Routledge International Handbook of Participatory Approaches in Ageing Research

Edited by Anna Urbaniak and Anna Wanka

ROUTLEDGE INTERNATIONAL HANDBOOK OF PARTICIPATORY APPROACHES IN AGEING RESEARCH

This Handbook presents established and innovative perspectives on involving older adults as co-creators in ageing research. It reorients research and policy toward more inclusive and adequate designs that capture the voices and needs of older adults.

The Handbook:

- introduces types of participatory approaches in ageing research;
- highlights key methodological aspects of these approaches;
- gives insights from projects across different cultural contexts and academic disciplines, showing ways in which older participants can be involved in co-designing different stages of the research cycle;
- examines key issues to consider when involving older participants at each step of the research process;
- includes the voices of older adults directly;
- draws out conclusions and points ways forward for future research.

This Handbook will be essential reading for researchers and students interested in the field of ageing and/or participatory methods, as well as for those policy stakeholders in the fields of ageing and demographic change, social and public policy, or health and wellbeing who are interested in involving older adults in policy processes. It will be useful for third-sector advocacy organizations and international non-governmental and public agencies working either in citizen involvement/participation or the ageing sector.

Anna Urbaniak is a social sciences researcher with expertise in life-course transitions, the re/production of social inequalities across the life course, and participatory approaches in ageing research. She is a founder of PAAR: Research Network on Participatory Approaches in Ageing Research and a chair of COST Action CA22167 on Participatory Approaches with Older Adults (PAAR- net). She is also a co-chair of the Research Network on Ageing in Europe (European Sociological Association). She is working as a Postdoctoral Researcher at the University of Vienna (Austria) and Jagiellonian University (Poland), and as an Assistant Professor at Cracow University of Economics (Poland).

Anna Wanka is a sociologist and critical gerontologist interested in the social construction of age. Her areas of expertise comprise the social practices of un/doing age, life course transitions/retirement and the re/production of social inequalities across the life course, ageing and technologies, age-friendly cities and communities, mixed-methods, and participatory research. She is co-founder of PAAR: Research Network on Participatory Approaches in Ageing Research and a co-chair of COST Action CA22167 on Participatory Approaches with Older Adults (PAAR- net). She is working as a research group leader at Goethe University Frankfurt/Main, Germany.

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Claudia Müller, PhD, is an Assistant Professor for 'IT for the Ageing Society' at the Institute of Information Systems, University of Siegen and a Professor at Careum Health, Zürich. She follows a praxeological and participatory design approach for assistive technologies in the domains of health and ageing. She is the Vice Chair of the National German Expert Commission for the 8 Ageing Report 2020 'Digitalisation & Ageing' and also a member of the working group 'Ageing & Technology of the German Society of Gerontology and Geriatrics e.V'.

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FOREWORD

This book was written to contribute to the debate around participatory approaches in ageing research and on a broader level the democratization of knowledge societies to include the voices of an increasingly ageing population in the 21st century.

Idea for it evolved from our joint interest in ageing research and especially in social exclusion of older adults. In numerous projects and activities that we took part in, such as the COST Action "Reducing Old-Age Social Exclusion: Collaborations in Research and Policy" (ROSENet) or the European project "A life course perspective on the GENdered PATHways of social exclusion in later life, and its consequences for health and well-being" (GENPATH), we jointly researched aspects and forms of exclusion in later life. In the course of working on this topic we increasingly realized that we, as most researchers, found it hard to gain access to older adults living in deprived circumstances, and to get them to talk about experiences of exclusion. Neither lack of skills or effort on our side nor lack of interest and engagement on the side of older adults was to blame for that, we figured, but the ways that research works in an academic system and the way life works for socially excluded people do not always match. It hence became clear to us that we needed to explore ways through which diverse voices of older adults can be better included and heard in research and policy-making alike.

This has led us to developing a citizen science project with the title "Socially Excluded older adults: Voices and Experiences" (SEVEN) funded by the Austrian Science Foundation FWF. In the course of the submission process, we obviously conducted the necessary research and found that literature on participatory approaches with older adults was scattered across different disciplines and research fields. There was not yet one book that would gather those insights and provide support to researchers interested in applying participatory approaches in ageing research – the book we would have needed at that time. We eventually received funding for the SEVEN project and were thus able to work on social exclusion with older adults, which increased our need for learning more about challenges and solutions in participatory ageing research.

Fuelled by this need, we started bringing together ageing researchers interested in participatory approaches to form a network of exchange and support. Soon enough we discovered that our colleagues across different disciplines are committed to engaging older adults in

research and eager in exchanging their experiences on this topic. The idea to bring them together in a joint publication became more and more concrete. When we issued a call for contributions, however, we had never expected to experience such a huge interest from so many great researchers around the whole world interested in contributing. We were absolutely overwhelmed by the positive response we got and it reassured us that there is a great interest in (and need to) bringing participatory approaches in ageing research into a dialogue and developing them further based on our shared experiences.

The process of publishing this book was guided and supported not only by all contributors but also by a lot of side activities evolving out of it: We were able to organize three symposia on participatory approaches in ageing research that attracted wide audiences all around the world at the Annual Scientific Meeting of the Gerontological Society of America in Phoenix, USA in 2021; at the 26th Nordic Congress of Gerontology, Odense, Denmark in June 2022; and at the European Sociological Association conference (Research Network on Ageing) in Vienna, Austria in July 2022. The most sustainable and inspiring activity that emerged out of putting this book together is, however, the Research Network "Participatory Approaches in Ageing Research" (PAAR) with which we were able to build a long-term infrastructure for exchange and collaboration and gained funding for COST Action "Participatory Approaches with Older Adults" (PAAR-net, CA22167).

Without the contributors to this book, we couldn't have made any of this happen. They were tremendously supportive from the very beginning of our process not only by timely preparing their contributions but also by contributing valuable feedback to the other authors involved. Our special thanks go to Emily and Lakshita from Routledge who enabled a smooth publication process. Additionally we would like to thank Angela Friedrich, our research assistant at Goethe University Frankfurt, to help us stay on top of the formatting. And of course there are people who are not directly linked to this book but whose support has constantly motivated us to continue our work on participatory approaches in ageing research: We want to thank each and everyone of you!

The aim of this volume is to further develop participatory approaches with older adults as a means of driving inclusive social innovations across research, policy and practice, for heterogenous and fair ageing societies. In doing so, we bring multiple participatory approaches (e.g., citizen science, feminist participatory research, participatory action research, collaborative inquiry, community-based participatory research) together across multiple disciplines (e.g., health and social care, critical gerontology, gerontechnology, sociology, social policy, social geography, psychology). As this volume showcases, participatory approaches in ageing research is an emerging field that still has several shortcomings, but also great potential, especially in terms of increasing the inclusivity and adaptability of research by broadening the scope of involvement of diverse groups of older adults and further developing tools to increase inclusive and meaningful involvement of experts by experience in research. Last, but not least, this book shows how much we can achieve if we work together across research fields and disciplines, and how support and solidarity can not only lead to great academic outcomes but also societal impact and mutual learning.

1

PARTICIPATORY APPROACHES IN AGEING RESEARCH

An Overview

Anna Urbaniak and Anna Wanka

Introduction

The inclusion of older people in research as co-creators of the research process is a relatively new concept, predominantly explored in the UK, US, and Canada (Fudge et al., 2007). There are a number of approaches to this type of research, and this plurality is apparent in the terminology appearing in the academic literature. "Inclusive research" overlaps with terms such as "user-led research", "community research", "participatory action research" (PAR), "collaborative research", and "co-research" (Blair & Minkler, 2009; Guijt, 2014; INVOLVE, 2012). In this book, we decided to use the umbrella term "participatory approaches" to refer to different approaches that aim at including older adults as co-creators of the research cycle. Studies that have involved older people as collaborators are applied mostly in research relating to health and social care (Fudge et al., 2007; Leamy & Clough, 2006). There are also examples of community-based inclusive research projects exploring deprived urban neighbourhoods (Buffel, 2018) and inclusivity in lifelong learning (Patterson et al., 2016), where older people themselves direct the project with support from academics. Work undertaken in Ireland under the Touchstone Programme provided opportunities to explore themes with older people such as how to deal with media, ageism, and the older person as a researcher (Scharf et al., 2016). Participants were offered the chance to initiate their own small-scale community projects – the older person was positioned at the centre of this experiential learning process aimed at increasing older people's community/political engagement. A growing body of evidence shows that what we deemed "participatory approaches" may increase the relevance and applicability of the research (Corrado et al., 2020a; Walker, 2007). Contributions provided by older people when designing, implementing, and disseminating research may make studies more effective, credible, and cost-effective (Clough et al., 2006). Additionally, there is growing acknowledgement of a moral imperative to involve individuals who are the focus of research about them. However, participatory approaches among many benefits imply also numerous challenges; critical concerns include the potential for the marginalisation of older people from deprived communities, who risk being labelled as uncooperative or unproductive if they do not volunteer to get involved in community projects (Baars et al., 2013;

Martinson & Halpern, 2011). This might partially explain why the involvement of older people as co-creators of the research process is not yet common practice.

In this chapter, we discuss different aspects of involving older adults as co-researchers across multiple research domains and in different cultural contexts across numerous jurisdictions to present a systematic overview of "participatory approaches" in ageing research with their potential benefits and challenges in different research stages.

Understandings and definitions of participatory approaches in ageing research

In a broad understanding, participation relates to different kinds of involvement in social practices – including, but not limited to, research practices (Aner, 2016). In application to ageing research, participatory approaches hence refer to different forms of involvement of older adults in research and will be used here as an umbrella term for different approaches such as citizen sciences (CS), PAR, patient and public involvement (PPI), co-creation, or participatory design (PD). However, independent of the terms used, most (review) studies agree that we lack a uniform definition of participation in research, as well as a consensus regarding the standards of participatory approaches. Hence, studies that label themselves as participatory deploy a wide range of methods, ranging from advisory councils to focus groups or quantitative surveys (Levac et al., 2019; Merkel & Kucharski, 2019; Schilling & Gerhardus, 2017). Those differences are also resembled in this book, where authors of different chapters develop their perspectives on what participatory approaches are, how they can be conducted in various ways, and what benefits they bring for research.

However, there are some common aims, orientations, and principles guiding participatory approaches in ageing research. With Spinuzzi (2005), we can describe participatory approaches as a research methodology with their own theoretical (social-constructivist) and methodological foundation to facilitate "equitable participation [in research], co-learning, community mobilization, and personal and social transformation" (Corrado et al., 2020b, p. 314).

In general, "participatory research approaches aim to incorporate individuals' voices and knowledge into understanding, and responding to challenges and opportunities facing them and their communities" (Levac et al., 2019, p. 1865).

National bodies, like the national advisory group to the National Health System (NHS) in the UK, the Patient-Centered Outcomes Research Institute (PCORI) in the US, or the Canadian Institutes of Health Research (CIHR) define participatory approaches as active and meaningful involvement of persons that would usually be considered as research subjects, and thus implying that research is not carried out "about" or "for" these persons, but "with" or "by" them. In line with this, Green and colleagues define participatory action research (PAR) as "systematic inquiry, with the participation of those affected by the problem being studied, for the purposes of education and action or effecting social change" (Green et al., 1995, p. 2).

At the core of a participatory research style therefore lies a specific relationship between the research participants, co-researchers, or citizen scientists on the one hand, and the academic researchers on the other hand, namely one that is based on equality, knowledge sharing, and respect, and orientated towards empowerment of older adults and democratisation

of research. With this goes a redefinition of what ageing research usually treats as their research subjects – older adults.

> Instead of being understood as research subjects, participants are involved as co-researchers and recognized as having intimate experiential knowledge and robust knowledge systems.
>
> *(Levac et al., 2019, p. 1867)*

They are regarded as "experts by experience" or "experts of their lifeworld" (Merkel & Kucharski, 2019, p. e17) whose (tacit) knowledge is as valuable as the academic knowledge of researchers. This shakes up the hierarchy and power imbalance between researchers (active) and older adults (passive) and requires academics to act, and perceive themselves, primarily as facilitators, and not creators, of knowledge. This is particularly promising for persons that are not only marginalised because of their age but also because of age in intersection with other categories of social difference (e.g. gender, ethnicity, socio-economic status). Hence, as Blair and Minkler (2009) put it, a central guiding principle of participatory approaches "is a power shift from academic institutions to communities, with participants becoming more than subjects of study and outside researchers" (p. 652).

Hence, if applied thoroughly, participatory research can empower older adults by increasing their control over the research process and its results (Zimmerman, 2000), and, in doing so, facilitate a bidirectional co-learning process for both older adults as non-academic researchers and academic researchers (Blair & Minkler, 2009). However, not all applications of participatory approaches go far enough to fulfil these aims. Rather, many of them can be placed on a continuum, ranging from more minor involvement where, for example, older adults gather data, to more major involvement, where older adults might be in control of knowledge production, budgets, and the interpretation and dissemination of results (Bradbury & Reason, 2008). In the following section, we outline different examples of such applications of participatory approaches in ageing research, focussing first on different research fields and then on different research stages.

Application of participatory approaches with older adults across different research fields

Participatory approaches in ageing research have different forms and vary across different disciplines. In this section, we present results of meta-review of reviews on participatory approaches with older adults. We focus on possible application of participatory approaches with older adults across those research fields that employ participatory approaches most often so: health & care provision, technology, and place & community. We focus on the type of involvement and methods used for participation of older adults in the research process, as different disciplines and fields have different points of focus when considering older adults as co-researchers in terms of the research themes as well as in expected benefits of applying participatory approaches with older adults and special considerations related to co-creation.

In research on health, for example, the most often applied participatory approach is PPI. Baldwin et al. (2018) highlight that benefits for older co-researchers involved in PPI projects included psychological and social benefits, new learning, and activism and career opportunities,

while challenging impacts included demanding workloads, difficult relationships, and dissatisfaction with level of involvement. Benefits for academic researchers entailed new learning and shared workloads; challenges related to demanding workloads and difficult relationships. It's important to notice that one of the sub-domain in medical research that continuously develops co-creation with older adults is dementia research. Involving people with dementia in peer research can generate several benefits, including empowerment and opportunities for inclusion for the peer researchers and the research participants living with dementia, challenging academics' traditional views on research processes, and gathering enhanced research data (Rivett, 2017). As suggested by Tanner (2012) principles involved in including people living with dementia in research can be applied to people living with dementia as co-researchers. Still the question of consent, assent, and ethical issues around involvement of co-researchers living with dementia remains an important point in current discussions in dementia research (Di Lorito et al., 2017).

Additionally, in research on mental health and well-being, older adults often are involved in interventions and solutions that rely on participatory art. The term "participatory arts" concerns art making rather than art observing and in this sense the main focus here is on involving older adults in dance, writing, theatre, and visual arts. Participatory arts' wellness studies constitute a relatively unploughed field (Noice et al., 2013, p. 742) and remain out of scope for what we consider participatory approaches in ageing research as they don't focus on research process but rather on interventions and impacts of participatory arts on well-being of older adults.

In research on care and care provision older adults are often involved in co-creating interventions and recommendations aiming at improvement of care delivery in institution-alised settings. The involvement of older adults in research on care and care provision highlights both: ethical and practical motivation for including older adults in the research (Schilling & Gerhardus, 2017). Participatory approaches with older adults in the field of care and care provisions allow us to better understand lived experiences of older adults in need of care and include them as co-researchers and not subjects of care interventions. It is recognised that co-researchers possess knowledge and ability to present their needs which might translate into designing and developing practical solutions that fit more to diverse needs and abilities of heterogeneous groups of older adults (Backhouse et al., 2016).

In research on technology, there is also a growing interest in involving older adults in the research process. Intersection of ageing and technology creates a new growing research field of gerontechnology. As the scope of technological applications addressing ageing and old age ranges from smart homes, telecare systems, remote care, robots to services and software, the main focus in gerontechnology is on understanding the needs of older adults in relation to technology. Researchers here focus mainly on co-developing technological solutions with older adults to make sure that their perspectives as end-users are sufficiently addressed already at the development stage. Merkel and Kucharski (2019) in their review of PD in gerontechnology highlight that PD could help to avoid negative age-related stereotypes and ageism as modern devices targeting older users are often oriented toward a deficit/compensatory instead of a more proactive approach of focussing on engagement and empowerment (Peine et al., 2014; Rogers et al., 2014). Interactions between technology and older users require participatory approaches to better understand not only needs of older adults but also meanings assigned to such interactions by older adults.

In research on place and communities, as in human geography or urbanism, one of the main areas of research projects co-created with older adults is an age-friendly environment.

Age-friendly framework promotes the role of neighbour and community relations, as well as the participation of older people in the design and development of policies addressing local challenges. Age-friendly debate is involved with ideas relating to co-production and co-creation for a while (see, among others, Buffel, 2015; Buffel & Phillipson, 2016). Most projects that involve older adults engage participants in crowdsourcing information on barriers and facilitators in local environments (for example, by using photo elicitation) or in developing new technologies and increasing technology acceptance (Rosas et al., 2021; Tuckett et al., 2018). Community-based PAR, citizen science, and photovoice are the most often employed in research on place and community. Older adults, next to collecting the data might be involved in discussions with local stakeholders in order to design places and spaces that would be more age-inclusive and more aligned with needs and abilities of older adults in specific communities.

Application of participatory approaches with older adults across research stages

As outlined above, a core tenet of participatory approaches includes the facilitation of a "collaborative, equitable partnership in all phases of research" (Israel et al., 2017, p. 5). However, very often, older adults are only involved in selected stages of the research process – something that contradicts 'deep' involvement in terms of ownership and control over the whole research. In this book, we wanted to showcase how ageing researchers apply participatory approaches in ageing research throughout different stages of the research cycle. This is also partly resembled in structure of the book that differentiates between specific research stages, but also entails sections on more cross-cutting aspects, such as methodologies or future perspectives in participatory approaches in ageing research.

In the most recent literature review on co-creation with older adults (James & Buffel, 2022) in social research authors identified 27 studies that involved older adults as co-researchers in more than one stage of the research cycle. This review highlighted that older adults most often are involved in data collection (all identified studies) and in analysis (23 studies). The least common stage where older adults were involved was recruitment (six studies) and evaluation (one study). In studies included in this review, older adults were involved in research design of 20 identified studies, and in 14 they were involved in dissemination activities.

Involvement of older adults in developing the study is rarely reported. As this process requires a lot of resources (in terms of time and money) it is not always possible to co-create it with older adults. This might be primarily related to the fact that funding bodies rarely have mechanisms in place to allow for the study design to be co-created. Studies that were co-developed by older adults have in common partnership approach and efforts in building trust between agencies, academics, and older adults early in the project (e.g. Brown et al., 2017; Fenge et al., 2010; Yankeelov et al., 2015).

Information on involvement of older adults in research design is not always reported in an elaborated way. Quite often it's just a statement that older adults were involved in research design without providing any details on the actual way that older adults participated in this step. This is often due to the fact that there are no standards in reporting co-designing with older adults. Older adults in this step might contribute to designing approach to recruitment and data collection and provide their feedback or co-create research tools (e.g. Buffel, 2019; Hand et al., 2019; Ward & Gahagan, 2010).

Studies that involve older adults in data collection most often rely on qualitative methods such as qualitative interviews (including semi-structured interviews or biographic-narrative interviews), focus groups, or methods employing visual approaches (such as photovoice or photo-ethnography). Few studies identified by James and Buffel (2022) used questionnaires and surveys. Older adults in this stage of research can either: be involved as researchers who collect data from research subjects, be involved as subject of the research and use their own experiences to address research questions or be involved as both researchers and research subjects (e.g. Fenge et al., 2010; Shore et al., 2018).

Data analysis with older adults is the task that requires either a prior extensive training to develop needed skills or an approach that is easy enough to be applied by those who might lack professional training. The few studies that report their approach to join data analysis with older adults most commonly relied on collaborative thematic coding framework arguing that collaborative ways of analysing data lead to richer findings (Gutman et al., 2014), allow to bring the analysis together securing the same focus (Mey & van Hoven, 2019) and reduce the risk of individual biases leading to dismissing some issues while focussing on the others (Buffel, 2019).

Involvement of older adults in findings' dissemination is most often accomplished through public engagement events and workshops, co-producing materials for partner organisations, or presenting at public conferences (e.g. Shore et al., 2018; Yankeelov et al., 2015). Studies involving older adults in this stage of the research cycle highlight that the co-researchers are particularly motivated to aid in the dissemination of findings, highlighting issues that they believe are of particular significance, but that may be dismissed as trivial by academics (Littlechild et al., 2014).

Finally, participatory approaches also entail "commitment beyond the funding cycle-based relationships typical in social research to long-term collaboration for social and academic goals" (Blair & Minkler, 2009, p. 652). However, few studies report on such collaborations that extend the duration of a research project. In general, there is no one clear definition and no common guidelines on how to report participation of older adults, which makes it difficult to fully understand how older adults are involved in the research process. This was highlighted by many reviews on involvement of older adults in participatory projects (James & Buffel, 2022; Merkel & Kucharski, 2019).

Structure of this book

As outlined above, there is neither a clear consensus on definitions and aims nor methods and applications of participatory approaches. Depending on the field of research and the specific target group, participatory approaches can hence follow different objectives and deploy different methods in different research stages, and entail different challenges. Consequently, a project exploring potentials of assistive technologies for older adults with Parkinson's might differ in its design quite a lot from a project on place attachment in rural communities, and require different skills and strategies from both the academic researchers and the older adults as researchers. In this book, we want to share the knowledge gathered in this diverse field by providing conceptual, empirical, and methodological examples of participatory research with older adults, and facilitate a discussion of the challenges encountered with them. Figure 1.1 represents the structure of this book. We start by exploring methodological challenges of participatory approaches in Chapters 2–5, then move to specific research stages in Chapters 6–19. The following Chapters 20–22 reflect
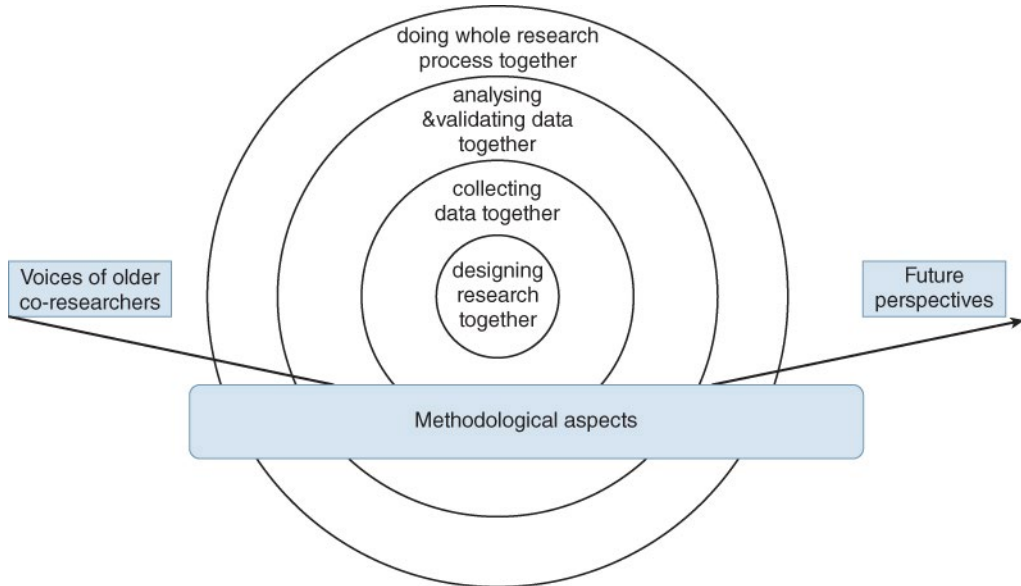
Figure 1.1   Structure of the book.

upon doing the whole research process together, whereas Chapters 23–27 present voices and experiences of older co-researchers. Finally, we outline future perspectives for participatory ageing research (Chapters 28–31). In the last chapter, we summarise learnings from the previous chapters in order to ask questions that participatory research needs yet to answer.

Methodological aspects of participatory approaches in ageing research

As presented in Figure 1.1, we consider the voices of older co-researchers as the primary input for participatory approaches in ageing research. Participatory research practice with older co-researchers should apply appropriate methods to capture their voices throughout the whole research cycle and bring further development in this field. Therefore methodological aspects and challenges of participatory approaches in ageing research are presented in Figure 1.1 as a cross-cutting dimension of participatory research practice that impacts all research stages. Four Chapters in this book are dedicated to capturing the state-of-the-art discussion on methods of participatory approaches as well as the potential for their further development.

In Chapter 2, A. Urbaniak drawing from lessons learned in Austrian citizen science project "SEVEN: Socially Excluded older Adults: Voices and Experiences" highlights the role of reflexivity in harnessing the full potential for inclusivity that participatory approaches with older adults have to offer.

In Chapter 3, A. Seifert considers the openness and motivations of older adults to engage in participatory research. Using data from surveys conducted in 2020 in Switzerland he compares willingness, motivations, and attitudes towards participatory research projects among two groups: adults aged 18–64 and those older than 64. He provides evidence for the potential and barriers of involving older adults as co-creators of scientific research.

In Chapter 4, J. Nolte and H. Turker review existing literature to capture different approaches to roles of older adults in data analysis: from verifying expert analysis to working in parallel with expert analysis to leading analysis. Based on this review they present advantages and challenges of involving older adults in data analysis and suggest a very practical list of questions to consider to address the limitations of older adult co-analysis.

In Chapter 5, B. Aigner-Walder et al., present experiences from practice concerning the essential development of an interdisciplinary, jointly supported research strategy. Consideration is also being given to ways in which the strengthening of active participation of older people in the context of quadruple helix co-operations (including university, industry, government civil society) can succeed.

Designing research together with older adults

This section of the book looks at the process of designing research projects together with older adults from the very start.

In Chapter 6, M. Sanchez and R. López-López argue that contribution of older people in gerontological research tasks can be classified as a form of productive ageing. Authors claim that this sociological perspective of productive ageing, which looks at how human agency and social forces are interlinked, represents a point of union between the (productive) manner in which some people wish to and can age and the (also productive) societal value of research.

In Chapter 7, C. Waldegrave et al., present research carried out in New Zealand with indigenous Māori elders, reflecting on the methodology of applying co-creation participatory research methods with cultural groups that don't fit easily into the Western and Northern countries' assumptions (such as refugees, indigenous cultures, colonised cultures, and foreign labour groups). Authors conclude that If survey questions related more to the assumptions and norms in their worlds, then it would seem likely that they would provide more useful evidence for culturally congruent policy development and service provision.

In Chapter 8, C.A. Maddock et al., reflect on two renewable energy research projects which have participatory approaches embedded at different levels of their implementation in the UK and Indian context. Authors claim that participatory approaches help to redress the imbalance between the lack of understanding of the value placed on people's energy decisions and how energy is used and focus on "end-user" perspectives. Authors present a helpful list of what worked well in their processes of co-designing research with older adults and where improvements can be made.

Collecting data together with older adults

This section of the book deals with conceptual and practical aspects of data collection in participatory approaches with older adults. The chapters present insights across three different cultural settings, as well as challenges and opportunities that joint data collection might create.

In Chapter 9, C. Hammond et al., showcase a project through which Montreal became a creative platform for the urban knowledge of older citizens. By applying oral history, urban scenography, and place-based creation strategies, authors sought to create a shared, public platform for older Montrealers' living memories of the gentrifying neighbourhood. Authors describe how dynamic co-creation processes are and how co-researchers acted

as mentors for academic researchers and took positions of authority contributing to the success of the project.

In Chapter 10, V. Ross considers the best ways to create an optimal research context to elicit responsiveness from older individuals, irrespective of the complexity of the social setting or the support required for optimal participation. Drawing on two distinctly different examples in South Africa, this chapter sets out the principles informing the active participation of older individuals in data collection methods.

In Chapter 11, K. Klincewicz et al., discuss key challenges of co-creation processes with older adults (such as recruitment of participants, the organisation of creative processes and the facilitation of discussions), leveraging the practical experiences of Consumer Engagement Labs that involved more than 200 older adults across 14 European countries. The chapter offers practical suggestions that could enhance the researchers' sensitivity and responsiveness to the needs of participants enabling the successful implementation of co-creation initiatives.

Analysing and validating results together with older adults

How do we know whether our academic interpretation of findings is in line with what the people we were researching about think, and how to make complementary or even contradictory interpretations productive? Validating results together with older adults is the main area of concern for the four chapters in this section.

In Chapter 12, I. Zemaitaityte et al., present their experiences with member check developed as a follow-up of the project "LoGaSET – Location-based games as a contemporary, original, and innovative method of seniors' teaching and learning". The specificity of this research is that it was done in the country where there is no culture of participatory research generally and especially with older adults. This experience could add to the learning path of beginners in participatory research. The research showed that older adults are willing to participate yet due to cultural context might find participatory methods challenging.

In Chapter 13, T. Tambaum discusses the role of including experts on ageing into research projects aiming at developing befriending services in Estonia. In the second phase of research, four forms of data were collected including immediate feedbacks and focus group interviews that were analysed on an ongoing basis to identify strengths and weaknesses in the service design and to make immediate improvements during the research. Author concludes that being part of the participatory research may work in such a way that participants embrace the service they have co-produced.

In Chapter 14, G.C. Lorenzini and J. Persson present case studies designed to actively involve older people in the data collection and validation about their day-to-day experiences of using multiple medications and the medication packaging. The case presented reflects about the participatory approach of completing a solicited diary with photo elicitation through the perspective of the diarists. Authors present a series of methodological challenges found along the way and make recommendations to respond to those challenges. These recommendations might be useful to other academics and practitioners using participatory approaches to design research with older people and home care personnel.

In Chapter 15, M. Bieńsko and D. Kalita present a project that actively involved women aged 65+ who assumed the role of the researchers and evaluators in a project on sexuality and intimacy in Poland. Authors discuss how older adults can serve as citizen scientists performing critical functions within participatory research in order to promote positive

and healthy ageing. The essential part of this chapter concerns the research approach and practical aspects of older people's commitment to researching a sensitive topic.

Disseminating results together

As the chapters in this section showcase, engaging older co-researchers in the dissemination of research findings can be a very creative process that not only increases involvement of older co-researchers in the research but also allows to reach wider and more diverse audiences.

In Chapter 16, A. Goulding and T. Scharf reflect on how the process of co-producing three different models of lifelong learning and cultural participation contributes to social inclusion in later life. Authors focus on three case studies from the UK: contemporary dance programme, and two classroom-based learning programmes with different groups demonstrating how symbolic exclusion is absorbed or internalised and how discussions function to challenge negative stereotypes.

In Chapter 17, S. Campbell and A. Clark outline the development of a series of graphic magazines (or "zines") as part of a participatory approach to disseminating findings from a research project exploring the experiences of neighbourhoods for people living with dementia in the UK.

In Chapter 18, A. Reuter and T. Scharf consider the creation of the Later Life Audio and Radio Co-operative (LLARC) as an outcome of a PAR project in the UK with a focus on facilitating later life civic participation. By showcasing diverse talk-based audio content created by older adults, the LLARC advocates for greater representation of older adults in public debates relating to key concerns of ageing societies.

In Chapter 19, B. Vanhoutte and N. Dymond-Green present how living library events at the end of the research life cycle can be a way to enhance the communication of results. A living library is an event targeting interpersonal dialogue between the public and people with a certain (prejudiced) characteristic.

Doing the whole research process together

In this section, three chapters present insights from Belgium, Australia, and Canada on the ways in which older co-researchers can be involved in the research cycle from the very beginning to the very end.

In Chapter 20, N. De Witte et al., present the research project "Belgian Ageing Studies" (BAS) Each BAS project, which by the end of 2021 was executed in more than 200 Belgian municipalities, assessed the living conditions and quality of life of older people. In this project, older people were involved as key stakeholders and participated both in the development of the project and in the continuously ongoing project in different municipalities.

In Chapter 21, M. Polacsek and T. Porter present a service provider's perspective on rights-based research to guide innovative, evidence-informed programmes and activities. The organisation's efforts to embed rights-based research are illustrated through two case studies: "Smoothing the way: A co-design approach to improving aged care transitions" and "Measuring quality of life in older adults with a cognitive impairment".

In Chapter 22, Lillian Hung and Mario Gregorio describe specific issues their research team encountered while conducting research in Canadian Long-Term Care (LTC) homes during the pandemic. Their present also practical tips about applying Collaborative

Action Research (CAR) principles to continue supporting patient partners as active research contributors.

Voices and experiences of older co-researchers

This part of the book collects insights from the perspectives of both academic and lay researchers in the UK, New Zealand, Switzerland, Germany, and Austria. Even though all five chapters in this section follow similar logic, each of them is a unique expression of voices and experiences of academic and non-academic members of teams who were involved in different participatory projects, and each showcases what we can learn from doing research together.

In Chapter 23, Diane Seddon, Teresa (Dory) Davies and Hannah Jelley reflect on working together to research the everyday lives of people living with dementia and those supporting them in the UK.

In Chapter 24, Charles Waldegrave and Monica Mercury lead parallel conversations presenting insights from expert-by-training and expert-by-experience in researching loneliness and Social Isolation among older Māori and Pacific People in New Zeeland.

In Chapter 25, Shkumbin Gashi and Erich Kohler lead parallel conversation presenting insights from expert-by-training and expert-by-experience in co-design and co-create a caring community in Switzerland.

In Chapter 26, Anna Wanka, Miranda Leontowitsch and Horst Meier lead parallel conversation presenting insights from expert-by-training and expert-by-experience in co-design and co-create a caring community in Germany.

In Chapter 27 Katrin Lehner and Charlotte Gruber lead parallel conversations presenting insights from expert-by-training and expert-by-experience in researching social exclusion from social relations in Austria.

Future perspectives in the field of participatory approaches in ageing research

In the final section of the book, we highlight future pathways for participatory approaches in ageing research. Chapters discuss new ways of understanding policy, consequences of digital transformations on participatory ageing research, innovative knowledge generation practices, and how to combat ageism with participatory research. Thereby this section captures not only how participatory approaches with older adults might change in the future but also how they might help us understand societies of the future.

In Chapter 28, Julian Stubbe et al., explore which challenges for participation go hand in hand with a mission-oriented understanding of politics and how the role of participation can be systematised in this context.

In Chapter 29, H.R. Marston et al., present project 'Adjust Tech, Accessible Technology' (ATAT) project that aims to understand via citizen science what basic adjustments are required by older adults; to access and use affordable technologies and software – such as mobile apps.

In Chapter 30, H. Kaspar et al., provide insights from a community-based participatory research project initiating caring communities as a social and health initiative to support ageing in place in Switzerland to showcase how production of knowledge in participatory approaches allow inspiration and information flowing in both ways between science and society.

In Chapter 31, M. Leleu et al., propose a comparative dialogue on participatory methods of Age-friendly Cities and Communities to show how they can influence not only the ageing process but also representations of old age within society and our relationships with older adults.

In the final Chapter A. Urbaniak and A. Wanka discuss learnings we can take from involving older adults at different stages and in different realms of research. Contextualising these learnings with major societal trends ageing populations are facing now and in the future, they outline future pathways for participatory ageing research.

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PART 1

Methodological aspects of participatory approaches in ageing research

2

ROLE OF REFLEXIVITY IN CHALLENGING PARTICIPATION INEQUALITY IN PARTICIPATORY APPROACHES WITH OLDER ADULTS

Anna Urbaniak

Introduction

Participatory approaches, as conceptualised in this handbook, in broadest terms are designed to increase the participation of non-academics in research. The main assumption behind those approaches is that knowledge of experts-by-experience (in case of this handbook: older adults) should be harnessed and added to the knowledge of experts-by-training (academics). Increased interest in participatory approaches reflects ever-growing trend to democratise science (Gubrium et al., 2015; Stilgoe et al., 2014) and also ambition to bring research as close to lived lives as possible (Buffel, 2019; Forster et al., 2021; Yankeelov et al., 2015). Within this framework, more and more researchers (Walker, 2007) and funding programmes (see e.g. European Commission, 2021) call for applying participatory approaches such as for example inclusive research, user-led research, community research, participatory action research, collaborative research or citizen science with different populations. All of those differently labelled approaches by design are intended to address social injustice (Kollewe, 2020) and include disadvantaged groups. Participatory approaches thus challenge not only traditional notions of how research is being done but also who is supposed to do research and be "an expert". As such they challenge a sense of certainty and security based on well-established and familiar scientific norms and practices. This, in turn, leads to blurring the lines between process and content and shifts power relations in the research process. The production of knowledge(s) together with (rather than about) older adults can act as an inclusive practice that has the potential to challenge hermeneutical epistemic injustices (Fricker, 2007), and support marginalised groups in being heard (Spivak, 2003) and included in the representation of knowledge on a wider level. However, significant challenges arise when inclusion is tokenistic and when voices of some older adults are listened to/or heard over others. This participation inequality might lead to (re-)producing epistemic injustices, distort inclusive policy and practice development, and contradicts the inclusivity potential of participatory approaches with older adults. Against this backdrop, reflexivity

is essential not only to further develop participatory approaches but also, as I argue in this chapter, to make sure that the inclusivity potential they encompass is fully harnessed.

How inclusive are participatory approaches with older adults?

Active and meaningful involvement of older adults in research is particularly important as they are the fastest-growing population across European jurisdictions. They are, however, not a homogenous group and hence we need specifically tailored approaches and methods that capture the diversity of their needs and experiences. The differing experiences for diverse groups of older adults (e.g. migrants; LGBTQIA+ community members, homeless, oldest-old; institutionalised older adults; people with mental health issues or cognitive disabilities) remain under-researched (Betts, 2021; Korkmaz-Yaylagul & Bas, 2021; Okamura et al., 2020). In research with such groups that are at-risk-of-exclusion participatory approaches are especially needed in both qualitative and quantitative enquiries to make sure that their experiences are captured and their voices heard. They have the potential to harness the knowledge of older adults as experts-by-experience at all stages of research process and to contribute to advancing more inclusive, lived-experience research that informs creative policy designs and suitable practical support. Inclusive participatory approaches capture the voices, the lived experiences, possibilities, and the needs of diverse groups of older adults as experts-by-experience. They allow researchers to gain insights into older adults' experiences and enable older adults to express their voices.

However, current participatory approaches with older adults are often criticised, and that is for variety of reasons (James & Buffel, 2022). Most often critique highlights that research processes are designed too narrowly, lack adaptivity, lack closeness to older adults' life worlds, and remain shaped by strong hierarchies between academic researchers and older adults (Salvo, 2001). For example, Müller and Wan (2018) described a participatory project that received funding to develop a Global Positioning System (GPS) for older adults who wander where participants' voice was limited to contribute to this development and other, non-technological solutions that older adults identified were not considered. This is also due to the fact that older adults are often not involved in the formulation of research problems and questions, but their participation is often limited to specific stages of the research process (Corrado et al., 2020; James & Buffel, 2022; Merkel & Kucharski, 2019). For example, participatory research and the development of new technologies with older adults rarely go beyond usability tests (Fischer et al., 2020). Projects deploying participatory approaches with older adults often neglect the heterogeneity of this group. There is a risk that older adults involved in the research primarily represent the more educated, youngest, and more included groups of older adults. This diminishes the full potential for inclusivity and responsiveness of research that is at the heart of participatory approaches (Czaja et al., 2019; Merkel & Kucharski, 2019; Poli et al., 2019), and thus creates participation inequality.

What highlighted those inequalities even further was the recent COVID-19 pandemic. Numerous resources emphasise that in pandemic circumstances ageism became even more apparent and heterogeneity of older adults, their voices and experiences are often not recognised (Ayalon et al., 2021; Ehni & Wahl, 2020; Fraser et al., 2020). There is still not enough research that focuses on the diverse abilities of older adults and how societies can benefit and could benefit further if there were tools to harness their potential. With its focus on deficiencies and care needs, existing research might nurture age stereotypes and sometimes

unintentionally legitimises ageism (Corrado et al., 2020). Even though a growing body of evidence highlights that participatory approaches may challenge ageist attitudes, practices, and systems (Corrado et al., 2020) the ageism that is rooted in micro-, mezzo-, and macro-structures remains one of the most fundamental challenges to inclusive research practice in participatory approaches with older adults.

On the micro level, ageist beliefs may implicitly lead researchers to make assumptions about older adults' desires, capabilities, and motivations, which create barriers to enacting fully participatory practices, demonstrating the need for ongoing critical reflexivity regarding ageism and its influence on individuals (academics and non-academics alike) involved in research. Researchers, as traditional 'owners' of the research processes feeding into policy and practice intervention designs, have the primary responsibility to challenge these societal and personal ageist assumptions, practices, and attitudes and aim for increased inclusivity in participatory approaches with older adults (Trentham et al., 2015). Yet we still don't know enough about what practical tools can they use to accomplish these goals.

Even though diverse participatory practices have contributed to the advancement of democratisation of science and enhancing inclusion (Stilgoe et al., 2014), more and more researchers critically reflect on the ability of participatory practices to be more socially responsive and just (Stirling, 2015; Wynne, 2006). For example, a relational coproductionist orientation, suggested by Chilvers and Kearnes (2020), problematises meso and macro-structural dimensions highlighting how particular "atmospheres of democracy" (Latour & Weibel, 2005) and "political ontologies" (Marres, 2013) in given institutions or in a wider macro-structural context are produced through the performance of participatory practices to the exclusion of others. Older adults face exclusion in diverse domains of social life (K. Walsh et al., 2017), including research (James & Buffel, 2022) hence I consider the question of inclusivity of research practices with this group of people in participatory approaches as elementary.

In this chapter I follow an understanding of inclusive research practice in participatory approaches as such that allow to form "collaborative, equitable partnership in all phases of research" (Israel et al., 2017, p. 5). From this perspective, inclusivity of participatory approaches with older adults refers to (1) the meaningful involvement of (2) diverse groups of older adults in (3) contributing their perspectives and experiences (4) as co-creators of the research process. Hence, a better understanding of how inclusive research practice in participatory approaches with older adults is followed, considering the underlying dynamics forming inclusion/exclusion needs to be unpacked in relation to the four dimensions listed above.

Reflexivity in participatory approaches with older adults

As already noted in the introduction of this chapter, all participatory approaches assign a unique value to the co-constriction of human knowledge. This implies that each participatory research project, by design, involves some degree of mutual exploration and discovery between academics and non-academics. The, so far unmet, challenge for researchers working with participatory approaches with older adults is to document this process in an open and honest way.

The previous part of this chapter highlighted potential challenges to the inclusivity of the research practice in participatory approaches with older adults. In this section, I want to invite readers to practice their reflexivity in the context of previously highlighted

challenges. Following Guillemin and Gillam (2004) I understand reflexivity in research as a process of critical reflection both on processes of knowledge generation, and the kind of knowledge produced from research. In the following part, I suggest to organise this critical reflection around four challenges to inclusivity in participatory approaches with older adults: meaningful involvement, heterogeneity of older adults, the contribution of perspective and experiences of non-academics in the research process, and power relations in co-creation processes. I consider those four dimensions as a cornerstone of inclusive research practice with older adults and are entangled with the micro, mezzo and macro-structural contexts of the research practice. In this chapter, I suggest using the term microstructural context to refer to individuals, mesostructural context to refer to institutions, and macrostructural context to refer to wider sociocultural aspects of a given country or region of the world.

Critical reflection on the meaningful involvement of older adults in participatory research practice should start with the basic concern of what meaningful involvement means. Is their involvement meaningful for themselves? How is the meaningful involvement of older adults in participatory research practice perceived by researchers? How do institutions and funding bodies conceptualise meaningful involvement of older adults in participatory research practice? Does the culture and societal norms in the country where we perform participatory research practice recognises the need for the involvement of older adults in the research process as meaningful? How can we make the involvement of older adults in participatory research practice meaningful thought the whole research cycle across micro-, mezzo- and macro-spheres?

This list is not complete and does not fully cover all topics. Those questions are merely an invitation to a reader to start thinking about the processes of knowledge generation, and the kind of knowledge produced through participatory approaches with older adults. The meaningfulness of involvement is inextricably linked with diverse perspectives of academics, older co-researchers, institutions, and funding bodies. The question of diversity of perspectives is a natural aspect of all participatory approaches. In the context of participatory approaches, it gains further meaning as older adults are not a homogenous group. Therefore, in the next section I suggest some more questions worth considering when reflecting upon inclusivity of participatory research practice in the context of heterogeneity of older adults.

Critical reflection on heterogeneity of older adults involved in participatory research practice should start with the question: Who is involved in participatory approaches? Do older co-researchers involved in the research represent different voices of older adults? How does our research design capture heterogeneity of older adults? How applied methods cater for diverse needs and possibilities of older adults? How do recruitment processes support heterogeneity of older adults included in the research sample and in the research team as co-researchers? Do researchers have the necessary competences to handle and nurture heterogeneity of the research team consisting of a diverse group of older co-researchers? Are institutions ready to support heterogeneity of the research team? Does the culture and societal norms in the country where we perform participatory research practice recognises the heterogeneity of older adults? How can we capture heterogeneity of older adults in participatory research practice through the whole research cycle across micro-, mezzo- and macro spheres?

As in the previous dimension, the list of questions suggested above does not claim to be comprehensive. Its main goal is to highlight the main areas of participatory research

practice where heterogeneity of older adults needs to be reflected upon when considering the level of inclusivity of participatory research practice. Heterogeneity of older adults is reflected also in the heterogeneity of perspectives and experiences they might contribute to participatory research projects. The section that follows presents some issues worth considering when reflecting upon inclusivity of the participatory research practice in the context of the contribution of perspective and experiences of older adults in the research process.

Critical reflection on the contribution of perspectives and experiences of older adults in participatory research practice is connected to the depth and scope of this contribution. We might want to consider in what capacity older adults are involved during the research process. Are older co-researchers involved as advisory board members whose contribution remains limited? Are older co-researchers equal partners in all research stages? How much can they contribute their perspectives in areas traditionally assigned to academia and academics? How can we accomplish the understanding between academics and older co-creators? Are institutions ready for creating an environment enabling the contribution of perspectives and experiences of older adults in participatory research practice? Does the culture and societal norms in the country where we perform participatory research practice support expressing the voices and experiences of older adults? How can we accommodate contributions of perspectives and experiences of older adults in participatory research practice through the whole research cycle across micro-, mezzo- and macro-spheres?

Again, the presented list should be considered as an invitation to pose more questions on the depth and scope of the contribution of perspectives and experiences of older adults in participatory research practice. Those questions refer to all research stages and pose more questions about research design, methodology, data collection, and dissemination strategy. They bring also attention to the fundamental issue of power relations in the co-creation processes.

Critical reflections on power relations in research practices remain the fundamental aspect for researchers working with participatory approaches with older adults. The main question here is on the scope and depth of power older adults have in the research process, their action scope, and ability to make decisions in the research. Are researchers ready to give up control over the research cycle and share their power with older co-researchers (for example, also in terms of how to spend research budgets)? How participation is conceptualised by all interested parties involved in the research process (academics, older adults, funding bodies, gatekeepers, and universities)? Do the culture and societal norms in the country where we perform participatory research practice support equal partnerships with older adults? How can we accommodate partnerships in participatory research practice through the whole research cycle across micro-, mezzo- and macro-spheres?

As mentioned in the opening section of this part, the challenge for researchers working with participatory approaches with older adults is to document reflective processes in participatory practice in an open and honest way. In the next section of this chapter, drawing from experiences gathered during the citizen science project "Socially Excluded Older Adults: Voices and Experiences (SEVEN)", I develop a dynamic reflexivity model of participatory research practice with older adults. I hope that this model might be useful for researchers working with participatory approaches with older adults who seek practical tools to help them navigate through challenges around inclusivity in participatory research practice.

Towards more inclusive participatory research practice with older adults

In the previous sections of this chapter, I presented an overview over the current state of research on inclusivity of participatory research practice with older adults. I highlighted four main challenges that need to be addressed when considering the level of inclusivity of participatory research practice with older adults: meaningful involvement, heterogeneity of older adults, the contribution of perspective and experiences of non-academics in the research process, and power relations in co-creation processes. I highlighted that those four dimensions are entangled with the micro-, mezzo- and macrostructural contexts of the research practice. In this part, I present briefly the citizen science project "Socially Excluded Older Adults: Voices and Experiences (SEVEN)" and how reflexivity was implemented during this project.

Research context – the SEVEN (socially excluded older adults: voices and experiences) project

Insights presented here stem from an Austrian Citizen Science project that was funded within the framework of the FWF Top Citizen Science Funding Initiative. In the context of this initiative, citizen science is understood as the active involvement of citizens and their knowledge, resources, and commitment to scholarly research and the generation of new scholarly insights.

The project approached the following main research question: What can we learn from the lived experiences of socially excluded older adults and how can we capture their voices in research and service designs? Three objectives helped to address this question:

1 Capturing the lived experiences, expectations, and needs of socially excluded older adults; unpacking the role of life events, practices, and gendered norms in the construction of in- and exclusion from social relations;
2 Facilitating and advancing ways to express the voices of socially excluded older adults, to empower them and their self-advocacy;
3 Harnessing learning from socially excluded older adults, developing policy and research recommendations, and helping to ensure their applicability to the needs and preferences of older adults.

A voice-led approach to addressing in- and exclusion from social relations in older age was employed in three steps: (1) Organising a consultative forum 1 (CF1) to inform data collection; (2) peer researcher training (PRT) and citizen researcher data collection and (3) Organising a concluding consultative forum 2 (CF2) for data presentation and recommendations for policy/service and research.

First and within CF1, six socially excluded older adults and five stakeholders with relevant professional roles in service provision and representative voice/advocacy for older adults (e.g. social service organisations, non-profits, and care organisations) were recruited. The aim of CF1 was to co-produce a research strategy with both stakeholders and socially excluded older adults. Primary goals included developing/advancing research questions, recruitment strategies, peer-research training programme, and a data collection methods guide.

Second, nine socially excluded older adults were trained as peer researchers. All trained participants decided to contribute to the data collection and each pursued a project in

partnership with the academic researchers.[1] Co-researchers themselves determined the exact focus of these projects. Sensitive to a wide range of abilities and backgrounds, the PRT involved presentations, discussions, and workshop elements. Co-researchers were continuously supported by the research team in their analysis and write-up of findings through joint interpretation groups and individual face-to-face meetings and phone conversations.

Third, the consultative forum 2 with invited stakeholders and older adults and six presenters (three older co-researchers and three academic researchers) was organised to review emerging findings and develop recommendations for implementing participatory approaches with older adults in different institutional settings represented by stakeholders. The additional purpose was to review and discuss the findings from the first stage and to agree upon priorities for subsequent strands of work, identifying on-the-ground knowledge deficits that need to be addressed and potentially developing innovative solutions for service delivery and/or evaluation. Consideration was specifically given to practicable and measurable recommendations for stakeholders.

Reflexivity in the making

Reflexivity during the project was a crucial part for our research practice. The research team consisted of three white female researchers at different stages of their academic career with two being in their mid to late thirties and one in her mid-twenties. Co-researchers were all while older adults living in Austria: five women with experience of homelessness aged between 57 and 60 who joined the project at the latter stage and four co-researchers who were involved in the project from the very beginning: one 68-year-old man with recent experience of bereavement, one 69-year-old woman living in a rural environment and two participants with the experience of living in Senioren WG (shared flats for older adults) – one 73-year-old man and one 76-year-old woman. One man in his mid-seventies decided to withdraw from PRT after the first two hours of the meeting arguing that this seems less challenging than he anticipated.

During the whole research process, we have been organising our critical reflection on the type of produced knowledge and on the processes of knowledge production with a special focus on personal, interpersonal, methodological, and contextual aspects Walsh (2003).

Personal reflexivity is focused on the researcher and the attitudes and expectations that shape the research project. In our case, this referred to researchers' attitudes towards older adults and expectations for co-creation processes. After the first training session with older adults from the first group, we realised that even though we put a lot of effort into making the presentations accessible and interesting for non-academics we might have started the project with too high expectations toward older co-researchers in terms of learning capacities. Our not-adequate expectations towards co-researchers became even more apparent when we felt that enlarging the font in some exemplary materials would be a sufficient way of making them accessible for non-academics. Whereas one of the co-researchers from the first group had experience with transcripts before, the other member of this group looking at an exemplary transcript with time stamps said: "I can't read it. It makes no sense to me" and put the paper down with a visible frustration. This led to a change in our expectations and also increased our motivation to make participants feel included regardless of their educational background and made us conscious, yet again, of the heterogeneity of older co-creators involved in SEVEN. It made us check with older co-creators how meaningful they consider tasks we planned for them and based on their feedback we decided to adjust the

programme of PRT and give them more power by negotiating the content of the training that initially was controlled by us as academic researchers. At the latter stage of the project, when working with the second group of co-researchers we were also faced with the observation that our drive to somewhat "protect" older co-researchers from being overwhelmed with the academic knowledge and feeling underappreciated might have come alarmingly close to paternalistic and ageist attitudes. Those examples show how attitudes of academic researchers and expectations toward older co-researchers might change during the project and contribute towards renegotiating meaningful involvement, recognising the heterogeneity of older adults, expanding the scope of contributions of non-academics in the research process, and renegotiating power relations in co-creation processes

Interpersonal reflexivity is concerned with the relationship between the researcher and, in our case, older co-researchers and also between older co-researchers themselves. As the project consisted of numerous meetings with older adults and academic researchers we have developed a relationship that goes beyond the researcher-research subject. We experienced a relationship built on trust, mutual interest, and attachment build during a year of regular meetings. We noted that this resulted in a high level of motivation for older co-researchers. On the other hand, it made us aware of the fact that some of the older co-researchers might be willing to go the extra mile in order to make us happy as we no longer were impersonal representatives of an academic institution. The relationships within the groups also led to a situation where some older co-researchers felt more entitled to share their opinions whereas others shied away from being active participants of the discussions in the plenum. This required a high level of emotional labour to stop minor tensions from escalating and navigating through existing social relations in the second group where participants knew each other for a longer period of time. The dynamic element connected to interpersonal relationships built during the research process was evident when comparing the depth of discussion and level of openness that we conducted at the first meetings and during the last workshop meeting where both groups worked together for the first time. We noted that the interpersonal relations developed through this project contributed not only to gathering more authentic data but also to creating supportive relationships between older co-researchers and the whole project team (including academic researchers). We have witnessed and experienced dynamic changes in power relationships through the project that contributed also to different levels of contributions from older co-researchers thought the project (increased during the project) and dynamic understandings of meaningful involvement (from being a listener in CF 1 to becoming an active presenter during CF2)

Methodological reflexivity acknowledges the theoretical commitments that surround each research project. In our case, this referred to the fact that we conduct a citizen science project with older adults on the topic of exclusion from social relations. The topic we wanted to address in this project can be described as a sensitive one. Therefore we didn't want to use any stigmatising language. We also decided to go through gatekeepers and a network of contacts gathered in another project on social exclusion to recruit older co-researchers. We recognised that this might have excluded some older adults that were not available through our networks and not identified by gatekeepers as "suitable" highlighting not only the power dynamic but also difficulties in reaching a heterogenous group of older adults. After CF1 we noted that not all participants considered taking part in PRT as meaningful and didn't want to contribute in the scope going beyond taking part in CF1 and CF2. We assumed that this might be an option therefore we continuously worked on the recruitment of members of the second group at the latter stage. We have entered the

field with the second group of co-researchers already enriched by the experience of meetings with the first group and suggested a shift from interviews and autoethnography to photovoice as a method that caters to the diverse needs and possibilities of older adults. We moved away from the model of training co-researchers in numerous methods and giving them freedom from picking a method to a model where we trained them in one method that was most inclusive. This shift in power allowed for applying a more inclusive method that was allowing for meaningful involvement was easier to learn and gave co-researchers more freedom in data collection.

Contextual reflexivity is concerned with situating a given study in its cultural and historical milieu. In our case, this refers to the fact that SEVEN was conducted partially during the COVID-19 pandemic in Austria. The fact that Austrian Science Found designates funds toward research applying participatory approaches (citizen science) already distinguishes this context from other jurisdictions where participatory approaches are not funded straightforwardly. Having this funding available we felt confident in planning a flexible research project that maximises inclusivity. The fact that the project took part during COVID-19 pandemic limited planned inclusivity to some extent. This meant we needed to organise CF1 in an online format and CF2 in a hybrid format. Therefore we needed to adjust the format of the meeting and face the challenge of including those who are digitally excluded. As some of the older participants lacked the technical equipment and skills to take part in an online meeting we hired student assistants to train them in using Zoom and be on-site during the meeting to offer any kind of support needed. This resulted in some participants discussing with student assistants and not in the forum. Especially for participants with hearing issues, this was the preferred form of being involved in the CF1. This made us question the meaningfulness of such participation as they didn't contribute to the plenary discussion. COVID-19 infections excluded some participants from some meetings during the project impacting power relations within the groups and limiting contributions from absentees.

During the whole research process, we have been implementing reflexivity in each stage of the research cycle by:

1 Scheduled regular reflexive meetings, where three academic researchers met and discussed ongoing developments in the project on a weekly and later on a bi-weekly basis.
2 Ad hoc meetings of academic researchers with older co-researchers to address emerging issues.
3 Debriefings for at least two academic researchers after reaching milestones of the project and after each meeting with older co-researchers.
4 Analysis of reflexive meetings – conducted separately by each academic researcher and jointly discussed with co-researchers during reflective parts of the meetings and one separate reflective meeting at the end of the project.
5 Collecting ongoing feedback from older co-researchers during the workshops and meetings.

This approach to applying reflexivity in our participatory research practice allowed us to be more critical towards our own work and be more aware of limitations and opportunities faced by all involved in SEVEN as a citizen science project. We were able to observe how our personal attitudes change through the project (we developed more realistic expectations toward older co-researchers, and became more aware and sensitive to our paternalistic behaviours), how dynamic relationships in the group of co-researchers are (we noted that

from meeting to meeting participants become closer to each other and are willing to engage on a deeper level in discussions), how contextual circumstances related to COVID-19 plays out in making decisions and moving towards next step of the process (postponing the start of the project, adapting meetings to an online format, adjusting the budget of the project due to unexpected expenses). It also allowed us to be more flexible and responsive in making the project as inclusive as possible even if this required substantial changes in our initial planning, including time and resources allocated toward this project. The fact that this project was more flexible and more dynamic than projects not involving older co-creators made us look for a tool enabling a more systematic approach to organising and evaluating our participatory practice. Gathering lessons learned from this project, I propose a dynamic model of reflexibility that might contribute towards more inclusive participatory research practice with older adults.

Dynamic reflexivity model

This model does not focus on specific participatory practices but rather describes ways of facilitating dynamic reflexivity in participatory research practice with older adults. Within this framework, the distinctions I propose are focused primarily on individual research projects and the concrete practices therein. However, I believe that such a constrained focus can better inform the participatory practices, and in that sense may contribute to the movement across disciplines advocated by Holland (1999) and increase the inclusivity of participatory practices with older adults. With this in mind, I present below a dynamic model of reflexivity for inclusive participatory research practice with older adults (Figure 2.1).
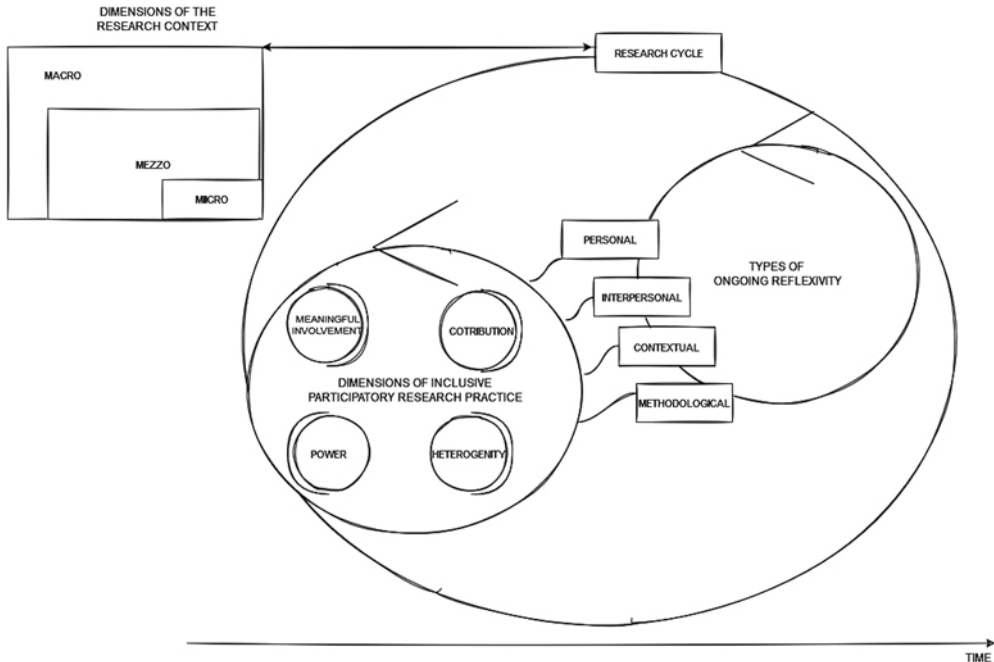

Figure 2.1 A dynamic model of reflexivity for inclusive participatory research practice with older adults.

