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Digital Health

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Introduction

What is digital health and in what sense is digital health a topic in STS? Digital health is a conjunction of health and digitalization. It points to an approach to health that involves turning certain aspects of health into data and subjecting these data to computation and to electronic storage and exchange. The concept of digital health does not refer to any fixed set of technologies: it simultaneously describes and performs a number of remarkably different technologies. Over the years, a range of practices have attracted their own attention in STS under different labels: electronic health records (digitized archival and monitoring systems), telemedicine (diagnostic and treatment forms depending on communication across distances), as well as eHealth (including Internet-mediated health services) and mHealth (a broad term covering the use of personal mobile devices including wearables to measure physiological or mental phenomena). These digital health technologies each form part of overlapping assemblages, if we by assemblage mean a social phenomenon kept together across scales and sites through practices. As with other such assemblages, they are enacted through powerful interests, are met with often forceful reactions, and stimulate unwarranted implications (Lupton, 2018).

The political interest in ‘digital health’ enacts these technologies as something many researchers want to know more about. Some of these scholars come from computer science or health informatics and related fields, and they primarily work to develop the technologies. Other researchers come from fields close to or even overlapping with STS, such as sociology, anthropology, organization theory, ethics, and health services research. In the course of studying digital health, many of these researchers have been drawn to STS. Rather than claiming digital health as an STS topic per se, it is therefore probably more accurate to say that digital health is a topic that has made researchers from many disciplinary fields seek inspiration in STS theory. There are good reasons for this. STS has had a lot to offer to the study of digital health. Also, by working with digital health technologies, STS researchers have developed and nuanced key debates in their own discipline. In short, STS has influenced how digital health as well as STS is taught and practised across a number of disciplines. This is partly because digital health has been an incubator, as well as a showcase, for two classic tensions in STS: between technological determinism and social determinism (or essentialism) and between technology optimism and technology pessimism. Increased awareness of these key tensions is something STS has offered many of the scholars drawn to the discipline through their engagement with the assemblages of 'digital health'. It has allowed people to make more balanced analyses, opened up for unexpected insights, and made them reposition themselves vis-à-vis the political forces of the assemblage.

We structure our introduction to digital health as an STS topic according to the four technological fields outlined above (electronic health records, telemedicine, eHealth, and mHealth), and refer to the two above tensions as we discuss these fields to highlight how awareness of these tensions provokes more interesting analyses and questions for future research. The four technological fields also represent a form of historical progression – both in digital health innovation and in STS's engagement with the issue, though not in any straightforward way. We use the historical grounding here also to remind readers that no technological invention or theoretical insight emerges in a vacuum: there is always something preparing the ground for any new assemblage.

When healthcare systems digitize: STS and the role of standards

Though presented with great hopes for the clinic in the 1960s, the computer first became embedded into the everyday practices of healthcare systems to support administration and remuneration (Greene, 2022). STS first became really interested when computers moved from being only in administrative practices to being deeply involved in the clinical workflow, in particular for electronic health records. With inspiration from Actor Network Theory and Symbolic Interactionism, Marc Berg and colleagues explored the 'ordering' and standardizing capacities and effects of digital devices, such as computer assisted decision-support tools and emerging electronic health records (Berg, 1997; Winthereik et al. 2007). Prominent symbolic interactionist researchers such as Anselm Strauss (1985) had already shown with concepts such as 'articulation work' and 'patient work' that medical practices include and depend on more than physicians' explicit medical knowledge. They depend on articulation of what is to be done, how, why and by whom. These concepts have had continued influence in STS and beyond. They have also served to counter the sometimes overly optimistic expectations among policymakers and shown the need to continuously explore how new technologies involve unexpected, and sometimes unwarranted, implications for people and for the organization of work.

