercial and community interest environments, and finish back in industry and naval shipyards. These environments, and the people I met and worked with there, interconnected and cross-fertilized along my songline. Some names and connections crop up in several places, illustrating those interconnections and what flowed from them.

### *Care*

In her twenties, my mother worked with Francesca Wilson (1888–1981) and Edith Pye (1876–1965) to create a safe environment in Barcelona for refugees displaced by the Spanish Civil War. Fred Sanger (1918–2013) and my dad, and the many others at the Spiceland Training Centre, were creating a new environment, seeking to imagine and construct it in everyday community life. I lived for the first twelve years of my life in the rural environment of a large residential children’s home run by my parents, caring for twenty-five English children, separated from their broken families, and helping them develop and grow. It was a good environment, founded quite simply, in a lovely, very large house, twenty acres of fields, woods and streams, children playing, eating, sleeping, fighting, climbing and falling from, trees, coping with personal trauma and distress, scarcely ever visited by family they had lost. It was a safe and orderly place, and it was a caring environment—that was what made and helped knit back together the pieces of each fragmented picture in each person’s mind. It did a lot to reintegrate the fragmented wartime lives experienced by my parents. A picture of health is also a picture of care. Information utility is a picture that connects health and care.

### *Education*

Some environments are transformative, some are short-lived and others last. Some are revolutionary and others stabilizing. For me, later years at school and in university days were transformative. I advanced further and did not much look back. Life was busy and fun. It opened outwards—a shy boy isolated in a children’s home that was organized around the needs of community more than family, found liberation in study and skills in maths that led to a physics scholarship at Magdalen College, University of Oxford. The experience and learning that came from coping within the children’s home community bore fruit and helped to convey this boy into an industrial scholarship with the Vickers Group of companies. Sponsorship from a family friend funded him on an exchange visit to the USA, from New York and Washington to Louisville, Kentucky, and friendships made there lasted through many decades, until his family hosts died. These were totally new

and complementary environments and experiences, and, taken together, they added up and I was lucky.

### *Medicine and Health Care*

My songline has taken me through a diversely connected range of health care working environments, from neonatal to adult intensive care, in primary, secondary and tertiary care institutions, in diverse clinical specialisms—cancer, cardiology, ophthalmology, nephrology, mental health care and care of older people—and in imaging and other hospital-based medical physics departments. I have worked in and visited them in the UK and overseas, comparing and contrasting. Connecting from one to another of these has been a formative experience for how I think of the professional context of the care information utility.

After leaving industry and moving to University College Hospital (UCH) in 1969, I experienced the everyday working environments of academic medicine and health care service departments, and hospital life, for the first time. Over the following years, I experienced them as an outsider, inside, engaged in the academic, professional and practical worlds of medical physics and medicine. To an outsider, the increasing fragmentation of health care, as it headed into the Information Age, was already in expanding view. Perhaps this was not so visible from the pedestals of the medical profession, betimes intrigued and threatened by the new technologies and tools transforming clinical measurement and intervention of the Information Age, but also facing increasing challenge about its own discipline and professionalism. This reflected in local institutional and national politics of rivalry, complexity and confusion, about the interplay of different levels and specialisms of health care. It was a prelude of transition from trusted and delegated professionalism of services to centrally controlled management of the organization and delivery of health care. It was also a tough era. In how it was received and used, the infant computer both enhanced and exacerbated this scene—on the one hand, it brought an increasingly magnificent new quality of medical imaging; on the other hand, it brought increasingly costly, time-consuming contention over largely unwelcome, often dysfunctional, computerization of hospital workflows and management.

By the good fortune of sponsorship by John Dickinson (1927–2015), who saw potential in my PhD programme as an innovative addition to his predominantly educational mission as the new chief of medicine at St Bartholomew's Hospital (Bart's), in 1976 I landed in the middle of an academic and professional clinical environment. This environment was a department situated immediately above the main medical and surgical

wards of the hospital. I was, once again, an outsider, inside, viewed with understandable suspicion by the College authorities, the College physics department and some of the senior clinicians! I worked alongside the clinicians, but not with them, as they worked long hours. I got to know and helped some of the junior doctors cope with the demands of research and career progression. There were other non-clinicians there, integral to the department's academic mission. Among them was David Perrett, a creative and practical biochemist, pioneering high-pressure liquid chromatography, who became a close colleague. We were a bit like a servant community, below stairs in a country house, with the clinicians as family aristocracy! They were sometimes lonely years. David's practical grounding and commitment established him as a key player in a wide range of clinical research. He was on his similar, quite isolated, journey in the Department, that turned out very well for him, too, in his field.

I was equipped for such a challenging environment. It was not a million miles from how life in childhood had felt: viewed with suspicion by some in the children's home, because of my otherness, and perhaps resentful of my privileged parenthood; and viewed with suspicion by some primary school classmates, perhaps a bit envious of my academic success. I was used to being an outsider and in so far as there are outsider skills, I had them, combined now with a sense of their utility in times of change.

I discovered new opportunities as I helped the young doctors and continued my mathematical modelling work with John. With the combination of interest, skill and experience I brought, I quickly found my way into new national programmes of educational computing, and later into creating innovative educational resources for charitable foundations, such as the Marie Curie Foundation for cancer care, and the Wellcome Trust for tropical medicine. This was the time that Wellcome became hugely endowed with investment funds and transitioned into its rapidly growing role as a major international funder of biomedical research. Each of these environments brought new experiences of health care community and environment. In each, I interacted with multiprofessional teams and their leadership—we were engaged on high-profile projects. Established medical journals showed little interest in educational innovation, being focused on new frontiers of medical science.

I was sought out as supervisor of medical physics PhD students, the first being Bill Flatman, who went on to a successful career in health care informatics. Through Paul Turner (1933–94) and Jim Malpas (1931–2019), eminent academic colleagues leading the Departments of Clinical Pharmacology and Oncology, respectively, who got to know me, I was asked to take on statistical peer review for medical journals. With my mathematical background and having taken on some statistics teaching in

the medical student curriculum, this was a world I had come to know quite well. From there, I was made a fellow of the Fellowship of Postgraduate Medicine and member of the editorial board of its journal, connecting me with the world of publishers. Knowing the world of finance from my industry days, I was made Treasurer, and set about reorganizing and re-tendering the management of its investment portfolio, connecting me with the world of investment managers. There, I recall meeting the young Kate Bingham, years later the leader of the much-feted national Covid-19 vaccine task force. The Fellowship drew together a very interesting group of people from right across medicine. And then I was made a professor and my career made another step change into the creation of new environments, which I describe below.

### *Academic*

Academic environment is a haven-harbour, place of safety and refuge, providing and sustaining a home base and favourable opportunities for explorers. It is a place where ideas and idealists find their home, and my perception of this environment is idealistic in nature.

Academic departments are harbours of academic life, dotted around the coast of the sea-faring island that is the institutional home in which they belong. Harbours face different seas, build and sale different ships, and require different captains and crew, tuned to the weather and missions they undertake: the small fishing harbours of Devon of my childhood holidays, the base, now, of highly systematized trade in large amounts of fish; the shipyards of the north that I spent time in, in my industry days, producing and servicing naval vessels for defence; the trading ports of the east coast ferrying containers from suppliers to markets; the transport hubs of the south-east coast, running ferries to and fro to the continent; the sailing marinas of the south-west, homes of sport and leisure.

Academic harbours connect across many disciplines and domains and their missions interconnect. The academic harbour masters must look inwards to support the needs of the island and outwards into the seas of discovery and endeavour, on which they and their members sail. Some succumb to the lure of the sea and tend not to see the community, harbour and island behind them, where they are based. They lose connection when they cast off their boats and take for granted the support and constraints of their home base. Some find it no longer there for them when they need to return and may sink at sea. Some stay land-locked and never sail.

Balancing these perspectives is crucial and is the responsibility of the academic harbour master. In a new harbour, which must make necessary

new connections with other harbours, some of which are likely resentful and fearful of loss of trade, it is a considerable load. Making connections that help make this new harbour a haven is hard work—onerous if it fails and a privilege and joy when it works out well. It is up and down in real life. Academic harbours thrive as a balance of support of their parent institution for distinctive discipline and mission, freedom conferred on the harbour master to frame and pursue that discipline and mission, and capability of the different captains and crews, and their ships based there, all drawn together into a distinctive home base culture, environment and trust. The ships and their captains and crews earn their reputations at sea and need the port for shelter, sustenance, regeneration and repair. The harbour is a home base. It is where ships are built, and teams and teamwork grow. It is a place where trust can grow and must be continuously renewed, and nets repaired.

The spirit of adventure, connection and trust was what underpinned my efforts on being head-hunted in 1995, to create and lead an innovative new academic centre at UCL, to be established on the Whittington NHS Trust site as a department of the Medical School of UCL, at the time of its merger with the Royal Free Hospital Medical School. This harbour was to be the home base for three founding and complementary flotillas—health informatics; medical and multiprofessional education; and health services research. The seas they encountered, nearby and further away, were usually quite stormy! I reflect further on this experience, in the section below about creating new environments.

### *Public Sector*

My experience of the wider public sector came in part from becoming involved as a volunteer, in managing the Churches Housing Association in St Albans. The interaction with national policy and institutions like the national Housing Corporation, and their regional governance structures and networks, provided me with insight into legislation, the bidding process for funds, running building projects and maintenance services, and their financial management. The most important experience was the weekly interaction with tenants and the complex network of support agencies that those in need had to negotiate. It illustrated the fragmentation of care services, among multiple competing and discontinuous agencies, much as Bob Jones had focused in the ConCaH charity that I described in Chapter Seven—all requiring and suffering from lack of good interface of public sector and voluntary sector engagement and governance.

I continued to experience the public sector in many other guises, throughout the era charted in Chapter Seven—covering the interaction of information technology with health care policy and practice of the past fifty years. I saw at close quarters, many agencies involved in health care, at the local NHS level in London and on a national scale, in matters of finance, contract, infrastructure and operations, spanning from ministries in Whitehall to City Livery companies, professional bodies, governing boards of NHS Trusts, research funding agencies and research institutes, charities, publishers and national libraries... The emerging health informatics domain connected throughout—truly a Whitehead anarchy of transition!

### *Commercial and Industrial*

In my first post after university, I experienced environment and community of largescale industrial engineering production, contract, finance, project control and corporate management. This was, at one time, where I had expected to pursue my career. But the career path ended abruptly when the group of companies I had joined landed me in a dysfunctional commercial environment. Large amounts of corporate money were piled as chips, staking misguided corporate ambition, fuelled by hubristic promises of technological innovation in medical engineering that came to grief a few years later. The experience of this environment gave me the eyes to see, in later years, at a senior level, how the NHS mismanaged and repetitively came to grief over policy for information technology. Luckily, I was able to change course and head to the starting gate of academic computer science and medical computing at UCL, and its teaching hospital, UCH.

The hugely successful entrepreneur Hermann Hauser was involved in the early stages of the first UK school microcomputers, developed at Acorn Computers in Cambridge and in partnership with the BBC. This was the BBC Micro, and Hauser became a very rich venture capitalist, in taking the technology on much further. This led to the reduced instruction set computer (RISC) architecture machines and micro-processors at the heart of many mobile phones, and the ARM company, globally. My wife and I received social invitations to celebratory events—an Acorn Computers company sponsored concert in King's College Chapel at Cambridge, hosted by its CEO, was a memorable such event. In my work on educational computing, I came to the notice of major publishers and computer manufacturers, dipping their toes in the sea of informatics and its potential in their different domains.

From Cambridge at that time also arose *Autonomy*, a talisman of AI arising from a collaboration of computer science and text processing researchers in

the University. It was where Mike Lynch was gaining traction in devising algorithms for machine learning, parallel to the rise of the Google pioneers at Stanford University. Google was an Information Age phenomenon that ballooned to become a new globe. Autonomy bubbled and burst. I had heard a bit about its rise through a partner in its parent Venture Capital company Apax Partners, John McMonigall. We were both Trustees of the StartHere charity, along with a board of industrial, commercial and legal titans and a young team of immense devotion and dedication to its cause. StartHere features as one of the examples of creation of new environments, below.

### *Charitable and Voluntary Sector*

The voluntary sector has provided some of the best examples I have experienced of good environment. Where participants feel motivated to offer themselves and their time, freely, there must be good and resilient qualities in play, united in shared values and mission. As mentioned above in connection with public sector environments, for ten years I held office in a local Churches Housing Association. The stretch to provide daily shelter for the homeless and accommodation for those unable to purchase homes, within an umbrella of public finance of building and benefits agency support of tenants in financial difficulty, illustrated the breadth of disconnection between public and voluntary sector services. The gap between services and needs is often bridged by the local generosity and goodwill of those able and willing to volunteer.

A decade or so earlier, in the late 1960s, I had been a member of the British Executive Committee of the fledgeling Amnesty International, in London, encouraged by my late father-in-law of the time, Eric Baker (1920–76), the co-founder of Amnesty with Peter Benenson (1921–2005), and the Campaign for Nuclear Disarmament (CND). In Amnesty was illustrated and exposed the immense solidarity and commitment of communities thrown together as exiles from war in Europe, towards concerted action in support of those imprisoned for their bravery in speaking out against oppressive governments.

The breadth of wider community support for this activity was revealed in fundraising events in the City of London, organized by supporters. A concert at which The Amadeus Quartet played for us (themselves and their families motivated by experience as wartime refugees) drew an audience connected widely across local communities, commercial and public sectors, professions and politics. The Lord Chancellor, Gerald Gardiner (1900–90) spoke at one such event. A future Solicitor General, Peter Archer



(1926–2012), chaired our Board—I started there to see the workings inside Parliament.

The global work of Amnesty of that time combined synergistically with the mobilization of local support groups in concrete action to maintain communication with, and support the families of, those imprisoned. It showed how global mission and local mission could be connected in concrete action that anyone, thus motivated, could engage with—fundraising, letter-writing, sending food parcels, campaigning. This synergy did not rest on local actions of national bodies, but did rest on their global agreements, as expressed in the UN Declaration of Human Rights. Maybe there could be models there for global and local governance of the care information utility. There would be much less of a political overtone to such governance arrangements, I feel sure.

### *Community Interest Company*

The coherent interface of health care information as a utility, with individual citizen, local community, profession, organization, business, technology and voluntary sector, is a circle that must be squared within conducive environment and governance. We have evolved utilities of water, electricity, telephony and broadband. We need an evolved coherence of care information as a utility, too.

Stephen Lloyd (1951–2014) was a Quaker lawyer who helped to modernize the charity sector and conceived the idea of the community interest company. I first met him when we were Trustees, together, of the StartHere charity, which I describe below. He advised government and pioneered changes in Charity Law in the UK, to align public, private and voluntary enterprise, to promote new ways of working together, based on sound economy, and squared with the pursuit of shared goals of common interest in wider community. Thus arose the legal framework of the Community Interest Company (CIC). At its centre is the concept and guarantee of asset-lock—shared ownership of community assets and the co-creation and governance of community enterprise, wherein all partnering sectors share roles and responsibilities. Very sadly, Stephen died in a sailing accident, a few years later.

Stephen's law practice, Bates Wells and Braithwaite, and his successor there in supporting Community Interest Companies (CIC), Abbie Rumbold, played an invaluable role in supporting me to translate the UCL-anchored mission of openEHR into the openEHR International CIC, in 2018. My anchoring support at UCL came throughout from Cengiz Tarhan, Chief Executive of the UCL Business organization and a long-term,

invaluable and trusted colleague. OpenEyes had followed the same route and Peter Coates (the founding CEO of the Apperta Foundation, which took OpenEyes under its wing), along with Bill Aylward and my openEHR Foundation colleagues Ian McNicoll and Thomas Beale, and EU colleague, Gunnar Klein, supported me hugely in this process. This two-year period of legal steps, consulted on throughout within the increasingly worldwide openEHR community, brought into being the Community Interest Company structures through which the IP-owning openEHR Foundation and the self-governing operating company, openEHR International, now exist.

### *Cost-Plus Environment*

During my early career in the 1960s, major public projects to construct national infrastructure and complex systems, like warships, were handled through what were called 'cost-plus' contracts. This was implicitly a sharing of risk, much as the rapid production of the Covid vaccine, at scale, was negotiated in the UK. Unpredictable and potentially costly risk carries a high commercial insurance premium. In large institutions a choice may be made to carry the risk internally, avoiding payment of the premium but at further risk of carrying the larger loss, should it be incurred. Large shipping fleets were sometimes not insured, where the wealthy owners (the Onassis's of the shipping world) could cover, internally, the costs resulting from the occasional sinking at sea.

The building of warships at Barrow-in-Furness was where I saw cost-plus in operation. A meticulous internal process was set up and funded to enable focus on quality of manufacture and to minimize the risk that the project would not be completed as planned. The government accepted these costs, subject to its own independent and ongoing review of the manufacturing processes. The shipyard got on with building the ships and submarines, relieved of the concern about financial consequences to them, should the uncertain innovatory nature of the project delivery run into unpredictable difficulties.

Given the extreme emphasis given to supposedly rigorously risk-managed contracts for the National Programme for IT, and the considerable associated cost and furore arising from its subsequent failure to deliver, one wonders whether a more rigorously monitored cost-plus approach might have both delivered much more and cost much less. It is arguable that limitations lurking under the bonnets of the products and services purchased could, much more readily, have been revealed and managed that way. Of course, this would have required a different culture and competence of purchase as well as of supply. In earlier times of innovations

of physics in medicine, the NHS valued and invested within hospitals to create and sustain that kind of in-house competence. A culture of purchase contract that encourages hubris, pretence and protective overcharging is not a harbinger of good environment for achieving quality of product and trust in outcome, in complex and uncertain domains of innovation spanning the public and private sectors—and so it proved in this case.

### Creating New Environment

Creating the future is about creating new environments that are adaptable and aligned with new purposes and goals. I have been closely involved with three such endeavours during the second half of my career. Their stories reveal patterns that reinforce one another. They have led to wide-ranging impacts, although their innovative and creative phases have now passed into history. I reflect on these experiences, here, and how they connected along my songline.

#### *The StartHere Charity—Signposting to Services in the Public and Voluntary Sector*

Originally founded with support of the British Telecom corporate giving department led by Richard Worsley, and pioneered and inspired by Sarah Hamilton-Fairley and Richard Crofton, StartHere set out with the mission to bring order to the ballooning and cross-cutting domains of citizens advice and support services of the Information Age—every sector creating its own brands and initiatives, all focusing on the same population. For some years, I had been discovering that the fragmentation resulting from the poor connection of a plethora of different public and voluntary sector services, all working with the same clients, was frustrating, wasteful and confusing for all concerned. Dependence upon pervasive but non-coherent IT systems and services, seemed, if anything, only to be making matters worse! This had been illustrated by my work with a pioneering West Country GP, Bob Jones, on the Marie Curie Foundation *Cancer Patients and their Families at Home* videodisc-based educational resource, and in his ConCAH initiative, as described in Chapter Seven.

Sarah and Richard had previously created a small company called Whitewater, providing marketing and public relations services. They knew well the arts of communicating with wider audiences. The StartHere charity created a unique brand with the strapline, 'Where to go when you don't know where to go'. It was an outstanding, but sadly ultimately unsupported, initiative to standardize the signposting of citizens to high quality help

and guidance, throughout the voluntary sector and local authorities. My connection with this endeavour provided fascinating insight into the interplay of voluntary-sector charities, national and local government, industry, and the legal profession.

Founding members of StartHere, like Sarah Jane Vernon, had worked with Esther Rantzen in creating and running the widely applauded national Childline charity. The StartHere office, with its highly motivated team and governing board, drawn from a wide and complementary range of communities and joined together by a common vision, was a memorable environment and provided a thought-provoking experience. Over time, they strongly influenced my ideas about care information utility. Sarah Hamilton-Fairley has, and demonstrates to wonderful effect, the most outstanding networking and humble leadership skills one will ever come across, and Richard was stubbornly insistent and persistent in piecing together the technology team. There has been a great alliance.

Together with Richard Worsley and several others working in influential commercial sector roles they drew luminary figures from industry, finance, law and public service onto their board. They won grants and created the StartHere team and environment, in stages: collecting and standardizing information about services and advice, connecting across the voluntary and public sector, prototyping and evaluating the use of free-standing kiosk terminals for use in libraries and at other publicly accessible sites. I first came across their radar at an event hosted by the Nuffield Foundation, to bring together a network of people working across health care and IT communities. I became one of their early targets as a Trustee and was 'lunched' by the chair, Richard, and Sarah, and asked to join. I am very glad I did—it opened many doors for openEHR through its formative years, as described here.

Sarah is a most capable and charismatic social entrepreneur. She creates and leads great teams, of all ages but uniformly young at heart, raising money very widely, engaging politicians and journalists, drawing together and cajoling a wide-ranging group of Trustees and supporters—among them, board level members of companies, consultancies and social enterprises. The charity succeeded in pilot projects. One of the first test sites was in the early 2000s, in the outpatient department at the Whittington Hospital, where I was then based with CHIME. Matthew Bond, a health services research lecturer and colleague of Ann Bowling, helped to evaluate its use.

Through my membership of the StartHere board, I gained awareness of the intellectual property law expertise of Oliver Bray at Reynolds Porter Chamberlain, who assisted Sarah, Richard and StartHere on IP matters. Oliver generously held my hand through the legal shaping and assignments of IP to the openEHR Foundation.

The entrenched and muddled bureaucracy characteristic of the domain that StartHere had sought to standardize eventually defeated Sarah's energies. StartHere had to close, and its wonderful team dispersed. StartHere mission's loss was OpenEyes' gain and Sarah helped Bill Aylward and me to stabilize OpenEyes through some destabilizing times, associated with unfortunate disturbances in Moorfields management that interrupted its development for a while. Sarah became frustrated, as did Bill, with the politics there and moved on to work with one of the other trustees of StartHere, Richard Harris, with whom she joined forces with Ron Daniels, a charismatic intensivist, to transform the national Sepsis Trust into the powerhouse national campaign it now is. In five short years, the talents of this triumvirate and their board and team have catapulted concern for sepsis into public awareness and action. Just look at the website to see what they have done—generating publicity, fund raising, action plans, volunteering, support of victims and more.<sup>60</sup> This is a tribute to their combined knowledge, ability, *savoir faire* and determination. A triumph of the new environment that they created and led.

In Sarah, such power was born from honour to her beloved dad, who was very briefly also my colleague in the mid-1970s at Bart's—he at the height of his professional eminence and me in my early academic post. He was the oncologist Gordon Hamilton-Fairley (1930–75), who was killed accidentally while walking their dog, by an Irish Republican Army (IRA) bomb placed near their home in London. Sarah was still at school. He is commemorated in a plaque in the crypt of St Paul's Cathedral and her family gathers there, each year, to remember and celebrate him. Her life and career, and its connections, are an amazing parable of where innovation and leadership come from and how they are expressed in the teams and environments they create. It was through the connections I made between openEHR and StartHere, that the idea of care information as a utility started to take shape in my mind, ten years ago.

### *Clinical Skills Centre at Bart's—Clinical Skills and Informatics*

I told this story in outline in Chapter Four, in the context of my career shift from mathematical modelling of human clinical physiology to the standardization of digital health record architecture. Here, I discuss it in the context of the creation of a new environment.

In the terms used by Kahneman, Sibony and Sunstein, clinical judgements are noisy-level, pattern and occasion bias and noise prevail in the

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60 Sepsis Trust, <https://sepsistrust.org/>

judgements of individual practitioners and their coherence among different groups and populations of practitioners.<sup>61</sup> In their final examinations, medical students, all highly intelligent cohorts, must perform prodigious feats of memory, rehearsal of theory and demonstration of practice. The validity of the assessment of this performance has itself been the subject of long-standing assessment and debate. Is a method of assessment *relevant*, *reliable* and *reproducible*, measuring the right things consistently over time. How does the dialogue of teacher and learner *review*, *reflect* and *respond*, to promote learning? In improving assessment methods, the mantra is to *reduce*, *refine* and *replace*. The three R's of primary school learning (reading 'riting and 'rithmetic) have ramified into these three more threes of R's to govern assessment, learning and improvement! A complementary trifecta of tripods, again!

In the late 1980s, two schools of thought arose in medical and nursing education, recognizing the increasingly team-based and multiprofessional culture of clinical practice and the need to create a correspondingly balanced and interprofessional environment for teaching clinical skills. The two collaborating Deans at Bart's at that time, Lesley Rees (1942–2022, the first female dean of Bart's Medical College) and her counterpart, Sue Studdy, Head of the Nursing School, asked me to take a group to Maastricht University, to observe its pioneering work on skills laboratories and then create something similar at Bart's. Its motivation was to be twofold. First to gain a handle on a more objective approach to assessment of complementary clinical skills, in the curricula of clinical practice, and second to build a bridge between medical and nursing education. My role in leading the implementation team was to bring senior professional staff from both institutions together within a shared mission, chair and broker the planning process, accountable only to the two Deans, and help build a productive working environment in which to explore cooperation and collaboration.