First, and most importantly I argue that reflexivity must extend throughout the entire research cycle, encompassing each stage, and addressing four fundamental dimensions of inclusive participatory research practice:

1 meaningful engagement of older adults,
2 acknowledgment and celebration of heterogeneity of older adults,
3 the contribution of perspectives and experiences of non-academics in the research process,
4 recognition of power dynamics within co-creation processes.

Participatory research practice with older adults is a dynamic process and during the research cycle, the project might move from being more to being less inclusive (or the other way around) and may be susceptible to different forms of exclusion. Hence the level of inclusivity of participatory research practice with older adults might fluctuate during the whole research cycle. Something we considered as inclusive research practice at the beginning of the process might change across and during each element of the research process (e.g. some conflicts among co-creators might emerge leading some to be more withdrawn or even leave the project, some institutional settings might change, during the participatory practice sets of beliefs and attitudes of researchers and co-researchers might change and challenge settings existing at earlier stages of the cycle). Therefore, it's not enough to critically reflect upon the listed four dimensions of inclusivity of participatory research practice only at the beginning or at the end of the research process. As research processes are dynamic, so is the level of inclusivity of participatory practices, and therefore critical reflection needs to be an ongoing procedure that starts simultaneously with the first sparks of the new research idea.

Second, I argue that reflecting upon four dimensions of inclusive research practice (meaningful involvement, heterogeneity of older adults, the contribution of perspectives and experiences of non-academics in the research process, and power relations in co-creation processes) requires applying personal, interpersonal, methodological, and contextual lenses simultaneously. For example, considering the meaningful involvement of older co-researchers we need to reflect not only on personal attitudes (how researchers' expectations shape the inclusivity of the research practice) but also on interpersonal relations (how relations between co-researchers, and between co-researchers and academics contribute towards/hinder meaningful involvement of older adults in participatory research practice), methodological aspects (how applied methods contribute towards/hinder meaningful involvement of older adults in participatory research practice) and contextual circumstances (how cultural and historical milieu contributes towards/hinders meaningful involvement of older adults in participatory research practice).

Third, I highlight that the micro-, meso- and macro-dimensions of the research are not only the context we reflect upon but also the context that dynamic reflexivity might change during the lifecycle of the project. In practical terms, this means reflecting upon four dimensions of inclusivity of participatory research practice with older adults while being aware that this practice of critical reflection might challenge the existing status quo across the micro-messo and macrostructural context of the research. For example, reflecting upon any aspect of inclusivity we might realise that some of our motivations or attitudes have changed which already means that the microstructural context of the participatory research practice has changed. We might also realise that there are many challenges and opportunities in the institutional aspects (masso level) or related to the wider participatory culture

and position of older adults in a specific cultural setting (macro level). Critical reflection on the inclusivity of the participatory research practice, in the long run, might contribute to challenging the existing status quo across all dimensions of the research context: Starting with the examination of individual motivations and expectations, progressing to the examination of the institutional context, and ultimately addressing the issue of ageism.

Conclusions

Participatory approaches with older adults positively impact research quality, and its relevance, outcomes, and integrity. However, they might contribute to participation inequality through different mechanisms specific to research with older adults such as e.g. involving only certain groups of older adults, involving older adults in a limited capacity through the research process or nurturing age stereotypes. Reflexivity actively applied to all stages of the research process and during the whole research cycle has the potential to increase the inclusivity of participatory approaches with older adults by addressing the key question of how meaningfully involve diverse groups of older adults to contribute their perspectives and experience as co-researchers in participatory approaches. There is unquestionably much work to be done on participation inequality in participatory approaches with older adults. This chapter is merely an initial effort in exploring possible ways that reflexivity might contribute to this discussion that goes beyond individual researchers and co-researchers highlighting how important institutional and cultural contexts are to fully harness the inclusivity potential of participatory approaches with older adults.

Note

1 One participant conducted three different projects collecting data on experiences of others through interviews and one focus group.

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3

THE WILLINGNESS OF OLDER ADULTS TO ENGAGE IN PARTICIPATORY RESEARCH

Empirical Findings from Switzerland

Alexander Seifert

Willingness of older adults to engage in participatory research

This chapter aims to present empirical evidence of the willingness of younger and older adults to engage in participatory research via citizen science projects by involving them as co-creators in these research studies (Wanka & Urbaniak, 2021).

Citizen science – the involvement of non-scientists in scientific research – has become more popular with researchers in recent years (Fritz et al., 2019; Gura, 2013; Vohland et al., 2021). The goal of citizen science is to bring the public sphere and science worlds closer together, to consider possibilities for the more active involvement of non-scientists in research, and to enable research that includes the views of laypeople (Bonney et al., 2016) while promoting the co-creation of scientific knowledge (Dickinson et al., 2012). One definition of citizen science interprets it as "partnerships between scientists and non-scientists in which authentic data are collected, shared, and analyzed" (Jordan et al., 2012, p. 307). For the layperson, this research approach promises positive effects on their scientific literacy and attitudes toward science in general (Bonney et al., 2016). More generally, citizen science is seen as a way to "democratize" science (Irwin, 1995) by incorporating participants in the research process, thus strengthening the bond between science and society (Haklay et al., 2021). Despite the recognized benefits of citizen science, these research approaches "must strive to reach a wider range of audience and participants" (Bonney et al., 2016, p. 12). In order to precisely address a group targeted at citizen science, it is necessary to find out what potential of interested persons exists in the entire population and which factors motivate the audience to take part in citizen science projects. To date, how large the overall potential of citizen science is, which factors shape people's participation, and how a wider circle of participants could be mobilized remain open questions (Lewenstein, 2016). One exception is a Swiss study (Füchslin et al., 2019) that reported 36% of respondents in a national survey were either interested or very interested in participating in scientific research projects. The survey also demonstrated that attitudes toward science are significant antecedents of respondents' interest in participating in citizen science. Nevertheless, this study

only asked about a person's general willingness to participate in scientific research projects, and not about participatory research projects, as described below.

A meta-analysis showed that the participants in citizen science projects are often well-educated and have a tendency to have previously participated in other research projects (Pandya & Dibner, 2018). Therefore, it can be assumed that there is an element of "participation inequality" (Hakley, 2018). However, the studies referenced in the meta-analysis described people who participated in citizen science projects, not the openness of members of the general population to being a part of such research projects. Only a general population sample could address such an evaluation of openness to participation.

While the term "citizen science" has gained importance in recent decades and is now mostly used to refer to laypeople's participation in research, it can also be understood as an increasingly fashionable label applied to a subset of initiatives promoting public participation in scientific research (Strasser et al., 2018). In this context, a similarly used term, "participatory research," is more often seen as rather old-fashioned, though it nevertheless emphasizes the core of laypeople's voluntary participation in research (Cornwall & Jewkes, 1995). We use the term "participatory research" in our study because, on the one hand, it is a term that is perhaps easier to understand for the general population (as the study will show), while on the other hand, it allows us to emphasize that we are talking about participation in participatory research projects, not about participatory participation in, for example, non-governmental organizations or public research projects. Engagement in participatory research ranges from data collection only to full inclusion in the definition of the problem and involvement in research actions (English et al., 2018). Therefore, it is also important to ask not only the general population if they are open to participating in these research projects but also with which tasks (Land-Zandstra et al., 2021). The present study addresses these questions.

One population group that has been considered a partner in research projects for quite some time, at least in gerontological research, is older adults (McWilliam, 1997; Ross et al., 2005). Viewing older adults as partners in research enables insights into their experiences and promotes their voices, as such, in aging research (Partridge, 2022). This approach helps direct research and policy toward more inclusive and appropriate designs that capture the views and needs of older adults (Blair & Minkler, 2009). This co-design approach engages older adults as co-creators at various stages of the research cycle. Besides the potential for involving older adults in research, the question remains open concerning who is willing to engage in participative research and which requirements must be fulfilled for them to act. The current study answers these questions to evaluate the potential for participatory research involving the main target group of sociogerontological research.

Research interest

Citizen science and participatory research rely on the fact that private citizens are motivated and interested (and able) in participating voluntarily in scientific projects. Surveys such as the Swiss Science Barometer (Wissenschaftsbarometer, 2022) provide information about the general population's interest in research and the trust they place in it. Other studies that have investigated the motivation for citizen science are based on information from people who have already participated in one or more such projects (Agnello et al., 2022; Land-Zandstra et al., 2021; Raddick et al., 2009), or they are convenience sample studies (Asingizwe et al., 2020; Kam et al., 2021; Seifert et al., 2020). These studies provide little

information on how great the willingness of the Swiss population as a whole is concerning active participation in research and which framework conditions must be fulfilled to attract participants.

From this starting point, information on the willingness to engage with participatory projects was collected via a representative population survey. Three research questions were the guiding principles:

1 What is the willingness of the Swiss population to actively participate in participatory research?
2 Which people are motivated and willing to devote time and energy to engaging in participatory projects, and under which circumstances will they do so?
3 What attitudes do Swiss participants have about participation in research?

One additional goal of the study – the focus of this chapter – was to uncover the differences between younger adults (those 18–64 years) and older adults (aged 65 years and older) and to evaluate existing age group-related differences in willingness and attitudes regarding engagement with participatory research projects.

The national citizen science survey of younger and older Swiss adults

The study was conducted between October 12 and December 12, 2020. A total of 1,360 adults aged 18 years and older from all language regions of Switzerland (German, French, Italian) were interviewed using a computer-assisted web interview format (n = 1303); a paper-and-pencil-based survey was provided for households without internet access (n = 57). The response rate of the survey was 19%. All respondents consented to participate in the study. A standardized questionnaire was administered with questions about personal details (age, sex, education, sports, subjective health, and subjective quality of life) and openness to participate in participatory research. A random sample of the permanent-resident population of Switzerland aged 18 years and older was selected from the AZ-Direct database (based a.o. on a public phonebook). The sample was post-weighted according to age group, language region, gender, and education. The ages of the respondents in the sample ranged from 18 to 93 years, with a mean age of 48.4 years; 52% were female.

For our analyses, we contrast our sample by two age groups: 1097 people aged 18 to 64 (described here as "younger adults") and 263 people aged 65 and over (described here as "older adults"). This cut-off was chosen based on the retirement age in Switzerland. Table 3.1 provides a description of the study sample.

Findings of the national citizen science survey

In the next sections, the descriptive findings of the national study are outlined with a focus on the differences between younger and older adults.

Familiarity with the terms "citizen science" and "participatory research"

At the beginning of the questionnaire, participants were asked whether they were familiar with the terms "citizen science" and "participatory research." With the term "citizen science," 8.5% were "rather" or "very" familiar, while for the term "participatory

Table 3.1 Sample description (unweighted data) and group descriptions (weighted data)

Parameter	Sample		Persons with interest in participatory research	Persons without interest in participatory research
	N	Percentages (unweighted)	Percentages (weighted)	Percentages (weighted)
All	1360	100	48.5	51.5
Gender				
Female	699	51.5	43.9	56.1
Male	657	48.4	53.5	46.5
Age group				
18–25	166	12.2	65.7	34.3
26–44	392	28.8	66.3	33.7
45–64	539	39.6	47.6	52.4
65–93	263	19.3	24.3	75.7
Education level				
Primary	80	6.0	22.7	77.3
Secondary	834	62.1	46.0	54.0
Tertiary	429	31.9	73.2	26.8
Living Area				
Urban or suburban	993	73.1	50.4	49.6
Rural	366	26.9	44.6	55.4
Living situation				
Lives alone	182	13.6	46.6	53.4
Lives with others	1159	86.4	48.8	51.2

Table 3.2 Knowledge of the terms "citizen science" and "participatory research"

Knowledge	"Citizen science"			"Participatory research"		
	All	18–64	65 +	All	18–64	65 +
	Percentages					
Not at all familiar	60.1	57.9	67.7	46.6	44.1	55.1
Rather unfamiliar	31.4	34.1	21.5	37.9	40.0	30.5
Rather familiar	7.4	6.8	9.7	14.1	14.5	13.0
Very familiar	1.1	1.1	1.1	1.4	1.4	1.4

research," only 15.5% were rather or very familiar. These differences between the terms can be assumed by the fact that "citizen science" is an English term rarely used outside the research world, whereas "participatory research" can be derived by many in the national languages – at least as individual components (i.e., "participatory" and "research"). We found no statistically significant differences between the age groups (18–64/65+) regarding the term "citizen science," but regarding the term "participatory research" ($t(1290) = 2.341$, $p = .020$), younger adults (M: 1.73) were more familiar with the term than older ones were (M: 1.61) (Table 3.2).

Terms' definition

After all respondents answered the question about their familiarity with the term "participatory research," they were presented with our definition of participatory research:

> In the further course, we will more often speak of "participatory research." Participatory research means that the research process is designed in such a way that citizens have the opportunity to participate in research projects on an equal footing with researchers. The participants decide whether, in what form and how intensively they want to participate. Participatory research means that one is not just an "experimental respondent," but is involved into research project.

On the basis of this explanation, all those being surveyed were able (on the same level of information) to imagine something about the concept of participatory involvement.

Previous participation in research projects

Of the respondents, 66 people (5.1%) stated that they had previously been involved in a participatory research project. In 61% of these cases, this participation took place at a Swiss university or a university of applied sciences. A plurality of participants had collected or classified data (42.7%), but some of them had also helped to interpret results (19.2%) or determine research questions (14.4%). More older adults (those 65 years and older) indicated that they had participated in participatory research projects than younger adults (18–64 years) had, with responses of 7.2% and 4.5%, respectively; nevertheless, there was no statistically significant difference between the age groups (Cramers-V = 0.052; p = 0.060).

Willingness to participate and factors for this

After defining the term participatory research for all participants, we asked them, "Would you like to be involved in participatory research once (or again)?" Here, 48.5% answered "yes" and 51.5% answered "no." This indicates a willingness of approximately 49% of the total sample to participate in such projects. Younger adults (18–64 years) were statistically significantly (Cramers-V = 0.285; $p < 0.001$; 56.8% to 24.3%) more open to joining participatory research projects than older adults (65+) were.

As shown in Table 3.1, in addition to age, males (Cramers-V = 0.096; $p = 0.003$) and people with higher levels of education (Cramers-V = 0.327; $p < 0.001$) were more open to participating in these projects than women and people with lower education levels. Regarding the residential aspect (urban vs. rural areas) and the living situation (living alone or with others), we found no statistically significant differences.

The survey also demonstrated that people who know a scientist personally are more open (Cramers-V = 0.290; $p < 0.001$; 65.1% to 35.8%) to participate in research projects than those without such contacts in their close social networks. People's openness to engage in participatory research is often influenced by their "interest in science" (Schäfer et al., 2018). Thus, the analyses included information about people's attitudes toward science or, more precisely, their interest in science and research. This was based on the statement, "I am very interested in science and research," which was rated on a Likert scale from 1 ("does not

apply at all") to 5 ("applies fully") (M: 3.53; SD: 1.115). Regarding this interest in science, the comparison between those who were open to participatory research projects and those who were not showed that people with a high interest in science were more open to joining a participatory project than people who were less interested in science in general (t(917) = 13.824, p < 0.001; M: 3.99 to 3.04).

In addition to the sociodemographic factors and the closeness to science (contact with a scientist and interest in science), a person's health can influence their ability to participate in research projects. Here, the analyses showed that people with a higher level of subjective health were more open to joining participatory research (t(949) = 3.394, p < 0.001; M: 4.24 to 4.06). A person's general socio-cultural activity level is important when asking if they are open to participating in projects. Thus, the analyses included information about people's daily life activities. This was based on five activities (meeting friends, taking day trips, visiting cultural events, participating in educational activities, and doing volunteer work), which were rated separately on a scale from 1 ("never") to 6 ("daily") and calculated in one variable (mean of all separate activities) (M: 3.05; SD: 0.626). The analyses showed that people with a higher number of socio-cultural activities were more open to being part of a participatory research project than people with low levels of those activities (t(947) = 7.152, p < 0.001; M: 3.20 to 2.91).

Additional analyses were conducted to check the bivariate results using a multivariate approach. Table 3.3 shows the results of a binary logistic regression to address willingness to engage in participatory research projects. In the model, the willingness groups [1 = willing, 0 = not willing] were considered the dependent variable, while age, gender, education, living area, interest in science, subjective health, and socio-cultural activities were included as independent variables.

Tests of the full model showed statistical significance (see Table 3.3 notes), indicating that the predictors, as a set, reliably distinguished between the two groups. Model A (all participants) shows that age, education, interest in science, and socio-cultural activities are significant prediction factors, whereas gender, living area, and subjective health are not statistically significant predictors based on the multivariate analyses. Thus, younger people, people with a high number of socio-cultural activities, and those with a high interest in science are generally more open to engaging in participatory research projects than older adults, people who are less often involved in socio-cultural activities, and those with a low level of interest in science.

Model B (only participants aged 65 years and older) shows that education, socio-cultural activities, and interest in science are significant predictors, whereas gender, age, living area, and subjective health are not predictors based on the multivariate analyses. Thus, the participants with higher education levels, people who are more active in socio-cultural activities, and those who are interested in science are generally more willing to participate in research via participatory projects than those with less interest in science and who have lower education and activity levels.

Areas of involvement and time amount

When the people interested in participatory projects were asked what they would specifically like to do in a participatory project, a majority of them stated that they would like to collect and classify data (see Table 3.4). However, there was also a group of people who hoped to do more than "just" collect data (e.g., to have a say in the research questions or research design). This shows that involvement is not limited to one area of the project cycle

Table 3.3 Multivariate binary logistic regression analysis for the predictors of willingness to partici-
pate in participatory research

Parameter	Model A: All[A]			Model B: Only 65+[B]		
	OR	p-value	Wald	OR	p-value	Wald
Age	**0.959**	**<0.001**	71.335	0.948	0.108	2.580
Female (ref. male)	0.924	0.630	0.232	1.970	0.064	3.426
Tertiary education (ref. primary or secondary)	**1.942**	**<0.001**	**11.105**	**3.516**	**0.007**	**7.234**
Urban or suburban (ref. rural area)	1.027	0.881	0.022	0.974	0.951	0.004
Interest in science[a]	**2.317**	**<0.001**	**105.256**	**1.826**	**<0.001**	**11.217**
Subjective health[b]	0.944	0.580	0.306	1.083	0.706	0.142
Socio-cultural activities[c]	**1.551**	**0.001**	**10.351**	**1.951**	**0.023**	**5.179**

Notes:
[a]*Interest in science* ("I am very interested in science and research"): scale from 1 ("does not apply at all") to 5 ("applies fully"); [b]*Subjective health*: scale from 1 ("very bad") to 5 ("very good"). [c]*Socio-cultural activities*: scale from 1 ("never") to 6 ("daily"). A: All participants: model fit (χ^2 = 295.741 [7], p = < 0.001, Nagelkerke's R^2 = 0.373, n = 893). B: Only participants who are aged 65 years and older: model fit (χ^2 = 52.311 [7], p = < 0.001, Nagelkerke's R^2 = 0.305, n = 196). Bold = significant values (p < 0.05).

Table 3.4 Desired areas of participation

Areas of research	Percentages		
	All	18–64	65 +
Collect and classify data	50.0	51.6	39.3
Interpret the results with researchers	42.6	45.7	21.1
Co-determine the research questions	32.5	34.4	19.7
Participate "only" as a research subject	31.1	29.4	42.6
Co-determine the research procedures	25.0	26.3	16.4
Present the results	22.0	23.3	13.8

and that participants want to be involved in different areas of the study. This also means that not everyone wants to be actively involved in all stages of a research project.

Regarding the differences between the two age groups (18–64 vs. 65+), a similar priority list can be seen (see Table 3.4); however, older adults are more likely to want to be only research subjects, compared to the other age groups.

In addition to the areas of involvement within a research project, the survey participants who were open to participation in research were also asked how much time they would be

willing to invest in this kind of research participation. A majority (55.6%) answered "a few hours per month,"; another 27.1% answered "a few hours per year," and the rest (17.3%) would like to invest more time than only a few hours per month. There were no statistically significant differences between the age groups, as both groups seemed to prefer the same expenditure of time.

Interesting topics of involvement

In addition to people's general interest in participation, it was also important for us to find out which topics the respondents who are open to participating could most likely imagine becoming involved with. Popular topics were society and social issues, environment/animals, and technology/natural sciences (see Table 3.5). Nevertheless, other topics were also preferred by certain people, such as the area of arts and culture. There were no great differences between the age groups, implying that both age groups have an interest in similar subject areas.

Obstacles perceived by people who are not interested

As the study shows, 48.5% of respondents indicated their desire to engage in participatory research projects, which means that the other half of respondents do not want to participate in participatory projects. To find out the reasons for this, these respondents were given various reasons to evaluate (see Table 3.6).

Over 26% of respondents answered "lack of time" and "no interest" as reasons. However, the reason "I don't have the necessary knowledge/skills" was cited most frequently (40.8%). This signals that the respondents think they lack the necessary "skills/tools" needed for involvement in participatory research projects. Therefore, participatory projects

Table 3.5 Interesting topics for participatory research

Subject areas of interest	Percentages		
	All	18–64	65 +
Society and social life	55.5	57.2	44.7
Environment, plants, and animals	48.3	50.0	37.0
Technology and natural sciences	44.5	46.1	34.0
Medicine and health	43.4	44.3	37.4
Arts and culture	20.9	21.3	18.2

Table 3.6 Obstacles perceived by people who are not interested in participatory research

Obstacles to participation	Percentages		
	All	18–64	65 +
I don't have the necessary knowledge/skills	40.8	30.7	57.4
I lack the time	28.9	43.5	4.9
I have no interest	26.7	29.2	22.5
I do not know what projects are available	13.6	14.8	11.8
Other reason	6.1	1.7	13.5

should work precisely on this hurdle and try to reduce the fears of potential co-researchers by clearly and transparently explaining what is specifically required for participation.

When looking at the list of obstacles in terms of differences between younger and older adults, it becomes clear that older adults mainly mention their lack of skills, whereas younger people mainly mention a lack of time, which was not a problem for the older participants in this survey. It is also interesting that older adults were more likely to cite other reasons for non-participation; we can only assume that these reasons might be health-related (e.g., mobility problems) or have other explanations.

General opinions on participatory research

At the end of the survey, all respondents, both those interested in participating in research and those not interested, were presented with generally positive and negative statements about participatory projects (see Table 3.7). On a scale of 1 ("do not agree at all") to 5 ("agree completely"), the negative statements ("I do not want to invest my free time in research" and "I am afraid of not knowing enough to participate well in a research project") had mean values of about 3, indicating that these aspects are affirmed by some, but also denied by many. The majority of the positive statements (see lower statements in Table 3.7) were rated with high affirmatives (at value 4); this indicates that the Swiss population has a fundamentally positive attitude toward participatory research.

An outlier in this field is the statement "I can contribute a lot to research." Here, the agreement is rather reserved. However, this also fits in well with the obstacle "I don't have the necessary knowledge/skills" (see Section "Obstacles Perceived by People Who Are Not Interested"). It seems that the respondents believed their own experiential knowledge would not contribute much to research, even though it is not seen that way in the principle of participatory research. If these statements are subdivided with regard to the two groups "Interested in participatory research" and "Not interested in participatory research" (see Table 3.7), we see that people who are interested agree even more strongly with the positive statements than those who are not interested. This also becomes clear in the statement "I can contribute a lot to research." Here, it is primarily the people who are not interested who are of the opinion that they themselves have nothing to contribute.

Regarding the differences between younger and older adults, Table 3.7 shows that, among people who are, in general, open to engaging in participatory research, statistically significant differences exist only between the two negative statements; that is, older adults agree with both of these negative statements less often than younger people do. Among those who are not interested in this form of research participation, age differences are evident in whether people can contribute enough to the research and whether the place of research is also a social meeting place; here it is evident that younger people assume they will contribute more to the research and meet more new people there.

Discussion

The study's findings indicate that there is a notable interest among non-scientists in Switzerland who wish to actively participate in research. In all, 48.5% of our survey respondents showed an interest; this is a high percentage of the Swiss population, considering that only 5% had already participated in such a project. However, the survey results highlight that not everyone is interested in participating in the same way, or in the same topics or areas

Table 3.7 Negative and positive aspects of participatory research

Aspects	Persons with interest in participatory research			Persons without interest in participatory research		
	All	18–64	65 +	All	18–64	65 +
	Means					
Negative aspects						
I do not want to invest my free time in research.	2.30	2.37*	1.78*	3.55	3.65*	3.37*
I am afraid of not knowing enough to participate well in a research project.	3.07	3.11*	2.77*	3.46	3.37*	3.61*
Positive aspects						
I can contribute a lot to research.	3.18	3.20	3.10	2.08	2.16*	1.93*
I think participatory research is fun.	4.13	4.14	4.09	3.17	3.16	3.17
Through participatory research, I can meet people who are interested in the same things as I am.	4.18	4.16	4.34	3.31	3.42*	3.11*
Through participatory research, I can increase my knowledge in a certain area that interests me.	4.43	4.43	4.47	3.37	3.41	3.29
I think participatory research is basically very useful.	4.25	4.24	4.37	3.61	3.59	3.66

Notes:
Scale: from 1 "do not agree at all" to 5 "agree completely". * = significant group differences between the age groups ($p < 0.05$).

of activity. Younger people, those with a high number of socio-cultural activities, and those with a high interest in science are generally more open to joining a participatory research project than older adults, people who are less often involved in socio-cultural activities, and those with lower levels of interest in science.

With this in mind, it is important that participatory projects are able to address their target group well. As the study showed, not all older people are interested in the same topics, nor in the same tasks in the research process; therefore, participatory projects should advertise not only the research as such but also the possible benefits for participants, e.g., learning more about animals or social issues and getting an insight into research. When addressing them, researchers should aim to keep the barriers to participation as low as possible from the outset and mention any "hurdles" (e.g., fears of a lack of knowledge)

at an early stage (Land-Zandstra et al., 2021). Moreover, this would also mean making it clear at an early stage what participation in research actually means for the older person and what requirements are needed.

For future participatory research projects, we recommend that they:

a target their specific groups by outlining explicitly the benefits of participation;
b make clear the different subtasks in the research project, and bring them closer to interested persons;
c reduce possible hurdles (both formal and perceived ones); and
d make participative projects more visible to the public.

Previous research findings furthermore show that "providing opportunities for involvement is only part of what accounts for community scientists' expanded participation. Dialogic negotiation of participation is also necessary, through bids and responses to bids, and through proffered guidance and scaffolding" (Hinojosa et al., 2021, p. 1). It must be made clear to potential participants what tasks they can take on, what decision-making opportunities and forms of participation they have, and what specific knowledge they may need to build up to do a specific task. To achieve this, potential participants must be informed transparently at an early stage and, if necessary, trained. It is important to emphasize that the participants can also leave the project at any time and can determine their form of participation at any point in time; thus, participation in the research process could also consist of only taking note of certain steps in the research process or voting through a survey about the next decisions on the project and not actively participating each time. Moreover, power differentials between researchers and older adults should be limited, as older adults should be considered as co-partners within the research projects (Corrado et al., 2020).

This study is the first to provide insights into the willingness of the Swiss population as a whole to engage in participatory research projects. Future projects can use these study findings to sharpen their offerings. From a social point of view, these results make it clear that a considerable number of both younger and older adults value participative research and would like to be a part of it. For researchers, this means they should make use of this potential; however, doing so will require a willingness on their part to allow citizens to participate in their research. This point in particular is still largely unexplored; we don't know exactly how many and which researchers are willing to make their research participatory and use this method. We often assume – as a matter of course – that we only need to convince potential laypersons, but researchers also need to perceive the benefits of laypersons' participation and offer those participatory research projects.

Limitations

Several limitations of this study must be noted. First, the present study has a specific regional focus (Switzerland), so the findings have limited generalizability. Second, the data provided only a cross-sectional view of the various interplays examined in the study. Thus, future studies should investigate the dynamics of these interplays, especially the evaluation of openness pre- and post-participation in participatory research projects. Third, because the population survey was conducted online and by mail, we were unable to reach all older persons (e.g., those living in long-term care facilities). Nevertheless, our study had a good response rate for those population surveys. Fourth, because of the limited width

of the study variables that could be used, other important background factors, such as personality, were not controlled for. With these limitations in mind, further studies using longitudinal designs and a wider range of variables may be required to examine this topic in greater detail.

Conclusion

This study has presented representative data from Switzerland regarding the openness to engaging in participatory research projects among the general population aged 18 years and older. The results indicate that around 49% are open to participating in such projects. Nevertheless, the analyses show that younger adults (18–64 years) are more open to participation than older adults (65 years and older). Multivariate analyses also indicate that education, socio-cultural activities, and interest in science were specific predictors of willingness to join participatory research projects.

The findings reveal that, at present, more educated and active older adults with a marked interest in science are the ones who are most interested in participatory research. The current study also provides evidence for the potential of involving older adults as co-creators of scientific research, in general, and for gerontological studies, in particular. Future projects should not only focus on research-affine older people but also on those with a certain distance to research and no experience with involvement in research to avoid participation inequality.

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4

INVOLVING OLDER ADULTS IN THE DATA ANALYSIS PROCESS

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Nowadays, many funding agencies, service providers, and government institutions want patients and service users to be involved in research efforts (e.g., Health Research Authority, 2017; HelpAge International, 2002; NHS, 2017; UNESCO Chair, 2020). This demand has its biggest impact on older adults: adults over the age of 60 represent the world's fastest-growing demographic and an increasing proportion of societies' healthcare and service users (e.g., National Center for Health Statistics, 2017; OECD, 2016; United Nations, Department of Economic and Social Affairs, Population Division, 2017). And yet, older adults' involvement in such "co-research"[1], where citizen or lay researchers work alongside expert scientists, lags behind that of other age groups (Blair & Minkler, 2009; Littlechild et al., 2015). In general, involvement of laypeople in the analysis process lags behind their involvement in other stages of research (Byrne et al., 2009; Lockey et al., 2004; Nind, 2011). As a result, older co-researchers are less likely to contribute to data analyses (and interpretation) than to other aspects of a research project (e.g., Blair & Minkler, 2009; Clarke et al., 2018; Fudge et al., 2007).

In this chapter, we review examples of older adults' engagement with data analyses, most of which stem from social science domains and focus on qualitative analysis contexts (for syntheses of additional examples, see Blair & Minkler, 2009; Corrado et al., 2020; Dudley et al., 2015; Mysyuk & Huisman, 2020). We group these examples into three broad categories: older adults (1) verifying and enriching expert analyses, (2) working in tandem or in parallel with expert researchers, and (3) taking charge of analysis efforts. These categories of involvement in co-analysis correspond well to a "continuum" of co-research described elsewhere, differentiating between (1) consultation/advice, (2) partnership/collaboration, and (3) user-led or user-controlled research (e.g., Beresford et al., 2008; Bigby et al., 2014; Schilling & Gerhardus, 2017). We also outline advantages and challenges specific to older adult co-analysis and present questions researchers should ask themselves to overcome common limitations of the process.

Verifying and enriching expert analyses

At the least-involved level of co-analysis, older adults may be asked to accept or reject experts' analyses of data collected from themselves or from other older adults with a similar

background (e.g., people with the same illness they themselves have). In this context, two methods are frequently used: Member checking and secondary analysis (e.g., Corrado et al., 2020). Member checks entail participants correcting, adding to, or confirming analyses expert researchers have conducted on data the older adults themselves provided to the research team (e.g., through interviews or surveys). Secondary analyses entail a re-analysis of data by the co-researchers, sometimes with the goal of comparing expert and lay results.

Member checking

The 'Grandparent Caregiver Study' (Oakland, 1990–1991) assessed the health status of middle-aged and older African-American women who were raising their grandchildren as a result of the crack-cocaine epidemic and used member checks in the data analysis stage. The interviewed grandmothers were asked to review and confirm the themes identified in the interviews by the research team (Minkler et al., 1992). A similar approach was chosen after collecting data on service users' preferences for stroke services: After participants participated in interviews or focus groups, they were able to evaluate summaries of the collected data (Jones et al., 2008).

Another example of member checking is evident in a study that assessed how older Aboriginal women experienced a health promotion programme: After analysing interview data collected from each woman, Dickson (2000; also see Dickson & Green, 2001) presented her findings to the women in a weekly group meeting as well as through drafts of the project assessment report. This enabled the women to offer edits or accept the assessments. Through this process, two middle-aged Aboriginal women were hired and trained as research associates, which included contributing to the initial content analysis conducted by the lead researcher (Dickson & Green, 2001).

Secondary analysis

In an example of secondary analysis, 34 people living with or caring for someone with dementia underwent four 2h-workshops to analyse interview data (Clarke et al., 2018, 2020). The interviews had been conducted with other people who have personal experience with dementia and had previously been analysed by groups of expert researchers. In the context of co-research, older adults were prompted to examine these data through two pre-selected theoretical lenses: a "risk and resilience" framework and an "ethic of care" framework. Expert researchers examined how the co-analysis challenged their views of the original data as well as the theories used to analyse them.

In a similar vein, four people living with dementia engaged in the secondary analysis of interview/focus group data concerning how those with mild to moderate dementia understand and discuss risks (Stevenson & Taylor, 2017). (Note that although the research team did not use the term "secondary analysis" (or "re-analysis"), they had previously analysed and published on the dataset without involving co-researchers). These older adults analysed the data in one 2h-session that focused on the "risk concepts" and "risk communication" described by other people living with dementia. In doing so, the co-researchers got to emphasise viewpoints that reflected their own experiences and highlight viewpoints that contrasted with their own (e.g., differences in how patient-physician relationships were experienced).

Working in tandem or in parallel with expert analysts

At a more involved level of co-analysis, older adults can help to spot data patterns during, rather than after, (expert) analysis – either by themselves, in collaboration with, or in parallel with professional researchers. Often, these activities can be summarised under the umbrella terms of "content analysis" or "thematic analysis": The extraction and interpretation of themes that emerge from data, typically using qualitative data.

Content or thematic analysis

Cowley and colleagues (2019) taught thematic analysis skills to older adults who were part of the "Dementia, Frail Older People and Palliative Care PPI Advisory Group" in Nottingham, England. This 6h-training covered the theory, strengths, and weaknesses associated with qualitative research, and how to code independently and in a team. The older adults then practiced applying thematic analysis to "mock interviews" about factors that are linked to medication adherence among patients. Undergoing this training led to one of the older advisory group members becoming involved with data coding for a different, actual research study.

A thematic analysis approach was also employed by seven patients and carer researchers involved in a mental health research project (Gillard et al., 2012). While analysing data on mental health self-care, these co-researchers were asked to come up with their own coding categories, based on themes they came across while reading interview transcripts. These themes were then discussed with the whole research team and, together, the expert and lay researchers created a unifying analytical framework to refine the coding approach. In the next step, this framework was applied, mostly by the patients and carers, to all interviews. Once all coding was completed, the results were presented to a larger panel of people, including patients and carers who had been interviewed for the study. These people were invited to comment on the identified themes and to provide interpretations of the data that had been overlooked.

Participatory theme elicitation

Participatory theme elicitation has been proposed as an avenue for co-research that can be used by itself or in tandem with thematic analyses that are being carried out by expert researchers (Best et al., 2017). This approach asks co-researchers to group data such as interview excerpts in different piles, based on patterns they themselves see emerging. The process consists of five steps: (1) selecting data to use, (2) instructing co-researchers ("capacity building"), (3) independent sorting by each co-researcher, (4) comparing and aggregating themes across co-researchers, and (5) analysing and interpreting emerging core themes. In one such study (Best et al., 2022), nine laypeople ranging in age from 20 to 63 years underwent a 2h-training in which they learned about quantitative and qualitative research, the involvement of laypeople in participatory theme elicitation, and how to sort data based on different strategies. Analysing excerpts from a depression intervention study (Best et al., 2019), co-researchers created between three and 12 groupings of excerpts each, which led to the identification of six core themes across co-researchers. (For a study involving co-researchers up to the age of 59 years, see Yap et al., 2020).

Photography

Several photography-based approaches exist that involve older adults in the research process, such as participant-generated photography, photo novella, and auto-photography. In many cases, these approaches blur the lines between data collection and data analysis/interpretation: After helping to (co-)create photographs in the first step, participants are invited to sort, analyse, or provide context for these photographs in a second, analysis-focused step. Employing a so-called "photovoice" method, Baker and Wang (2006) tasked middle-aged and older adults with taking pictures of everyday objects that illustrated their experience of living with chronic pain. Among these pictures, each participant selected four that best captured their pain experience. For these pictures, the participants provided a title and narrative to summarise the symbolic nature of the photographed object. For instance, one participant titled their picture of a knife "What My Pain Feels Like", writing: "My everyday pain feels like someone is stabbing me with a knife. […] Sometimes my pain is so bad that I feel like taking that sharp knife and chopping both hands off" (Baker & Wang, 2006, p. 1409). The participants aided the research team in the analysis and interpretation process by identifying the most relevant pictures and extracting their meaning themselves (Blair & Minkler, 2009).

In their review of 43 photovoice-style studies involving older adults, Mysyuk and Huisman (2020) note that through photographs, older adults can contextualise and deepen researchers' understanding of a wide range of topics, from people's leisure activities to their living with HIV/AIDS. Although photography-based methods often require training, photovoice is less cognitively demanding than other approaches to data collection (Tishelman et al., 2016) and might thus be more suitable for vulnerable populations (Mysyuk & Huisman, 2020).

Self-analysis

Somewhat similar to the photovoice approach, the "Grandparent Caregiver Study" (Roe et al., 1995) opened the analysis process to all those who contributed to the study, including study participants. In addition, while being interviewed, middle-aged and older women responded to dialogic (i.e., challenging, analysis-driven) questions about their caregiving experience and personal well-being. These questions aimed at prompting an examination "of the root causes of the situations" (p. 465) the caregivers were relaying to the research team.

Although not always considered "participatory" methods, probing questions and think-aloud techniques can serve a similar purpose: Encouraging older adults' self-analysis and providing context researchers would not otherwise have access to. In this vein, older adults can be encouraged to articulate their thought process (i.e., thinking aloud) while considering interview or survey questions or probed for added details about their responses. For instance, older Australian adults reporting on their level of physical activity by means of the think-aloud technique were asked follow-up questions such as "What activities are you including in your answer?" and "How did you come up with this answer?" (van Uffelen et al., 2011, p. 3).

Appreciative inquiry

Appreciative inquiry can be understood as a collaborative attempt to identify, examine, and value the strengths of a process (or other target), with the goal of creating positive change for the future (Reed, 2020; Reed et al., 2002). This approach contrasts with other

(co-)research methods, many of which focus on problems or weaknesses. Although research involving older adults in an appreciative inquiry is still limited, existing studies have followed a "4D" framework consisting of the following four stages (Reed, 2020): (1) discovering achievements, (2) dreaming of ideal states, (3) designing approaches to achieve ideal states, (4) delivering necessary change. Crucially, these studies treated older adults as "research partners" and "explicitly used [appreciative inquiry] as a template for research methods both in data collection and analysis" (Reed, 2020, p. 286).

To provide one example, Reed and colleagues (2002) involved older adults in the evaluation of hospital discharge practices. Through a series of three workshops, participants (1) appreciated the benefits of existing discharge practices, (2) thought about what the practices could or should be like, and (3) developed an action plan to generate change. During the second workshop, older adults analysed interviews that had been conducted with people who had previously been discharged from the hospital. Specifically, each older adult identified three key themes and then helped to compare and connect themes across co-researchers, leading to the development of goal statements.

Leading analyses

At the most-involved level of co-analysis, older adults acquire the skills to manage multiple or all aspects of a research project, including the data analysis process. Typically, these efforts can be grouped into one of two types: Some initiatives train older adults to lead or co-lead one specific study whose topic, scope, and aims have already been specified by expert researchers or stakeholders. Other initiatives instruct older adults how to devise and conduct their own original scholarship, with older adults selecting their own topics, study scope, or aims to pursue.

Study-specific training

One example of study-specific training is the 'Translating Research into Action' project that involved older adults in the assessment of age-friendly communities in Manchester, England. Under the guidance of expert researchers, 18 older adults learned how to design a study within a specified topic, collect and analyse the data, and interpret and share the findings with their community (Buffel, 2018; Doran & Buffel, 2018). Data analyses entailed extracting themes from interview transcripts according to theory-driven, pre-selected codes (such as "transportation", "safety") and new codes that emerged from the data (such as "racism" and "community change"). In a collection of the co-researchers' experiences working on this project (Buffel, 2015), one older adult described the coding process as "looking at the paragraph, seeing what comes out to us, discussing what we understand by it, and putting names to the paragraph, such as loneliness, civic engagement" (p. 100).

A different approach was chosen by the 10-week 'Certificate in Social Research Methods' course held in Lancaster and London, England (Clough et al., 2006; Leamy & Clough, 2006). This course enrolled 22 older adults who were instructed in qualitative and quantitative research skills, with a focus on conducting interviews and coding interview data. The course emerged in the context of a three-year study on 'Housing Decisions in Old Age', with students completing around "200 in-depth interviews with older people in their own homes, residential homes, sheltered housing and retirement communities" (Leamy & Clough, 2006, p. 2). Although older adults' training was study-specific, to begin with,

the course led to the formation of a research group called 'Older People Researching Social Issues' (OPRSI). This group has since completed and co-authored other projects, including one on older adults' views concerning social workers (Manthorpe et al., 2008).

Original scholarship

Research courses specifically targeted at older adults go back several decades (e.g., Bass, 1987; James, 1995) and have, just like the OPRSI, led to the creation of original re-search projects driven by the older co-researchers' interests. One such course was offered by Israel's Bar-Ilan University Brookdale Programme in Applied Gerontology. Although participants in this course were "not being trained as research technicians, interviewers, statisticians, or experts in research methodology", they were being "trained to be able to make use of statistical and methodological consultation" (Glanz & Neikrug, 1997, p. 825). This approach generated at least six research projects led by older adults, with research topics ranging from elder abuse and life-long learning to pre-retirement training and older adults' worries about ageing. These projects resulted in several scientific journal articles (e.g., Neikrug & Ronen, 1993; Neikrug et al., 1995), seminars, and conference presentations.

At Anglia Ruskin University in Cambridge, England, a 15-sessions training course fa-miliarised an initial 15 older adults with social science research skills, including a range of data analysis approaches (Munn-Giddings et al., 2009). Following completion of the course, some members expressed interest in obtaining additional training (including ac-quiring more data analysis skills) and pursuing research opportunities. This led nine par-ticipants to form the 'WhyNot! Older People's Research Group (Essex)', which has since attracted additional members over the age of 50. By 2009, the group's original research efforts had generated at least one conference contribution and three seminars held across two countries. Fifteen years later, the group still maintains its own website summarising 13 projects that have been completed since the formation of the group in 2007 (Older People's Research Group Essex, 2021b). This includes projects on the role of arts in care homes and the usefulness of library services for housebound individuals.

Advantages and challenges of older adult co-analysis

Gauging the advantages and challenges of older adult co-analysis is difficult, for multiple reasons: Sample sizes of older co-researchers are typically small (e.g., Best et al., 2022; Bindels, 2013; Garfield et al., 2016; Gillard et al., 2012) and at risk of attrition (e.g., Best et al., 2022; Blair & Minkler, 2009). Based on case studies (cf. Blair & Minkler (2009), Brett et al. (2014), Corrado et al. (2020), and Dudley et al. (2015) for syntheses), many projects describe older adults or expert researchers' subjective experiences partaking in co-research efforts (e.g., Bindels et al., 2013; Buffel, 2015; Dawson et al., 2020; Scheffe-laar et al., 2020). However, it appears uncommon for co-analysis to provide quantifiable results or pre- and post-project assessments of the process. For instance, in a review of 30 older adult co-research studies, only four provided a formal evaluation of the process (Fudge et al., 2007). Another issue rests with the fact that older co-researchers are rarely recruited for the analysis stage by themselves (e.g., Blair & Minkler, 2009; Fudge et al., 2007). As such, untangling analysis-specific experiences from other aspects of co-research is often not possible. Although much can and has been said about the pros and cons of

older adult co-research (e.g., Buffel, 2015; Corrado et al., 2020; Dudley et al., 2015; Littlechild et al., 2014; Ray, 2007; Ross et al., 2005), we outline some considerations specific to the analysis stage below.

Advantages

Despite concerns that older adults may not be "interested in being involved in […] data collection or analysis" (Blair & Minkler, 2009, p. 652; also see Bentley, 2003), partaking in co-analysis can be desirable and enjoyable for older adults (Cowley et al., 2019; Dawson et al., 2020). For older adults, co-research can also develop and sharpen abilities, strengthen feelings of self-confidence and worth, be a source of respect and empowerment, and foster social or community connections (Brett et al., 2014; Buffel, 2015; Jones et al., 2008; Littlechild et al., 2015; Schilling & Gerhardus, 2017; Scottish Dementia Working Group Research Sub-Group, 2014). Co-researchers also report an improved understanding of the research process and more knowledge about the researched topic, such as information about disease treatment and management (Brett et al., 2014).

Research-wise, older adult co-analysis allows for the provision of unique and insider perspectives, emphasis, or context that researchers would otherwise be missing (Garfield et al., 2016; Gillard et al., 2012; Mysyuk & Huisman, 2020): Older adults can either serve as experts on a certain topic (e.g., being part of a patient population, Stevenson & Taylor (2017); using certain services, Reed et al. (2002)) or on historical and cohort-related phenomena. As such, older co-researchers can make data analyses (and interpretation) more authentic and credible than they would be without their involvement (e.g., Stevenson & Taylor, 2017). For instance, older co-analysts have been credited with helping expert researchers overcome overly narrow perspectives, conduct exploratory analyses to address questions that newly emerged in the context of co-analysis, and rethink how "statistically relevant" results compare to older adults' subjectively relevant and lived experiences (Brett et al., 2014; Garfield et al., 2016; Gillard et al., 2012). Because in doing so, older adults may challenge commonly held views and methodological conventions followed by expert researchers (Gillard et al., 2012). Their involvement at the analysis stage or in other aspects of research may also help to democratise and diversify the research process (Byrne et al., 2009; Reed, 2005). Specifically, one systematic review found co-research involving (health) service users to lead to greater diversity within research teams (Brett et al., 2014).

Finally, at a societal level, involving older adults in co-analysis can allow older adults to shape the policies and services that are informed by said research (Blair & Minkler, 2009; Buffel, 2015; Jones, 2008). To illustrate, co-research can increase awareness of community or health issues and improve the distribution of information to service users within a community (Brett et al., 2014). The involvement of laypeople in research projects also helps to foster trust between the community and expert researchers (ibid.), which may make the former more willing to accept and apply research findings. Co-analysis may also help fight ageism, by challenging perceptions that older adults lack the abilities or skills to contribute to co-analytic efforts (Buffel, 2015; Nind, 2011) and by reducing power hierarchies between experts and co-researchers (Godfrey, 2004): Many case studies and reviews voice concerns about the tokenistic treatment of older co-researchers by expert researchers (e.g., Brett et al., 2014). Such power hierarchies can lead to older adults' input being overruled by the scholars who "know best" or "own" or "control" a research project, including its analyses and results (see the section on "Ownership" below). A systematic review, however,

highlights that co-research involving service users can lead expert researchers to develop more respect for co-researchers or the population they are studying and to take on advisory rather than leading or controlling roles in the context of co-research (ibid.).

Challenges

Ownership

Ownership of and control over knowledge creation represent the most ambitious level of co-research (Blair & Minkler, 2009; Bradbury & Reason, 2008). Although only a few publications specify which rights and products are shared by older co-analysts, it stands to reason that often, older adult co-analysis does not reach this level of knowledge production. To illustrate, Dickson and Green (2001) state that in their case,

> Control of the whole project was not [the older women's] because the project was administered by the clinic and financed through it. Without a commitment to conducting research and authority to run the project, the initiative was never fully *owned* by the advisory committee or grandmothers.
>
> *(p. 477)*

Control over the project rested with the expert researchers in other cases, too (e.g., Clarke et al., 2018), with a synthesis of 40 studies concluding, "the majority of [co-research] studies did not include older adults as full research partners as they typically did not have an opportunity to shape the research question, learn about the research process, or influence change" (Corrado et al., 2020, p. e415). Nevertheless, some projects do cede control over specific study aspects to the older co-researchers (e.g., Corrado et al., 2020; Groot & Abma, 2019).

Data

Not all data may be equally suitable for co-analysis involving older adults: Most studies focus on qualitative interview data, although older adults can also be trained to assess questionnaire responses or concept maps (Gutman et al., 2014; Marks et al., 2018). Even though some training efforts extend to quantitative analyses (Best et al., 2019; Clough et al., 2006; Leamy & Clough, 2006), not much is known about successfully involving older adults in the analysis of quantitative data; older adults are also unlikely to analyse clinical or health data (e.g., Garfield et al., 2015). This might be due to the time and resources required to teach the relevant analysis skills (e.g., statistical programme licences, programming training, clearance to access, and ability to interpret clinical or health data). However, it has also been argued that (older adult) co-research simply does not lend itself to generating empirical or generalisable data (Blair & Minkler, 2009; Littlechild et al., 2015; Mey & van Hoven, 2019).

There are further concerns about older co-analysts accessing distressing, confidential, or sensitive information (Garfield et al., 2015; Gillard et al., 2012). It is possible that data about topics such as abuse, health, cognitive performance, widowhood, or mortality could upset older adults or reinforce ageist stereotypes. Confidential data may be unsuitable for sharing if older co-researchers are also involved in the recruitment or data collection

process, seeing as co-research tends to focus on local communities (e.g., Mey & van Hoven, 2019) and participants may be drawn from older co-researchers' social networks. As a result, participants may be uncomfortable with co-analysts accessing their data or may edit their own responses to avoid disclosing certain types of information to their peers. (Note, however, that studies do not typically detail whether the participants who provide data are aware or approve of co-researchers accessing said data. In the context of secondary analysis or for studies in which co-researchers are not part of recruitment and data collection efforts, the (future) involvement of older co-analysts may not be known to participants at the time of data collection).

Representativeness

Co-analysis with older adults may sometimes lead to non-representative results, that is, results that do not faithfully reflect the target populations' views (e.g., the views of dementia patients, service users, or of a specific age group). Three main reasons may be at play here. First, undergoing research training and contributing to analyses is a time-intensive and effortful process that can take weeks or months to complete (e.g., Gillard et al., 2012, Gross et al., 2020). Thus, co-analysis can exclude older adults who (1) tire easily or are in poor health, (2) experience accessibility, mobility, or cognitive issues, (3) take on care responsibilities or require care, (4) are still part of the workforce, or (5) cannot partake unless financially compensated (e.g., Gillard et al., 2021; Iliffe et al., 2013; Lockey et al., 2004; Schilling & Gerhardus, 2017).

Second, some researchers voice concerns about a lack of guidelines, infrastructure, or rigour in older adult co-research (Blair & Minkler, 2009; Garfield et al., 2016). For instance, some worry that older adults' lay perspectives will skew findings in non-representative ways (Gillard et al., 2012): This seems to be especially relevant if co-analysts are non-representative members of the target population or "cherry picked" (Beresford et al., 2008, p. 1392) and/or when co-analysts' own experiences contrast with data provided by participants (e.g., Stevenson & Taylor, 2017). For instance, laypeople may put more emphasis on personal anecdotal experiences than on statistically relevant findings (Brett et al., 2014) that are likely to apply to a broader target population.

Third, there is a possibility that results derived from co-analysis fail to reflect an actual lay perspective: On the one hand, power imbalances between expert and lay researchers (Ray, 2007; Schilling & Gerhardus, 2017) may lead to the suppression of older co-researchers' viewpoints where they clash with established research principles or expert researchers' views. On the other hand, older adults' pre-existing knowledge and skills (acquired through careers that involved data analysis or through serving on research boards and panels, Garfield et al., 2016; Gillard et al., 2012) could "professionalise" their viewpoints too much, as might receiving intensive research training (Dudley et al., 2015).

Overcoming limitations of older adult co-analysis

To address the limitations of older adult co-analysis detailed above, we suggest that expert researchers consider the following questions when collaborating with older adults, especially at the analysis stage. Ideally, these questions should be discussed with co-analysts prior to beginning a research collaboration.

Control

- Will co-analysts have (partial) control over some or all parts of the research project?
- Will co-analysts (co-)own data or scientific products resulting from the project?
- Can or should changes be made to cede more control to co-analysts?

Data

- Will co-analysts (1) verify/enrich the expert analysis, (2) work in tandem or parallel with experts, or (3) lead analysis efforts themselves?
- What data are co-analysts possibly or definitely going to encounter? Are there data likely to induce negative affect or negative views on ageing?
- Are there data co-analysts are concerned about encountering or would prefer to avoid?
- What support exists for co-analysts who encounter distressing data?
- Should co-analysts have access to confidential or sensitive data? If so, what training or agreements are necessary to enforce confidentiality? If not, how will this influence co-analysts' results or power imbalances between expert researchers and the co-analysts?

Representativeness

- How are disagreements between the experiences of participants portrayed in the data and co-analysts' own experiences to be resolved?
- How are disagreements (e.g., about analysis approaches and data interpretation) between expert researchers and co-analysts to be resolved?
- What is the professional or scientific background of co-analysts? To what extent can they be considered authentic lay researchers? How does this affect the project?
- Can the co-analysts be considered as representatives and/or the co-analysis results be considered as generalisable? If not, why?

Conclusion

Older adults are both under-represented and non-representative partners of co-analysis efforts, most of which focus on qualitative data from social science fields. Although their involvement is often limited to consulting or collaborating on the data analysis process, older adults can also learn to spearhead analyses. The control, credit, or compensation received for their time and contribution varies, with some older adults serving as un-credited, unpaid volunteers and others being hired as research staff and/or sharing in the authorship of scientific products. Careful consideration of common limitations may allow for the successful and fair engagement of older adults in co-analyses.

Note

1 Under this label, we include a range of relevant terms with variations in meaning and scope, such as "community-based research", "community-engaged research", "peer/user/lay research", "collaborative research", "action research", "participatory research", "participatory action research", "patient and public involvement research", etc. (e.g., Blair & Minkler, 2009: Corrado et al., 2020). Given the scope of this chapter, we do not discuss differences between these terms in detail.

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5

PARTICIPATORY RESEARCH AND DEVELOPMENT APPROACHES IN APPLIED AGEING RESEARCH

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Introduction: the added value of doing it all together in applied ageing research

Demographic change, specifically the ageing of the population, is a worldwide phenomenon caused by decreasing fertility and rising life expectancy rates. This structural change in populations leads to various challenges, for instance in the labour market, for the financing of pension and healthcare systems, as well as for economic development, especially in rural areas. These dimensions are interconnected, therefore necessitating interdependent research questions.

Answering interdependent research questions often requires teams of researchers from different backgrounds to work together. In these interdependent and intercomplex research areas (i.e. care innovation, health technologies, multidisciplinary and transdisciplinary evaluations), expertise in only one field can unlikely address the complex problems and questions sufficiently, while the combination of expertise from different fields and backgrounds can have a significant impact on the quality of research and the later implementation of results in societies. The merging (transdisciplinary) and co-working (in a multi- or interdisciplinary form) of expertise make otherwise impossible goals achievable, often in an even shorter time frame (see i.e. Brauer et al., 2018). Such exchange and collaboration, however, requires a mutual general understanding of the research aims and expertise of the different fields.

In 2016, the Institute for Applied Research on Ageing (IARA) was founded at the Carinthia University of Applied Sciences. Researchers of three different disciplines – economics, social sciences, and technical sciences – decided to conduct applied ageing research together, with the mission to develop innovative interdisciplinary solutions to improve the social, health, and economic situation of older people. Since then, various interdisciplinary and mostly participatory research projects have been carried out.[1]

Since IARA focuses on applied research, the group specializes in social problems and solutions that will benefit society, individuals, and groups. In order to adequately address these problems and to generate solutions that are effective in the long term, it is indispensable to

involve target groups in the entire research process starting at the formation and shaping of research questions. A society's problems should be worked on with the affected society so that the most suitable solutions can be identified.

The interdisciplinary IARA projects address a variety of challenges and potentials of an ageing population. Some focus on participatory innovation, i.e. through the implementation of Active and Assisted Living (AAL) pilot regions (i.e. Smart VitAALity). Others examine aspects of regional development through the inclusion of vulnerable groups (i.e. Dementia-friendly Model Community Moosburg) or the participation of citizens on questions of well-being and quality of life (i.e. Citizens4Science – Living Well in Carinthia).

Drawing on the author's experience, as well as literature on interdisciplinary and participatory research, this chapter focuses on different participatory approaches and methods that can be implemented in an interdisciplinary context, as well as potentials and challenges of applied participatory ageing research. To this end, foundations for a successful collaboration in an interdisciplinary project team, criteria of equitable inclusion, and stages of engagement of older adults, as well as participatory approaches and communication methods will be discussed. Moreover, these aspects of research projects will be illustrated in three different examples. Finally, ten guiding principles for an interdisciplinary participatory ageing research approach are derived.

Foundations for successful research

To successfully collaborate in ageing research, the following considerations should be included: Who needs to be involved and how can we generate a common understanding of the research concept, goals, and design? We will draw on practical experiences regarding the development of an interdisciplinary, jointly supported research strategy.

Who needs to be involved? Conducting a stakeholder analysis

At the beginning of every interdisciplinary research project, the question of who should be involved must be answered. During the selection of consortia participants, it is important that experts from all relevant disciplines for the topic are included. In general, interdisciplinary research can lead to novel and innovative insights within as well as across the participating disciplines (Morss et al., 2021). In addition, the inclusion of the target group and its needs has to be secured. This is usually ensured through collaboration with practice or community partners as early as possible to jointly define research questions and objectives.

To identify relevant practice partners, it is recommended to carry out a stakeholder analysis based on the quadruple helix approach (see i.e. Yawson, 2009). The quadruple helix approach is an advancement of the triple helix approach (Etzkowitz & Leydesdorff, 1995), which both focus on the relevance of interactive participation of stakeholders from different domains during research and innovation processes. While the triple helix approach includes university, industry, and government, the quadruple helix approach also contains civil society.

Businesses as originators and academia as knowledge creators have been seen as the essential players for innovation since Schumpeter (1942). In addition, governments play an important role concerning regulation and financial support. As introduced by the quadruple helix approach, civil society should be included in the innovation process as user of innovation (in form of goods and services) and contributor of information about user needs and experiences (see guiding Principle 2). Although different definitions of the fourth

helix exist, Cavallini et al. conclude that "social inclusion, user-centrality, and creativity have been encompassed in the knowledge production process as essential elements (…)" (2016, p. 15), as participatory innovation approaches might shed completely new light on a research topic. Figure 5.1 provides a visual overview of the quadruple helix approach. For more information on the approach see Etzkowitz and Leydesdorff (1995).

Creating a common understanding: concepts, goals, and research design

Working in an interdisciplinary participatory setting can therefore unveil new aspects and provide innovative insights during the research process. However, cooperation between researchers from different disciplines and various stakeholders from diverse spheres can also be a great challenge. Contradictory interpretations of concepts or terms, the use of varying methods, or simply different ways of thinking and acting due to specific working cultures can lead to discussions and conflicts. To ensure efficient and productive cooperation, various aspects, shown in Figure 5.2, should be considered.
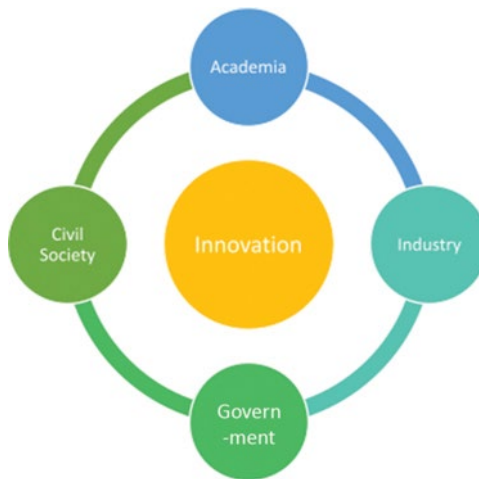
Figure 5.1   The four domains of the quadruple helix innovation approach (own graph).