Contributing with a symmetrical analysis which also accounts for non-human actors, STS researchers have shown how standards, materially engrained in software, are sociotechnical all the way through. This insight not only tempers political hopes; it also takes the analysis beyond simple technological or social determinism. First of all, the standards – for instance medical nomenclatures or diagnostic categories – by which medical work can be digitized are never neutral: they do something. What they do cannot be controlled by any select group of social actors. Secondly, in order to get these systems to work in practice, they have to be translated through negotiations with the many other heterogeneous elements of medical practice – technology does not act on its own. Thirdly, these elements may provide new options for control or resistance. Finally, this move of STS, which has been termed sociotechnical, has served to temper sociological and ethical fears of the digital de-humanization of medical work. The human element simply cannot be eradicated: the tools remain social all the way through. Even when decision-making power is delegated to algorithmic systems, the process incorporates many of the 'human' idiosyncrasies into the tool that it was often initially envisioned to eradicate (Berg, 1997).

The issues of clinical autonomy and discretion have been persistent in studies of digitalization in medical practices, but rather than presupposing a simple transfer of powers from human agents to computerized systems, STS scholars have used detailed empirical studies to account for subtle redistributions of work and (new) risks (Vikkelsø, 2005). While the introduction of electronic health records has made individual physicians more dependent on and accountable to standard-following (Winthereik et al., 2007), the medical professions as collectives simultaneously use the new modes of access to data to reinforce professional influence in ever wider networks (Greene 2022). Digitalization can shift authority and responsibilities around among professional groups. New tasks and roles appear as health professionals become data workers (Bossen et al., 2019), and as hospitals and health systems increasingly see data as the core substance of medical work. Also, patients are increasingly enrolled in data work for purposes beyond their own immediate treatment when asked, for instance, to fill in digital Patient Reported Outcome Measures for quality assurances and financial management schemes (Prainsack, 2017).

STS's empirically grounded analyses of standardization and electronic health records have been developed in dialogue with the Computer Supported Cooperative Work (CSCW) tradition. CSCW has implied a call for approaches to healthcare IT-development that are more critical and participatory (Fitzpatrick and Ellingsen, 2013). The hybrid CSCW/STS field continues to argue that designers and managers need to recognize both the upstream scripting of systems as well as the downstream translations of such scripts in practice.

The fact that electronic health records have facilitated new opportunities for the reuse of data for secondary purposes has also sparked new lines of STS inquiry (Winthereik et al, 2007). Here scholars explore who – and what – defines the rights and responsibilities related to knowing, using and sharing the data produced as part of clinical work (e.g. Vezyridis and Timmons, 2021). The new emphasis on data reuse is associated with potential dangers, as Petersen among others have pointed out, whether locating these dangers lie in the mistrust of political intentions or in the power of the technologies themselves (Petersen, 2019). As policymakers in the Global North invest heavily in cross-border infrastructures for health data (e.g. the European Health Data Space, Real-World Data infrastructures for pharmaceutical products, etc.), and as health promotion in low-income countries is becoming increasingly centred on data collection and exchange (Adams (ed.), 2016), the early insights into the performativity of standards continue to prove their relevance as a means for balancing our understanding of digital health.

Health at a distance: telemedicine, telecare and distributed agency in health

For many years, telemedicine was a term much more widely used than digital health. It primarily referred to the mediation of medicine through telecommunication technologies to overcome distances. Arguably, the STS attention to telemedicine came after the engagement with electronic health records, but as telemedicine became an object of wider political interest, it also reinvented its own history whereby telemedicine came to be seen as old as telecommunication itself. Telecommunication was not always digital, of course, but probably any type of communication technology has been used also for medical purposes (Greene, 2022). In countries with many people stationed at sea or in colonies, a regular and institutionalized form of 'telemedicine' (understood simply as medical practices mediated over distances by communication technology) developed through the second half of the twentieth century. But it was only with political mobilization of local clinical use, in everyday practice, of information and communication technologies – labelled ICTs – that 'telemedicine' became a regular STS topic. This was in the 1990s. Particularly in European welfare societies such as the UK, the Netherlands and the Scandinavian countries, the idea took hold among decision-makers that ICTs such as interactive video, digital imaging, and electronic data transmission might work as tools for welfare reforms. Everyday medical practices carried out in GPs' clinics and hospitals were to be made more efficient in managing the growing challenges related to an ageing and increasingly chronically ill population by circumventing the need for physical presence, and treating patients at home.