I was probably thought a good candidate as I was neither doctor nor nurse, but was diplomatically and culturally attuned to conducting myself, often as a peacemaker, or insider mediator, perhaps, in areas of potential tribal conflict. I was never going to make it as a high-profile leader! My style always flew below the radar, and the team around me included some who much better attuned as high-flyers in high-profile leadership, as is needed at the top! Leaders who fly below the radar may, incidentally, be no bad thing when tackling wicked problems, where tribes of complementary perspective, and their leaders, often do battle. Working as an outsider and on the margins was what I had been used to for much of my life—as a child

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61 Kahneman, Sibony and Sunstein, *Noise: A Flaw*.

in a children's home, a country boy at the University of Oxford, and in the marginal domain of medical informatics.

There were also significant benefits, for me personally, in being cast into this new leadership role. My position for twenty years in the Bart's Medical College had always been side by side with clinical professionals and their everyday health care practice. These developing relationships afforded me uniquely adventitious opportunity as well as important insight into and feel for the ambivalences and ambiguities of health care services. There was, however, a double edge to this position—one of personal isolation, and this had also made it uniquely challenging, given the breadth of mission I had undertaken.<sup>62</sup>

With Lesley Rees and John Dickinson, we recruited Jane Dacre, and Sue Studdy appointed Maggie Nicol. Together with other colleagues, we formed a small team to plan and implement a joint medical and nursing Clinical Skills Centre at Bart's. Jane had been a junior doctor with John Dickinson and was pursuing her specialism and research in rheumatology with Ted Huskisson, at Bart's. She came from a medical lineage; I remember her father, an anaesthetist, who had an office in the adjacent Surgery and Anaesthetics Department, in my earliest days working on the top floor of the UCH Medical School, experimenting with the PDP-8 computer in the early 1970s.

John Dickinson organized the building and Jane and Maggie pioneered a joined-up curriculum for teaching and assessment of clinical skills. I kept the peace and held things together within and between the two institutions, with the senior faculty on the project committee. In practice, we assembled a good team, in a good environment, and they led, and held, themselves together!

The project was a success, the Skills Centre created a first of its kind and, thanks principally to Jane and Maggie, the progenitor of many such resources, nationally and internationally, thereafter. Clinical teaching now makes use of clinical skills laboratories and associated models, simulations

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62 Many very successful people I have known, whose contributions have bridged between information technology and health care, have occupied niche positions situated at a safe distance from the pressures faced in mainstream environments combining academic medicine and health care practice: in academic computer science, epidemiology and public health, medical physics, professional organizations and biomedical technology research centres. Others took a special interest in informatics and combined this with clinical professional and academic roles. In America, stellar early careers in the field have bridged the heights of academic medicine and informatics, benefiting from wealthy sponsoring institutions and substantial government pump-priming funds. Some of their colleagues established companies and became very rich.

and standardized assessment methods, very widely. The environment we co-created and managed was a safe harbour where Jane and Maggie could create and grow into captains of their ships. Jane's ship was the development and enactment of Objective Structured Clinical Examinations (OSCEs) which sailed through the world of clinical examinations from those days. It is a fond memory to recall her ringing the skills lab bell, to sequence students from one OSCE station to the next, in their assessments. Her personal skills—honed, no doubt, in the highly competitive worlds of television and newspaper journalism and medicine, that she bridged in life—brought her great accomplishment. She later came with me to UCL, both of us having trained there—she as a medical student and me as a PhD student. There she established a Clinical Skills Centre for the new combined UCH and Royal Free Medical School, at the Whittington Hospital campus, under the auspices and protection of its Vice-Dean, David Patterson, who I worked with closely during those years, to create the CHIME harbour that I describe next. Jane took her work into the examinations of the membership of the Royal College of Physicians, alongside the medically trained psychologist, statistician and medical education researcher, Chris McManus. Chris became a joint member of staff between the Psychology department and CHIME. He was feisty, determined and no sufferer of what he felt foolish or unjust. There was occasionally some mayhem!

The Skills Centre was a creative environment—based on a culture of shared endeavour with a clear goal, and set within a wider long-term mission, enabled and supported by the two institutions. It was a springboard of new careers. It also provided an environment to bring together the existing audio-visual and medical illustration departments. For me, it connected with a wider environment that I developed, pioneering computer-assisted learning for the medical students, creating the first networked computer system and support team for the medical school clinical campus, and collaborating with Donald Jeffries and David Perrett in establishing a new biomedical science degree course.

At this pivotal stage of my career, Sam Heard drew me into the bid for the GEHR project, and I switched from my focus on modelling clinical physiology to development of health record architecture, and to establishing my first department, with the small team that had grown around me in the Clinical Skills Centre project. We called it Clinical Skills and Informatics and established it close-by to the academic department of General Practice and Primary Care, as I described as the second of three sliding doors along my career trajectory at that time, in Chapter Four. This new environment was a creative one. The department was closely anchored in the primary health care community of East London, and with local endeavours seeking to improve computerized care record systems, in the pioneering work



led by Sam Heard, Paul Julian and Dipak Kalra, as described in Chapter Eight. General practitioners (GPs) were also battle hardened from years of establishing themselves in the hierarchy of academic medicine, much as medicine, decades before, had struggled to establish itself within the hierarchy of academia more widely—surely it was just apprenticeship and trade, was the airy perspective of those days! I am remembering, here, how the then Astronomer Royal, another Airy (George Airy), dismissed Babbage and his computer, long ago, as mentioned in Chapter Five.

GPs were thus great allies through these times, with their implicit understanding of the situation faced by the marginal discipline of medical informatics. This stage of building my new working environment within academic medicine was a battle, pursued on ground where wide-ranging alliances were supremely important.

### *CHIME at UCL*

I wrote in Chapter Four about the opportunity to create CHIME, describing it as the third of three sliding door moments in my career transition of the early and mid-1990s. Here, I reflect on the experience in the context of the creation of a new environment, with a brief to foster connections widely across disciplines, professions, organizations, industries, communities and governance of health care. CHIME was an exercise in creating an inclusive environment, bringing together a team drawn from diverse walks of life and complementary perspectives, joined under a vision and mission of multiprofessional education and health informatics—a conjunction somewhat contrived to spell out CHIME! For whatever reasons—and overloaded expectations of our mission at Archway was, I think, one such reason—the nursing and medicine multiprofessional elements did not gel as well at UCL, as they had done at Bart’s. The story of CHIME is also illustrative of generic and multi-faceted challenges of innovation across boundaries of public and private sectors, locally, nationally and internationally. It illustrates how informatics has become entrained, entwined and confounded with everything! AI, a now exploding domain of informatics, looks poised to become so, likewise!

As a founding team, we were dedicated to and attuned to learning by doing. I am indebted to and celebrate all the colleagues who joined with me along this part of my songline. There were invigorating and significant successes and wearisome struggles and failures, with important learning in all respects. We will all have experienced things differently, learned different lessons and drawn different conclusions. These are my recollections. The account I give does not attempt to cover all who contributed within and

in connection with CHIME. It draws on those closest to me in my work and roles as its leader and I have sought to illustrate the wider context and challenge implicit in creating such an environment, which is inevitably an ambitious, risky and contentious endeavour. The trifecta of ambition, risk and controversy expresses a complementarity—such is the nature of disruptive change. Stories from the CHIME years appear throughout the book. They provide an illustrative context for, and examples of, the present-day predicament of our overloaded and, almost intrinsically, messy health care services, and how the computer can contribute to their reform and reinvention for the Information Society of tomorrow.

For as long as I could then remember, dragons of medical politics had been breathing fire as London's historic NHS Hospitals and University Medical Schools were merged into larger groupings. Weighty lords of the realm did battle within the federal University of London, merging and reconfiguring some twenty separate medical schools into five principal centres. The battles came to a head near to me in the early 1990s, as the venerable Bart's Hospital, with its close ties to the City of London, was required to merge, reluctantly and sometimes angrily, with the London Hospital in Whitechapel, and their two separate medical schools into Queen Mary College, close by in the London East End.

In North London, one of the new groupings was centred on UCL, where the brave and formidable Provost of the era was Derek Roberts (1932–2021), formerly a titan of the electrical engineering industry. One of the UCL Medical School clinical campuses was in Archway, North London, at the Whittington Hospital NHS Trust. The chair of this Trust at the time was Helene Hayman, soon to become a Labour health minister in the first Blair government of the late 1990s and then leader of the House of Lords. Through the then Dean of the Medical School, John Pattison (1943–2020), and the Vice-Dean at the Whittington, David Patterson, advised by my long-standing colleague, Mark Leaning (who was then based in the Clinical Operational Research Unit of UCL (CORU)), I was approached to bring my team, which had grown together through the Skills Centre and GEHR projects at Bart's, to UCL. There we were invited to establish a new health informatics and multiprofessional education centre within what is now the UCL Biomedicine Division, to be based at the Whittington Hospital as a joint University and NHS initiative.

These senior leaders were hugely supportive, always, and organized generous funding and wonderful new accommodation for us. David Patterson worked astutely and effectively to fit everything together and make things possible. It was David who christened us CHIME—Centre for Health Informatics and Multiprofessional Education. If ever opportunity knocked, it knocked then! We saw and welcomed the opportunity, trusted

as a team, made few preconditions and jumped as a group. It was quite a jump! Bart's was a bit shocked, but impressed and generous, and wished us well.

Derek Roberts had met and corresponded with me prior to deciding to go ahead with the invitation to our team, and Jane Dacre had held discussions with the Whittington Trust, where she was to become an NHS consultant rheumatologist. I said from the start that I was keen to make the move. Derek then drafted and signed the letters to each of us, individually, as UCL Provost, offering us our new appointments. We did not seek salary increment in the move—that eased the transition. David Patterson later remarked to me that the Provost had been agreeably surprised by the straightforwardness of my response to his invitation, having expected he might have to raise his bid! Apparently, being head-hunted tends to go to the head, and the negotiating tactics of sought-after academics were sometimes aggravating to this former industry titan! The straightforward negotiation helped set us off on a good footing.

The diverse founding team of CHIME had an adventurous spirit in common, honed by some years of working together in different groupings at Bart's. It included nationally recognized leaders—some already at or near to professorial level—with anchoring in health informatics, medical education, clinical practice and health services research. Together with close-by colleagues in Primary Care, the multiprofessional and interdisciplinary environment of CHIME became a unique and special harbour—not always a peaceful or approved of one, but how could it have been! It was a home for a creative mix of vivid personalities and perspectives, connecting very widely beyond its base. There was always a Herodotus-style ensemble of contending eyewitness viewpoints and narratives in play, connecting far and wide. CHIME made a difference and mostly survived for the nearly twenty years until my retirement, when it had had its day. Derek Roberts was, from the start, wise and prescient about its mission, telling me that he saw it as disrupting patterns and seeding new ones, and that we should keep it going while it was working and worthwhile, and adapt and change it as times moved on, as they always do. How we tackled its challenges was going to be as important as what we did.

In the summer of 1995, I moved with ten colleagues to begin to create and run this new centre. Those who came with me in stepping through this third sliding door of my health informatics career songline, and those who joined us there to develop and extend it over the following years, have been principal actors and leaders of many of the endeavours that are joined together along the storyline of this book.

My role as the harbour master of CHIME was different from that of colleague UCL heads of department in well-established academic fields and

organizations; it challenged me to the core. We had to discover what was needed by creating it, and this was inevitably a highly uncertain endeavour. The brief was an open and formative one—open opportunity, open playing field, but no open sesame! No genie and abracadabra to magic solutions to the sorts of difficulties and ills that our recruitment there reflected as having been rather intractable ones. To address these innovatively, CHIME needed connections with many well-established harbours of discipline, profession and practice, spanning the worlds of medicine, information technology and health care. Some new alliances that we worked on, worked out well, and others did not prosper; everyone tried hard, and variously adjusted, adapted and moved forward.

Marcia Jacks, who had starred as the project administrator with me for the GEHR project, as described in Chapter Eight and a Half, was an amazing harbour manager. Strong and assiduously loyal and determined, she became a trail blazer of good practice and ethnic minority leadership in UCL and went on from CHIME to manage the UCL Institute of Women's Health. Espy Rodrigues succeeded her as centre manager—sadly dying very young, from cancer, several years after my retirement.

CHIME was never an easy environment, for anyone. In health informatics, alone, there were many and disjoint perceptions about us, and expectations of us, in play. One might parody these as spanning from providing a service to 'keep my printer working' to fulfilling a delegated role to 'create an information technology panacea for the woes of hard-pressed health care services'. Indeed, we needed to help organize much of the IT infrastructure and education facility required for the new Archway campus.

CHIME did, though, provide unique opportunities and we set out to make it a straightforward, inclusive and friendly home, where everyone had encouragement and freedom to lead the pursuit of their interest. I summarize here and in Chapter Eight and a Half some of the connections and contributions made, achieving many kinds of impact and success, nationally and internationally. Of the team that came together in the CHIME environment, there are now more than ten UCL professors or emeritus professors. They found and sustained their own successes in what was both a fertile and demanding environment, as creative environments always are. Two of its clinical leaders went on to become presidents of medical Royal Colleges—of General Practice and Physicians. Others moved into senior appointments and responsibilities further afield.

Leading CHIME through those formative years was complex and subtly hard work, perhaps mitigated somewhat by the experience of coping in challenging environments that had been instilled in me since childhood in a children's home. Not that any CHIME folk were in the slightest bit child-like! It was a grown-up and adventurous community and attracted adventurous

people to it, interested in the adventure of ideas. It had a good balance of age, gender and ethnicity and Marcia, our Centre Manager, told me that the UCL Human Resources department, that she dealt with on a daily basis, considered the way CHIME conducted itself to be a model of good practice—very much an achievement of her generous but firm character and diligence in her work with us all. I also knew, from experience of feeling isolated and left largely to my own devices in my early decade at Bart's, that a capacity for both alliance and self-reliance matters greatly when seeking to identify and create a distinctive contribution to any worthwhile challenge, especially perhaps one involving wicked problems, albeit that its enforcement on one is not always appreciated!

Leadership in the tackling of wicked problems is substantially about enabling and protecting others, operating below a radar that seeks to probe and interfere from further afield. Strutting one's stuff above the parapet in such quests tends not to cut any eventual mustard! But great things can proceed from challenging environments, given vision and sense of mission and freedom to pursue it. My approach was to help connect people and endeavours within their multidisciplinary and multiprofessional contexts, enabling and protecting practical engagement as widely as possible across academia, health care and industry. It was a risky and ambitious strategy in almost every way imaginable, and utterly dependent on the encouragement and enablement of successive UCL Provosts, Vice-Provosts, Deans and Vice-Deans of the times. I did my best with what was possible, and our achievements were not without honour!

That CHIME environment has now gone, and rightly so. The people who created it have moved on and their contributions have disseminated to other centres, nationally and internationally, sowing seeds of new environments and endeavours. Some of them engage with me still, today, although as a follower and not a leader, anymore. I am now a more stationary point of reference on numerous new and dynamically connected personal songlines! It seems an important time, now, to reflect on some of the battles that raged around me through those formative years and my connection with them.

### Battling Environments

In one perspective, the idea and creation of CHIME was a brave exercise in high-level wish fulfilment! Inevitably, some of the wishing-well wishes were well-fulfilled, and others not so well. At a local level, it was an ambitious attempt to create an innovative and inclusive new mission that would help bring new impetus to the healing of some long-standing institutional difficulties and resentments. CHIME, and especially informatics, found

itself at the centre of multiple battles in multiple contexts. Two urgent agendas occupying the UCL senior management team at that time were linked together in the ideas generated for the recruitment of our team and the establishment of CHIME. The first concerned medical education and the second the relationship between UCL and the Whittington NHS Trust.

For the first, UCL was looking to catalyze new thinking and help unite fragmented endeavours that had come together in the successive mergers into UCL of the previous Middlesex Hospital Medical School and Royal Free Hospital School of Medicine. Unsurprisingly, some *ancien régime* loyalties and rivalries persisted and played out in the manoeuvres of senior staff! The creation and operation of a new merged undergraduate medical education curriculum was a battlefield of disciplines, professions and organizations, as to who would play, how they would play and who would pay and be paid.

The wider clinical relationships between the specialist clinical research institutes and NHS Trusts, by then all closely linked with UCL, and the research teams based there, was another battlefield. And, as in all universities, there were culture clashes and rivalries between clinical and non-clinical faculties—the latter somewhere between envious and resentful of the perceived advantages of income and autonomy that are afforded to those clinically qualified, and thereby accorded practising clinician status and remuneration in their terms of university appointment.

The Whittington's relationship with UCL and its larger and more specialized UCL Hospitals and Royal Free Hospital NHS Trusts had long been a tricky balance, with sections of the Whittington community feeling themselves historically disadvantaged in terms of recognition and resource. The UCL and Whittington senior management were looking for an initiative that brought new capacity and capability in support of current UCL and Whittington missions, and a distinctive new dimension of UCL academic mission—in our case that being health informatics. There were tensions around this plan among the already well-established academic teams based at the Whittington, with understandable resentment that resources they had long felt deprived of, was being offered to newcomers. This was echoed in tensions among the medical education community members based at the different hospital sites of the newly merging medical school, reflecting again a sense of unjust distribution of resources in relation to contributions made. Such tensions are writ large, professionally, academically and geographically, in hard-pressed universities and overburdened NHS services. And in addition to this, on the Whittington campus academic medicine was part of UCL, and academic nursing was part of Middlesex University, which gave rise to some further interprofessional and inter-university contention over space, status and influence at Archway.

CHIME was variously envisaged as bringing both balm and creativity to these severally connected battlefronts. Hence, in retrospect, how I have jokingly characterized it here as an exercise in wish fulfilment! It was a good example of a Dreaming in the Dreamtime, and that appealed to me. You might say that CHIME chimed in both David Patterson's dreams and mine! Other battles quickly woke us up!

Computing services for the UCL academic and service departments was another site of rumbling conflict. Large departments, each claiming special requirements, wanted to retain the early freedoms they had gained in implementing their own IT services, and to continue and be resourced to run their own local show.<sup>63</sup> Similar battle played out over library services, between departments and campuses. And central university service divisions had battles among themselves, over custodianship of their respective IT systems supporting human resources, libraries, estates, finance and so on. The UCL central Information Services division, run by the redoubtable physicist, Roland Rosner, provided and championed the need for corporately standardized systems and services, as the only sustainable and affordable way to meet the bulk of service requirements. Dependency on separate local teams was inevitably also unsustainable for keeping pace

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63 There were, for example, many tens of separately configured and managed email servers operating across the UCL community, each run by a small team determinedly defending its own base. These local teams also provided locally configured scientific and administrative support services for their local academic colleagues, who, in turn, feared loss of local budget and services that they depended on, following merger into a central university service. Each local community deployed arguments of exceptionalism and deployed the power of its strong and exceptional leaders to defend their interests. The ensuing dialogue played out the universal narrative of global versus local interests. This was a fragmented, costly and vulnerable community and scene, and its tensions absorbed too much resource and effort. It knew that it had to change, but individual components feared disadvantage and there was resistance to change. The central UCL IT department was a battle-hardened environment and reluctant to countenance federated arrangements. It had enough on its hands in holding together all the other central academic services departments and their separate relationships with the arts and humanities, law, science, medicine, built environment, and engineering academic faculties. The same issues of integration and teamwork arose with all of these, in context of libraries, estates, finance, human resources and so on. One of my delegated roles, over time, was to gain the trust of both 'globalizers' and 'localizers' across the whole of UCL Biomedicine, and, with strong backing from the Deans and Directors involved, work constructively with both, to temper inevitable power plays and encourage cooperation. That meant years of regular engagement, helping find and implement a good way forward for the many highly-motivated people employed, focused on getting them involved in creating a better and more cost-effective future working environment, for UCL and for themselves.

with the rapidly changing requirements of both technologies and related patterns of work. The central IT services were on a torturous uphill path towards a standardized, reliable and serviceable infrastructure for the whole institution. I was drawn into this fray, as well, to help in establishing network connections and library infrastructure for the academic community at Archway and more widely across the very substantial biomedicine faculties and their related NHS Trusts. Biomedicine had by then grown to constitute approaching one half of the financial turnover of UCL. Its power and influence were a continuing source of friction and controversy within this wider community, as life science and biomedicine grew and powered forward in the Information Age.

The creation of a high-profile and innovative new centre like CHIME inevitably disturbed these battlefronts, as it was, in part, intended to. At the senior level, there was hope and expectation of us helping to bridge the multiple divides. But some quite weighty incumbents felt that the Deanery had acted deceptively in persuading the UCL and Whittington Trust senior leaders to bring us in to disrupt their lives; we were not universally welcome! My prior association with some of the senior clinicians through my membership in journal editorial boards—where I had perhaps been seen as a helpful and peaceable outsider—may have somewhat smoothed the pathway. I knew Barry Hoffbrand (1934–2020), a senior Whittington physician, who I had worked with for some years in the Fellowship of Postgraduate Medicine and on its journal editorial board. He was welcoming to me and, given his reputation as an established and opinionated figure in the Whittington medical community, his approval may have helped in assuaging understandable doubts among those who felt David Patterson had been a bit too adventurous in recruiting us there! I also knew Neil McIntyre, a Royal Free Hospital physician prominent in medical education, who also had a strong interest in informatics. He subsequently published a full history of the hospital and proudly gave me a personal copy.<sup>64</sup> Neil was quite angry and affronted by what he saw as a disruption of his own efforts, along with Neville Woolf, a former Middlesex Hospital physician, to shape and manage the new UCL medical education curriculum. But he was quite pleased, as well, that I was coming to UCL, he told me.

Given these swirling undercurrents, David Patterson had been nervous when arranging for me to deliver an inaugural lecture at the Whittington before we arrived, with Helene Hayman presiding and many staff filling the lecture theatre. John Dickinson and Lesley Southgate came to give me moral support. I started by recounting my family's history in connection with the

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64 N. McIntyre, *How British Women Became Doctors: The Story of the Royal Free Hospital and Its Medical School* (London: Wenrowave Press, 2014).



home village of Dick Whittington, which is where my parents met. I used multiple visual aids in seeking to capture and communicate the breadth of CHIME's initial informatics and education missions (see Figures 9.7 and 9.8): one linking with the changing pattern of clinical skills and practice, and another with the emerging discipline of health informatics. I did not venture too far into how the computer might prove instrumental in a transition from Information Age to Information Society health care, changing the nature and skills of health care and professional practice! Luckily, the lecture was generally well-received, David told me later, although I imagine that it did not, and probably could not, connect or resonate with all.

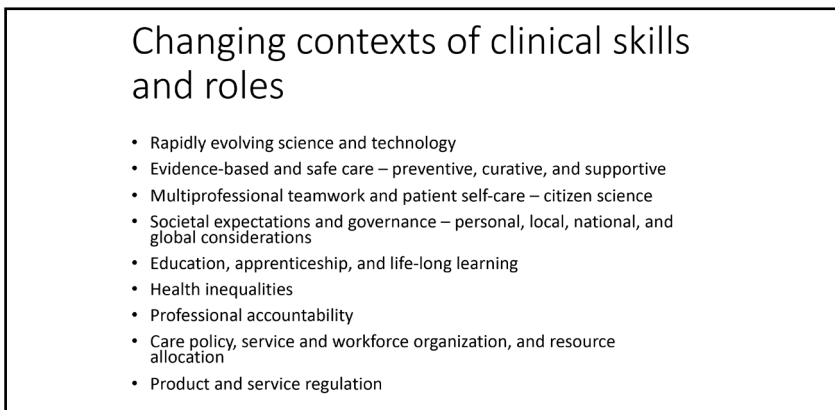


Fig. 9.7 An early slide highlighting the changing nature and scope of clinical skills and roles. Image created by David Ingram (2010), CC BY-NC.



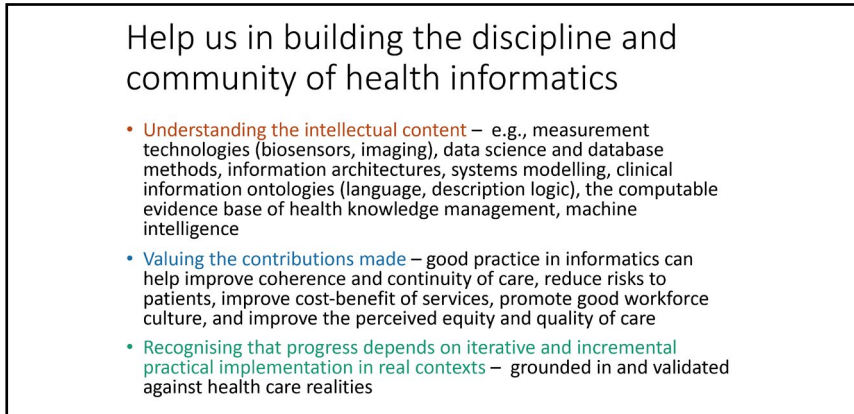


Fig. 9.8 An early slide highlighting the changing nature and scope of care information systems. Image created by David Ingram (2010), CC BY-NC.