Figure 5.2   Creating a common understanding of project goals and processes (own graph).

As stakeholders can pursue diverse aims within the framework of a project, it is of high relevance to define common research goals. From a participatory point of view, the research problem and goals should be defined early in the process by the project consortia. This includes finding a common definition of relevant terms and concepts. Moreover, the research design, i.e. how the research goals should be achieved methodologically and the corresponding role of each project partner, should be specified in detail. A "unified understanding of each other's scientific point" is an essential foundation for interdisciplinary work (Ibsen & Eriksen, 2022, p. 319). Regardless of whether the research design is created by a project leader, research partners, or the whole consortia, it must be clearly communicated to all project partners. As Brown et al. (2019, without page number) summarize: "A shared mission is considered important to maintain a sense of direction and purpose, which is particularly critical in the face of inevitable failures and setbacks likely to occur in groundbreaking interdisciplinary projects" (see guiding Principle 3).

Interdisciplinary research is heavily dependent on successful cooperation. Thus, regular meetings to clarify the project status, including a presentation of previous project results and further project steps should take place. Within such meetings, but also within the project in general, open communication is of the highest importance. Otherwise, working together in an interdisciplinary setting can mean misunderstandings or a lack of understanding of others' research methods or results (Ibsen & Eriksen, 2022), as already stated above. However, especially open communication, which allows for questions, helps to disseminate knowledge and to broaden the horizons of all parties, often shedding new light onto the research topic.

Furthermore, the project leaders must guarantee the inclusion of all project partners. Effective project communication is therefore essential to the engagement of the project consortia (Magezi et al., 2021). Hence, the design of an efficient and effective structure of teams and communication channels is substantial. It is vital to include all project partners, even if some are only temporarily involved in active project work.

Finally, a code of conduct for cooperation should be defined together. Standards of communication, common working platforms, and procedures for addressing problems within the project should be clarified collectively. Such participatory developed principles and values can further facilitate collaboration and communication within the project (Brown et al., 2019).

Experiences from practice: development of an interdisciplinary research strategy

One example that specifically provides insight into the challenges of generating a common understanding of the research design, concepts, and goals is the project Smart VitAALity. The key facts about this project are presented in Table 5.1.

In the project Smart VitAALity, the necessity of answering interdependent research questions was clear from the beginning. The merging (transdisciplinary) and co-working (in a multi- or interdisciplinary form) of experts from different fields was consciously chosen to make otherwise barely achievable goals more realistic within a shorter time frame. From the start of the project, this exchange and collaboration required a general understanding of the research aims and expertise of the different fields of the entire project team. The implemented research strategy therefore identified three necessary levels of interdisciplinary understanding:

Table 5.1 Smart VitAALity – project outline

Smart VitAALity- Carinthian pilot region AAL and smart living technology	
Project aim	The pilot region project Smart VitAALity aimed to develop and evaluate a technical system to support older people in sQoL domains related to health, well-being and social participation. The Smart VitAALity system included technical applications to measure, visualize and automatically analyse the health and well-being status (i.e. blood pressure, ADL ability of the older user) and related services (i.e. a health coaching service). Parallel to the implementation targeting prevention, escalations could be recognized, for instance via a smart-watch-based active alarm system and automated recognition of vital parameters. The system was developed in an extensive participative approach together with all quadruple helix stakeholder classes and relevant eco-system partners. It was evaluated in a controlled trial, based on a multidisciplinary mixed methods approach, against several domains (UX, acceptance, sQoL efficacy, socio-economic potential) over 16 months with n = 230 participants.
Project partners and stakeholders	Carinthia University of Applied Sciences (lead), Joanneum Research, ilogs Mobile Software GmbH, Hilfswerk Kämten GmbH
Interdisciplinacy team	Technology development, social science, economic science, care and medical expertise
Participatory involvement	n = 30 older participants in the initial participative definition and development process, n = 20 interdisciplinary experts from the fields of care, medicine and health prevention in the definition phase n = 230 older participants in the field trial n = 10 experts from the field of business development, legal issues and eco-system analysis
Impact – voices from the practice	Female participant, 79 years: *"I am happy that I, as a test person, probably the oldest (...), can take part at all."* (own translation) Female participant, 71 years: *"All these visualizations [of vital parameters] are very interesting Back then (…), when I had high blood pressure, I even took the tablet to the health insurance company. (…) And she thought it was great, the doctor."* (own translation) Female participant, 74 years: *"What I also find positive, (…) if I haven't measured my blood pressure for a few days or after a week, a nurse gets in touch, I think that's good."* (own translation)
Project duration	36 months
Funding framework	FFG-Österreichische Forschungsförderungs GmbH

- A common language, formats, and definition of terms for targeted knowledge exchange (Level 1)
- A clear understanding of methodologies and results for each discipline and the interconnections between those outcomes, to guarantee a valuable transfer of information and knowledge between the fields (Level 2)
- A clear understanding of the research implementation strategy in the different disciplines and related timelines (Level 3)

Level 1 – Knowledge exchange: In the project Smart VitAALity, a lack of knowledge of interdisciplinary interactions and communication processes initially made collaboration challenging, which is often the case in interdisciplinary research projects and teams. The urgent need for a clear knowledge exchange strategy became apparent during the early stages. In response, interdisciplinary exchange and conversation were actively pursued and defined in a clear interdisciplinary management process. The core team implemented strategies not only to establish formats to share knowledge among the different researchers and their work but also to raise awareness of the benefits of reciprocal information exchange.

Level 2 – Interconnections: To ensure access to results and theory-based intervention designs in the Smart VitAALity project, clear strategies for data presentation and data transfer were defined. For instance, results of a social science-based mixed-methods need analysis were transferred to a (socio-)technology-based scenario description, use case definition, and architectural concepts (Oberzaucher, 2021). The described data presentation and transfer strategies were based, on the one hand, on the defined knowledge exchange strategies and, on the other hand, on an interdisciplinary team strategy that included "mediators", who understood the overall results in each research discipline and their interconnections. These mediators also played a crucial role in the third level of interdisciplinary research strategies.

Level 3 – Research implementation strategy: Based on the ability to communicate and exchange knowledge in interdisciplinary teams, and the clear plan of how to transfer results and corresponding methods from one discipline to another, a deep understanding and definition of research implementation strategies (study design, technical validation, impact evaluation processes, etc.) and corresponding time- and resource constraints can be achieved (a more detailed description can be found at Oberzaucher & Krainer, 2021). Through the mediator roles, the structure of the research lines (i.e. serial for RCT trials vs. iterative for acceptance and UX analysis) was identified in the Smart VitAALity project. It follows, that Level 1 and Level 2 had to be achieved to implement the last level, which required a deeper inter- and transdisciplinary understanding of the research needs of different teams (see guiding Principle 4).

The implementation of these core elements (Levels 1 through 3) of an interdisciplinary research strategy is nevertheless dependent on the fields of application, experience of the multidisciplinary teams and abilities, and permitted free spaces of the mediators (in terms of research participation, resources, and responsibility). Especially the roles of interdisciplinary managers, mediators, and domain-overlapping experts are widely underestimated in interdisciplinary research projects and teams. This has been identified as a major cause of failure to unfold the full potential of projects by creating a common understanding of project goals and processes and connecting researchers from various disciplines, practice partners, civil society stakeholders, interested citizens, corporate partners, decision-makers, and other stakeholders.

Equitable inclusion and ongoing engagement of older people in research and development processes

Strategies for equitable inclusion and ongoing engagement of older people in interdisciplinary research and development processes must also be considered. Further, ethical issues of collaborative research processes must be identified for each project (see i.e. von Unger & Narimani 2012). A conscious approach to the risk of reproducing social inequalities

through participatory projects is essential. With a special focus on hard-to-reach groups of stakeholders, such as people with physical or mental disabilities, this section will discuss varying stages of involvement and criteria of equitable participation to set up a diverse pool of participants in the research team. Concluding this section, aspects of equitable inclusion and ongoing engagement are reflected on hands-on practical experiences in a project on health equity.

Reaching the hard-to-reach

As one of the reasons for the growth in participatory research since the 1990s, sometimes described as the participatory turn (Ziegler et al., 2014), increased attention to disadvantaged groups and minorities, such as people with disabilities, is described. In ageing research, specific hopes are associated with the engagement of older people as co-researchers and experts in their own cause. In addition to gaining a deeper understanding of the social reality of older adults, these key stakeholders should experience empowerment and be supported in their ability to act. Participatory research is thus also intended to highlight social injustices and contribute to social change (Kollewe, 2020). In science and practice, there should be focus on opening up spaces for participation in gerontological research processes. This is intended to strengthen the democratic control of research and practice by turning target groups into active participants and influencing what and how research is carried out. According to the Critical Gerontology Working Group of the German Society for Gerontology and Geriatrics, this opening of space also includes the joint reflection and evaluation of research results or of tailored offers for shaping the living environment of older persons (Arbeitskreis Kritische Gerontologie der DGGG & Aner, 2016). However, challenges of participatory research and critical perspectives also need to be considered.

Just as in the promotion of political and civic participation, in participatory ageing research, the question has to be asked is whether it is not predominantly a group of older people who have high social and cultural capital, higher formal education, and a comparatively high socio-economic status (Böhnke, 2011), who participate. Participative projects are not able to compensate for structural social inequalities in society; these require changes in society as a whole (Arbeitskreis Kritische Gerontologie der DGGG & Aner, 2016). However, in order not to contribute to further exclusion of marginalized groups and thus to a reinforcement of the asymmetry of social inclusion through self-selective participation, these challenges should be met with systematic inclusion strategies (Selle, 2021). Fostering the engagement of people of high age, adults with health restrictions, older migrants, and other hard-to-reach groups, requires favourable framework conditions, accessible meeting spaces, inclusive communication processes, and specific support (Kollewe, 2020). In particular, participatory gerontological research provides the opportunity to learn more about the representation of different groups in participatory projects, to understand who is not participating and why, and to ensure systemic inclusion and targeted participation. In addition to transparency, a specific set of criteria to reflect and evaluate participation of older adults in research and practice has been developed by the Critical Gerontology Working Group of the German Society for Gerontology and Geriatrics (Arbeitskreis Kritische Gerontologie der DGGG & Aner, 2016). One of those criteria states that participation needs to be integrated into a larger context, such as the community participants live in, in order to initiate democratization of conditions and to counteract the reproduction of social inequality (see guiding Principle 5).

Stages of participation

In addition to the question of who can (not) be reached for participation in gerontological research, the central question that arises is to what extent older people are actually involved in participatory projects. Available conceptual models on the stages of participation focus primarily on the influence and decision-making power of the co-researchers involved (e.g., Arnstein, 1969; Wright et al., 2010). For research projects, this examination is important, because it allows reflection about which level of participation was aimed for and actually achieved. In summary, according to the Critical Gerontology Working Group of the German Society for Gerontology and Geriatrics (Arbeitskreis Kritische Gerontologie der DGGG & Aner, 2016), a distinction can be made between four stages of participation:

- Being informed: as a prerequisite for all further stages of participation, there is a need for an addressee-appropriate communication of important information as well as appropriate accompaniment and support, in order to reduce barriers to participation due to differences in knowledge.
- Being listened to: this requires conditions that enable all participants to express themselves. The extent to which the opinions expressed are actually implemented or considered remains to be seen.
- Determine and decide together: a new distribution of power among the participants is created on the basis of partnership-based cooperation and the right to vote in binding negotiations. Support for acquiring the necessary competencies in the context of co-determination and co-decision-making must be provided.
- Being self-organized: Those affected take their concerns into their own hands, make decisions and monitor the implementation of these decisions. Types of institutionalization often form over time, such as the establishment of associations.

According to the stage model of participation of Wright et al. (2010), we can only speak of the actual participation of co-researchers starting at the level of co-determination or co-decision-making. The steps below are only preliminary stages of participation. This should be disclosed very transparently in participatory research projects (see guiding Principle 6). As a quality criterion, it should be clear in publications who participates or has participated, at what point, and how (Bergold & Thomas, 2012).

These considerations and criteria are subsequently discussed at hand of the health equity project "Dementia-friendly Model Community Moosburg."

Experiences from practice: Equal inclusion and ongoing engagement of older people throughout the research and development process

As an example of diversity-sensitive participation throughout the research process, we selected a project that focused on people living with dementia and their family caregivers as a particularly vulnerable target group. For a better understanding of the participation of citizens as stakeholders, it must be explained that the project Dementia-friendly Model Community Moosburg was a practical project with the goal of developing and implementing an activity and action plan together with interested citizens and also evaluating it together in a participatory approach. The key facts of the project are presented in Table 5.2.

How can systematic inclusion succeed? A continuous presence and the comprehensible dissemination of information are basic prerequisites for reaching diverse target groups.

Table 5.2 Dementia-friendly Model Community Moosburg– project outline

	Dementia-friendly Model Community Moosburg — together.for a better life with dementia
Project aim	The project aim is to improve the quality of life for people with dementia and their families by initiating social change toward a dementia-inclusive living environment and the development of a participatory care network in the model community. Through measures in three fields of action, the community population in general and professional groups working in the public sector in particular, people with dementia as well as their relatives and trusted persons are reached, sensitized, encouraged to participate and supported. Activation and participation methods used were an open citizens' forum, stakeholder workshops, a future conference, events for the general public (such as the Carinthian Dementia March), a lecture series, training courses and the establishment of inclusive meeting spaces, such as the Dementia Café.
Project partners and stakeholders	Carinthia University of Applied Sciences, Action Dementia Moosburg association, Carinthian provincial government, Municipality Moosburg, Carinthian regional public health insurance
Interdisciplinary team	Health and nursing care, personal care, medicine, health sciences, geronto-psychology, sociology, healthcare management, community policy and administration, validation and animation, social work
Participatory involvement	*n* = 660, including people with dementia, caregiving relatives, professionals in public services, interested community citizens, students
Impact - voices from the practice	Woman, 66 years, caring relative of a mother with dementia: *"Before the initiative existed, we didn't know where else to go with mom. Now we have meeting places that she looks forward to and we all get out more."* (own translation) Man, 60 years, primary practitioner: *"By removing the taboo, the fear is no longer great (…) through our work the population is enlightened and sees that this is simply a disease and can be accompanied you can't cure it but you can accompany it and there is help."* (own translation)
Project duration	24 months
Funding Framework	Fund for a Healthy Austria, Carinthian provincial government, Municipality Moosburg

In the project presented here, personal contact, the associated opportunity to build trust, actively approaching people, and personally issuing invitations (i.e. at the family doctor, in the nursing home, by mobile services) proved to be particularly effective in encouraging participation and to embed activities in community life. The work highlighted the visibility of active persons, models for participation and a differentiated picture of life with dementia, which certainly offers possibilities for action and above all makes the importance of the social environment clear. Important information channels to reach the target groups included the community newspaper and homepage, posters and notices as well as social media channels, which can be seen as an essential networking source.

The target group of caregiving relatives is described as especially difficult to reach. Within the framework of this project, contact with affected families was established through the implementation of dementia counselling and the Dementia Café. The organizational form of offering the Dementia Café and training for relatives at the same time contributed greatly to the usability of the offer for family caregivers.

Stages of participation of older adults in the research and development process: After an early initiator called for people to become active on the topic of dementia, a group of stakeholders was formed. This group consisted of representatives of the addressed stakeholders from the community environment as well as caregiving relatives. Subsequently, cooperation with IARA was established. After two years of cooperation, the stakeholders joined together to form the association Action Dementia Moosburg and continue to pursue their objectives in a self-organized manner, even after the end of the project (see guiding Principle 10). The cooperation with IARA is still maintained, and various events and initiatives are implemented together.

The experiences in the project have shown that offers that aim at the participation of people with dementia and their relatives in the social life of their community, require joint planning to be aligned with the needs of these target groups. The involvement of older stakeholders and interested parties was central throughout the project. Within the framework of a citizens' forum, for example, planned measures were discussed with about 50 community citizens and adapted accordingly. Starting from the information stage, the opinions, knowledge, and experience of older activists were integrated into the project planning in the consultation stage. Moreover, the practice partners and citizens were involved in the decision-making processes over the course of the project. Without this involvement, the implementation of the project would not have been conceivable. The project evaluation was also designed with a community-based participatory research (CBPR) approach. The design of the CBPR is based on a fundamental attitude of action research in which the further development of the field of investigation is the objective (Israel et al., 1998; Morgan et al., 2014). Interested parties and active participants in events and measures, relatives of people with dementia and those affected themselves were continuously surveyed (including peer-to-peer surveys), and their feedback was integrated into the planning of further activities. The results of the citizen participation were thus transferred continuously (presentation and discussion of the results of ongoing data collection and evaluation in the working group as well as in a stakeholder workshop and future conference), and included in the design of a programme as well as in recommendations within the framework of a sustainability concept.

Participatory approaches and communication methods in applied ageing research

Besides the identification and equitable inclusion of relevant stakeholders, the approach to participation, as well as communication methods, need to be defined to guarantee ongoing engagement. Next, a short overview of approaches to participatory research as well as communication strategies and exchange formats is provided.

Participatory research approaches

According to Bergold and Thomas (2012, without page number), "[p]articipatory research methods are geared towards planning and conducting the research process *with* those people whose life-world and meaningful actions are under study." Participatory research is not an independent research method and does not use specific research methods, but all the methods are usually used in the social sciences. Participatory research can rather be seen

as a *research style* that uses different research strategies, which constantly promote and demand the inclusion of practice partners and those whose environments are concerned in the research process. The participation of all partners – research and practice partners – becomes the decisive basis of research activities (Bergold & Thomas, 2012). Participatory research, however, goes beyond the participation of co-researchers. It is "a joint process of knowledge-production that leads to new insights on the part of both scientists and practitioners" (Bergold & Thomas, 2012, without page numbers, included as guiding principles 1 & 9).

Apart from the different research methods used in participatory projects (e.g. interviews, focus groups, photo/video talk, and participant observation), different research strategies such as Participatory Action Research (PAR), Citizen Science, Co-Operative Inquiry, Participatory Rural Appraisal (PRA), CBPR, Design-Thinking, Open Innovation or the Living Lab strategy can be applied. All these approaches aim for the changing of social realities "while gathering data in traditional and innovative ways. They intervene and study in a continuous series of feedback loops" (Reinharz & Davidman, 1992, without page number). In the following, the research strategy PAR, as well as the Citizen Science approach, is presented in more detail, as these are used repeatedly in various IARA projects.

Participatory Action Research (PAR)

First of all, it is important to mention that participatory research is not the same as PAR. In principle, action research and participatory research can be conducted independently of each other. Within action research, the participation of the practice partners can be designed differently, as the different PAR approaches (e.g., PAR or PRA) show (Bergold & Thomas, 2012). Stringer (2007, p. 8) defines action research as a "collaborative approach to *inquiry* or *investigation* that provides people with the means to take systematic *action* to resolve specific problems." While then the focus of action research is on interventions and researchers seek to contribute to problem-solving and the expansion of knowledge in parallel (Robra-Bissantz & Strahringer, 2020), participatory research emphasizes the joint design of research and not primarily the action and change itself (Bergold & Thomas, 2012). According to McNiff and Whitehead (2011, p. 8), action research means that "[p]ractitioners research their own practices, which is different from traditional forms of social science research, where a professional researcher does research on practitioners."

Stringer (2007, p. 8) outlines a "Basic Action Research Routine" that should help to conduct the PAR in a straightforward manner:

1 "Look: Gather relevant information; (…) Describe the situation (…).
2 Think: Explore and analyze: What is happening here? (…) Interpret and explain: How/why are things as they are? (…)
3 Act: Plan (Report); Implement; Evaluate."

What all these approaches have in common, is the continuous recycling of the different steps of planning, acting, observing, and reflecting, originally defined by Kurt Lewin (Dickens & Watkins, 1999)

Stringer (2007, p. 11) identifies the following characteristics of action research, which at the same time also represent advantages of participatory research (see guiding principle 5):

- "It is *democratic*, enabling the participation of all people.
- It is *equitable*, acknowledging people's equality of worth.
- It is *liberating*, providing freedom from oppressive, debilitating conditions.
- It is life *enhancing*, enabling the expression of people's full human potential."

Citizen science

In order to discuss the importance of a diversity-sensitive and effective communication framework throughout the entire course of a participatory research or development project, a project based on the Citizen Science research approach has been selected as example. This approach has been adopted by the German Citizen Science Platform "Bürger schaffen Wissen" (citizens create knowledge) in the Green Paper on the Citizen Science Strategy 2020 for Germany. In this strategy, which was developed by the German-wide participation of more than 700 people interested in Citizen Science, (both individuals and representatives from over 350 organizations), Citizen Science is defined as

> "the participation of people in scientific processes who are not institutionally bound to this field of science. Their participation can range from the short-term collection of data to the intensive use of free time to delve into a research topic together with scientists and/or other volunteers. It is important, however, to adhere to scientific standards…"
>
> *(Bonn et al., 2016, p. 13)*

This definition goes further than the frequently known Anglo-American approach, which involves citizens primarily in data collection, usually in environmental research projects (Bonn et al., 2016). Thus, it corresponds more closely to the understanding of participatory ageing research at IARA.

Communication strategies and exchange formats

Ideally, participatory research projects involve practice partners or co-researchers during different stages of research. An important instrument for a long term and satisfied participation and an essential factor for good practice in user involvement is communication with stakeholders. The successful inclusion of different stakeholders and target groups in the research process places special demands on communication and exchange formats. On the one hand, these are demands on the way communication takes place and is maintained, but, on the other hand, they address how different stakeholders are integrated into the communication process. Conflicts that may arise in communication can be guided, for example, by the principles of non-violent communication according to Marshall B. Rosenberg (2016). Furthermore, examining the five axioms of communication according to Watzlawick et al. (2011), they could be used to guide every kind of communication and to analyze conflicts, even in participatory research: (1) you cannot not communicate, (2) every communication has a content and a relationship aspect, (3) communication is always cause and effect, (4) human communication uses analogue and digital modalities, (5) communication is symmetrical or complementary (Watzlawick et al., 2011).

However, conflicts should not necessarily be seen as negative but should be understood as indicators of the quality of participatory and interdisciplinary cooperation. In connection with

the phases of team development, conflicts result in further developments and consolidation of structures. Conflicts arise because different needs, interpretations, or interests collide in heterogeneous teams; when they occur in the process of cooperation, they are a calibration of equity and empowerment. (Self-)reflection, the transparent and adequate handling of conflicts as well as an appreciative approach and empathy for opposing positions are central elements in the work of heterogeneous teams (von Unger, 2014). At IARA, it has been shown that the cooperation of complementary persons – in terms of personality, background, and discipline – is powerful and has made it possible to achieve the research successes of recent years.

For different reasons, it happens that communication processes throughout a project are selective, not consistent. From an ethical point of view, but also from the perspective of creating long-lasting and appreciative relationships, continuous communication is crucial. It is also important to see communication in a broader way, not only the frequency, measures, written or oral word but also the appearance in person. There are critical contact points in the course of a participatory design and evaluation process, which can make the difference between participants dropping out or participating further (see guiding Principle 7).

In addition to the conscious use of communication models, it is necessary to maintain communication within and outside the interdisciplinary team. Communication can be synchronous and asynchronous. Regular project meetings – weekly, biweekly, or monthly – ensure that team members and relevant stakeholders can meet and discuss issues at hand. This promotes a sense of community and exchange among team members. The regularity of meetings can be adjusted according to specific needs: for example, in times of much uncertainty it may be necessary to convene more frequent meetings, or in times when work and process steps are clear to all stakeholders, meetings could be shortened. The experience of the COVID-19 pandemic and its limitations has shown that online formats can also be chosen for meetings, as long as all participants have the required access and competencies, or are supported to achieve them. However, it should be emphasized that online meetings should be conducted when necessary and appropriate, but they are not an exclusive alternative in terms of quality to face-to-face meetings. Participatory research relies heavily on personal interaction, which is why a balance must be found when choosing online or face-to-face meetings (see guiding Principle 8).

Asynchronous communication can take the form of a common platform where information is made available to all team members and stakeholders. The experiences in the IARA team show that this gives all stakeholders equal access to documents and information and thus enables them to inform themselves asynchronously about project processes. It is recommended to use a clearly structured information platform to avoid duplication of communication or information overload (see Schweiger & Beck, 2019).

Experiences from practice: Facilitating a joint research and development process

In the following section, experiences with communication plans and methods as well as with the integration of participatory online research strategies during the project "Citizens4Science – Living Well in Carinthia" are described. In this project, the involvement and participation of older adults were important to identify criteria for well-being and high quality of life in Carinthia. The key facts of the project are presented in Table 5.3.

In the project "Citizens4Science – Living Well in Carinthia" several participation-based formats were implemented. These included, for instance, workshops for the joint collection of criteria that constitute a high quality of life and the subsequent development of a

Table 5.3 Citizens4Science – project outline

Citizens4Science — Good life in Carinthia	
Project aim	Citizens4Science is a citizen science project aiming to motivate Carinthian citizens to become co-researchers in participation-based research and to participate in researching what constitutes high quality of life in Carinthia. Furthermore, the project aims to expand the knowledge of participatory research methods among university teachers, researchers and students. Through continuous involvement of stakeholders in the participation processes, the project also aims at their empowerment. For this purpose, process support as well as further education offers (citizen workshops) are implemented. Some of the methods applied in the project are: participatory decision-making methods, co-design of a questionnaire about life in Carinthia, distribution and completion of a citizen survey, panel discussion, open space workshop and focus groups
Project partners and stakeholders	Carinthia University of Applied Sciences
Interdisciplinary team	The team consists of members from the following disciplines: nursing science, migration studies, public administration science, health science, philosophy, psychology, sociology
Participator involvement	$n = 595$, including young people and students, older adults, job-seekers, people on maternity leave, self-employed, employees, people working in the household, people with and without migratory background, as well as local and regional stakeholders and multipliers from the fields of care, integration support, gender & diversity, regional management, local public administration, regional development and professionals working with people with various (dis-)abilities
Impact-voices from the practice	Female multiplier and co-researcher in the project, who is experienced in initiating participation processes: *"For me, participation also means informal education, in the sense of community education. And I believe that if we start to think about participation in this way and to teach it more, then it will also be less likely to cause disappointments. Because people will also recognize through their actions that, aha, I can do something, I have confidence, I am somebody and I have a self-image for the world outside, for myself, for my little world, but also this self-confidence. I am somebody, I can do something, no matter from which background I come or which education I have enjoyed and I can participate in something and I can also move something, because I was there"*. (own translation)
Project duration	26 months
Funding framework	Carinthia University of Applied Sciences

questionnaire. Except for the first workshop, all participation formats had to take place online due to the COVID-19 pandemic. This included reflection rounds with the participants on their satisfaction with the participation process itself, which were conducted using a video conferencing tool. With the help of online break-out groups, group discussions were facilitated on a smaller scale, and online whiteboards helped us to 'cluster' the content collected through participatory brainstorming.

Due to the pandemic, there was great understanding among the practice partners for the implementation of online formats. Everyone wanted the process to continue and not be suspended or stopped because of Corona. Nearly all participants were already familiar with video conferencing tools, as they had used them in their professional, volunteering, or private lives. This also applied to older participants, some above the age of 80. Although the online setting prevented face-to-face interaction and informal conversations during breaks (to get to know one another or informally exchange ideas), the switch to online communication also offered a distinct advantage: People who otherwise might not have taken part because they live in remote districts of Carinthia were able to participate.

The online implementation, necessitated by the COVID-19 pandemic, required a well-thought-out communication and participation strategy with the citizen scientists. In regular update e-mails the coordinating team tried to inform all who were interested in the project or had already participated, about its current status and next steps. The prerequisite for this was a complete and continuously updated list of practice partners and stakeholders. Ongoing communication of the interim project results to the practice partners is also important. At the beginning of each online participation format, the preliminary project results were communicated. When the coordinating team noticed that some participants were particularly interested in the process of participation itself, having acquired knowledge about participatory processes in their professional or volunteering contexts, online meetings were set up to foster the informal exchange of participation-based experiential knowledge.

Ten guiding principles for interdisciplinary participatory ageing research

Based on the presented theories and experiences of participatory research and development projects in the field of applied ageing research at IARA, the authors can summarize ten guiding principles of participatory ageing research:

1 Work towards an understanding of participatory research that facilitates the joint production of knowledge useful for academia and practice and goes beyond the participation of co-researchers.
2 Include all relevant stakeholders to guarantee a broad consideration of needs and effects.
3 Create a common understanding of the project aims, the research design, and relevant terms within the project consortia.
4 Establish participation throughout the research process as a vital part of the comprehensive research strategy.
5 Develop strategies for systematic inclusion, in order to foster engagement of hard-to-reach groups of stakeholders.
6 Clearly define, communicate, and critically reflect the extent of participation of diverse stakeholder groups (who participates, at what point, and how), according to the project's objectives, responsibilities, and opportunities.
7 Establish a diversity-sensitive and effective communication framework to guarantee engagement of the project consortia throughout the research process and beyond.
8 Establish communication methods and formats that address the needs of various participating research partners and provide support where necessary.

9 Identify learning processes of all participants as an objective of participative research and support them through appropriate participatory methods.

10 Design collaboration processes that are integrated into a larger context and capable of development and change - even beyond the research project.

Note

1 Detailed information about these projects as well as the structure of the institute can be found at IARA 2022:https://www.iara.ac.at/

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PART 2

Designing research together with older adults

6

SETTING THE RESEARCH AGENDA TOGETHER AS A FORM OF PRODUCTIVE AGEING. RATIONALE AND EXEMPLARY CASES

Mariano Sánchez and Raúl López-López

Introduction. What is productive ageing?

The central hypothesis of this chapter is simple: the participation of older adults in setting the agenda for research on ageing can be a form of productive ageing (PA). In the 1980s, the gerontologist Robert Butler introduced the concept of PA to highlight the capacity of older adults to take part in the labour market, do volunteer work, help their families and continue to be independent for as long as possible (Butler, 1986); in short, the capacity to contribute to the general interests of society and its economy. For Butler, not making the most of this capacity in societies with growing longevity was a waste that could not be permitted. The concept of PA was founded on the premise that the skills, knowledge, and experience of older people were not being sufficiently, or efficiently, used. Four decades later, this early vision still makes sense, although the original idea has been reformulated.

Bass et al. (1993) broadened the original concept's scope and redefined PA as "any activity by an older individual that produces goods or services, or develops the capacity to produce them, whether they are to be paid for or not" (p. 6). For one thing, using the words "any activity" expanded the possible modes of PA, as long as the activity in question had some type of economic value. In this context, the contributions made by people usually described as "old" through employment, civic involvement, or as caregivers, were clear examples of PA. The range of possibilities is enormous and can certainly comprise research activities performed by older adults.

In addition, this reformulated PA placed the accent on the role that older adults could play in society. Bass et al. (1993) decided to leave out of PA those activities whose purpose was personal enrichment – for example, physical or spiritual activity aimed at individual well-being. They were also aware that not all PA should be considered positive—imagine, for example, the harmful effects that intense childcare sessions can have on the health of grandparents (Sun, 2013)—and also that PA should not become an obligation for all older people since many of these individuals might decide they do not want to age productively, while others simply cannot because of the obstacles in their way. In brief, it was clear that

the most interesting aspect of PA was not the obligation to participate productively but rather the opportunities to do so, and also the forms and the repercussions of such participation (Morrow-Howell et al., 2004).

This new formulation of PA by Bass et al. (1993) was revised subsequently, with the incorporation of further nuances, two of which are of interest in this chapter. The first of these nuances was that alongside the initial economic emphasis, another key issue had to be considered: the sociological aspect. "The study of productive aging includes attention to the older person within the situational context of societal structures. […] the individual is envisaged in a societal context" (Bass & Caro, 1996, p. 265). What does this mean? It means that the activities were not only productive because of their economic value but also for their significance within a specific social structure. It was the "social value" (Burr et al., 2007) of activities, i.e., the value that accrues to the community and larger society, that really made them productive endeavours. This revised concept of PA incorporated a broader understanding of what *productive* means, beyond the strictly economic interpretation: contributing to society by adding social value became the real key to understanding this type of ageing (Caro & Sánchez, 2005). Compared with other concepts of ageing discussed in the scientific literature, such as active, healthy, successful, or satisfactory ageing, PA stands out because it is based on older people's contribution to meeting society's needs and alleviating relevant social problems linked to collective well-being in a given context and time. To put it another way, PA places the accent on what socially significant contributions older adults can make (Caro & Sánchez, 2005).

In consequence, this paper puts forward that in societies in which ageing is a socially significant phenomenon that must be analysed, the contribution of older people in gerontological research tasks can be classified as a form of PA. This sociological perspective of PA, which looks at how human agency and social forces are interlinked (Taylor & Bengtson, 2001), is especially interesting because it represents a point of union between the (productive) manner in which some people wish to and can age and the (also productive) societal value of research. This is the bridge that justifies this chapter.

The second relevant nuance in the revision of the PA concept was the idea that attention must be paid to the interplay between productive activities or sectors, instead of approaching them separately (Caro & Bass, 1995). Often, productive activities are grouped together in clusters, the composition of which depends, for example, on their degree of complementarity and obligatoriness (Burr et al., 2007, p. S268). For instance, working and volunteering might be complementary and volunteering can be obligatory in certain contexts (e.g., volunteering for the religious organization to which you belong). This cross-sector vision must not be lost if we hope to fully examine the productive potential of the contributions made by older adults in research contexts: think, for example, of an older individual involved in setting the research agenda of a study about caregiving during old age and, at the same time, acting as the caregiver of another older person. This combination of two forms of PA (conducting research into caregiving and being a caregiver) broadens the horizon of that research and at the same time poses specific methodological challenges.

If PA, because of its potential for social change, can be understood as a means to transform ageing at the community level, this transformation needs to be based on solid knowledge, for example, about the problems, needs, challenges, programmes, and policies associated with ageing, then *basic research* and particularly *applied research* in this area can become a channel of PA, just as Caro et al. (2005) argued years ago.

Older people, research and productive agency

In gerontology and sociology, reflection is underway on the importance of involving older people in research (Munn-Giddings et al., 2016). Such reflection is not new but it is different insofar as the idea of co-research has gained ground: the ageing of the population along with the need for more inclusive policies and services have sparked interest in co-research with older people (James & Buffel, 2022). What can PA contribute to this reflection? It can provide a complementary reading of what might happen when older people, with productive intent, become involved in research tasks. For example, PA can enrich the aforementioned reflection with proposals regarding how it can create new opportunities to increase productive participation by older co-researchers; and how it can design and implement these opportunities in ways that encourage, creatively and cost-efficiently, older persons to take an interest in what their communities need (Morris y Caro, 1995). The job of setting the research agenda could be one of these forms of productive agency.

Now, if the term productive agency appears in the title of this section, it is because, in this case, to make the most of the productive perspective it is not enough to simply talk about actions (i.e., what tasks older people can perform when they are involved in research processes), positions (i.e., in what specific phase of these processes can they do what they do) and dedication (i.e., the time they devote to these tasks). It is also important to take into account not only the sociological concept of agency but also the life-course context. Why? Because it is simply not possible to understand a human being, and much less an old one, as a social actor without considering that person's life trajectory and looking at how, during his/her life story, that person has dealt with the interconnection between his/her individual life and social structures. The idea is this: if the sociological emphasis of PA compels us, first of all, to gain awareness of what is truly significant in a given social structure (for example, ensuring the cycle of care) and also to recall that "what social structure primarily does is to shape and define the individual's consciousness, within which intentions and purposes are formulated and externalized into agentic action" (Dannefer & Huang, 2017, p. 6), then the very social structure within which research is taking place may already be strongly embedded in the discourse of the older adults when, as research agents, they externalize their conscious intentions of action. To put it another way, it is reasonable to think that when it comes time to define the ageing problem to be studied, the proposals that older people make regarding what actions are needed – proposals that may become part of the research agenda – could be very useful for understanding how these problems are really embedded in the social structure. Would anybody be surprised, for example, that research about widowhood and the choice of which specific aspects of the experience of losing one's spouse should be examined, with a view to intervention, would be something more effectively externalized by older persons who became widowed long ago? And not so much for their subjective experience of widowhood, but primarily because of their knowledge of widowhood as a field of interaction in which people live their lives in close interconnection with the social patterns of widowhood that enable and restrict what they can do as widowed individuals and how they can do it.

Especially productive forms of agency can be found in the fact that the accumulation of ageing experiences in older adults can allow for singular access to the ways, practices, and problems of ageing that are more relevant in a specific societal context. This particular form of access can bring with it singular contributions by older adults in the process of setting the gerontological agenda.

Specific impacts of the agenda-setting process

Prioritizing what is most significant

Incorporating a PA perspective like the one proposed can help remedy the error commonly made in ageing research: it is undertaken based mainly on the priorities of academic and institutional agendas that are not always aligned with what is truly relevant for a community. Ensuring that the topics, the aspects of the topics, and the specific questions to examine – the three elements that are basic components of a research agenda – are truly significant at the local or community level and have the "social value" discussed above will increase the relevance of the research. Obtaining –in a well-designed and well-executed manner–, the point of view of older adults when formulating the research questions of a study that hopes to be productive can help transform the research results into strategic actions to improve ageing services, programmes, and policies at the community level (Morrow-Howell et al., 2004).

The participation of older adults in the formulation of truly significant research questions can open up new possibilities of agency and empowerment both for them and for other older persons, as shown in the three cases described in this chapter. These possibilities can give rise to pathways of change in their communities and to the development of individual and group skills that favour voluntary participation in relevant community issues (Chen et al., 2020).

Making visible what is hidden

Sometimes the capacity of older people to do research is questioned without being aware of one of the consequences of such questioning: involving older people can make visible issues linked to ageing that would otherwise remain hidden. An example? The case of elder abuse or battering within the family. Or possible conflicts connected to the inter-vivos transfer of assets and the designation of beneficiaries. Or the difficulties faced by small artisan businesses trying to survive when there are no younger people who want to take charge of the business and the know-how passed down from one generation to the next is thus at risk of being lost. These are all problems related to ageing that can be difficult to access. Therefore, to see the light of day they need inside voices, the voices of people who experience these problems or know the issues close-up and can see problems that others do not perceive. In the examples listed, and in similar ones, the older adults involved can play a productive role if they are given the opportunity to participate in the agenda-setting of gerontological research. Also, the presence of older adults on the teams would make it possible to access the often ignored, undervalued, or rejected opinions of these persons. In short, all of this would lead to an expansion of the contents of the agenda by bringing to light matters previously in the shadows.

Reducing ageism

According to the WHO (2021), age discrimination is present in many institutions and sectors of contemporary society. In the specific case of discrimination against older people, the impact of ageism can cause lower quality of life and increased loneliness and social isolation, which can have serious consequences on their health.

We know that ageism is an institutionalized obstacle, at least for certain modes of productive participation. How to fight this problem? Both quality intergenerational contact and improved self-perception of ageing and self-efficacy can be good strategies for reducing the negative impact of age discrimination on the potential of productive engagement (Kang, 2020; WHO, 2021). Drawing attention to the value of older adults as a group and questioning age-based judgements regarding their skills and needs can also help bring change in this direction. In this last regard, productive participation by older people, when done right, can challenge age discrimination by highlighting the importance of older adults who thus cease to be perceived as "vulnerable folks". In this context, the value that older people can add to the setting of the research agenda in projects hoping to have an impact on significant community issues can also reduce ageism.

When older adults act as co-researchers, age-based stereotypes can hinder their participation (Gutman et al., 2014). However, a good intergenerational strategy in research – for example, ensuring the multigenerationality of the teams in which older people take part – can help reduce or avoid ageism. In fact, this was observed in two of the three cases described below.

Cases of interest

The three practical cases selected to illustrate the ideas set forth above have been analysed based on the following four questions:

1 How did the collaboration between researchers and older people come about? Hand-in-hand – researcher-led – older people-led.
2 Where was the agenda-setting process located within the research timeline? Pre-stage (prior to research) – initial stage (at start of research) – later stage (after start).
3 Which were the main singularities in the agenda-setting process as approached by each particular case?
4 What about potential impacts identified in terms of PA?

The Frank J. Manning certificate in gerontology

While it was in place, this programme, organized by the University of Massachusetts in Boston, one of the foremost institutions in the field of PA in the United States, consisted of a year-long course in gerontology intended for persons aged 60 and over exempted from fees in a context of multigenerational learning: "more than two-thirds of each class are students who are themselves 'older people,' ranging in age from 60s to mid-80s" (Silverstein et al., 2004).

The programme's overall objective was to improve the capacity of students to contribute effectively and productively in services related to ageing, and also to become involved in the defence of older adults (Caro, 1999). With that aim, students devoted a semester to an applied gerontological research project, generally on a topic previously selected by the instructor.

Researcher-older people collaboration: researcher-led

In this case, the usual practice was that the researchers led the investigation process and guided the agenda-setting; the older participants basically had to follow the guidelines laid down by the researcher in charge. Older students had a vital but limited role (Caro, 1999, p. 12):

The process is initiated by the instructor who selects the topic. With the aid from research assistants, instructors develop a variable list and draft research questions. In their substantive discussions of the topics in class, students make contributions similar to those of focus groups. Since the studies address issues of concern to elders, students often bring experience and insight on these subjects to class discussions. Students bring substantive insights which sometimes lead instructors to add variables to the survey agenda.

Also, in the process of setting the agenda, there was usually a stakeholder involved as well, a community organization with interests in the topic to be studied.

However, according to Professor Nina Silverstein (University of Massachusetts in Boston)– deeply involved in this programme from 1994 to 2012 – the standard process for choosing the questions to study could vary:

- The students themselves raised the topic (e.g., grandparents raising grandchildren, health and social service needs of older women veterans, older learners on campus, the driving decision – when to stop and who should decide).
- A community organization pointed out a relevant issue (e.g., eligibility and access to Supplemental Security Income, wandering behaviour, and the Alzheimer's Association's Safe Return programme).
- Faculty interest was the reason (e.g., adult day health care and dementia, livable and age-friendly communities, acute care, and dementia).

Building the agenda: pre-stage

The agenda was generally set before the research process began but the final decisions were often made later with the participation of the older students. The teachers and students – most of whom were elders – met with community leaders and public agency representatives to better identify the issue of concern that would be studied. During this period of agenda-setting, if deemed necessary, preliminary meetings with a community organization were also held, to discuss the various expectations at play and sometimes in the process a project advisory team was created – another way that older adults could participate –. Also, the dialogue between the older students and the researchers regarding the substantive topic to be studied was helpful, from the very beginning, in determining the final framing of the topics and the research questions, which had usually been provided by the researchers based on needs formulated by the community's different ageing services (Silverstein et al., 2006).

Singularities

In relation to the agenda-setting process, the following characteristics constitute specific features of this case:

- Older adults work not just with the researchers but also with a community organization in deciding the details of the final agenda.
- The agenda-setting process takes place in parallel with training in applied research and also with the research itself. Thus, the process is not an isolated act but rather part of the ongoing collaboration of older students in the entire research cycle.

Impact in terms of productive ageing

- Listening to the issues raised by community organizations that work with older people or by older adults themselves, along with their families and caregivers, is essential for setting a research agenda that will eventually produce effective recommendations for practice.
- Many of the older students who signed up for the programme and completed the cycle of applied research later became role models for PA. Some of them got involved afterwards in the Massachusetts network of ageing programmes and services and were very active in obtaining significant improvements for older citizens (Silverstein et al., 2006).
- During the fieldwork, these older students were able to easily establish rapport and identify with the older persons they were interviewing. It can be assumed that their participation in the research project from the outset helped them in establishing such rapport due to their holistic comprehension of the study – the students were not mere interviewers but researchers in a productive project intended to improve the experience of ageing in the area.
- An additional benefit of an educational opportunity such as this one was that it gave older people involved greater capacity to face their own ageing in better conditions; some could also help friends and family members thanks to the productive action research activities carried out.

OFECUM: research by entrepreneurial older citizens

This second case, situated in the city of Granada, in the south of Spain, has been chosen as an example of research on ageing conducted by older citizens who wanted to be entrepreneurs. It describes the experience of a study performed with and by a group of older adults enrolled in the University of Granada's Aula Permanente de FormaciónAbierta (APFA), a centre which offers informal educational programmes to persons over the age of 50. The study involved applied research in which the older adults themselves explored a problem that affected them and proposed ways to intervene in it. It can be considered an experience of immediate reflexivity (Sánchez et al., 1999): older people, as active social agents, investigated themselves – analysing aspects of their own ageing as well as that of other older people –. How? Older people led a process explained below.

OFECUM, which stands for Oferta Cultural de Universitarios Mayores(Cultural Offerings by University Older Adults), is a non-profit organization founded precisely as a result of the research project presented herein. A group of older people belonging to APFA's first "graduating class", accompanied by two university instructors and two undergraduates, comprised the team performing the study which led to the creation, in 1998, of OFECUM, an entrepreneurial project dedicated to organizing and facilitating participation by Granada's older population in sociocultural and community development activities.

Researcher-older people collaboration: older people-led

In contrast with the preceding case, here older adults took the initiative from the very beginning, although it is true that the researchers and the older people had already been interacting in the framework of APFA educational activities. It was these activities that in

one way or another prompted a group of ten of older people who had taken the course to ask themselves the question that launched the entire process: "What can we do after three years in the APFA programme, besides keep coming to class?". Nobody had asked such a question before and it caught the university teachers responsible for the programme by surprise. It was suddenly necessary to look at the question of how to apply in the city what had been learned in the university classrooms.

A dialogue process was quickly put in place so that researchers and older students could discuss the matter. During the process, an analogy arose that would give meaning to the entire research process: if young students, upon finishing their undergraduate studies, embark upon entrepreneurial activities, join the labour market and contribute to society's improvement, why can older students not do the same? Following this line of argument, and in the framework of open, unstructured conversations, the conclusion reached was that culture had to be the raw material of the older students' contribution. The final idea eventually took shape: Why not take advantage of the wide array of cultural activities available for free in the city as a means to encourage participation by older people, who were presumably left out of the community's cultural life?

Building the agenda: initial stage

After several different work sessions, in which the approach used was one of total symmetry between researchers and older adults and which followed no pre-established methodology, the central theme of the research project was decided: the problem of the lack of participation by older people in Granada's cultural activities. Next, the aspects of the theme that would be the object of study were decided: the reasons and conditions that enabled older people to take advantage of the cultural offerings, on the one hand, and the obstacles and impediments that made it difficult to take advantage of such offerings, on the other. At this point, the researchers spent some time designing the study, paying special attention to the data collection methodology (through several discussion groups), as it had been agreed that it would be the older people themselves who would carry out the fieldwork, after being trained.

Finally, the discussion groups that took place were supported by scripts that had been drawn up initially by the researchers and then revised and adapted to their final format in collaboration with the older people – who, by this time, considered themselves researchers as well.

Singularities

- Reflexive self-recognition between older researchers and older researchees – through visual identification, initially, and empathic identification, afterwards – helped to avoid the risk of the research being instrumentalized by either the method or a pre-constructed knowledge objective.
- The central role played by the older researchers, in this case, had a transformative and empowering effect, in contrast to the external forces at work in the broader social context, which lead to a very different understanding of old age and older people. In the words of one of the older people, "doing research is a way to change" (Sánchez et al., 1999, p. 94). This alludes to the meaning of the concept of productive agency with consciousness introduced above.

- The qualitative technique used (the discussion group) and the specific implementation method devised made it possible for the older researchers to introduce questions at their own initiative since they were thoroughly immersed in the communication flow with the older people whose reflections they sought to obtain. This means that the agenda-setting process remained partially open for the duration of the research, far beyond the initial stage.
- The generational distance between the academic researchers (aged 22–31) and the older people (aged 50–70) in the research team was intentionally capitalized on so as to put into practice a type of intergenerational contact and interaction capable of improving intergenerational perception. At the end of the study, the researchers reported having improved their vision of the participating older persons as productive citizens capable of introducing very significant innovations with a view to improving the conditions of ageing in the city.
- Some of the older people doing research were housewives with previous experience in volunteer work – they had collaborated with the local association of housewives –. During the setting of the agenda, that experience – a productive activity, after all – proved to be useful in exploring, particularly, what specific barriers older housewives might have when it came to enjoying the city's cultural offerings. The involvement of housewives-volunteers in the fieldwork is an example of the clustering factor discussed above: some productive activities (e.g., volunteer work) can be combined with others (e.g., research) during the agenda setting and thus increase the productive potential of ageing research.

Impact in terms of productive ageing

Holding discussion groups was a gratifying experience for the older researchers, who ended up with a great desire to continue researching. Their initial sensation when they thought about what it would mean to become involved in a research project – especially having to take charge of the data collection – was a concern, because they did not know how it would all happen. As the project progressed, and as older researchers saw the reaction and mood of the older persons with whom they interacted, they felt more and more comfortable and sure of themselves. After doing a self-evaluation exercise about the experience they concluded that this type of research that heightens the productive capacity of older people could help reinforce a sociological consideration of old age more suited to the times in which we live. Older people – said the participants – should cease to be the object of research projects performed by social scientists and become allies and agents of such research.

The most evident impact of this case in productive terms was the founding of OFE-CUM, a non-profit association of cultural services whose mission is to promote social participation of older people in Granada by taking better advantage of the city's cultural offerings. The results of the research identified two basic barriers to the participation of the city's older residents in cultural activities: lack of information about the daily calendar of cultural events and absence of a social network of people with whom to attend the chosen activities. Today OFECUM continues its activity and facilitates the mobilization of hundreds of older people, for cultural reasons and, more broadly, to promote active and PA. The significance of its work in the city has been recognized by the public authorities with different awards.[1]

CUIDÁNDONOS:[2] *economy of caregiving for development and well-being*

This last case is an example of participation by older people in intergenerational working groups formed to set the agenda for research on caregiving at the community level, as a form of productive activity. Funded by the provincial government, this experience took place in 2021 in the northwest territorial district known as Montes Occidentales within the province of Granada, in Spain, an area which is comprised of the following four municipalities: Montefrío, Moclín, Íllora, and Zagra.

The initial question was that the implantation and development of an economy of caregiving in sustainable communities require spaces in which intergenerational caregiving at the community level can take place. So there was a need to create a working group in each municipality and to jointly plan an ecosystem of spaces for intergenerational caregiving (e.g., community-based intergenerational centres, intergenerational playgrounds, and so on). The ultimate objective of the research was to understand and assess the current and future caregiving system and resources, as a driving force in the local circular economy. Since the vocation of this process was to bring change, an adapted version of the methodology proposed by Theory U (Scharmer, 2018) was used. This theory focuses on how groups can sense, see themselves and actualize their highest future potential by moving from an ego-system awareness to an ecosystem awareness.

Researcher-older people collaboration: hand-in-hand

The agenda for this caregiving research was decided in a process characterized by shared control, through dialogue and co-creation between researchers and the older people involved in the intergenerational working groups. The project's different actions (i.e., participatory diagnosis, pilot action, and follow-up event), were carried out by the participants in these groups (i.e., professionals in the field, older people, women, collaborating agencies, and other caregivers) but a voice was also given to other community stakeholders.

The participation of senior citizens, as older users of caregiving services, and the lively dynamics of the intergenerational working groups that explored issues affecting them directly (the caregiving system and its resources) were possible thanks to an intergenerational collaboration (researchers-informants) closely interwoven with the social and economic conditions present in the community. How exactly were older people agents in the decision-making process? Through their straight involvement in the agenda-setting process.

Building the agenda: later stage

The setting of the agenda took place at a later stage in the research process. The intergenerational working groups in general and older participants in particular started out by jointly formulating their concerns – that is, that which later should be the object of research, i.e., the agenda –. Then they put forward different proposals for change by means of a mapping exercise and developed prototypes and a preliminary action and research plan for the territorial district. The process ended with the creation of a larger intergenerational working group that would advice in the future design and execution of this plan, and with the formulation of a collective proposal for change. Finally, interviews with members of the intergenerational working groups were carried out: older people and other participants reflected on what they had done.

As a result of this initial research effort documents (the material outcome of this process) were drawn up which, once examined by the provincial authorities, should pave the way for the true agenda for research and intervention in the area of caregiving in the territorial district. It will be an agenda conceived with the priorities and visions of the area's inhabitants in mind and based upon the main caregiving services already in existence.

Singularities

- The participants in the intergenerational groups acted at all times as co-creators of the future agenda: they had the opportunity to express their points of view about the issue and its true social relevance, and they had a positive opinion of the procedure followed. From this exercise in collaborative creation, some conclusions were drawn about the aspects in need of priority attention because of their significance – e.g., improving home care and the importance of looking after the mental health of caregivers.
- The steps of co-initiating, co-sensing, and co-creation, inspired by Theory U, helped the older people become aware of their power and capacity as important actors in the intergenerational working groups. This strengthened their collaboration in the process of agenda setting, reduced external impositions and prejudices, and brought a vision of hope regarding possible individual and collective transformations in the future.
- The older people, working closely with younger people, explored a problem that affects them, proposed forms of intervention in it, and, what is most interesting, decided what needed to be researched later on, and how. In this context of intergenerational interaction, and taking into account the methodology used, it was found in the end that the image of what older people are like and what they can do had improved, something that helps reduce possible ageism.
- In this case, it was also possible to take advantage of the clustering of productive activities. Older people who had no choice but to provide care to another person decided to become involved in a process of research about caregiving. While the relevance of the first task (caregiving) was clear from the beginning, the significance of the second task (working on the creation of a research agenda) only appeared thanks to the productive framework given to the experience.

Impact in terms of productive ageing

The research experience described shows the interest in productive contributions by older people in the community in relation to the provision and the reception of care. In addition to the significance of this matter in many communities, it is important to underline that in this case the research undertaken involved building a preliminary research agenda that would later give rise to new studies and specific interventions, i.e., an agenda for public authorities. Also quite remarkable is the fact that this task was put in the hands of a multi-generational group of people who use community caregiving services.

The older participants and the project's stakeholders pointed out some of the project's impacts in terms of productivity that are worth mentioning. For example, the older participants are exploring new means of productive participation in their communities; the local governments, who are responsible for planning and intervening in this area, benefited from the experience and the knowledge of the older people who use the caregiving services. The participants in the working groups acknowledged having gained a feeling of empowerment

when, instead of the activity coming to an end, it was proposed that they continue with their experience of co-research beyond the initial project, and that they increase their participation in other productive community activities.

In conclusion

The bibliographical review by James and Buffel (2022) about older people as co-researchers underlines some of the benefits of what was called productive agency earlier in the chapter: greater knowledge, awareness, and confidence; the opportunity to meet other people in similar situations; the satisfaction of participating in political decisions that affect them at the community level. More specifically, this chapter has focused on recognizing the value of involving older people as co-researchers in the setting of the gerontological agenda in general and of the agendas of specific ageing projects in particular. In addition, the chapter has discussed some keys that can be useful for putting into practice this form of PA.

However, it is important to keep in mind that limitations do exist: for example, the difficulty some older participants may have in understanding the research process or the potential health problems related to old age that may limit their participation. Also, time and resources are needed to develop and maintain working groups and older participants in research processes, without forgetting, as a further obstacle, the divergences that can arise between co-researchers and community stakeholders (Gutman et al., 2014).

Participation of older adults in research projects is not something new. More than a decade ago, in a bibliographical review on participatory action research, Blair and Minkler (2009) argued that it seemed the time had come to take this possibility more seriously. However, it is not inaccurate to say that to date the question of how to productively incorporate older adults into ageing research, in general, and in the formulation of research questions, in particular, has received little attention – this is certainly the case of Spain–. The PA perspective can provide yet another argument in favour of facilitating opportunities for older people to participate in different stages of such research, with a view to making significant contributions at the local or community level. Let us hope these pages have served to help us move in that direction.

Notes

1 More details on awards conferred to OFECUM at https://ofecum.es/relaciones-institucionales-y-premios/
2 CUIDÁNDONOS literally means "taking care of ourselves and of each other".

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7

CO-CREATING CULTURALLY NUANCED SOCIAL MEASURES WITH INDIGENOUS ELDERS

Charles Waldegrave, Chris Cunningham, Catherine Love,
Giang Nguyen and Monica Mercury

Introduction

Research social scientists, as their collective name implies, endeavour to apply impartial and unbiased methods to the collection of evidence on individuals and groups of human beings. They variously observe behaviours, seek patterns, identify indicators, and measure reactions. The data they collect is studiously explored for repeating themes or statistical significance that add weight to the papers they write and the lectures they deliver (De Marrais and Lapan 2004; Mabry et al. 2008). They produce material that carries an authority of knowledge which is often considered to be more reliable than the observations of people untrained in such disciplines.

Tools are often employed to differentiate levels of intensity or impacts of, for example, personality traits or social interactions, or economic deprivation. Certain consistent individual reactions or group interactions are identified and given descriptors like loneliness or resilience, which in turn lead to behavioural prescriptions of how to diminish or increase them (Scott 2012; UNDP 2018). In doing so, they promote certain ways of doing things and demote others. Authority is often accorded to these assessments because the social science disciplines they emerge out of have gathered results over decades and have been assembled into predictable patterns.

These processes have not proved to be problem free, however. Although social scientists endeavour to be impartial and unbiased, they are human beings themselves brought up in cultures that value certain behaviours more than others and promote certain ways of doing things as being preferable or even superior. Underlying these choices are assumptions of what constitutes, for example, health, wellbeing, and social good (Stats NZ 2022; WHO 2022). These assumptions engender powerful norms that are inclusive for many people but can be exclusionary for others. Some people are excluded for example, simply because they can't afford the balance of food and exercise recommended by health educators for healthy living. Others can be excluded from social relationships when the people around them are intolerant of their religious beliefs.

A number of social assumptions and the notions of normality associated with them have been challenged strongly in recent decades. During the 1960s and 1970s when

most social scientists were men, critical gender assumptions of normality were often not questioned. At that time, sexual abuse, for example, was largely neglected, or at least unattended to, as a traumatising catalyst of not simply physical damage, but deep psychological ill-health (Satter 2003; Delap 2018). Some economists' prescriptions for economic growth as a path to prosperity and happiness are currently being seriously challenged by the call of environmental social scientists to discredit assumptions that lie behind endless economic growth that exploits much of the earth's resources (Mann 2015; Söderholm 2020).

It has been very important that the unquestioned assumptions, and the consequent norms that were created in the social sciences, have been seriously challenged and found wanting. It is simply not possible to be totally free of bias in the social sphere, due to our own and others' socialisation and enculturation. This is particularly true when the various branches of the social sciences professionalise and speak with the perceived authority of their disciplines because new norms are often created. These in turn can include many but exclude others. Over time the excluded groups, be they the rainbow community, disabled groups, various cultural groups, etc. challenge the norm, and once again bias and partiality are exposed (Smith 1999; Lawson 2001; Paiz 2015).

This chapter focuses on developing an inclusive research methodology with cultural groups whose assumptions and ways of doing things are different from those of the dominant majority white cultures in Europe, North America, Australia, and New Zealand. The methodology involves co-creating social questions and scales that reflect the understanding and experiences of older people in cultural groups whose assumptions and ways of doing things have been excluded. These questions and scales are then applied as questionnaires to a substantial sample of older people from that cultural group to test for reliability and validation. The resulting scales are expected to provide rich cultural data for more nuanced policymaking and the provision of culturally congruent services.

Socially excluded cultural groups

Some of the most excluded groups in Europe and elsewhere in the world are cultural groups whose way of life and mores are substantially different from the dominant cultural group or groups who make up the political, professional, and business leadership of their country or society. These cultural groups include refugees, indigenous cultures, colonised cultures, and foreign labour groups. Their social assumptions and norms of health, wellbeing, and social good are often quite different from the mainstream majority because their origins were in different places from the so-called Western and Northern countries. There are strong lines of evidence of systemic inequities where minority cultural groups persistently fare more poorly, and these systemic biases extend to the methods and tools of social science research itself (Hitti et al. 2011; Cogburn 2019).