Generally interested in 'technology as politics by other means', STS scholars spotted – in these attempts to transform healthcare – a technology in-the-making with great empirical as well as conceptual potential. Not only was it important to debunk politicians' essentialist and deterministic understanding of technology, but the technologies as empirical cases also drew together a heterogeneous range of actors and issues otherwise practically and conceptually separate – in particular, the patients as actors in a new participatory role, and the physically distributed character of this form of medical practice. The first ethnographic STS studies on major telemedicine initiatives have – again – documented how these technologies do both less and more than policymakers expected of them. On the one hand, the distributed actors – health professionals as well as patients – proved difficult to mobilize and sustain. Computers and networks failed. Diseases were difficult to translate into numbers and stakeholders had a range of different aims (e.g. Mort et al., 2003). On the other hand, actors have been shown to be re-configured in interesting ways in telehealth projects and they can use the technologies to pursue modes of living not envisaged by the designers. To understand how it is possible 'to act at a distance' with telemedicine, agency has to be seen as a relational capacity distributed among a complex network of human and non-human actors – images, standard protocols, network connections, patient records and more – not reducible to either human agency or 'the technology'. Again, there is an obvious inspiration from Actor Network Theory.

With the concept of script (Akrich, 1992), STS researchers have also pointed to the ways in which specific technologies and standards – such as software interfaces for entering illness data and disease categories – both afford and restrict human agency by laying out a distinct yet often unarticulated 'geography of responsibility' (Akrich, 1992) among actors and spaces involved in the telemedicine set-up (see, e.g. Mort et al., 2003). With telemedicine, clinical and technical tasks are not just delegated to machines – as the 'efficiency narrative' used by many policymakers would have it – but often displaced to patients, relatives, and low-paid health professionals as invisible work (Oudshoorn, 2008).

Also, spaces of care have to be rethought with telemedicine, as the home and everyday life become increasingly enlisted as legitimate spaces of medical intervention. Place and materiality continue to matter also when care is presented as 'placeless' (Ivanova, 2020). As in many other empirical fields, the concept of infrastructure has proved helpful in pushing to the fore the materiality and 'sunken-in' character of sociotechnical relations on which distributed care depends, as well as the invisible and often gendered work needed to build and maintain the arrangements (Langstrup, 2013). This issue of the changing politics of care has continued to be a central theme in STS. One point here is to nuance the opposition between 'cold technology' and 'warm care' (Pols, 2012). Through the tinkering efforts of (collectives of) patients, relatives and health professionals, technologies produce local effects valued variously by diverse stakeholders (Pols, 2012). So, while on the one hand often critical toward the delegation of work and responsibilities onto patients and teleworkers, STS has also found reasons for optimism in the creativity and collective efforts of users. Today, however, the concept of telemedicine has largely given way to other concepts, including eHealth and mHealth.

Health moves onto the internet: new hierarchies of knowledge and agency

At the turn of the twenty-first century the very new phenomenon of 'the Internet' started to attract the attention of scholars interested in questions of medical expertise vis-à-vis the information needs and knowledge of patients. eHealth was born. The new accessibility of medical information for anyone with a computer and an internet connection drew authors to predict an upcoming epistemological struggle over medical expertise between doctors and the new 'reflexive' patient-consumers (Hardey, 2001). Medical knowledge 'e-scaped' the control of the medical profession (Nettleton, 2004), and new forms of citizen science emerged, for example through platforms such as PatientsLikeMe.