And thus, on arriving at UCL and the Whittington, I found myself beckoned and shepherded onto at least four well-defended and contested battlefields, albeit that offensive battle was not my scene or mien! In addition, not far off, and more consequentially for the wider CHIME health informatics mission, were battlefields of health care IT infrastructure and services, at NHS Trust, regional and national levels, and in the interface of NHS and university organizations and communities.<sup>65</sup> Finding constructive ways to

<sup>65</sup> It had been part of the expectation in our recruitment to UCL that I would engage in supporting change in all these dimensions, and this took considerable time and energy, alongside the work of building and supporting the team for the new department's academic mission. To those ends, I was appointed, over time, to central UCL IT and finance committees and the biomedicine executive, as well as to the board of academic heads of department of UCL, working for successive Provosts and Deans. Seen as a flag carrier for such a contentious field as that linking IT and health care, this placed me close to the front lines of many institutional dialogues and rivalries, both within the University and in its relationship with local and national NHS organizations and activities. I saw these roles as somewhat akin to those of Francesca Wilson, working as she described in *In the Margins of Chaos: Recollections of Relief Work in and between Three Wars* (New York: Macmillan, 1945). In such situations, how a goal is tackled is as impactful as how it is defined. It was a checkered history—some of it successful and some less so. Among my consequential relationships of those times were those with successive UCL Vice-Provosts, Deans and Vice-Deans of the Medical School—John Pattison, Roland Levinsky (1943–2007), Dave Delpy, David Price, David Patterson, Robert Souhami, Michael Spyer, Leon Fine, Ed Byrne and Ian Jacobs, and with Cengiz Tarhan as head of UCL Business.

engage and develop as an innovative academic centre in these battling and divergent contexts, was the brief we had accepted and we gave it our best, although it did not work out well for us all. I could only approach it based on my own understanding and experience, learning how to do it as I went along. I was not about to build walls, install canons and close doors. No one and nothing would have benefited had I attempted to do so, and we would quickly have been closed down, ourselves. I wanted to stay open. That is where I gained traction to open openEHR and work with OpenEyes. Many connections and alliances had to be established and worked on. Great trust was placed in me, and I received invaluable support—within CHIME, locally at the Whittington and across UCL and its NHS Trusts.

The CHIME mission was, and proved, a very big ask, and the answer was only good in parts. We had to pitch tents, simultaneously, on multiple discipline, profession, institution and care sector battlefields! The common ground was one of innovation and change, penetrating across UCL, health care professions and the NHS, locally, nationally and internationally. We were implementers—learning by doing. We were participants drawn into the battles, much more than documenters of the scene. Attempts to innovate in health informatics academic mission, conducted within a clinical academic environment, have been few and far between and usually short-lived. The guns of established rival faculties and departments usually tend to shoot down such upstart startups, within a year or two. We were agents of a higher-level plan, but this did not mean we were, or could be, protected from the heat of the multiple battles! As Sun Tzu would have advised (as I discuss below), this was crossroads ground, and it was imperative to build alliances. I now focus on this aspect of the creation of new environments, with the complementarities of perspective and capability that they express, which imbues them with their strength.

### Alliances and Complementarities

Perhaps the anarchy of transition through the Information Age might be described as one of navigating multidimensional crossroads. It switched off traffic lights and left everyone rather frantically eager to get to the other side along their crossing tracks! Moreover, it was a time when roadworks teams arrived to reconfigure all the road! People tend to ride crossly across crossroads, and there are racy behaviours and crashes! Best to organize an alliance and convoy of like-minded travellers.

Our new alliances at Archway, UCL-wide, and nationally, were many and varied and expressed many complementary perspectives and needs. I will give a flavour of them here. They were central to the remit and freedom given

to CHIME and its ability to pursue its objectives in academic, professional and health service contexts. My alliances were directed towards connecting more widely rather than digging more deeply, in finding common ground and pursuing endeavours that drew together complementary perspectives, capabilities and purposes.

My foremost alliance at CHIME and the Whittington was with the Vice-Dean, David Patterson, who had been instrumental in our coming there. He supported us magnificently in our relationship with the Whittington Trust and linked his long-standing interest in health informatics with Dipak Kalra and his team, joining in with our European Union research consortia and building systems piloting the Comité Européen de Normalisation (CEN) and International Standards Organization (ISO) 13606 health record communications architecture standard, that Dipak masterminded with David Lloyd (1940–2023). We joined in to support his development of the Archway Campus.

I also quickly sought to connect with the academic primary care community, joining their departmental board, and Jane Dacre, likewise, with the Whittington clinical community. Successive heads of primary care were welcoming towards us—Andy Haines (later the principal of the London School of Hygiene and Tropical Medicine), Michael Modell, Paul Wallace and Anne Johnson (later a trustee of the Wellcome Trust and chair of the umbrella Academy of Medical Sciences) were always supportive colleagues. In due course, Trish Greenhalgh set up her shop just down the corridor from CHIME, as a stepping-stone in her progress to stardom as head of Primary Care at the University of Oxford.

I attended the Whittington Trust Medical Committee over a long period, but I found little that I could connect with in its proceedings, and eventually my membership lapsed. I had many engaging discussions with clinical staff in the Trust, at lunch times. I also connected with the IT department and its heads—notably Glenn Winteringham—became valued sounding boards as we progressed our research on digital health records. We also reached out to Whittington consultants expressing interest in collaboration in health informatics; for example, in the specialisms of dermatology, chemical pathology, rheumatology and diabetes, to explore how these might link with CHIME. Several Whittington staff enrolled on the new and highly successful CHIME health informatics graduate programme, built up and run for many years by Jeannette Murphy and Paul Taylor. Two collaborations that took root and persisted were those led by Jane Dacre, in her dual roles as a Whittington NHS consultant and academic lead on medical education, in the new Archway Clinical Skills Centre, and Dipak Kalra's with David Patterson and the cardiology department.

David Patterson had long worked hard and skilfully to form win-win bridges with the Middlesex University leadership and its Nursing School based at the Whittington. This aimed at building a new and distinctive partnership between the trust and the two Universities, expressed through joint investment into the new Archway campus development that he masterminded. The Archway Skills Centre, run from CHIME and building on Jane's leadership at Bart's, progressed well, as did the library. Our wider alliance with the Nursing School proved more problematic and disappointed expectations, as I reflect on further, below.

Ronald Mason, the eminent physicist chair of the University College London Hospitals (UCLH) Trust of the time, had been warm and welcoming as I set up shop more widely across UCL and its partner NHS Trusts. He invited me to lunch and to talk on several early occasions after we arrived, to help me get settled. Derek Roberts had encouraged him to get to know me. Also, soon after our arrival, the UCL academic chief of medicine, the American renal physician Leon Fine, quickly put me in front of his formidable team, to explain myself. He offered to incorporate CHIME within his huge Department of Medicine. But, having lived in that department at Bart's for twenty years, I knew that I needed him as an ally but not as a chief. To be seen as a sub-field of his battlefields would not have been a good idea, I thought. There would be one very solid defensive line and ten sharp shooters taking aim from outside! And the internal rivalries of the medicine department would impinge as well—all these clever people would have a view that I should see things their way and prioritize their needs. John Pattison wisely and helpfully confirmed CHIME as a fully independent UCL department, thus giving me copper-bottomed status as my own boss, reporting as Head of Department, directly to the UCL Provost.

Leon became a good and long-standing ally—we were quite different people but got on well.<sup>66</sup> He commented once about his bemusement that I remained peaceful and optimistic about chaotic events where he was pessimistic, and his instinct was to do battle! I knew that my mission, if pursued as aggressive battle, would be doomed from the start—I had to embody cooperation and collaboration and a softer and 'under the radar' style of leadership. I reflect on the contrast of such styles in the section on leadership, below. I always took on whatever task he asked me to help him

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<sup>66</sup> Leon subsequently became Dean of the Medical School and brought me onto his executive team, where I remained with all subsequent Deans. When he returned to the States some years later, he contacted me as I neared retirement, asking if I would consider joining him at Cedars-Sinai, Los Angeles, I think it was, to help sort out their informatics services, as I had been doing for UCL Biomedicine, for him and the other UCL Clinical Deans. It would not have worked for us, but it was nice to be asked.

with, such as in creating a clinical research network and database of clinical researchers and their projects, across all the NHS Trusts and institutes linked to UCL. As also described in Chapter Five, this was a project developed with Al Aynsley-Green, research lead at the UCL Institute of Child Health at Great Ormond Street. Anthony Peacock in CHIME wrote the software. It was one of several wide-ranging UCL and NHS integration roles that I was asked to take on and oversee.

Further afield I had quickly discovered Charles Vincent and Pippa Bark and their pioneering work on clinical risk management in UCL's highly rated Psychology Department. Pippa joined us in CHIME, and we secured approval to host her new Masters course. The opportunity to align patient safety concerns with health informatics seemed a clear win-win and a good conjunction to give example to CHIME's multidisciplinary and multiprofessional mission. Chris McManus in the Psychology Department also worked closely with Jane on assessment methods for the Royal College of Physicians membership examination and we appointed him to a joint post between the two departments.

My CHIME medical education colleagues were also extending their scope and remit. Lesley Southgate had been a powerful figure in East End Primary Care where she became a doughty campaigner in the world of medical politics and ministers, and the battles over the Medical School merger in East London. The health minister of the time, Brian Mawhinney (1940–2019), had himself, in a previous life, been a lecturer in medical physics at the Royal Free Medical School. Building on these connections, Lesley sailed into the world of the General Medical Council (GMC), leading its work on the assessment of underperforming doctors and recertification of doctors' competence to practice, along with its then President, Donald Irvine (1935–2018). The research team supporting her in this challenging role was based with us in CHIME. It was in an era of national focus on failings in the children's cardiac surgery department at Bristol and the GP Howard Shipman's (1946–2004) murders of many of his elderly patients.

Lesley created and piloted the working methods for the GMC and became President of the Royal College of General Practitioners, nationally recognized for all this work in being made a Dame. Unfortunately, she and Brian Jolly had both felt disappointed by their lack of connection with medical education at UCL. Brian quite quickly decided to leave, to take up a position in Australia, and Lesley left much later for a position in medical education at St George's University of London. One of the principals there was Peter Kopelman (1951–2021), who had briefly worked with Jane and me, at Bart's, in the era of our Skills Centre project. He had earlier pioneered the Diamond system for managing digital records in diabetes care. In later years he became interim Vice-Chancellor of the University of London.

Bernadette Modell brought the programme of work in her prestigious World Health Organization (WHO) Collaborating Centre for the Community Control of Hereditary Diseases into CHIME. I profile her pioneering contributions in Chapter Eight. One of my subsequent PhD students, Matthew Darlison, was a key colleague of hers in development of an information system for genetic counselling for the community affected by thalassaemia, called APoGI (Accessible Publication of Genetic Information) in conjunction with the haematology service run by the Whittington Trust. This was exemplary in its everyday connections between epidemiology, clinical service delivery and the affected patient community, locally, nationally and globally. Bernadette and some of her illustrious team of professional colleagues from around the world, including Arnold Christianson, from South Africa, became much-valued contributors to our CHIME community. One of her PhD students was leading thalassaemia services in her country.

Jane was appointed to a personal chair in CHIME and went on to lead UCL Medical School. She and her growing team needed to establish their own academic harbour, separate from CHIME. This felt a wrench for me, but I understood the necessity and it worked out well. She took up the mantle of accreditation to practice at the GMC, bringing her Royal College of Physicians (RCP) connections to this. She was later elected RCP President and had a highly regarded reign there, during the height of the tensions, nationally, over the aftermath of the conservative government Lansley reforms of the NHS. In recognition of all this, she, too, was made a Dame.

On his appointment as the UCLH Hospital Trust Chief Executive, Robert Naylor wanted to recruit a previous professorial colleague of his, Paul Bate, to lead a formal programme of organizational development for the newly merged hospitals of the wider trust. I was asked to provide Paul with an academic home and he joined CHIME from Chris Ham's Health Services Research Centre in Birmingham, along with his close colleague, Glenn Robert, who later became a professor at King's College. Those sorts of alliances and arrangements were taxing diplomatic and managerial balancing acts—Robert Naylor and the UCL Finance Department had rather different worldviews of the financial commitments and risks involved! Paul connected us with the work of Donald Berwick, a guru of organizational development at Harvard University and adviser to the NHS. Don Detmer, a clinical doyen of health informatics in the USA, became a much-valued member of the CHIME informatics community, while on sabbatical at the Judge Institute at Cambridge.

Among the Deans and Vice-Provosts of Medicine that I worked for was Mike Spyer, who had known of me before I came to UCL, through his research interests that connected him with John Dickinson at Bart's. He asked

me to be responsible for coordinating the merger of the disparate IT support teams in its, by then, fully merged medical schools and research institutes, each closely connected with their local teaching and research communities. I was also asked to chair the UCL-wide IT Infrastructure Committee, overseeing the changing relationship of corporate academic services and academic departments across all faculties, and join the Information Strategy Committee. These two roles were synergistic—to be effective in one I needed to take on the other.

I was asked by John Pattison to create and lead a national academic forum for health informatics, bringing together its leaders from all UK universities. John had by then left UCL, to take on the leadership of NHS Research and Development. He was at that time taking up the reins in framing and initiating the NHS National Programme for IT (NPfIT). In the context of the local clinical mission, I represented the University in its discussions about research that linked with clinical data arising in everyday health care, where there was long-standing national debate about how this could be achieved securely and confidentially. This brought contact with the IT teams of all the local hospitals, in the context of local Trust mergers and implementation of the ill-fated NPfIT. Alongside these ramifying connections, Mike Spyer nominated me as UCL representative on the NHS Modernization Board for London, chaired by Ara Darzi, and John Pattison appointed me to the national NHS Information Policy Board. The interest for me was to listen to and understand what these different groups were facing and what mattered to them, in the context of CHIME's wide-ranging mission.

On the research funding front, I was asked to participate in numerous activities of the UK Research Councils, involving health and bioinformatics (Medicine (MRC); Engineering and Physical Sciences (EPSRC); Biological Basic Sciences (BBSRC); Economics and Social Sciences (EESRC); Central Computing Laboratory of the Research Councils (CCLRC); Wellcome Trust) as well as the AIM and Framework European Programmes. The MRC appointed me to the national e-Science board overseeing the programme led by Tony Hey, and I supported Christopher Taylor in his efforts to formalize national professional validation of health informatics skills, under the aegis of the British Computer Society. On the libraries front, I was asked to join a multidisciplinary network convened by the innovative and adventurous Chief Information Officer of the British Library, Richard Boulderstone, to consider research information curation in the digital age. From this, the British Library and Wellcome Trust asked me to join and subsequently chair the board overseeing developments linked with PubMed in the UK.

One can see, here, how quickly connections ramify, as a hub and spokes, from a central role in health informatics. They extend within an organization and outwards from it into many and varied academic, professional and care



service activities. I treated these as alliances focused on bringing value to UCL and thereby ensuring permission and breathing space for CHIME's team members to develop their different missions. When Chris Llewellyn Smith was Provost, he awarded me an annual bonus, given to a group of heads of department nominated by faculty Deans. When Derek Roberts returned for his second period as Provost, and with Mike Spyer then as Vice-Provost, they deliberated over my performance in post and gave me a very significant salary increase. Derek expressed his satisfaction with the straightforward way I approached him to review my position and remuneration, when my leadership responsibilities across UCL had significantly grown from those when I was first appointed. But there were disappointments, too, which I now consider, a decade on from the fray.

### Reflection

Advances on all sides in the Information Age have brought to the fore the need for new kinds and organizations of health services. These both illuminate new opportunities and add new dimensions of challenge. The creation and sustaining of good environments that can combine learning about new methods, roles and relationships of multiprofessional teamwork, with continuing attention to current practices, is hard work and slowly won. It might ruefully be characterized as a brief to disrupt and supplant current practices without causing too much mayhem along the way! Success in calming such troubled waters depends more on insider mediation at ground level than on orchestration from above.

The ambition that CHIME would help advance the three-way consolidation of institutional missions at the Archway campus in the end disappointed, although there were some considerable successes, as well. Maybe it was too large scale and high profile to take root. Smaller and complementary initiatives might have worked out better and indeed some of that kind did succeed. Notwithstanding considerable efforts on all sides, the significant differences of environment, culture and expectation of the two Universities and the NHS Trust prevailed and persisted. Bridging and healing such divide requires strong and mutually respectful focus, expressed in joint endeavours on the ground, in care services, education and research. David Patterson and the Middlesex University leaders worked very hard to enable this. Matching David's and Ken Goulding's high-level investment in that alliance proved a difficult and time-consuming challenge, as it was always bound to be. Nearer to the ground, there was often an awkward mix of personalities and perspectives in play, and, given the diverse wider battlefields across UCL and beyond, on which we were quickly exposed,

these sometimes proved more than we could influence, and manage constructively, in a practically sustainable way.

For me, CHIME was seventeen years of citizenship, collaboration, insider mediation and wider diplomacy, enabling and supporting initiatives in many complementary domains through many growing pains and stress tests! Second to alliance building, I knew that sustaining an environment that enabled the careers of teams to progress and prosper, free to martial their own efforts to that end, was most important. This required support and protection, such as I had benefited from in my twenty years at Bart's. CHIME was both a fertile and demanding environment, typical of any such ambitious and creative endeavour.

A central focus for me, personally, was on achieving technical rigour, clinical and industrial engagement, and wider trust in iterative and incremental implementation and adoption of sustainable methods for capturing and communicating mutually coherent digital health care records. A long sentence, and achieving it a career-long sentence, too! A recognized Grand Challenge of the field for over forty years. The openEHR and OpenEyes communities were created, nurtured and led in the 1990s and 2000s, in the context of my involvement at CHIME and Bill Aylward's at Moorfields Eye Hospital, as described in Chapters Eight and Eight and a Half. They are CHIME health informatics achievements that will, I hope, remain on the landscape of health care in the future world of the Information Society.

CHIME was fertile ground on which to evolve the health informatics discipline within a robust medical academic community and authentic clinical service context. Jeannette Murphy and then Paul Taylor took on the undergraduate medical education and CHIME graduate programme developments, in close partnership with the NHS's wider national graduate training programme. Paul was awarded a personal chair in recognition of this innovative educational contribution, and according to today's lights, Jeannette would have been, too. There is no better way to frame a new subject and learn how to teach it than by engaging with students and learning from them in the process. It is a journey of continuing discovery in a rapidly changing field, to learn how to teach and determine what is important for students to learn. Students and teachers alike have proven to be great leaders on that pathway.

Times changed and when my moment for stepping back arrived (paralleling the situation I had faced when John Dickinson approached retirement at Bart's), the wide Medical School, University and NHS-bridging roles that I had fulfilled for successive Deans and Vice-Provosts were no longer important and the original integrative mission of CHIME lost traction. Perhaps these different leaders had harboured the expectation that

the CHIME mission would be a tide that floated more boats. Our employer was UCL and perhaps I focused too greatly on alliances there. Perhaps we were unable to tick enough boxes of academic and service excellence and impact. In my last years in full-time work, ambitions to establish CHIME-linked commercial spin out companies under the aegis of UCL Business were unsuccessful, resulting in some unhappy frictions on all sides, and I subsequently withdrew from them. There were thus disappointments on several sides in the way that CHIME came to an ending, balanced by pride in our range of significant and enduring achievements, too.

CHIME was a good environment for its time but my efforts to pass it on to successors in defensible shape failed. There was neither the will nor the way for this to happen and it fell apart quickly when I retired from the fray. The reorganization of UCL faculty structure brought Primary Care and CHIME within the aegis of the Population Health Division, and the team moved from Archway to accommodation in UCL's central London campus. A new and narrower mission of population health informatics inherited its legacy. The wider UCL ambitions for the field that had been invested in CHIME lived on in separate faculty endeavours, where focus was more circumscribed. The health informatics outputs of CHIME were well connected in the world of practical contributions to IT developments and services, but not well in the world of speaking and writing about them. Given the needs and context of the times, this was probably inevitable. Time will tell whether the balance was right. Fortunately, most of my appointed colleagues have prospered well in their new environments and that is good and satisfying. Several years later the Archway campus building, for which we had devoted considerable energy and resource, supporting David Patterson in creating it, was closed down and sold, as part of the rationalization of UCL and NHS estate.

On reflection now, some twelve years later, as I write this section, CHIME proved a catch-22. If we had focused too heavily on a narrow range of activities, the wider community would have likely isolated us as they each had different expectations of the breadth of connection that we had been recruited to achieve. Where we collaborated and connected widely, depth of academic endeavour lessened and communication through publication, that UCL research ambitions also required and expected, suffered.

Implementers on wide fronts are often not people with motivation, time and energy to write at length, as many I profile in this book show. Life is too busy and short for them to do so! More realistic perspective now prevails, in both scope and scale of recognized contribution and output. This would have been more consonant with the CHIME mission, but it was not the culture of its time. It is said that a picture is worth a thousand words. In the context of openEHR and OpenEyes, perhaps their design and implementation in

clinical, technical and organizational contexts—and their scaling to self-governing community interest ventures, in a worldwide context, across academia, health care services and industries, over thirty years—may come to be seen as a picture worth more than the thousand journal articles that their creators never wrote about them, or put their names to! I could not do both, as I had been forewarned would prove the case!

On the positive side, from CHIME as a harbour, in its several complementary multidisciplinary and multiprofessional contexts, many sailors found their sea legs, as shipwrights, captains and crew—single-handed and in teams. They learned and practised their craft, built their ships, recruited and trained their crews, and sailed on their different seas. They conducted sea trials near to port, sailed further out and established new harbours, on the same island and as citizens of different lands. That feels a worthwhile accomplishment of the CHIME community and its enablers.

So why does any of this matter and how does it connect with wider issues of health care and information technology? If one travels and experiences the environments of NHS Trust IT departments, as I have done, and connected the story with that of medical physics of decades earlier, as I was also able to do, one sees a concerning pattern:

- Early pioneers developed in-house capability and capacity to innovate within applicable, real-world health care contexts;
- Over time, cost and other pressures led to reduction in these roles and their replacement by a managed outsourcing of innovation in the IT needed to support care services;
- This drew in consultants lacking practical and current knowledge and experience of the delivery of health care, and poorly placed to learn by doing;
- System developers and suppliers were similarly not well placed to understand the changing nature and continuity of everyday frontline health care services that the IT was needed, and expected, to support, from a multiplicity of often conflicting perspectives;
- A focus on watertight contract management compounded the inability to frame requirements, iteratively and incrementally;
- This led to weakened alliances of developers, providers and users of information systems. The squaring of the circle was delegated to a growing market of similarly disconnected consultancy. It is unsurprising that efforts to tackle this both Grand Challenge and wicked problem, have not easily cohered, and their products likewise.

The battlefields of health informatics, both academically and in practical health care and industrial contexts, remain diverse and wide-ranging. They reflect both complementary and conflicting perspectives and drivers and will, inevitably, extend yet further in the coming age of AI. We must continue our efforts to create new environments of community interest, bridging public and private sectors, and encompassing both a vision and the capacity to succeed, over time, in all the complementarities of Implementation One, Two and Three.

### New Environment for the Care Information Utility

The previous sections have described personal experience of working in and creating different and complementary kinds of environments along my songline. What makes for a collaborative and innovative environment and how is it created and sustained? And what special qualities are needed for creating environments to tackle radical uncertainties and wicked problems, such as those encountered in creating a trusted and sustainable care information utility, whereby we seek to support the balance, continuity and governance of health care services and what we all do to enable and support them to be good? We must learn the answer to this question by making and doing it. A good environment is, as Wollheim said, a necessity, but it is hard to create and sustain, and easy to undervalue when we have it.

Specialized and bounded domains have a more straightforward task in creating good working environments—their shared vision and purpose is more clearly understood, articulated, enacted and externally validated. Environments that carry the burden of coping with wicked problems have a harder task—here there are often multiple battlefields, and the key is to have vision, discover mission and draw together different threads of leadership, that combine to embrace the wholeness of complementarities rather than exploit their differences. Interestingly, and perhaps paradoxically, the strategy for creating good environments for tackling wicked problems, and the strategy for coping in military battlefield environments, have aspects in common, as I explore below!

The human body has a good internal environment, learned along its evolutionary pathway, that copes as best possible with radical uncertainties and makes life tick. Claude Bernard (1813–78) called it *le milieu intérieur* and focused on its homeostasis. Body and mind connect and find expression within external environments, both near to and at a distance across the world. We might call these *les milieux extérieurs*. The two interact and the personal becomes collective, in sharing experience, meaning, purpose and motivation. Life unfolds in environments that are discovered and sought

out, created and sustained. Some meet their members' personal needs and others do not. Experience of external environments evolves along personal songlines of discovery, creation and coping. What makes *them* good at coping with radical uncertainties and making life tick? Charles Darwin is said to have said of humankind that those who have learnt to collaborate and improvise most effectively have prevailed. Maybe the environments required for reinvention and reform of health care and for creating a trusted care information utility that support a healthy life, should learn from one another more, in emphasizing collaboration and improvement.