Many of these socially excluded yet much-researched cultures, for example, prioritise extended family groups and collectivity over nuclear family boundaries and individualism. This naturally leads to different expectations and practices of social connection and interaction. Resources will be allocated differently with decision-making and responsibility being much wider in more collectivist societies than individually based ones. Likewise, spirituality is frequently integral to notions of health, wellbeing, and public good in these societies, as distinct from the predominantly secular institutions and aspirations of most Northern and Western countries (King et al. 2009; Varnum et al. 2010).

Quantitative datasets frequently show the inequities experienced by many of these groups registering lower socio-economic and health statuses. They are more often found among higher unemployment counts and lower educational attainment statistics (Wang et al. 2020; Raleigh and Holmes 2021). Theming and categorisation in qualitative research often draw out the struggles they have surviving and trying to flourish in societies where the rules and expectations are often different from their own (Latulippe et al. 2017; McKinn et al. 2017) So much of the data suggests that the social and wellbeing goals of most Northern and Western countries fail to include many of the members of these cultural communities.

Social measures and scales

As noted above, social measures and scales used in social and economic research carry assumptions and norms around these key notions of health, wellbeing, and public good that do not capture certain critical aspirations and ways of doing things these cultural groups value. A standard universal social indicator like loneliness, for example, is measured by a question or scales in numerous national and smaller surveys that emerge out of Northern or Western norms (Hughes 2004; De Jong Gierveld and Van Tilburg 2017). While they have certain questions that draw out universal aspects of loneliness we all experience, they do not draw out culturally specific aspects. They don't ask questions about loneliness experienced by older people in these societies whose role as elders has been reduced in modern societies, for example. Nor do they inquire into their spiritual experience of loneliness while living in predominantly secular societies.

Other indicators like wellbeing and social connection are designed with the same dominant assumptions that usually don't include the norms of societies that prioritise extended families and genealogical identity, as well as spirituality notions of wellbeing. When their norms around critical indicators of health, wellbeing, and public good are not included in the surveys that provide the evidence base for social and economic policy, then it is fair to say they are experiencing social exclusion regarding that evidence base. This is because there is an incongruence between their aspirations and way of life and the accepted norms that emerge out of the surveys.

Furthermore, as the evidence base is used to generate both social and economic policy, as well as service provision, in most Northern and Western countries, they will be developed along the lines of the data that is collected. This data usually excludes key aspects of social indicators that would help reduce loneliness for example, or increase wellbeing in these communities. In this sense, the evidence base not only excludes their cultural norms but also generates further exclusion because future policies and service provisions will be designed in ways that don't include significant aspects of their way of life.

The 'one size fits all' surveys used in many regional, national, and international studies are not value-free and impartial. They apply questions designed to extract certain information about social or economic indicators and do not seek others. The information sought is usually constructed on norms in the dominant Northern and Western societies which tend to exclude many of the values that are primary in the marginalised cultures within their countries. The unfortunate outcome of this practice is that these latter values are not included in the evidence base used to create effective policies and well-focussed services for them.

Participatory inquiry into social indicators

The research that follows in this chapter seeks to overcome this bias through a participatory research process. It has been developed in Aotearoa, New Zealand in partnership with Māori and Pacific researchers. The description of the research that follows has been carried out within the Māori community which is indigenous to New Zealand. The research focusses on co-creating social indicator scales for older Māori (50 years and over). It seeks to create Māori specific indicator scales that address the values and experiences of older Māori as they define them.

Critically, it initially involves a participatory qualitative approach that explores with groups of older Māori their understanding and perspectives on key social domains like loneliness, wellbeing, social connection, and discrimination, for example. We indicate that we are looking for their experience and their views on the ways other older Māori experience the matters we are enquiring about. This involves the researchers surrendering assumptions and definitions concerning each domain as we seek their views, or their take, on their experience and the explanations they give for them. We simply select a domain indicator and invite discussion of their experience, as well as their knowledge of the experience of other older Māori they are associated with, about the domain. We ask probing questions around their responses to gain specific information from them. This is carried out with Māori researchers in settings familiar to Māori using Māori processes and protocols as set out in the methods section that follows.

The composition of the research team is critical to the process of the research. In the work referred to here, our team consisted of one Pākehā (NZ European), three Māori, and one Asian New Zealander – the dominant NZ population group is deliberately a minority in our team. We have two males and three females. Three of the five would qualify as respondents (Māori aged 50 years +); four of the five have some fluency in te Reo Māori (Māori language) and the three Māori team members belong to (have grown up and lived within) the geographic area in which we have undertaken the research. Such pre-existing relationships facilitate access to otherwise difficult-to-reach populations. While a collective team approach to analysis and interpretation helps to identify biases, it is the very nature of our competing perspectives that provides the fertile ground for progressing culturally responsive and culturally nuanced ideas – ideas that are at once distinct, yet diverse.

The data collected is themed and draft scales that authentically reflect the responses of the gatherings of older Māori, are devised around each indicator. These scales are then administered to a research population of other older Māori along with a standard universal scale of the same domain. The results are statistically compared for correlation, and both are tested for reliability and validity. If the results demonstrate consistency and reliability and are statistically validated, then we know we have developed a co-created scale for use in quantitative research. It is important to note that though the standard scale and the Māori specific scale demonstrate a significant correlation, the information for both is quite different and participants score differently on both scales.

This scale, if applied to a population of older Māori, can be expected to provide a more robust database of evidence for policy formation that is in their best interests, because it contains responses to the questions of importance to them. It can also be expected that the evidence base will provide a more robust and culturally nuanced base for developing effective services.

This addresses a substantial gap in current research on social indicator measurement scales for groups different from the dominant 'world view', raison d'être, or cultural meaning, that too easily (probably unintentionally) impose mainstream norms on groups of people for whom they are quite inappropriate. The co-created participatory approach begins with the undiluted views and experiences of those who have been marginalised from having their perspectives contribute authentically to the evidence base, out of which policies and services are developed. These perspectives are then developed into a co-created scale with Māori researchers. They are then tested statistically for reliability and validation.

The rest of this chapter describes this work in progress, developing this method for more effective use in both policy and service provision. It has been designed to reverse the current exclusionary impacts of policy and social provision, and in the case of Māori, to overcome the consequences of colonisation and exclusion as they apply to the measurement of social domains and the consequent evidence base used for developing policies and services that directly affect them.

Method development

The participatory process

The aim of the research is first to explore the predominant features of participants' experience of key social domains such as loneliness, wellbeing, or social connection. This is qualitative, participatory research where we are seeking their worldview, or their take, on the key area of social interest. The researchers include people from the grouping of the participants, who in our research are older Māori, but in other research could be another cultural group, women in the labour market, or victims of abuse, for example.

The research consciously and openly declares its accountability to the broad group we are researching, ensuring the data collected will be available to participants and assessed by them and experienced members of the broader group they represent. A reference group of trusted people by the participants and researchers is appointed to ensure the descriptions authentically reflect the responses of the participants. The later development of domain scales is made similarly accountable. The reference group members are consulted individually or as a group throughout each stage of the research and there is a clear understanding that the researchers will not proceed through each stage without their support of the descriptions and analysis.

As noted earlier, the research process involves a surrender of assumptions and definitions concerning each domain by the researchers, in order to record the experiences that participants outline and the meanings they give them. The researchers from the same broad group as the participants and the reference group ensure documentation and analysis is consistent with the broader population's experience that the participants represent.

In this research with older Māori, our initial project centred on loneliness. A purposive sample of 200+ Māori, 50 years and over, in the southern third of New Zealand's North Island, was approached to participate. As they inquired what questions about loneliness we would be asking, we showed them the de Jong Gierveld and van Tilburg 11-item Loneliness Scale (De Jong Gierveld and Van Tilburg 2017). Some stated from the outset that they thought some, but not all, of the questions were inappropriate and made little sense to them.

We inquired into what they were referring to and they presented a range of responses to us. They said, for example, that it wouldn't be wise to ask the question, '*I miss having a*

really close friend'. They stated that in most cases, they gained their closeness and comfort from their whānau (extended families) and that it could seem embarrassing or even shameful to need to go outside the family for this type of companionship.

To the poignant questions like, *'I miss having people around me'* and *'I often feel rejected'*, they said they didn't usually focus on individual personal feelings as Europeans do, because they are more moved by collective experiences within their families and cultural communities.

These comments and others like them persuaded us to develop the participatory process noted at the beginning of this section on method development. Instead of pressing ahead with the Loneliness Scale, we decided to meet older Māori in marae settings. (Marae are the traditional gathering places for Māori). Our research unit has Māori and Pacific sections with their own staff and so we have quite authentic connections with the marae in our region and beyond.

We met with members from all the marae in our region. Some wanted us to meet at their marae with their members only, others preferred to meet in larger groups at one marae with people from different marae. We observed the protocols of the marae which included being welcomed by Kaumātua (elders with a traditional leadership role on the marae), responding formally with a speech (whaikōrero) that acknowledged the spirituality of the marae, the Kaumātua and all the others gathered, and briefly outlined why we had come. We finished with a waiata (a song at the end of a whaikōrero). We were then greeted by everyone individually, as is the custom.

Once we were assembled to discuss the matter we had asked to discuss with the older people, we provided a fuller explanation of the research we were carrying out on loneliness. Time was allowed for discussion and questions. We then indicated we were looking for their experience as older Māori, and their views on the ways other older Māori experience loneliness.

We assured them that they were the experts in their own knowledge, and that we were seeking an older Māori understanding of loneliness, which we thought, would probably be different in a number of ways from that of non-Māori and younger people. We endeavoured to help them feel comfortable and know that their opinions were valued. We sought permission to record the discussion and take notes. We also used a whiteboard to transparently record key phrases and sentences they shared.

We then began a discussion on loneliness. We invited them to tell us about their experiences of loneliness as older Māori, and the experiences of others like them that they knew. We were interested in what they considered typical examples of loneliness for them and how they understood them. We inquired into what they thought caused loneliness for them and others, and what they thought reduced loneliness.

We asked a lot of probing questions about their responses to get more specific information from them. We explored their responses with them sympathetically drawing out examples so we could understand what those examples actually meant for the speakers. As we gained a clearer picture of what they were describing about loneliness, we shared our understanding of their responses back to them to check if we have understood them adequately. We encouraged them to correct any misunderstandings we may have had so that we could be sure we were recording their (not our) perspectives on loneliness. After that discussion was complete, we asked again if there were other things they thought were important for us to understand about loneliness.

Developing a culturally specific scale

The second aim of the research was to develop a culturally specific Loneliness Scale for use in survey studies with older Māori, which addressed the critical issues they identified in their experiences of loneliness. This is a co-created scale whose base data was entirely drawn from groups of older Māori who had articulated their experiences, meanings, and notions of loneliness within their own cultural context.

After the marae hui (meetings) referred to above, we gathered the notes written at each meeting and studied them carefully. Our interest was to explore the richness of the data generously given to us by the participants. In the best tradition of good qualitative research, we wanted to explore the values, meanings, beliefs, thoughts, and experiences which we now had in a textual format. We also had pictures in our minds of the dialogue with its descriptions, stories, laughter, debates, and sometimes passion that accompanied the discussion.

The analysis of data was strongly informed by the Māori research method Kaupapa Māori (Love 1999; Smith 1999; Pihama 2001; Love 2006) which views Māori ways of being and perspectives as normative. It is a de-colonising methodology that affirms Māori self-definitions and self-valuations. It is not a new research methodology, but rather the application of longstanding Māori values, worldviews, ethics, and processes to modern research contexts. As noted in the previous section, the questioning viewed the participants as informed or expert advisors in relation to their own experiences.

The results from this initial study enabled us to successfully apply for funding to further develop the project by initiating research with a New Zealand national random sample of 1,500 Māori 50 years and over. The funding has also enabled us to co-create five other scales and apply them in the same survey. These are wellbeing, social participation/connection, discrimination, abuse, and neighbourhood wellbeing and safety draft scales.

Developing the co-creation work beyond our region and throughout the country has been critical to gain a broader view of the experiences of older Māori and the repeating themes of different groups in different regions. In order to keep a more accurate record, we sought permission to record the co-creation meetings and transcribe them, which enabled us to study the text more closely and quote, albeit anonymously, enlightening comments and reflections. We have been able to generate the national random sample from the New Zealand Electoral Roll which records all New Zealanders aged 18 years and over who identify as Māori. The national random sample enables us to test the social domain scales we construct for reliability and validation.

In this larger study, we have systematised our processes of analysing the co-created data. While we have the capacity to utilise qualitative analytic tools for discourse analysis, such as NVivo, our preference in this context was not to use such tools. Our experience is that standardised discourse analysis tools can miss important aspects of the context in research with Māori, including the cultural use of metaphors and allusions that carry meanings amenable to a more complex level of analysis. For these reasons, we applied a standard method of thematic discourse analysis incorporating within-culture analysis.

The critical themes that recorded important aspects of loneliness were identified and coded. Each was categorised and subcategorised with further codes in a manner that was faithful to the participants' descriptions and worldviews. The recurring themes and significant patterns were captured, categorised, and again further coded. Every attempt was made to draw out the meaning participants according to their dialogue.

The analysis in the initial study, interestingly, provided some categories of loneliness that appeared to be universal, because they mirrored behaviour captured by the international scale we had initially planned to administer. However, they also produced categories which were uniquely Māori. We carefully converted the various categories into questions that could be responded to on a four-point scale. Out of these, we constructed a draft set of questions on loneliness that addressed the changing role of older Māori and questions around meaning and purpose which they identified as creating loneliness for them. These were all checked with the reference group and the number of participants. They were excited by the transformation of data into survey questions. They suggested small improvements and points of fine-tuning which we adopted.

The new questions were included in a large survey instrument that incorporated a range of demographic, health, wellbeing, and socio-economic questions and scales. The de Jong Gierveld and van Tilburg 11-item Loneliness Scale were also included to compare results with the draft indigenous Loneliness Scale we were developing. As noted above, the survey instrument was administered to a purposeful sample of 200+ Māori 50 years and over, in the southern third of New Zealand's North Island. Factor analysis, Cronbach's coefficient alpha, item-total correlations, and principal component analysis tests were all applied to the loneliness scales.

Some of the research outcomes of the co-creation process and formation of the draft scales will be reported in the following results section, along with the loneliness scales. We have completed the co-creation process for the new draft scales and they, and a refined Loneliness Scale, will be administered to the large national random sample very soon, along with standard international measures of the same domains for comparison. The comparison is important to demonstrate Māori responses to both the universal scales and the Māori specific ones. Each will be tested for reliability and validation using factor analysis, Cronbach's coefficient alpha, item-total correlations, and principal component analysis tests which were all applied to the earlier Loneliness Scale.

In this way, a participatory co-creation qualitative research methodology creates important knowledge in its own right and is then used to develop more culturally responsive and culturally resonant measures of important social domains in quantitative research.

Emerging results

Initial study co-creation meetings

The early hui (gatherings/meetings) with older Māori on marae in the initial project on loneliness, were immediately engaging. The older people said they were thrilled we were concerned about the wellbeing of older Māori, and loneliness in particular. Participation in the discussions was spontaneous and energised with many sharing their perspectives, stories, and knowledge. As facilitators, there was no work required to animate people and draw out discussion. The participants engaged immediately, as though they had waiting to talk about the subject for some time. The role of the facilitators was to ensure everyone was given a chance to share their views and help move the conversation across a broad range of understanding about loneliness.

Speaking for themselves and others they knew, they referred almost entirely to the specific issues older Māori face that create loneliness, rather than individual personal feelings of loneliness. The recurring issues they named were the disconnection many had from their

culture and whānau (extended family) support, the loss of role and respect for elders, negative perceptions of Māori in the broader New Zealand population, the consequent losses of meaning and purpose and the grinding problems of living on low incomes and sometimes in poverty.

Participants told stories about the post-World War II urban migration from their iwi and hapū (tribal) land in rural New Zealand to the cities for work. They left villages and marae to live in cities in other tribal areas, where the predominant population was Pākehā (NZ European) and their previous ways of doing things were not valued. They, and often their parents, were punished in schools for speaking te Reo Māori and so quite a number of families became disconnected from their culture. Colonised values usually predominated, disrupting their sense of identity and undermining confidence.

Participants said the impact of these processes often led to feelings of loss and loneliness. Not only was it a struggle in the new environment, but the loss of cultural practice sometimes distanced them from their relatives and the marae they migrated from. The housing in the cities made it more difficult for extended families to live together and their houses were often distanced from one another because of cultural assimilation housing policies. While many found resilient ways to remain connected and affirm their cultural identity in the cities, others struggled and the sense of exclusion led to a loss of confidence for them in both the Māori and NZ European worlds.

There was a strong emphasis on the loss of the role of elders in modern New Zealand as being causal to loneliness. Whereas many were brought up respecting the role of elders, now that they are in that position themselves, they are often not accorded that same respect. The primary income resources of families were usually in the hands of the generation below them. Older people often feel a loss of mana (power and influence) and are peripheral to important decision-making. The loss of role, particularly in whānau leadership was accompanied by a parallel loss of meaning and purpose that left them feeling distanced and alone.

Though there was considerable confidence and pride in their way of life and deep cultural connections and identity, they spoke of the negative perceptions of Māori in the broader New Zealand society, which impacted negatively on them. Media stereotypes and negative results in socio-economic reports were not only demoralising to them but also, in their view, led to lower expectations from professional and business personnel as well as people in the community. They referred to examples like health services where they often felt doctors didn't give them the information they wanted because they didn't think they would understand it. They considered they were treated suspiciously by landlords when seeking housing because of unsubstantiated perceptions they would not be good tenants. These discriminatory perceptions sometimes ground them down, leading to feelings of loneliness and even hopelessness at times.

They also associated these feelings with the problems many of them experienced living on low incomes. Their history of being colonised and losing so much of their land and potential for development, along with their collective values and obligations to extended family, meant that a greater proportion of them and their whānau live on lower incomes. The combined sense of injustice and the pressures of financial and material poverty reduce the opportunities to connect socially and lead to a sense of exclusion.

As these matters were discussed, it was agreed they saw these issues combine for numbers of older Māori in a manner which could be summarised as 'a loss of meaning and purpose'. The overall devaluing of their place as elders in modern New Zealand reduced their sense of meaning and purpose. These were the matters they considered were missing

in the standard questions on loneliness we had informed them about. To measure loneliness authentically for them, they thought this dimension needed to be added to the standard questions on feelings of closeness (or rejection) and social connection that made up a relevant Loneliness Scale.

The co-created questions

After considerable discussion between the research team, the reference group, and the number of participants, we decided to administer the de Jong Gierveld and van Tilburg 11-item Loneliness Scale, a modified version of that scale and a set of questions about participants' experience of meaning and purpose. The latter two are the results of the co-creation process.

The de Jong Gierveld and van Tilburg 11-item Loneliness Scale. We wanted to test this scale with the 200+ sample of Māori and compare the results with the two sets of co-created questions.

Modified de Jong Gierveld and van Tilburg Loneliness Scale. Taking into account the participants' critique of the 11-item Loneliness Scale for older Māori, we changed the direction of each question from being individually based to becoming family/whānau (extended family) based and we removed three questions that focussed on individual personal feelings.

A set of questions on meaning and purpose. We developed nine questions that addressed the erosion of the eldership role in modern society and the reduction in meaning and purpose.

It was also decided that issues of discrimination and living on low incomes were domains themselves, and would be addressed separately. The income matters simply required questions about individual and household income and material living standards. We used a standard discrimination scale in the initial study and developed a co-created one with participants for the larger study with a national random sample.

Here are two examples of changes to the modified Loneliness Scale.

I miss having a really close friend was changed to *I miss having a really close family member I can talk to*

There are many people I can trust completely was changed to *There are many members of my family I can trust*

The response possibilities were *Yes/More or less/No* as in the original scale.

The questions about meaning and purpose and their association with an erosion of the eldership role are set out as follows.

a   *At my age now, I feel I have a significant role in my family or community*
b   *Sometimes I feel my contribution to my family and friends is not valued*
c   *I miss having people around that know and understand me*
d   *I can call on family and friends when I want to*
e   *I am needed less often in my family and/or community these days*
f   *My family looks to me for leadership in some matters*
g   *Some of my support for family members is taken for granted*

h I worry very deeply about the younger members of my family
i I am homesick for my Tūrangawawae (place of belonging and identity)

The response possibilities were Strongly agree/Agree/Disagree/Strongly disagree.

Initial survey results using the co-created questions

Using the database of responses from the survey, we applied Cronbach's alpha test to the Loneliness Scale and the two sets of co-created questions to check for statistical consistency and reliability. All three, the de Jong Gierveld and van Tilburg 11-item Loneliness Scale, the Modified Measurement of Loneliness that takes into account family effect and the set of meaning and purpose questions, demonstrated strong results, with each being over the test threshold of 0.7 for consistency and reliability.

Each set of questions, the Loneliness Scale, the Modified Measurement of Loneliness, and the set of meaning and purpose questions, were all strongly correlated with each other, with a p-value of <0.001 for each relationship.

However, when we analysed the results of the relationship between the de Jong Gierveld and van Tilburg Loneliness Scale and the Modified Measurement of Loneliness Scale, we found a number of observations that score high on the original Loneliness Scale scored low on the Modified Measure. Likewise, quite a number of observations that scored high on the Modified Measure, scored low on the Loneliness Scale. This suggests that while both address key issues of loneliness which are probably universal, the modified scale is probably measuring older Māori specific aspects of loneliness.

This interpretation of the results was further confirmed when the relationship between the de Jong Gierveld and van Tilburg Loneliness Scale and the meaning and purpose questions were analysed. Despite the strong positive relationship between the two measures, there were many variations in the Lack of Meaning questions that were not captured by the Loneliness Scale. So, while the co-created questions addressed certain universal aspects of loneliness, they had the added value of capturing older Māori specific aspects of loneliness, which offered a richer evidence base for policy and service provision for those communities.

The development of further co-created scales

As noted above, we have been able to develop this co-creation work from the initial meetings with local marae to meetings with eight separate Māori organisations across the country, including urban and rural settings. Furthermore, rather than surveying a purposeful sample of 200+ older Māori, we have generated a national random sample of 1,500 Māori 50 years and over which will enable us to test the reliability and validity of the loneliness scales and the other older Māori specific scales we have been developing.

At the time of writing, these initial sets of questions are fully prepared for the survey and are ready to be administered. The same participatory co-creation process that was used to develop the Loneliness Scale has now been applied to develop initial draft scales on wellbeing, social participation/connection, discrimination, abuse, and neighbourhood wellbeing and safety.

The co-creation hui (meetings) for these new sets of questions were recorded with the permission of the participants. This has enabled us to theme, code, and categorise the data with greater accuracy. It has also allowed us to quote verbatim statements from participants

that illustrate their thinking and experience more clearly. The results of this work will be written in another paper, but two brief examples of quotations and question formulation taken from the co-creation discussions on wellbeing follow. These particular quotes and questions illustrate some of the older Māori specific emphases. Other aspects around good health and adequate income were more universal aspects of wellbeing that they also referred to.

In the co-creation process on wellbeing and quality of life, we asked participants questions about what they saw as the key thing that gave them happiness. We asked them about what made them feel comfortable and secure as older Māori and what gave them a sense of fulfilment. We also asked questions about what reduced happiness and these other qualities for them.

Some typical repeating responses are characterised in the following two quotes:

The support! If it's around your health and you have got good strong whānau (extended family) Māori support, your health will be much easier to manage. Everything aligns.

Identity. Like having a really strong basis for your identity as Māori. And I think knowing that our kids have their strength as well. That really enhances my sense of well-being as the well-being of the many rather than the individual.

In the draft scale of twelve questions on wellbeing, the following three pick up this important theme:

I feel a sense of belonging with whānau and community
○ Agree   ○ Neither agree nor disagree   ○ Disagree
I feel well supported by my whānau
○ Agree   ○ Neither agree nor disagree   ○ Disagree
I feel valued as a Māori
○ Agree   ○ Neither agree nor disagree   ○ Disagree

These perspectives on wellbeing were fundamental to discussions on wellbeing and quality of life in each group. They reflect the important collective sense of identity and fulfilment participants consistently reported and they are couched in the terms, like whānau, they value.

Discussion

This chapter applies a co-creation participatory research method to deconstruct the common assumptions and norms of social measures and scales that are often used to quantify social indicators like wellbeing, loneliness, discrimination, and social connection. These have usually been constructed in Western and Northern countries that value individualism, nuclear family units, and secular approaches to living. Many of these scales provide important social indicator measures that have been designed to quantify both resilience and disadvantage to produce an evidence base for policies and social provisions that reduce social exclusion.

The co-creation research reported in this chapter suggests that while the assumptions and norms that underlie the measures probably produce sharp results for groups of people

for whom those assumptions and norms apply, they may be more blunt for others whose assumptions are different. Many cultures, and indeed many of those that are more likely to be socially excluded in Europe, North America, Australia, and New Zealand, have underlying assumptions that relate more to collective notions in extended family cultures and for whom spirituality is integrated into notions of health and wellbeing. Further, the classical European and North American measures of loneliness tend to focus on human relationships and the mismatch between expectation and reality. Our research has observed feelings of loneliness towards a perceived loss of culture. Elders spoke of the loss of a cultural social contract, where inter-generational support mechanisms, such as a large family of children operating as a form of superannuation, were disrupted by new patterns of family formation and mobility. Measures that ignore their assumptions and norms are unlikely to be helpful for designing policies that address their issues. They may, in fact, unintentionally further exclude them.

While this research was carried out in New Zealand with indigenous Māori elders, the methodology of applying co-creation participatory research methods with cultural groups that don't fit easily into the Western and Northern countries' assumptions, may be useful for developing better social indicators with them. Some of the most excluded cultural groups in Western and Northern countries include refugees, indigenous cultures, colonised cultures, and foreign labour groups. If survey questions related more to the assumptions and norms in their worlds, then it would seem likely that they would provide more useful evidence for culturally congruent policy development and service provision.

This research addresses a substantial gap in the development of current research on social indicator measurement scales for groups different from the dominant 'worldview'. Not only does it deconstruct the underlying cultural bias in many measures, but also offers a methodology to create robust measures that can be expected to provide more workable policies that may begin to reduce the social outcome gaps that many excluded groups continue to experience. Essentially a qualitative participatory methodology can produce a survey tool for quantitative measures.

This research does not suggest that standard social indicator scales have no role in modern policy development. Rather, it highlights the populations that they are more likely to be useful for and those for whom it is less likely. It suggests that no scale is value-free and so the norms applied need to be deconstructed or at least assessed. Furthermore, this research has developed a methodology to address bias and more importantly, include the norms and assumptions of cultural and other groups that are different from the dominant view in their country. A parallel cultural view provides much richer detail which is more likely to result in interventions that are based on a culturally nuanced view of the 'problem' and the attendant strategies to address them.

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8

TENSIONS IN TRANSFORMATION

Participatory Approaches in Sustainable Energy Technology Projects in the UK and India

Carol Ann Maddock, Vanessa Burholt, Deborah Jane Morgan, Khushboo Ahire and Charles Musselwhite

Introduction

Population growth and population ageing present challenges for meeting sustainable development goal (SDG) 13, which calls for urgent action to combat climate change and its impacts. The achievement of SDGs will require action from civil society in addition to science and business (Sachs et al., 2019).

Older people are 'contributors, casualties, and champions of climate change' (Haq, 2017, p. 8). Some older people contribute to climate change through carbon-intensive lifestyles, others may be casualties of climate change because they have fewer physical, financial, and/or emotional resources that enable them to recover from or be resilient to extreme weather events (Thomas et al., 2019). However, older people also have much to offer as champions with respect to climate knowledge and actions (Pillemer & Filiberto, 2017).

To date, advances in decarbonisation science and technology have resulted in renewable energy (RE) projects '*derived from natural processes (sunlight, wind, rain, tides, waves, biofuel and geothermal sources')* (Wee et al., 2012). These projects focus on supply (including knowledge and technology transfer), manufacture, and distribution of renewable energies. Although the supply chain includes 'demand' there has been little attention given to older consumers of renewable energies. Public (consumers) are arguably the most important agents of the energy transition: catalysed from the bottom-up (REN21).

In Europe, the Americas and Australia members of the public are increasingly agents of change in the energy transition. Processes in India are generally more top-down with governments expected to play a catalytic role (REN21). Despite a burgeoning body of participatory research involving older people in health and social care settings (Buffel, 2018), there has been less co-created ageing research concerning climate-related activities: the voices of older people are often overlooked in RE research (Devine-Wright et al., 2014). Co-design of research can have multiple benefits in supporting the development and uptake of RE technologies within older populations (Fischer et al., 2020). Moreover, social scientists are well-placed to work with stakeholders (e.g. engineers, policymakers, the public) to

respond to the challenge: to explore the role of participatory approaches to research with older people, and devise approaches that are fit for purpose in the energy transformation process (Chilvers & Longhurst, 2016).

The chapter will draw on two projects: the Active Building Centre Research Programme (ABC-RP)[1] in the United Kingdom and The Strategic University Network to Revolutionise Indian Solar Energy (SUNRISE)[2] in India to illustrate how older people co-designed elements of these projects with a multidisciplinary team of scientists and researchers.

Introduction to two case studies

Older people participated in the ABC-RP project in the UK and SUNRISE project in India. However, the participatory approaches were embedded at different levels within the overarching research framework. Table 8.1 outlines project aims, guiding principles, and practices of participation used in both settings. Participation aimed to create positive discourses and shared learning between stakeholders and to improve understanding of the different and possibly competing value sets of those involved (Brown et al., 2014).

Case Study 1: Active building centre research programme

The Active Building Centre Research Programme (ABC-RP) was funded by the Engineering and Physical Sciences Research Council (EPSRC) as part of the UKRI Transforming Construction Challenge. The ABC-RP project focussed on contributing to a more sustainable built environment mainly via technological developments such as heat storage, building design/optimisation, software development. However, one sub-study used a participatory co-design approach. This was intended to better understand how older people use, interact and are impacted by new energy technologies embedded within active/low-carbon homes.

Research approach

Underpinning the sub-study was an ethos of doing research 'with' rather than 'on' participants and ensuring the rights of 'researched communities' to be involved in the research. The team sought to respect different expertise and claims to knowledge, to use research processes designed to facilitate participation in different research stages and be transparent about the values informing the inception of the work (Beebeejaun et al., 2014). The research team was cognisant of the 'diverse, multiple and interconnected ways' that "publics engage with energy transitions" (Chilvers et al., 2021, p. 250).

Methods used to co-design research

The sub-study brought together a mix of people with different knowledge and expertise (lived and experiential) across sectors and disciplines. This group contributed to a research design that could challenge traditional scientific approaches and address the complex nature of sustainability challenges (Essén & Östlund, 2011; Norström et al., 2020).

An Expert Panel (EP) comprised of older people ($n = 6$) and an Advisory Board (AB) with a mix of lay older adults ($n = 3$) and co-opted members ($n = 7$: members of stakeholder organisations such as National Energy Action (NEA), Public Health, Housing Learning and Improvement Network (LIN), Care and Repair Cymru) were established. These groups

Table 8.1 Overview of case studies

Key project steps including participatory activities	Active building centre research programme ABC-RP (3/2020– 9/2022)	Strategic university network to revolutionise Indian solar energy SUNRISE (9/2017– 3/2022)
Project aim	To develop tools and technologies to ensure buildings of all scales contribute to reduce carbon emissions and a more sustainable built environment.	To build a long-term, global, sustainable energy collaboration; develop/evaluate low-cost solar technology; research capabilities UK/India teams; apply the technology to real-life contexts.
Aim of participatory approaches	To inform and advise on planned research activities intended to understand tenants' wellbeing outcomes of move/retrofit to low-carbon homes.	To ensure the views of diverse community members are heard in defining the space and functionality of a planned community building to meet community goals; embedding processes of participation and empowerment. Capture and share learning via project-wide knowledge transfer.
Guiding principles	National Standards for Public Involvement in Research (NIHR, 2018).	National Standards for Public Involvement in Research and Public Involvement, Principles of Engagement, Remit and Strategy for SUNRISE (PIPERS for SUNRISE).
Level at which participation occurred within overarching research project.	Sub-study planning level. Sub-study reports to overarching research project.	PIPERS for SUNRISE adopted by the overarching research project at: (i) Strategic level (organisational structure); (ii) Operational level (demonstrator villages – community end-users); (iii) Learning and knowledge transfer (other projects).
Participation	An Expert Panel (EP) and Advisory Board (AB) recruited to sub-study. AB advised on strategic research plans, activities and the underpinning conceptual model that informed research design (Figure 8.1). EP tested methodological approach, contributed to design and tested data collection tools (e.g. surveys, interviews) and lay marketing materials.	Participatory arts-based approaches conducted in a rural Indian village – intended to develop individual, collective and structural processes of empowerment resulting in identification of meaningful solutions to community needs (Coy et al., 2021). Results incorporated into a social development action plan designed to inform building design, purpose, and maintenance.

supported the research activities with residents of new build or retrofitted social housing homes throughout Wales. An advert posted on the Centre for Ageing and Dementia Research (CADR) Cymru website,[3] social media platforms and the Health and Care Research Wales Involvement Network[4] facilitated recruitment to lay positions. The advert detailed the purpose of the posts, time commitment and monetary reimbursement.

The members of the EP were expected to be involved in the design and testing of questionnaires and interview schedules. These would be used to capture data including financial, health and social wellbeing relatable to tenants' personal/household energy use and broader impacts (e.g. fuel poverty, health impacts). EP members offered advice on public engagement, especially how this may be achieved through their networks.

EP and AB members were recruited who had expertise or interest in low-carbon housing technologies and/or energy efficiency schemes, fuel poverty, housing (particularly social housing), or health and wellbeing. The AB members also had relevant experience meaning they were able to contribute to the strategic research plans and activities, troubleshoot research problems and use their networks to support knowledge translation and research impact beyond project completion. Members of the EP and AB were expected to prepare for and contribute to meetings. Appointments were initially for one year with the potential to continue for a further 6 months. All opted to continue for the full project duration.

Terms of reference setting out mutual expectations for AB and EP roles were agreed. There were planned learning and networking opportunities for the entire team (including researchers) through seminars and workshops on aspects of the active build technologies and site visits to active buildings.

Results of co-designing research

The researchers and nine applicants for the AB and EP posts visited a low-carbon/active home within a new social housing development in the second month of the project. This provided an opportunity to view the renewable technologies in situ, meet some of the researchers, hear about the research, lay roles and ask questions. Subsequently, three attendees became lay members (2EP and 1AB). This was the only 'in person' event held before public health COVID19 restrictions in Wales prevented similar activities for the 18 months of the sub-study.

All planned meetings subsequently shifted to an online video conferencing platform. Two separate two-hour workshops for the EP and the AB were held allowing introductions, presentation of the overarching research project, the sub-study aims, expectations of all parties and practical arrangements for ongoing updates, meeting durations, times and reimbursement for their time (NIHR, 2018). The pace of these meetings was set by the groups.

At the AB meeting, additional members were identified. Personal contacts in public health for instance meant that previously futile attempts to recruit were now successful. An additional lay member from a tenants' housing association was recruited bringing current relevant experiences. Although the AB and the EP were intended to provide different functions and meet separately, as the project unfolded this became less feasible. The two groups were combined when two EP members could no longer continue due to ill health. Reduced EP members and increasing familiarity with video conferencing meant that the combined EP/AB meetings were manageable. There were seldom more than 12 people attending the videoconference at any one time. Use of the chat function and raising of real/virtual hands

to speak ensured equitable opportunities to participate. Detailed meeting notes and action summaries were distributed afterwards and all (attendee/non-attendees) alike were encouraged to contribute opinions to these via email and this worked well. We continued with this format for the remaining four meetings. Specific activities (e.g. piloting tools) were carried out by willing group members between meetings.

Meeting arrangements were fine-tuned over the project. For example, the duration of meetings and breaks, and the format of documents were adjusted. Videoconference meetings were recorded and shared with those unable to attend. Furthermore, all group members were able to reflect and respond to the discussion in their own time. New ways of working made this option more accessible. Between meetings, the research team progressed actions that had arisen and updated the group via email bulletins.

Testing the conceptual model

The key research question was 'Will a move to, or retrofit to achieve a low carbon home have an impact on the financial, health and social wellbeing of residents who have moved/retrofitted?' During the first EP meeting a conceptual model (Figure 8.1) depicting potential pathways to wellbeing (health, social and economic) was presented The EP examined the 'value' of being warm and comfortable at home from their perspective and how this may be contrasted with other stakeholders' perspectives The meaning and value of home, thermal comfort and how this may vary according to personal circumstances were explored in detail. Our research aimed to redress any potential imbalance caused by considering success in terms of economic and technological outcomes (Burton et al., 2011), by focusing on
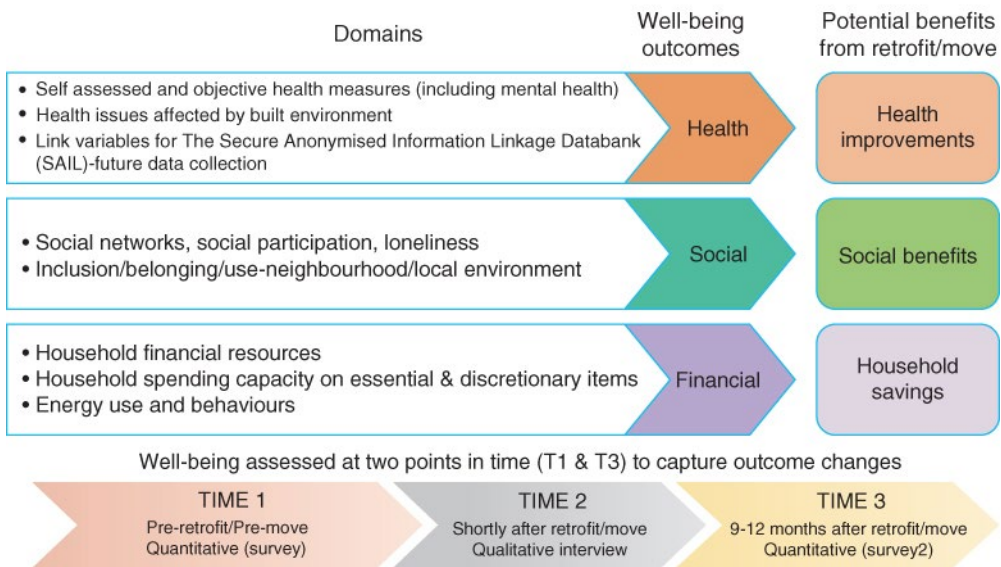
Figure 8.1 ABC-RP conceptual framework.

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"end-user" values, experiences, energy behaviours and preferences for low-carbon living and the potential wellbeing benefits. As one of the AB members noted:

> *Energy can be an abstract concept and it may be hard to equate the value of welcoming and entertaining others into your warm, well-lit home to the cost of 'energy' activities.*
>
> *[AB-1;Male>50]*

Design of questionnaires and interview schedules

At the first meeting, we explored existing skills and knowledge gaps within the EP group relating to survey design and delivery, in order to ensure that EP group members would be adequately supported at future meetings. This gave the group members the opportunity to ask questions and establish what role they wanted to play (e.g. reviewing draft versions of data collection tools). Additionally, at the first meeting, the proposed data collection tools and delivery mechanisms were outlined (e.g. a quantitative survey pre-and post-intervention (move/retrofit) with a qualitative interview post-intervention). Collectively we agreed the best use of time was to use the workshop sessions to thoroughly explore the topics that the interviews and survey should cover. EP and AB members were keen to explore the extent of tenants' control (perceived or actual) in determining what was installed as part of the retrofit process.

> *One of the things we appreciate in our own homes is the autonomy – we get to be in charge and having it adjustable rather than pre-set. I want control over my home and don't want things done without me having influence over it.*
>
> *(EP3; Female >50)*

Others were concerned about obligations to use new technologies and the associated assumptions made about older people's understanding and operational use of the digital interface. For example, members noted:

> *[The] assumption is that people can use technology – the view that people are using technology is being stretched – people don't necessarily want this new technology in their home.*
>
> *(EP1; Female>50)*

> *Not everyone is OK with using a smartphone to control their energy. I've only just got one and I'd rather have a remote, like the TV which may be easier for older people.*
>
> *(EP2; Male >50)*

Similarly, they wanted to know how tenants would be provided with information about how to manage the new technologies as 'you don't want to be walking around with a manual for the first 6 months' (EP3; Female >50)

Subsequently, interview questions were developed with the EP/AB group members that explored motivations, experiences and choices within RE transformations, and accessibility of information and technology. These were refined with the groups via email and video/phone communications over a few months and following piloting of the tools. Marketing materials were developed with group members over the same time frame.

Co-design benefits to ABC-RP

The workshops were beneficial in clarifying key actors, processes and for whom and how 'value' would be created in a wider return on investment model (Norström et al., 2020). Extensive discussion corroborated our literature review findings, highlighted assumptions, and identified further questions to capture how interventions (RE transformations) could impact tenants. Discussion supported the methodological approach and improved the accessibility of the data collection tools for tenants. An exchange of information between the research team and the AB/EP member's broader networks was a valuable conduit for involving more older people in co-design.

Case Study 2: Strategic university network to revolutionise Indian solar energy

SUNRISE is an international project to counter global energy poverty by developing and implementing technology to erect solar-powered demonstrator buildings in off-grid communities in rural India. 'Principles and Strategy for Public Involvement and Engagement' (PIPERS)[5] was developed based on a review of best practices. PIPERS was adopted by the project AB earlyin the project (Feb 2019) and an implementation plan embedded it within SUNRISE at a strategic level, operational level (demonstrator villages) and via knowledge transfer mechanisms to similar projects/communities (Table 8.1).

Research approach

PIPERS provided the framework for public participation throughout the SUNRISE project. It was produced in consultation with the SUNRISE AB, operational team and CADR involvement and engagement team. The document also outlined the methods of piloting participatory arts-based research activities in a rural Indian village so that villagers would have an informed input into the use of the building and solar-generated power. Piloting activities was intended to assess if approaches were feasible and viable in sustaining meaningful involvement to identify capabilities and needs.

Methods used to co-design research

Villagers' scientific literacy was limited, and participatory arts-based methods were particularly important to help participants visualise the topic of study (RE) (Beebeejaun et al., 2014), to obtain perspectives on diverse community needs and aspirations and to enable individual, collective and structural processes of empowerment. Necessary permissions and consent were obtained from the required authorities including village leaders (Gram Panchayat)[6], local stakeholders and community members.

Participants were recruited to take part in the activities (n=53 with 33 women and 20 men), intending to reflect diversity within the village. Of these, eight men and eight women were aged over 50 (some were uncertain of their exact age). Participatory arts-based research activities were delivered in a particular order to facilitate the development of a picture of community capabilities and needs (Figure 8.2). Activities moved from (1) an individual perspective (body mapping), through (2) social connections (convoy model of social relations) to (3) a broader understanding of the range of roles and occupations within the village (occupational mapping). The final session identified participants' priority

Body Mapping (Meiring& Muller, 2010)

Embodied experience
Captures feelings
Physical atributes
Physical limitations
Capabilities
Constrains
Difficult experiences
External factors that can impact them

Convoy model – social relations (Antonucci, Ajrouch & Birdit, 2014)

Details social network
Closeness of relationships
The number, range, quality and geographical location of network members,
Shows if/how these social relations contribute to the individual's identified capabilities

Occupational Mapping (Hout & Rudman, 2015)

Daily activities
Enabling/ constraining environmental factors
Interactions with others and nature
Conversations describing places of political/civic engagement, employments, social roles and leisure activities

Participatory Diagramming (Kesby, 2000)

Rank capacities/choices
List capabilities (choices, abilities and opportunities)
Ranking: most important community needs
Gaps in local facilities
Prioritize action areas to improve / wellbeing of the wider community

Figure 8.2 Artefacts produced during participatory arts activities. Author Photograph available at https://www.cadr.cymru/en/pipers-for-sunrise.htm

action areas (participatory diagramming) and how the SUNRISE building could be utilised to realise some of these ambitions.

Attention was given to the social, cultural and economic context in which the co-design was undertaken. Same-sex groups and three different age ranges were planned to reduce inhibitions when talking in mixed-age/sex groups. COVID-19 public health restrictions impacted participation rates and on-time and availability of people resulting in changes to original designs, while single-sex groups were maintained age ranges were mixed with only the younger men (aged 18–34) separated. The older adults were therefore part of single-sex but mixed-age groups. Research activities were conducted in a community hall which was previously an Anganwadi (pre-school). This was the most convenient place, providing easy access and adequate space and privacy.

Results of co-designing research

Piloting the co-design approach identified some issues to be considered in future rural RE projects, such as reimbursement for time, and the use of particular materials in arts-based activities.

First, in relation to reimbursement for time, millions of people in India engaged in the informal wage sector do not receive a decent living wage. While some older people accrue enough financial assets throughout their lives or have access to alternative sources of income and are able to retire, others, less financially secure have to work until they are physically unable to continue. The latter represents the situation of many older villagers, thus

engaging in research during the day (in the harvesting season, and peak time for migration during monsoon and summer) would entail a loss of wages.

Second, in relation to using particular materials in arts-based activities, older women were reluctant to use pens/paper. As such, pilot recommendations in PIPERS had suggested using traditional tools such as those used in some traditional art forms using rice powder and sticks. However, combining age groups in workshops due to COVID public health restrictions meant reassessing this. In particular, there were concerns that the traditional art methods may be considered outdated by younger people and result in them making fun of older people's depictions of solar panels/wells. However, as rapport developed over the sessions the experience and knowledge of the older adults were valued by younger people, resulting in greater intergenerational cooperation. Older women asked the younger ones to draw the artwork following their illustrative stories to capture issues important to them. All groups created art-based outputs with lively discussions and clear preferences decided on for the positioning (next to a school) and functions (electric mills, rice husking machines and refrigeration units) of the demonstrator building.

The artefacts produced during the activities were used as visual prompts to encourage the participants to discuss their thoughts and to reflect on their physical/mental health, social relations, livelihood and aspirations. Additional participant commentaries supported the research process (Coemans et al., 2015). These illuminated community needs and capabilities and fed into the wider community and project discussions. The participatory approaches helped boost older participants' confidence, develop leadership, and plan strategies for a common purpose to address the issues that mattered to them, resulting in the specifically purposed demonstrator building.

Co-design benefits to SUNRISE

Ultimately, the participatory arts activities used in the field (alongside survey data gathered as part of the research) informed a social development action plan (SDAP). This 'living' plan incorporates identified needs and proposed solutions into the design, purpose and planned maintenance of the solar-powered building. The plan represents the interaction between the communities, researchers and stakeholders and details the repurposing of the building in response to communicated needs and issues.

An interdisciplinary 'Community Involvement Working Group (CIWG)' established at the strategic level ensured that the SDAP could be progressed quickly: key CIWG members straddled the operational-strategic groups. Enhanced knowledge and confidence of villagers participating in research activities facilitated involvement in ongoing negotiations around the construction and functionality of the SUNRISE building alongside local SUNRISE project partners, community leaders, other villagers and NGOs operating in the village.

Key changes in building functionality were instigated by the community participation activities and facilitated by the mechanisms of communication (through community to operational and strategic project levels) that provided wider project understanding and support for change. The SUNRISE building was always intended to be a community resource that could benefit villagers. For example, it was envisaged it would be used for socio-economic development and providing support in agricultural activities, a venue for NGOs to provide skills training and to enhance health facilities. The building was not originally intended to provide electricity to individuals and homes. However, as a result of the participatory arts-based activities and the co-design of the research the building was repurposed so that

it could provide individuals (without access to electricity) mobile charger points, and a 'borrow a battery scheme' supporting lighting for homes. Hence, through the co-design activities, villagers were able to be an integral part of the research and development process and to collectively take action to address the issues around their everyday livelihoods and longer-term aspects of wellbeing.

Comparison of the two case studies

As the two case studies demonstrate, participatory research can be undertaken at different stages of a project. Both case studies were underpinned by the UK National Standards for Public Involvement in Research (NIHR, 2018). In the SUNRISE project the standards were incorporated within a robust guidance document (PIPERS) that included definitions of public involvement, engagement and participation and the theoretical underpinning of methodological approaches planned that were adopted at project level. In contrast, in the ABC-RP project, the standards were adopted at sub-study level and were not integrated into the overarching study. This meant that there were missed opportunities for older people to influence aspects of project design at an earlier stage. For example, the EP/AB made recommendations on improving the interface of new technologies and/or how they may be better introduced into homes to better suit the needs of an ageing population. If these recommendations were adopted as the project developed (rather than fed into the project on completion) this may have improved the experience for older tenants receiving and using new technologies in their homes. In contrast, earlier involvement of the community in participatory research in the SUNRISE project led to changes that met the needs of the community from the outset.

The UK National Standards for Public Involvement in Research provided a benchmarking structure to identify areas of good practice and opportunities for improvement within both projects. The practical aspects of the participatory approaches used in co-designing the research are contrasted in Table 8.2.

Lessons learned across the two cases

It is important for researchers to share the difference that participatory approaches to co-designing research with older people can make and where improvements can be made.
What worked well:

• Time spent exploring lived experiences and different knowledge and value systems of intended beneficiaries challenged some assumptions. There were 'drivers to decarbonise' at government level and at project level, while intended beneficiaries were more concerned about affordable heating or facilitating community spaces to support livelihoods. The adoption of PIPERS from the outset and across project hierarchies within the SUNRISE project facilitated greater opportunities for negotiating change. The co-design opportunities facilitated greater understanding of what energy use meant to older adults elucidating insights to be incorporated into plans for change (Itten et al., 2021).
• Opportunities to share understandings throughout both wider projects within reporting frameworks and conferences revealed the different and sometimes competing value sets of those involved within the studies and were useful. Sustainable energy transitions will

Table 8.2 Meeting the NIHR public involvement in research standards

NIHR standards public involvement	ABC-RP	SUNRISE
Inclusive opportunities	☺: Recruitment and selection of an Expert Panel and Advisory Board; roles clearly defined with equal emphasis on lived and work-based experiences; reimbursement for time £25 vouchers, travel and subsistence paid for in-person meetings; Alternative media (zoom, phone, email) offered. Tasks allocated according to interest, experience and willingness to perform them. ☹: Reliance on digital forms of communication excluded older people without technological products or expertise.	☺: Local NGOs familiar with the community supported a diverse recruitment strategy. Updates about research were conveyed in advance through the key informants in the village. Arts-based activities used to reduce inequities associated with low scientific literacy ☹: No financial reimbursement for participation and time lost from productive activities; this was likely to limit participation of the most impoverished participants. More traditional materials (familiar to older people) could be incorporated into arts-based activities in future.
Working together	☺: Meeting times, durations and formats jointly agreed. Meetings documented, recorded and shared decisions with contributions valued and acknowledged including final reporting. ☹: Useful suggestions regarding improvements to design or functionality of technologies on home visits although fed back were outside other sub-study remits to gather/alter (potentially missed opportunities).	☺: Convenient times and places used for participatory activities to fit around agricultural responsibilities. Seating arrangements and frequent breaks considered comfort and mobility issues. Refreshments were provided with some taken away for family members. Feedback on community requirements fed into social development (joint) action plan (SDAP). ☹: Times and durations of activities are difficult to suit all with many demands on participants' time-flexibility required; consider lengthening the overall time frame with shorter sessions.
Support and learning	☺: Initial in-person site visit was invaluable in viewing technologies in action, meeting the team and asking questions. Access to video-platform meetings initially required instructions and practice but as all learned together this aided rapport building. Meeting recordings and notes helped understanding. Additional learning opportunities regularly signposted via bulletins. ☹: The planned seminars and workshops could have supported additional learning and prompted questions and wider networking.	☺: Briefing visits were crucial in developing an understanding of the geographic, environmental, socio-economic and cultural aspects of the community. NGO's knowledge and connections provided additional information to aid required permissions. ☹: Timing (harvest) and restrictions meant opportunities to explore arts methods in more detail and greater movement around the village for understanding daily activities/roles was more limited than planned.

Tensions in transformations

(*Continued*)

Table 8.2 (*Continued*)

NIHR standards public involvement	ABC-RP	SUNRISE
Communication	☺ A variety of flexible forms of communications (e.g. email, phone, videoconference). Lay terminology used in technical discussions. Agendas, minutes and notes were provided promptly. Requests for feedback on surveys etc. were given as much time as possible. ☹: In-person events may have supported wider project communication and additional networking opportunities.	☺ The local dialect, language was used and respected throughout the activities (including information and consent). Arts-based methods facilitated individual and group communication and participation. Initial discussions with the community members via local NGO helped in building trust and rapport. ☹: Separating age ranges within groups as planned may have opened-up other discussion areas not covered. Gender-matched researcher/group may have made certain topics easier to discuss (e.g. health concerns).
Impact (on co-design of research)	☺: Co-design impacted positively on accessibility of marketing and data gathering tools and added nuance to findings' interpretation. Briefings on value of warm/comfortable homes to whole project highlighted personal and technical requirements. AB/EP members reported benefits to their networks from sharing their learnings. ☹: COVID-19 public health restrictions impacted on planned seminars. Possible adaptations to technologies/design in other sub-studies based on this co-design approach not capitalised on.	☺: Co-design of the research fed into the purpose and function of the building. Communities could collectively take action to address the issues around their everyday livelihoods. ☹: COVID-19 public health restrictions may have limited access to more vulnerable individuals -but working with NGOs in the village reduced this risk.
Governance	☹: Standards were adopted at sub-study level and were not integrated into the overarching study.	☺: Embedding PIPERS at strategic project level made a difference to wider project understanding. Ultimately the SDAP influenced the use, location, timing of construction and maintenance of the demonstrator building. The CIWG ensured actions reported at strategic level were implemented.

require governance structures that facilitate involvement of citizens throughout (Lennon et al., 2019) as was attempted within the SUNRISE project.

- Changes to ways of working caused by COVID-19 public health restrictions demonstrated that hybrid ways of working offered flexibility. Multimedia materials and asynchronous contributions were preferred by some participants.

Improvements needed:

- All potential exclusionary practices should be explored and mitigated at the outset of co-designing research. For example, online working requirements (ABC) and the negative impact on productive wage labour (SUNRISE) potentially excluded some older people from participating. Without representation from diverse and underrepresented groups circumstances may be worsened (Axon & Morrissey, 2020). Adequate time, recompense and working with for example NGOs already operational within communities can help with this.

  - Careful planning and flexibility of participatory approaches used such as timeframes and activity durations should account for specific requirements (e.g. seasonal considerations, grandparent caring responsibilities around school holidays).

- RE transitions should be based on shared values, resources and understanding of needs. More extensive opportunities for co-production/public participation embedded throughout projects are recommended. This could be supported by agreement of a set of principles or standards. Participatory methods should always consider the specific context of each project to be successful. Meaningful participation implies scope for negotiation within the project, and clear role definitions and governance structures can facilitate this. Therefore, time taken from the outset to agree the best approach can help develop trust, both for current and future RE transitions (Lennon et al., 2019).

The case studies demonstrated that renewable energy technologies can be applied in different spaces from community buildings to individual homes. There are often multiple people and agencies involved within the design, development, installation, maintenance and use of technologies requiring an understanding of processes, relationships between actors, and planned and desired use of technologies. The costs and measures of success for academics, and public and private sector organisations (e.g. vital to the project's implementation) do not necessarily resonate with the value and successful outcomes as defined by intended beneficiaries. The importance of deliberative and inclusive citizen participation in RE projects has been emphasised (Haggett, 2010). Individual, collective and structural processes of empowerment through research co-design should be considered as a method of shifting power. Older people have much to share, they can be the drivers of improvements and social innovation around research and programme design and delivery which can impact positively their lives and their communities.

Acknowledgements

Notes

1 https://abc-rp.com/
2 SUNRISE – Solar Power For All (sunrisenetwork.org)
3 https://www.cadr.cymru/en/
4 https://healthandcareresearchwales.org/researchers-support-and-guidance-researchers-develop-research-idea/involving-public-your-research
5 SUNRISE public involvement strategy (2).pdf
6 A Gram Panchayat is the local self-government organisation in India

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PART 3

Collecting data together with older adults

9

PROMENADE PARLANTE

Intergenerational Dialogue, Urban Scenography, and Co-Creation

Cynthia Imogen Hammond, Shauna Janssen, and Eric Craven

Introduction

The urban landscapes of Montreal (Canada) were not designed for older citizens, yet they are home to more than half a million people aged 65 and older. Montreal's iconic outdoor staircases, high curbs, and relative lack of accessible public transit make participation in this city's public life a challenge for ageing citizens. Yet older residents are a significant and largely untapped repository of urban knowledge that could and should be part of the city's public memory. Montreal, like other deindustrialising cities, has seen significant and often divisive urban change over the past two generations. Entire neighbourhoods were razed to the ground in the 1960s and 1970s because they were associated with poverty, race, or sex work. Other areas were decimated through invasive urban infrastructure, such as the expressways built through working-class neighbourhoods (Charlebois et al., 2014; Drouin, 2005). Equally, however, there has been spectacular community resistance to such changes, ranging from sit-ins and occupations to concerted organising (Grenier, 2009; Helman, 1987; Kruzynski, 2004). In such a context, the urban memories of ageing citizens are a precious and often overlooked resource for understanding how and why the city has changed over time.

How might such a city become a creative platform for the urban knowledge of older citizens? In 2018, fine arts professors Cynthia Hammond and Shauna Janssen, and community librarian Eric Craven set out to collaborate with a small group of older Montrealers who had come together through the Atwater Library and Computer Centre. We were inspired by this group's own past creative work that explored personal and neighbourhood memories. Using oral history, urban scenography, and place-based creation strategies, we sought to create a shared, public platform for these Montrealers' living memories of the gentrifying neighbourhood in which both the library and our university are located. Our goal was not to rehearse the "single-story narratives of decline" that are too often associated with ageing citizens (Chazan, 2018, p. 10). Instead, we sought to make palpable the experiences, knowledge, and creativity of our small group of co-creators through site-responsive research, oral history, and the temporary claiming of public space (Hammond, 2019, p. 38; see also Grosz, 2008; Hayden, 1995). For one year we collaborated with the group on a

two-part public artwork in which our collaborators – their memories, stories, artistic decisions, and their bodies – were at the forefront of the work: a public walk, punctuated by creative "episodes" designed by our co-creators themselves.

Background

Our partnership came at a time when predictions of an older population boom were front-page news in Quebec. In July 2019, L'Institute de la statistique du Québec produced Perspectives démographiques du Québec et des régions, 2016–2066, a report on changing demographics in Quebec as these pertain to age. Summarising the report, the Montreal Gazette observed that "the number of Quebecers age 85 and over could explode over a 50-year-period, rising from 188,000 in 2016 to 736,000 in 2066" (Montreal Gazette & Presse Canadienne, 2019). This statistic projects an increase of 391% in the number of older people in Quebec, a genuinely dramatic rise. This and other reports predict the transformation of Quebec and Canadian society into a population of predominantly older citizens within the next decade.

This prediction surfaced fears and prejudices about the financial implications of such a boom, particularly the anticipated cost for an already-overburdened public health care system (Korzinski, 2019; Russell, 2017; Simpson, 2014). Debates about the costs of the "grey tsunami" (Grant, 2014) have certainly been criticised in terms of the ageism that characterises this discourse (Chazan, 2018; Sawchuk & Crow, 2010). Nevertheless, media and scholarly accounts of ageing Canadians tend to rehearse the notion that older citizens no longer contribute value to broader society and further, because of their growing "demands" for adapted housing and accessible transportation and public spaces, our urban landscapes are about to change in costly ways (Shedletsky, 2021; Simpson, 2014). In this view, ageing citizens – alongside other groups such as new immigrants, single mothers, and impoverished or un-housed individuals – are too often dismissed as "deficient or needy" (Eubanks, 2011, p. 32).

We see ageing citizens differently. We posit that older individuals are "asset-bearing" (Lafontaine et al., 2020, p. 195) instigators of social and cultural change, and rich in situated knowledges (Haraway, 1988). We align ourselves with approaches to ageing citizens that foreground the sustained participation of ageing individuals throughout the project (Lafontaine et al., 2020; Zembrzycki, 2015). As such, we sought to build our partnership out of existing relationships in which our five collaborators – Wendy Allen, Ramsay Blair, Penelope Cumas, Lilian Harper, and Wanda Potrykus – would not simply be "active participants" but rather the co-creators of our project. In our respective work as educators, artists, and leaders of community- and neighbourhood-based projects, we value arts-based methods as a crucial aspect of such transformation. We have developed working methods that centre the creative agency of the individuals and communities who agree to be part of the journey (Janssen, 2014; Vaughan et al., 2016). Our work might be less pragmatic and more poetic than other community-built projects, however, our experience has shown that engaging unexpected actors in public urban spaces (and not-so-public spaces), through their own creativity and presence, can be transformative (Hammond & Janssen, 2016).