STS researchers such as Sally Wyatt and Flis Henwood were also interested in the impact of the internet on expertise and patienthood, but they were critical of pre-established assumptions of the empowering (for patients) or disempowering (for doctors) capacities of the internet (Henwood et al., 2003). With the conceptualization of 'non-use' and 'non-users', they thematized both resistance to and exclusion from online spaces of health knowledge and the role of design in inscribing such exclusion (Wyatt, 2003). Even today, their points about ambiguous implications have continued relevance. What may remain their main contribution was to point out that determinism could be equally found among those enthusiastic about the empowering capacities of the internet, as well as among those superimposing wholesale sociological concepts such as consumerism, deprofessionalization and medicalization onto the phenomenon. Also, the need to explore empirically digital exclusion and inequality in online health spaces only becomes ever more pertinent as the withdrawal of public welfare services is legitimized by 'freely available online resources'.

On a methodological note, patients' and citizens' activities in online space have also provided STS researchers new and rich possibilities for exploring health without having health professionals as gatekeepers, and also for using new digital ethnography methods tracing the data left by citizens to inform STS understandings of everyday behaviours and new social formations. On the internet, as a consequence of social media such as Twitter or Facebook, the medical profession no longer holds as central an epistemic position as was the case with electronic health records and telemedicine. eHealth is characterized by affording what STS scholars have called 'uninvited participation' (Wehling, 2012), new 'epistemic communities' (Akrich, 2010) and 'digital health activism' (Geiger, 2021).

These forms of STS research have documented how patients and relatives use the internet to mobilize alternatives to formalized care and support, challenge disease categories, and initiate new types of innovation and research. We can say both that the internet mobilizes patients, and that patients use the internet to mobilize. Once online, patients leave data traces. Such traces enable also commercial actors and health researchers to enrol citizens as 'prosumers' in new and ambivalent forms of global knowledge and value creation (Lupton, 2014). Examples include patient data platforms such as 23andMe, where citizens buy diagnostic services or pursue 'recreational knowledge' about themselves – while their data are simultaneously offered for sale to third parties. As patients search for information online, they leave data traces that are used for targeting them with particular forms of information or unproven treatments, again showing how new opportunities are woven together with new risks.

Tamar Sharon (2016) has coined the term 'googlization of health' to account for the effects of the major tech-players' increased focus on health data markets. STS researchers' most important contributions from studying online health practices and epistemic controversies might be the identification of such new types of hybridity: by connecting and combining patients and researchers, market and civic logics, data and experiences, these very categories are re-configured in tandem with the values we attach to them. This same point is also relevant for mHealth technologies.

Personal digital health devices: self-monitoring health practices

Patients and citizens have probably always used various personal devices to monitor, enumerate and manage issues of health and illness: self-monitoring clearly precedes *digital* health devices and what is now often called mHealth. In particular, the empirical phenomenon of self-tracking and the activist 'Quantified Self'-movement outside of formal healthcare have attracted a number of STS analyses, exploring peoples' multi-faceted affective and embodied engagement with self-tracking data (Sharon, 2017). The well-known anti-determinist STS-argument, that devices and data may shape but not determine use and outcomes, has been showcased in relation to mHealth and further nuanced here with a focus on 'data repair work' (Schwennesen, 2019). Users of self-monitoring devices will often experience these devices as incomplete or problematic. They engage the user actively in 'repairing' data according to other norms and values than those inscribed in the tools. The data collected on such devices can be experienced as having shifting meaning and significance in different contexts and at different times. The devices and the data they involve operate through emotional engagements and keep developing through the use.

Showcasing users' creative engagement, STS researchers typically seek to strike a balance between emancipatory accounts of quantified selves and critique of objectifying the datafication of everyday life. Everyday cyborgs have a messy existence, and mHealth continues to have inherently ambivalent effects. Ambivalent effects proliferate not least because self-monitoring can be used not only by people themselves and their health providers, but also by insurance companies and employers. Digital health monitoring operates in the uneasy borderlands between self-empowerment and surveillance capitalism (Zuboff, 2019).