A stimulating and challenging environment is fundamental to how we approach the adventure of ideas, cope with anarchy of transition and focus on programme for reform. There will always be both adequate and inadequate environments—nothing is ever perfect and sustaining and improving the environment requires constant effort from its participants and enablers. In learning how to cope with and improve environments that are perceived as bad, or not good enough, we learn to balance our sense of their weaknesses with knowledge about the strengths of those seen as good, or good enough. In both cases, how have they been created, supported and sustained?

Missions make sense when one listens to and observes those who sustain them and ponders how they articulate them. Working environment is a match of the skills and motivations possessed by the teams and communities that populate it and work together on its mission and challenges. Shared goals and fair and inclusive participation are fundamental. Atul Gawande explored the quality of environment in health care services in his book, *Better*.<sup>67</sup> He visited different centres specializing in the treatment of cystic fibrosis, comparing their qualities and achievements. Health care services are not always good working environments—the good ones are held together by their participants as much as their governors, if they are allowed and enabled to do so.

Gawande highlighted good team communication as a key determining characteristic of the better environments he visited. It depends on everyone there, to engender and sustain. I recall reading a similar study in the 1960s, that looked at the quality of nursing care and highlighted the connection of quality of clinical outcomes achieved, such as prevention of bed sores, with the description of the working environment concerned, as reported by its nursing staff. It focused on communication within the nursing team—the more junior staff feeling able to communicate with their seniors. Trust, listening and personal give and take are central to good communication.

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67 A. Gawande, *Better: A Surgeon's Notes on Performance* (New York: Metropolitan Books, 2007).

Good environments have their day, and their goodness is not solely a matter of narrowly perceived successes and failures in prescribed intervals of time. They may be long-term investments and experiments, with their importance and value slow to emerge, sometimes more widely than within their initially envisaged scope and circumscribed locality. Creation of a good environment is a blue skies endeavour and requires permission, freedom and support in navigating through sometimes stormy seas. Environments collapse, and their participants can be left adrift. Times change and new pastures are sought.

The concluding sections of the chapter look at issues of capability and capacity, connection and community, money, leadership, governance and alliance, required to support and sustain endeavours.

## Enabling and Sustaining Efforts

Sustaining mission, environment and endeavour can pose their own wicked problems. Like conducting an orchestra—it is more straightforward when everyone knows the score, but much trickier when challenged with diverse new instruments, music and concert halls.

## Capability and Capacity

Creating and working in innovative environments is not to everyone's taste. It is not a safe or easy life, but it is challenging, and these are places open to creative scope and new discovery and learning. In times of anarchic transition, all environments are to some extent new, although old patterns will tend to persist. The distinguishing feature of pioneers is their joy in the adventure of ideas, in the face of what King called radical uncertainty, and their commitment to programmes for reform. The radical uncertainty of the Information Age exemplifies fundamental issues for health care—about discovery of common ground and teamwork needed for creating and governing a coherent balance and continuity of information.

Key steps in creating a desired future are the identification and growth of the capability and capacity required. These are accompanied by questions about skills and their assessment and accreditation—how criteria are set, and how they are recognized as met. In the world of education, there is continuously evolving dialogue about these issues. In the wider economy of work and service, there are questions about citizenship and participation in the pursuit of common good, and how contributions are recognized, valued and rewarded. These debates have ranged far and wide over the past century—from the writings of Tawney and Beveridge to their successors,

today, such as Goodhart, Sandel and Putnam. They resonate through the threads in a braid, as described in the earlier section of this Chapter.

Echoing Whitehead once again, the creation of a care information utility, and the culture it embodies, will best be approached as both an adventure of ideas and a programme for reform. To reform is to re-form—to reinvent and create new forms. In a spirit of re-formation, Goodhart and Sandel argue for radical re-evaluation of how contributions to the common good are judged and rewarded.<sup>68</sup> In *Tyranny of Merit*, Sandel argues that there should, belatedly, be greater humility on the part of winners, recognizing the luck they have enjoyed, and that we need to rethink and not take for granted the role of universities as arbiters of opportunity. In *What Money Can't Buy*, he emphasizes the importance of the ability to listen attentively and that this matters as much as the rigour of argument. He argues there for greater mutual respect and inclusion of everyone participating in the 'public square'.<sup>69</sup>

These thoughts are echoed in Topol's landmark book, *Deep Medicine*, connecting AI with his diagnosis and prescription for treatment of the manifold ills he rehearses of 'Shallow Medicine' today.<sup>70</sup> In his focus on 'Care, Period!' there are echoes of Tett's alternative AI, anthropology intelligence, as set out in her book *Anthro-Vision*.<sup>71</sup> Putnam's *Upswing* is striking in its visual presentation of economic, educational, industrial, political and social data, which exhibit an identical inverted U-shaped curve of progressive convergence from what he describes as the fragmented and egotistical society of the early twentieth century, to a peak of community in the 1950s and subsequent decline over six decades, back to a level of cultural fragmentation that had persisted a century before.<sup>72</sup>

Leaving aside reward, how will skills, contributions and achievements be judged, recognized and accredited in the building and sustaining of care information utility? In this regard, it is interesting to observe the granular and precise culture that has evolved in the Slack online forum of discussions about physics, for accrediting contributions from among its members. This community exists to provide answers to questions posed by its members. Participants are assessed in a process of peer review in which all members participate—in relation to questions asked, responses posted and how these are valued within the community. It is a carefully categorized process. To

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68 Goodhart, *Head Hand Heart*; Sandel, *Tyranny of Merit*.

69 M. Sandel, *What Money Can't Buy: The Moral Limits of Markets* (New York: Farrar, Straus and Giroux).

70 Topol, *Deep Medicine*.

71 Tett, *Anthro-Vision*.

72 Putnam, *Upswing*.



qualify those allowed to propose responses to questions, there is a pretest of relevant knowledge and expertise.

In this forum, each question posed creates a new thread of responses, and the questions are also rated in terms of their importance to the community, as evidenced by the interest they generate and sustain. This creates a dynamic environment, adapting in time to the needs of the group of participants—as researchers, teachers, practitioners and students as well. This community is learning how to become open to and inclusive of any participants, but guarded against abuse, misinformation, noise and bias that might be introduced along the way. It prizes authority and authenticity—it is a head, hand and heart appraisal of value of contribution.

The creation of this kind of community is an adventure of ideas. Its purpose is adventurous discussion and clarification of ideas. And it looks to have a reforming influence and potential, regarding the capability and capacity of the community it embodies. I love it—it educates me about an evolving world I once mastered, sadly am no longer capable of fully navigating, but still have the capacity and will to stay connected and informed. Care information utility should, likewise, grow from the adventurous ideas and needs of its participant communities, and will have educational and re-forming influence and potential for health care.

Another area of re-formation is in health care research and development and its translation to and fro with practice. Individual citizen science was very much the norm before the rise of modern universities, where capable minds had the capacity to explore—having means, time and motivation. Universities have professionalized research, but citizen science is again on the upswing, now in more widely connected communities. Tim Spector has in recent times championed this movement in health care, notably with the four and a half million citizens who he signed up to track patterns of Covid infection. I remember him as a junior doctor in the Medical Unit of the Department of Medicine at Bart's, many decades ago. A remarkable generation of young doctors started their professional careers at that time, in that environment, my close-by colleagues Jane Dacre, John Wass and Ashley Grossman, included.

In well-established disciplines and their well-ordered departments and institutions, there exists a published framework of research endeavours, on which participants and teams are focused. New students are recruited to pursue a topic within that framework. The student is at the outset a trainee in the methods of research appropriate to the topic, and in creating and implementing a plan of investigation. A research programme can still be akin to a bobsleigh ride, a risky and exhilarating experience, but to a largely predetermined and channeled endpoint. The energy, motivation and skill of the rider makes the difference between a slow and bumpy descent and

a winning performance, surviving the risks of random over-steering that might result in untimely ejection from the channel! This process risks becoming akin to that of a degree factory, admitting the students at one end of a machine, rejecting those failing quality appraisals along the line, and ensuring that a quality-assured thesis product emerges at the end of the line, neatly dove-tailed with research publications. One view of the product is of a typically little read and unused document. The test applied is that the student has shown themselves able to follow the channel faithfully and reach a prescribed and recognized endpoint. The more important product is a new person—a work in progress in a creative and productive life.

In domains of radical uncertainty and discovery, the attributes of student and supervisor are of a different order. Proposal of a new way of investigating or framing a subject or activity, and making it real, is as likely perceived as heresy or irrelevance as of revelation. There have been examples of this in stories told elsewhere in this book—the computer, prions, bioenergetics, ship design and propulsion! Believe it or not, I have had senior clinicians opine that the X-ray CAT scanner would prove a quite minor innovation! The stethoscope detractors of the Information Age! Heretics are burned at the stake of establishment. Henry Kissinger once said that the reason why academia is cutthroat is because the stakes are so low! The low stakes of well-established discipline do not risk much. Discovery is for higher stakes and risks more. Failure is frowned upon, but some failure is normal and may be protected if the endeavour has insightful and sustained support and patronage.

The relationship of student and supervisor in the uncertain world of discovery is especially close. Two reputations are equally at stake—a trusted or established one and an unformulated one. Unformulated reputations typically grow slowly, on foot, and established reputations depart on a fast horse, paraphrasing, slightly, a well-known saying. In the best of these relationships, the experience is one of catalysis and chemistry, and mutual learning. There is ebb and flow, the supervisor is a sounding board and inquisitor, helping to find productive channels of enquiry, encouraging and drawing the student into them. Stage one is for settling into research method and framing of topic; stage two is discovering that implementation is hard, and progress hard-won. Stage three is drawing together the threads and expressing the results in a satisfactory and examinable form.

As Richard and Daniel Susskind noted, life's problems do not always fit neatly within province of one discipline or profession or another.<sup>73</sup> Where a unifying framework of discipline and profession are lacking, limited

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73 Susskind and Susskind, *Future of the Professions*, p. 43.

or under-developed, goals pursued are necessarily about creating and evolving a new mission, iteratively, through a wide range of initiatives and engagements. The researcher here enters a different environment: one attuned to discovery of the world outside, as an explorer in search of both desired endpoint and route to reach it, as the Stable Diffusions picture in Figure 1.1 of the Introduction so well depicts. Health informatics has been such a domain of discovery, and I was one of the lucky ones enabled and supported to discover, rather than follow a pattern.

Academic identity exists and competes within institutions. Academic initiative in health informatics has been pursued in two ways: as a component of established discipline—computer science, chemistry, physics, biology, mathematics—or as a self-defining and separate entity. By and large, those of the former kind have engaged less widely but survived longer. And those of the latter have had a more exhilarating lifestyle and a more limited lifespan! For me, it has felt more authentic, although personally riskier, for health informatics to be based as an integral part of establishments engaged in health care education, research and service delivery. This provides both an umbrella and a big tent, enabling collaboration between complementary disciplines and professions that are connected there, inclusively, in pursuit of everyday health care endeavours. There have not been so many opportunities like this, and I was lucky to be given two in my career, which made all the difference.

The danger of being based too remotely from the domain being studied is that it risks pointless endeavour. As described in the Introduction, the *New Scientist* reported on a review conducted by the Cambridge Image Analysis Group.<sup>74</sup> They had studied three hundred papers published from 1 January–3 October 2020, on the use of machine intelligence algorithms to interpret chest images from patients suffering from infection by the Covid-19 virus.<sup>75</sup> Their stark conclusion was that ‘something has gone seriously wrong when more than 300 papers are published that have no practical benefit’.<sup>76</sup> Issues were identified with every stage of the development of the tools. Papers did not include sufficient detail to enable reproduction of their results. Significant biases were identified with the data collection methods, the development of the machine learning systems, and the analysis of results. Little attention had been given to whether these models could pass

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74 M. Roberts, ‘Machine Churning’, *New Scientist*, 250.3335 (2021), 23, [https://doi.org/10.1016/S0262-4079\(21\)00873-3](https://doi.org/10.1016/S0262-4079(21)00873-3)

75 M. Roberts et al., ‘Common Pitfalls and Recommendations for Using Machine Learning to Detect and Prognosticate for COVID-19 Using Chest Radiographs and CT Scans’, *Nature Machine Intelligence*, 3.3 (2021), 199–217.

76 Roberts, ‘Machine Churning’, p. 23.

regulatory requirements to be used in practice. There was publication bias towards positive results. This volume of inauthentic output is noise which risks overwhelming significant, authentic signal of good endeavour and trustworthy and sustainable output.

The extremely low level of what was deemed to be authentically new content of publications in one clinical domain, that I came across in preparing my 1991 Royal Society of Medicine (RSM) talk (see Appendix I of the book's additional resources),<sup>77</sup> seems closely analogous to the situation uncovered in this study. There can easily arise an unvirtuous circle of mutual self-interests pervading research, development, practice, commercial exploitation and publication. It has been evidenced in alliances between pharmaceutical industry, clinical research and publications parading the development and use of new drugs. The marginal efficacy of many commonly used drugs was highlighted in Peter Goodfellow's Royal Society presentation (he had led on drug discovery in a major pharmaceutical company of the time) that I listened to many decades ago, and again, in recent years, for example in Topol's book making a case for 'Deep' not 'Shallow' medicine. Topol adds that 'shockingly, up to one third of medical operations [procedures] performed are unnecessary'.<sup>78</sup> Confabulation among different vested interests led to outcomes such as those starkly exhibited by the congenital malformations associated with inappropriate use of the drug thalidomide. Such black swan events might now be nucleated in careless clinical environments that deploy inadequately accredited AI interventions, adversely influencing human judgements about health care.

A key question is what should a more fully integrated endeavour seek to achieve, and what expectations should be set? I was lucky to be trusted and enabled to set both vision and plan, with the explicit understanding that the successful bits might need to migrate and become rebranded elsewhere, over time, and the unsuccessful bits die away. Taken individually, the outputs of such exploratory and creative endeavours might be deemed to score anywhere between zero and nine, on a ten-point scale. Taken together, they may turn out in the middle and that would probably be a good and fair result. Those who do not risk a zero cannot expect or justify a nine. Scoring all zeros in a real-world challenge is a failure from the outset. Scoring all nines would look unreal.

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<sup>77</sup> Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

<sup>78</sup> Topol, *Deep Medicine*, p. 26.

## Connection and Community

Much creativity today resides in teamwork. This flourishes in connected communities and harmonious environments. In my university days, I had the immense good fortune to live and learn about physics in the most creative and connected educational environment imaginable. There, eminent and dynamic people, feted in many different fields of study, walked, talked, ate and rubbed shoulders in everyday life. They brought their global eminence into their teaching within this local community and engaged in their global work from their rooms in the College and in the nearby University departments. They broadcast and communicated their work and ideas, travelling the world to link with similar such communities, near and far. And as the Information Age developed, they collaborated and communicated more widely. It was the quintessence of the Oppenheimer vision of complementarity—people, disciplines and walks of life drawn together and made whole within community and environment.

It was, of course, an elite environment and living there was a privilege. It made me feel elated, after my early life in a children's home in a rural village, attending a tiny village primary school, and then in difficult, not well-off years of struggle and hard work, as our family moved to re-establish itself many miles away in a city centre. My parents found new bearings in life, and I became good at mathematics at my new secondary school and sailed into University of Oxford, with Cambridge also on offer.

The quality of college community and environment that I experienced, and the luck of being a part of it is intrinsically localized and not scalable. How can the Information Society enable community and educational environment that provides opportunity, motivation, and inspiration of that kind, and enable such experience and enrichment to be more widely, relevantly and justly shared in today's age, as a young citizen of Globalton? I find it hard to imagine but would hate for such quality of opportunity to be lost. All my recollections of those times are of people, community and environment, and such are uniquely personal, special and unscalable. We need to create more of them. Here are some personal recollections of connection and community, to bear out my comments here.

For example, as I read around for this book, thinking about Chapter Six and the 'what is' questions discussed there, I realize it had been a missed opportunity for me, that I failed to get to know the philosopher Gilbert Ryle, who championed philosophy of mind. He was a Fellow of Magdalen College and featured, in my memory, only as a wiry, tall and bald don, of few but crisp words, often encountered walking briskly around Longwall quad to his study beneath my own rooms there, in my second year. There were many such people, eminent in their different fields, who I passed

by regularly in my three years at the college and I can see them in my mind, now.

Our physics tutors, James Griffiths (1908–91) and Dirk ter Haar (1919–2002), became akin to colleagues in our small college group of five undergraduate physics students, who studied hard. James had a network from his wartime signals work at the Royal Signals and Radar Establishment (RSRE) Malvern, where he invented a new thermionic valve. This led in later years to his appointment for several years as the vice-chancellor of the University of Malaysia, and then back to Magdalen as President of the College. My special appreciation of Dirk is included in the book's Acknowledgements. My historian friends at college told me of their tutorials with Alan Taylor (1906–90), historian of the Second World War, Angus MacIntyre (1935–94), social historian of the nineteenth and twentieth centuries, and Bruce McFarlane (1903–66), the medieval historian. McFarlane lived downstairs from me and led a quiet and almost monastic life, with Siamese cats for company. He fitted the image of a medieval monk. MacIntyre, by contrast, was the most avuncular and approachable of dons. Guenter Treitel (1928–2019) was an authority on contract law, shy but smiling to all students he passed by in the College. Taylor was a media celebrity and famed for his *ex-tempore* lectures that filled lecture theatres. He was a crusty political operator, stirring things up in the senior common room. It was he, thank goodness, that pushed the College to become a coeducational community, doubtless against the terrified reaction of some his comfortably, monk-like bachelor colleagues of the era that I knew!

I got to know these people by a combination of observation in daily life and my friends' stories of their encounters with them. There were many others, eminent in their fields but just everyday personalities to me—some shy and some noisy, some closeted and some worldly, all no doubt clever and lucky, as we students were, to be there. As students at the College, the quirks and personalities of these teachers entertained us, and their abilities and eminence challenged us. Like the inukbooks on my bookshelves, these tutors were human inuksuks on the academic landscape and the College a memorable place that I travelled through along my songline. The memories of the people and the place, them, echo in my mind as I read about them, and hear stories about them, in later years.

Our student education was built on a rich substrate of people and environment. It provided a safe harbour in which our minds could open, and develop outwards, equipped to sail on the seas beyond. It was hard work, motivating and satisfying. Architecturally, the environment was an inspiring and peaceful place; beautiful buildings, if archaic, and many rooms very chilly in winter; superlative gardens and grounds, with rich wildlife. As a student community, it was spirited and full of life, where

social divisions born of wealth and education, mixed with social cultures of students and teachers drawn from across the country and the world. This mixing of disciplines and people made it a magical place and time.

I studied physics and listened every day to lectures from eminent physicists drawn together from the many College communities of the University. This was another kind of local community, interacting around the shared purposes of academic physics, a stage removed from the mix of disciplines in daily college life. And within the University, different departments and fields of study formed another community, this time a local federation, a stage separated from the departments. They were still local, being located within a circle spanning about a mile in diameter. Local colleges, departments and universities joined and ramified within national and international communities and federations, separated by distance and lacking immediacy of connection.

The world moves on and Magdalen is now a different place. The senior common room is the liveliest of hubs and hubbubs, at lunchtime. I doubt that conversation at breakfast is now so sternly frowned on, to assuage monk-like concentration and fragility. They still eat very well but the alcohol is less in evidence! Gender balance is a blessing and after the first female students and fellows of the 1980s, there is, at last, the first female President of College, the lawyer, Dinah Rose.

The Information Age has turned this environment upside down. Telepresence is ever closer and more pervasive. Our physical likenesses, activities, words, records and ideas can be shared immediately to ping and populate devices and screens globally throughout the Internet. The Covid-19 crisis accelerated virtual working community, and physics at Oxford did very well in this. Whereas I would occasionally drive with friends to a Saturday morning programme of lectures in the Department, within more recent times I could enrol and participate in a lecture hosted there and attended from all over the world. Students have worked mainly at home in isolation, with their work supervised and moderated in new ways, by teachers similarly isolated and connected. Recruitment of new staff and students, teaching and examinations, and research collaborations, have proceeded quite satisfactorily, as reported by all involved. In the past week as I write, I have attended a seminar drawing together and discussing with physicists appearing online from the IceCube Neutrino Observatory at the South Pole, along with their theoretical physics team colleagues, speaking from several different countries and a small and very lucky participating audience, including me.

The lockdown has brought some needed gains in the flexibility of systems to cater for the educational needs of isolated individual learners. This adaptation would have been largely unachievable even fifteen years

ago, such has been the pace of attrition and maturation of serviceable component technologies. New devices, systems, networks, software and the engineering standardizations that underpin the new skills and ways of working of today, enable increasing alignment within a worldwide ecosystem.

Of course, there is inevitably loss of human immediacy and experience of the academic environment in such rearrangements. This presence has been transferred, with compensatory benefit in family and community life, to local community within our local Globalton. We communicate much more than before along our avenue in St Albans, and through our local WhatsApp group. There is richness of experience and connection to be shared there, that I have previously passed by as I rushed to commute elsewhere for so much of each working day. I have discovered amazing people, hitherto unbeknown to me, living and working nearby. John Snelgrove, an optician and self-made engineer, with a shop practice four hundred metres from our house, has pioneered a technology which may bring personally fitted spectacles, adjusted to personal visual acuity, astigmatism and physiognomy, within global reach for the estimated hundreds of millions of people in the developing world whose lives are seriously impaired because they lack them. And this as a kit and service delivered from the back of a Land Rover or carried on foot, at an all-up cost, including micro-enterprise eyesight-testing and spectacles fitting services, of around twenty pounds! I am connecting him into investment and user communities in Africa, Malaysia and Australia, to arrange pilot production and field trials once his production line is proved and he can produce the kits at scale. Globalton can also be a richly creative and inventive environment!

I formed working relationships from the early stages of my career that can continue, still full of life, now, only because of information technology. This morning, I paused my writing to take a call, screen-to-screen, from Alice Springs in Australia, with Sam Heard, my doctor colleague with whom I conducted the foundational research for, and created, the openEHR Foundation, as described in Chapter Eight and a Half. He is now a medical director for the Aboriginal Community health services, there. Yesterday, I was catching up with work spreading the openEHR open platform for clinical computing across thirty centres of research in Germany. Last week, I was in discussion with a doctor in South Africa, about supporting his pioneering work enabling uptake there of the OpenEyes software for eye care, with which I have been involved for now nearly twenty years. This week, the board of the openEHR International community is discussing with a Finnish colleague the establishment of an educational resource to support education about these new platforms, across countries. These are not unusual weeks.



They are examples of local initiative, enabled by and taken forward within globally extended and mutually collaborative and connected communities and environments of the Information Age. In this evolution, there are new motivations, inspirations, enrichments and satisfactions—and new vulnerabilities, pitfalls and disappointments, too. Money raises its head in new guises.

## Money

Money, money, money  
 Must be funny  
 In the rich man's world  
 Money, money, money  
 Always sunny  
 In the rich man's world  
 Aha  
 All the things I could do  
 If I had a little money  
 It's a rich man's world<sup>79</sup>

I have not said much in the book about the money required to bring health care into the Information Age—apart from lamenting how much has been and is wasted—aiming high and delivering low. This is in large part a reflection of too much thinking Big, which politicians and policy makers naturally tend towards.

The amount of money required will likely not prove such a central issue once these endeavours are approached more collaboratively, both nationally and internationally, achieving economies of effort and scale. Too much is already spent disjointly and unproductively—the approach of the pioneering initiatives described in Chapter Eight and a Half can lead to massively greater efficiency, effectiveness and value for money, permeating throughout health care economies and across the world. And, as with Arthur Guyton's (1919–2003) remark to me all those years ago, about research funding, too much can prove as limiting and harmful as too little. Not a popular sentiment among those pitching for billion-dollar contracts, no doubt!

I admit to some considerable cynicism about the role of money in fostering useful innovation. Too little and too much are both bad. Lack of money is seldom a problem for those with power to set goals, borrow and spend. Small budget items, however significant, do not merit their time; they prefer to decide, and act, big, albeit being somewhat prone to missing

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79 ABBA, 'Money, Money, Money', *Arrival* (1976).

their targets! Maybe this is because there is bias in their rifle sights, or just noise—upon later reflection, after reading Kahneman's new book *Noise*, I am not sure which!

Money certainly matters but a relatively small amount of new money is needed, at risk, if an incremental path of implementation of a citizen-focused care information utility is followed. Each stage can be tasked to deliver sustained value. The work described in Chapter Eight and a Half has arisen and been nurtured with very small amounts of money, capitalizing on insight of a small group of pioneers. It has expended, I would guess, about one millionth of what the world has been spending (implicitly as well as explicitly), year on year, while the wicked problem addressed, overall, has, if anything, got worse. I suspect that is a generous estimate—the real number is probably much higher; we just don't know how to measure it.