Conceptual approach

Rosalyn Deutsche asks, "what does it mean for space to be 'public', the space of the city, a building, exhibition, institution, or work of art?" (Deutsche, 1998, p. 269). Our

approach takes the city and its spatial stories as vital collaborators in creative responses to urban change. In theatre, scenography has been understood as design for performances in purpose-built theatre spaces. The term refers to the "sum total of the visual, spatial, and aural components of a performance" (McKinney & Palmer, 2017, p. xiii). Recently, contemporary scenographic practice has expanded and "is no longer defined by the architecture of the theatre or the confines of the stage or the conventional relationship of the spectator and performer, or the performer to the design" (Aronson, 2012, p. 87). In urban settings, scenography proposes the city itself as a performance, and as a site in which to stage stories in built environments that were not designed for such purposes. In this view, the city is not merely a backdrop for urban performances; rather, urban scenography "casts" the city as a collaborator in the process of engaging publics in the often overlooked social and cultural histories of an urban location.

We also see urban scenography as a tool to critique top-down urban revitalisation projects and "as a crafting of place orientation" (Hann, 2019, p. 45). Some of the sites we chose for our work no longer exist, or have been repurposed, or were being demolished at the time of our project. Urban scenography in such a context was a powerful method through which our co-creators could "rehearse" and make public their right to the city. For Deutsche, urban public spheres are more than physical or fixed spaces; they are sites of practice. This idea becomes particularly acute in our work, given the obstacles that older people face when trying to intervene in the city. "The right to the city," David Harvey argues,

> Is far more than the individual liberty to access resources: it is a right to change ourselves by changing the city … the freedom to make and remake our cities and ourselves is …. one of the most precious yet most neglected of our human rights.
>
> *(Harvey, 2003, p. 23)*

As we discuss below, the episodes conceived and performed by our co-creators underscored their right to make public (Miller et al., 2017) the often overlooked memories, experiences, and knowledge of urban change that ageing citizens hold.

Methodology: living memory and arts-based approaches

Originally, the Atwater Library's Digital Literacy Project (DLP) was created to address the digital divide between those who face barriers to using computers and the rise in digital culture in general. This programme evolved to a more participant-led model, which increasingly embraces participants' creativity and their lived social complexities. The DLP's offerings have grown from single-afternoon sessions to far longer engagements. About a year prior to the Promenade Parlante project, the DLP initiated a seniors-led "Living History" project. Older adults collected oral histories that were connected to various neighbourhoods surrounding the Atwater Library, focusing on ageing residents' urban knowledge. This approach, combined with a special level of engagement within the group, led directly to the collaboration with researchers and students from Concordia University, who received funding from the Canadian government to explore the possibilities of research creation and intergenerational collaboration. The year-long format of Promenade Parlante allowed the DLP to support the co-creators and encourage their sustained encouragement with the project's core themes. Through the library, the co-creators had ample space in

which to follow through on ideas, while also being firmly "situated" within Shaughnessy Village, our shared site.

The individuals who became our co-creators in Promenade Parlante previously had undertaken digital projects through the DLP. But the DLP was seeking opportunities to be a "fuse box between the academy and community," as Eric puts it. "This relationship with Concordia," explains Eric,

> Gave us a chance to expand our reach by collectively pooling a larger scope of resources. The partnership allowed the participants to have some exciting opportunities for "going public" with their work that would never have been available through the library's connections alone.
>
> *(E. Craven, personal communication, March 3, 2022)*

Through weekly meetings over the course of one year, mutually-supportive relationships were nurtured. The students and researchers offered practical and emotional support to the Living History group, and these older adults offered a wealth of lived experience and past oral history research to the team. For example, most of our co-creators had never previously participated in a site-specific, urban research creation project, but many had mounted important events in their careers, participated in community theatre, or had organised cultural events such as poetry nights. What we found through Promenade Parlante was that creating a space that honoured what we had in common was the key to fostering a rich, intergenerational, and collaborative environment.

Case study 1: An apple is a complicated fruit

One of our first activities was a collective mapping workshop in the spring of 2018. We met in a bright, spacious room at the Atwater Library. Cynthia and Shauna brought a large roll of brown craft paper, sticky notes, markers, and other mark-making tools. We covered a long table with paper and drew a simple line from one end to the other. The line represented Saint Catherine Street, home to many shops, businesses, and theatres, as well as boarded-up buildings, expensive new condo projects, and unhoused individuals. At one end we marked Concordia University, and at the other end the Atwater Library. Then we asked Wendy, Ramsay, Lilian, Penelope, and Wanda to note down as many memories as they could, wherever they could best situate those memories on our minimal map. Hesitant at first, the group became enthusiastic about locating their own stories on the paper, debating the location of cross streets, and conferring on specific events that they had learned about during their oral history interviews. By the session's end, we had mapped many key places that no longer exist or have changed dramatically over time. In so doing, we entered the realm of urban memory together.

In our second session, we conducted a "shoebox" workshop, which Shauna had previously developed in collaboration with other artists (Janssen, 2019). Participants chose a specific urban site that was meaningful to them within Shaughnessy Village and recreated it, in miniature, in a plain brown cardboard shoebox. We provided a wide range of craft materials for this activity. The group needed input and reassurance that they really were free to make whatever version of their memory they wished, inside their box, and furthermore that they had the skills necessary to do so. Once people got started, however, there

was a joyful, even frenzied energy as colours and materials were selected, and people raced to complete their boxed scenes. Some individuals completely dismantled and rebuilt their boxes; others created tiny dioramas. Wanda Potrykus chose to work on a memory that she had shared with us about her early years in Montreal. After arriving from England in the early 1970s, Wanda eventually settled in Shaughnessy Village and soon discovered some gnarled apple trees on a wooded slope on the grounds of the nearby Grand Séminaire. The seminary, a stately Roman Catholic institution, was surrounded by gardens, fields, and former farmlands. There, Wanda tasted a very special apple. She would later write, "It was a smallish red apple with green or cream markings, juicy, snow-white flesh, and a strawberry-like aroma, with spicy and sweet notes. It was called La Fameuse, or the famous one" (Potrykus, p. 1).

In making her shoebox miniature of that site, Wanda focused on multiple embodied memories that she had of the seminary grounds, including the trees in apple blossom in spring, and a long, elegant reflecting pool. Her box, filled with frothy, green gauze, sprays of white flowers, and even a tiny mirror, literally reflected this beauty. There was a hushed silence as we gazed into Wanda's box, and she told us about biting into that aromatic fruit. "Over the years," she explained,

> tastes have changed. La Fameuse fell from fashion, and only the very elderly and the nostalgic pine after it. The last Fameuse apple trees in Quebec were cut down in the last 30 or 40 years, not long after I first tasted one myself.
>
> *(Potrykus, p. 2)*

We encouraged Wanda to develop this powerful memory in the next phase of the project, which we presented to a limited public in October 2018 as part of a conference on oral history at Concordia. For this event, each of our five co-creators produced an individual, site-specific "episode". These episodes together constituted the itinerary for our walk through the neighbourhood and were thus the point of encounter between our audience and each artist. Wanda wrote a script encapsulating her story and performed her episode on the grounds of the seminary itself. She chose a specific spot between two heritage towers under some mature trees, facing a low run of stone steps where our audience could sit. As Wanda addressed the audience, student assistant Jen Townsend handed out Mcintosh apples – the successor to La Fameuse – to the attendees, who all tasted or sniffed their fruity gift, thus creating a haptic link between Wanda's memories and the present moment. She spoke:

My name is Wanda and, as you can tell, I am no longer young, however, my life in Montreal has brought me back frequently to this area. I learned more about the neighbourhood and fell in love with its architecture, dating from almost all periods within Montreal's 375 year history (Potrykus, p. 1).

As part of Wanda's performance, she wore a modified tablet on a custom lanyard. The tablet screened a digital slideshow throughout the event, representing Wanda's extensive architectural research. Each gifted apple bore the name, inscribed on a paper leaf, of one of the buildings featured. The audience sat enraptured as they listened to Wanda make connections between the apples in their hands, the quiet leafy spot where we all sat, and the urban and architectural history surrounding us (Figure 9.1). Through her episode, Wanda embodied a past that no one else present could personally know, but which was nonetheless present in a powerful, subtle, and uplifting way.

Figure 9.1   Wanda Potrykus, "La fameuse" (performance). Part of Promenade Parlante, October 2019, Montreal, Canada. Photo © Lisa Graves.

Case study 2: The crazy walk!

Ramsay Blair is an adult literacy learner who loves to walk all over Montreal. For Promenade Parlante, he created an episode that showcased several of his interests and skills. Before this collaboration, Ramsay had worked on many creative media projects through the DLP. As someone who is always present, yet consistently independent, his work was deeply connected to the overall project but his approach was uniquely his own. Ramsay had previously participated in the DLP's digital music and sound project, through which he created sound pieces based on field recordings that he made in empty food courts in nearby malls. After this, he took to carrying a small recording device and developed the practice of recording what he heard on his walks. This practice attuned him to neighbourhood sounds. He began to record in an intentionally experimental way, capturing quiet and subtle noises as well as loud and strange sounds, developing a unique archive of unexpected yet quotidian sounds in Shaughnessy Village.

Ramsay is a natural storyteller, however, his relationship to literacy makes working with text challenging. In digital media, he found a powerful means to tell the stories of the city as he heard them. After recording urban sounds, Ramsay then turned to creating digital slideshows with internet-sourced images. This subsequently inspired him to draw for the first time since childhood and to learn stop-motion animation. With the help of a laptop camera, Ramsay shot hundreds of photographs of his drawings and stitched them together. Using his sound library, Ramsay developed a creative college for his film's soundtrack, which sounded less like field recordings and more like electroacoustic music. This wonderful

fusion of digital and analogue methods led to an energetic and funny film. But Ramsay's hand-drawn, cut-out images of buildings and tiny people were not arbitrary. Instead, for his content, Ramsay chose to focus on the locations of the other co-creators' episodes. Thus his film, titled The Crazy Walk!, linked all five projects in one.

We opened the first public performance of Promenade Parlante with The Crazy Walk! Ramsay's chosen site was a student "Welcome Centre" on the Concordia campus. There, on a large digital flatscreen, In place of the typical institutional infomercial, attendees watched Ramsay's animated drawings set to his avant-garde soundtrack (Figure 9.2). As the introduction to our walk, and orientation to the neighbourhood, Ramsay's film did not answer many practical questions. It did, however, encourage our audience to adjust their expectations of what a project, led by older citizens and encountered within a university setting, might be. It was especially moving to launch our shared journey through the neighbourhood with Ramsay's highly skilled work, given that Ramsay had never been to university himself.

Case study 3: The Cabot Square project

Wendy Allen created an audio walk for a small public park located across the street from the Atwater Library. This park, Cabot Square, is named after the 15th-century Italian explorer, Giovanni Caboto, anglicised to John Cabot. In 1935, a seven-foot cast bronze figure of Cabot was installed in the centre of the park atop a 15-foot stone pedestal, commemorating Cabot's expedition to North America in 1497. The pedestal is surrounded by

Figure 9.2   Ramsay Blair presenting his short film, The Crazy Walk! At the Student Welcome Centre of Concordia University. Part of Promenade Parlante, October 2019, Montreal, Canada. Photo © Lisa Graves.

bas-reliefs, illustrating Cabot's colonial exploration. While Canada's settler-colonial history thus looms large in the park, it is also home to many marginalised citizens, particularly unhoused Indigenous and Inuit people. Wendy explains,

> When I first explored Cabot Square, at a time when there was a lot of talk about public monuments [representing colonial conquests], I noticed the bas-relief right behind the Indigenous people sitting on the steps at the base of the statue.
> *(W. Allen, personal communication, March 11, 2022)*

During Promenade Parlante, this park was also the epicentre of the neighbourhood's urban beautification project, which continues to threaten essential services in the area, including Chez Doris, the city's only homeless shelter dedicated entirely to Indigenous and Inuit women. With the increase in real estate speculation and the decrease in shelters and social services, and the ongoing presence and struggles of unhoused Indigenous and Inuit people living in Shaughnessy Village, Cabot Square can be thought of as a "point of intensity". Points of intensity are sites that encapsulate claims and contestations over the right to the city, but which do not consistently reveal these claims and contestations, nor do they always easily speak for themselves (Weizman, 2007). For Wendy, Cabot Square became such a point of intensity, and an urban place from which to critically stage, to use Stó:lō scholar Dylan Robinson's words, "new ways to engender public, felt forms of 'un-rightfulness' to the city [that] require the public to answer questions about how and why they have claimed the right to the city" (Robinson, 2016, p. 32).

For her episode, Wendy wanted to redress the perception that Cabot Square was a blighted site in need of "renewal" and foreground the ways that Cabot Square has become a vital gathering place for Inuit and other Indigenous nations through community events that advocate for their sovereign right to the city (Breitkreutz, 2014). Wendy created an audio walk using excerpts from an oral history with Nakuset, Executive Director of the Native Women's Shelter of Montreal. Wendy designed a soundscape, in collaboration with Eric, using digitally-altered field recordings from Aboriginal Day events organised by Nakuset, which took place in Cabot Square (Allen, 2020). For Wendy's episode, we assembled our audience on the periphery of the park, where we supplied them with mp3 players and/or a link they could access on their own devices. We visually "cued" our audience to press play by opening a large white umbrella, which was also the signal to begin the walk into the park while listening to Nakuset's story.

Wendy wanted the audience to be choreographed so that, by the end of the audio track, everyone would arrive at the base of the Cabot monument. "Without being explicit," Wendy explains, "I was hoping that participants might also discover the 'Doctrine of Discovery' panel [on the monument] as they walked around the Square listening to Nakuset" (W. Allen, personal communication, March 11, 2022). When the audio track ended, we signalled our audience to remove their headphones. Then, wonderfully, Wendy's episode concluded with a live performance by two Inuit throat singers, Lucina Gordon and visual artist Niap (Nancy Saunders), at the foot of the Cabot monument (Figure 9.3). Shifting from the pre-recorded track, which was experienced in an isolated and individual way, to an intimate and live performance by two Inuit women, completely restaged the park and the monument as sites of resistance to colonialism, and as places in the city that are already fully inhabited by Inuit and Indigenous citizens.

Figure 9.3   Lucina Gordon and Niap (Nancy Saunders) performing a traditional Inuit throat singing as part of Wendy Allen's episode titled The Cabot Square Project. Part of Promenade Parlante, October 2019, Montreal, Canada. Photo © Lisa Graves.

Shifting mentorship

As a group, we were happy with the way our first event went. The sunny fall weather was perfect, and our attendees seemed to love the episodes, as well as the opportunity to have refreshments and conversations with the artists at the Atwater Library following the walk. We began to reflect, however, on the project's dynamics. Our goal had been to foreground the living urban knowledge of older Montrealers in ways that also showcased their creativity. But our public-facing research creation methodology had led to some self-doubt for our co-creators. Because we had dedicated most of our resources to supporting the creative process and public outcomes, we had underestimated how stressful the performance aspects of the project might be. The related drop in confidence for some of our collaborators was something we needed to address. Our first walk had been an opportunity to see what worked, and what hadn't. We had always intended to end the project with a second public walk in April 2019. And so, in dialogue with our co-creators, we decided to shift our approach to one in which they, through their extensive urban knowledge, would become our mentors. Our co-creators were free to recreate their existing episode, or produce a new one, with our support as before. But this time, Cynthia, Shauna, and Eric also produced episodes and asked Wendy, Ramsay, Penelope, Lilian, and Wanda to help us.

Case study 4: Manoir du Souvenir

For Eric, the possibilities within Shaughnessy Village were vast.

> Shaughnessy Village has no shortage of places to be inspired by. I had the advantage of learning about dozens of sites through the process of supporting the seniors with their projects and through our interviews for the Living History work.
> *(E. Craven, personal communication, March 3, 2022)*

Eric, a long-time resident of this neighbourhood himself, finally settled on the building in which he lives, the aptly-named Manoir du Souvenir (house of memory). The house was built on Hawarden Street in the 1830s when the area was known for its mansions and views over the southern half of the city. Today these views are blocked by the adjacent train tracks and modern high-rises, while the Manoir has become an apartment building. Inspired by Ramsay's process, Eric collected everyday moments through still images, video fragments, and recorded sound. He collaborated with his son, Sy, ten years old at the time, to develop narratives that celebrated the secrets and mysteries of this almost hidden street. Sy's narration in English and French reflected the building's past but also noted the animals that lived nearby in the unplanned nature preserve beside the train tracks.

In developing his own episode, Eric drew from our older co-creators' knowledge and expertise. "I ran some of my ideas by the group during our sessions to see if a more personal reflection might add something positive to the overarching scope of the walk," he recalled.

> Wendy Allen nudged me to work with sound, given that we had collaborated on her sound pieces in the past. It was nice to feel the support of the co-creators and hear their notes about the piece. [Shifting roles] allowed me to understand the steps to creation that they had undergone in a more direct way (E. Craven, personal communication, March 3, 2022).

To present his episode, Eric collaborated with two student assistants, Eduardo Della Foresta, himself an artist, and Melissa Tamporello, who has a background in theatre. For the event, Eduardo loaned us his specially-equipped mobile art van, which allowed Eric to present his video, with sound, outdoors (Figure 9.4). Attendees were led to Hawarden Street, where they found the van parked beside the Manoir du Souvenir, near the train tracks, its rear doors wide open. The 100 attendees crowded around the van, watching and listening to the piece. They saw various moments captured at the Manoir, from Sy dancing in a rainstorm to trains rushing past, interspersed with time-lapse images of windswept clouds seen from Eric's apartment and shots of the building's reflection in spring puddles. Working with various opacity levels during the editing process, Eric allowed multiple images to be visible simultaneously. Sy's narration, layered over a drone guitar, combined with the ambient sound captured on site. Overall, Eric's episode brought the audience into a private world in a public setting, just steps from the busy thoroughfare where the Atwater Library stands.

Case study 5: The Seville: a phantasmagoria

Shauna's episode was a scenographic intervention that focused on the physical absence of a former theatre. The Seville Theatre held particular interest for Shauna; she remembers walking by the theatre on a daily basis when she was studying theatre at Concordia in 1989. Thirty years later, the presence of this building's absence from the cultural landscape

Figure 9.4   The audience enjoys Eric Craven's episode, Manoir du Souvenir, shown as part of the second walk of Promenade Parlante in Montreal, Canada in April 2019. Photo © Lisa Graves.

of the neighbourhood was still remarkable for Shauna. Wanda assisted Shauna with research and mentored her in the history of Montreal's former movie palaces and repertory theatres. When Shauna told the group that she would be focusing on the former site of the Seville, Wanda introduced Shauna to the Historic Theatre Trust (1989–2006), a not-for-profit organisation that sought to preserve Montreal's movie palaces. Their archive, held at the Canadian Centre for Architecture, contains photographs, newspaper and magazine articles, and official reports pertaining to the heritage value of Montreal's movie palaces and theatres. This archive was crucial to Shauna's creative process since no material or architectural traces of the Seville otherwise survived.

The Seville Theatre, one of the first atmospheric theatres in Montreal, opened its doors in 1929. The building was designed by Joseph Cajetan Dufort and the interior by Emmanual Briffa, known for his work in other Montreal theatres. At first, the movie palace offered performances and screenings. Then, towards the end of the 1940s, it also became a venue and concert hall for live music. The Seville was an architectural landmark of great cultural value. However, when the neighbourhood began a period of economic and commercial decline in the 1980s, the Seville closed its doors in 1985 and sat abandoned for the next 25 years. In 1990 the building was declared a heritage site by the city of Montreal. Despite this designation, what remained of the Seville was demolished in 2010 to make room for the development of a mixed-use project called "Le Seville", a mixed-use development aimed at revitalising what had become a socially and economically marginalised neighbourhood.

The concept for Shauna's episode, The Seville: a phantasmagoria, was to invite viewers into a virtually "real" encounter with the spectres of the theatre. We guided our audience to a Starbucks at the corner of St. Catherine and Chomedey streets, where the Seville had once stood. Our public was provided with virtual reality glasses through which to watch a silent film collage of imagery inspired by the theatre's live performances and movie screenings. Shauna's concept, to use media to evoke the spatial history of the Seville's past, was partially inspired by an exchange with Wanda, who wrote:

I do think the green theatre stage curtain decor in the current Starbucks, operating on the former site of the Seville, was intended to be some interior decorator/architect's symbol of the former Seville. The Starbucks itself also works as a social commentary on the evolution of mass media entertainment from lots of people sitting together watching one big screen to lots of people sitting together watching/streaming entertainment on many small screens. "The communal to the individual (W. Potrykus, personal communication, 14 March 2019)."

Shauna used binocular imaging and the virtual reality (VR) glasses to create a contemporary "theatron", or place of viewing, from the Greek verb theasthai, meaning to "behold" (Figure 9.5). Shauna's aim was to evoke a theatre of witnessing and memory by drawing from the Seville's cultural landscape as it had been remembered by many former patrons in blog posts, press clippings, and advertising ephemera gathered from the Historic Trust Theatre archive.

Figure 9.5   The Seville: A Phantasmagoria, by Shauna Janssen. Part of the second walk of Promenade Parlante in Montreal, Canada in April 2019. Photo © Lisa Graves.

Case study 6: The lipstick caryatids

At the centre of Shaughnessy Village is a mansion, from which the district gets its name. Once home to some of Canada's most powerful and wealthy families, Shaughnessy House is today part of the Canadian Centre for Architecture (CCA), a world-class museum and sculpture garden whose mission is to share knowledge about the built environment. From the 1930s to the early 1970s, however, Shaughnessy House was home to single women of various backgrounds and ages. From a palliative care facility for older women to a half-way house for young, working women, Shaughnessy House provided a space of refuge and community that was shared with the Sisters of Charity, an order of nuns who oversaw the space.

Shortly after moving to Montreal in 1994, Cynthia learned how, in 1973, a photographer named Brian Merrett had realised that Shaughnessy House was going to be sold and demolished. Hoping to save it, he photographed the building and shared the images with activist Phyllis Lambert, who would later purchase and restore the mansion. Among Merrett's images is an interior view of what was, at the time, the bedroom of four young women. Here, Merrett captured a special detail: marble caryatids that adorned the pilasters on a fireplace surround. The residents had added their own irreverent embellishments to these figures, giving them rouge, mascara, and bright red lipstick (Hammond, 2021). Merrett's photograph of the lipsticked caryatids is one of the few traces of the decades during which Shaughnessy House had been a home for women. Sadly the fireplace was lost in a fire prior to Lambert's purchase.

Cynthia shared this story with our co-creators, and with Wanda's help discovered that the Living History project had interviewed a man who once helped young women find their way to the house from the train station. Planning a new episode of her own in the CCA sculpture garden, Wanda did substantial research on the Sisters of Service and shared traces of the house's gendered history with Cynthia. This exchange led Cynthia to her own episode on the site of the CCA for the second Promenade Parlante. We met our attendees at the entrance to the CCA grounds, handing out mp3 players. These players were preloaded with a six-minute audio piece in English and French. Once everyone pressed "play", they were brought past the CCA's gates, where they discovered 15 women standing motionless on the institution's vast lawn, dressed in white and wearing bright red lipstick (Figure 9.6). These women were all art and architectural historians, or architects. As the audio piece described the building's gendered history, the performers walked slowly in a line until they faced the long white façade of the CCA. The moment that the attendees heard how Lambert saved the building, the white-clad women all blew the building a kiss. As the contemporary embodiment of the lipsticked caryatids, the performers commemorated the former occupants of the house, and paid homage to Phyllis Lambert, through whom this building survives today.

Conclusion

In the second half of our project, the dynamic of our collaboration changed. Because our co-creators acted as our mentors and took positions of authority through their important knowledge, our second walk was a far greater success. We had an unexpectedly high number of attendees; over 100 people joined us on the streets of Shaughnessy Village to see our seven episodes on a cold but bright spring day. As with our first walk, we invited our audience to join us at the Atwater Library for refreshments and conversation after the walk.

Figure 9.6 The Lipstick Caryatids, by Cynthia Hammond. Part of the second walk of Promenade Parlante in Montreal, Canada in April 2019. Photo © Lisa Graves.

This time, we did exit interviews with attendees and co-creators alike. One attendee told us that for her, the walk had been "a great opportunity to find meaning and connection in the neighbourhood." Responding to the urban scenographic approach, another attendee said, "There's a dramatic dimension that makes one think differently than just hearing words." Reflecting on the spirit of the event, another woman remarked,

> It was really wonderful and I'm going to remember each section. But I'm also going to remember the kind of respect and care that everybody had for each other, that the participants had for each other.

Our co-creators also had reflections on the event. Lilian told us that, through the project, "things that meant a lot to you 50–60 years ago all the sudden come leaping back." For Ramsay, "the biggest thing I learned is how much I don't know. And how much is out there to learn." Penelope, musing on the relationship between individual memory and the episodes seen on the walk, told us: "The past is never past, it's always with you … They can knock down buildings but they can't destroy the past" (Hammond, 2019).

The central objective of the larger volume to which this essay belongs is to explore different ways of amplifying the experiences of older adults by involving them as co-creators in research that places ageing at the forefront. Promenade Parlante was an oral history research creation project that took the form of two, "talking walks" in 2018–2019. Each walk had a distinct itinerary that brought the viewing public into intimate performative episodes, through which the audience would encounter one of the participants in our project, staged in a specific

location, sharing their urban story as a soliloquy, an installation, or an immersive digital media event. Our weekly dialogues with our co-creators and student assistants ended up shaping the second half of the project in new ways. Prior to our first walk, when our co-creators were building their confidence, we took on the role of project leaders and mentors. But, during the last six months of the project, we changed this approach by asking the co-creators to be our mentors as we embarked upon our own "episodes" as additions to the walk. In this way, Promenade Parlante is an example of intergenerational co-creation and "shared authority" (Frisch, 1990, p. xxii; Summerskill, 2021, pp. 37–38) which, through participatory creative strategies, temporarily transformed the neighbourhood where we did our work. Significantly, however, it also challenged our research team to find co-creative strategies that would empower our collaborators to see themselves as the urban experts that they truly are.

Acknowledgements

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10

OLDER INDIVIDUALS' ACTIVE PARTICIPATION IN DATA COLLECTION IN DIVERSE SETTINGS IN SOUTH AFRICA

Vera Roos

Introduction

The opportunities presented by global longevity offer an excellent case for conducting research on ageing. Unfortunately, research in this field is mostly planned and implemented top-down, on or for older persons, without necessarily involving them in any part of the process. However, researchers are increasingly acknowledging the rights of (older) participants to be involved in research issues affecting them. If research on ageing is acquiring priority status and the rights of older individuals to be actively involved in this is being widely acknowledged, one may ask why the literature on data collection strategies involving older persons is limited, or what principles should inform practical research decisions. Drawing on two distinctly different examples in South Africa, this chapter sets out the principles informing the active participation of older individuals in data collection methods. First, an overview of data collection strategies of participatory research involving older persons is provided. Next, the two examples are described. Last, the principles which informed participatory research decisions are presented.

Overview of data collection strategies employed in participatory research with older individuals

Participatory research on ageing is a clear directive of the Madrid International Plan of Action (MIPAA): older adults should be able to participate in research conducted in an enabling research environment and benefit from the findings (World Population on Ageing Report, 2013). Inclusion of older participants in research is driven by broad human rights and participant-focused perspectives. A rights perspective assumes that it is every individual's fundamental right to be involved in research in which they have a vested interest (Opperman & Schröder, 2022; Walker, 2007). A participant-focused perspective acknowledges that those affected by the research should be directly or indirectly involved in some aspect of the process, and not merely be consulted (Walker, 2007). However, acknowledging rights and accepting that people should be the focus of the research process is only one side of the coin; the other has to do with the conduct of participative research. This chapter therefore focuses on the principles informing the application of research decisions in data collection in two diverse research settings.

Box 10.1   Insights obtained from collaborative data collection examples

- Older individuals are central to data collection in varying degrees.
- Involving other people helps older individuals to participate in data collection.
- Data collection methods have been modified to fit the needs of older participants.
- A variety of data collection methods and research materials cater to individual preferences.

Literature on older participation concentrates mainly on people with dementia. The following examples provide some insights relevant to the participation of older individuals in data collection. A summary of the insights obtained from participatory research examples is presented in Box 10.1.

Bartlett (2012) modified the conventional diary method for which individuals with dementia keep a written diary with daily entries about their thoughts and feelings. In the adapted version of the method, participants are informed beforehand of the researchers' expectations, the time frame allowed, and that it is permissible to use other means of expression (e.g. audio or photo entries) besides writing. Findings obtained from implementing the revised diary method not only provided useful information about older participants' personal reflections but also showed how they used their social networks to obtain information to present a detailed account of an event. This diary method of data collection slowed the pace of the process, which, in turn, allowed time for reflection both by researchers and participants. However, this method seems to work well only with participants who can read and write (are literate), or have the financial means and technological skills to produce audio recordings or take photographs.

In another example, Gregory (2014) drew on performing arts to collect data involving people with dementia. Researchers initiated a process of collaborative poetry by first conducting semi-structured interviews with participants. The interview data were used to write poems which were read back to the older co-authors, their carers and families. To challenge the social stigma associated with dementia and to forge connections with people with dementia, visual artists, musicians, poets, photographers, and the social scientists involved in the project took photographs, produced music using the poems as lyrics, or created three-dimensional collages. The collaborative collection was exhibited publicly to reach a broader audience (Gregory, 2014). Although this performing arts-based method involved older persons in a process of expressing their social and emotional experiences, it is unclear how the participants felt about the creative interpretation of their poems or the public display of personal meanings. The use of a verbal data collection method furthermore assumes that all participants with dementia have the verbal capacity to express themselves, which could exclude people with limited verbal capacity.

In participatory research with older people with late-stage dementia, Smith and Phillipson (2021) involved participants directly in body mapping and the development of transitional objects (scarves and blankets) to foster a sense of being at home. These older individuals related their experiences to family members who, by using a body outline and adding images, symbols, and words in a structured conversation, identified the individuals' relationships with the external environment. In creating the scarves and blankets, the participants visually expressed their interests, likes, and dislikes by actively engaging with the fabric and other decorative materials through their participation in the research activities. Providing concrete materials to assist with data collection created an avenue for older participants to express what they might otherwise have found challenging to express verbally.

However, the literature is still unclear on the following questions:

What role does context play in participatory research on ageing?
What is the role of relationships in facilitating older individuals' participation?
How can a research environment be adapted to facilitate participation?
What other data collection methods can promote participation by older individuals?
How can data collection events enable socially transformative practices?

These questions guided the subsequent discussion on involving older South Africans in data collection. They will be addressed and supported with literature after the two examples have been presented.

Positioning research on ageing in (South) Africa

Africa, as the youngest region in the world with its youthful population, also experiences rapid population ageing (World Population on Ageing Report, 2015). It is estimated that South Africa will see an increase in older persons from the current 3.7 million to 4.6 million by 2050 (Makiwane et al., 2020). The older population in South Africa is diverse mainly along the lines of huge inequalities resulting from the destructive apartheid legacy, pre-1994 (Hoffman, 2022). The majority of people aged 60 years and older still bear the scars of a socially engineered system based on race classification that enforced the removal and dislocation of people to allocated destinations with limited infrastructure during the 1960s. This also disrupted family life and weakened social bonds (Roos et al., 2014). People grew older in these locations and, in 2021, in their advanced age, the majority (99%) of approximately 5.51 million people (9.2% of the total South African population) were still suffering the injustices of a policy that excluded them from essential services and prevented them from living a reasonably dignified life (Stats SA, 2021). In research conducted in 2017–2018, the South African Audience Research Foundation (SAARF) universal living standard measure (SU-LSM™) (Haupt, 2017; SAARF, 2017)—a tool which categorises people according to living standards with one being the lowest and ten the highest— indicated that previously disadvantaged (Black) older persons scored the lowest LSM measures, confirming their entrenched levels of poverty (Roos, Du Plessis, & Hoffman, 2022).

In the main, Black older adults were prevented from obtaining a quality education in their formative years (Makiwane et al., 2020; Stats SA, 2014). Consequently, 40% of Black older individuals continue to suffer the consequences of lower literacy levels (Hoffman, 2022). The potential vulnerability of Black older persons, in association with limited financial resources and literacy, could lead to their marginalisation in research, thus highlighting the need to find ways to involve them in this process.

Examples of participatory data collection with older individuals

Two examples of the active participation of older South Africans in data collection focus on research in an unstructured, random community-based setting and in a more formal, controlled residential care environment. Pre-1994, residential facilities for older South Africans were reserved exclusively for White people and, despite being opened up for older people of all races, representation remains skewed towards White individuals (Makiwane et al., 2020), while their Black counterparts live mostly in community-based settings.

Example 1: Older persons' cell phone use in community-based settings

The plight of many older individuals resulting from a lack of appropriate service delivery in age-unfriendly communities with limited infrastructure (see Hoffman, 2022; Keating et al., 2013; Makiwane et al., 2020) informed research on their cell phone use. Bearing in mind that most Black older individuals in South Africa, as well as in this example, find themselves living in multigenerational households (see Hoffman, 2022), researchers (two White socio-gerontologists) conducted a small-scale study (iGNiTe)[1] in 2014 to obtain a basic understanding of how older persons navigate cell phone technology. The findings of the iGNiTe study were subsequently used in 2017 to include more older individuals across different geographical (urban/rural) settings in the we-DELIVER project[2] to reveal their needs and experiences relating to municipal service delivery (see Roos, 2022). This project focused on older persons in various socio-cultural settings. Participants in the selected settings spoke mainly isiZulu, Setswana, and Sesotho, with a small number using Afrikaans and English.[3] The selected communities are situated in a rural area (Lokaleng in North West province) and large towns (Sharpeville in Gauteng province and Ikageng in North West province) (Department of Cooperative Governance and Traditional Affairs in South Africa (DoGTA), 2016).

Contextual considerations and participants' needs

Gatekeepers (individuals with a vested interest in protecting the welfare of older individuals) and community organisational structures (e.g. the headman and advisory board) facilitated access to the older participants in the respective settings (see Roos, Segalo & Ntombela, 2022). The type of data collection activities selected and their practical application aimed to promote active participation.

Selection of data collection methods and application

Tailored questionnaires were developed for the iGNiTe study and the we-DELIVER project (see Erasmus et al., 2022). To enable the participation of older individuals with limited technology skills and, for some, lower literacy levels, younger people (student fieldworkers) familiar with the socio-cultural context of the sample communities were identified and invited to participate in collecting data from older individuals. Before the fieldworkers entered the different research settings, they attended workshops presented by the researchers responsible for project implementation on how to create an optimal (safe) interpersonal context before they introduced technology for the study. They welcomed participants in their shared vernacular and explained what participation in the project by these older individuals would entail. The fieldworkers then captured on mobile devices the participants' responses to the questionnaires, which had been translated into the participants' spoken languages. Data were collected on an individual basis (See Figure 10.1).

At the conclusion of the data collection session, research participants and student fieldworkers socialised over refreshments (Roos, 2022).

Three qualitative data collection methods were used to obtain more in-depth information about older persons' cell phone use: the Mmogo-method,[4] semi-structured interviews, and focus groups.

Figure 10.1   Student fieldworkers facilitate older individuals' participation.

The Mmogo-method. This visual data collection method encourages optimal participation and allows those taking part to express their meanings related to the research question by constructing objects using research materials (lump of clay, colourful beads, and sticks of different lengths) and talking about them (Roos, 2016). The method adopts an onto-epistemological approach: first, it focuses on the subjective experiences of older people's cell phone use, and then on the analysis and interpretation of data. The researchers observe the visual representations of the participants and their discussions about the visual images in relation to the research question (Roos & Baart, 2016).

Researchers applied the method in four phases. Phase 1 dealt with creating a safe inter-personal and group context to promote the optimal participation of (older) participants (Van Biljon & Roos, 2016). This was achieved by members of the research team (researcher, research assistants, and translators) explaining what the study entailed and what would be expected of participants and assuring them that they could withdraw from the research setting at any stage. Participants were also told that they would be asked to respond to a prompt to stimulate the construction of visual images, and that the information they provided when explaining their visual representations would be shared in a group (Roos, 2016). The group was asked to treat the information as confidential. In Phase 2, researchers invited participants to organise themselves into groups of between eight and ten and to use the research materials to create the visual representations. The prompt for Example 1 was: *Please use the materials and make anything when thinking of your cell phone.* A group of older women participating in the Mmogo-method is shown in Figure 10.2.

Participants completed their visual presentations within 35 minutes, and they explained their visual constructions in Phase 3. Researchers posed questions about the participants' constructions and the meaning of the visual images in relation to the research question. By being mindful, researchers avoided imposing their own interpretations when posing questions (Van Biljon & Roos, 2016). A visual representation of a participant's construction from a Mmogo-method session is presented in Figure 10.3. The participant's explanation of the images is also provided.

Figure 10.2   Older participants construct visual representations as part of the Mmogo-method.

Figure 10.3   An older woman applies the Mmogo-method to illustrate her cell phone use.

Participant:	I made a couch, a person, and a cell phone. When the phone rings the person stands up to answer the phone.
Researcher:	Who is calling?
Participant:	I am calling my kids. Inside the house, a cell phone is useful because I am able to buy electricity with my cell phone, rather than having to waste money on transport to go to town and buy electricity.
Researcher:	Can you tell us more about the couch and the flowerpot you have made?
Participant:	I did it because it is a house setting.

After the explanations offered by each individual participant, the researcher invited the rest of the group to join the conversation as soon as the process permitted; these group discussions contributed further to new meanings. Finally, in Phase 4, research participants shared

any emotional content elicited during the study with the research team individually. When the participants had left the research setting, the research team engaged in a debriefing discussion about the impact of the research on them.

Semi-structured interviews and focus groups. Gatekeepers identified participants capable of coherent communication and informed them of the data collection events. Questions were formulated to explore the subjective experiences of older persons in their intra/intergenerational interactions involving cell phone use. Semi-structured interviews and focus groups as qualitative data collection methods with older persons are well presented in the literature (see for example, Forster et al., 2021; Gregory, 2014).

Older individual participation and findings

For the iGNiTe study, student fieldworkers collected questionnaire data from 128 older participants. Of those, 52 participated in the Mmogo-method (*n* = 19) and semi-structured interviews or focus groups (*n* = 33). The findings of the qualitative data are reported elsewhere (see Leburu et al., 2018; Roos & Robertson, 2019; Scholtz, 2015; Steyn et al., 2018). Statistical analysis of the questionnaire data and the findings of the qualitative data informed revisions of the questionnaire used for the we-DELIVER project. In the we-DELIVER project, older persons completed questionnaires (*n* = 302), and participated in semi-structured interviews (*n* = 14) and focus groups (*n* = 22) (see Roos, 2022). The findings both of the iGNiTe study and the we-DELIVER project informed the development of a technology artefact (Yabelana ICT system) to yield information about service provision in local context-specific settings (see Roos, 2022).

Example 2: Residential care environment

The Older Persons Act (13 of 2006) (RSA, 2006) makes provision for three categories of residential facilities in South Africa: Category A—independent living, Category B—assisted living, and Category C—frail care. In Category C, the focus is mainly on the physical care of older adults. The example of participatory research with older people in a formal care environment involved functional residents who were still able to care for themselves in independent and assisted living care settings.

Contextualising participatory research with older individuals in a residential environment

In 2013, the director of an independent non-profit organisation approached researchers at the North West University (NWU) to explore residents' lifestyle experiences with the aim of enhancing the services offered. The care setting, situated in the city of Johannesburg, Gauteng Province, South Africa, provides accommodation and 24-hour care to older people (RSA, 2006). The residents consisted mainly of White Afrikaans- (90%) and some English-speaking (10%) people between the ages of 50 and 95. This care setting is home to over 100 residents, with living arrangements ranging from cottages, where functional residents live on their own or with their partners, to studio apartments and frail care facilities. At the time the research was undertaken, the care setting accommodated approximately 350 residents and a support staff of 35 assistant care workers, 90 volunteers, seven permanent nurses, a centre manager, and a lifestyle consultant who developed

specific programmes for every day of the week, with time slots allocated for different activities (snooker, bingo, line-dancing, bridge, Scrabble, choir singing, and brisk walks) in which she encouraged the older people to participate. The care setting adopted an active ageing approach (improving people's functioning to raise their quality of life and to promote their active engagement in community life) and encouraged older residents to participate in activities and interactions with other people in and outside the facility (Roos & Zaaiman, 2017).

Procedure

After obtaining approval from NWU's Human Research Ethics Committee, posters were put up in the care setting to inform residents of the research and to invite them to participate. On the day of the data collection, an introductory meeting was held with the research team, relevant staff, and voluntary participants. Informed consent was obtained before data collection began. Participants were informed that, due to group participation in the Mmogo-method and World Café method, only partial confidentiality could be ensured because all participants were known to one another.

Methods of data collection

On the first day, 16 residents (3 men and 13 women) participated in the Mmogo-method. To obtain more detail on the types of activities in and outside the care environment, as well as the types of activities older residents engaged in, 12 person-centred interviews were conducted with three men and nine women. The World Café method involved 18 individuals (2 men and 16 women). The data obtained from these three data collection events were analysed and provided the basis for discussions between the older residents and management, as well as the lifestyle consultant, using a group reflecting technique. Some residents participated in more than one of the data collection activities.

Mmogo-method. To elicit rich data about residents' living experiences and the lifestyle they sought in this care environment, the Mmogo-method was applied and participants created visual constructions stimulated by the following prompt: *Please make a visual representation with the materials provided that can tell us more about how you experience your life here at the residential facility* (Figure 10.4).

The visual representation in Figure 10.5 illustrates the social meanings an older man attributed to living in this care environment.

> This is my new life. I decided myself that I wanted to be here. About four, five years ago, I walked in here and they told me I can gym with them. I then started as a gym instructor. The main idea I had when I arrived here was to encourage people. When people are ill, I want to go to them, knock, and if they give permission for me to enter, I walk in. When I see that I am unwelcome, I talk to them a little, shake their hands and run along. We paint and play ball, walk and do things. We have arrived [here] and not retired.

Person-centred interviews. The interviews were conducted to further clarify the participants' experiences in the residential care environment (see Roos & Zaaiman, 2017 for a discussion of findings).

Figure 10.4   Older residents in a care environment participating in the Mmogo-method to study their lifestyle experiences.
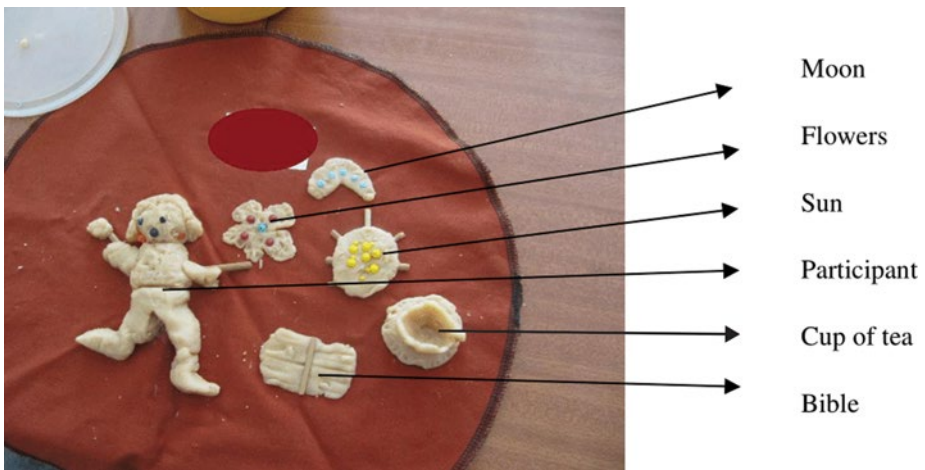
Figure 10.5   Example 2. Representation of an older man's active engagement in a formal care environment.

World Café method. This method enables a large group of people to share their opinions in a participatory manner (http://www.theworldcafe.com/keyconcepts-resources/world-cafe-method/). To initiate the process, researchers explained the research purpose and procedure. To facilitate collaboration in smaller groups, the 20 participants were assigned random numbers from one to four and asked to gather according to number at an assigned table. Each table was provided with a blank A2 sheet, colourful stationery, and

refreshments. A trained student fieldworker and nominated host/hostess were assigned to co-facilitate the group discussion elicited by one of the following four prompts regarding the lifestyle older participants desired in the residential care environment:

1 Write or draw something that is meaningful in your life.
2 Represent something to indicate the people with whom you have special relationships.
3 Draw something that shows what the environment looks like where you take part in activities.
4 Imagine your children will be living in this residential care setting when they are your age: how you would like it to be for them?

By rotating the fieldworker and host/hostess roles among the participant groups—to accommodate participants with limited mobility—each group addressed all four prompts. The fieldworker and the host/hostess spent 20 minutes with each group gathering further information related to their specific prompt. When all the groups had contributed to all four prompts, the sheets with collated information were put up on a wall to ensure visibility, and the host/hostess provided feedback on the responses obtained from all the groups. The student fieldworkers helped the host/hostess to handle the microphone and present a thematic summary of the discussion topic they had facilitated (see Figure 10.6).

Figure 10.6   An older resident assisted by a student fieldworker in World Café.

In the larger group, the older residents discussed the themes, asked clarifying questions, and decided on a list of ten key issues they wanted to share with the management and staff of the residential setting regarding ways of improving their lifestyle in this residential care environment.

Group reflecting technique (GRT). This technique facilitates active listening between two groups (Andersen, 1990; Roos, 2011). In applying the GRT, the representatives of the management team assumed a listening and reflective position while the older residents shared the ideas they had identified in the World Café:

- Their appreciation of a safe environment which was well-organised;
- The range of activities supporting an active lifestyle, which they found meaningful;
- Appreciation of respectful and friendly interactions with staff;
- Staff members' attentiveness to the needs of residents, which affirmed them as people;
- Appreciation of the flexibility, friendliness and accessibility of management and staff;
- The importance of social relationships with people in and outside the care environment, including friends, close and extended family members;
- Threats to the independence of some older residents as a result of limited financial resources or deteriorating health;
- Feeling obliged to conform to the norm of active participation, which compromised the need for solitude and emphasised older residents' abilities to regulate the social environment;
- Being too occupied, without meaningful interpersonal contact;
- Neglect of emotional needs, such as dealing with loss.

The residents also made the following recommendations based on information obtained from the World Café:

- Establish a support group to deal with loss and bereavement.
- Use group activities as opportunities for deeper, more meaningful interactions with other residents.
- Support the inclusion of new residents.
- Support the voluntary disengagement of residents without fear of being labelled.
- Involve older residents in planning and implementing activities.
- Support residents to replace a complaint discourse with an effective expression of needs.

At the end of the discussion of these themes, staff and members of management reflected on the issues raised and presented the group of older residents with a summary of the ideas put forward, without imposing their own meanings.

Principles guiding older individuals' active participation in data collection

For the purpose of this chapter, five principles are discussed, drawing on the two examples presented here: a community-based setting and a residential care environment. According to Kelly and Westoby (2018), principles are fundamentally important ideas that shape practice. The foundational principle guiding the selection of data collection methods and practical application is the situatedness or contextual relevance of the setting in which older participants find themselves.

The importance of context

Community-based research is often unpredictable (read messy) and requires researchers to move beyond acontextual checklist competencies to think about complexity presented in the setting and adapt accordingly (Dzidic et al., 2013). In contrast, the bounded system of the care environment is much more contained, with a clear programme or rhythm set out in a daily routine. Data collection in a community-based setting thus requires field-based and longitudinal engagement (six years in this study), while the easy access to and predictability of the care environment enable researchers to collect data in a short period of time (three days).

From an ecological perspective, researchers should consider the interlinkages and interdependence between broader environments, the more immediate contexts in which people live, relational interactions, and the individual (Arcidiacono, 2017). Hence data collection aims to obtain individuals' perceptions in the immediate contexts, because the content and structure of the setting produce, sustain, or limit behaviour, according to Bronfenbrenner (1993).

In Example 1, researchers considered how the broader historical socio-political environments shaped the lives of this cohort of Black older individuals, as well as the community settings in which data were collected. The research settings in which data collection took place faced several contextual constraints (e.g. lack of financial resources, strained interpersonal relationships, limited mobility, and so on). Researchers accordingly considered what complementary actions could support older individuals' active participation, including the type of data collection methods selected, and modifications needed.

Example 2 illustrated the ecological principle that behaviour is a function of the individual and the environment (Lewin, in Barker, 2016). The active care environment, on the one hand, reciprocally complemented and elicited residents' behaviour associated with an active lifestyle, while, on the other hand, it also (unintentionally) led to withdrawal behaviour in those with a need for deeper connections, or a desire to disengage from the active environment without feeling obliged to participate (see Roos & Zaaiman, 2017 for a discussion of this finding). The settings theory, according to Barker (2016), explains residents' behaviour as follows: "Social situations almost always have a normal programme of activity that is rarely escapable once you enter the setting" (p. 44). The implication for human behaviour in a bounded residential care environment is that "if a person reaches the threshold of person-setting incongruity, they are literally forced away" (Lounsbury & Mitchell, 2009, p. 215).

Adopt a relationally focused approach

A relational approach has implications for (older) participants and researchers, as well as for the application procedures. With regard to participants, the assumption is that they are central in research on topics related to matters that directly and indirectly affect their lives. In Example 1, the lack of useful information about older South Africans' cell phone use hampered appropriate service delivery through technology or the development of *e*-Interventions, thereby contributing to further exclusion of an already marginalised group. It was therefore essential to obtain information directly from the affected older individuals. Researchers, sensitive to relationality in the research context, should adopt an other-centred approach, interact respectfully, and be mindfully attuned to participants.

The literature confirms that these relational qualities are conducive to promoting inter-personal safety, collaboration, and sharing (Harrell, 2018; Rogers, 1951). Displaying effective relational qualities is particularly relevant in cross-cultural and intergenerational research, as in Example 1, where the presence of two White researchers in community settings with Black older individuals contributed to the dynamics in the research set-ting. Participatory research from a relationally focused approach is therefore synony-mous with reflective practice: researchers engage in what Dzidic et al. (2013) describe as "iterative-generative reflective practice and being attuned … and responsive to the con-textual requirements of the social settings in which we engage" (p. 7). Reflective practice contributes to new forms of understanding which researchers apply when they are in a social situation. From a relationally focused approach, researchers adopt an empathic po-sition in selecting suitable data collection methods; flexibly adapt data collection methods and procedures to fit the needs of individual participants; and create an optimal research context conducive to eliciting responsiveness from participants. In both examples, stu-dent fieldworkers familiar with the social-cultural context of the older participants were purposely recruited. The principle guiding this research decision was both for older and younger people to register familiar social cues, and in dyads or small groups to engage in an optimal interpersonal context, and limit reactivity associated with the often unfamiliar research setting.

Adapt the research environment to fit the needs of older participants

In the two examples, the principle of creating a person–environment fit was applied to per-form appropriate actions, drawing on Stirling (2010, p. 35), who suggests that the social and physical environment should be adapted and "changing the person" avoided. To take account of the needs of older participants, student fieldworkers supported them in the ap-plication of the data collection methods. In Example 1, the fieldworkers used technology to capture the older participants' responses. In Example 2, student fieldworkers helped older residents to engage in small group discussions as part of the World Café and to present a summary of the issues to the larger group of participants, management, and staff. Providing support for older participants draws on the notion proposed by Stirling (2010) that people are able to participate competently in research, "irrespective of the assistance they require to carry out the activity" (p. 70). The research environment was also adapted to the needs of older residents who participated in the World Café: the method of application was al-tered to accommodate the limited mobility of some participants so that the host/hostess and student fieldworkers moved to the different tables while the participants remained seated at their tables.

Multiple data collection methods

The use of different methods of data collection in participatory research is not only good practice in qualitative research for providing multiple perspectives (see Ellingson, 2009) but also facilitates different avenues for a diverse group of people to express themselves. In both examples, the rationale for selecting the specific data collection methods was informed by the specific research question, the context, and participants. The Mmogo-method was applied as a relational method of collection to obtain a basic understanding of the interac-tions between the individual older persons, social contexts, and the broader environment

(see Roos, 2008). The method was developed to give a voice to the individual participant, obtain the meanings co-created in a group, and promote communication between participants, irrespective of the diversity of participants or researchers. By using a visual data collection method, participants could express social meanings visually and verbally. However, not all individuals enjoyed group participation, and thus semi-structured interviews were also used. Researchers thus selected multiple methods of data collection to accommodate individual preferences.

Enacting socially transformative practices

In participatory research, researchers challenge the underlying systemic inequalities that contribute to the marginalisation of older persons (see Prilleltensky, 2001). In both examples, this is addressed by including older individuals, who are often overlooked in research, using appropriate data collection methods, and adapting the environment to fit their needs for interaction. However, data collection does not only aim to collect useful information in collaboration with older participants to inform practical outcomes but also to support the ongoing ability of people to relate and interact in complex social settings, even after researchers have left the setting (see Dzidic et al., 2013). In Example 1, older and younger people engaged in a formal context, intentionally creating an effective interpersonal space with clear goals. Reflections both of older and younger people confirmed the broadening of their intergenerational experiences (see Roos, Hoffman & Oduaran, 2022). It would be naive to assume that a few interactions between older and younger people will necessarily change the existing structures or processes of intergenerational relations, according to Lounsbury and Mitchell (2009), but at least they present the possibility of questioning less effective intergenerational interactions. In Example 2, a cumulative strategy of data collection methods was followed to obtain information from the older residents. The use of the GRT aimed intentionally to shift the power balance to favour marginalised groups of (older) people: a forum was created for older residents to share their views with the management team to inform decision-making. They demonstrated citizen participation and control in expressing their views on issues affecting their lives in the residential care environment.

Conclusion

The growing awareness across disciplinary fields of the need to include older individuals actively in research informed the choice of including two fundamentally different research examples in South Africa to illustrate participatory data collection principles. Research on ageing—whether implemented in community-based settings, which are sometimes unpredictable and chaotic, or in a more organised setting, such as a residential care environment—requires researchers to be attentive, reflective, and responsive. The active involvement of older persons depends not only on the researchers' consideration of how the broader and immediate environments shape human behaviour, but also on creating an optimal research context, modifying data collection methods, and introducing supportive strategies in the practical application. If researchers agree that it is a basic right to involve older participants in research about issues affecting them, that it is possible to conduct research from a participant-focused perspective and to learn from examples in the field, the only unanswered question remains: Why not?

Notes

1 iGNiTe: Older Individuals' Cell Phone Use and Intra/Intergenerational Networks.
2 we-DELIVER: Holistic service delivery to older people by local government through ICT.
3 South Africa now has 12 official languages.
4 The Mmogo-method has been trademarked by the North-West University, South Africa.

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11

CHALLENGES AND OPPORTUNITIES OF NEW PRODUCT CO-CREATION WITH OLDER CONSUMERS

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Introduction

Participatory research with older adults has been gaining popularity in social sciences. The field of consumer studies adheres to this trend, especially as the importance of the needs of older consumers is increasingly acknowledged within aging societies. Co-creation initiatives engage consumers and companies in the joint development of products and services. This chapter discusses the experiences of the EIT Food RIS Consumer Engagement Labs project (henceforth: Consumer Engagement Labs), focused specifically on the creative participation of older adults. The co-creation processes implemented in 2019–2021 involved more than 200 older adults divided into small teams collaborating with the representatives of food companies. The creative processes were organized in 14 European countries and yielded 22 new food products that were introduced to the market.

The chapter discusses key challenges of co-creation processes with older people, leveraging the practical experiences of Consumer Engagement Labs. Its structure is inspired by the steps of the typical co-creation process. The chapter will start by presenting co-creation as a participatory research method and an approach to the development or improvement of products and services. Then, it will discuss key characteristics of older adults as consumers and co-creation participants. Subsequently, practical challenges of co-creation endeavors involving older adults will be presented, including the recruitment of participants, the organization of creative processes, and the facilitation of discussions. After the characterization of co-creation process, the chapter will also analyze the expected co-creation outcomes, both for companies (new product proposals) and for participating consumers (personal benefits). The discussions will conclude with ethical considerations pertaining to co-creation initiatives involving older adults.

Co-creation

Co-creation involves inputs by users into product design (Prahalad & Ramaswamy, 2006, 22) and can be understood as a creative process, in which multiple actors jointly create new products or services, or shape experiences and values derived from the use

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(Ind & Coates, 2008). Co-creation can bridge the gap between producers and users, allowing companies to identify specific requirements and better comprehend the experiences of users. This might prove particularly relevant while designing products and services for older adults, as the involvement of users as co-creators can be expected to improve the product designs and stimulate their adoption.

Co-creation might involve various social actors, expressing their needs and contributing to creative developments, but particularly popular is the involvement of customers who inspire the creation or refinement of products (Prahalad & Ramaswamy, 2006, 22). Enhanced understanding of user needs is linked to successful sales of new products (Ottum & Moore, 1997). Co-creation differs from traditional approaches to product development, carried out within corporate research and development laboratories, and is more focused on technologies than actual needs – it could also be characterized as DUI: doing, using, and interacting (Jensen et al., 2007).

The role of users in the refinement of physical artifacts is widely recognized in social sciences (Bijker et al., 1989; Sanders & Starppers, 2008). Von Hippel (1976) was among the first scholars postulating that companies extend invitations to users and involve them in new product design processes, and this involvement is expected to enhance the functionality and acceptance of products designed with and for older adults (Davidson & Jensen, 2013; Mahr et al., 2014). Co-creation as participatory activities enable "implicit design by customer presence" (Dahlsten, 2004, 146), enacted through dialogues between product design experts and potential users. It has the potential to increase the designers' empathy (Leonard & Rayport, 1997, 103) and result in more useful and creative proposals than ideas generated by corporate experts (Kristensson et al., 2002; Nishikawa et al., 2013). Depending on the extent of their involvement, customers may supply information, work alongside corporate designers or carry out innovative activities (Cui & Wu, 2016, 519–520). Their participation might concern multiple stages of product development, ranging from the description of needs or the generation of ideas and concepts to the evaluation, prototyping, and testing of specific product designs (Kaulio, 1998; Lagrosen, 2005).

The food industry presents a particularly interesting setting for consumer participation (Busse & Siebert, 2018). Co-creation of food is linked to the everyday experiences of consumers who engage in innovative culinary practices by creating or modifying recipes, substituting food ingredients, and experimenting in their kitchens. This means that barriers for consumer participation in co-creation activities are relatively low when compared to other industries, where companies usually need to offer dedicated tools to enable consumer involvement in the creative activities (von Hippel, 2005, 128).

The term co-creation used in organizational context does not always denote participatory research but is sometimes used to describe stakeholder consultations, innovation contests, or collection of user feedback and suggestions through online platforms. The increased popularity of co-creation in public policy discourse makes the term prone to diverging interpretations, but the chapter focuses on the original scope of co-creation, implemented through dialogue with individuals, ideally through participatory workshops.

Older adults as consumers

The process of aging involves changes and adaptations in various spheres of life, including consumer behaviors. Food-related practices of older adults as consumers are influenced by a wide variety of factors. Firstly, they include individual biographical events, such as

retirement, becoming a grandparent or widowhood (Rosenbloom & Whittington, 1993), earlier-in-life experiences and historical events alongside their interpretations (Moschis, 2007) as well as collective experiences of the age cohort (Devine, 2005). Secondly, some older adults experience deterioration of health and chemosensory declines that influence their food choices. This could further be exacerbated by the decreasing financial resources of retirees, who become more attentive to the cost of food. Scholars highlight the importance of healthy eating, including through the supply of proteins (Hung et al., 2019; Lonnie et al., 2018) and micronutrient intake (Sharkey, 2008), changing sensory experiences related to eating (Krondl et al., 1982; Bédard et al., 2020) in the context of oral comfort (Vandenberghe-Descamps, 2018) and the chemosensory decline of gustatory (taste) and olfactory (smell) functions (Kremer, 2007). Thirdly, food-related behaviors are highly influenced by factors affecting some of the older adults, such as functional limitations (Micheli, 2018), limited mobility (Meneely et al., 2009), deteriorated manual dexterity (Rowson & Yoxall, 2011), as well as psychological and cognitive changes affecting decision-making and emotion regulation strategies (Drolet et al., 2019). Moreover, physiological, psychological, and societal conditions increase the prevalence of the loss of appetite (Cox et al., 2020) and food neophobia – fear of unknown or novel foods (Soucier et al., 2019) – among older adults. Older consumers share various characteristics but remain highly heterogeneous, and attempts to identify common denominators present a risk of unification, simplification, and stereotyping (Mumel & Prodnik, 2005). Participatory studies, including co-creation, leverage qualitative approaches to consumer insights, and have the potential to enhance the understanding of the aging process by taking into account intra-group differences of the participating older consumers (Moschis, 1992).