STS has found new fertile ground in those personal digital health technologies involving Artificial Intelligence (AI). AI reintroduces classic questions about determinism in new ways because technology development can be seen as simultaneously independent of human interference and more thoroughly inscribed in reified social norms. This is so because the technologies are trained on data sets construed by humans. Inscriptions may become increasingly opaque and inaccessible to users and researchers – and even to the designers themselves. Some strains of STS research fear getting stuck in the 'machine zone' of systems designed to make human capacities redundant (Schüll, 2012). Other STS researchers embrace 'everyday algorithms' and see a point in contributing to their design (Pink et al., 2022). Irrespective of their choice, automation involves new forms of distributed agency that researchers need to take into account (Schwennesen, 2019).

Summing up and going forward: the questions raised by STS

As medicine becomes increasingly data-intensive, the digital health technologies discussed above converge: clinical decision-making and the content of the electronic health record may come to use data from personal digital health technologies; telemedicine infrastructures become essential for sharing patient-reported outcomes for financial management; platform-economy players mobilize individual sensor-data as the basis for commercial cloud-health services (e.g. Google's acquisition of Fitbit); patient activists share sensor and record data for patient-driven innovation and research, and so on. The arguments made by both early and recent scholars in STS that digital health needs to be understood in the specific relations – at all scales – that enable practices and shape the actual implications, continue to be pertinent for these developments.

In this entry, we have covered some of the numerous insights presented by STS scholars working with digital health technologies. We have shown how two core tensions in STS has been showcased through these studies, one concerning social versus technological determinism and the other concerning normative judgements of technology. STS Scholars were among the first to problematize how the specific ways of accounting for changes in healthcare – and elsewhere – gave technology either all power or no power at all. Digital health is full of hyperbolic promises and warnings (Petersen, 2019) – of algorithmic medicine, platform healthcare, digital phenotyping and more. Both promises and warnings should continuously be met with awareness of empirical nuances and the need for finding a middle way. Still, these developments also point to a third tension in, and future challenge for, STS. This tension lies between the local and the global: between exploring digital health primarily with approaches that emphasize local, experiential and user-oriented practices (and thereby remaining focused on what happens *within* the network and *for* those using the technologies) and approaches emphasizing the global, political and economic aspects of digital health (thereby critiquing the technologies for what they do *beyond* networks of users and what they do *not* do for those who are excluded or marginalized in various ways). Increased awareness of this third tension may also provide better opportunities for identifying and accounting for the non-digital, the analogue, and those who fall between the digital cracks.

The three tensions all point to the productive potential of placing an analysis in-between hegemonic knowledge forms and dominant narratives. It implies valuing doubts and uncertainties. Such an attitude, acquired through engagement with STS, has greatly benefitted technology designers, health services researchers and educators in digital health. In this spirit, and as an acknowledgement also of the way in which STS always points to local specificities, we might best summarize the STS contribution to digital health as questions of enduring relevance – questions that each analyst can bring to new areas of study to learn something relevant for each individual case. For example: How do digital health technologies distribute benefits, risks, and burdens? Which types of knowledge take prevalence in digital health assemblages? How do digital technologies affect issues of accountability and responsibility? Who and/or what does the work in digital health, and how may technology distribute work in new ways? How does a digital technology reconfigure access to information? STS invites scholars to ask such questions and thereby uncover who has what at stake which is not otherwise heard and acknowledged. To do so, it is usually necessary to bracket off the normativity otherwise characterizing the contributions from other disciplines claiming to work for the greater good. STS research implies learning to counter their claims with questions like: Good for whom? Good according to which criteria? By balancing social and technological determinism, optimism and pessimism, as well as providing a balance between being too close or too distanced, STS scholars can generate understandings of digital health that are fairer and more inclusive. Because people depend on digital health when they are at their most vulnerable and most exposed, such analyses are of key importance; and because technologies continuously evolve, the job is never finished.

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