In terms of required information technology infrastructure, the money needed is already being spent, as it has been repeatedly, and often inefficiently and ineffectively, for decades. This money needs to be spent more coherently, realistically and carefully. New investment is most needed to enable and mobilize practical contributions of citizens and health care communities. There are very many capable people in the world with the skills, motivation and enduring commitment needed to weave their part in, and contribution to, the growth and sustaining of the care information utility—the challenge is to create common ground of global synergy from coherent local efforts. I reverse the usual order of such communities of endeavour: motivated volunteers; students of computer science keen for practical assignments in which to hone their skills and experience; citizens eager and able to be involved; health care professionals, technologists, academics, industries ready and able to work innovatively and collaboratively in support.

I have seen this pattern of motivation in several international communities that I have known. We do not nurture and use such complementary breadth of community well—above all, all want to belong, make a difference and be valued. As one very senior friend in international business said to me: making a difference comes to be valued as much as making a dollar.

## Leadership

The best ruler is one whose presence is unknown [...] When the goal is achieved and the job is done, everyone says, 'we did it'.<sup>80</sup>

It is the long history of humankind that those who have learnt to collaborate and improvise most effectively have prevailed.<sup>81</sup>

This first quotation might suggest that good leadership can prove a thankless task—it may well, in some quarters, but this is not the same as it being unsatisfying or personally unrewarding. Poor leadership is more surely a thankless task, even if financially rewarding. A leader who imposes rather than enables, however wealthy and powerful they become, may likely end up wracked by feelings of impostor syndrome, insecurity and self-doubt. Poor leadership reflects a crisis of values. Poor leadership easily leads to intractable conflict—I saw this in employment tribunals I chaired, seeking to understand and resolve issues raised in complaints from staff.

Care Information Utility is clearly destined to be a very tricky area in which to exercise leadership! Adam Galinsky says that speaking out requires conviction, insight and allies.<sup>82</sup> He discusses the range of acceptable behaviours for navigating the double-bind of power, which he sees as: speak too loudly and get punished; keep quiet and remain unnoticed. His proposed tactic: speak on behalf of others, retain no personal skin in the game, keep psychological distance. He quotes Martin Luther King (1929–68) about keeping perspective: 'don't be self-focused, find balance in context'. It is a personal matter whether you chose to believe, as he did, that 'the arc of the moral universe bends towards justice'. It is a sombre caution that 'we will remember the silence of our friends'.

Good leadership has many threads, not all immediately obvious, balancing individuals with the teams and endeavours they connect with and advance. The Information Age has brought leadership under a new microscope and 'macroscope'. But the second quotation above is as relevant to ponder today as it was one hundred and sixty years ago. Diverse qualities encapsulate the term: connecting with head, hand and heart; choosing and enabling good teams; imbuing trust, motivation and collaboration; coping with lack of clarity and certainty about goals; discerning signal amidst bias and noise; taking risks in linking people, science and engineering

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80 Lao Tzu, *Tao Te Ching*, trans. Wu, p. 40.

81 Quote attributed to Charles Darwin.

82 'Adam Galinsky: What Drives Us to Speak Up?', *TED Radio Hour* (7 April 2017), <https://www.npr.org/2017/04/07/522857511/adam-galinsky-what-drives-us-to-speak-up>

with money—man on moon, nuclear submarine, changing science, changing engineering, changing health care in changing society; coping with irreconcilable imperatives; making itself dispensable; planning for succession...

My former university employer has evolved a clear statement of what it expects of its academic leadership. It is a statement of values in research, education, enterprise and public engagement, and institutional citizenship, emphasizing balance and teamwork. Despots and egotists will fall short of a balanced score card on these scores, however long their list of publications. One publication a year is now considered a norm. Fifty in a career—that fits back to what was being suggested thirty or more years ago, around the time of my RSM talk. The discussion of a career-long evolving account, a songline as opposed to a list of publications, also rings true.

In tackling wicked problems, less is sometimes more. I recall a former Government Treasury Permanent Secretary, George Young, who, when asked in an interview to comment on the main lesson he drew from his years in charge, said: 'thank goodness we could not do more!' Focus on individual citizen and population data, on what matters to and what is the matter with, on Little Data in a personal context and Big Data in general, are all balances that care information utility must navigate. We should increment and iterate on these, not follow paths and press buttons that force us one way or the other. Doing too much, at the press of a button, has become all too easy in the Information Age. I recall John Dickinson's remark to me in my early years as his lecturer at Bart's, that one of his principal functions as chief of medicine was often to persuade those engrossed in the buzz of the moment in medical science and engineering, eager to do ever more, that they should rather do less!

### *Leadership in Context of the Wicked Problem*

The most difficult situations in which to lead are those characterized by King's radical uncertainty—where the honest answer is that we do not know but must act, nonetheless. This conundrum lies at the heart of the wicked problem and how we frame and conduct leadership in conditions of shifting sands of both context and perspective, goal and method, ownership and responsibility. These are confronted, and leadership conducted, in situations where no action is an action, no decision is a decision, and where nothing can ever be adjudged right or wrong, perhaps just better or worse, and is either accepted or rejected, leading to further wicked problems.

Leadership here defies rationalization as it arises and evolves within infinite varieties of need and contexts of Open Society, as Popper discussed.

In closed society such musings get short shrift. Popper described and characterized the enemies of Open Society. The thirst for certainty opens the door to beguiling and comforting authoritarian siren voices calling for closure. When we stray there, we bring on the clowns, or the despots—sometimes they are one and the same.

Wicked problems can lead to situations where abstract and putative goals predominate, and practical means are in short supply and of uncertain efficacy. Here, connection, listening and being heard are vital qualities, both near to and at large. The solution to a wicked problem is often said to lie in education. But as Norman Davies says, for every person wanting to educate, there are twenty not wanting to learn! The exhortation to educate must in some way balance with capacity and inclination to learn. Achieving this balance requires Tett's anthro-vision.

Leadership in the interconnected worlds of discipline, Grand Challenge and wicked problem must speak in many tongues. It must nurture trust in its capacity to identify, communicate and act successfully in the challenges of the here and now. It must be versed in the art of war—allies, positions, trade-offs, battles worth fighting. It must build, sustain and define context of endeavour and the teams and terms of endeavour.

The burden of leadership of wicked problems is thus severe, and the hat of such leadership best not worn for too long, as over time it will cease to fit. Leaders must be careful before donning the hat, and remain focused on helping others to share it, and then take it and wear it for themselves. 'It's tough at the top', as every leader discovers, and some quickly find they are unsuited or unwilling to be there, or prefer to critique, or pot-shot, sometimes cheaply, at those who are.

### *A Songline of Leadership Styles*

In the same manner as I reflected above on formative environments experienced along my songline, in this section I set out, side by side, a diversity of leadership styles that I have encountered and worked under.

#### Chief Executive and Titan of the Shipbuilding Industry

My early experience of the Vickers Group took me to the most unlikely of places, given my home background, but introduced me to some extraordinary and dedicated people, including the barons in that era of the shipyards of Barrow-in-Furness and Newcastle, and the coke-fired furnaces of the steel industry in Sheffield. I met Leonard Redshaw (1911–89) and his team who led the UK Polaris programme to build its first nuclear submarines. He had

left school at age sixteen and became an apprentice draughtsman at the shipyard, rising to a knighthood in later years. I saw him at work at the yard, in the two huge, back-to-back offices where he habitually conducted two simultaneous meetings. He moved between them to take charge, sort out an issue requiring quick investigation, issue instructions to the team there, for actions to be completed before he returned an hour later, and then moving to the second office to do the same. Here was an iron and often abrasive will, at the control centre of extraordinarily complex endeavour, showing the prodigious energy that comes when personality and mission match well. He flew and piloted a private plane, to and fro to the Group London Head Office, for management meetings where he represented one of the most profitable parts of the group. He was a gliding enthusiast in his free time. A legendary leader and an astonishing accomplishment, from design and production to seaworthiness trials. But all on cost-plus remuneration, of course.

There I saw how the leadership role and contract was one of balancing expectation, risk and reward. That in contracting for this most complex and uncertain of endeavours, commissioners could not and did not attempt to force all the risk in one direction, onto the organization chosen to deliver on their expectations. This is also true at a more personal level in health care, where there must be a fair balance of expectation, risk and reward, between those who expect services and those who deliver them. This can best reside in common understanding between them, expressing shared values and principles. Lacking such balance, a managerial culture tends towards a spreadsheet culture, abstracting the spreading of expectation, risk and reward, from a human balance to a balance sheet. The dramatic cost inflation of health care services and recurrent failure of its information policy, as exemplified by Topol's 'Shallow Medicine' and the litigation of failures in the UK national programme for IT, are illustrations of where this can lead. It reflects failed leadership of complex and uncertain endeavour. The spreadsheet framing of human endeavour requires little by way of human head and heart, and the computer's hand will likely do it better!

#### Chief Executive in the Medical Engineering Industry

My first boss, just for two years until I escaped, was a clinician who switched into medical engineering. He was very bright, ambitious, charismatic and with feet of clay, as it turned out. He established close connections with government ministers and found himself at the centre of the Poulson Affair, where this corrupt architect had spun a web of illicit developments and ventures across the world, especially focusing on new hospitals. Poulson

ended up in prison and his business empire collapsed. My boss had run rings around the staid senior management of the Vickers Group, naive in their abilities to switch from military cost-plus contracts for weaponry into a competitive world of medical engineering. They believed in his claimed mastery of a panacea of new technologies for treatment and cure, in the form of hyperbaric oxygen chambers, automation of laboratory chemistry and new hospital design. They backed his dreams and lost a huge amount of money.

It all ended in tears, exposing a dark side of industrial life and international business in the process. He had an unchallenging team around him and those who doubted were thrust aside. Not until the unpaid bills mounted did the group leadership become engaged and they then sent in a ruthless and hard-headed former military brigadier to sort out the mess. He quickly pulled me in to help him understand the problems, which I could readily do, and helped me move away unscathed. Here was my first experience of hubris and pretence of knowledge, and how unquestioningly it is accepted and believed in wider circles.

#### Head of Medical Physics in an NHS Trust

John Clifton (1930–2023), the Head of Medical Physics at UCH when I worked for him in the early 1970s, became President of the Hospital Physicist's Association, both in the UK and internationally. He was among the first NHS professionals to adopt this role; it had previously been the preserve of illustrious pioneering academic physicists like Jack Boag (1911–2007) and Joseph Rotblat (1908–2005). These pioneers had worked in biomedical research and its NHS affiliated organizations, to unfold the professional domain of radiation and hospital physics. The field metamorphosed into a wider domain of biomedical engineering and biomedical physics. Heads of such departments had to battle with their hospital leadership for recognition of professional status, tending to be treated as lesser mortals in the ruling medical committees and hierarchies of the day. Hospital physics provided supporting services that were scientifically highly innovative, principally in nuclear medicine, radiotherapy and clinical measurement and imaging services. John was a mix of clever, cunning, motivated and disgruntled. He was a very competent administrator and an effective campaigner on the department's behalf. He had a loyal, capable, if sometimes rather grumbling, team around him, and the hospital was well served. He exemplified the coping side of leadership—dealt low-scoring cards, he yet managed to win tricks. The world beyond the hospital gave him an environment where he felt more valued, which he surely deserved. He died quite recently in February

2023, and colleagues from fifty years ago assembled at his funeral. He was, I learned there, a lifelong gardener and scout leader. Quite illuminating of his personality and leadership style, I reflected.

#### Chief of Medicine in a Medical School

John Dickinson was a much more widely known and completely different kind of personality. He played a leading role in the world of hypertension research and was a very insightful and charismatic clinician. He had little time for forceful behaviour, albeit having had a military service period of his own career, and sometimes speaking admiringly of the character of military leadership and discipline. He himself was always sure of his ground on clinical matters but steered clear of personality jousts among contending, more strutting colleagues of the time, charming them with his erudition, practical skills and musical accomplishments.

John was my first experience of a leader as president more than chief executive. He believed his central roles as leader were in appointing good staff to the institution and sorting out their quarrels—quite frequent in the hotbed atmosphere of academic medicine of the era. He believed that his main clinical responsibility was to advise and persuade colleagues when to do less in terms of treatment, rather than more—somewhat counter to the ethos of Industrial Age medicine and the exploratory science of the times.

#### Vice Chancellor of a Leading University

Derek Roberts was Leonard Redshaw revisited, for me. He was sometimes dour, possessing northern common sense and wielding an iron fist within a variety of determined and persuasive gloves. He was a leader, as Provost of UCL, in two spells from the 1990s and banged heads together with great effect in shaping UCL's future. Derek was a renowned electrical engineer, who had led the post-war industry that pioneered semiconductor devices. UCL, with all its complexity, was easy-peasy as a management challenge for one as robust as he. He recruited me there in 1995, to create the new CHIME centre in the Faculty of Medicine, linking it with clinical professional education. He described to me his straightforward approach to recruitments to his senior team. 'Decide what you want to do, locate people who you believe can help you do it and find out what they need'. His disarming, but deadly follow-up line, as he looked you in the eye from across the huge circular table at the centre of the provost's office, was: 'so what do you need?' The approach I took was twofold—express the plan in a



simple diagram and frame the ask in terms of the team, not oneself. He liked it and the rest was history.

I reported directly to Derek, as a UCL Head of Department. John Pattison, the then Dean of Medicine, had quickly decided this was the right approach, to give me freedom and keep me out of established departmental clutches! I saw Derek infrequently, thereafter, but he kept in touch and paid state visits to the department. At various meetings that he asked me to join, bringing together leaders from different departments, he came with the aim of encouraging partnerships among disciplines. Equipped with his formidable personality and a single overhead slide depicting an unlabelled set of overlapping ellipses, he extolled a focus on common grand challenges. This he used as his sole visual aid, ascribing the ellipses to different departments and faculties, as he spoke, according to the occasion! This was the most powerful example of intelligent and tough leadership through force of personality and a straightforward, pragmatic approach to management. Mervyn King would have recognized him as an audacious pessimist. I suspect they would have got on well. Derek was a hugely respected power in the land and the successful mergers that led to the UCL of today were his work. His gamble in appointing us achieved and pleased in a lot of ways, and failed and disappointed, in some others. Many years on, during his second period as Provost, Derek and the then Vice-Provost for biomedicine, Mike Spyer, awarded me a considerable hike in salary, so I cannot have disappointed too much! I greatly admired and looked up to them.

### *Leadership as Battle*

Leadership is often seen as doing battle. Two contrasting threads weave together, here, in ideas about battle—one of culture and the other of strategy. One concerns practical focus, as dramatized in the writings of Denis de Rougement (1906–85), which he called thinking with the hands.<sup>83</sup> Very French and to be appreciated in that tongue. It has echoes in Goodhart's book.<sup>84</sup> The other concerns strategic focus, drawing from the classically poetic writing of Sun Tzu (544 BCE–496 BCE) in *The Art of War*.<sup>85</sup> This thread is modelled on warfare but generalizes well beyond the military world. The extracts from the book, here, are intended partly as tongue-in-cheek clowning, but, as ever with clowns, with some more serious intent!

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83 D. de Rougement, *Penser avec les Mains* (Paris: A. Michel, 1936).

84 Goodhart, *Head Hand Heart*.

85 J. Minford, trans., *Sun Tzu: The Art of War* (London, Penguin Group, 2002).

The book was given to me by my final PhD student, Seref, who is now a humane and battle-tempered, loyal warrior friend!

Denis de Rougemont (1906–85)–*Penser avec les Mains* [*Thinking with Your Hands*], 1936

Denis de Rougement was a non-conformist cultural theorist whose views were honed in the interwar years, leading him to strong advocacy of European federalism. It is easy to get a rough translation of his words from Google Translate, but the text only fully connects in its original French tongue! It is a call to hands, not arms in combat!

It is time to proclaim vain any work which leaves its author intact, and the reader to his comfort. Vain and bad any work which does not seize you as with a hand, which does not push you out of yourself, in the scandal or in the joy of your creative vocation.

Too many harmless thinkers conceal correct philosophies, too many harmless dramas are played out in our novels, too many harmless scribes ape us with fury, or revolt, sceptical indulgence, or distinguished peace. Harmless, all those whose work is not the place of merciless combat where something he can no longer flee attacks the author and all that he reflects in a domesticated atmosphere.

It is high time that thought returned to what it really is: dangerous for the thinker, and transformative of reality. ‘Where I create, there I am real’, wrote Rilke. And that is why we will take this distinction seriously: There are men who are the pride of our spirits—and others who pride themselves on our spirits. There are men who create, others who record: they should no longer be confused. There are Pascal and Goethe, Dostoevsky, and Kierkegaard—there are also the literate, the good minds, the teachers, for whom thought is an art of pleasure, an inheritance, a liberal career, or a well-placed capital. Brains without hands! and who judge from above, but from afar, and always after the fact, the multitude of brainless hands who work endlessly through the world, toil perhaps in vain, if not for the loss of us all. Now, these people form opinion, without a doubt, and they know it. All the opinion in the world is pretty much there, that thought can only come after fatal events and which do not care about its stops. It is that we confuse thought with the inoffensive use of what creators have thought, often at the cost of their lives, and always by an initiating and revolutionary act.

Some think, they say, others act! But the real condition of man is to think with his hands.<sup>86</sup>

A rather dicey translation, but the gist is there. I asked ChatGPT-3 to clarify and summarize the text from Google Translate. It thought for a couple of minutes and then offered the following:

Denis de Rougemont believed that there was a disconnect between thought and action in modern society. He argued that people had become too reliant on technology and had lost touch with the physical world. Rougemont believed that by engaging with the world through physical activities such as craftsmanship and manual labor, people could reconnect with their humanity and improve their mental and emotional wellbeing. He saw this as a way to counteract the alienation and existential despair that were prevalent in modern society. Rougemont's philosophy of 'thinking with your hands' emphasized the importance of integrating the mind and the body in order to achieve a more holistic understanding of the world.

Both are fun to read!

#### **Sun Tzu (544 BCE–496 BCE)—*The Art of War***

The failures of successive reorganizations of health care have come to look like failed military campaigns. There are those who view government in that way, as aficionados of the OODA loop model of the former fighter pilot John Boyd, which has been influential in some political circles of recent decades. His model of campaigning was based on steps to Observe, Orientate, Decide and Act, pursued with the aim to surprise, and disorientate, to overcome the perceived enemy. This is a strategy that can win the war but lose the peace. It focuses attention on combat over disputed territory rather than collaboration on common ground. Finding common ground rests on strength of arguments rather than force of participants, as well as trust in motivation and fairness.

Leadership of successful campaigns is a cornerstone of military prowess and, to appropriate the sayings of Sun Tzu, from two thousand and five hundred years ago:

War is  
A grave affair of state;  
It is a place of life and death,

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<sup>86</sup> De Rougemont, *Penser avec les Mains*, pp. 146–47. Translation using Google Translate.

A road  
 To survival and extinction,  
 A matter  
 to be pondered carefully.<sup>87</sup>

In the one hundred pages of *The Art of War*, the words are poetic, but the focus is on success in battle of any kind, and best won without conflict. The book is nowadays a standard text in leadership courses, where military battle is used as a metaphor for campaign and leadership more generally in society. We touch on such metaphor when speaking of the war on poverty, want and disease. Language of survival and extinction is staring from the front pages of most newspapers this week, in the context of the crescendo of concern about AI. So maybe our information strategy for health care will start to assume the vestments of military campaign. The strategy for combatting cyberwarfare already indicates this is on a war footing.

The modernization of health care has been a battle and it has certainly been pondered, repetitively, in many different countries and at many different times. It is a battle not yet won. According to Sun Tzu, in combat:

Victory should be  
 Swift.  
 If victory is slow,  
 Men tire,  
 Morale sags.  
 Sieges  
 Exhaust strength;  
 Protracted campaigns  
 Strain the public treasury.<sup>88</sup>

Bill Gates might well approve of this strategy—he has championed the need to take innovation quickly to scale. I am cautious that wicked problems may not be amenable that way. The history of information for health has been reminiscent of a new hundred years' war and the above extract captures very well the energy-sapping impact it has had within health services.

National Strategies are strategic offensives. In Sun Tzu's classic, the most quoted and remembered verse is:

Ultimate excellence lies  
 Not in winning  
 Every battle  
 But in defeating the enemy

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<sup>87</sup> Sun Tzu, *Art of War*, trans. Minford, p. 1.

<sup>88</sup> *Ibid.*, pp. 7–8.

Without ever fighting.<sup>89</sup>

In thinking about information strategy for health care, there is no clear enemy, but there is battle, nonetheless, on many levels. And some leaders seem to have fixated on vanquishing perceived enemies more than achieving necessary goals. Strategy is of paramount importance. For Sun Tzu, the highest aim is not to destroy but to overcome by dint of strategy. In this:

The victories  
Of the skilful warrior  
Are not extraordinary victories;  
They bring  
Neither fame for wisdom  
Nor merit for valour.<sup>90</sup>

And:

The victorious army  
Is victorious first  
And seeks battle later;  
The defeated army  
Does battle first  
And seeks victory later.<sup>91</sup>

This echoes the concern that Douglas Black (1913–2002) raised in his critique of the Körner Report in the 1980s, as highlighted in Chapter Seven, where he distinguished the role of IT in the clinical management of individual patient care from that in the organizational management of health care services. The NHS saw and planned a battle over information for health focused on the latter, consequently neglecting the former. Quiet and uncelebrated progress on the former is a precondition of a successful campaign on the latter. Thus, in the military perspective and language of Sun Tzu, health care got its strategy wrong—it fought on the wrong ground (organizational management rather than individual patient care), divided its troops (managers and clinical professionals), made enemies from friends (IT professionals and the industry) and neglected its allies (citizens and what matters to them). The battle was approached as one of target-driven, up-down taming of professions and organizations by politicians and managers. It has achieved a sickening stale mate. It should now focus on creation of care information utility to serve the individual needs of citizens

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89 *Ibid.*, p. 12.

90 *Ibid.*, p. 20.

91 *Ibid.*, p. 21.

and professionals and engage and support them in their shared mission in health care, on common ground.

This will be a new battle and will have winners and losers and face concerted battling forces. These comments are not intended as accusatory—all endeavours discussed have predominantly been well-motivated and diligently pursued. But Sun Tzu does find relevance here; and there are several other parts of his epic that should also give pause for thought. Those familiar with the multifarious battles of five eras of NHS IT strategy, seeking towards new equilibrium in health care for the Information Age, may recognize in their own experience, the relevance and wisdom of many of his verses. Here are a few more that struck a personal chord in the context of health care and IT.

The highest skill  
In forming dispositions  
is to be without form;  
Formlessness is proof against the prying  
Of the subtlest spy  
And the machinations  
Of the wisest brain.<sup>92</sup>

This is advice about staying below the prying radar and avoiding becoming a target!

Victorious campaigns  
are unrepeatable.  
They take form in response  
To the infinite varieties  
Of circumstance.<sup>93</sup>

This is a call to keep in close contact with the uniqueness and everyday unfolding of the battle, adapting to it and not forcefully pursuing a disconnected master plan.

Victory belongs to the man  
Who can master  
The stratagem of  
The crooked  
And the straight.<sup>94</sup>

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92 *Ibid.*, p. 36.

93 *Ibid.*, p. 37.

94 *Ibid.*, p. 43.

The challenge is to bring tractable and useful order to an intrinsically disorderly domain.

Leave a passage  
for a besieged army.<sup>95</sup>

In this we must operate inclusively and not punish.

Hence the saying  
Know the enemy,  
Know yourself,  
And victory  
Is never in doubt,  
Not in a hundred battles.<sup>96</sup>

As Mervyn King and others have advised, based on their own experiences, we must cultivate greater awareness and humility.

When starting a fire  
Be upwind;  
Never attack  
From downwind.<sup>97</sup>

And avoid self-harm!

I consulted ChatGPT-3, asking for a summary of Sun Tzu's message about battle. It was quicker to reflect on this request, and replied as follows:

Sun Tzu believed that effective leadership in battle was essential for success. He emphasized the importance of knowing one's own strengths and weaknesses as well as those of the enemy. He also stressed the need to be adaptable and to be able to adjust one's strategy based on changing circumstances. Sun Tzu believed that a leader should inspire loyalty and confidence in their troops by setting an example and treating them with respect. He also believed in the importance of communication and the need to keep one's troops informed about the overall strategy and goals. Sun Tzu believed that a good leader should be able to make decisions quickly and decisively, but also be willing to listen to advice and consider alternative perspectives. Overall, Sun Tzu's message about leadership of battle emphasized the importance of strategic thinking, adaptability, communication, and leading by example.

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95 Ibid.

96 Ibid., p. 17.

97 Ibid., p. 91.

The battle for health care IT has been a multifaceted struggle, involving various stakeholders and interests and unfolding on multiple fronts. The ground-level insider mediation and peace-making now necessary requires a flexibility of approach combined with focus on goals that transcend the battle lines—better balance, continuity and governance of health care. In this, the focus must be on the citizen, not the service.