Recruitment of participants

The heterogeneity of user needs (von Hippel, 2005, 33) is an important aspect of participatory product design and calls for an appropriate selection of participants in co-creation initiatives, with a view to generate ideas that consider the expectations of a wide variety of consumers. Companies may derive tangible benefits from the insights provided by the co-creating consumers (Mahr et al., 2014, 604), as long as the participants have meaningful experiences and are capable of offering relevant contributions. Even though the overall number of participants was quite large for a qualitative study (ca. 200 people), the country-level samples were relatively small (ca. 15 participants each), so they could not ensure sufficient representation of all relevant segments in the general population. In each country, the participants were split into three consumer teams (42 teams in total). Furthermore, the participants' willingness to attend the creative sessions co-occurs with certain personality traits or other characteristics such as specific interests in the topic of the co-creation process or the focal product category. For co-creation initiatives, including initiatives involving older adults, the diversity of participants appears more important than the representativeness of the consumer sample.

As regards the issue of financial remuneration of the research participants, there are different stances presented in the literature. According to Thompson (1996), financial remuneration helps to maintain equality in the relation between the researcher and the research participant. It is also a relatively efficient way to ensure participation in research activities (Bell & Salmon, 2011; Kelly et al., 2017). Others claim that in the case of vulnerable persons, offering financial rewards for participation may de facto limit the scope of one's

freedom to decide about the study involvement as participants may feel pressured to do so (Tyldum, 2011). However, it is essential from an ethical point of view to consider who benefits from the research, especially as the co-creation process is based on consumer work that is later appropriated by companies commercializing their product ideas (Zwick et al., 2008). That is why it is an important ethical question of how to reward the participants appropriately. The participants of the Consumer Engagement Labs did not receive direct financial compensation for their contributions; however, all of them were offered tangible incentives (valuable sets of food products) from the companies that took part in the project.

In the Consumer Engagement Labs, the older adults were selected for the co-creating panels based on quotas intended to increase the variation of several variables: age groups (people aged 65–69, 70–79, 80, and more years), gender, household sizes (including couples and single dwellers), places of residence (urban or rural), levels of education and specific food product preferences. Each panel was organized in a single country, involving local residents with relatively uniform cultural backgrounds and fluency in the local language (ethnic diversity was not purposely maximized nor controlled). Consequently, each team of older consumers working together in the co-creation process included participants with distinctively diverse backgrounds, and these differences ignited creative discussions, as well as opened up opportunities for understanding the diverging needs and consumption habits. For older adults invited to engage in co-creation discussions of new food products, the balance between genders and levels of education appeared difficult to achieve in some of the consumer teams.

The recruitment procedures were focused on non-experts, unfamiliar with food manufacturing processes, professional cooking, or marketing techniques since the lack of technical knowledge or domain expertise of co-creating users was not expected to impair their creativity (Kristensson et al., 2007, 485). For co-creation initiatives that expect breakthrough results, "average" users might lack the necessary foresight and focus on familiar problems and solutions, unable to go beyond their everyday experiences (von Hippel, 1986, 791–792). Instead of representative or diverse participant samples, the co-creation organizers could look for "lead users", who have significant experiences with the focal product category and have strong motivations to look for improvements as they are dissatisfied with the existing product features (von Hippel, 1986; Vernette & Hamdi-Kidar, 2014, 155). Another option is the group of "emergent nature consumers", imaginative and visionary, capable of setting new trends or anticipating future technology developments (Vernette & Hamdi-Kidar, 2010, 155–156; Juaneda-Ayensa et al., 2019, 676). Recruitment procedures of older adults involve additional challenges that should be considered by researchers, as some applicants might be affected by chronic illnesses, limited physical mobility, or available time (Dibartolo & McCrone, 2003; Fudge et al., 2007). For example, online promotion and registration might not be acceptable for many older adults, even if they are Internet users. Promising channels include non-governmental organizations, universities of the third age, catering establishments, health centers, shopping venues, and churches. While selecting co-creation participants, the organizers should refrain from accepting circles of friends or life partners attending the same creative workshop, as they are likely to share similar experiences that limit the diversity of the consumer panel.

The recruitment needs to clearly outline benefits for participants. Co-creation participants follow a multitude of intrinsic motives, including: the feelings of autonomy and competence, task enjoyment and the sense of community (Füller et al., 2011, 262–263), which are likely to outweigh the possible financial benefits. Interviews with the Labs participants

helped better understand their perspective and revealed that the identified benefits included: sharing and acquiring knowledge, achieving meaningful outcomes, doing something good for the society and the older population, but also meeting new people, enhancing one's own creativity and spending time in an interesting and entertaining manner.

Co-creation processes

Co-creation processes may take place either in physical or online environments and each option creates specific challenges for the organizers and participants. When the co-creation takes place in a physical space, the organizers need to ensure safe and hygienic conditions. Some older adults experience health problems and mobility limitations. It is recommended to carefully select the workshop location and eliminate physical barriers, which could impair the participants' mobility. The organizers should also ensure easy access to toilets as well as drinking water. The food should meet the health and nutrition requirements for older persons, and this needs to be explicitly communicated to the catering suppliers.

In 2019, the first Consumer Engagement Labs were organized as physical, face-to-face meetings, lasting altogether two days. The COVID-19 pandemic, which spread across Europe in 2020, made many researchers implement significant changes in the methodology they applied (Dodds & Hess, 2020; Roberts et al., 2021; Surmiak et al., 2021). The Labs needed to switch to the online format and adjust the design of sessions. The online workshops rendered some of the practical challenges of workshops held in physical space irrelevant, but other problems emerged.

There is a need to take account of group's needs in terms of breaks etc., and online meetings should follow the same good practice. Excessive time in front of computers may cause headaches, spine, and sight problems, which could be exacerbated through long and intensive video conferences (Abida, 2011; Shoshan & Wehrt, 2022). The Labs were split into shorter sessions, spread over multiple days, to reduce the strain on participants' health (Gewin, 2020). Two days of physical meetings were transposed into ten online sessions, each lasting about two hours, taking place over two weeks.

Despite the increasing usage of computers and Internet, older adults tend to encounter more challenges in using the Internet and computer applications than younger generations (Gatto & Tak, 2008; Chang et al., 2015; Hill et al., 2015), but their participation in online workshops becomes a trigger for learning. The use of Internet helps overcome the obstacles that prevent people from meeting acquaintances, such as limited physical mobility or chronic illnesses (Hill et al., 2015). Formatting of materials and presentations might need to be adjusted to the requirements of older adults, particularly when using video conferences (e.g. larger font size, contrasting colors, shorter texts displayed at once). Unexpected problems with computer or Internet connection increase the stress levels, so the organizers might establish channels for backup communication (e.g. call the participants, who experience temporary connection problems to offer technical assistance).

Older adults appear particularly vulnerable when it comes to protecting their privacy in online collaboration. Video conferences dismantle the division between the private and public spheres (Davis & Jurgenson, 2014), and others may see the house interior or background events of an unaware participant. Therefore, the participants should be advised how to turn off their cameras and microphones when it is needed to protect their privacy. A good practice implemented in the Consumer Engagement Labs was the organization of a pre-session, dedicated to testing the software and connectivity of participants. Such a "tech

walk" allows participants to get to know each other and intensifies their collaboration during the subsequent, creative sessions. Many older participants turned out to be avid users of smartphone communicators, maintaining contacts with their peers and facilitators via group messaging between the workshop sessions.

Challenges of facilitation

Facilitators of co-creation processes can leverage experiences from various research techniques including focus group interviews, in-depth interviews, observations, and teamwork. The facilitators need to create a safe and friendly atmosphere, in which participants share their experiences, opinions, and ideas, without being insecure or exposed to criticism (Powell & Single, 1996, 501; Salvo, 2001).

An important challenge concerns the continuous engagement of participants throughout the process, which might be difficult, especially in online workshops. Video conference might not be an obvious setting for older adults as its communication dynamics differs from physical meetings. For example, it is much harder to have vivid discussions among multiple participants, and group talks are difficult to facilitate. Consumer Engagement Labs were implemented as a sequence of sessions, and this helped maintain participants' engagement, especially as avoiding drop-outs became vital for the effectiveness of the creative process. The engagement was linked to positive working relationships with the facilitators, established during recruitment and onboarding. Furthermore, the attractiveness of tasks retained the interests of consumers. For example, the generation of new ideas required time for individual analyses in conjunction with the creative teamwork, and participants were inspired by a variety of assignments, e.g. a supermarket visit proved essential to verify products already available in shops, alongside fact-checking related to the contents of own kitchen shelves and fridge.

The facilitator should not excessively control the participants (Bloor et al., 2001), but rather support the group dynamics, manage conflicts among team members, and react to any signs of abuse. Divergences of views may be the source of inspiration (Barbour, 2007) that spurs new ideas. Nevertheless, the team dynamics need to remain balanced, especially as personality traits or professional experiences might predispose some participants to assume control over the discussion. The constructive group dynamics rest upon the creation of a safe space for participants, who do not feel ashamed or intimidated while putting forward their proposals. The atmosphere can also minimize the risk of silencing some voices, as this could yield less innovative outcomes (Davidson & Jensen, 2013). Enhancement of interactions among participants can inspire synergies, e.g. by virtue of dedicated group exercises. At the same time, the control of time by facilitators becomes important, particularly as discussions of highly-engaged participants might last longer than originally planned.

The organizers of the Consumer Engagement Labs explicitly acknowledged the quality of creative outputs generated by consumers. Each consumer team was offered a specific award at the end of the process, with all participants receiving positive feedback. The categories of awards were named in ways that made them credible, but at the same time eliminated the competitive dimension (awards were not given for the "best" product idea, but rather acknowledged the sustainability, revival of ancient and forgotten ingredients, or creative modification of traditional recipes). The non-competitive character of the endeavor proved important for the participating older adults. This approach diverged from the experiences of companies, which were accustomed to idea competitions, contests organized

for startups, or hackathons for young individuals, and needed to be sensitized to the non-rivalrous context of working with consumers.

Co-creation outcomes – perspective of companies

Co-creation outcomes, expected by companies, would be ready-to-implement proposals of new products, but the actual results appear more nuanced. The ideas of consumers tend to be less technically sophisticated than proposals put forward by experts (Poetz & Schreier, 2012, 252), because co-creation participants lack the specialist knowledge of technologies, manufacturing, or marketing techniques. The ideas are also relatively conservative and do not represent radical technological breakthroughs (Bogers et al., 2010, 868; Enzing et al., 2011, 246). Nevertheless, they can be very inspiring, including non-obvious creative features that could not have been conceived by corporate designers, whose excessive familiarity with the products, technologies, and manufacturing methods restricts creativity (Kristensson et al., 2007, 486). The creativity of users results from their discontent with known products and aspirations to improve their experiences.

The experiences of Consumer Engagement Labs revealed distinctive features of new product proposals. First, new product ideas, put forward by older adults, represented rather incremental than radical innovations. The ideas proposed by older adults usually concerned new product flavors, packaging shapes, unit sizes, and aspects increasing the usage convenience than fundamentally new product formulations. This was consistent with the dichotomy of symbolic and functional innovations: symbolic innovations focus on aesthetics, convenience, product positioning, and meaning to users, while functional innovations increase product performance, add previously unknown features, and address user problems in novel ways (Sääksjärvi & Hellén, 2019, 588).

The co-created proposals often seemed to only have limited technical feasibility or commercial viability. This should not be surprising as the participating consumers were not marketing experts. Certain expectations could not be met by producers, e.g. combinations of ingredients, impossible health benefits, longer than realistic product shelf lives, and elimination of sugar or other ingredients without impairing the sensory experiences.

An important tendency observed in the co-creation processes concerned the outputs initially discarded by participants, which proved particularly useful sources of inspiration for companies. The outcomes included not only well-defined product proposals but also proto-ideas (Klincewicz, 2021): consumer insights and suggestions which were mentioned during the team discussions but were not pursued later by the consumers. Interestingly, these proto-ideas were often as inspiring for companies as the final product proposals picked up by the consumers themselves, because they shed light upon various aspects of products expected by older adults, including e.g. unit sizes, weight, packaging, easiness of sealing and resealing, preferences to eliminate certain ingredients or highlight selected aspects on product labels. The proto-ideas could be spotted through careful analysis of the transcripts of discussions. They offer important insights into specific consumer requirements and could inspire producers to introduce product innovations, leveraging not merely the final product proposals identified by consumers but also acknowledge various suggestions put forward by participants in the course of the co-creation process.

An important part of the co-creation experience is the appropriate management of expectations of participants, as there could be no guarantees that products proposed by consumers would be eventually introduced to the market, and final products might differ

substantially from the original proposals because of technological, marketing, or manufacturing constraints. A dialogue between consumers and companies offers a way of overcoming this potential problem, by increasing the reciprocal awareness of the needs of older adults and producers and paving ways for further experimentation, prototyping, and product testing.

Co-creation outcomes – the perspective of individual participants

The tangible results of the Consumer Engagement Labs were 22 food products, introduced to the local markets in multiple European countries. Selected products proposed by the older adults during the Consumer Engagement Labs are briefly described. One of them is "Sunca Gourmeticus Academicum Senior", produced by the Romanian company Agronomia Agro Food Innovation SRL, made from the small chunks of meat of an exquisite breed of pigs with the addition of spicy jam. Owing to the fusion of high-quality meat and spicy condiments, older consumers get an affordable product that answers their nutritional needs, while offering value for money. It has an interesting texture that makes the product easier to bite, chew and swallow than in the case of typical ham-based cold cuts. Another product example is "Grikola", a granola made of buckwheat, produced by the Lithuanian company Ecofrisa UAB. Grikola is softer and less sticky than its cereals-based counterparts, which makes it more suitable for consumers with weaker teeth and dentures. In Portugal, ideas of older adults resulted in the creation of "Bolachas Equilíbrio" (producer: Vieira de Castro – Produtos Alimentares S.A.), a healthy version of digestive biscuits, which contain rice bran, oats, and whole-wheat flour, being low in fat, sugar, and salt.

The co-creation outcomes include also personal benefits for participants, and the creative process can foster social contacts between the consumers. The participants meet like-minded people and gain new knowledge through the peer learning and the exchange of experiential knowledge. These aspects were highlighted by the participants as perceived benefits in the ex-post evaluation, and they contributed to the cognitive empowerment of consumers. Moreover, new interpersonal relations resulting from the workshops proved particularly valuable for the participating older adults, experiencing periods of social isolation and loneliness due to the COVID-19 pandemic.

One of the positive consequences of taking part in co-creation activities is the development of creative self-efficacy, understood as the belief in one's ability to produce creative outcomes (Tierney & Farmer, 2011, 1138) that leads to the feeling of autonomy and agency, and increases in individual creativity (Haase et al., 2018). Enhancing self-efficacy may be particularly important in the case of older adults (Karwowski, 2016). This self-reinforcing process was observed in Consumer Engagement Labs. In the beginning, the older participants were a bit anxious and doubted their abilities to create innovative product concepts. Owing to creative exercises and group discussions, they've gained self-confidence and perceived themselves as capable of proposing new product ideas. The participants' self-esteem positively affects the results of creative processes (Engström & Elg, 2015, 513), and could also lead to the empowerment of participants.

Ethical considerations

Engaging older people in participatory research may pose several ethical challenges related to the risk of reproducing inequalities, and incoherent expectations of organizers

and older adults concerning their roles, time, and scope of engagement (James & Buffel, 2022, 19–21).

One of the key values in social research is the respect for participants' autonomy, enhanced by the use of informed consent (Brody, 2001, 1–2; Alsmadi, 2008). The prospective participants should understand the aim of the research, the expected use of outcomes, their right to withdraw from the process at any time, and the planned processing of their personal data. They are also entitled to understand, how the results would be used for commercial or scientific purposes (Alsmadi, 2008). The informed consent should be expressed in writing. In the Consumer Engagement Labs, the organizers were collecting signatures on the consent forms before the initial session to avoid interference with the creative process and allocate sufficient time for explanations related to the scope of the given consent. Nevertheless, the high standards of informed consent prove difficult to meet in some practical cases. First, in qualitative research, specific research questions evolve during the research process. Second, the participants may not want to get acquainted with the explanations offered by researchers (Perrault & Keating, 2017) or may misunderstand them (Wiles et al., 2007), so despite the researchers' best efforts, the participants run the risk of not paying sufficient attention to or fully comprehending the details of their research projects. Such a situation was indicated in ex-post interviews with some of the lab participants, who happened to be surprised by some of the co-creation and participatory elements of the workshops. Even though they had been informed beforehand about the aims and the form of the creative process, they still expected that the workshops would be more traditional educational activities, involving a unidirectional transfer of knowledge from expert presenters to listeners. The pre-existing imagery of hierarchical order, in which the knowledge and solutions are created and developed, proved more powerful than the explanations communicated to workshop participants.

Participants may also not possess the competencies to thoroughly understand the description of the research process if specialist terminology of social research or marketing is used. The participants should also be informed about the information they share that would stay confidential. Especially in online workshops, participants may experience anxiety regarding their privacy and the safety of the sensitive data (Bloor et al., 2001; Stewart & Williams, 2005). In co-creation processes, sensitive topics related to individual health, purchasing power, or family matters might not need to be revealed at all, e.g. the participants of EIT Food RIS Consumer Engagement Labs were discussing profiles of personas, projecting some of their own characteristics upon these idealized consumers.

Finally, co-creation processes leading to new product developments tend to be designed in ways that primarily benefit the companies. Many authors suggest that co-creation may lead to disempowering and dispossessing the participants from their insights, ideas, and experiences without getting anything in return (Zwick et al., 2008; Ind & Coates, 2008). Therefore, from the perspective of research ethics, it is crucial to pay special attention to how the participants may benefit from participating in the co-creation process.

Conclusions

Co-creation belongs to a broad array of participatory research methods. It may engage various stakeholders: citizens, companies, or non-governmental organizations. Co-creation allows the participants to express their needs and participate as equals in the process of creating new products and services. Older adults were rarely targeted by such initiatives and the experiences of the EIT Food RIS Consumer Engagement Labs project fill an important

research gap. The primary advantage of co-creation is the consideration of the heterogeneity of older adults and their empowerment as consumers and participants of the creative endeavor. The consumers working together on specific tasks reciprocally negotiate their needs and preferences on multiple levels, including their sociodemographic and psychographic characteristics, consumption practices and beliefs, as well as their approaches to products and benefits (van der Zanden et al., 2014, 160).

The chapter offered an overview of typical challenges of co-creation with older adults, leveraging the experiences of a large-scale co-creation project implemented in 14 European countries. It discussed important aspects of co-creation practices: the recruitment process, good practices recommended for face-to-face and online workshops, the scope of expected co-creation outcomes, and key ethical issues that need to be considered by the co-creation organizers. It offered practical suggestions that could enhance the researchers' sensitivity and responsiveness to the needs of participants and their potential vulnerabilities, which will in turn enable the successful implementation of co-creation initiatives.

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PART 4

Analysing and validating results together with older adults

12
EXPERIENCE OF MEMBER CHECK WITH OLDER ADULTS IN NON-PARTICIPATORY-RESEARCH-CULTURE

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Introduction

Participatory research methods used with and by older adults are widely used in many countries; however, it is not the case in Lithuania. One of the first such attempts is presented in this chapter. It was done as the follow-up of the project LoGaSET – Location-based games as a contemporary, original, and innovative method of seniors' teaching and learning (project number 2017-1-PL01-KA204-038869, https://logaset.eu/), which was implemented in four countries: Poland, Great Britain, Lithuania, and Slovakia. The project aimed at determining whether location-based game is an effective method in older adults' education in the field of information and communications technologies (ICT). Digital competence is more than just ICT functional skills, as it involves critical, creative, and collaborative uses of ICT (Jurczyk-Romanowska et al., 2019). The main objective of the project was the development of an educational location-based game model, based on Tkaczyk's (2012) conception which emphasizes condition of winning, the goal, action, obstacles, and rules. Location-based game is the method consistent with the strategy of edutainment and usually is played in an urban area (Jurczyk-Romanowska et al., 2019). The project was dedicated to older adults as well as providing new knowledge that will inform educators working with older adults and the opportunity to use this model in the training of people in their late adulthood. The project is expected to provide more attractive programs for older adults in line with their needs and expectations, to improve qualifications of teaching and training staff, and to obtain more effective activities for the benefit of local communities. Target group were people at age 60+, participants included in the location-based games should be able to walk up to 1.5 km, needed to possess a smartphone or an iPhone with internet access, and have a basic knowledge of smartphones or iPhones. After the training, a standard course's evaluation research for quality assurance purposes was done. However, the researchers went further and carried out a follow-up research incorporating member check approach aiming to validate the data of older adults' experience about training course and acquired digital competence.

The aim of the chapter is to present older adults' reflection on the text which presents their experience during the training. The main research question is what do people recognize as their experience in the presented to them text of research data analysis.

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Framework and methodology for member check research

Participatory research is widely used in many countries; however, it is implemented in Lithuania quite rarely. One of the first articles about such type of research was published in 2015 and discussed researchers' opinions about the value and challenges of the method in the research at organizations (Jarašiūnaitė et al., 2015). Twenty researchers from social and biomedical sciences in six higher education institutions during focus group interviews agreed that participatory research is a promising method, however, is very versatile and its implementation depends very much on researchers' competence. The consequent participatory studies were scare and became more prominent only in general education research field (Neifachas et al., 2022), however it almost absent in other sectors. Looking more specifically at the social service field only one participatory action research was implemented in four organizations which provided short-term and long-term services for older adults searching for possible changes in organizations for a better services provision (Varžinskienė et al., 2015). However, in the country, there is no participatory research which would include older adults as active research participants. Non-participatory research culture caused opportunities as well as challenges for the researchers' team. Researchers were eager to meaningfully involve older adults; however, lack of experience and suspiciousness of research participants brought some difficulties.

The idea to implement participatory research grew up from the concept of the project which emphasized an active involvement of the participants. The project was based on the concept of edutainment – the fusion of valuable educational content with elements of entertainment, being one of the more effective methods of transferring knowledge, acquiring skills, and shaping social attitudes. To a large extent, the effectiveness of this method is based on the informal character of education. The educational content is usually hidden in a formula attractive to the recipient, who is often unaware of the fact, that s/he is participating in education – acquiring new knowledge or developing new skills (Jurczyk-Romanowska et al., 2019). The fundamental idea of the LoGaSET project was the creation of a course for older adults in the use of smartphones. This course was realized using two methods: the location-based game method and the class lesson method. For the purpose of this project, researchers have accepted the following definitions of the two methods used:

- Location-based game – includes elements such as: condition of winning (i.e. a clear definition of when the game is won); the goal (i.e. what the player has to achieve in order to win – in each game, there are usually more goals and their achievement conditions of winning); action (i.e. clearly defined actions which the player should achieve during the game); obstacles (i.e. all the difficulties to be overcome for the player to achieve the goal – this is therefore the essence of the competition, providing the joy of the game); rules (i.e. various restrictions which must be respected during the game, but thanks to which the joy of winning is achieved) (Tkaczyk, 2012). Usually, location-based games are played in an urban area.
- The class lesson method is based on the division of students into classes. Each class, grouping students of a certain age and with similar preparation, is aimed at equipping them with a certain amount of knowledge, skills, and habits established by the curriculum of a specific subject. At the same time, the curriculum of each subject in each class

is divided into sections, and these are divided into individual lessons. Lessons in each subject are held according to a fixed timetable, either daily or every few days.

(Okoń, 1950)

The location-based games method is an innovative method in comparison to the traditional class lesson method. It is becoming more and more popular form of activity, combining entertainment with social interaction and education. However, this method previously had been aimed at young learners, raising the question of possible health related limitations for older people (Jurczyk-Romanowska et al., 2019).

The project aimed to dispel the myth and to suggest location-based game method for older adults. The games were conducted in London, Trnava, Wrocław and Vilnius. This chapter discusses location-based games in last mentioned town, revealing the experience of Lithuanians. Four groups of 10–12 people aged 60+ were formed. The training course lasted ten days with the same topics for each group. During the course, participants studied how to use the basic functions of a smartphone e.g.: camera, voice recorder, video, and useful applications such as WhatsApp, Google Translator, QR codes, Google Maps Navigation, and TripAdvisor. After the training course, qualitative research aiming to investigate learners' experience about training course and acquired digital competence was done. Focus group interviews with each group were conducted with an average duration of 40 minutes.

After the summarizing of research results, an additional step was taken by Lithuanian researchers in an attempt to get feedback from the research participants. Member check (also known as respondent validation, project's reviews) was chosen not so much for methodological reasoning (Hayashi et al., 2019; Jurczyk-Romanowska et al., 2019; Silverman, 2020; Creswell & Creswell, 2021) thus allowing to avoid controversiality of the method (Guba & Lincoln, 2005; Lincoln, 2010; Birt et al., 2016; Morse, 2016) but rather **as members reflections** as described by Smith and McGannon (2017), initiating a dialogue between a researcher and research participant for the better understanding of the phenomenon (Bygstad & Munkvold, 2007). Member check gives a possibility for research participants to check and approve their provided data, to find out if data and/or data analysis reflects the experience they have shared (Doyle, 2007). Initially researchers worked with research participants on transcribed interviews, lately methodologist like Creswell (2009) suggested that member check is better to use for analyzed but not raw data, that data or results could be discussed with participants to check for accuracy and resonance with their experiences (Creswell & Miller, 2000). Bygstad and Munkvold (2007) describe different forms of member check, including sharing and discussing interview transcripts with research participants, group meetings for discussing different interpretations of data, and presentation of report or data summary for approval prior to publication. For this research, the later form of member check was applied. It gave the possibility to engage more and to activate older adults; by constructing joint interpretative reality to keep both sides – researchers and participants – involved in continuous meaningful relations.

Member check research started by deciding on what written piece of information from the research will be presented. The extended research report was already written, so it was necessary to decide which part of the text could be presented to research participants. The chosen extract of the text is presented in Box 12.1.

Box 12.1   Text from research report which was presented for member check

When sharing their training expectations and whether those expectations were met, the informants noted that they had registered for the training hoping to increase their knowledge in the field of information and communication technology. "*I used to think what I need that app for, I don't really need it at all, but now I see that I, actually, need it!*" [I4], "*True, true, it was very useful. In fact, the expectations came true, and, as I hoped, that the topics would be somewhat known or somewhat practiced before but we would master to use them very well*" [I2]. The informants confirmed that all their expectations were met "*We got a lot*" [I7], "*We upgraded significantly*" [I3], "*It is very good that everything was activated simultaneously: we try, we do, you facilitate us*" [I1].

The informants emphasized that previously, when buying a phone, there used to be function descriptions given, "*and now they don't give it anymore, now, suit yourself*" [I1], "*the instructions are about the phone, but they are immense in length <...> but they are all on the phone, nothing about the apps*" [I8]. According to the participants of the focus group, it is very important that during the training they gained knowledge about the principles of application, "*because one cannot know everything, nor all the recipes of the world, but it is important to understand the essence*" [I6]. The informants also stated that participating in the training helped them to overcome the fear of pressing something on the phone "*that fear of pressing something wrong, not ruining what I have*" [I10], "*I really enjoyed learning the* navigation, *someone asked what would happen, if I press the "center" button, I said press and you will find out, ...so press and you will find out*" [I1],

> I am just afraid to press something, because there were all kinds of curiosities, Israel cost me a lot. I accidentally pressed the video chat, and the video chat costs a lot, probably for an internet connection. I'm turning off my mobile all the time now. You live and learn.
>
> [I7]

"*There exists fear all the time. We are afraid to catch virus because it corrupts all the information. When I go abroad, I am afraid that I will press something and then will have to pay*" [I5].

When responding about the participants' experiences in the training, what was the easiest for them, what they liked or did not like, and what emotions they experienced during the training, the informants mentioned that some felt they had returned to school.

> I was living in my school times, can you see that, my school times. God, it was my eleventh grade, something new, getting to different places, that joy of cognition, so childish, at least it was like that for me.
>
> [I3]

The participants enjoyed a very warm, friendly environment during the training, which gave them the opportunity to ask a wide range of questions without fear to appear ignorant. "*And the feeling that it is not scary to be ignorant, one feels, to put it mildly, not a fool to ask*

questions" [I6], "*You may not know, you may ask the same ten times, we have always received an answer, it is a very positive emotion here*" [I2].

However, some informants mentioned that as it sometimes happens, you seem to know a lot, and when you start learning, you see how much more can be learned. "*I am quite sensitive and I was shy to ask anything, I had thought before that I knew something, and now I feel I know nothing any more*" [I9]. All participants thanked the trainers for their patience, for giving them the opportunity to feel secure, not to be afraid to ask. "*I would like to thank that you are really wonderful in the sense that you give us courage to ask, you make one feel not ashamed and not a total fool for that, it is your approach*" [I4]. "*We would like to thank you for your great patience, in a word, we are really grateful for the courage you have inspired, for your words"press it, press it and you`ll make it*" [I10].

By sharing their experiences with the new applications on their smartphones, the informants enjoyed that they found a lot of new things, learned to be bolder encountering the new information, and gained more self-confidence. "*The Translator function was unexpected, new, to be able to write by hand and the program itself scanned. I didn't know that such things exist*" [I5], "*And my surprise is that there may be a voice translation, that translation is done by hand, it is clear, but that by voice*" [I1], "*I didn't use QR codes, for example, and Whatsapp I didn't. For me it was news*" [I8],

> I was surprised that the photos could be made in black and white. I must add here this, Whatsapp I used and seemed to know everything, but that there is a button for sound message ... it turned things exist I didn't know of, didn't think of, now we know more, deeper.
>
> [I11]

The participants of the training were happy that the time for the sessions passed very quickly, there was never any boredom, the teachers kept offering new forms of learning, inventive methods "*The most important thing there was no boring moments, there was nothing monotonous to get tired and bored of. There was something new*" [I2], "*So you come to that lecture and think about what else the girls will come up with*" [I7].

Sharing experiences that may have caused reluctance to undertake the trainings, the focus group participants mentioned that at the beginning it seemed a bit strange that the training would be game-like "*I thought, God, I came here not to play, but to learn the programs, but I don't remember what was the program*" [I2]. One informant suggested changing the WhatsApp task [requiring messages and various tools for different groups in different audiences to model the library and make it a sketch], in her opinion the task could be more relevant to the participants, true to life, "*because people did not and will not organize engineering decisions*" [I3].

Asked how valuable/useful is what they have learned and what they plan to apply their new knowledge to, the focus group participants were quite unanimous that they would like to reinforce the acquired knowledge, repeat the training "*We plan to use all, and we will apply again, we will come in autumn to secure knowledge*" [I6], "*We will certainly use this, but we would like* to *know what other courses are planned to improve the existing knowledge*" [I1], "*I want to learn more…*" [I9]. It was also mentioned that friends ask about the trainings and envy

participants. "*I think there are a lot of people around us who are in jealousy*" [I8], "*we try to send something to our junior relatives – they are stunned, surprised and, most importantly, we get praise*" [I4], "*I showed to one acquaintance how to install Whatsapp and she immediately got a message from her daughter when she logged in. "Oh, mom, what are you doing here?"* [I10]. The training participants also mentioned that they did not really expect to learn so much "*What was once a utopia is now a reality*" [I5].

For member check research non-probability convivence sample was used, 6 older adults agreed to participate. The main principles of research ethics were followed. In order to ensure confidentiality names of the participants were coded – PRI1, PRI2, etc. They were asked to read the text and to reflect on it during the interview with the researchers who provided them with training and did course evaluation research. Member check interviews were recorded, transcribed, and interview data were analyzed using qualitative content analysis which revealed two main themes: recognition of own experience and sustainability of training (Table 12.1).

Table 12.1 Themes and subthemes of member check data

Theme	Subtheme
Recognition of own experience	General impression
	Recognition of uncertainty during training
	Recognition of activation
Sustainability of the training	Sharing experience after the training
	Continues learning
	Better relations with younger generations

The validity of the member check research was ensured during data collection and analysis. The data were collected by two inside researchers who implemented the training and research participants knew them. For data analysis and interpretation an outside researcher was invited and data analysis was done together by three via constant asking, checking, and discussions.

Member check research results

Recognition of own experience. Research participants recognized their own experiences as described in the provided text. They singled out that what was described corresponded perfectly to their own experiences: *this is exactly how I remember how it is written there, what memories there are [PRI5]. Here really, really is reality [PRI1]. I recognize a lot. A lot, yes, what we learned [PRI4].*

Reflecting on their experience, research participants talked about various types of uncertainty. They pointed out that participation in the training helped to overcome fear, fear of not knowing something, fear of asking, distrust of oneself: "*Oh, it must be fear here or, I don't know, somehow it is inconvenient to ask. There sits a senior lady and she knows nothing, and her young teachers are standing in front of her [PRI1]*". "*Of course, from the start all was complicated*" [PRI4]. Several participants stressed fear of doing something

wrong, ruining their smartphone. "*I would like to add that there is still fear of doing something, thinking that some material may be lost [PRI5]*", "*Well, with all this, we are no longer afraid of the phone after your lectures, we used to be afraid, it seemed just a touch and everything will disappear*" *[PRI3]*. They also mentioned that some lacked basic knowledge at the start, and the group was too big. "*I remember what I was missing. I lacked just some initial knowledge. I had a phone and apparently I needed to first read how to use it, the instructions for use, and then just move on with the apps*"*[PRI2]*. "*The group was large and the teachers didn't have enough time for everyone*" *[PRI5]*. Also, research participants noted that people with different experiences took part in the training, some of them felt stronger and bolder, while others felt that they needed more attention. "*The group was strong and knew a lot. That Basics, The Basics of Navigation were known to others, but not to me. That's why it was problematic for me*" *[PRI6]*.

Research participants reflected that their active involvement, their own active participation, helped a lot in learning new things, they reflected that curiosity, striving for knowledge, and active participation in various learning activities encouraged them to take an interest in everything and to be active. Active participation and involvement in learning activities gave me the courage to act, try and experiment. "*But courage came very quickly, we asked all sorts of questions, and if we were dumb, we asked the same question a few times*" *[PRI2]*, "*Because you said you were going somewhere – return and you want to start exploring again. And then one such time, second time and you are getting used to the fact that nothing happens to the phone*" *[PRI1]*, "*It's important to ask because without training, you can't learn everything yourself. You have to be shown where to pay attention because you can't know everything. There is training for that, there is talk, you are presented, explained, shown*"*[PRI6]*. Moreover, the participants in the training experienced a strong bonding sense "*Our group was so good, well, that the teachers helped, that's one issue here. But there were other parallel issues, we didn't asked our teachers' attention a lot, we asked each other*" *[PRI4]*.

Sustainability of the training. Reading the text research participants were glad that they were not only active participants during the training, but they become active advisors to other older adults, they teach others themselves. "*So I say, don't look at the instructions so much, but try. You need to try, if it doesn't work out try again, then you see that it is only a laughing matter*" *[PRI3]*, "*Encourage the need for desire – they are afraid*" *[PRI2]*, "*I liked that when I was involved, I mastered that material and was able to teach others: a neighbor, a co-worker. Once you know, you start sharing*" *[PRI6]*,

> Once a friend called, oh do you have Kristina's phone - I say right away - and how do you do that - I say I hang up and then a plus where another call or phone number is connected and everything, I know - and I didn't know that, she said.
>
> *[PRI1]*

A participant also mentioned that it is very good to be able to consult a friend.

> I'd say it was not very difficult for me, I would not say. True there are questions, as is the case now. It seems like you know everything, but just if you don't use that thing, you need to either remember it, or call a friend, ask, and just do it, and so much ... <if you don't apply> you forget very quickly. Well, the age is not helping and a lot is forgotten. What you need – to remember, and continue again.
>
> *[PRI4]*

"I mean, some questions still arise. Someone should be around"[PRI5].

Research participants emphasized that it is very important to keep learning. *"It is necessary for everyone to have the desire to learn, to expand their views"[PRI2], "Now there are many newer applications. Therefore, I think the knowledge should be updated periodically"[PRI5],*

> Maybe we are too curious here, maybe what we know is enough. Children are calling or what, they say, well, mother how do you speak here, connect through this and it will be cheaper for us, programs are free, choose better. Well, we are moving forward ourselves.
>
> *[PRI3]*

The participants acknowledged that without their active subsequent use and application of the acquired knowledge and skills, it would be difficult to recall what they had learned. *"If a person is willing then, sure, your teachings are very good, but if you do not search, do not look around for anything, nothing will help, you will not succeed just by asking questions" [PRI6],*

> We, when we bought phones and came to you. It was a lot of fun for all of us. But in reality, all comes with practice, practice does everything. If you don't check out, if you don't try, then neither will you open a Facebook nor a Viber, nothing.
>
> *[PRI3]*

Nowadays, at a distance of time, research participants mention that they can appreciate what they have learned, that they are proud of themselves, and that this further activates them to delve into various new things. They expressed a wish that they would be happy to participate in other similar trainings, as the experience gained enriched them, allowed to become more active. *"It is good that you do not forget me. This and I mean I can be a participant in other such trainings" [PRI5], "Whatever I want, that's what I'm watching, because now, without messenger, without Youtube, without Facebook, it's not a day spent. All this new technology is of great interest to me and I would really like to go deeper" [PRI5], "It is important to reflect and share your experiences. This motivates as technology moves forward, now everything is different" [PRI6].* They pointed out that when they discussed the training at the end, they could not even imagine how this would help later in the pandemic period. *"We put the opportunity passport on the phone, we used it, there were no problems. We downloaded it when needed" [PRI3], "Especially during the pandemic, while sitting at home, we learned during that pandemic most such things" [PRI2].*

> Now a lot has been done by the pandemic, all is done remotely and we need to master that software even more. Registering with a doctor, for example, was not the case before. Obtain a passport or expired rights. You have booked in the past, you have gone and now you will not be accepted, you have to book in advance, you have to book an appointment. This is where computer literacy comes into play.
>
> *[PRI6]*

The ability to master new technologies has not only improved the quality of life of research participants, but also helped to understand better the younger generations. *"Today I repeat*

again I am tied up as the young are, so I am an old person, without this phone, I have no idea how my life would be here" [PRI1]. "The beginning was really fun and really was such a moment - I know. You are already going on and not only young people clicking" [PRI3].

Researchers' reflection and conclusion

Even if the member check was not done in a rigid methodological way, it gave better understanding of the results from three lenses: researchers, participants, and at later stages – external readers (Creswell & Miller, 2000). Member check hasn't brought any big contradictions between presented data and members' reflection but gave an additional data for further communication and future – possibly – participatory research.

The research didn't go in a smooth way and the researchers encountered some difficulties. First of all, it was challenging to attract older adults to take part in the interview. Some of the people interviewed after the training declined the request to participate in member check interviews, saying that no one is likely to be interested in their views. Another issue was research participants' unwillingness to disclose their opinion, and modesty, i.e. when asked to reflect on provided text, they tended to direct the talk to training but not about themselves and their reflection on the text. It can be related with the stereotypical national characteristics of Lithuanians, which developed in the course of history, when talking about oneself, one's feelings, experiences was treated as rudeness, not modesty. Also, in the country, it is not common to be asked about what has already been done, namely by reflecting on one's own experiences. It was quite difficult for older adults to reflect on their experiences at least in the context of this research. However, it is important to note, that older adults who agreed to participate, indicated that they felt proud to be invited to the study, they were happy not being forgotten, and to knew that their opinions and reflections were important and interesting.

The specificity of this research is that it was done in a country where there is no culture of participatory research generally and especially with older adults, so the researchers had to learn from their own mistakes and enjoy their own achievements. This experience could add to learning path of beginners in participatory research.

The research showed that older people are willing to participate in participatory research. It gave them opportunity to share their experiences and insights, and to feel important and useful to the society and science. The authors of the paper, in close cooperation with various organizations of older people (such as the Bočiai Society, the Third Age University), plan to continue applying participatory research and to involve more older people in such activities, also target group could be expended to working-age older adults. Another potential avenue to explore is initiating participatory research in other sectors, such as healthcare.

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13

"WE TALKED ABOUT YEARS THAT I EXPERIENCED AS WELL!" – THE ROLE OF AGE IN THE PARTICIPATORY DESIGN OF PHONE BEFRIENDING SERVICES IN ESTONIA

Tiina Tambaum

Sustainable and effective phone befriending to address social isolation in later life

Loneliness is a painful human experience, a pervasive one among older people (Chen & Feeley, 2014). It is defined as the unpleasant state of acknowledging a gap between the desired and actual amount of contact or emotional support that is available in one's environment (Perlman & Peplau, 1981). Loneliness in late life is a key predictor of depression (Cacioppo et al., 2006), it is linked to poorer physical health (Cornwell & Waite, 2009) and is negatively associated with subjective well-being among older adults (Windle & Woods, 2004).

Loneliness experienced in later life is not due to a low frequency of social contact but due to a perceived lack of interpersonal intimacy or low quality of social relationships (Chen & Feeley, 2014). According to Weiss (1973 in Van Baarsen et al., 2001), feelings of loneliness may result from experiencing a deficit in relational function(s), including social integration, or reassurance of worth. Therefore, not only the contact but also its substantive quality of it is important in decreasing loneliness.

One way of reducing social isolation among older people is through befriending schemes that emphasise one-to-one relationships (Cattan et al., 2008). The phone as a specific tool of befriending has few accessibility barriers. A recent pandemic experience has shown that phone calls may be the only way to stay in touch for many older people. Thus, using the phone as a tool for befriending to alleviate the loneliness of older people is one that demands careful consideration.

Phone befriending is the act of making regular phone calls with the aim of providing the recipient with a sense of security and belonging, increasing his/her self-efficacy, supporting

self-esteem, and enriching him/her emotionally and mentally, thus affecting the receiver's subjective health and reducing loneliness. Phone befriending stands out as a service that does not deal with participants' problems, but instead, it offers participants a chance to engage in "ordinary" conversation (Cattan et al., 2008). Therefore, it can be considered as a form of intervention in which older people are treated in such a way that they do not feel themselves to be a burden to others.

Regularity must be emphasised as a key factor in phone befriending to achieve the aim of reducing loneliness. Regular phone calls can frequently become a vehicle for other activities as well, which contributes to the sustainability of the scheme (Cattan et al., 2008).

The few studies that have been done in the field of phone befriending have rather not been focused on the content of reciprocal communication. In everyday life, the calls are often driven by some practical concern or problem, or they are made as poorly concealed so-called control calls. The content of the problem-based call is obviously determined by the problem, but the alternative—calls without urgent motives, i.e. calls with the aim of reducing social isolation—should not be overlooked.

In the case of regular activities like phone befriending, the quality of the content plays an important role. Our preliminary observations refer to the fact that topics in ordinary phone conversations between older (socially isolated) person and his/her relatives, volunteers, or friends tend to be repeated, and there are few productive topics discussed (weather, news, personal health problems, etc.), which in turn may offer a low satisfaction for the CP of the conversation. Additionally, the reciprocity of the interaction tends to be low, as the CP rather assumes to perform as a listener.

According to the social cognitive theory, the interplay between personal, environmental, and behavioural factors takes place in interaction. If the phone call receiver keeps repeating the topics, it forms an environmental factor for the CP. Possibly boring or minimally relevant content forms the personal factor that influences the CP's expectation for the next call, which in turn may change his/her behaviour: e.g. the duration of the call may become shorter over time, or subsequent calls may be postponed.

Thus, based on the social cognitive theory, an assumption is made, that the call should be arranged in a way that provides satisfaction to the CP in particular. In that case, also the satisfaction of the call receiver can be assumed if the content of a phone call is derived from the previous and present life of the call recipient (CR).

Based on this hypothesis, the development research was conducted in which a series of content materials were created and tested to equip regular phone befriending in a way that ensures satisfaction for the CP in particular. The aim of the development research was to gather feedback on the materials and methodology used in phone befriending service where they can assemble inputs for their further development.

As phone befriending is a type of intervention accessible and usable for all, including older people as CPs, the participatory principles were implemented in the research. The advantages of older people as co-producers are used to confirm the urgency of the manifesto for the age-friendly movement described by Buffel and Phillipson (2018). According to these authors, in responding to the challenge of widening participation, a key task will be to develop partnerships with groups that may be disengaged from age-friendly issues. In the current research, it is claimed that without involvement, both the quality of older people's lives and the quality of the service will suffer.

Co-design as a form of participatory approach

Adopting the participatory approach is an attempt to change the power relations inherent to research that tends to be owned and controlled by researchers (Swain & French, 2004). According to some authors, with no inclusion of problem stakeholders, achieving a socially desirable outcome is not possible, and the proposed solution would face a legitimacy problem (Walker et al., 2002). The stakeholder's participation helps data triangulation, interpretation, and understanding, and enables critical reflection on researchers' own biases and assumptions (Zhang et al., 2021).

Involving older adults and utilising their skills are important ways to enhance research projects and maximise their programme reach (Davies et al., 2021). Utilising a participatory approach provides a conscious shift from the notion of developing *for* older people to building meaningful services *with* and *by* older people (Buffel et al., 2012).

Based on the literature review on older people's participation in research, Fudge and colleagues (2007) point out that evaluation has been focused on the impact on participants rather than on the impact on research processes and outcomes. According to their conclusion, to demonstrate the impact of user involvement on research quality, the definition of user involvement requires clarification. Whether a study can be considered participatory research and when the people approached, interviewed, or observed are simply a source of data for researchers depends on several conditions; for example, whether the opportunity for local stakeholders to view themselves as contributors and decision-makers, or what kind of specific creative and qualitative methods are selected and implemented throughout the participatory research (Fang et al., 2018). When it comes to older people's involvement, whether the research addresses the concerns of older people, and whether the solution the research aims to develop promotes the target group's control over the decision-making processes that shape their lives are also important (Swain & French, 2004).

These prerequisites are met in the present case. The current development research on phone befriending content and methodology addresses the concern of older people, i.e., the risk of loneliness and reduced opportunities for meaningful communication. Also, the way phone befriending service is designed and implemented is important for promoting older people's control over their lives.

Nevertheless, the emphasis of the current research is not only so much on the "opportunity to participate" or *doing with* for older people but also on the task of co-design or co-production (Davies et al., 2021). There is a need for obtaining different perspectives on phone befriending content and methodology in order to improve the quality of the development result – a training course that includes instructions on how to use the material and conduct the phone befriending call in a sustainable way. The impact on older participants is measured rather indirectly, with the focus being instead on the impact of older people's participation on research processes and outcomes.

In the current research, older participants are involved as experts of ageing, rather than as experts of the community, or some specific problem as often described in the literature on participatory approach. The differentiated contribution of the older participant compared to the younger ones is described, i.e., the contribution that may not be obtained in the study if only the younger co-designers are involved. In other words, the inevitable role of the ageing expert in designing a service for older people is shown.

In this chapter, I discuss some details that should be considered for achieving the benefits of the participatory approach as compared to the involvement of older people as a data source in conventional ways.

Research design and methods

In 2020–2021, the two-phase developing research has been conducted in Estonia, which aimed at the development of the phone befriending methodology, including the provision of the content in a way that provides the possibility for achieving satisfaction for the call provider.

The formative research methodology was implemented by using instruments of participatory research, specifically co-production. Co-production consists of activities that aim to fully involve end-users in the development of interventions, by viewing the experiential knowledge of these end-users as core to the success of their development (Oliver et al., 2019). In formative research, methodology the researcher is expected to be personally involved in "design experiments", i.e. in the operationalisation of the methods and the analysis of relevant situations. Therefore the author personally in the role of CP was engaged in the first phase of research. In the second phase of research, four forms of data were collected including immediate feedback and focus group interviews that were analysed on an ongoing basis to identify strengths and weaknesses in the service design and to make immediate improvements during the research. It is suggested to interview participants during the implementation of the design instance to avoid the memory-loss problem of interviews. At the same time, interviews during the implementation have less external validity because of intrusiveness (ibid.). Therefore two types of feedback were also gathered after the implementation of the design instance.

The possible age-related barriers or other age-related factors that may affect the outcome of co-production in phone befriending content and methodology is investigated in the current paper.

In the two-phase developing research, first, the researcher was the CP, and the 81-year-old AK, was a call receiver (CR), as well as a validator of the new content used in phone befriending conversation. The first phase of the survey lasted for 12 months. In the second phase of research, 12 call providers were found by the researcher as a result of a media campaign and separate consultations. Then, every CP found his/her CR who was retired and preferably in social isolation. Five CPs had two CRs. The CP/CR-pairs conducted phone befriending on regular bases once a week. The first phase of the research programme lasted for three months All research participants provided written informed consent before joining the development team. They also confirmed that their CRs are informed about the fact that their CP is involved in the development research.

In addition to AK from the first pair, the other older participant, 78-year-old HK, was one of the CPs in the second phase of the development research. She, like all other CPs in the second phase, tested the content and reported the results immediately after every call by filling out the web-based questionnaire. In addition to immediate feedback, three focus groups were organised among CPs during the research. The main discussion themes in focus groups were experiences of phone befriending conversations and the impact of phone befriending conversations on the relationship with CR. On the base of workshop discussions, the content of the following calls was modified. Workshop discussions also confirmed the questionnaire responses.

At the end of the three-month testing and developing period, the CP-s created general final feedback for the types of themes and tasks used and evaluated and made suggestions for the further development of the methodology and content of the phone befriending calls. In addition to these tasks, the final deliberative dialogue was held with HK to obtain feedback from the experience of participating in the participatory research.

HK is the main participant I am focused on in the current research. Next to HK, the data of the youngest 28-year-old participator MK is included in the analysis. HK and MK formed the two extremes of the CP's group in terms of age. Both HK and MK knew their CR very well – MK had the phone befriending call with her relative, and HK with her long-term friend. Results indicated by MK form the context or the base of comparison for interpreting HK's results.

A reflexive thematic analysis was used to analyse the focus group interviews and the general final feedback as well as the open answers in immediate feedback forms. Through a thematic analysis of the focus group's notes, I identified the key themes which formed a base for the final deliberative dialogue with HK. The triangulation method was implemented by two researchers while analysing HK's general final feedback and notes of the deliberative dialogue. Data quantification was used to analyse the closed answers in immediate feedback forms. Quantitative and qualitative data were used in a mixed way. Feedback provided by HK, MK, and other participants was analysed from three perspectives: how they operated during the calls; how they performed the content and methodology as developers, and how they used the instruments of the participatory research. Results are presented in the next chapter.

In the current paper, age-related issues in the process of co-production are in the focus and the feedback of other co-researchers forms the context of the current results. Nevertheless, the data of all participants were analysed and used as a base of re-modelling the service. These processes will be published in the future.

Results

I describe HK's participation in the study primarily in comparison with the youngest performer MK. I am focused on the results that became evident due to the fact that one of the developers was an older person, i.e., factors that place HK as an older participant in a different position compared to the younger participant in the process of interacting with her CR and providing development ideas. I also observe HK as an older person by executing the participatory research methodology.

Age as an objective cause for differences between younger and older participant

HK and MK made calls once a week, as outlined in the research project. They showed a significant difference in the duration of the call. While the average duration for MK was 27.6 minutes (median 27), the average call conducted by HK was 1.5 times longer at 41.7 minutes (median 40).

In the opinion of both, there were no completely failed calls. HK reported complete satisfaction with her calls ten times, and MK seven times. MK justified her satisfaction with the call more from the "me"-position and HK more from the "us"-position ("us" referring to HK and her CR together).

HK highly appreciated the reciprocal nature of the conversations and felt mostly positive emotions during the call. The recovery of one's own memories as a result of commonly experienced reminiscence was also highly evaluated by HK. ("I can say that we both gained knowledge", "We came to an opinion together…"). In fact, MK also appreciated the opportunity to have a say, but for objective reasons, MK had significantly less opportunities for that.

> MK: "Finally I was able to say a lot here, because at one point, we talked about years that I experienced as well."

MK relied more on self-interest to bring out the benefits of the phone company. She appreciated the fact that she herself had received support from CR, which had revived her own memories. Also, she felt good to be able to help the CR ("I once praised CR, and she laughed so heartily, it was nice to hear that"). HK never saw herself in the position of a so-called benefactor of the CR.

The overall assessment of the impact of the phone befriending calls on CR was positive. Table 13.1 shows how HK, MK, and the rest of the group of participants assessed the impact of calls on CRs.

Table 13.1 Assessment of the impact of the phone befriending calls

	MK, % of calls (Total number of calls 12)	HK, % of calls (Total number of calls 12)	The rest of CPs, % of calls (Total number of calls 150)
Yes, CR's cognitive abilities (memory, relationships, spatial perception, etc.) were stimulated	100	92	85
Yes, CR got ideas for the future	25	25	23
Yes, CR's general trust in the environment increased	0	8	17
Yes, CR's sense of belonging was supported	50	0	72
Yes, CR learned something new during the call	25	67	43
Yes, CR received support to analyse his/her attitudes and values	8	42	29
Yes, CR's belief in his/her ability to cope improved (self-efficacy)	8	42	26

There were three indicators among results of HK and MK in which MK had fewer such calls than the average, and HK had more than the average: these indicators were improving the self-efficacy of the CR, offering substance for the CR to analyse his/her attitudes and values and gain new knowledge. This raises the question of whether the difference is associated with CP's age difference.

At the end of each call, the participants also assessed the reciprocity of their interaction. HK rated the parties' contribution as 50/50 in nine calls, and MK in five. HK differed from all other CPs in this result. Thus, HK had more balanced conversations than others, and other CPs were more in the role of questioner, allowing CR to speak. It is possible that this is why HK also managed to provoke a discussion on values and support the self-efficacy of the CR.

Younger and older participants as developers during the calls

The instructions given to the study participants allowed them to change the given material at their own discretion, according to the CRs and their own preferences and situations. There was a significant difference between the actions of MK and HK. HK used the material unchanged eight times out of twelve, and MK only three times. Both rarely exchanged content, MK once and HK twice. What HK did less frequently than MK throughout the study was shortening the material: MK omitted one part of the material seven times; HK did so twice. The reason HK found it necessary to shorten the material was that the CR had some problems (e.g. did not hear well). With regards to MK, in addition to CR's problems, she shortened the material without providing any justification.

A characteristic example in which both HK and MK had difficulties with the material: the task asked them to describe their first meetings with certain relatives in the past. In both cases, CRs were known to have complex family relationships. MK did not ask about several relatives *because* she was aware of CR's complicated relationship with them and "did not want to hurt CR"; HK left out no questions, *although* she was aware of CR's difficult relationship with them.

HK did not omit the task, although the CR expressed fatigue, or argued that she did not know the answer. In response, HK gave the CR a "longer time to think", because it was certain that CR knew the answer. As HK was a peer of the CR, she was therefore able to be more consistent in her demands.

As a participating co-developer, MK was more of a formal questioner than an equal interlocutor. From MK's feedback, it can be concluded that she has difficulty managing the conversation in a way that would stimulate the CR to make a moderate effort. At the same time, one context-free keyword may be enough for HK to switch the topic of the conversation:

> MK: "CR didn't like this task, and I personally also would have had difficulties memorising four words at one time on the phone to put them in a queue. CR came out with it, but I realized she felt like I was testing her memory, and so on.."

> HK: "In our conversation, the word 'tooth drill' on an issue sparked a longer discussion. The story almost reached childhood."

HK did not take full responsibility for conducting the survey but shared responsibility with the CR. MK was making calls *for* CR rather than *with* CR. HK saw the role of the co-developer as her main role, while MK saw the role of the conversation partner as her main role.

As mentioned above, both MK and HK did rarely change the content of phone befriending calls. One task that both changed was the task to roll a dice to determine the year to be discussed. Both abandoned the use of the dice, but the ways in which the situation came out were different. HK herself determined the "good years" for CR, the recall of which was likely to evoke positive emotions. However, MK applied a tactic of cooperation: together with the CR, she chose to discuss the years from which they could both have a say, i.e., the years of MK's life. Older CPs such as HK do not need to define "common years" because they are automatically available due to her age.

HK's direct motivation in the dice task was to refrain from evoking negative memories. This was the only time during the study where HK herself assumed which topic in the given material would not give a positive result, and refrained from addressing it. MK made such assumptions constantly, often before the call and without knowing the facts, which the CR could not or did not want to talk about certain topics. For example, MK omitted the question, "When did you last smoke", knowing that the CR does not smoke. However, MK's knowledge of CR's smoking history was limited to her own (relatively short) lifespan, i.e. her acquaintanceship with CR.

On a few occasions, both reported problems with their CRs (MK pointed to CR's distress; HK to CR's distraction), but they addressed the situation differently. MK shortened the material without any additional effort; HK experimented with and combined some previously developed tactics.

> HK: "Because the CR had a hearing problem, she asked to repeat almost everything. I understood what she had caught and what she hadn't. The content remained the same, but if the CR didn't understand correctly, I gave an example of my own life. And then we were able to move on with the talk".

A comparison of HK's and MM's feedback records showed that both indicated a certain type of poor timing of the phone befriending calls, but the risks they pointed out were different and partly due to their age-related lifestyle. MK repeatedly indicated that her own fatigue, distraction, and general speaking time in the evening changed the quality of her call ("I was tired myself, and I could have talked longer, but I felt I couldn't", "We agreed to call at lunch, which was actually a bad idea because I was distracted and not as focused as I could be"). HK never referred to the obstacles she posed, although her calls were made at different times during the day, and once in the evening.

Younger and older participants' proposals for the service development

In the feedback, HK suggested one type of topic that she repeatedly had to talk about in her phone befriending, which can be summarised as "life in youth". The conscious contribution as a service developer was reflected in HK's recommendations on how to prepare for a phone call. HK repeatedly emphasised the need to prepare the conversation as if she were to be the CR, and to answer the questions.

> HK: "I liked to do everything on my own before calling. I knew how to express myself so that the CR wouldn't feel bad. When the CR paused for thought, I would quickly gave an example from my own experience. Our conversations were almost all 50/50."

HK recommends that the CR's worldview and hobbies need to be clarified, but not for the purpose of compiling phone befriending call content, but for tactical purposes: to be able to quickly find a new topic if the topics suggested in the call are not suitable. She also suggests remembering what the CR has said, precisely in order to be ready to temporarily switch to "everyday topics" at a difficult moment in the call.

> HK: "I have noticed that if the CR's stories are repeated, or if the CR remains thinking for a longer time, I have changed topics. For example, since the CR's younger son had a birthday yesterday, the children became the topic of our conversation. At the same time, we linked everything given by the research to the topics of conversation".

In similar situations, MK reached a zone of discomfort from which she felt trapped. Here, HK's suggestions on how to prepare a speech would have helped MK.

MK was unable to encourage CR to discuss topics that the CR knew that CP is also familiar with. For example, they were unable to develop a conversation about neighbours they had both encountered, although this would have been an opportunity to develop a balanced conversation. For HK, on the contrary, the common experience had a triggering force on the conversation.

When HK deliberately did not make suggestions about the content of the materials, she did have recommendations on how to re-use the best topics and tasks. In the following calls, she suggests recalling and revisiting the tasks of the previous calls, arguing that "many of the topics covered will probably be soon forgotten the CR soon". In the final interview with HK, as the actor of the participatory research, HK confirmed that they have continued the regular phone befriending calls with the CR in spite of the project's end. HK re-used the material because she was "unable to compile new material herself".

In subsequent calls, HK also recommended reminding the CR of some of her own plans or dreams which she had talked about or promised to do in previous calls. Another tactic that HK continued to use was to advise the CR to use these tasks they have completed during the calls independently at other times.

> HK: "For example, if you are not able to fall asleep, think about some activities we have done in our calls."

Older and younger participants as users of the research instruments

In the feedback completed after each call, HK repeatedly expressed concern about her own near future while sharing observations about changes in the CR's health and functional capabilities. HK tended to transfer CR's changed health status to her own future, which, in turn, reduced her satisfaction with the call.

> HK in the final interview: "In general, such aging made me sad. You are like the last person still alive."

There were no additional ideas on how to develop the type of tasks expressed by HK; at the same time, HK described the course of the conversations during each given task without generalisation at the type level. Therefore, the final questionnaire duplicated the feedback

given at the end of each calls. MK followed the instructions for completing the final development form more accurately, and also suggested new tasks within each type of task.

The goals of the phone befriending call support the basic idea of phone befriending, namely that the call should offer satisfaction to the CP in particular. The final questionnaire directly asked the respondent to assess the convenience of using each type of task. As a result, MK gave feedback more in terms of her own comfort, and HK in terms of another person's discomfort.

MK: "I was very reluctant to ask this question about physical touch."

HK: "My interlocutor encountered an error with this question about physical touch."

Both HK and MK repeatedly expressed themselves that although they failed with some tasks during the call, this does not necessarily suggest that the task itself was unsuitable. MK directly recommended the use of certain tasks that she personally preferred, and HK shared the same idea by apologising to the CR.

MK: "We skipped this task, /… /, but I liked it myself, and I should do similar tasks."

HK: "This time it was a bit confusing. We discussed all the characters one by one. I believe that CR just had a negative day…"

Thus, in both cases, assessing the convenience of the tasks depended not only on how well the task was performed but also on how highly the assessor values the task itself.

It was convenient for MK when it was easy for the CR to discuss a given topic, and inconvenient when the topic did not stimulate the CR. HK did not have such a problem, because she was always thoroughly prepared for the call. However, in addition to the preparation, the CP's convenience of the topic development was supported by the fact that most of the tasks led to thinking about events and things from the past. In these cases, the content of the phone befriending calls forms the generational knowledge for older CPs like HK and her CR, but for younger CPs like MK, it forms either semantic knowledge or none at all. The lack of common knowledge between the generations may be one of the reasons why HK did not perceive the tasks as "testing" the CR or as "cross-interviewing", which was true for MK.

The second participant in the current research, AK, was the CR in the first phase of the research. Her CP took notes during the calls without involving AK. However, AK was involved in validating the phone befriending content that was used in her calls. In this role, AK was not able to provide objective feedback, as she had approved almost all topics and tasks.

Interpretation of results from the perspectives of the call providers' age difference

The research highlighted the importance of inclusion of an older co-developer, as without her probably there would not have reached some eloquent results.

I saw that in some cases older CP had better preconditions to achieve the balance of interaction due to her age. First, because she has had a longer coexistence (as a peer) with the CR, as the past and (historical) experience are important in phone befriending materials.

In addition, it should be noticed that a conversation is a sequence of connected utterances, and each subsequent utterance has a relation to the previous one. The older CP has objectively more knowledge to relate with what she hears from the CR. At the same time, I do not want to claim that younger and older people differ in their amount of knowledge, but rather in the amount of knowledge that can be associated with the CR's utterances. Here, it is necessary to encourage younger CPs to open up in subtopics in which they have more competent than the CRs.

Achieving positive emotions through a provision of moderate cognitive challenge also demonstrated possible age-related mechanisms as far older CP as a CR's peer may have more confidence about the CR's general cultural and historical knowledge, which provided an opportunity to be more patient and consistent in the phone conversation.

Additionally, a risk of using older CPs was revealed. The older the CP there higher might be the risk that he/she would transfer CR's higher age-related negative feelings and experiences in his/her near future.

The current case showed that CPs did not have age-related differences in refraining from activating CRs' negative memories and achieving positive emotions, but used different techniques to achieve a positive result. The younger CP tended to exclude material that she thought was "risky" or involved making unfounded assumptions in advance; the older CP did not rule out "risky" topics but was prepared to skip over them on an ongoing basis if necessary.

Observations with regard to involving older people in a participatory research

It is emphasised that non-researchers should be involved as research participants in all phases of the research (Swain & French, 2004). HK participated only in selected parts of the research – in data collection and partly in data analysis as issues discussed in focus groups had risen from the preliminary data analysis. Despite the fact that HK was not deliberately involved in setting the research agenda and method of dissemination, she in fact, did contribute to its dissemination. She made phone calls following the same methodology she was asked to practice in the research project. This may indicate the difference between the participants who are co-producers and those who are included as members of the sample of the research. Being part of the participatory research may work in such a way that participants embrace the service they have co-produced.

Unlike HK, the second actor in the research – AK – remained primarily a source for data collection despite the fact that the role of the validator was proposed for her. The attempt to involve AK in data collection and analysis essentially failed. This may have been due to the fact that AK felt a hierarchical relationship in the research project, which made the first phase of the research a non-participatory one (Swain & French, 2004). AK did not feel responsible for the research, nor did she feel like a co-producer, because the academic researcher in the role of the CP had not given her the authority to evaluate the content of the call on an ongoing basis during the series of calls. However, this was the case for HK, who was very clearly mandated to participate (along with other CPs) in data collection and methodology development.

In parallel to the role of a co-producer, HK was the research subject as well. Her feedback contributed unique knowledge on how the phone befriending methodology should be instructed in the case that the CR and the CP are representatives of the same – older

– generation. The same appeared, for example, in the research conducted by Zhang and colleagues (2021), in which the boundary between the researcher and the research subject was blurred. Their study involved two Chinese immigrant volunteers teaching English in Chinese communities who were treated as both "participants and researchers". Zhang and colleagues saw them making a tremendous contribution to knowledge production because these older voluntary teachers "were knowledgeable about the context and had personal experience of volunteering". According to Swain and French (2004), the use of a dual role is justified as "there are not two types of research, participatory and non-participatory, but an imperative for researchers to critically reflect on projects in terms of the realisation of participatory principles".

The emphasis of the current research is not so much on providing the "opportunity to participate" or, as it is re-phrased by Davies and her colleagues (2021), "doing with" older people, but the service design of the phone befriending needed the perspective of an individual service user; in other words, the prospective service user, and therefore the service user was "involved in her own use of service" (Braye, 2000 in Swain and French, 2004). However, it is true that if HK had not participated, the service development would have remained "doing for" older people.

According to the literature, non-academic people with sensitive problems like menopause (Sydora et al., 2021) or mental health issues (Zanjani & Rowles, 2012) are invited to participate in participatory research. In the current study, HK was in the role of an expert of ageing. I assumed that she as an older person could "reflect, explore and disseminate the views, concerns, feelings, and experiences of research participants from their own perspectives" (Swain & French, 2004). This is a precise description of HK's role in the study. In addition to the reflection on her views, concerns, feelings, and experiences as the CP, she also reflected on the process from a CR's perspective, as she embodied herself as a CR when preparing the call. HK also saw herself in a dyad with CR, and she did not separate herself as a researcher looking at the CR from a distance. HK did not bear the responsibility to be the study participant alone but also included CR.

If the idea of involving community members in participatory research is to change people's contribution and perception of the community in which they live (e.g. Chojenta et al., 2018), the question arises as t whether expertise in ageing can be considered equivalent to expertise in a community. HK's participation in old age was indeed affected, albeit rather negatively, as she reflected signs of CR degeneration as an inevitability of her personal future. Therefore, the psychological risks (Swain & French, 2004) were manifested in the current participatory research.

Conclusions

The current case of the inclusion of older people as co-producers in the development of services that aim to improve their quality of life was encouraging. Inclusion can be beneficial for older participants and highlights nuances in the service that would not be possible without older people's involvement in development research. The importance of inclusion of older persons as CP in phone befriending service development is manifested through shared coexistence (survivorship), which in turn may provide an opportunity to achieve a better balance in the interaction. The advantage of a peer may also help to avoid the phenomenon that in the current case characterised the younger participant – making advance unreasonable assumptions about the choice of material.

It was shown that the older participant is able to mediate the experience from the perspective of both the service provider and the end user of the service. Nevertheless, replications and ongoing formative research studies are needed in the future to validate the current results of cases.

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14

WHEN CARE IS MOVING IN – PARTICIPATORY APPROACHES TO ELICIT NEEDS AND DESIRES WHEN HEALTHCARE HAS BECOME A NATURAL PART OF YOUR DAILY LIFE

Giana Carli Lorenzini and Johanna Persson

Designing for sustainable care of older people

If we were to describe a person by 2050, she would have gray hair, wrinkles, arthritic hands, diabetes, and high blood pressure. By then, she would be one of the more than 1.5 billion people aged 65 or older (United Nations, 2019). However, she would not be in a hospital bed. Instead, she would most likely be taking many medications at home to keep her health stable and perform her daily activities. At a certain point, she would probably need to get help from assistive technology but sometimes also from a nurse or a home care aide.

This illustrative example reminds us that we are here to live longer supported by extensive developments in healthcare that allow many treatments for chronic conditions to be taken at home. The shift from hospital settings to home settings brings independence in the process of care, but it also puts additional responsibility in the hands of patients and their informal caregivers (Genet et al., 2011). Society must be prepared to support a healthy and active life of older people, while simultaneously being able to meet changed disease patterns including comorbidity, polypharmacy and increased needs for long-term home care (Nordic Council of Ministers, 2014). In this context, participatory approaches are of relevance to understand how users interact with healthcare artifacts at home, and how users can be involved in decisions that impact directly on their processes of care.

This chapter builds on experiences from two empirical cases, where qualitative participatory data collection and validation methods were used regarding the design of home care products used by older people. Based on the cases, we present learnings, methodological challenges, and recommendations when involving users in participatory research in home care.

Participatory approaches in design research

Participatory Design has its origins in Scandinavia, in response to "the transformation of workplaces driven by the introduction of computers" in the early 1970s (Ehn et al., 1987; Simonsen & Robertson, 2013). The core idea was that those impacted by a certain technology should actively participate in their design. Participatory Design challenges an expert-led perspective, where designers "instinctively design for their own capabilities and skills" (Keates & Clarkson, 2003), and users are often excluded from the design process or excluded from the use of the design solutions – to genuine participation, where users collaborate as partners in co-creating (Sanders & Stappers, 2008). Participatory Design also stems from the civil rights movements in the 1960s (Arnstein, 1969; Sanoff, 2000), the aim being to empower citizens guided by democratic practices where power relations are equalized, giving voice to those who are affected by the design solutions and by working with users in real context (Kensing & Greenbaum, 2013).

Participatory Design in design research comprises some participatory approaches in which a toolbox of methods can be implemented to activate and engage users (Ehn, 1993). The design researcher takes the role of facilitator, leading users in their expressions of creativity and self-expression (Sanders & Stappers, 2008), as well as advancing theory and methods for participatory approaches to design. This role differs from the traditional role of "translator" when a design researcher merely translates insights from users to professional designers.

Levels and modes of user participation

Overall, different levels of participation take place at different stages of the design process and imply using distinct methods. Scholars seem to agree that user participation at earlier stages of the design process creates opportunities for genuine participation when users are then invited to actively elaborate on their experiences and co-create having designers as facilitators (design *by users*). As users are involved in later phases, their participation tends to take a consultative role, where solutions previously created by designers are then presented and commented upon, and design is made *with users*. Finally, participation can be limited to designing *for users*, when users act as informants, i.e., a source of data to designers, with limited say on how products are designed (Damodaran, 1996; Kaulio, 1998).

The different levels of participation also imply a selection of different forms through which users actively or passively participate (Vines et al., 2013). In that sense, users can simultaneously become the producers and consumers of content through different media – e.g., through digital platforms where they can upload videos and photos, or just comment on content posted by others. This can also be done in an analog way, through co-creation workshops, bodystorming, or prototype testing, for example. Using multiple forms of participation can potentially enrich the participatory process, at the same time it lets users take a reflective role.

Participatory approaches in home care research

Participatory approaches have been called for from many fronts in home care but are rather recent, with scarce empirical studies. Research conducted with users and their interaction with healthcare products often have users displaced from home, with testing of products in

laboratory settings that either simplify or exclude the complexity of the home environment. Home care is a collaborative care context with patients, caregivers, and family members often working closely together (Christensen & Grönvall, 2011). Home care requires much equipment and material, which tends to make parts of the home hospital-like. It is a challenge to create good working conditions and high safety for all parties, without losing the character of the home. Therefore, it is important that participatory approaches used in the home care setting include this highly collaborative perspective, capturing the characteristics of the home care setting.

Differently than for other commercial products where users are invited to participate and co-create when a marketing opportunity is foreseen, for home care products participatory approaches are ultimately meant to empower users (e.g., family members, healthcare personnel) in their processes of care. When participatory approaches move into the home, there are further challenges due to the diversity of people's home environments as compared to the hospital or nursing home. Additionally, it has been shown that the motivation for older adults to participate might be to break routines, differentiate themselves from other seniors, or hope contributing to improve care (Frennert & Östlund, 2016). This is in line with Grönvall and Kyng (2013), who point to the divergent interests of participatory design of home-based (technology-assisted) treatment among older people.

Case 1: Participation in design research about medications and their packaging

In the processes of self-care at home, patients and carers often face a daily use of multiple medications, which come packed in different types of containers. Medication packaging is known to be designed with emphasis on its protective function but with a lack of consideration of user needs (de la Fuente & Bix, 2011). Surprisingly, research in this field has focused on investigations of interaction that exists between people (especially older people) and packaging in situations where participants are displaced from their home environment (Lorenzini & Hellström, 2017) and where study participants have a minimal role in reflecting about their experiences with their treatment and how medication packaging takes part on it.

Considering that, the case described here was designed to actively involve older people in the data collection and validation about their day-to-day experiences of using multiple medications and medication packaging. The case presented reflects about the participatory approach of completing a solicited diary with photo elicitation through the perspective of the diarists (i.e., older people).

Solicited diaries and photography to elicit participation at home

Solicited diaries are, in nature, different from personal diaries: they are meant to fill a purpose and they bring strong awareness about the presence of another reader (e.g., the researcher) (Elliott, 1997). Through a note-taking process, participants report in writing their experiences with life events, products, and daily routines with the intention of allowing the researcher to read and take part in the interpretation of it. Solicited diaries follow the pace of the diarists, giving them time to reflect about feelings and experiences lived in an environment where the researcher is not present to make inferences. Solicited diaries

have been used for decades in healthcare research as a useful methodological approach to uncover otherwise trivial or difficult to capture experiences (Milligan et al., 2005), especially in relation to "symptom identification and management, use of health services, and responses to medical and nursing interventions" (Burman, 1995, p. 151). Solicited diaries allow a participatory approach to home care.

A classical approach is to intercalate the solicited diary with interviews in what is known as the *diary interview method* (Zimmerman & Wieder, 1977). The interviews become a meeting place where power relationships become balanced, having the solicited diary as a common ground for discussion. As highlighted by Rosner et al. (1992, p. 263), interviews with older people about their health conditions are often seen "as a social visit, an unhurried opportunity to talk about themselves to an interested listener", taking on "the feeling of conversation". Lately, researchers have started to increment the use of a solicited diary, adding other resources for data collection through participants, such as photography. Taking photos elicits significant moments for the diarists, creating an opportunity for them to build on their narrative of daily events, and inviting the researcher to become acquainted with the life of the diarist (Kantrowitz-Gordon & Vandermause, 2016).

Method

Data was collected with older people through the diary interview method. Invitations were made in community facilities for social gathering and through a patient education center. People who were 65 years of age or older at the time of the study, using three or more different medications daily, and interested in reporting their routines and experiences with their medication packaging were invited to participate. Participants could also indicate other people to be contacted.

Fifteen people (ten females, five males), mean age 76.2 years (range=65-88 years) enrolled in the study as participants, i.e. diarists. Two-thirds of them had to take up to seven different medications daily, whereas one-third had up to 15 medications for everyday use. For most of them, medication had been part of their lives for many years, with 12 participants reporting the use of at least one medicine for a chronic condition for over a decade (e.g., high blood pressure, diabetes). Other medications were added to their treatment over the years (Lorenzini et al., 2022).

First, one interview was carried out with each diarist by one researcher, either at the home of the participant or at the university facilities. This initial interview was an opportunity for the researcher to know about the context of living of each diarist, their history of using medications, and the daily routines for taking them. At the end of this interview, the diarist received: one instant photo camera to take pictures of the medication and their routines; one step-by-step manual with instructions about how to operate the instant photo camera; a glue stick; a copy of the signed consent form; and a diary. The diarist could ask questions and try to use the instant camera before starting to complete the diary on their own.

For seven consecutive days, each participant filled out the diary. The diary had one cover page and seven double-sided A4 sheets. In each sheet, there was a space to paste the photo of the day, followed by a description (*I took this picture because…; when I see this picture I feel…; this picture reminds me of…*). There were general questions about general well-being and self-care routines (e.g., *What did I do today to take care of my health; How was my experience today with my medication packaging?*).

Figure 14.1   On the left: storage of medications at home. On the center: variety of medication packaging used. On the right: routines for the intake of medication.

Within three weeks of diary completion, a follow-up interview was booked. In this interview, the same researcher sat down individually with each diarist to reflect about the entries made in the diary, but also to talk about the overall process of completing the diary, the intentions and reasonings with each photo taken, and the notes associated with it. The participant could explain the photo and the general memories of that day. All the interviews were audio recorded and transcribed verbatim.

Reflecting about the use of medications and their packaging design

Diarists, in general, wrote the diary and took the pictures without problems (Figure 14.1). The solicited diaries were filled with idiosyncrasies of the daily living of entirely different people, who shared the situation of being old and in need of managing multiple medications for chronic conditions (Lorenzini et al., 2022). Many diaries had a very objective approach to the task, with photos of medication and packaging followed by descriptive notes. For those, short sentences or a single word seemed to be enough to respond to the prompted questions. Nevertheless, other diarists preferred to write very detailed answers and tidily hand-written notes. They were committed to the task of completing the diary and making the most in their contribution to the research process.

More than just describing the routines built around their medication management, diarists reflected about inherent facts related to the use of multiple medications, for instance, when taking photos and commenting about the waste generated by the plastics used in the packages, how taking the medication impacted in their lives, and how they perceived home care (Lorenzini et al., 2022). Common aspects of the narratives in the diaries allowed the researcher to identify the frustration with medication packaging, e.g., packaging that was difficult to open or packaging that made the removal of the medication complicated or time-consuming (Figure 14.2).

A few diarists had a creative approach to the process of completing the diary, deviating from the main task by taking photos of other ordinary facts of their lives and commenting about this in the follow-up interview. One example was a diarist that pasted a photo of her training shoes. She explained she did not manage to exercise because of the side effects of her medication. Later in the week, she added another picture, this time of a bicycle, commenting she was finally able to ride her bike again. In the follow-up interview, she explained that it was important for her to be able to exercise after having

Figure 14.2   On the left: a package difficult to open. On the center: multiple blister packages, indicating the time spent to remove the medication from their packaging. On the right: tools used to open the medication packaging.

a stroke, and to feel active in her daily life. Similarly, another diarist added photos that were not related to medication but to her life in general – flowers at her home, which were given to her in celebration of her birthday, the image of a bus referring to a trip with friends, a picture of students to symbolize her work at the university. For her, these were pleasant moments that seemed more important to register amid the use of many medications.

Revisiting the process of writing a solicited diary

The process of revisiting the diaries together with participants was an enriching process, where diarists could describe orally about their choices of what to depict or comment on the diary, adding information to it. Together, diarists and researchers could spend time talking about the overall experience of completing a solicited diary and contributing actively to research about self-care and the management of multiple medications and their packaging. Differently than in other data collection processes, the blank diary pages with question prompts and the camera gave autonomy to the diarists to depict their own narratives in the diary. Despite that, it was clear from their comments in the final interview that there was an invisible presence of the researcher, which led those diarists to ask, for instance, *What do they want with this answer?*; *What is important here?*

By answering the question *How do you feel today?*, diarists were instigated to reflect about their feelings in regard to their health, but also about stressful experiences in their healthcare that, otherwise, would not be acknowledged. In this process, some diarists put themselves in a perspective in relation to other patients, showing empathy with other older people living with chronic conditions, who also needed to manage several medications a day.

When asked about the process of writing the diary, it became evident that filling a diary with the same prompt questions became monotonous as time passed by, with an evident loss of interest as life mostly went along as usual. By the end of the week, it was not uncommon to see diarists were out of ideas about what to write, as one diarist mentioned:

It went well for three days, then I thought 'aff, should I do that again?', It was because I'd grown tired of the repetition. Doing the same thing every day. The diary asks how I am and so on, and if nothing dramatic happens, you [the researcher] just get 'no, okay, well' […]

[extracted from Lorenzini and Olsson (2021)]

Regarding this, another diarist commented that completing the diary was *nice and easy* as he just *had ideas and suggestions for seven days*, probably indicating he had planned his diary ahead according to the timeframe the researchers gave him. Likewise, another diarist said: *It was only a week, so really nothing at all. If it had been three months, one could complain about it.*

Case 2: Participatory design of equipment for home care – a home for one and a workplace for the other

The aim of the study presented in this case was to develop solutions which combine ergonomics and aesthetic aspects to improve home care both for the resident and the care personnel. This case looks at the participatory methods performed throughout the three phases of the design process: (1) exploring the home environment, (2) generating product prototypes that support home care, and (3) developing and evaluating these prototypes. Emphasis is put on the methods that have served to make the process participatory both for residents and care workers.

Safe care and a home-like feeling

A home environment represents personal values and lifestyle and contributes to a sense of security. The atmosphere associated with one's home is important to an older person (Gillsjo et al., 2011). Research on how the introduction of home care and the design of artifacts for this purpose affect the older person's sense of being at home is sparse. A few studies investigate design for achieving a home-like feeling in nursing homes (de Veer & Kerkstra, 2001; Vihma, 2013), pointing to the importance of finding a good balance between the common spaces and the resident's private space, to help the residents to feel as at home as possible despite being in a nursing home. For care personnel, the home becomes their workspace and many studies point to a number of work-related risks in the home care setting (Carneiro et al., 2017; Hignett et al., 2016). The needs of the two user groups in home care patients and residents on one hand, and home care personnel on the other hand – may hence be contradictory. Ergonomic equipment and adjustments of the home is necessary to deliver safe care and support a sustainable work environment. On the other hand, all equipment needed for home care may transform parts of the home into a hospital and cause stigma for the resident.

Method

The study was divided into three phases, each one involving activities together with the different user groups: (1) exploring the home environment with a focus on the home care situation, (2) innovating and designing product prototypes to support home care, (3) developing

and evaluating the prototypes. Phase 1 explored the home environment in homes where a resident received home care and potential improvement areas were identified. This phase consisted of interviews and observations. Eight contextual interviews were conducted with home care patients in their homes. Five interviews were also held with care personnel (three nurses, one doctor, and one biomedical engineer). Finally, 11 observation sessions with home care personnel were carried out. The observations were full-day sessions, where one person from the home care team was followed throughout their workday. The observations were carried out in the form of shadowing (Czarniawska, 2014), which means that the researcher, as a "shadow", observes in the background, without disturbing or influencing the person being observed.

In Phase 2, students from product development, product engineering, and design education were engaged to generate new product ideas for the home care setting. The ideas should be functional but also focus on preserving the home-like feeling. In the students' own design process, they had to involve users, for instance, through design workshops with older people. In the third and final phase, the most promising ideas from Phase 2 were further developed into functioning physical prototypes. To check the validity of the proposed products, they were evaluated through interviews, workshops, an exhibition, and actual usage in the home.

Perspectives of home care from two user groups

Phase 1 served as an entrance into the private sphere of people living with home care, allowing them to display their living space and how their care situation was entangled in their home and social life, and what they liked and disliked about the situation. Following home care personnel around provided an opportunity to see an even bigger variation of homes, how care was organized in these different settings, how relatives acted, but – most importantly – that the home is first and foremost a home, and not customized for the care situation. The observed home environments looked very different depending on how large the living space was, how the home was furnished, and how much care material was needed.

A hospital or a nursing home has spaces adapted to the activities that are to be performed, whereas a home can never be adapted in the same way. A threshold between two rooms may suddenly be a hindrance for the patient to move around, a risk for falling, and a work environment problem for home care personnel. The home may be adjusted to some extent for certain equipment. Ramps may be used to overcome the worst threshold problems; lift support at the bedside or sofa and a walker are aids that increase the patient's ability to move around. There are also a number of other aids of various sizes to support either the patient or the personnel. In several of the homes, spaces were crowded, and boxes with different disposable materials were often stacked in different places. The combination of supporting equipment and disposable material for providing proper care was not optimal since there was seldom space to use the equipment without certain modifications in behavior. Figure 14.3 exemplifies what the environments with home care looked like.

Being able to access the home environment together with different user groups, i.e., both with patients, other family members, and care personnel, was necessary to understand the different perspectives, and sometimes contradicting needs, that are unique for this specific context. It was furthermore valuable to meet the various user groups one at a time (or at least separate the care personnel from the patient and family) to be able to speak about

Figure 14.3   An example of how the home environment might look like when home care has moved in.

the care situation without filters. Care personnel might have a good relationship with the patient but still, be able to point out issues in the patient's home that they know would be sensitive to mention in front of the patient. Likewise, the patient might have many ideas about how their care situation could be supported in ways that are beyond the scope of what the care personnel can do. For the patient, it was also about power structures since speaking their mind towards the municipality, which they are dependent on for receiving good care, might feel awkward. Having someone neutral facilitating the process was hence advantageous.

Participatory design of product ideas

The product ideas that were generated in Phase 2 – a total of approximately 150 ideas in different stages of development – were generated with various levels of participation. On the lowest level of participation, knowledge about the users generated in the first phase served as a source of data for the designers to create product ideas. From a participatory perspective, this can only be considered to be an informative level (Damodaran, 1996) since design is only informed by data about the users, while the users were not actually co-creating the product ideas.

Figure 14.4   Design workshop with older users.

The majority of the student design processes reached a consultative level of participation, where user groups were consulted throughout different steps of the process (Damodaran, 1996). This was, for example, achieved by showing sketches or prototypes to users and discussing them together. One example of an activity that reached even further on the participatory design scale and approached the co-creating level where users take on the role of designers (Damodaran, 1996), was a workshop in which older persons were invited to interact with sketches or physical mock-ups of the product ideas (Figure 14.4), in order to develop the ideas further.

A few product ideas were built as physical prototypes that were close in functionality to a final product. These were: a storage furniture that can modulate to different needs, a tray table, a stool, a leg support, and a wearable light. These product ideas were evaluated at the end of the project and two of the methods – testing in the home and holding an exhibition – will be described and discussed here.

The storage furniture was built in two copies and placed in the homes of two different patients and used for a few weeks (Figure 14.5). After this time the residents were interviewed and personnel that had worked in these homes gave feedback on the product. Both user groups were hence able to be active in the evaluation of this product. As pointed out by Damodaran (1996), in these later phases of the design process, user participation is more on a consultative level since the design cannot be changed as easily but merely

Figure 14.5   The prototype of the storage furniture tested in the home environment.

commented upon. On the other hand, the residents were able to actively elaborate on the product and provide ideas that would feed directly into the next iteration of the product.

Testing in the actual home environment is a desirable method but it must be done with the highest consideration. No hazards to the care situation, or to the people in the home, can risk to be introduced. The storage furniture was considered useful for all patients and all home environments and was not considered to induce any additional risks. It basically just collects all material in one place and offers a clean and ergonomic work surface.

To get a practitioner perspective, an exhibition with prototypes was created. All home care personnel could visit the exhibition and see, feel, test, and provide feedback on the product ideas. Although the personnel were not asked to think from a patient perspective, it often happened that they did just that, or at least from the perspective of working in a person's home. This group of people is used to create solutions for their work situation departing from the needs and desires of the patient and the patient's home. So, it is quite natural for them to include this perspective in their way of thinking, and, in this way, the personnel served as proxies to the patients and the homes.

Learnings, methodological challenges, and recommendations for participatory approaches of home care products in older people's lives

Both cases brought a series of fruitful learnings that presented us with advantages of involving older people and healthcare personnel in participatory approaches of design research that can, ultimately, lead to the design of better home care products.

In Case 1, participation was activated in the data collection process, where participants became diarists, narrating their experiences with multiple medications and their packaging embedded in their self-care routines. Many diarists were interested in advocating for a change in medication packaging design. They wanted to share their knowledge about living with chronic conditions, as well as they shared empathy with other older people dealing with similar issues. The knowledge generated and the active participation of diarists gave rise to the unmet needs, often not evident by other traditional research approaches in this field.

We learned that it is important participants find purposefulness in their participation in design research to keep the engagement throughout the process, especially when the researcher is not there. In Case 1, this was done through communication and open dialogue from the early start. Simply giving the diary with instructions to participants would probably not be enough, which stresses the importance of using a combined method to increase the participation level. Through the interviews, researcher and diarists became familiar with one another; while through the diary completion, diarists were given time to frame their thoughts, take photographs, and write about them. This process gave ownership to diarists of the data collection process, which differed consistently from what would have happened if the researcher had taken all the photos. Through their photos, diarists showed different angles of living with multiple medications to take, and the role packaging played in their experiences with chronic diseases and treatment. More than this, by reflecting about the photos and notes, diarists allowed the researcher to enter their reality, seen through their eyes. It is known, for instance, that medication packaging can be difficult to open by shaky hands that have lost strength. However, it is less known that an older woman needs to buy several household tools to open different sorts of containers or that managing medication routines makes sense when built into other daily life routines.

In Case 2, participation was created in the exploration of the home environment where home care was performed, followed by the generation and evaluation of ideas for new product design. The contextual interviews with elderly care recipients gave a rich and descriptive view of the situation with home care and – in combination with the observations performed together with home care personnel – the home care situation was observed and understood in its actual context. Since the home is a private sphere, and the patients might be in a vulnerable state, it is not always possible to access the home or involve older patients in design and research. Relatives, home care personnel, or other persons with vast knowledge about the home care setting might then serve as proxies in the design process. In Case 2, we were able to access the home environment together with the different user groups, older people/residents as well as care personnel, which was crucial for understanding the various and sometimes contradicting needs. However, doing observations with home care personnel did highlight the perspective of this user group rather than the patients, which one must keep in mind.

The participatory approaches in Case 2 involved a lot of sketches, models, and other visualizations of the product ideas. Working with such design material is useful to direct the discussion toward the artifacts and the environment rather than the people in it, which was noticeable both when testing prototypes in the home and with personnel in the exhibition.

Table 14.1 Summary of key learnings, methodological challenges, and recommendations

Summary of key learnings	Methodological challenges identified	Recommendations to tackle methodological challenges
Participants actively involved in the data collection and validation process became responsible for their own narrative through multiple sources (e.g., personal notes, photography) and could present the data from their perspective.	- Extensive, in-depth qualitative data that are complex to analyze. - Loss of focus on the main task and deviation can compromise data collection.	- Concise coding scheme. - Consultation with participants during different phases of the data collection process. - Consultation with research peers throughout the coding process. - Clear instructions. - Explain how their participation contributes to the research. - Pre-formatted tools and prompt questions to avoid deviation.
Older people are capable of using technical gadgets to collect data and can learn from participatory approaches to design research.	- Technical disturbances can compromise data collection. - Technical limitations can annoy participants and demotivate them.	- Conduct a pilot study. - Use intuitive gadgets. - Provide demonstrations and instructions. - Establish contact while data collection is ongoing.
Participants may represent different user groups and highlight different challenges or needs.	- User groups with possibly contradicting needs participate. - Home care personnel may represent both their own perspective, the care recipient's perspective, or a relative's perspective when expressing challenges or needs.	- Analyze the results through the lens of the user group's perspective and be extra attentive to who's needs the personnel express. - Let participants from one user group have an opinion on ideas emanating from other user groups.
The home is a private sphere and doing participatory design research there, with potentially vulnerable people, is not always possible.	- Those who can participate only represent a subset of those receiving home care.	- Home care personnel or relatives may serve as proxies for the real users. - Make sure that the proxy person is asked to answer on behalf of their own perspective as well as the patient's or the home's perspective.
Evaluating design prototypes in the home environment increases the chances of active participation and relevant feedback.	- The prototypes that are being evaluated must not impose any risks in the care process. - If high-fidelity prototypes are used, it must be clear to all users that they are prototypes and not completed products.	- Only prototypes that do not impose any risks may be tested, ethical considerations must be taken and information about what is being tested and the state of the prototype must be clearly communicated.

Adapted from Lorenzini and Olsson (2021).

The design material, whether being simple cardboard mock-ups or high-fidelity prototypes, enables the stakeholders to make their own experiences and knowledge more explicit, which encourages the participants to take a more active role in the design process (Ehn, 1993).

In parallel with the learnings from the two cases, methodological challenges arose. In Table 14.1, we present a series of methodological challenges found along the way and make recommendations to respond to those challenges. These recommendations might be useful to other academics and practitioners using participatory approaches to design research with older people and home care personnel.

Finally, it is important to acknowledge that, even though it is recommended to let users also participate in the definition of the research process, for instance, by defining methods, tools, and techniques used (Vines et al., 2013), both of our projects did not reach that far. Our efforts were focused on later stages, where users were given voice to express themselves. Their participation happened at a consultative level (Damodaran, 1996).

Doing participatory research in the home care setting is challenging mainly due to the privacy of the home and the vulnerability of the person receiving home care. The effects of home care on the home environment are an insufficiently studied field of research that will need more attention due to the increasing amount of older people living with complex care needs in the home. It is furthermore a challenging environment for providing care, which means that both the residents, including care recipients and their relatives, and care personnel should be made active participants in the continuous development of home care. We are strong advocates of participatory approaches that allow older people to reflect upon their own capabilities and needs in their daily care situation to design healthcare products that fit with real user needs and that promote good health and well-being.

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15

OLDER ADULTS IN RESEARCH

A participatory approach to sexuality and intimacy based on an example from Poland

Mariola Bieńko and Damian Kalita

Introduction

There exists the myth of asexuality or "sexual old age" – a specific stereotype suggesting that older people do not evince sexual or erotic interests, needs, desires, and wishes, and that their erotic life is coming to an end (Bieńko, 2015). Researchers dealing with old age point to the emergence of a new "sexy oldie" stereotype. It is based on the conviction that a sexual act is an expression of healthy and perfect old age; that sex at this age is delightful and expresses true love; and that in some cases, full sexual prowess requires medical intervention (Gott, 2005). Globally, a high percentage of those in their 70s and 80s thinks about, and misses, sex (AARP, 2010).

Sexuality of people at an older age is an important component of health. Entering into a sexual relationship improves the quality of their lives as well as eliminates risk factors for civilisation diseases (diabetes, neoplastic diseases, atherosclerosis, cardiovascular disease, overweight and obesity, allergies). Contemporary research proves that sexual activity promotes longevity, improves older adults' psychological and physical well-being, and generally mobilises the immunity system towards health outcomes (Gott & Hinchliff, 2003; Lindau & Gavrilova, 2010). According to WHO specialists (2015), sexual health is the centre of increasing the quality of life as well as the resource which guarantees development. Sexual activity of old people can be indicative of their vitality, cognitive openness, and mental health. A fulfilling sexual life influences a person's self-image and gender self-identification, thus helping with the creation of one's own gender identity and enhancing the emotional bond with the male/female partner; it brings joy of life and a feeling of happiness as well as it is conducive to maintaining health and young looks (Healthy People, 2020).

The sexual behaviour of those aged 65+ has not been extensively explored in scientific literature. Alfred Kinsey's report published in 1948 concluded that older people are incapable of engaging in sexual intercourse. The few existent research studies on sexuality in old age have focused on sexual dysfunction in both men and women, as well as on the link between health and sexual activity. Also, new research is emerging proving that sexuality is an important part of many older adults as well as revealing the diversity of sexual agency and sexual expression in middle age and later in life. Many older people lead an active sexual

life, deriving from it even greater pleasure than they used to, although sometimes the forms of this activity undergo changes (Brecher, 1993; Lindau & Gavrilova, 2010; Graf & Hicks Patrick, 2014; Hinchliff & Gott, 2016).

A part of the population of senior citizens reveals a high level of sexual activity within informal relationships (Hooyman & Kiyak, 2011), they are in a committed, intimate relationship with each other without cohabiting (LAT-type cohabitation), or live in non-heteronormative relationships. The so far scarce research into the group of older gay men and lesbian women in homoerotic relationships (LGBTQAI+ elders) also indicates a high level of sexual satisfaction and positive aspects of the partners growing old together (Heaphy, 2007; Rowntree, 2015). Some contemporary surveys prove that senior citizens devote more time to sexual activity than representatives of the younger generation do. Representative research in Western countries shows that a third of 70 year olds reveals various forms of everyday sexual activity (masturbation, fondling, and sexual intercourse) (DeLamater & Karraker, 2009). In the few existing reports on Polish people's sex life, it is emphasised that senior citizens are sexually active and considerably more satisfied with their sex life than what is commonly believed (Izdebski, 2012).

Both in Poland and globally, there is a lack of qualitative or quantitative studies concerning older people's lived experiences with regard to this theme (Towler et al., 2021). In particular, qualitative methodology is underused in research on older persons' sexuality and sexual health (Sincović & Towler, 2019). The qualitative research on old people's sexuality described in this chapter constitutes sensitive research in three ways, namely because of the very subject; because of the older research participants; and because of the researchers, who are also older people. A sensitive topic in research has been defined as a topic that poses a potential threat for those involved, causing data collection, holding, or dissemination to be problematic for participants, researchers, or both (Lee & Renzetti, 1993). Admittedly, there exist scientific works on the challenges that sensitive research entails (Dickson-Swift, James, Kippen & Liamputtong, 2007); however, there are only a few analyses devoted specifically to the sexual activity of older adults as a sensitive topic. A number of researchers have written reflectively about their own experiences of researching sensitive topics (Warr, 2004). Despite the many difficulties identified by researchers, very little empirical work focusing directly on the experiences of researchers has been undertaken to date. Some exceptions include the studies by Johnson and Clarke (2003) as well as Campbell (2002). They identified that the researchers faced many challenges including emotional and physical safety as well as conflict over roles when researching sensitive topics. There is a knowledge gap with regard to how to make use of older adults' knowledge and experiences on sensitive topics, and how they could contribute to research that may concern them. The research reported here adds to the sparse empirical work in this area.

There is a clear gap in the literature on the subject when it comes to research on sexual life of older people in which older people are both the participants and the researchers. The few participatory research studies in Poland concerning older people refer to different spheres of life: social, political, economic, cultural, spiritual, or civil. They do not, however, refer to older people's sexual life at all. It is a subject matter which is extremely significant in the process of informal education, and yet it is also absent from programmes of Universities of the Third Age, which usually offer issues in the fields of art, health, and culture and physical culture, without evoking in older students feelings of embarrassment or awkwardness. Generally, Poland also lacks research projects which would bring up the theme of older people's sexuality but taking them on board as participants-researchers. The participation of older

people in international participatory studies is, similar to the case of Poland, relatively rare (Blair & Minkler, 2009). Learning opportunities were not prioritised for the older adults. In the majority of the Participatory Action Research (PAR) studies, there was no evidence to suggest that academic researchers actively pursued capacity-building with older adults through the sharing of knowledge regarding research or the teaching of skills related to data collection, data management, and analysis, or knowledge mobilisation. Older adults in participatory projects were often positioned simply as participants rather than as active co-researchers or collaborators. A small group of studies that incorporated older adults as active participants made efforts to share power and form an equitable partnership (Corrado et al., 2020). Only a handful of participatory studies demonstrated direct attempts by academic researchers to enhance older adults' research skills and knowledge (Ellins & Glasby, 2016; Buffel, 2018). The project described in this chapter takes up all these challenges of participatory research.

The description of the research project

The "archipelago of generations"[1] educational course as an introduction to participatory research

The "Archipelago of Generations" is an educational course for people aged 55+, realised by the Association of Creative Initiatives "ę" and the Institute of Applied Social Sciences of the University of Warsaw. The very name of the action directly refers to the core; young people and old people are compared to two islands which, through shared activities, create one archipelago of different generations. The project was run in the period of 2012–2019, including breaks, and 30 people took part in it, the vast majority of whom were women. The feminisation of old age translates into the fact that there are more women than men in social projects. Soft projects, i.e. ones connected with empathy and an 'intangible' effect, have always seemed to abstract to men. The point of departure when inviting female and male inhabitants of Warsaw to the Archipelago was the willingness to find a bridge between generations as well as education of older adults on the subject of changes in the contemporary world. In the course of three editions of the project, senior citizens participated as listeners, discussants, and active and creative participants in:

- A cycle of lectures, e.g. about contemporary models of family life, sexuality, fashion, modern art, language which young people use, non-heteronormative persons, as well as the LGBTQIA+ community;
- Creative workshops (e.g. film, photography);
- Studio visits in non-governmental organisations dealing with culture, human rights, and social actions;
- A cycle of debates in fashionable cafés in Warsaw, where older individuals brought up subjects important to senior citizens, e.g. sex, the feeling of happiness, or personal and public areas of life in the society.

The workshops 'unblocked' the older women in searching for their own forms of expression while using interesting and innovative techniques and materials. Studio visits broadened the range of their knowledge on the value of partnership in participatory activities for the benefit of older people in Poland. The subject of sexuality and the sexual life of senior citizens

was reappearing several times during the course. It was brought up in the Institute of Applied Social Sciences twice and it appeared twice during the discussions in Warsaw cafés. It should be noted that the subjects of the debates were chosen together with the course participants, and the discussions within these meetings were heated and emotionally marked. One of the effects of recognising the shortage of empirical analyses and any increase of awareness of the tabooisation of this sphere of social reality in Poland was the decision made by female senior citizens participating in the course to conduct research among their peers into older people's sexual activity. That initiative gave rise to participatory research within the Archipelago Lab. The research project used the creative potential and knowledge obtained by the female senior citizens taking part in the three editions of "Archipelago of Generations" the education course. Old people should participate in research which is really significant to them. In this case, female citizens asserted that interviews concerning intimacy and sexuality of people aged 65+ are a broader matter for discussion within the positive aspects of ageing and showing this process as a natural phenomenon in a human being's life cycle. The exploration of this subject is important not only for equalising the deficiencies in academic knowledge but also for changing the social awareness of sexual old age. The presented backroom of the senior women taking the decision to conduct research connected with the theme of sexuality constitutes a really important element of the description of the project. This backroom confirms the necessity to select a suitable offer of thematic classes preceding the participatory research; classes which would be developing and motivating to undertaking research as well as learning about the potential group of female researchers, their resources, and their deficits in the context of researching sensitive topics.

Challenges and tasks facing older adults – female senior citizens as research partners

The described participatory research had two editions. The first participatory study was carried out in 2016. Its second edition took place in 2022. The same group of six women aged 67–75 years old participated in both editions (in 2017, initially, the group comprised seven female senior citizens, but one of the women withdrew at an early stage of working on the research project). In 2016, the female senior women were novice social activists. They were only in the process of recognising what participation is and how one can change the surrounding world. In 2022, they joined the second edition as experienced activists who had already been part of a dozen or so projects in favour of a local community. They now realised – and emphasised this openly – that participatory research is essential for the process of knowledge production, because it promises a new and different take on the subject under study, and, thereby, enables a discovery of new aspects.

Only women joined the two editions of the project both on the side of the researchers and on the side of the researched persons. All of the female senior citizens were given the possibility to join the research process. They were given active roles in this participatory research and its evaluation process, which translated into a real influence on producing new knowledge or insights about their community. In practice, participation is closely related to a sense of community, which was very important to the participants of the "Archipelago of Generations" course. The female senior citizens, who took part in both editions of the projects, decided to co-create a research community with which they would be connected at each stage of the research process. The authors of this chapter were the project's coordinators, representing the Association of Creative Initiatives "ę" (a female university professor,

who is an experienced researcher in the area of older people's sexuality, and a social activist, who is a practitioner of projects which activated senior citizens); they both conducted the meetings and training sessions, supported all the female senior researchers who were committed to the project, and they helped them to acquire the skills necessary to fully participate in the process of collecting, analysing, and interpreting data.

Therefore, we first developed – and worked towards – a code of practice with explicit values; second, we worked with skills. Both in the first and the second editions of the research, the older adult co-researchers received three training sessions on various aspects of the research process. The first one concerned the discussion and acceptance of the objectives and the schedule of the research project; the second one was a workshop on methodology; and the third meeting was devoted to ethical research considerations. On their path from retired people to fledgling researchers, it was necessary for the female senior citizens to: understand the context of social research, assess their individual and collective capacities, develop new skills, and establish themselves as people who are capable of undertaking research work. As such, those older adults were able to be actively involved in designing interview tools, recruiting participants, carrying out interviews, participating in data analysis, and sharing the findings. The female senior researchers were encouraged and motivated by us to comment on the project at its every stage. They developed some knowledge and skills with regard to discussing the nature of involvement, too. It involves participation in a community of practice that refers not just to engagement in certain activities with certain people, but to a more encompassing process of being active participants in the practices of a research team and constructing identities in relation to this team. Participatory dynamics – such as, e.g. workshops, meetings, group discussions – were an opportunity for feedback in the validation process.

The first meeting – making a contract

In both editions of the project, the building of egalitarian relations between the coordinators and the female senior researchers was looked after. In such a situation, it is critical that all the members establish parameters defining an "equitable partnership" (Blair & Minkler, 2009). The senior citizens worked out their shared stance that participation is voluntary, and must rely on credible information on the subject of expressing – and the meaning of – the senior researchers' viewpoints and opinions as well as on the subject of the possibility of their participation and involvement at each stage of the research, and that they have to have a possibility to initiate activities and realise their own ideas. During the first meeting, before starting with data collection, a specific contract was made between the two project coordinators and the senior women; a set of expectations had been worked out regarding what should be undertaken within the project. At the procedural level, the time and place of conducting the project, the timeframe of activities, and the composition of the research team were all determined. In accordance with the rules of a successful contract (Steiner, 1974), four rules of cooperation were negotiated, namely: (1) co-responsibility for fulfilling the task, i.e. mutual agreement (without a sense of being coerced into anything) as to the objective, the method, and the result of the work as well as the commitment of both parties; (2) the equality of parties and a just exchange involving both parties deriving benefits from this exchange (mutual exchange of suitable experiences, qualifications, and skills needed for the task to be fulfilled, as well as the readiness to incorporate suggested solutions or tools); (3) defining the competencies of both parties; (4) clarity and transparency, i.e. the

subject of the contract is ethical and complies with the law and the good of the society (it does not harm other people). The contract enabled easier navigation between the areas of responsibility and agency of individual senior researchers, defining, e.g., the rules of solving disputable issues, the rules and forms of participation (e.g. the professor-researcher can be more managerial at the stage of data analysis, organising the validation process, and popularising research results, while the senior researchers can direct more at the stage of choosing a method, a technique, and a tool, as well as when recruiting the respondents).

Ethical and emotional considerations of doing research on sensitive topics with and by older adults

PAR is not only methodology, but also an ethical obligation. The question of ethical issues was dealt with during the second meeting. The senior researchers verified the joint arrangements regarding their participation in terms of their suitability and relevance to their values. The ethics they found important for meaningful participation included respect, tolerance, willingness to listen, openness, and inclusion. Both editions featured discussions on the subject of the way and possible consequences of using sensitive data obtained through interviews. During the workshops, it was repeatedly emphasised that both the very process of obtaining information and the process of using it requires researchers to consider the ethical rules of conducting scientific research. The senior researchers were prepared for the fact that each researchers encounters numerous ethical dilemmas and challenges, as it is an inseparable element of their work. It particularly concerns research into sexual practices and behaviours, as these issues belong to that which is ethically sensitive. In the course of the workshops, several key rules for the senior researchers to mind during the study were established: (a) the necessity to obtain the respondents' formal agreement to participate in a research project, which was, in turn, connected with the necessity to provide them with full information about the very process as well as the way of analysing data and presenting the collected information later on; (b) the necessity to ensure that the researched persons are comfortable, particularly with regard to the confidentiality of the disclosed information, and that no harm is done to them; not allowing any conscious omissions, exclusions, or manipulations in the processes of collecting and analysing the research material. In both editions, due to the nature of the sensitive topic, during the interviews, senior researchers emphasised that participation in the study was voluntary; that one may interrupt it at any stage or refuse to answer specific questions; and that full anonymity would be assured. They were encouraged to use active listening skills: face the participant, maintain eye contact, use frequent and brief responses such as "okay," "I see," and "uh-huh", and avoid interrupting. The researchers referred to themselves as caring, empathetic, and patient. They felt that they had been afforded a privilege by being allowed to listen to stories that were private and intimate.

In fact, researching the topic of older adults' sexuality and intimacy turned out very challenging with regard to the social competencies of the senior researchers, such as the skill to establish relations or listening and respecting other points of view. They were trained to be intentional about keeping their experience out of the language they use with topics such as sexual preference and orientation (non-heteronormative) as well as sexual techniques. In the course of the research, with the help of discussions, a proper relationship was monitored between being a theoretically impartial researcher and being a spokesperson for the community of older adults. During joint meetings, the risk of the senior researchers'

over-involvement was discussed, which would potentially endanger the scientific knowledge production.

The questions of emotions that accompany the researcher undertaking the theme of sexual practices and behaviours were not omitted in the discussions. As a consequence, strategies for researching sensitive and confidential data were worked out.

The methodological workshop

Within the Archipelago Lab, the female senior researchers took part in the third meeting, namely the methodological workshop. In 2016, together with the professional female researcher, the older women – based on the knowledge gained in the field of the methodology of social sciences – defined the objective, chose the method and the technique, and prepared a research tool, i.e. the disposition interview questions and the way of selecting a sample. In 2022, they discussed and once more accepted all the enumerated elements of the research strategy. In both editions, the studies had an exploratory character. The purpose of the kind of research discussed here is to find ways to represent people's sexual experiences as well as the context in which they live their lives. To accomplish this, researchers have to find ways to tap into people's lives. Upon discussing this matter, we decided that the most appropriate research perspective in this case is a qualitative analysis, which considers the subjective views accessible through a direct conversation. Qualitative research rooted in the interpretive paradigm is exploratory in nature, thus enabling researchers to gain information about an area about which little is known (Liamputtong & Ezzy, 2005). A qualitative approach was chosen for this study as we aimed at getting a subjective picture of older adults' sexual practices and their opinions about undertaking qualitative research on this sensitive topic by their peers.

As a result of a brainstorming session, the senior researchers worked out – with the help of the professional researcher – the scenario of an individual in-depth interview (IDI). The first part of the interview concerned the researched persons' sexual experiences as well as their reflection on this subject:

1 The frequency of sexual intercourses;
2 The role of sex in the researched senior citizens' lives;
3 Taboos and preconceived ideas about the sexuality of older adults.

The second part of the interview was devoted to the specificity of research on sexual activity of older people, as well as to opinions about assuming by the senior citizen the role of the researcher of this theme:

1 Is research on older people's sexuality needed, and why?
2 What features should a researcher exploring the matter of older people's sexual life possess?
3 Is it desirable that research on the opinions and sexual experiences of older people should be conducted by the researched persons' peer, i.e. a senior citizen?

The emotional charge which is associated with the theme of sexual practices and behaviours can be overwhelming not only on the part of the researched persons. One challenge was shame and embarrassment which accompanied the senior researchers already at the

stage of building the research tool. One of the participants of the methodological workshop resigned from the participation in further work done by the senior research team; she justified this with the questions in the interview being too personal.

Data collection

As the senior researchers stated, "the best way to learn how to do research is by doing it". In 2016, the first stage of the research was about each of the senior researchers conducting one pilot interview with a peer-recommended by her friends. The purpose of the interview was to verify the research tool as well as to preliminarily self-evaluate the senior women's strong and weak points in the context of them assuming the role of researchers for the first time. The novice researchers evaluated their particular sensitivity and the purposeful research innocence in a positive way. However, they indicated the necessity to correct in the subsequent editions their communication skills and their concentration on the participants' utterances, including remembering them better. The researchers recruited all the participants through recommendations of persons from their own groups of acquaintances using a snowball strategy. They did not know the participants personally; the criterion of selecting persons for the research included age (65+), an interest in the subject, and the willingness to participate. All the interviews were held in the participants' homes. In the second edition of the project in 2022, due to safety reasons during the pandemic, the older researchers conducted the interviews with the use of Internet communicators: Skype, Microsoft Teams, and Facebook Messenger. Each of the senior researchers conducted audio interviews with the use of the above-mentioned communicators during the pandemic. The selection of the participants by the female researchers in this edition was purposeful with regard to not only the age but also the ability to use the communicators. The project coordinators organised two meetings with the senior women on the MS Teams platform in order to remind them about the adopted rules of conducting research. One of these meetings was devoted to the rules of conducting online interviews. A variation of the traditions of brainstorming, namely brain netting, was also applied. The questions and answers were sent between the participants of the session, stored, and/or analysed. As a result, the senior researchers supplemented their skills of establishing relations and holding a conversation with the aid of Internet communicators.

The research was carried out in Warsaw. When beginning the research, the female senior citizens suspected that the group of persons with whom they will conduct the interviews would not be big because of the social conditionings behind the researched subject matter. The sexual life of older adults is treated as something sinful and shameful. In each case, they introduced potential participants to the research topic. However, they experienced many refusals to participate in the interview, especially from men. Despite the efforts which they made towards recruiting men in both editions of the research, they firmly refused to talk and were even surprised that this sphere of life was under research. In the conviction of the senior researchers, the theme of closeness and intimacy is particularly difficult for men due to the gender stereotypes preserved in the patriarchal social system, in which they were brought up. Older men more often stay silent about their sexual needs and desires than women do. Men"s silence is a common problem, female researchers say. Men are expected to be strong and most importantly emotionless, therefore they avoid sexual discussions due to embarrassment and shame for being sexually active and particularly having any sexual "problem". If they ever bring this matter up, they usually try to trivialise it. The lack of men

in the role of the interviewees was not considered by the mature researchers to be a failure; they justified it and interpreted it as a consequence of the right to refuse to participate in the research.

Eventually, the data was collected during 19 individual in-depth interviews; 13 women agreed to tell of their sexual life in the first edition of the research, and six in the second one. They were peers of the senior researchers; they were aged 65–75. Some researchers reported feeling a little uneasy about the level of disclosure that occurs in some research interviews, while others felt that the act of listening to the story often validated the experiences of the participants by giving them the time to talk about them. The interviews were recorded with the permission of the interviewees. After data collection, the senior researchers transcribed the interviews according to Gail Jefferson"s (2004) transcription rules and learned during the methodology workshop.

Sharing the results

The senior researchers were invited to a final communication activity. The project's coordinators organised on the university campus a meeting with the third-year students of the second-cycle full-time studies in the Institute of Applied Social Sciences at the University of Warsaw. During the meeting, the senior researchers presented knowledge they had gained from conducting research on sensitive topics with older individuals and defined the role of a senior-assuming-the-role-of-a-researcher of older adults' sexuality and intimacy in a participatory project. In the second edition of the research in 2022, organising such a meeting turned out impossible due to the outbreak of the pandemic.

Findings from the interview data

The findings concerning research conducted by older people on the subject of their peers' sexual life (the first part of the interview)

1 The findings revealed that sexual activity is an important aspect of life among older persons, although frequency is gradually decreasing. Older adults who have physical limitations or have certain health conditions which make their sexual life more challenging have a lower ability to engage in sexual activity. Health, not age, is what truly impacts sexuality.
2 Older persons still enjoy sexual practices and romantic love as part of a satisfying later life. Sexually active senior citizens experience sexual contact as pleasurable and comforting. They still want and need intimacy, or have sexual desires as they grow older. They report both physical and psychological benefits from engagement in sex, e.g. the reduction of stress and anxiety. They also find sexual activity as preventing depression and relational issues. The lack of sex causes self-worth and confidence to plummet.
3 On the one hand, the sexual life of older persons is gradually ceasing to be treated as something sinful and shameful, while on the other hand, social conventions make it difficult for older adults to express their sexuality due to taboos and preconceived ideas about older adults' sexuality. The findings revealed that older adults have the impression that most people assume that they are asexual and, thus, they often feel sexually invisible. Older adults who internalise these values and norms are often ashamed of

their bodies and are less likely to express their sexual needs and desires for fear of being judged and excluded.

The findings concerning research on the role of research on old people"s sexuality and old people as the persons conducting this research (the second part of the interview)

1 According to the interviewed women, research concerning the sexuality of older people is really necessary, because in Poland, sex, sexual preferences, and even social life all constitute themes where older adults feel socially marginalised or excluded. The older participants stated that they did not know any results of Polish studies on this subject, and that it was the first time they had been invited to participate in such interviews. Socially, old age is perceived as a decadent period during which nothing new awaits senior citizens. Moreover, the subject of sexuality is also a taboo among older people themselves. The participants of the researched group were in agreement that research was needed that would challenge the stereotype of the sensual and erotic latency, showing that old age can be both sexually active and satisfying. In their conviction, efforts should be made to reduce the stigma surrounding continued sexual activity and expression among older persons.

2 According to the interviewees, a researcher exploring the matter of older people's sexual life does not have to be a professional scientist. It can be a woman or a man, who knows the issues connected with the process of ageing and sexual life (as a result of their own experiences as well as appropriate training prior to the interviews). A senior, as a researcher, should inspire trust of an old person, be open, explicit, sensitive, empathetic, subtle, and, what is very important, discreet. Patience and persistence may be required for obtaining informed consent from the participants. An understanding, accepting attitude can help promote a more comfortable discussion about sexuality during interview. The interviewed women recommended: 'Try to be sensitive to verbal cues and body language. Don't assume that an older adult is heterosexual, no longer sexually active, or does not care about sex.'

3 According to the interviewees, it is desirable that research concerning sexual practices and behaviours of old people should be conducted by their peers, i.e. a senior person. In their conviction, the involvement of older women as co-researchers in the data collection process has various advantages and disadvantages. One major advantage is that the co-researchers have first-hand knowledge of sexual practices. Therefore, they understand this group of people's way of thinking and can be able to obtain better and faster access to the wanted informants. The interviewees trusted the female researchers of their own age more, and they declared more openness towards them. One disadvantage is related to the lack of experience with scientific research, especially researching sensitive topics. Health problems can turn out to be another barrier. Before committing to the role of a researcher, a senior person should do a medical examination in order to confirm their good physical and mental condition.

During that meeting with female and male students, the senior citizens confirmed their motivation to get involved in subsequent editions of PAR with Older People, and the students expressed their willingness to take part in such a project. This is a good start towards an intergenerational project (and dialogue) in the area of sexual practices and behaviours.

The validation and recommendations

In practice, evaluation of social projects is taking place continuously. At each stage, changes are implemented so that a particular activity can be tailored to the participants' needs. Traditionally, it is crucial for researchers that the results of their study are characterised by accuracy and credibility. These are advantages also in the case of participatory research. Hence, the subject of the validation done during a meeting after the first pilot interviews – as well as at the end of research in both editions of the project – involved the following issues:

- Is it feasible to acquire knowledge in the area of older people's sexual life with the use of particular methods and techniques?
- Are the selected methods and techniques suitable to explore this knowledge?
- Are the selected methods and techniques adequate to the researcher's skills?
- Can the researchers apply a given technique in a reliable way and subject the research results to analysis?

As a result of the feedback received in the course of conversations and group discussions of the senior researchers with the project's coordinators, each of the above-mentioned issues was verified positively. The mature researchers repeatedly emphasised that IDI is the best technique for collecting data on their peers' sexual practices and behaviours. It makes it possible to follow the threads brought up by the interviewee. The qualitative method gives an opportunity to elaborate on important themes and provides the respondent with a sense of agency. As the senior researchers stated, a direct conversation and contact with the respondent allows a deeper understanding of the meanings ascribed to sexual experiences decisively more than a distributed questionnaire with closed questions would. On the other hand, face-to-face contact requires focus and more effort for an authentic connection with the respondent to be maintained. In the senior researchers' conviction, during an interview, a researcher can always ask after certain issues.

Despite these declarations, in the researched group, the senior researchers admitted that they did not always ask after topics which the researched persons did not want to discuss in detail. This was the case with the topics of, for instance, masturbation or oral and anal sexual practices. The conducted research has confirmed that there exist many different issues accompanying research into old people's sexuality. One of the main such problems is the cohort effect, which denotes a situation in which older people, brought up in a less tolerant and liberal age, are not used to talking about topics referring to sexuality. This concerns men in particular; they were consistently refusing participation in both editions of the project. According to the senior researchers, this was the effect of the tabooisation of older people's this sphere of life, which, as it turns out, evokes shame and embarrassment both in the female researcher and in the researched person, despite the previous training during the methodological workshop. The female senior citizens in the role of researchers came to the conclusion that conducting PAR requires the researcher to be humble and respectful of the complexity of the social reality, which does not always yields to research procedures effortlessly, and in which the very process of researching is equally important to its results, particularly when it concerns the subject of the researchers' peers' sexual life. It is a dilemma of a methodological and ethical character, one requiring more detailed discussions at the stage of planning research in future participatory projects of this kind.