For me, the most thought provoking of Sun Tzu's advice relates to strategic alliance. This is the topic I reflect on at the end of the chapter.

### *Stages of Leadership*

Leadership proceeds in styles and stages. Simplifying the description of an untidy world may clarify and represent it well, or alternatively obfuscate and misrepresent it. There are contexts in which the imperative is to close in on narrower goals, and those where it is to open out onto wider goals.

The opportunity of implementation of the care information utility is to combine global and local endeavour. New and worldwide communities that pool their endeavours within new networks of connection and collaboration on common ground. New local community endeavours that inherit approaches and methods globally and collaborate locally to implement in local contexts. Creative contribution comes from all these participants. In the section of this chapter focused on Implementation One, I introduced ideas of Lionel Penrose, concerning human group behaviour. I relate these here to leadership challenges as a function of the scale of team and endeavour. There have been three stages of leadership of GEHR and then openEHR.

#### Stage 1: 1990–95, Lionel Penrose levels 1–3 and 3–10

This stage is characterized by the articulation of vision: from the formative framing of problems to formative iteration of architecture and design. This stage posed questions about coherence, connectedness and comprehensiveness of requirements, relating to purpose and goal, answering to early questions of what and why?

In this stage, team culture and environment were centre stage. It brought together and united people with clinical perspectives and expertise, already experienced in the world of electronic health records, and joined them with people with complementary technical, managerial and commercial experience and expertise—in small organizations and large. This stage needed to focus on a shared vision and worked from a bootstrap of an already instantiated product, Health One—a concrete example against which



to bounce new ideas. An iteration between forward-looking requirement and practical experience and example, looking back.

Stages 2: 1995–2015, Lionel Penrose levels 3–10 and 10–100

This stage is characterized by the articulation and practical enactment of the mission, involving the implementation of test systems, iterating to a refined architecture and design. Here we again encounter the importance of skin in the game in the world of developers and users of systems. If these incremental test systems proved unable to gel and connect, they were unlikely ever to achieve traction and scale in the wider world.

This stage entailed framing the culture of and creating the independent not-for-profit openEHR Foundation under the auspices of its founding organizations (UCL and Ocean Informatics) and assigning all IP to this organization. In turn, a community within clinical and technical domains was organized and built; roles and responsibilities were delegated, seeking traction and momentum, moving out into the wider world, ambitiously.

Stage 3: 2015–today, Lionel Penrose levels 100–10,000

This stage is characterized by a consolidation of the mission: creating and launching openEHR International as a free-standing, self-governing, self-financing community interest company.

Such pioneering is a hard track of endeavour that requires staying power and oftentimes involves considerable personal cost. Throughout, environment, team culture and feasible ways of doing things were fundamental. It is a precarious process to maintain these and remain solvent and true to the culture of the mission, as the scale of operations grows through its early stages. Leadership roles and recognition of contributions gradually become more widely distributed and shared.

*Leading from Below*

It can be hard to separate leadership and authority from power and position. Articulating and defending mission, creating and sustaining good order, resolving differences and enabling and achieving desired outcomes call on different skills and qualities of leadership, and expose different motivations. Leadership and authority are required and in evidence everywhere. They are not necessarily to be associated with power and position exercised from the top down. Micromanagement is not leadership. People at all levels can

be leaders and speak with authority. Leadership may sometimes be best approached from below, as Lao Tzu advised in the quotation that heads this section.

In his 1953 Reith Lectures, which I introduced in Chapter One and have several times referred to elsewhere in the book, Robert Oppenheimer (1904–67) discussed the idea of complementarity in science, and extended this to the human realm and the importance of articulating a shared vision that combines complementary perspectives. He called it ‘common understanding’. This process is one of learning fruitful ways to weave together complementarities, and such are well exemplified by the half and half approaches to and perspectives of health care, as discussed in the next and concluding chapter of the book—fruitful weaving together of human and machine intelligence or health and social care are two pressing examples. We need to learn their intermediation and approach the task from the ground up. Endeavour to create the care information utility must recognize and accommodate this aspect of the implementation tasks. It will require common understanding that guides the inclusive drawing together of complementary threads of implementation. Health care of the Information Age is struggling to achieve common understanding—what it is and what it does. Alongside, so is health informatics. Both have tended to view the quest too much from a top-down perspective of power and position. It is not that this isn’t important; it’s rather that it needs better balance with ground-level and bottom-up perspective of leadership and authority, as well.

UK health IT policy, strategy and plan of action have been found lacking in leading from below qualities, and its leaders have tumbled from the top—the higher they rose, the harder they fell. All sought, bravely, to keep order, stabilize the ship and chart a course, as further described in Appendix III in the additional resources.<sup>98</sup> There were the diverse credentials and temperaments of hospital administrator, physicist, IT consultant, IT manager, civil servant, management consultant, journalist and diplomat in these leaders, but very few practising clinicians in sight, and none in this list of those who have led from the top!

But without power and position, will people speaking with authority be listened to and heard? They, too, are leaders. There is conflict as well to be resolved among powerful leaders on opposing sides. In this context, the world at large is revisiting the resolution of difference and conflict, albeit extremely painfully, speaking more, now, the language of intermediation in finding and implementing solutions from the ground up, rather than in high-level power broking. There is discussion of ‘insider mediators’, emphasizing

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98 Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

the need for leadership in such processes operating discreetly, below the radar, rather than flying the world in jets, power brokering negotiations, speaking at conferences and giving press conferences.

As outlined above, Galinsky advocates for conviction, insight and allies when speaking out in situations of conflict. His approach sounds very much like leadership from below, the 'insider mediator' role. All very well, but it will be a long road to learn and accommodate this leadership skill in the way we do things today, albeit that many parts of the world that have long been embedded in intractable conflict appear to be engaging with it. How could these ideas be extended into health care reform? Only by trying and evaluating their impact can we truly know. Perhaps Implementation One, Two and Three of the care information utility could be one place to start.

As an example of what this sort of idea means in practice, in a completely different and more ethereal context, the Quakers have no priests as voices of power and position—they use poetic language in describing 'the priesthood of all believers' and of the spirit (common understanding, perhaps!) as leading. The role of Quaker business meeting clerks is not to lead anywhere, but rather to provide an open environment that enables all those who are present to express themselves. They sit quietly, reflect, summarize and draw the discussion to a conclusion by expressing it succinctly, there and then, in a written Minute, which is read out and approved by the group. I used to sit alongside a famous head of an Oxford College who attended Quaker meetings for worship every week, never spoke there and arrived and departed alone. He was friendly and approachable, though, and no doubt a good leader in college affairs and in the government commissions of the time that he chaired. It seems that, where there is a common ground of purpose, goal and method, a good environment and a common understanding, all who participate lead. He was a national leader who, you might say, was attending there to listen to leadership from below. He didn't come for peace and quiet as those meetings could sometimes be quite noisy, in my experience of them years ago!

On a lighter note, the leader's lot was beautifully parodied in the operettas of William Gilbert (1836–1911). I can still hear these being sung, sixty years ago, at the Bristol Old Vic, with the anguished police chief in *Pirates of Penzance* reiterating many examples of why 'a policeman's lot is not a happy one'. But as Lao Tzu wrote two thousand years ago, the best leadership is not seen. There is a huge amount of it in action everywhere, every day and hopefully we can link it better with the leadership we do see. Perhaps good leadership at the top and good leadership from below are another Oppenheimer complementarity, where we either have both or we have neither.

## Implementation Three—Governance

Reaching the end of the book's storyline I come to probably the hardest issue it encounters, that of governance—as if any of it was straightforward! I could have put it first but chose to put it last, as in that way its pivotal position and importance across the domain of care information utility is clearer. Good governance is the storm anchor of trust. It serves to engender trust in and obedience to rules and laws that are constructed and sustained democratically and discharged fairly and impartially. Governance of data and data systems serves to engender trust that data are faithfully, meaningfully, relevantly and securely captured, stored, analyzed and communicated. It needs to protect against exploitation and manipulation by bad actors, too. But badly conceived and enacted governance can be harmful, too. We need to keep learning about how to do it well. It is the third grand challenge of implementation of the care information utility.

Information has causative potential and information governance involves ethics, law and regulation concerned with those causes and their effects. It impacts widely on citizens, services, institutions, professions, industries and governments. It connects closely with information technologies and systems, impacting all aspects of the management and processing of personal data. For example, imposing the requirement that an information system be able to correct wrongly recorded information that is discovered, by tracing back through all the chains of intermediate processing of data to its original source, is a beguilingly easy imperative to sign up to and articulate, but a potentially nigh-on impossible task to enact in the combination of many highly interconnected information systems employed in handling personal health care data, lacking either semantic or technical coherence. To achieve it requires that aspects of the information architecture of the systems be framed around this as a central requirement. It will require rigorous and openly specified formal separation of data from program and application, and for these aspects of the architecture to be common ground across the intercommunicating systems with which the data connects. This makes a formidable case for their standardization, and challenge for their implementation.

Dissonance of theory, regulation and practice embodied in the ecosystem of information governance of personal health data has resulted in an onerous and noisy domain, in terms of what it attempts, how well it succeeds and how it interacts with and impacts on health care. We have dug deeply, over many decades, with ever more penetrating shovels, into a sometimes seemingly bottomless pit of contention about what this governance may mean for management of the complex and wide-ranging kinds, uses and sensitivities of personal health care data. It is hard to

broker and reconcile one perspective that holds that personal privacy of data captured in individual patient care must be absolutely assured, with another that holds that free sharing of these data is essential, to benefit both the patient concerned and wider population health services and research. They are both right, in principle, but point in different directions. They are complementarities—two halves that we must make whole. This debate about principles has continued for several decades.

What people say and what they do about these issues matter, and often differ widely. Social media has demonstrated this experimentally, with personal information made freely available by citizens, both in public and to organizations and individuals intent on using other people's data to serve their private commercial or other ends. Proponents of what should be framed in law and what is achievable in practice, butt horns. Those that value privacy and those that value access, talk past one another. Those that regulate the technology of information systems and those that regulate the performance of information services they support, talk different languages. Those that make money from exploiting personal data, think, perforce, about money.

Such concerns predated the Information Age, of course, but have become amplified by it. What information is being governed and why? Rarefied debate about matters that have not been explored in practice promotes cynicism. I remember the then new Gilbert and Sullivan light operettas, being performed on stage at Christmas time at the Bristol Old Vic in my school days—they were great family fun! There were messages about poorly framed ideas and resulting meaningless words. For example, set to staccato notes that I can still hear:

This particularly rapid, unintelligible patter  
Isn't generally heard, and if it is it doesn't matter,  
This particularly rapid, unintelligible patter  
Isn't generally heard, and if it is it doesn't matter,  
matter, matter, matter, matter, matter,  
matter, matter, matter, matter, matter!<sup>99</sup>

And elsewhere, about support for presupposed conclusions:

Merely corroborative detail, intended to give artistic verisimilitude to an otherwise bald and unconvincing narrative.<sup>100</sup>

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<sup>99</sup> W. S. Gilbert, *Ruddigore*, Act 2.

<sup>100</sup> W. S. Gilbert, *The Mikado*, Act 2

Undue focus on the individual at the expense of the community interest, also exercised William Gilbert:

When everyone is somebody, then no one's anybody.<sup>101</sup>

In more serious circles, report after report has pitched successive, and often conflicting, perspectives about Data Protection and the ethical framework that should pertain. Ideas about personal identity and anonymity play out in practical methods for identification and anonymization of data, and in narrow technical and wide philosophical debate.

Kahneman, Sibony and Sunstein discuss pattern, occasion and system noise and how they impact on judgement.<sup>102</sup> A key message is that judgement is best treated as a form of measurement, with the same approach to its bias and noise as used when analyzing data. Measurement arose as refinement and extension of human senses. Decision and judgement involve both sense and sensibility. Machine decision making is a refinement and extension of human judgement. In this context, the authors are not yet enthusiasts of machine intelligence, believing that it is going to produce major problems for humanity in the next few decades and is not ready for many of the domains in which judgement is required. The authors assert that good ideas should take twenty years to frame. That used to be the stated timespan of bench to bedside translation of scientific advance to routine treatment. But no longer so, in the Information Age. The problem is that short-term capability and judgement can propel innovation to activation much faster, while its consequences may still play out over the longer previously identified timescale. Does any government or governance process designer consciously think on such timescales now—or can they, even?

We must therefore be very cautious and clear-sighted about the extension or encroachment of machine intelligence into a matter as consequential as information governance for health care. There is already too much noise! In 2023, the likes of ChatGPT are racing ahead of this curve and normally ambitiously disruptive souls are expressing concern, cautioning in favour of the incremental and iterative approach characterized in the quotation from Whitehead that headed this final part of the book.

In Chapter Eight, we looked at information as a monetary system. Citizens and institutions own money and banks provide services to manage money. Governments and central banks protect and regulate the monetary system within national and international law, while many others may seek to game and corrupt it. We need law and practice to succeed in maintaining

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101 W. S. Gilbert, *The Gondoliers*, Act 2.

102 Kahneman, Sibony and Sunstein, *Noise: A Flaw*.

a resilient monetary system. Mervyn King said we need new ideas about monetary governance. Health care information flows within equally pervasive personal, professional, institutional and government communities and networks. We need new ideas about information governance, too.

Trust in personal ownership of money is fundamental to its value and governance within a monetary system. Otherwise, we would probably revert to barter, token or precious metal as means of exchange. Affirmation of personal ownership of health care data will be tokenism, and will remain so, unless and until we have personal data banking methods, by which we can learn how to operate, govern and regulate these personal data. This will require new focus on information architecture, new technology and new culture of citizen and professional relationship in health care, built on new common ground.

If citizens are to own their personal health care data and health care services are there in support of this personal autonomy, care records, co-created by multiple stakeholders, must logically be handled rather like money, by the owning citizens themselves, or by trusted professional data bankers or some other such trusted third-party brokers. Citizens will need something akin to a personal data transactions account, rather like a personal money transactions bank account. Consent will be akin to specific delegated Power of Attorney, allowing others to work with and manage the data in the account. Governance of this arrangement will formalize the delegated authority of the citizen and professional co-creators of the data, to manage the data on their behalf.

Foremost in formalizing the governance of personally owned data is the need for common ground that values the preservation of its meaning, couched within context, and its appropriate, timely and efficient communication—seamlessly, coherently, understandably and inclusively. This is the nature of the information governance that is required for oversight of the groupings of personal data that I have characterized as ‘omniscular’, in Chapter Three. Where non-coherent data sources proliferate and multiply, there is risk of noise, bias, discontinuity and imbalance in the uses made of them, and how these interact. Such incoherence may be costly, harm or impede health care, obstruct capacity to innovate, cause frustration and erode and destroy trust.

A long-term task in Implementation Three will be one of learning how to enact personal information governance centred on changing and trusted values and principles. This will play out over a Kahneman twenty-year timescale, at least. It will need to be locally enacted, within a globally-evolved framework of methods and regulations. For this to be feasible, a common ground of information architecture, adequate to the task, will be essential. Chaotic diversity of intercommunicating database and knowledge representation architectures will lead to biased and noisy judgements.

In all this, we must be mindful that not universally, and not always, will patients wish to avail themselves of the transparency enshrined in a right of access to their care records. For some patients, a terminal diagnosis will feel best left unknown. There will also be understandable caution among clinicians—for example, in committing suspicion of child abuse to a likewise transparent clinical record. Clinical information governance must seek to accommodate such realities safely, for all concerned.

This set of imponderables and their implications for governance and leadership are not new but have become much amplified in the Information Age. Alongside governance, one further issue now stands out as requiring new ideas for the creation of the care information utility. In parenthesis of this chapter, I reflect on alliance.

### Parenthesis–Alliance

Sun Tzu's writing, from long ago, mapped the different characteristics of battle terrain and described the importance of developing strategy within context. It is remarkable how it has endured as a course text of leadership academies, to this day. The terrain of health informatics is in parts blocked at a crossroads, on intractable ground, and it needs to be opened up. Strategy in such contexts is well-captured in his words, here:

[...] On open ground,  
Do not block.  
On crossroad ground  
Form alliances.  
[...] On intractable ground,  
Keep marching.<sup>103</sup>

There has been a blockage of open ground—we have seen this as a characteristic of challenged leaders on landscapes navigated by great innovators in history. We have needed to keep marching on intractable ground through the Information Age, for fifty years. And we are now at a crossroads, halfway to the Information Society. We need to be good at building alliances.

Building good alliances is a social skill and I have learned from and been good friends with some outstanding builders of alliances. Alliances do not always endure or work out, but they are essential for sustained progress in complex, multi-sector and multifactorial domains, like health informatics. Here is one story to end with.

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<sup>103</sup> Sun Tzu, *Art of War*, trans. Minford, p. 75.



In my early twenties, I saw how life experience as refugees in wartime motivated the individuals and teams that created Amnesty International. I saw this from a time of small evening gatherings of like-minded citizens, including lawyers, businesspeople and politicians, in pubs just off Fleet Street in London. That was Penrose stage one. I saw it grow through stages two and three, establishing a UK secretariat on which I served for several years with one of Amnesty's co-founders, Eric Baker (1920–76), my then wife, Jenny's, dad. It grew into an international community, with national affiliated movements and an overarching board, where Eric was a founding member and voice for its mission. He had worked alongside his co-founder, Peter Benenson (1921–2005) from Amnesty's earliest days in the 1960s. The international scene was then led by Seán MacBride (1904–88), a prominent Irish politician (son of the English-born Irish republican revolutionary, suffragette and actress Maud Gonne) who briefly led the IRA, subsequently serving on the Council of Europe and at the United Nations. He was awarded the 1974 Nobel Peace Prize. A thought-provoking example of allegiance and alliance in pursuit of the resolution of intractable challenge!

All this sprang into life after Benenson's article in the *Observer*, entitled 'The Forgotten Prisoners' (Prisoners of Conscience, Amnesty termed them).<sup>104</sup> It caught a concern, established a common ground for campaign and connected groups of citizens with practical support for families and advocacy on behalf of individuals imprisoned. Leaders of industry, musicians, politicians and many others found common ground and common cause, and created vibrant concerted action that spread worldwide. It had and continues to have its noisy and complex ups and downs.

Witness the individual human focus, the alliance of community interest on a common ground of concern, the local and global impact, affiliation and governance, the organization to scale through four Penrose squared levels of endeavour. openEHR is happening and progressing to level four. openCare can happen, too. It can be made, and it can be done!

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104 P. Benenson, 'The Forgotten Prisoners', *Observer* (28 May 1961).

# 10. Half and Whole–Halfway between Information Age and Information Society

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The previous chapter will have left no doubt that there remains a huge amount still to do. Echoing Bon Jovi, this final chapter builds on a theme of being halfway there! We are at halftime in the transition from Information Age to Information Society health care. The chapter is a halftime report to the new teams girding their loins to come on for the second half. Human societies define themselves by their values and traditions and how they adapt and change in times of anarchic transition.

In whatever way we evolve as individuals and communities in the coming years, the information technology and utility that inform, support and enact health care systems and services will only contribute in half measure to what is needed to create and sustain health and health care for the Information Society. I recount, with her approval, the personal struggle through medical accident, intensive care and prolonged rehabilitative care of my doctor wife, over a two-year period. The story of her survival and recovery is bipartite: half about the health care services and support she experienced and half about her character, struggle and determination to get well.

The book comes full circle, having connected around Shiyali Ramamrita Ranganathan's (1892–1972) circle of knowledge and a cycle of learning about the coevolution of health care with the science and technology of the Information Age. This has been a first half of transition played out on a landscape populated with emerging and immature information technology. It is a preface to a second half, yet to come, to be played out in the context of maturing information technology and new bioscience, artificial intelligence and robotics, accompanied by an emerging and supportive, citizen-centred information utility. It will play out in the context of new device technologies, information systems and networks that enable much more of health care to be based at home and in the local community, be that in city centres or the most remote of outback communities in the world. There will be a continuing adventure of ideas, anarchy of transition and reform, played out around new circles of knowledge and cycles of learning.

To my brothers and sisters—the half and the whole.<sup>1</sup>

This, my first school, was a school for four-year-olds to twelve-year-olds. I remember the windows looking out onto the valley. We were half prisoners and also half special, to be able to see the valley and everything that was happening.<sup>2</sup>

Woah, we're halfway there  
 Woah-oh, livin' on a prayer  
 Take my hand, we'll make it, I swear  
 Woah-oh, livin' on a prayer.<sup>3</sup>

Writing this book has been a process of discovery. Looking back on how it has unfolded, it is striking how many times the issues discussed, chapter by chapter, have played out in half and half stories: theory and practice, lifespan and lifestyle, local and global information governance and standardization, discipline and profession, health and social care, Localton and Globalton village life,<sup>4</sup> science and engineering, Grand Challenge and Wicked Problem, Big Data and Little Data, defeasible and infeasible knowledge, object orientation and functional programming, information models and message protocols... the list goes on! The novelist Charles Dickens (1812–70) wrote in the language of half and half when describing the era of the French Revolution as the best and worst of times.

We might think of two halves as a dichotomy—one or the other, either a) or b). But as Robert Oppenheimer (1904–67) set out insightfully in his 1953 Reith Lectures,<sup>5</sup> which I have drawn on in several chapters of the book, they often appear, and can more usefully be engaged with, as complementarities, reflecting that the two in combination describe something more whole, encompassing different perspectives and points of view—both a) and b), as in Dickens's description of the best and worst of times.

The ongoing Information Revolution and the anarchy of transition that it has unleashed might also be described as the best and worst of times. Laurie Lee felt he and his classmates to be 'half prisoners and also half special' in their rural village school. We all might somewhat echo that feeling, in how we experience the information technology 'school' that both corrals

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1 Laurie Lee, dedication of his book *Cider with Rosie* (London: Penguin Books, 1959).

2 L. Lee, *Down in the Valley: A Writer's Landscape* (London: Penguin Books, 2019), p. 55.

3 Bon Jovi, 'Livin' on a Prayer', *Slippery When Wet* (1986).

4 On Globalton and Localton, see Chapter Seven.

5 J. R. Oppenheimer, *Science and the Common Understanding* (Oxford: Oxford University Press, 1954).

our lives and widens our view of the world! In concert with this revolution, we are living through the best and worst of times in health care.

Information technology has changed everything and will continue to do so. Having traversed seven decades of the Information Age, all around the circle of learning, drawing this book to a conclusion, here, brings a sense of an ending, but not of completion. Realising my dilemma over when to call a halt to the three years of work that it has involved, my astute consultant cardiologist son, Tom, advised me two weeks ago that it was 'Time to bookend your book, Dad!' Best to follow one's wise children's advice! No doubt there will be odd stray bits of its evolving DNA still floating around in the text. At least that would be true to life; there is no advantage in being too pedantically tidy in telling such an evolving story!

This book ending is where we are, today, in exploring the relationship of information technology with the reform and reinvention of health care. The field feels to have metamorphosed significantly, even as I have been writing the book. Some of the topics covered have donned new colours, chameleon-like, and might already be ripe for some reinvention, too! That is inevitable in such a fast-moving field and the book is offered more as a personal career songline than a definitive history—I doubt that any such history could yet be written. I have recently added some further reflections and speculations about artificial intelligence (AI), in the context of the 2023 debate about its feared considerable downside potential. This builds on coverage of the topic in Chapters One, Two and Eight. I will aim to add useful updating commentary, from time to time, in the online additional resources for the book.<sup>6</sup>

Today's reality feels like a Bon Jovi 'halfway there' stage in the adventure of ideas that has been unfolding in the encounter of the computer with health care, in the transition through the Information Age towards the Information Society. Health care services and professional practice face the challenge of integrating various threads of this adventure together, weaving without knots, shaping the many halves into useful wholes, and keeping clear of rabbit holes and black holes! Exploring how to deploy and enhance the best, while correcting, mitigating, or avoiding the worst.

Health care services, among many components of the systems and services that are 'there' for us in life, are crucial in enabling us all to be and keep well, and to flourish to the best of our opportunities and abilities. But they only get us or keep us, in Bon Jovi style, 'halfway there'. The other half concerns what we do, and are enabled and capable of doing, for ourselves. This involves many dimensions of awareness and discovery about our

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6 Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

bodies and ourselves, our individual capabilities and interests, and the circumstances in which we live, which change and evolve uncertainly, as do our needs, expectations and behaviours, too, as we grow, live more fully and age longer.

It is best not to get too fixated on binary divisions in this discussion, conditioned into thinking of the whole as somehow comprising two separate and equally sized parts. We have plenty of that kind of thinking with the digital world of the computer and it is seldom true to life, except perhaps in the most abstract of realms of John Archibald Wheeler's (1911–2008) 'It from bit', which I discussed in Chapter Six!<sup>7</sup> It might be better to think of parts of a whole, as formal logic often does, but the language of halves is pervasive and persuasive in everyday life and behaviour. There are many ways in which we use this imagery.

The most recently contested Presidential election in Poland was decided 51.2 percent against 48.8 percent. Brexit, which set a generational change of course in UK national life as we left the European Union, was considered a clear mandate at 52 against 48. These might rather be described as half and half, noisy judgements. Binary choices made at random would lead close to a 50:50 result. 'Random' implies complete uncertainty and, less charitably, could suggest a lack of care or consideration. Some situations are described as a glass half full or half empty, signifying optimistic and pessimistic predispositions when thinking about them. 50:50 describes an equal cleaving towards alternative perceptions or predilections; it can signify dualism as well as dichotomy; complementarity as well as difference. 50:50 seesaw arguments between opposing viewpoints sometimes escalate, being expressed with increasing intensity on either side. As with the placing of increasing weight at each end of a real seesaw, when seeking a dominant position, the outcome is often neither dominance nor balance but a no-fun, broken seesaw! Much of politics in these stormy times, feels rather like a broken seesaw, and, sadly, much of health care, too. The computer has been closely implicated in the breaking, albeit in good ways as well as bad. In many dimensions and localities of health care services, it is the best of times, too, with achievably better to come, very widely.

We also talk about being too clever by half. This was the message of Mervyn King, when he suggested that sophistication in modelling and analysis was less useful in managing national finances and economies than it was given credit for, and that storytelling and ability to cope with, as much

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7 J. A. Wheeler, 'Information, Physics, Quantum: The Search for Links', in *Feynman and Computation*, ed. by A. Hey (Boca Raton, FL: CRC Press, 2018), pp. 309–36, <https://doi.org/10.1201/9780429500459-19>

as shape, uncertain events, were also important.<sup>8</sup> Norman Davies argued for the greater use of art and storytelling as sources in the writing of history, and less dependence on retrospective analysis and historicism.<sup>9</sup> I have taken their learned and experienced advice to heart while writing this book, and now in recounting some half-and-half personal stories, here.

Last year, I received a letter from a former colleague who had suffered a heart attack and was in continuing poor health. He commented on the sorry state of information systems in use in the wards where he was cared for, and how much time was devoted to battling them. It brought home for both of us the 'halfway there' stage in achieving the professional goals we had shared through our careers. We may not be 'livin' on a prayer', but we are, for sure, only 'halfway there' to health care services that meet the challenge and opportunity of the Information Age and match the needs and opportunities of the Information Society that we are creating. It is halftime in the match. The second half and the first half are different phases of a game. The first half may not go so well but the second can prosper nonetheless, overcoming and adapting to adversity, entering new spaces and finding new personal resources and fulfilment. Human nature and community are good like that.

I tell, now, a deeply personal and emotional half and half story, encouraged to do so by my Polish doctor wife, Bożena. It is half-and-half about her survival and recovery from a critical illness. I do so, not to dramatize or critique the painful and harrowing issues it exposed, but to give a detailed, albeit extreme, example of where information utility is fundamental in support of health care, and how its lack can greatly amplify the inevitable difficulty and distress of coping with a prolonged emergency, as patient and carer, as well as hamper and compromise the ability of professional teams to function effectively. It is also a story of the half-and-half of what medicine can do to both harm us and keep us alive and what we can and must do for ourselves, to recover and keep well. Bożena wanted me to tell this half-and-half story like this, as it was experienced by us both.

Five years ago, Bożena was in life-threatening haemorrhagic shock in provincial Poland, after emergency abdominal surgery that should never have been needed, nowadays. The ensuing struggle over four months—within and between two countries with different languages and contrasting clinical cultures, through two intensive care units and in wards of four hospitals, and in blue-light road and air ambulances—was a life and death experience never to be forgotten, from frozen November to Spring-like Easter. It progressed through all professions and levels of care, and, throughout, the struggle was

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8 M. King, *The End of Alchemy: Money, Banking and the Future of the Global Economy* (New York: W. W. Norton and Company, 2016).

9 N. Davies, *Europe: A History* (Oxford: Oxford University Press, 1996).

impeded and exacerbated by lack, non-communication and non-coherence of information. Lack of mutual fluency in spoken language was also an impediment that I had to struggle with each day, for two months in Poland. I was on my own there, visiting and staying with her through the day, based at night in a flat rented nearby to the specialist centre she was transferred to in Warsaw, remote from but supported amazingly by family and friends in the two countries.

Medical insurance company communication between the two health services was almost non-existent and depended solely on me, standing in busy hospital corridors outside my critically ill wife's wards, piecing together communications by mobile phone. I needed to keep in touch with family and friends, medical teams and colleagues, nearby and far away, to enable her to receive the care needed to save her, persuading one level after another of services to cooperate and then get her transferred back to England, to weeks of specialist care there and then home. It was often touch and go, throughout.

In the rescue stage of Bożena's critical care in Warsaw, secured for her by a close clinical academic colleague of mine, the intensive care unit (ICU) was exemplary. When conscious again, she could scarcely move and only with great pain and unsteadiness. As time went by and she was cared for in an acute surgical ward, her urgent needs for nursing attention—overflowing abdominal drains, frequent nausea, ataxia—stretched capacity. The ward nursing and post-operative rehabilitation care was wonderfully and sometimes quite fiercely, thorough. This approach was both effective and reassuring! Through the months in Poland, I worked as one of the hard-pressed ward team during my day long visits. For example, they would ask me to move her through long underground corridors for extremely onerous investigations, and help her, hour by hour and day by day, massaging her depleted limbs and supporting her in slow and incremental faltering steps away from her bed and up and down the ward corridor.

Bożena's condition first improved and then deteriorated again. Laboratory measurements and scan images came back from computers but the underlying damage to her gastrointestinal (GI) tract, resulting from the surgery, was not clear, although the ICU chief had suspected it. Clinically, there was evidence of abdominal fistula, because of the considerable fluid leakage now present, but the team had been unable to discern its origins. With no clear action plan, it was decided to pause further action through the two-week Christmas holiday period, when only a skeleton staff team were on duty.

Over Christmas, Bożena gradually became extremely ill once more and I asked an empathetic, more junior clinician on duty, who had befriended us, if it would be okay to provide me with the CT images on a compact disc.

I uploaded them from my laptop in the rented apartment, via the Cloud, to the UK, where my doctor daughter was able to draw on her own tertiary care network, to assist in getting a rapid specialist review of them. This helped to clarify and stabilize matters, by pinpointing the location of two abdominal fistulas through which fluid was leaking inside and outside Božena's body. Potential professional and legal sensitivities feel somewhat blurred in such situations! One wondered whether faster referral for a second opinion, like this, perhaps even to an AI algorithm, might have spotted and reported them on the original scan. That might have avoided and circumvented three weeks of considerable distress and the need for further, extremely uncomfortable radioisotope scans, which she could hardly endure.

After nearly two months of this oscillating clinical improvement and decline, and continuous parenteral nutrition, a clinical transfer to England, between the two health systems, was agreed. The transfer itself was very professionally executed by an air ambulance team that flew in from Germany to collect Božena from the ward in Warsaw and deliver her under the care of the NHS in England. I followed on to the next commercial flight. On arrival in England, the air ambulance doctor and nurse were professionally bound to stay with her until she was finally through the delayed and protracted process of admission to an isolation ward. None of the extensive clinical information that had been provided to the insurers—when they were agreeing and subsequently arranging the transfer, in multiple texts, emails and phone calls—had reached the admitting doctors on duty there and she was placed in an hours-long Accident and Emergency triage system. A further protracted queue of administrative delays ensued while a bed was arranged. The air ambulance had to miss its return time slot, and this no doubt escalated the insurance bill! Another part of the NHS subsequently investigated and sought proof of her eligibility for free treatment, although a British citizen and resident here for twenty-five years!

The receiving English district hospital clinical team quickly argued for and sought transfer for her to a specialist centre, the need for which had been clear from the previous history. This information had escaped the administrative protocols in operation between the insurance company and the two country health systems, when deciding where to receive her into the NHS. This further transfer was eventually accomplished, and everything quickly improved with the confident and calm treatment she received there, after the fistula fluid leakage had been endoscopically stemmed and the persistent infections defeated. Phew! Hard to write about, even five years on!

In the many hospitals and wards through which Božena passed, and the insurance, airline and intergovernmental systems dealing with the transfers, her personal data must have been keyed, processed and transferred through,



I would estimate, a hundred or more mutually incompatible information systems and onto inches-thick piles of paper. And in each ward where she lay, much professional and administrative time and capacity were devoted to battling with antiquated, poorly and slowly performing computers. Continuity of care from service to service was pieced together through human contact. Information utility failed to deliver on any of the monads, but not for lack of anyone's best efforts. Everyone was trying to help her and that did help, hugely.

But this emergency was only one half of the story. The struggles did not end after final discharge home, months later. Home-based services were still needed for stoma management and potentially for parenteral nutrition, that had not ceased for three months, inevitably risking infection and other complications, until just before her final discharge. There was a 50:50 chance that further reparative surgery would be needed. Fortunately, in the end it was not, although damage from the original surgical misadventure and its emergency postoperative management persists.

In retrospect, arriving home, together again, we were still only halfway there. From this time, my wife's iron will kicked in—herself a doctor, and so all too aware, gradually, of her situation. She was determined to get well and restore her disintegrated, bedraggled and shattered body. Always an exercise acolyte, she was determined to walk, once free from the beds that had imprisoned and disabled her, in extreme discomfort, for so long. We walked around the lake and park of St Albans every day for the next four months, watched the fish and the herons, geese, ducks, moorhens and coots, as they emerged into Spring and Summer, with their new broods. She spurred us on to two or three circuits, where I—tired, as well—was ready to give up for a coffee and baked apple at the nearby mill. Once more around and we will go there, she would say!

She made herself well and we started our dance classes again. We met a most lovely and skilful, former paramedic Pilates teacher with experience of surgical rehabilitation. Through her, my wife found her way to a nurse specialist offering abdominal massage for relieving postoperative adhesion, which was a significant problem. Her inspirational ballet teacher, who had retired from the Royal Ballet and now ran classes lovingly took us both on with weekly balance and posture exercises, based on ballet.

This was the other half of getting to the Bon Jovi 'there'. The goal of getting better and moving forward; my wife's knowledge of her situation and services that might help her; our shared professional network enabling us to find our way to them; our brilliant network of family and friends willing us on and supporting us—all of these were essential. But at the centre was my wife's ownership of the quest to get 'there'. It challenged even her iron but adaptable will, steeled in the forging of her resilient and independent

character in a former life feeling repressed under Communism. She did, and does, extraordinarily well. Our wonderfully balanced and insightful general practitioner (GP) blinked when he saw her months after the critical events, and having heard the history, telling her she was a miracle. Her specialists wonder whether they are needed any more—well we still need them, even if just to be ‘there’!

A less personal story, now. The Covid-19 pandemic had been exactly one year in duration as I wrote the first tentative draft of this concluding chapter. It has been a half-and-half story about treatment and containment. At the outset, it seemed that two years would prove a likely timespan of coping and recovery towards a more stable daily life. It seemed that we were, indeed, halfway towards that after one year, but the virus and the problems it presented continued to mutate, as they do still—a third year having elapsed as I finalize the manuscript, now. Given the global interconnectedness of both science and societies, and comparing with the 1918 Spanish Flu, the time duration of the pandemic today looks to have been lessened because of science and industry and increased because of globally rapid transmission. It seems that the two pandemics have thus followed somewhat similar trajectories, over time and season. Thankfully, thus far it seems that fewer have died before their time.

The key questions now are not about why preventive measures were not in place, that could arguably have enabled containment of the infection more effectively and manageably, but how new capabilities can and should be built into the health care services of tomorrow, to ensure things are better managed next time—half-and-half supporting treatment and prevention. A coherent care information utility will be central to such capabilities. Non-coherent data collected around the world has clouded understanding of the current pandemic. The global openEHR community had systems in place for devising, capturing and sharing a coherent and clinically standardized dataset to record the phenotype of the disease within a few weeks, working across the world where information systems already existed to capture it. This was because it had created and put in place the elements of a care record platform infrastructure and method, able to frame and host such coherent, vendor- and technology-independent, care records.

And a final half-and-half story on a lighter note. Science learns a lot from the study of twins (they, too, being akin to two halves of a whole). The elements twins share give extra opportunity for the more accurate study of those elements they do not. We have two pairs of twins in one of our families. It is wonderful to have seen them grow from childhood, through bonded years of development where identity is more at one, into differentiation of personality, sparring with one another as they grow, both in themselves and into the outside world. The oneness is balanced against

the twoness. And the twinness of the girl twins and the twinness of the boy twins is a new pairing of relationship. They spark uniquely and differently, just as in any family. They are a kind of half and whole, one on one, and two on two. The whole is greater than the sum of its two half parts.

As the foregoing examples and stories have illustrated, health care is replete with half-and-half complementarities. Health care intervention and the body and mind getting better, are half-and-half. Dependency and self-reliance are half-and-half. Effective action is half about what we know and can respond to, evidentially, and half about what we do not and cannot—thus acknowledging and coping with the implicit uncertainty of many consequential judgements and decisions that must be made. The idea that such half-and-half human balances could, foreseeably, be wished under the sole purview of AI, looks too clever by half!

A quotation from Whitehead, that featured also in the Introduction, seems prescient of the dilemmas now surfacing in relation to the human connectedness of machine learning and AI.

It is the first step in sociological wisdom, to recognize that the major advances in civilization are processes which all but wreck the societies in which they occur [...] Those societies which cannot combine reverence to their symbols with freedom of revision, must ultimately decay either from anarchy, or from the slow atrophy of a life stifled by useless shadows.<sup>10</sup>

Equally pertinent were the imaginings before the Information Age, of such as E. M. Forster (*The Machine Stops*), Aldous Huxley (*Brave New World*) and George Orwell (1984), and the recent novels of Ian McEwan (*Machines Like Me*) and Kazuo Ishiguro (*Klara and the Sun*), which have been referred to at several points in the unfolding storyline of this book. Today, in 2023, there is a new crescendo of concerns about AI. The difference is that that the dark imaginings of yesterday are rapidly emerging into the stark light of today. These are half-and-half expressions of optimistic concern that we realize the immense potential benefits of machine learning, and apprehensive concern about a potential Pandora's box of unregulated, or impossible to regulate, AI unleashing a chaotic evolution towards the Neocene.

In Chapter Seven, I visited Eric Topol's perspective of the constructive potential of AI to enable the rescue and reform of health care, as set out in his 2019 landmark inukbook.<sup>11</sup> We are today starting to think more cautiously

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10 A. N. Whitehead, *Symbolism, its Meaning and Effect* (New York: Macmillan, 1927), p. 88.

11 E. Topol, *Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again* (London: Hachette, 2019).

about the half-and-half of artificial intelligence and human intelligence. About what they are, and, probably more importantly, how their wholeness might play out in the balance of computer and human reasoning in the context of health care, for both patients and professionals. These issues have started to look more consequential as AI accelerates towards the Neocene and its potential impact on society is compared with that of the Internet. If comparison with the Internet's societal impact on machine and human communication and computation is the yardstick, surely an AI that burrows deeply into, and may take over, substantial domains of human skill and cognition, is doubly deserving of cautious concern. Revisiting Joseph Weizenbaum's (1923–2008) story of *Computer Power and Human Reason*, first published in 1976, is a good starting point.<sup>12</sup> My browning copy of this inukbook dates from those early times. Will these two halves function as a complementary whole or as conflicting and destabilizing forces? AI is a very rapidly evolving domain. As the song goes, 'You ain't seen nothin' yet'!

The first small academic unit that I created at Bart's, in around 1991 was called Clinical Skills and Informatics. I explained its origins in Chapter Four. As I wrote, there, little could I or my close colleague in creating the Bart's Clinical Skills Centre, Jane Dacre, have imagined how rapidly and remarkably the interrelationship of health care, professional practice and computer technology (including AI) has advanced over the years, with profound implications for health care education, service delivery, governance, regulation and legal accountability, as well as for citizen access and expectations of health care services, as well as their management.

My principal thoughts in relation to the use of AI in medicine are twofold. They revolve around the performance of AI algorithms in the defined context of performance of tasks that are currently the domain of clinically qualified and regulated specialists. And then around what might prove a Pandora's box of potential consequences that this could set in chain, reaching deep into the heart of health care education, professionalism, governance, regulation and legislation, on which rest checks and balances in the assessment of skills, adjudication of fitness to practice, litigation of clinical risk and harm to patients, and the trusted relationship of citizen and professional.

Alan Turing (1912–54) proposed a test to determine if a computer-mediated dialogue is being controlled by a human behind the scenes, or just by a computer program. Could the user detect the difference? Things moved on. Joseph Weizenbaum's experience of how human subjects 'conversed' with his ELIZA program, which I discussed in Chapter Eight,

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12 J. Weizenbaum, *Computer Power and Human Reason: From Judgment to Calculation* (Harmondsworth: Penguin Books, 1993), p. 209.

gave him pause for concern. Some were, he reported, easily drawn into engaging quite intently with ELIZA's simplistic level of machine-simulated 'empathy'. And other investigators reported, in the context of the elicitation of clinical histories of sensitive personal matters—for example, relating to alcoholism—that many of us are quite happy, and even happier and are more truthful, when interrogated by a machine algorithm rather than a human. Much as when we now give details of pre-existing medical conditions when taking out travel insurance.

Chatbots such as ChatGPT seem to have passed the Turing test threshold and now opine fluently on all subjects under the sun, even if a bit repetitive after a while—but aren't we all, especially as we get older; I certainly am! In his 'The Crack-Up' article, published in the *New Yorker Magazine* (1936), which I also discussed in the previous two chapters, F. Scott Fitzgerald (1896–1940) proposed a test of a different and more embedded ranking of intelligence, saying that 'The test of a first-rate intelligence is the ability to hold two opposed ideas in the mind at the same time, and still retain the ability to function'. Fitzgerald's point was, I think, that we need good intelligence to guide us in how we function in the face of inevitable half-and-half matters that point us in different directions. Being reflected, perhaps, in the way the two halves of our brains work—for example, in Kahneman's thinking and acting fast and slow. I wonder how such thinking about human intelligence will play out alongside the machine's intelligence.

It will be interesting, for example, to see how AI advisors might respond to a request for an opinion about the complex and multi-faceted ethical dilemmas concerning, say, a sick pregnant woman requiring aggressive treatment for an ovarian cancer and parallel concern for their near-term but still premature unborn child. Both will potentially be highly affected, whatever decision is taken. There may be urgent decisions to be made about inducing early birth and delaying treatment, in the context of the mother's wishes, her clinical condition and that of her unborn child, in the context also of term of pregnancy, risk of harm and maybe also culture and religion. In what ways, and to what extent, are we ready for an AI engagement with such complexity of clinical and ethical dilemmas?

It may not be too difficult to keep the real and virtual world of intelligence apart, at a careful distance, in this case. But that may not be so easy when seeking to draw boundaries between where AI does and does not engage in the broad spectrum of health care education and assessment, clinical practice, governance, regulation and litigation, anticipating the consequences that then might flow. If I were naming an AI health care guru that might be consulted for an opinion on complex and multi-faceted clinical decisions, not that I would feel at all qualified or competent to enter such a contentious domain, I think I might call it PandoraDoc! That name

came to mind remembering Sam Heard and Dipak Kalra's ParaDoc GP practice management system, from the 1980s and 1990s, which featured in my profile of Sam's contribution to health informatics, in Chapter Eight!

Over recent times there has been a growing emphasis on comparing AI system and clinician performance in the context of well-framed clinical domain tasks. These typically require an extensive reference data set, first to develop the AI method and then to test its performance, prospectively and compare it with that of clinicians, in terms of the sensitivity and specificity of the results obtained. It is very early days in which to review this domain since AI methods are advancing so rapidly. In a July 2022 study of breast cancer diagnosis, Christian Lebig and colleagues showed that radiologist performance consistently outperformed the stand-alone AI in use.<sup>13</sup> They conducted a carefully constructed set of trials where the AI was first used to triage cases and bank its answers for those where it was confident of its predictions, while referring the less certain ones to a radiologist for the decision. A variety of different triage criteria were investigated. This resulted in the combined system consistently outperforming both AI and radiologist acting alone, achieving improvements of several percentage points. This finding held true for the testing in many different clinical subgroup and imaging device subdomains. Such exhaustive study of Receiver Operating Characteristics (ROCs) of human and AI systems is the right way to proceed, as highlighted in Chapter Two, but it would potentially be important to know more granular clinical detail about the patients misdiagnosed, as to whether there are any patterns evident there.

More significant consequences would likely flow from similar studies where the AI is found always, or much more often, to significantly outperform expert clinicians. In that scenario, the standing of the human expert, which is very influential in the context of traditional clinical governance, risk management and the assessment of clinical skills and competence of clinicians to practice, will come centre stage. In the context of my leadership of Centre for Health Informatics and Multiprofessional Education (CHIME) at University College London (UCL), I was close to the unfolding domains of clinical risk and professional regulatory practice, with close-by senior scientific and clinical colleagues of mine playing leading national roles. In the litigation of cases involving potential clinical negligence, a common yardstick is 'how a competent professional might have been expected to act in the situation being discussed'. If the AI consistently outperforms professionals in the domain of action being litigated, are either

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13 C. Lebig, M. Brehmer, S. Bunk, D. Byng, K. Pinker and L. Umutlu,, 'Combining the Strengths of Radiologists and AI for Breast Cancer Screening: A Retrospective Analysis', *The Lancet Digital Health*, 4.7 (2022), e507–19.

the expert witness giving evidence about practice norms or the clinician under investigation still deemed competent to act? Would this start to raise legitimate concerns about clinicians' 'competence to practice', more generally.

I could invent more such hypotheticals and others could produce better ones. AI-related issues that bridge between professional practice, regulation and law will likely have snowballing and potentially far-reaching *sequelae* in the context of the regulatory and legal norms and legislation that apply. Further risks and conundrums then arise. What happens if the AI goes down for forty-eight hours and harm to patients is caused as a direct result? What human clinician backup must be kept there in reserve, to take over? All the passport e-gates in the United Kingdom failed for twenty-four hours yesterday, as I write, and caused many hours of delay for travellers, who were likely to be in an angry, holiday-spoiled, litigious mood!

Two final, clown-like and off-the-cuff, Aunt Sally hypotheticals!

Radiology reporting for a hospital is outsourced to a company using proprietary AI software. The company starts to underperform and bankrupts. The hospital, as with others, has economized on radiologists and fewer doctors, nationally, have developed such skills. Does the hospital switch to a new AI provider, if there is one, albeit risking that the company, perhaps sensing a monopolistic opportunity, might promptly double its price per report? Does it alternatively attract scarce radiologists to its side by doubling the fee it pays to them? If it finds and signs up to use another proprietary and equally opaquely reasoning AI, what about the coherence of the decision making of the two algorithms, by now persisting into the hospital's digital care records? Given their opaqueness, how can a case review decide what to do if the two disagree about historic clinical decisions and recommendations? Maybe the AI algorithm used by the now bankrupt former AI provider is no longer accessible for checking. Such investigations of different clinicians' practice do occur and usually involve scrutiny of care records. By then, maybe other AI chatdocs will be involved in creating these, too. How is the performance of such clinically engaged but opaquely reasoning AI algorithms to be weighed, and who will decide whether they are and remain 'fit to practise'?

Will AI chatdocs appear to prosecute in 'courts' adjudicating damage to humans in the context of medical accidents in this now heavily chatdoc-populated domain? Will they be 'called' as 'expert' witnesses to 'give evidence' in relation to a review of disputed practice and what was and was not done at the time? Will another expert chatdoc be the judge in this court and yet another be defendant, or act for the defence? How many chatdocs will be selected for a panel of 'expert' 'adjudicators' or members of a jury, and which chatdoc(s) will choose them?

These may be fanciful hypotheticals, but they could be improved on to illustrate more clearly the issues faced when deciding what can and should be safely delegated to the opaquely reasoning AI machine. And how the professionally regulated clinicians, and those who regulate them, should relate to the machine. What should remain wholly in the human domain? Health care interacts all around the circle of knowledge and is based on many checks and balances of discipline, profession, organization, industry and governance. Clinical governance and regulation are complex human concerns.

No one has answers to these sorts of hypothetical questions and indeed they may not yet be well-framed. There are likely not any right and wrong answers, just answers adjudged consistent with law and the values and regulations implicit in law. Both the questions and the answers must be learned as we will surely be presented with such grey area scenarios and half-and-half boundary zones. It is not enough that the AI works better than humans in a specific domain of competency. What are the consequences for health care and society if human professionals are no longer there able to do things and to be involved in critiquing how they are done?

Some of the AI of the future could play out in focused and bounded tools that relieve much time of human professionals from performing well characterized tasks that the computer can be relied on to perform better. Some could tend towards noncoherent and proprietary machine-devised and enforced decision-making protocols, based on opaque AI-based virtual caricatures of complex human decisions and judgements. Some could delve deep into human language whereby people express their health needs and concerns, missing or insensitive to nuances of a patient's usage of terms and non-verbal cues, lacking contextual knowledge about the patient and their home situation, constructing a virtual reality caricature of the patient and acting accordingly, but actually getting things quite wrong. We need to think carefully about the human relationships and fallback position if the AI fails. AI methods and their balance with human skills must be very carefully framed and their safe application assured.

Daniel Kahneman, Olivier Sibony and Cass Sunstein's recent book expressed caution about how AI will play out in society, while at the same time giving much evidence of demonstrably flawed human judgements and how they range far and wide in their knock-on consequences in society.<sup>14</sup> Topol's recent book proposed a bounded and evidenced use of AI as the

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14 D. Kahneman, O. Sibony and C. R. Sunstein, *Noise: A Flaw in Human Judgment* (New York: Little, Brown Spark, 2021).



saviour of health care from 'Shallow Medicine', by releasing much time for doctors to reengage more fully with direct care of patients.<sup>15</sup>

There will be much new learning needed in shaping the beneficial application of AI and adapting our human practice and governance alongside. Once again, a coherent care information utility seems a *sine qua non* of progress. I find it hard to imagine how something as potentially disruptive as AI could be constrained to evolve safely without a very large amount of coherently structured data on which to develop, test and assure it. One might anticipate that this will take decades to assemble and for the methods to be proved safe and digested into routine practices. It seems inevitable that AI will be widely experimented with, for better or worse, and regulatory ground rules in guiding this will be crucial. It will be by far preferable that testing be conducted *in situ*, in context of representative everyday practice and mutually coherent care record systems, rather than in a great number of non-coherent bespoke clinical trials.

As discussed in Chapter Two, formal logic has encountered much difficulty in bridging across defeasible and indefeasible domains in its reasoning about clinical knowledge—about particularities and generalities, as it were. One might reasonably anticipate that different but comparable difficulty may also beset AI methods, as they encounter the same noisy world of clinical appearances, as reported to them in omnisciences of observation and measurement collected from and about patients, in diverse everyday contexts. This will seep and accumulate into their empirically trained neural networks or whatever methodology they use, to hone their skills. The AI will then deploy its resulting virtual skills based on these virtual caricatures of the patients whose data it has been trained with, to make decisions about prospectively encountered real patients, where at one level or another every patient is in a sample space of one.

Clinical science relies on the methodology of randomized clinical trials to temper extraneous variability when tying down cause and effect in relation to clinical interventions. Over four or five recent decades there has been much focus on what became known as evidence-based medicine, which relies heavily on the yardstick of this methodology, albeit that some have argued that routinely collected data can be statistically modelled and analyzed, to achieve comparable reliability in estimation of the cause and effect of interventions.

In Chapter Seven, I traced this movement back to its founder, David Sackett, at McMaster University, who I used to meet, both there and when he came to establish the field in the UK and lecture at St Bartholomew's Hospital

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15 Topol, *Deep Medicine*.

(Bart's), at John Dickinson's invitation. Its motivation and importance are unimpeachable but how, then, is it that luminary authors like Topol, and the Deloitte team's report that I also introduced in Chapter Seven, describe so many of today's medical interventions as ineffective and so much of money spent on today's health care as wasted? Presumably they trust the evidence for these assertions, but I am always puzzled how this can be the case, if evidence truly does count in the way claimed for it? The situation they describe might suggest that formal evidence is not as significantly powerful a driver as might be thought, in relation to care quality. For me, the answer to this seeming contradiction seems likely to lie, to a significant extent, in the non-coherent, and disjoint scope and quality of information systems in use in health care, in how they have been envisaged and implemented, and in how they perform and are used. I am not so involved nowadays and stand to be corrected in that impression.

We will likely always be faced with coping with health care's intrinsically defeasible knowledge base and the difficulties in formal reasoning arising from the complexity reflected in the uniqueness of each presenting case, with its different contingencies, in different contexts, at different times. Oppenheimer also focused on this in his discussion of the uniqueness of how general laws play out in particular circumstances, and Bertrand Russell (1872–1970) in saying how all knowledge must be placed in a clearly defined context. Health care connects with multiple other services and the knowledge and skills they, in turn, encompass. In the face of this uniqueness of individual patients and their wide-ranging connections, we must be very careful in testing at each stage, as we open the door and give the floor to my AI PandoraDoc's paws and flaws. The Whitehead quotation at the head of Part Three of this book captures this reality rather emphatically well!

There is one final half-and-half that seems relevant to highlight here. This is one of both Grand Challenge and wicked problem. Deliberations about health care reinvention and reform often assume the language of 'Grand Challenge'. And the cap does fit up to a point, especially in the context of science and technology. Taming Big Data and AI and collecting population genomics datasets are major scientific enterprises. But we also need to think in the language of 'wicked problem', where everything affects everything else, and all manner of more human factors and uncertainties tend to assert themselves. How will the presence of whole genome sequences in digital care records play out in practice? How will the anonymization of unencrypted data be approached, in the face of the uniqueness of each patient's genome, assuming, of course, that encryption itself can still be kept secure in the quantum computing world?

The citizen-centred care information utility proposed in Part Three of this book can contribute a great deal to how successfully we tackle the

combination of Grand Challenge and wicked problem of tomorrow's health care. To have a chance of successful implementation, its values, principles, goals and methods need to be centre stage, guiding and communicating endeavours, coherently. And the teams and environments where they come together, iteratively and incrementally, likewise. Otherwise, as in the past, the problems of non-coherence, discontinuity, fragmentation and cost of services will continue.

This book has come full circle—from Shiyali Ramamrita Ranganathan (1892–1972) and the circle of knowledge, with its Grand Challenges and wicked problems, from Localton, to Globalton, from the invention of medicine to its reinvention in health care for the Information Society, from the foundations of knowledge and reason to the Pandora's box of the James Lovelock Novacene. We have moved from terrains of practical cubits to abstract qubits, and enriched and enhanced our scales of measurement and data to the zepto small and zetta large. Information technology and ambition have expanded our attempted gait, from shoes fit to step a metre to imagined seven-league boots. We exist locally and imagine and project ourselves globally. Ernst Schumacher (1911–77) wrote *Small Is Beautiful* to warn us about slippery slopes, there.<sup>16</sup> We have segued too far from acting locally and thinking globally, to thinking locally and acting globally.

I have gone full circle along my personal songline and am back enjoying the Oxford Physics Alumni Osborne Society, with the time and opportunity to tour the sites and meet the teams at places like the Culham Centre for Fusion Energy, the Harwell Diamond Light Source and the quantum computer laboratories in the Beecroft Centre in Parks Road. The artful design of this new centre is an architectural reminder of the interplay of theoretical musing and practical experiment. The labs must have extremely tiny levels of vibration as the entrained qubits get motion sickness! In order to work, they need peace and quiet, like any thinking brain, and are thus located deep underground. The building flows upwards through multiple levels, interconnected through central open wooden stairways within an atrium. The theorists and luminary sages of today and yesteryear live in the upper levels towards the clouds, where they, too, find their peace. And of course, there is an information network connecting throughout, communicating over the heights and depths. The building is an architectural parable of form and function, with the civil engineer's knowledge of foundations and structures and their vibrations underpinning it all. It is an ongoing story of people and computing machines, and their goals and capabilities. And it is advancing towards the Novacene—we do not know where to, but somewhere.

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16 E. F. Schumacher, *Small Is Beautiful: A Study of Economics as if People Mattered* (London: Abacus, 1973).

Will the machines break from the shackles of NP-completeness? Will they break the security of today's data transmission? Will they render humanly intractable wicked problems, machine intelligently tractable? *Zobaczymy [we will see]!*<sup>17</sup>

The parallel of all this with atomic physics of the 1930s and Los Alamos and nuclear weapons is sobering. Did we need to learn how to make and deliver these weapons, and did a Hiroshima inevitably happen, before sentiments to contain dangerous political adventurism asserted themselves in treaties and cooperation, much weakened though those now appear to be. Does the marrying of theory and engineering of quantum computation carry Los Alamos-like risk that we should be preparing for. John Houghton, in a pessimistic remark regarding climate change, wrote that humankind only takes issues seriously after a major disaster. Will the Covid-19 pandemic prove to have been such an event? Will AI?

Advanced technology advances the cost and impact of mistakes and the difficulty of containing and reversing them. One difference, today, is in the power and footprint of international corporations—Google, Microsoft, IBM, Meta, Amazon, Alibaba, Huawei, Twitter. These have immense and beguiling clout. They can commandeer and cultivate talent, dominate and sequester markets and revenues, and innovate within the private realm to defend and secure these positions. They can outspend governments in pursuit of transforming information technology. They can do it more efficiently because they are able and free to establish an organic and supported culture of talented people, not unduly influenced or constrained by the wider world around them. But at the same time, they are legally obligated to commercial and not social ends. Perhaps, and more hopefully, ESG (Environment, Social and Governance) awareness, born of VUCA (Volatility, Uncertainty, Complexity, Ambiguity) experience, will change that, as Gillian Tett surmises and hopes it will.<sup>18</sup>

A deep commercial enclosure of knowledge might have happened in molecular genetics were it not for its pioneers, notably the luminaries—Fred Sanger, Sydney Brenner, Max Perutz, John Sulston, Francis Crick, James Watson, Paul Nurse, Janet Thornton and more—that cracked and shared the codes and the methods to exploit them. Of equal importance was the philanthropy and dedication of such as the Wellcome Trust, in helping to see off the Craig Venter ambition to patent and enclose the human genome for commercial exploitation. Thank goodness for the balancing of private

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17 On this Polish expression, see Preface.

18 G. Tett, *Anthro-Vision: A New Way to See in Business and Life* (New York: Simon and Schuster, 2021).

wealth and collaborative social endeavour that people like Bill and Melinda Gates have seeded in their Foundation.

We need to remember these stories and seek to better understand and support the information commons, assert the value and values of its communal ownership, and provide for its continuing and collaborative improvement and enjoyment. This is a central task of the second half of the information revolution, and we are halfway there. It is about caring for the health of the information world. Good information is not cheap or easy to acquire and will have diseases—fakery and falsity, overload and obscurity—these are givens in any times. We are all prone to them; they are malignant mutations in our genome and destructive memes in our minds. We can all do better in our personal second half and improve and build on what has been achieved in the first. Only when we have better understood the first half of the Information Age can we build forward and safely confront the challenge of reinventing health care services for the future. To do this we must learn, iteratively and incrementally, the new balance, continuity and governance they require and how this can and must be supported by a new citizen-centred care information utility, matching to and evolving with the Information Society of the future.

In this, we must not dream of any coming Utopia; Gulliver discovered its wicked features. As in *The Tale of Two Cities*, the best and worst will sometimes occur simultaneously. Human problems will remain wicked, the solving of one leading to another. Our challenge is to stop them from becoming an ever greater and more complex danger to human wellbeing and survival. Good ideas can create global utility and bad ideas can unleash global disaster. Good ideas start locally. The little and local and the big and global must be made to balance, over time. In locally centred contexts, crashes are mostly local, too. In globally centred contexts, crashes are global, too. Big Data is not a panacea. An idea that scales 'bigly' from the little, becoming global and destroying the local that it grew from, is not a good idea for the future. The wake-up call of the 2020s is to use the local or lose the local, and thereby lose the global as well. AI must prove its potential and fit for human needs. Care information utility is an idea that will depend on its participants feeling part of it and playing, and being enabled to play, their part.

And politics as ever poses its own wicked dilemma, intrinsic since the Greek demos and polis. It alone cannot resolve wicked problems, and those problems cannot be resolved without it. We thus face a choice about where to work and what to do. In health care we must focus on making wholes from its half-and-half components, in concrete and useful ways, recognizing the paradox that one writes the script of the other. Health writes the script of care and vice-versa. Independence writes that of dependence and also vice

versa. But the one common language of health care is a half-and-half, too. It is human contact and information, joining the two halves of every citizen's lifespan and lifestyle and of their carers' everyday lives.

Is the idea of care information utility an example of Yuval Noah Harari's dataism? We must work to create it, and thereby show and engender trust, that it is not! Things don't need to progress as he fears. We can look back in anger or look forward with a mixture of audacious hope and pessimism—those, too, are half and whole. We must do our bit and stay the course. That is something we can all make and do. In creating the care information utility, we can all aspire to be one of Elena Rodriguez-Falcon's 'ingeniators', reflecting ingenuity, imagination and proficiency as a community of openCarers, bringing health care to a safe landing in the Information Society of the future.



# Postscript

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What we call the beginning is often the end  
And to make an end is to make a beginning.  
The end is where we start from.

–T. S. Eliot (1888–1965)<sup>1</sup>

History says, Don't hope  
On this side of the grave.  
But then, once in a lifetime  
The longed-for tidal wave  
Of justice can rise up  
And hope and history rhyme.

–Seamus Heaney (1939–2013)<sup>2</sup>

A preface starts a songline and a postscript, at its end, becomes a preface to new songlines, as life moves on. A postscript frames the start gate of a new circle of endeavour, with new horses for new courses, equipped and re-equipped with what has been learned on the previous circuit. There has been a great deal of invention and learning ongoing throughout the Information Age, and there is much relearning and reinvention yet to come, not least in the context of health care and its encounter with the computer. New devices, information systems and networks will lead to radical innovation in who does what, when, where, how and why, in furtherance of every citizen's health and health care. Not just in wealthy countries but everywhere, from the centre of cities to the most remote of outback communities. Low-level satellites can now provide the most remote of communities with solar and battery-powered one-hundred-and-twenty-megabit broadband connections to the Internet. My long-term clinical colleague, Sam Heard, uses this in his frequent visits as a doctor for Aboriginal communities living many hundreds of kilometres from Alice

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1 'Little Gidding', *Four Quartets*, ll. 213–15.

2 *The Cure at Troy*, ll. 1597–1602.



Springs. He attests to the transforming potential this will bring to the range of medical services that will increasingly prove possible there.

The aftermath of war was an optimistic preface to my life. And what now flows in the aftermath of the first half of transition through the Information Age towards the Information Society, as recorded in the now historical songline and storyline of this book, should, likewise, be an optimistic and creative one, where Seamus Heaney's hope and history do, and are made, to rhyme. One in which Robert Putnam's and Thomas Piketty's optimism about upswing in society proves well-placed.<sup>3</sup> Making and doing are about imagination and creativity. Realism resonates somewhere between hope and pessimism; imagination and creativity somewhere alongside audacity. My book seeks to encourage an imaginative and creative realism, as a complement to Barack Obama-style audacious hope, and Mervyn King-style audacious pessimism.

As with Erwin Schrödinger (1887–1961), I have connected at a considerable distance with Edward Gibbon (1737–94) and Seamus Heaney, through shared affiliation with Magdalen College, University of Oxford. Gibbon hated the place—I imagine few who have experienced its community and beauty would hate it today! Gibbon said he spent the most fruitless time of his life there—at aged fifteen, before departing to Lausanne, funded by his father, to start on his journey of literary and historical scholarship that informed my Chapter Two. Heaney had a better time in his regular visits, being a guest of the College President and welcomed and cared for most warmly. His poem *Postscript* has informed my *Postscript*, here. It is an emotional picture, evoking themes of nature, experience and time. He presents images that he says can only be experienced once, which cannot be repeated. Alfred North Whitehead's (1861–1947) more apocalyptic warning about major transitions in society, which I quoted at the outset of the book, has resonated with the uncertainty of transition through the Information Age. This, too, is not repeatable, but its damage is repairable and its good things sustainable.

The special times that have overlapped before and after the coming of the Information Age have seen events pivotal to human evolution that cannot be repeated. There is no way back. We are like Julius Caesar crossing a bridge over the Rubicon River. The Information Society on the other side of our crossing remains half seen, and half made. Personal songlines, like mine capturing an experience of the crossing, are unique assemblies from

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3 R. D. Putnam, *The Upswing: How America Came Together a Century Ago and How We Can Do It Again* (London: Simon and Schuster, 2020); T. Piketty, *A Brief History of Equality* (Cambridge, MA: Harvard University Press, 2022).

selections of sources, and also not repeatable. They cannot be retraced and discovered anew.

In *Zen and the Art of Motorcycle Maintenance*, Richard Pirsig (1928–2017) describes a motor cyclist on a journey across the States.<sup>4</sup> He takes in the scenery and muses about his life and its breakdowns and failures. He reflects on the motorbike and its breakdowns and failures. He connects his experience of life with the nature and behaviour of the machine. He had a more human appreciation of the good qualities and potential of machinery than did E. M. Forster (1879–1970) in the *The Machine Stops*, that led off this book's Introduction. What is a good machine, what are its qualities? How was it made, how does it work, how is it maintained? What is its quality? How is it characterized, created and sustained? Pirsig's motorbike, as a metaphor here for information engine, can be polished and adored and its devotees love to maintain and repair it—for them, the maintenance is a meaningful activity, akin to the enjoyment of art. But for the user who has a motorbike solely as a means of transport, the important meanings are elsewhere. The utility of the machine for them is captured in one question: is it working as I need and wish it to? For Pirsig, the motorbike took him on a journey through a panorama of personal meanings in his life and relationships. The care information utility of the Information Society will connect everyone in a similar potential depth and variety of ways—good ways and bad ways, and everyone will play a part in creating the difference.

Machinery is imagined, prototyped, improved, refined and produced at scale, over many years. Users of the machinery, working ahead of the curve that leads to a dependable machine that does not frequently break down, pay the price of all pioneers, and often gladly so. They tune, service, repair and replace components that are still unreliable, and quickly dysfunctional. Machinery is loved and revered by those who accompany it through its growing pains, even when it breaks down. Tending to these breakdowns is a lot of their fun. But for most others, the breakdown and malfunction of machinery is an inconvenience and annoyance. They have no interest or capability in the computer equivalents of carburettors, starter motors, radiators, brake pads and discs and spark plugs. These have no meaning for them, save in the absence of the machinery that they constitute, and on which their life, to a greater or lesser extent, depends. They do not see the connections.

Science has explored life from the human body to the cell, inside the cell and to the processes that link energy and the machinery of life, with integration of cell and organ within body and mind, and within natural

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4 R. M. Pirsig, *Zen and the Art of Motorcycle Maintenance: An Inquiry into Values* (London: Bodley Head, 1974).

and virtual environment, and over time. In the currently ascendent era of life science and medicine, enabled by computer and machine intelligence, our understanding of cellular function is bridging from the physics of energy, charge and membrane transport to the circuits and networks of chemical reactions, and the abstract information networks integrating biological components within circuits and networks of bodily function. A similar transforming trajectory beckons for genomics, machine intelligence and robotics in the support of health care. The disciplines of mathematics, physics, chemistry, computer science, biology, medicine, health and social care all peer in, at different levels, through research, education and practice. As understanding evolves and the focus of attention changes, these intermediate levels of study disappear, melting into background. They may likely re-emerge, from time to time, in new forms, to reconnect across new levels, in new and unexpected ways. They remain important areas of focus and study in themselves. But in everyday life, the body and mind are also focused elsewhere—on community, work, value and reward, and health and care in living.

Worlds move on and pages turn. Uncertain futures take shape and play out. A new environment and new balance arrive—new sickness, new health care. Care information utility will be located somewhere at the centre of illness and wellness services, in their quest for coherent balance, continuity and governance. That centre will be a David Goodhart ‘somewhere’, anchored in head, hand and heart.<sup>5</sup> We all share responsibility for creating the somewhere that we seek and for carrying the workload that is necessary to be carried to that end. Information utility created without meaning anchored somewhere and somehow, can quickly degenerate into noise and bias, anywhere, anyhow.<sup>6</sup> Science has learned how to use information technology to tame and keep a handle on somewhere signal and noise. Society at large has not yet come to terms with information—it has created and unleashed a legacy of anywhere, anyhow noise and bias, that must and will, somehow and in some way, become more tame. We have to work to ensure that this is achieved in ways that serve health care well.

Information utility for health care has involved computer machinery born in a wayward early era of new technology, just as early cars had wayward engines and transmissions. Early pioneers engaged fully with the circuits

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5 D. Goodhart, *Head Hand Heart: The Struggle for Dignity and Status in the 21st Century* (London: Penguin Books, 2020).

6 D. Kahneman, O. Sibony and C. R. Sunstein, *Noise: A Flaw in Human Judgment* (New York: Little, Brown Spark, 2021), published during the writing of the second draft of this book, was great to read and draw on, and I have added it to the list of my cited inukbooks.

and operations of their computers. I have watched the demonstrators of the earliest Pegasus machine at the Science Museum in London, joyfully threading paper tapes through tape readers and pressing buttons, to make lights dance on consoles and printers clatter, to print the results coming from a program that made the machine add up the first one hundred integers. *Parturient montes, nascetur ridiculus mus* [the mountains will go into labour, and a tiny little mouse will be born],<sup>7</sup> some might say, but one needs to know about the connections to understand that it was a mighty mouse, once! Maybe some future historian will opine that Big Data heaved and Little Data was born!

Users of an information utility will have neither an interest in nor understanding of the semiconductor junctions, where physics is enacted inside the information appliances they use. Nor in the electrical circuits which condition and route the signals and the software that organizes these circuits, for the machine to enact the functions and roles its users require and expect. The users of the information utility will have little sense of the information infrastructure that underpins it, but they will need a sense of the utility's meaning and how it is created and sustained, if they are to trust it. The artificial intelligence (AI) employed there should be able to explain itself to us, otherwise perhaps we shouldn't listen to it!

Information utility is continuously reinvented and there is no electricity, water, gas or telecommunications company to do that reinventing. This role falls to the creators of the utility—citizens and professionals, hosts and providers of systems and services, communities of users. That means everyone. Just as good environment is not a luxury, but a necessity, so collaboration is a necessity. And sharing of common ground is not a luxury; it, too, is a necessity. Sharing of value and contribution is a necessity.

There is a lot that needs to change. Finding common ground on which to implement change may be daunting and otherworldly as a goal, but that does not make it a bad or wrong-minded goal and it does not render it unachievable. The future can, and will, be different. Rigour, engagement and trust; people, environment and community; head, hand and heart; balance, continuity and governance; purpose, goal and method; leadership, governance and regulation—all these are tripods of endeavour. Careful attention to implementation, implementation, implementation is essential. We must create the future—not enclose, predict and manage it. We must make and do it, share it and own it, along with everyone else. And we should listen to and enjoy the music and the dance—keeping upright and balanced, imaginative and creative, in time, in step, trusting and together, and on common ground, of course!

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7 Horace (65 BCE–8 BCE), *Ars Poetica*, l. 138.



# Acknowledgements

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This book draws together many and diverse stories about people, organizations and events, and the ideas, endeavours and experiences that have connected them with me, along my songline. There are very many people acknowledged in this way, throughout the chapters. Writing about them is itself an acknowledgement of my good fortune in the insights, opportunities and enjoyment they have brought me. Rather as with authors of papers in science who have sometimes listed very many co-authors, only few of them having put pen to paper or tapped keys in preparing the manuscripts, I feel concerned not to be selective in their acknowledgement here.

Acknowledgement is also about recognizing the inspiration, enjoyment and support we have received in other ways. Words cannot adequately acknowledge and convey my gratitude and indebtedness to my family and friends, past and present. They have been my rocks. I hope I have done okay in showing them that.

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I have had some great teachers; we owe our teachers so much. My primary school head teacher, Mildred Maggs, in the tiny village of Woolton Hill in Hampshire, is still occasionally an actor in my dreams: chalking up weekly arithmetic test exercises on the blackboard and warming herself near to the coke burner in the classroom, as she read from books to the assembled pupils at the end of the school day! My maths teacher at the Cathedral School in Bristol, Dai Davies, showed me the difference between getting to a problem solution and getting to it clearly, concisely and elegantly, using the best available methods for the task. My lovably eccentric head teacher, Cecil Rich, kept me tuned to classical education while my eyes turned to maths and science. At Magdalen College, University of Oxford, where I then alighted, James Griffiths gently cajoled and pointed the way

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1 Available at <https://www.openbookpublishers.com/books/10.11647/obp.0335#resources>

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More recent participants along the author's songline are included in the extended acknowledgements of Appendix V and documented on the openEHR website.

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Cameron also produced the PDF, EPUB, HTML, and XML editions. The conversion was performed with open-source software such as pandoc (<https://pandoc.org/>), created by John MacFarlane, and other tools freely available on our GitHub page (<https://github.com/OpenBookPublishers>).

This book has been anonymously peer-reviewed by experts in their field. We thank them for their invaluable help.



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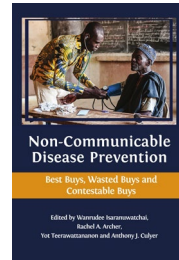
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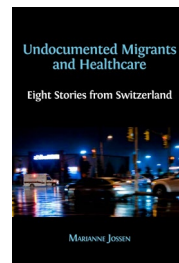
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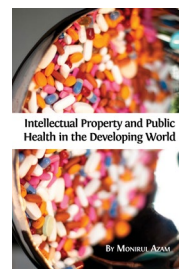
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# HEALTH CARE IN THE INFORMATION SOCIETY

VOL. 2

FROM ADVENTURE OF IDEAS TO ANARCHY OF TRANSITION

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