The senior researchers were motivated to participate at each stage of the project, which was confirmed by numerous meetings and validation-related discussions in both editions. Within the evaluation, at the end of the project, the female senior researchers were asked the following question: "How would you describe the main results of this project from your perspective?" All the women stated that, in their judgement, the research became a source of gratification as well as an opportunity for self-discovery, development, and critical knowledge on the subject of social life. In the course of the project, they acquired or broadened new skills (listening, probing) and attitudes (genuine curiosity, openness) regarding open interviews. Their participation in the project enhanced their trust in participation in shared research projects driven by social needs.

All of the women also claimed that promoting the participation of older people in research on sexuality entails many benefits, e.g. the development of the sense of subjectivity as well as the development of old people's competencies to counter the stereotypes referring to this sphere of life. In the process of being involved in research, older people can potentially change their own and other people's perceptions of later life; the older adults are not to be seen as frail and dependent, and with identical needs. For the senior researchers, collecting research conclusions is the crucial result. The results can assist in the recognition of the importance of working towards breaking down social barriers in front of certain age groups about what old age should be like, as these obstacles prevent older people from freely expressing their sexuality.

The initiated research increased the senior researchers' awareness and the discovery of new issues related to sexuality and ageing, which are worth further research. In their opinion, more qualitative exploration is particularly needed on the topics of male sexual desire and pleasure, sexual risk-taking in older adults, culture-specific influences on outcomes such as help-seeking behaviour and sexual satisfaction, and the impact of health problems on older men's sexuality. Another issue to be elaborated on in subsequent projects involves the strategies of the inclusion and participation of men both in the role of researchers and in the role of the researched persons.

The collected feedback leads us to believe that the project did satisfy the female senior citizens' expectations. In response to the question about what ensured the achievement of the project's main results, the senior women considered crucial the emergence of a specific community of persons who share passions, seek to solve a particular problem, and mutual learning through regular interactions and exchanges of opinions. There is no change in the female senior people researchers' beliefs across the time period 2016–2022. Participation in the described project let them deepen their own knowledge of involving older persons in research about sensitive topics through mutual, community-like learning. In the literature on the subject, such a group is defined as a "community of research practice" (Jeon et al., 2011). The interactions and mutual learning process proved to be crucial for the development of a shared understanding. In the team meetings, senior researchers were all engaged in searching for the best way to cooperate; this had not been preordained in a research plan. Together, they formed ideas about how to organise and prepare interviews. As the process proceeded, the coordinators and researchers felt more at ease with each other and developed a sort of working routine.

The goal of doing research on sexual practices with and by older adults is to create opportunities and new, previously unidentified possibilities for solving sexual problems of older individuals, as well as to increase the level and quality of their lives. The research results and the validating feedback revealed that there are many aspects worth developing

in the subsequent projects on older people's sexuality. Certainly, there is a need to anchor this subject matter in participatory research with older adults. As a result of a group discussion, senior female researchers are planning to broaden the group of both female and male researchers, discussions within the academic environment, but also the popularisation – within social journalism and with the participation of the female senior researchers – of participatory research into older people's sexual activity. The next step that the female senior researchers are planning to take in the subsequent participatory research is to establish cooperation with specialists working with older people on a daily basis. They believe that the challenge for professionals in this area is to recognise the importance of sexuality in old age through fluent, effective communication with older people about their concerns and worries with regard to their sexual lives. Finally, they consider developing courses for both groups (older adults and professionals) so that they can learn with and from each other.

Conclusion

This type of participatory projects involving older persons in research about sexual life are absolutely unique on the national scale, and perhaps even on the European scale. Both the female researchers and the female interviewees confirmed that the research on sexual practices with and by older adults is of innovative character for many reasons. First, it covers a problem which still remains a taboo in Poland. Second, it engages female senior citizens in the role of researchers and we can learn from the seniors researchers some ideas for research on the sexual practices of older persons attuned to the lives and perspectives of older adults. Furthermore, it is a challenge to build programmes of informal education for older individuals. It equips the senior women with new competencies and tools, which they can use in subsequent participatory research about sensitive topics. It reinforces relationships in the peer group; the meeting of mature women was considered as much value as the self-development and skills in the area of a social researcher's workshop. Finally, it has the potential to break stereotypes and counter younger generations' negative perception of old age and older adults. Therefore, the objectives of the project correspond with the needs of the community of senior citizens.

The described project should increase social activists' and academic researchers' interest in doing research on sensitive topics with and by older adults. In Poland, not only is research on older people's sexuality scarce, but also there is no tradition of participatory research into old people"s sexuality, where seniors would be researchers themselves. We foreground that participatory research with older people should be treated equivalently to academic research; not remaining on the margin of the latter. We argue that doing research on sensitive topics with and by older adults should be treated as a specific philosophy of research, not only as a toolkit full of interesting means, because this usually leads to oversimplifying and trivialising participatory processes as well as their critical potential and the inherent to them emancipation of the researched communities.

Note

1 Originally, in Polish – "Archipelag Pokoleń".

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PART 5

Disseminating results together with older adults

16

PROMOTING CIVIC PARTICIPATION

Comparing three co-produced models of lifelong learning and cultural engagement in the UK

Anna Goulding and Thomas Scharf

Introduction

Social exclusion refers to processes that separate individuals and groups from mainstream society. The concept enhances an understanding of disadvantage in later life because, unlike other conceptualisations of socio-economic disadvantage, it accounts for both relational and distributional forms of disadvantage (Atkinson and Davoudi, 2000). A multi-dimensional understanding is necessary to develop holistic support to alleviate the complicated range of factors that cause exclusion. Walsh et al. (2017) identified six common domains across which inclusion/exclusion can occur: neighbourhood and community; services, amenities, and mobility; social relations; material and financial resources; socio-cultural aspects; and civic participation. Clarity exists about the dimensions and importance of life course factors, and the wider social context, on exclusion in older age (Walsh et al., 2017). However, of the six dimensions, research concerning socio-cultural and civic forms of exclusion is least well developed. Moreover, research on the relationship between the two dimensions is underdeveloped (Serrat et al., 2019). This chapter directly follows on from Serrat et al. (2019) by examining these two interlinked domains.

This chapter develops research on socio-cultural and civic domains of inclusion and exclusion by examining the role of two models of participation in Newcastle (United Kingdom) in facilitating the inclusion of older adults:

- The first is a contemporary participatory dance programme for older people. The programme takes place in an area of socio-economic disadvantage but draws participants from across the region.
- The second is a classroom-based co-designed learning programme involving two different groups of learners in two different locations in the same city, both of which were socio-economically disadvantaged.

For both models, the university researchers were asked by the educators to bring their subject knowledge around ageing to inform the programmes. The researchers' role as co-educators, co-learners, and participant observers forms part of the analysis.

Co-production

The chapter will investigate approaches used to involve older people more equally in decisions affecting them. In initiatives aiming to develop age-friendly places, co-production has become an increasingly popular approach. Co-production aims to empower older people and reduce the asymmetrical power relationships between professional and older person community actors. Co-production is a way of using "experiential expertise" (Collins and Evans, 2007) which can highlight areas neglected by "experts" (Fischer, 2000).

However, in practice, co-production has been argued to be less politically emancipatory than feminist, post-colonial, indigenous knowledge, or critical theory (Facer and Enright, 2016). Unlike critical pedagogy, which involves a process of collective consciousness, which is argued to lead to social transformation (Freire, 2006; Kemmis, 2014), the co-production process tends to work within institutions (Farr, 2013). Changes have been found to be generally small scale (Donetto, 2014). It has been argued that to engender greater change, community actors' experiential expertise needs to be valued (Farr, 2013). Therefore, more research has been called for on how to include emotional and expressive contributions of the community actor (Barnes, 2008; Gibson et al., 2012).

Social exclusion/inclusion

Older people are disproportionally affected, compared to younger age groups, by the multiple forms of exclusions they encounter in economic, civic, social, social services, and community life (Walsh et al., 2017). Focusing on inclusion and exclusion in later life is critical as older people who experience social exclusion may do so for a longer part of the life course than people belonging to younger age groups (Scharf and Keating, 2012). Older people have fewer opportunities to lift themselves out of exclusion due to age-related declines to health and shrinking social support networks. Also, they face a lack of access to education and/or lifelong learning opportunities and the ability to generate income through labour market participation (Jehoel-Gijsbers and Vrooman, 2008; Scharf, 2015).

Civic participation

Participation in civic society is one of the ways in which older people can be included in wider social life. Civic participation has been described as active citizen participation "… in the life of a community in order to improve conditions for others or to help shape the community's future" (Adler and Goggin, 2005, p. 241). Adopting the approach of Serrat et al. (2019), Table 16.1 shows examples of both individual and collective forms of social and political participation.

Role of education in exclusion

In examining pathways to inclusion in later life, there is a clear structural reason for linking education to social inclusion. People who have not participated in educational opportunities previously, who are educationally disadvantaged, or who left school at an early age,

Table 16.1 Types of civic activity (drawing on Serrat et al., 2019)

	Civic participation	
	Social participation	*Political participation*
Individual forms	Type 1: Prosocial/helping/altruistic behaviours outside family. Donating money/in-kind support to charities/non-governmental organisations.	Type 3: Voting. Contacting political representatives Donating money to political parties and organisations. Signing petitions. Writing letters/emails/blogs/articles with political content. Boycotting and political consumption
Collective forms	Type 2: Participation in volunteering, community, or charitable organisations.	Type 4: Running for or holding public office. Working on campaigns. Participation in political organisations or forums Protest activities. Participation in social movement organisations.

experience a heightened risk of forms of social exclusion. The cumulative effect of low education levels, consequent type of employment or periods of unemployment, and corresponding socio-economic disadvantage experienced throughout the life course have been shown to impact on inclusion in later life, physical and mental health, and self-reported wellbeing (Jivraj and Nazroo, 2014; Stewart Brown et al., 2015). This chapter recognises the role of education in encouraging civic participation. Reflecting the rationale of the Workers' Educational Association, the UK's largest voluntary sector provider of adult education, lifelong learning has a social purpose, with a commitment to community engagement and, therefore, inclusion (WEA, 2018).

In examining the role of education in civic inclusion, we need to ask whether education plays a role in enabling people to become more politically active. Serrat et al. (2019) note that far fewer scientific papers explore political participation, compared to those addressing social participation. They argue that this disparity reveals that academic discourse presents older people as sustaining welfare states through their (voluntary) participation, rather than challenging contemporary political processes. Correspondingly, this chapter takes a critical pedagogical stance, examining how, through the educational process, the adult learner is challenged to examine power structures and patterns of inequality within contemporary society (Freire, 2006).

Socio-cultural aspects of exclusion

The second dimension of exclusion examined in this chapter concerns forms of socio-cultural exclusion. We define socio-cultural exclusion as encompassing exclusion arising from ageist societal discourse. Ageism, defined by Ayalon and Tesch-Romer (2018) as "the

complex, often negative construction of old age, which takes place at the individual and the societal levels" (p. 3), can be symbolic in nature, with narratives and imagery on ageing and old age affecting the ways in which old age is conceived and approached. Recently, growing attention has focused on visual ageism, reflecting "the social practice of visually underrepresenting older people or misrepresenting them in a prejudiced way" (Loos & Ivan 2018). Walsh et al.,'s scoping review (2017) identified 22 texts that focused on symbolic and discourse exclusion. They found that fixed social constructions of age excluded older people and noted the prominence of discourses emphasising frailty. Active and successful ageing was associated primarily with paid employment, consequently excluding people who were unable to work. Social policy could also be ageist (Biggs and Kimberley, 2013), with anti-ageing interventions being highly exclusionary (e.g. Biggs, 2001; Gilleard and Higgs, 2011; Laliberte, 2015; Walsh et al., 2015). To add a further dimension, Walsh et al. (2017) also highlighted specific groups that experience exclusion, including people who identified as LGBT (Harley et al., 2016) and people belonging to a range of black and minority ethnic groups (Zubair and Norris, 2015).

Research questions

This chapter explores interlinkages between the civic and socio-cultural dimensions of exclusion, with a particular focus on how adult participatory programmes of different types, as forms of "intervention", may contribute to reducing potential risks of social exclusion in later life. This might be by promoting civic participation or by challenging such symbolic forms of exclusion as ageism or the negative language and imagery used in discourse on ageing. The chapter also examines the contribution of associated forms and methods of co-production involved in promoting greater inclusion of participating older adults.

Methods

The selection of case studies was driven by the authors' involvement as co-educators, co-learners, and participant observers in the three programmes. The approach adopted here has been refined through a continual engagement with forms of adult learning throughout our academic careers. Data arising from participant observation, focus group interviews with learners, supplementary feedback from learners, and in-house evaluation were collected.

Context and format of the learning programmes

We examine how the form and content of the social participation can support critical engagement with civic and socio-cultural forms of exclusion. We selected two programmes using multiple forms of engagement, all requiring a combination of different skills.

Contemporary dance programme

Funding and lead organisation

The company is funded through Newcastle City Council Cultural Investment Fund. However, the funding is project based and time limited.

Format and content

The group, or company, was professionally led by the director, herself a trained contemporary dancer. The content of the dance performance was jointly choreographed by the director and participants. The collaboration between researchers and dance company started after the director sent a speculative email to the researchers. After three meetings during which the director and researchers discussed their shared interests in cultural participation and inclusion, they decided to use the researchers' scientific knowledge about ageing and old age to help inform a contemporary dance performance. The older people participants (referred to as company members), company directors, and university researchers met to decide themes related to ageing to be explored over the course of six sessions (see Table 16.2). For the first half of the session, the researchers led a discussion around the chosen theme. For the second half of each session, the company members warmed up and then either choreographed or rehearsed a section of their performance based on ideas generated during the discussion.

Group members

The group included four women and three men, ranging in age from 69 to 89 years. All were physically healthy, except one who had a heart condition which required medication and physiotherapy once a week. Contemporary dance is an activity all members have taken up post-retirement, as opposed to being a continuation of previous engagement. Two of the group had enjoyed dancing when younger and one had sung in a choir (Table 16.3).

Table 16.2 Content of programme

Week	Content.
1	Discussion around assumptions regarding older people, ageing, and later life.
2	Discussion about representations of ageing using photographs.
3	Discussion about representations of ageing continued.
4	Recap of previous weeks' discussion.
5	Discussion about social relationships in later life.
6	Discussion about social relationships in later life.

Table 16.3 Group members

Pseudonym	Age range	Gender	Ethnicity	Former occupation
Sandra	80–85	Female	White British	Administrator
Lesley	70–75	Female	White British	Nurse
Tim	80–85	Male	White British	Teacher
Louise	65–70	Female	White British	Teacher
Diane	70–75	Female	White British	Administrator
Stuart	85–90	Male	White British	Groundsman
Geoff	70–75	Male	White British	Farmer

Table 16.4 Content of programme

Week	Content
1	The researchers delivered a quiz based around statistics and assumptions regarding older people, ageing, and later life. How to find useful information, gather evidence and make a presentation.
2	Change and looking forward – facilitated discussion around understanding power relations.
3	Research and researching a topic; development of group/individual projects.
4	Media skills.
5	Group discussion and project work.
6	Group discussion and project work.

Classroom-based programme

Funding and partnership organisation

The learning programme was funded by the Big Lottery Fund and ran over the course of a year. It was delivered by a partnership between Newcastle Elders Council and the Workers' Educational Association (WEA) and was supported by researchers based at Newcastle University. The programmes were held in areas of socio-economic deprivation so, in theory, targeted people who may be at heightened risk of forms of social exclusion.

Format and content

The six-week non-formal learning course was led by an adult educator and two university-based researchers contributed to facilitating group discussions around the themes specified in Table 16.4. The university researchers, WEA, and Elders Council were equally involved in the project's development stages. The learning approach was co-constructivist, based on the learners' interests, with participants being invited, after the first two sessions, to vote on topics to be included in the subsequent four sessions. The first group chose to proceed with a session on "How to find useful information, gather evidence, and make a presentation", to be followed by a session on working together to make a difference.

Group members

The research draws from two groups participating in two different courses in different areas of the city facing disadvantage. In one group there were eleven participants aged 70 to 85 years. All were White British. Seven were female and one was male.

In the second group, there were four participants aged 50–88 years. Three of the group were Pakistani, Indian, and Kenyan women who had migrated to the UK in the late 1960s. A charity coordinator, aged in her 50s, was also involved as a participant. The course relied on the gatekeeper from the charity to encourage attendance, even though participants made their way independently each week. English was a second language for the South Asian participants, so their words were interpreted by the group leader. Hence in the narrative, direct quotations are not used. The women had run convenience stores or worked in factories. The other participant was a younger White

Table 16.5 First group

Pseudonym	Age range	Gender	Ethnicity	Former occupation
Anj	70–79	Female	White	Nurse
Penny	70–79	Female	White	
Gloria	80+	Female	White	Office admin
Mary	80+	Female	White	Psychotherapist
Brenda	70–79	Female	White	Civil servant
Arthur	70–79	Male	White	Project manager
Alice	70–79	Female	White	Administrator
Ettie	60–69	Female	White	Interpreter
Jack	70–79	Male	White	Lawyer
Kenneth	80+	Male	White	Architect
Emily	60–69	Female	White	Teacher

Table 16.6 Second group

Pseudonym	Age range	Gender	Ethnicity	Former occupation
Falga	50–59	Female	Pakistani	Charity worker
Graham	50–59	Male	White	Nurse
Bhavani	70–79	Female	Indian	Factory worker
Chandni	80+	Female	Kenyan	Convenience store owner
Daleela	70–79	Female	Pakistani	Homemaker

British male former nurse who had taken early retirement on health grounds. In the third session, it was participants sharing their diverse life experiences which helped to develop cultural awareness across ethnicity and social class. Two of the women had achieved formal academic success at school age in their countries of origin but had not had opportunities to pursue professional occupations or formal education in the UK (Tables 16.5 and 16.6).

Data collection

The discussions and focus group discussions were audio-recorded and transcribed. Each session was observed and field notes were made. A thematic analysis of the transcripts and field notes was conducted. Additional data included feedback from participants via emails to researchers and comments taken from in-house project evaluation.

Data analysis

The structured narrative that follows examines the three key themes:

- How participants view ageing and being old at baseline;
- The specific methods/approaches contributing to engendering critical pedagogy; and
- Whether and in what ways engagement led to further civic participation.

For each of the three themes, the narrative describes how each group in turn addresses the theme.

Baseline – How participants view ageing and being old and their perceptions of exclusion

To understand whether older people felt excluded from societal discourse or experienced ageism, participants were asked how they found being old and what they felt about ageing.

Dance group

Initially, participants denied challenges associated with being old. Members claimed they did not experience age-based prejudice. A representative quotation of how members described life post-retirement is as follows:

> There's a small window between leaving work and having the time and getting to that stage. You've got to pack it in.
>
> *(Diane)*

Group members described their experience of being old in a way which supports successful and active ageing paradigms. Taking part in the dance class was one of the ways participants felt involved in society. Two participants provided examples of the negative discourses associated with being an old person. While Diane referred to prevailing debates around older people's perceived use of healthcare resources, Sandra emphasised concerns about intergenerational tensions:

> You're bed blockers. You think to yourself, 'Don't ring the doctor!'
>
> *(Diane)*

> The press stirs it up – the battle between the young and the old.
>
> *(Sandra)*

These opinions reveal concern about discourse framed in terms of intergenerational conflict.

Classroom (First group)

The quiz activity in week one was designed with two purposes in mind. The first was to act as an ice-breaking exercise, which encouraged participants to discuss potential answers to eight multiple-choice questions. The second purpose was to challenge participants' knowledge and assumptions about the demography of ageing and characteristics of older people. This also involved addressing internalised stereotypes around ageing and the behaviours of older adults.

According to one male participant, the quiz met its objectives, encouraging further reflection on features of demographic change and the ways in which key characteristics of later life are defined:

> A good informative icebreaker – Gloria and I only got 2 out of 8 [questions] right. So need to do demographics homework. Much depends on definitions used.
>
> *(Arthur)*

Classroom (Second group)

The women all noted that since migrating to the UK in the 1960s, they have found people welcoming and that they have friendly neighbours. However, one talked about how for the first time in her life, she experienced racist abuse shouted at her from a window. She found this distressing. Group members also discussed how the area in which they live has become increasingly littered; they attributed the litter dropping to young people. The age-related difficulties they experienced relate to getting transport for medical treatment as none of them drive. They took part in the class because they wanted the opportunity to socialise and meet new people. The male participant had retired on health grounds and although he has a grown-up child, lives on his own. He wanted to take part in the class because he is interested in learning and welcomes the opportunity to socialise.

Methods contributing to critical pedagogy

The following section examines how the content, form, and approach of the facilitator/educator contributed to enabling inclusion and reducing the potential for exclusion.

Dance

One member of the company articulated how participatory dance is different to participating in exercise classes:

> Everybody will interpret something differently. We've learnt that being slow is quite a strong action in itself.
>
> *(Louise)*

In the second half of the programme, the group explored the theme of social relationships. In this section of the performance, as described in the transcript below, the company members wanted to convey socially isolated older people as they started to participate in group activities. The group began to block out a section of the performance, with members directing themselves into various tableaux:

Lesley:	*So initially they don't want to join [she adjusts three of the dancers to form a huddle, leaving one dancer not included in the group].*
Geoff:	*But I wouldn't join.*
Sandra:	*Oh yes, that's [referring to the group tableau] definitely showing isolation [audible agreement from majority of dancers].*
Lesley:	*Then someone can come along to the person outside the group offering a bingo ticket, someone else with a ukulele?*
Geoff:	*Well that [being offered to play the bingo or join a ukulele group] wouldn't work for me.*
Director:	*Well what would work for you?*
Lesley:	*Should we have an embrace?*
Geoff:	*Why would the audience want to see that [people embracing]?*

Director: We're having a physical conversation. I think the audience would want to know. What you did there [referring to a gesture made by Joanna] is important because it highlights that it's about choice. We're telling stories with our bodies. The audience don't have to understand everything.

Here the form learning takes involves working as part of a group to use physical movement and gesture to express social isolation and social relationships – after exploring social relationships, the group expressed more concern for people who might be socially isolated. Group members are developing choreography skills and using movement to express ideas. The group are preparing for a professional performance and practising diligently to ensure synchronicity. Creating a piece of work for a fixed performance date differs from more process-based exploration.

Using images (dance group)

For the third week, the researchers brought in photographic images that presented different aspects of old age. The group were asked to describe the images, what mood was being conveyed, and whether the images were accurate and representative depictions of later life. Follow-up questions used more targeted language, for example, asking whether participants found the images "inspirational" or whether they presented unrealistic expectations.

Participants felt the athletes shown in "A veteran men's sprint race" (2015) by the photographer Alen Golden were not representative of older people and would put ordinary people off trying to take up mild exercise. They felt an image of people joining in collectively with line dancing classes would be more encouraging:

> I can't run because I get exhausted. The majority of people don't run in races. It might put people off.

> *(Geoff)*

"My Physicist Dad: A portrait of my dad in a care home, drinking tea from a plastic kiddies mug" (2016) by Ross Samson was an image of dementia that made participants feel uncomfortable. None of them would like to be portrayed in this way. One noted, "unfortunately many of us may end up drinking through a straw". Using images depicting active ageing, decline, or dementia in ambiguous ways was felt to be an effective way of stimulating discussion that both foregrounded universal life themes and issues of immediate concern to the individuals – using images was a way of allowing participants to keep a distance if they felt the issue was too sensitive. It was important that the researchers facilitated the discussion, first analysing what the images showed almost as a comprehension exercise, before going on to speculate about the photographers' intention. Reading images is not necessarily something that people are trained in, and whilst different interpretations are valid, it is at least important to untangle possibilities.

Classroom-based (first group)

The classroom-based programme specifically drew participants' attention to power relations and how individuals could effect change. Critical pedagogy informed the programme throughout. In the first week when participants were getting to know each other, the

facilitated discussion was centred around change, why participants had joined, and what they hoped to achieve. Although participants had different interests and life experiences, learning was co-designed, with participants being encouraged to work with other group members to develop a project of mutual interest.

Discussions about power relationships were particularly valued by participants – learners wanted to be treated as members of an evolving society, in which they still had agency. One participant reflected:

'We don't normally get to talk about power now, it's a bit like sex was 30 years ago!'

(Arthur)

Another participant noted that the discussions made her feel valued for the first time in her life. She also enjoyed learning together with people who she had not previously known:

People's talents should be valued, and that's what I felt for the first time, you know, in my life. I feel that my talent was valued. Even though the course only lasted four to five weeks. A couple of hours at a time. I got a lot out of it and it was fun as well. We had some laughs. And it's learning to work with a group of people with whom you don't know.

(Brenda)

The older learners were encouraged to drive their own agendas for action and engagement. It was important for participants to discuss ideas with people they did not know – hearing other perspectives enabled them to co-construct new knowledge and understanding.

Classroom-based (second group)

For the second group, the facilitator faced a considerable challenge in developing course content which was relevant and of interest to a range of older learners with different life experiences within the same group. In the first week, the discussion involved pooling together the different social networks that the participants had access to. The facilitator responded to the group's complaint about increased litter by suggesting developing a litter picking initiative. This suggestion was met with politeness, but not with the enthusiasm and practical galvanisation to take up the suggestion.

In the second week, the session became much more lively when the group were asked to talk about their experience of migration to the UK and how they had found life subsequently. The participants made life maps, illustrated with interests that were important to them, such as gardening. The illustrations were punctuated with significant life events such as gaining academic qualifications in their native countries or moving to the UK. Gendered roles within the household were touched upon and the youngest group member, a charity coordinator, was vocal about the unequal division of household chores. This encouraged the other participants to agree. The women had dressmaking skills and brought in pattern books the following week. They talked about how their children, now professional adults, did not make clothes. One participant also brought in two hats she had crocheted as a gift for the researchers. The women subsequently expressed an interest in developing a project around dressmaking.

Further civic participation

The next section examines whether participation in the programmes led to further civic participation.

Classroom (first group)

In the first group, participants noted that taking part in the course had made them "more politically aware". One participant wrote to her MP and the local council about the up-keep of war memorials; another did some work on patient involvement in her general practitioner's surgery. Two cited being more confident in giving presentations as a result of participating in the course, with one participant particularly valuing an opportunity, within the context of a safe and supportive learning community, to improve his presentation skills:

> For some time I have had the feeling that the presentations I frequently give needed improvement, although audiences have been much too polite to tell me!!
>
> *(Kenneth)*

Group members also noted the strategies that they had developed to enable participation, such as preparing a checklist before talking to a group. Learning was co-designed and all participants noted the importance of contributions from the rest of the group in driving forward their own learning and collective projects. The learning could be used across a range of activities that participants were involved in:

> This was an amazing course which covered just about everything I needed to know in my role as a volunteer at various organisations (although I hadn't even realised it!) [..] The sessions covered power (who has it, how to use it, etc.) and how to do research or complete a project – both subjects chosen by us, covered from planning to completion. There was even a session covering the press and media, very useful as in these days of austerity you never know when you might need to call on them with help to raise funds or advertise your event.
>
> *(Jack)*

Classroom (second group)

After the second group had expressed an interest in sharing their dressmaking skills, the group was asked if they would like to visit a fabric shop to look at material and consider making something. Members were apprehensive about committing to a venture which had an uncertain outcome and might involve personal costs. The facilitator and researchers suggested taking their skills and interest in making clothes further by working with undergraduate fashion design students or curating an exhibition demonstrating their clothes-making skills.

When the course ended after six sessions, the male participant had not attended the final two sessions and the three female participants were not at the point where they wanted to take any of the ideas they had suggested further. In giving verbal feedback at the end of the course, the women said that they were interested in opportunities to share their life stories and socialise. They had welcomed meeting people from a range of different professional

backgrounds and expressed surprise that the research team had been interested in hearing about their experiences of migrating to the UK in the 1960s. When asked if they would like to develop any of their ideas, for one, Ramadan had cemented the fact that she wanted to conserve her energy and devote her time towards her spirituality. Despite being physically weak, she made the effort to walk to attend the class on the final week because she had wanted to say thank you and that she had enjoyed meeting the other participants, facilitator, and researchers. The group attended a celebration event later in the year.

In reviewing the format, the facilitators and researchers questioned whether further facilitated sessions would have led to the group continuing. The open and exploratory curriculum (there were themes, but these were not rigidly adhered to) was suited to people who had few years of formal education and for whom English was a second language. The lack of planned subject content meant that in the third week, through an open discussion, the participants were able to share their life experiences. This gave the facilitators and researchers the opportunity to suggest and help shape possible projects which were tailored to their interests and expertise.

Dance group

The group were asked about how they found taking part in contemporary dance and whether it differed from other learning experiences or forms of participation:

> People our age aren't expected to do certain things and it was to do that thing of break that mould of what people think about us.
>
> *(Lesley)*

The dance group were preparing for a public performance at performance cabaret which provides a platform for radical variety acts. The performance challenges the largely negative social construction of age. Group members had become more active in the cultural community and would co-ordinate visiting performances at art galleries or art exhibitions. Although they went as individuals, they met as a group. As meeting at various art events outside the programme continued, the director ceased to accompany the group. However, at sessions, she would ask company members for feedback.

Discussion

This chapter examines how structured participation opportunities led by professional facilitators for older people can overcome risks of social exclusion and contribute towards their social inclusion. In examining two different models of adult learning and engagement, it teases out the aspects which can best support changing negative social narratives around old age as a first step towards inclusion. It reveals how challenging ageist stereotypes can serve to develop participants' confidence and create networks and strategies for further civic participation.

Our analysis finds that socio-cultural dimensions of exclusion are related to civic exclusion, and that exclusion from societal discourses and ageism represents a barrier to full participation in civic activities. The socio-constructivist learning programmes encouraged civic participation as participants from all groups became more involved. One of the classroom groups became more civically/politically engaged, participants attributing this to the skills

and strategies the course had developed to enable them to engage with the local council and healthcare settings – notable examples of civic participation – writing to MPs, lobbying a local bus company to make the service age friendly, and taking part in public-patient involvement initiatives.

The second classroom learning group did not take the learning forward. At the end of the six sessions, the facilitator felt that the group was only just starting to be introduced to ideas around how they might develop projects. This introduces the question as to how long an introductory course should last. Whilst a longer duration would have allowed greater scaffolding of ideas, any longer than six weeks might have marked too much of an initial commitment on behalf of the learners. In terms of further civic participation, the educator made the learners more aware of ways to become involved in the community, for example, through introducing them to the Workers Educational Association and the Elders Council. The class itself, held in a former library building, involved participating in the community.

The dance company members were engaged in a journey that is likely to lead towards greater civic participation – in both symbolic and political terms. As the company members were becoming more aware of the wider socio-cultural context of older people performing in a radical cabaret night, they were being drawn into more radical forms of active citizenship. This is marked both in terms of performing at the radical cabaret night and attending contemporary dance performances and art exhibitions in the city, as well as being more socially engaged with a group of peers, which counteracts risks of exclusion from social relations. The Director views engagement in contemporary dance by older people performers as a radical political statement. She described how group members were ignoring age-limiting stereotypes through the development of contemporary performance:

> They wanted to start the piece with something graceful but then flip it to make the tone funny, yet still execute the moves in a slick, controlled way. What they don't understand is how radical that idea is for a group aged in-between 69 and 89 to perform that on a stage as a creative idea.

Part of countering ageism involves not underestimating the older person's capacity.

This chapter develops the literature by demonstrating how symbolic exclusion is absorbed or internalised and how discussions function to challenge negative stereotypes of learning. The experience of participation in the contemporary dance programme began to counter symbolic exclusion. On the one hand, participants in the dance group were in denial about ageism, were defensive about negative depictions of frailty, and presented themselves as active agers. On the other hand, they framed old age in terms of intergenerational conflict. Instead of viewing contradictions as reflecting an unreliable and invalid method of researching participants' feelings, thoughts, and attitudes, we argue that they can be seen as reflecting existing contradictions that people grapple with in everyday life (Giddens, 1984; Sølvberg and Jarness, 2019). The tensions were teased out by using photographic elicitation exercises and probing participants further on issues during discussions. Participants had not necessarily formally analysed images as part of a wider discussion about ageing. Also, leaving a week in between discussion allowed everyone to reflect. Research participants were not necessarily familiar with engaging in critical thinking, revealing the important role learning models and the educator plays in facilitating critical pedagogy (Hiemstra et al., 1983).

The forms and methods of engagement serve to reposition marginalised groups as powerful. Making the collage of their life stories provided the South Asian women with an opportunity to communicate their education in their native country and their children's professional careers to the facilitator and researchers. They noted that they were surprised that we were interested in hearing about their lives. Communicating their achievements and skills was a way of acknowledging them, thereby empowering participants as valuable members of their community.

The classroom-based model provided a co-constructivist learning environment. Facilitated discussion alerted participants to power structures and helped them think how to use their social capital to effect change. The development of strategies, operating in tandem with increased confidence, led to wider civic participation, specifically in political terms. A combination of greater confidence and strategies for civic engagement has the potential to facilitate social inclusion, which this chapter argues is important in improving wellbeing. The same learning model, but with two different groups of participants, led to different outcomes in terms of further engagement.

The dance company discussed working as a group, individual creative expression within the group, and how dancing has made them more conscious of how they move in their everyday lives. The participants have developed "bodily knowledge", which has been described as knowing in and through the body (Parviainen, 2002) which has changed their everyday movement. The reflection on the speed of movement – of being slow being a strong action – demonstrated the participant reflecting on the control over, intention behind, and impact, of gesture. The members touched on synchronicity of movement as a group as being important. The space for individual expression, whilst being part of a collective group, was recognised as a distinctive strength of this art form. Choreographing the piece on social relationships brought out more empathetic comments about the experience some older people may have of being socially isolated.

Conclusion

Developing a meso-level response to exclusion in later life is particularly important in taking responsibility away from the individual who may not be able to advocate for themselves, or be able to draw from previous knowledge and skills or social and economic resources. The chapter examines the potential that people can learn new things in later life which goes against the more structural approaches to understanding disadvantage, highlighting agentic opportunities to escape risks of exclusion. It responds to gaps in the literature by examining the experience of participation with an aim of informing the content and form of programmes.

In capturing people's experience of participation, we foreground the complex ways in which people articulate ageism. We advance the literature by revealing the difficulty in exposing ageism to then challenge it, precisely because older people deny it. Learning helps address ageism, particularly when people have internalised negative stereotypes associated with older people and ageing and see agency as being up to the individual. The different forms of engagement and methods – photo analysis; structured group discussion; expressive movement; life review – were found to enable an interrogation of experiences of later life and ageing.

A critical pedagogic stance is to be encouraged, we argue, due to a continued national programme of austerity and the failure of cross-departmental policy to keep up with

demographic changes, both of which have been shown to impact negatively on older people's wellbeing (Scharf et al., 2017). The benefit of engagement for participants makes a strong case for infrastructure to support continuation of learning opportunities after project funding ceases. Partnership working, for example between universities, learning and older people organisations, and city councils, can help support the longer-term continuation of programmes.

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17

MAKING GRAPHIC MAGAZINES WITH PEOPLE LIVING WITH DEMENTIA

The case for participatory dissemination

Sarah Campbell and Andrew Clark

Introduction

The social sciences have witnessed a burgeoning interest in creative and arts-based approaches to knowledge creation, data collection, and dissemination. As Boydell et al., 2012, para.1 remarks, "arts-based knowledge creation and dissemination strategies is driving an important shift in our understanding of what counts as evidence, as well as an appreciation for the complexity and multidimensionality involved in creating new knowledge". Such developments have coincided with efforts to engage more participatory approaches to research and to considerations around legacy and impact (Facer and Pahl, 2017). These include the involvement of participants and stakeholders advising on research processes, contributing to design and development, and engaging in data collection. Arguably, the result is not just a more emancipatory and transparent approach to the undertaking of research, but also the formulation of alternative, perhaps more authentic, types of knowledge about the social world. While participation in research formulation, design, and data collection has become widespread, we contend that participatory approaches to dissemination and knowledge translation are less well developed, or at least less frequently reported or appraised (Boydell et al., 2012). In response, this chapter contributes to how arts-based methods can enable a more participatory approach to this stage of the research process and a consideration of impact and legacy.

We report on the collaborative development of graphic 'magazines', herein described as 'zines', as part of a participatory and creative approach to disseminate findings from a longitudinal, international research project investigating what neighbourhoods mean for people living with dementia. The wider research revealed insight into how neighbourhoods might enable or restrict opportunities for informal and semi-formal support, as well as their potential to facilitate people living with dementia to live independently in the community. Primary findings emphasise the benefits of remaining connected, acts of kindness, reciprocity, and maintaining routines and habits among familiar people and places (Clark et al., 2020). Throughout the process, we aspired to a collaborative approach to the research, working alongside people living with dementia and their care partners. People living with

dementia were involved at various stages of the research, including input into recruitment, development of methods, production of participant information, and contributing to the emergent analysis. Alongside more conventional academic activities such as conferences and written outputs, we developed a collaborative programme of knowledge exchange to engage the wider public in debate about the purposes that neighbourhoods and local communities can and should play to support people living with dementia. These included events aimed at the general public to widen the sphere and scope of influence and impact of the research using a creative blend of audio and visual approaches. For instance, we staged exhibitions that engaged visitors in challenging and dispelling some popular myths and stereotypes about living with dementia. Many participants and wider collaborators in the research, especially those living with dementia, wanted a mechanism through which they could tell their stories in ways that were less reliant on textual or oral traditions. Hence, we worked with a group of people living with dementia or caring for a person living with dementia alongside an artist, to produce a series of zines to promote the research findings.

This chapter outlines the process of developing the zines and our reflections on working as part of a team of academics, artists, and people living with dementia and their care partners. We consider zines as a useful format for disseminating and translating knowledge from research and outline methodological and practical implications of engaging in such a practice. We detail the process to develop and produce the zines as well as the opportunities and challenges of using zines in research, drawing on our experiences as researchers, artists, and participants. We end with reflections on how more participatory approaches to dissemination might contribute to a more transparent, potentially impactful, research practice. By way of conclusion, we do not claim that zines are necessarily truer or more representative, or meaningful than other research outputs. Rather, we suggest that their collaborative production helped us to more closely understand the sorts of experiences that comprise our data and to present analytical ideas that resonate with those whose lives the research purports to understand.

The research context

The zines and the collaborative process we describe emerged from an ESRC/NIHR-funded research project investigating the neighbourhood experiences of people living with dementia. There are 944,000 people living with dementia in the UK, with numbers estimated to rise to over one million by 2030 (Luengo-Fernandez & Landeiro, n/d). Many of these individuals will live in their own homes, supported by family, friends, and health and social care services. Thus, there is a pressing need to understand how those affected by dementia experience their local neighbourhoods; and explore the ways in which local places might better support people living with dementia and their care partners. Particularly as there are associations between living with dementia and social isolation and those affected by dementia may experience a 'shrinking world' as they find it harder to remain socially connected to others to get out and about (Duggan et al., 2008). The research that forms the context for our discussion here was undertaken to understand first-hand, what neighbourhoods mean for people living with dementia. Data was collected and analysed about how neighbourhoods can support people living with dementia to remain socially and physically active. People living with dementia and a nominated care partner engaged in three methods of data collection (walking interviews, participatory social network mapping, and home

tours)[1] over a period of two years as a way of articulating and/or demonstrating the places where they lived and the people, organisations, and institutions that featured in their lives. We involved 56 participants from Greater Manchester in the research, 29 of whom were living with dementia and 27 were care partners. They came from a variety of backgrounds, were aged between 57 and 88, and lived with different types of dementia.

A more detailed discussion of the findings is available elsewhere (Clark et al., 2020; Odzakovic et al., 2020; Ward et al. 2018). For many participants, 'staying connected' represented the importance of interactions both in terms of ongoing communications, but also as a way of being seen by, and seeing others. Familiarity in local shops, cafes, and even on the street was considered important as a way of feeling a sense of belonging to, and welcome in, a wider community. Great value was highlighted through 'acts of kindness' carried out by neighbours unbidden but as routine acts that support people to continue to live independently. These ranged from putting out a neighbour's rubbish bins each week to providing support in times of emergency or distress. These acts were not unidirectional, and people living with dementia were carrying out acts of support in the neighbourhood too, such as 'keeping an eye out' for anything unusual, taking in parcels, and caring for grandchildren. Such reciprocity illustrates the valuable role that people living with dementia continue to play in their neighbourhoods, as active local citizens, looking out for others and engaging in the social life of everyday places. 'Routines and habit' are an essential part of everyday life in connecting people to their neighbourhoods by using the same routes to walk the dog, visiting the same café, or attending dementia peer support groups. Such activities are important to enabling recognition, which in turn facilitates staying connected, and more readily can prompt acts of support. Finally, for some participants, getting out and about had become more difficult and this increased the value of home, and of 'staying in'. In these cases, connections that link the home to a wider neighbourhood are particularly valued and include receiving visitors, telephone and Skype calls, chats over the garden fence with neighbours, and being able to sit by a window and see the comings and goings of the neighbourhood. It was these core messages that we were keen to promote to a wider public through a series of zines.

Our approach to zine-making

As a mode of predominantly visual representation and communication, zines offer similar sorts of benefits as other visual-arts-based techniques used in research. Colantonio et al. (2008) for instance suggest that knowledge conceptualised in this way is more accessible to diverse stakeholders. Arts-based research is thought to enhance general or public knowledge of relevant issues as well as foster a sense of community among the general public (Vaughn et al., 2008). By developing an explicitly visual approach to disseminating findings from research we are following an emergent tradition that makes use of comic-type media to inform others. Bartlett (2013: 216) for example has drawn on the widespread and playful position occupied by cartoons in popular culture, providing "light relief from the written word, they can illustrate and open up debate about serious and/or sensitive topics". She discusses the development of a series of cartoons to disseminate findings from a research project that explored how higher-functioning people living with dementia campaign for social change. Bartlett (2013) drew inspiration from work in health care research that used cartoons to enable participants to feel freer to discuss sensitive topics (Peterson et al., 2006), to make serious research more accessible (Lea, 2012), and offer a "visual

experience and open up other (non-linguistic) ways of knowing that cannot be achieved with the written word" (Bartlett, 2013: 219). In recent years, the use of graphic illustrations be it in the form of 'zines', 'comics' or even sketching has begun to capture social scientists' methodological imaginations (e.g. Heath and Chapman, 2018; Mickwitz, 2016; Priego, 2016; Wang, 2016).

Zines are typically produced using low technology and have limited (if any) commercial interest. They tend to be print-based and comprise a combination of text and illustrations, and as their initial popularity as 'fanzines' implies, focus on a specific topic, idea, or interest (Duncombe, 1997). In most cases, they will have limited distribution and are subject to small print runs. So, zines have long been considered an emancipatory and democratic form of DIY media making (Cameron, 2016), acting as a vehicle for voices rarely featured in mainstream media, produced by and often for, more marginalised lifestyle groups, that have little or no affiliation to a formal organisation and, almost certainly, no plans to generate profit for their producers (Weddel, 2018).

The idea to produce something akin to a zine came from a group of participants who had been working alongside us to engage in more participatory forms of dissemination. They were keen that the key findings and recommendations arising from the research were promoted to core stakeholders. Although the group saw the value of a collection of more conventional findings leaflets and briefing papers, they also wanted to produce something that was more readily digestible, could appeal to different generations, and was accessible to a wider public as well as people living with dementia. They wanted something they could imagine someone picking up in their local GP surgery. As outlined in the introduction, the academic team wanted to engage with participants as we took the work forward, where possible sharing the research journey, adopting a more equitable stance on the ownership and sharing of findings, and contributing to an open approach about who is able to retell research findings to others. In this way, we hoped to avoid some of the criticism that academics frequently claim ownership of research findings and the data that comprise them, to the neglect of the individuals whose experiences make up that data in the first place (Beresford, 2009). As a frequently overlooked collection of voices, we also wanted people living with dementia to engage in more prominent ways in the research, especially in those stages where participants have been less involved, such as dissemination and knowledge translation (Keady et al., 2017; Swarbrick, 2015). Finally, we wanted to present findings in ways that were less abstract or de-sensitised to the lived experiences they seek to explain, as well as remain consciously respectful and inclusive of the voices, and the owners of, the stories our analysis was based upon. Consequently, we aspired to remain as faithful as possible to the experiences of those people living with dementia who had contributed their time and experiences to us during data collection. The history of zine-making aligned well with how our substantive findings work to dispel some of the stigmatising discourses around dementia. These include an emphasis on recognising personhood and encouraging a sense of citizenship and active participation in society (Bartlett, 2014). Such work has also been seen in the mental health survivor movement through the work of 'Mad Pride' and organisations such as Southwark Mind, which created a monthly zine newsletter and published zine-type works finding alternative forms to share survivor stories (Dellar, 2014).

Producing the zines was a collaborative effort between two academics, a varying group of up to ten participants living with, or supporting someone with dementia, and an artist experienced in zine-making. The zine-making project took place between 2016 and 2019, after the fieldwork phase was completed, and ended at the end of the project in May 2019,

culminating also in the production of the third and final zine. During the zine-making project, membership fluctuated in response to ongoing changes in the members' personal lives. For instance, two participants withdrew due to health issues, and one couple contributed to only one of the zines and did not attend group meetings, preferring instead to meet individually with the academics. As such, the project was undertaken with a degree of flexibility, often required for participatory research (Liamputtong and Higginbottom, 2015).

Three group members with dementia lived alone, and three lived with their spouses. Four group members living with dementia were female, and two were male and there were two male spouses and one female spouse who took part in the zine-making. We did not ask participants to disclose their type of dementia, and we did not undertake any assessment of their dementia, nor did we consider what 'stage' participants were in their experience of dementia. We took care, though, to ensure all those who engaged in the process were able to fully consent to their involvement themselves and understood the purpose of the group.

The zines took shape through a series of meetings held on University premises where group members attended a series of regular two-hour meetings where progress was shared, feedback sought, and crucially, new ideas were discussed. Group members were recompensed for their time through high street vouchers. Certainly, improving methods of payment for co-researchers and the contributions of those with lived experience should be explored further to find more equitable ways of valuing contributions (McLaughlin, 2021); and we recognise that the project was fortunate to have funding available to provide this kind of support.

Outside of the meetings, the graphic artist spent time developing a narrative from the stories that he had been told, and a way to metaphorically and visually present the stories, while the researchers continued to undertake further data analysis. The graphic artist produced content while the researchers led the development of indicative text and engaged in ongoing analysis to identify further topics for possible inclusion in the zines. Meetings themselves were facilitated to create an enjoyable and inclusive atmosphere. We would start with lunch and a general catch-up. The group members brought different skills to the group and were all able to contribute opinions throughout the sessions. Sometimes less confident members of the group were supported by others, to provide space for them to share their own experiences in relation to the images and the narrative devised within the storyboard. As the zines developed, the group commented on storylines became more confident about offering ideas for key messages as the series unfolded, provided written content and details of specific illustrations and drawing frames, and offered their views on various formatting, stylistic, and presentational options. Those living with a diagnosis of dementia also reflected further on their own experiences. They had already shared some of these with the researchers during the formal data collection process, but they also offered new, additional insights prompted or elicited directly from engaging with the stories emerging in the zines.

The outcome:- zines as products

A series of three zines were produced in total between 2016 and 2019. Each zine is A4 in size and has a simple linear story told through comic frames. Group members requested an item that did not look like an information-giving piece, even though they were keen that was to be the primary purpose of the zine. The group felt A4 pages were easier for people living with dementia to hold and read, and enabled easier reproduction of the text in larger font size. The group also suggested the greyscale colour for the images was easier

to read and had more visual clarity than some of the alternative colour combinations that were considered. We were mindful of how dementia was represented in the zines, both in the illustrations and the stories that they told. The amateurish or comic-book-type nature of some zine styles could arguably give a childlike illusion which we were keen to avoid given some of the infantilising discourses around dementia that imply that those diagnosed regress to a childlike state of being. We believe we achieved a balance that means that while the products are comic-like in appearance, and evocative of participants' childhoods, they are not childish. Indeed, graphic novels have had a resurgence that has seen them move beyond superhero-type stories and have been found particularly useful and compelling for telling difficult stories (see: Alison Bechell's [2006] memoir 'Fun Home' or Joe Sacco's [2003] 'Palestine').

The first zine tells the story of 'Lily', a composite character who encapsulates the experiences of several participants through a series of vignettes (Figure 17.1). The zine presents key messages relating to three analytical themes outlined earlier; 'staying connected', 'routines', and 'reciprocity'. Through a series of short episodes over the course of a trip to the shops, the zine presents examples of experiences shared by several participants. Lily was diagnosed with vascular dementia five years ago. Now in her early 80s, a social person who enjoys 'looking out' for others. She strives to lead a busy social life and has become involved in different dementia support and campaigning groups. Several times a week she uses her local shops that are a short walk from her home. She is now recognised by, and recognises, shopkeepers and other local residents as she goes about her regular walks. On her trips to the shops, she often collects a newspaper for another older neighbour in her flats who is less able to get out. Lily's access to her neighbourhood is supported through the relationships she has built over the years with her neighbours, local shopkeepers, dog walkers, and other familiar strangers who she stops to chat with on her walks to the shops. Of course, living with dementia brings challenges, sometimes it can be difficult to be out and about when living with dementia. Some days, familiar places may look unfamiliar. It can be difficult to get on with everyday activities such as dealing with money or visiting a shop. These are also depicted in the zine, alongside a clear message arising from the research that positive connections and acts of kindness by others can make these challenges less difficult.

The first zine offers a simple but important message about the ways in which people living with dementia continue to play an active role in their neighbourhoods and are able to support others and offer kindness. It demonstrates how familiarity and connections with others can help someone feel orientated and a little safer. So too, can people living with dementia play a role in maintaining the social life of local places, undertaking small acts of kindness themselves for neighbours and friends. The zines make use of visual metaphors to represent aspects of life for those living with dementia. For instance, in our attempt to demonstrate how the environment can become disorientating, the images depict a disrupted landscape, such as when using an elevator (Figure 17.2).

We were keen that the zines not only raised awareness of some of the challenging aspects of the environment but also presented ways in which these could be lessened through ordinary encounters. In one instance Lily bumps into a dogwalker she knows, and they stop for a chat, and the second is in the newsagents where she is recognised as a regular shopper and greeted by the employee. We also sought to counter a sense that the individual becomes disorientated and 'lost' to the world with a view that the individual remains present and complete, and that it is the environment (be that social or physical) that needs to change, or at least better accommodate people living with dementia such that they might retain a sense
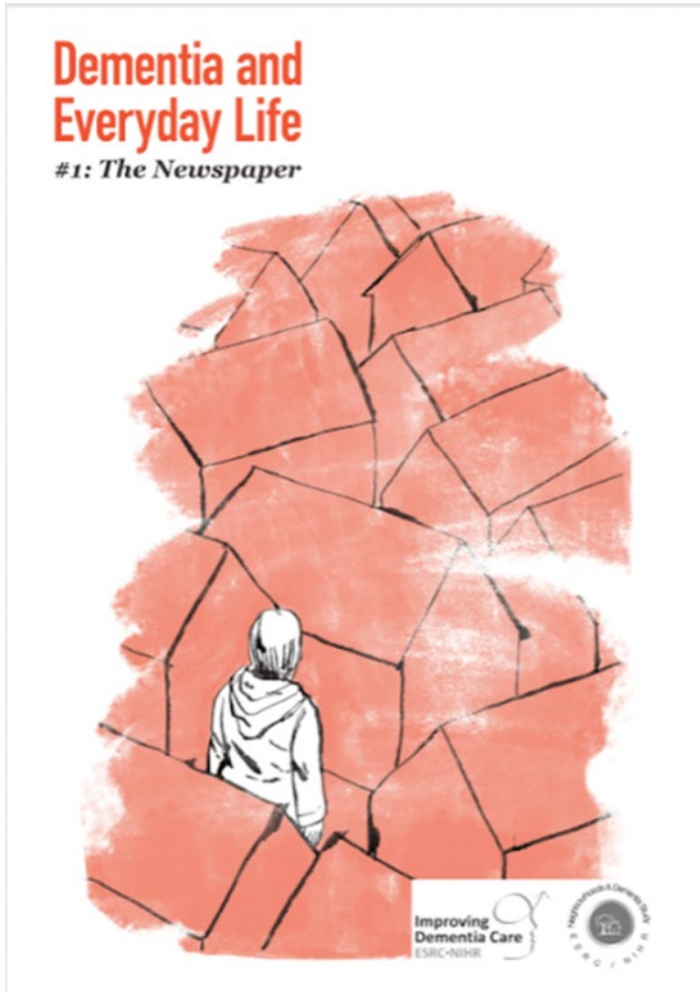
Figure 17.1   Dementia and everyday life, #1: The Newspaper.

of who they are as an individual who happens to be living with a diagnosis of dementia (Thomas and Milligan, 2018) (Figure 17.3).

It was important to find ways to create storylines where the central characters retain a sense of personhood but we did not want to focus on the experiences of one or two individuals who took part in the research. Instead, we created composite characters who portrayed many of the characteristics, or with similar experiences to a range of participants. In this way, we were able to maintain a direct link with the first-hand accounts that we did not want to lose sight of and to enable participants to recognise their own stories rather than struggle to identify themselves with the more generalised or abstracted outputs associated with some forms of research outputs. At the same time, this meant that no one individual became the 'protagonist' of the story, potentially alienating other participants or disrupting the rigour of the analysis process by focusing too much on a small number of cases or

Figure 17.2 Zine example of living with dementia (1).

an individual. It allows us to sidestep the somewhat thorny issue of whether the stories we present in the zines are 'true' in how far they might accord with a specific set of life experiences, or objectively depict 'real' or evidence-based events or experiences in the images.

The value of the zine-making process

At a time when alternative forms of dissemination from research are gaining attention, alongside growing expectations about achieving impact from research we believe the zines offer a useful way of accessing diverse audiences. We hope they stand out from the more typical resources arising from research, especially regarding dementia, where leaflets and research findings briefing papers are arguably prolific. At the same time, and as others who engage in creative and artistic modes of data collection and analysis have also argued, the process of producing the zine has been as impactful as the final products. This contributes to a notion of creating legacy from the research, both materially through the zine object and

Figure 17.3   Zine example of living with dementia (2).

for those involved in the process of production (Facer and Pahl, 2017). Indeed, one member of the zine-making group noted 'I felt really proud; especially seeing the comics. I feel like we are part of history – and my granddaughter can say my nana was part of that'.

Participatory work is understood to require time and resources to ensure that it is meaningful (Boyce et al., 2009). We were mindful to consider the practicalities of the work and ensuring enough time was a crucial part of the process. The process of zine-making was arguably slower than some other types of output. Each zine required four half-day meetings with the group. We had to take into consideration the availability of everyone involved, and while all the meetings ran to a predetermined agenda, catch-up time was essential to enable all members of the group to feel confident and secure within the group to be able to express views and work together.

The group did not always agree on the direction, shape, or form the zine should take. Though not wanting to downplay the significance for those with firm views on matters, for

the most part, concerns and changes were relatively minor, such as issues of colour choice. On some occasions, however, the group pointed to ways in which research findings might be reinterpreted by others. For instance, such as the way, a particular scene was illustrated and had the potential to be misinterpreted by readers of the zine. At other times disagreement might be over how the episodes were depicted, such as the potential confusion that arises from entering a lift, or when making purchases from a local store, which did not accord with their own experiences. Addressing such dissonance goes beyond a question or assessment of the amount of resonance or quality of the authenticity of the stories we thought might represent our research findings and speaks to issues of generalisability and representativeness in qualitative methodology, as well as ways in which cases from a data set can come to stand in for a wider collection of experiences through the identification or formation of an analytic theme. It was also important to reflect on how particular instances or experiences became central to the construction of 'overriding narratives' that are told from the research findings. We were able to discuss with the group how we came to develop such instances that, while not representing the entirety of the experiences of those who participated in the research, come to stand in as useful exemplars of themes that, in this example, show concern around becoming geographically disorientated or dealing with money, and explore how help might be offered or sought in cases of possible disorientation.

In resolving disagreement we were able to collectively sense-check the interpretations we offered from more formal data analysis, with an admittedly small group of participants. They, in turn, offered unprompted affirmations or alternative perspectives, which enabled us to reconsider our data analysis, or offer further recollections of their own experiences of living with dementia, or recast previous interpretations in a new light. In this way, the zine-making opened the analysis process to greater scrutiny as participants questioned where our ideas came from, and furthermore offered their own suggestions about how the analytical themes we had identified resonated with their own experiences. Ultimately, the researchers needed to ensure that the stories told reflected, as authentically as possible, the themes that emerged from the analysis of the full data set. Finally, there was a further layer of analysis undertaken by the artist who also reinterpreted the findings to create images and develop a series of metaphors that represented an idea or story with narrative coherence.

While differences in the direction of a storyline were resolved with recourse to what our analysis of the wider dataset was revealing, there were also differences of opinion about the aesthetic qualities of the zines. Given the subjective nature of such decisions, we tried wherever possible to reach a consensus within the group, usually on the basis of what might be best in terms of enabling legibility for someone living with dementia. In such instances, we were guided by the expertise of the artist who offered his work up for ongoing critique. At the end of each meeting, we summarised the issues that had been discussed and the decisions that had been agreed upon, with actions for the artist to undertake whatever revisions were proposed.

The zine-making progressed as a process of layering of analytical and experiential interpretations onto technical and aesthetic processes of artistic production. In doing, so, the work becomes the product of collective decisions and actions which, while not perhaps achieving the status of a work of a community of interest that other zine makers might aspire to (Bryant, 2014), was certainly the result of more than individual effort or the mere visual depiction of the fruits of academic labour. At the outset, we discussed with the artist how we hoped the work would develop in this way, and some of the resultant implications for formal (viz. legal) as well as more socially positioned understandings of ownership.

Like other forms of dissemination, we were conscious that the stories told through the zines did not depict individual experiences, but reflected composite experiences that, we hoped, would resonate with many participants, and others living with dementia. We have already described how we worked to ensure participants kept some sort of control over their own stories, but we also wanted the artist to maintain a sense of ownership of the process. As a result, the final zines are presented as joint authorship between the academic team, the artist, and the participants involved.

Zine-making and questions of empowerment and community voice

Our decision to produce a series of zines draws on a long history of zine-making as a potentially empowering process (Bryant, 2014; Duncombe, 1997). Feedback suggested that those who participated in the process felt their opinions were valued and acted upon, and a sense of engagement and shared ownership of the zine-making process was achieved. However, we are cautious to declare greater impact, at least in terms of how those we worked with might feel more empowered as part of the process. The final zines generated a sense of pride among the group and were well received outside of it. Nonetheless, it is not clear beyond the confines of the research and the zine-making process itself, whether participants feel better equipped to have their voices heard or to achieve positive outcomes in other walks of life.

Equally though, and as alluded to above, the academic team ultimately made final production decisions. In part, this was because we were privileged with an analytical understanding drawn from across the data which, for better or worse, might outweigh individual lived experiences that were brought to the group. Second, there is something of an imbalance in that the academic team and the artist were responsible for delivering the product, which meant that further decisions occasionally had to be made outside of the group meetings to advance the work. Although we repeatedly took the resultant work to the group for discussion, we would have liked to have been involved in all decisions. We were also fortunate to be well-resourced to bring the group together and recompense for their time. Given such resourcing came from a successful research grant, in the end, accountability and final responsibility, at least where funders were concerned, lay with the grant holders and those employed to deliver on the funding. Some may argue that, by drawing on the benefits of the institutional resources at hand, we appropriated methods used by subcultures and historically marginalised groups to further our own research successes (Radway, 2011).

Literature detailing the history of zines draws on conceptual debates about the nature of community, identity, and the coming together of people to share ideas and/or common interests as part of a 'community of practice' (Wenger, 1998). Indeed, the construction of an idea of community built around shared goals, beliefs, and practices, reproduces some of those ideals and beliefs in material form, and is at the heart of much work on how communities can be understood (Anderson, 2006). Bryant (2014: 81) surmises that zines enable community formation wherein zine makers form "their own communities or ha[ve] a community coalesce around them, either intentionally or incidentally as a result of making a zine". An alternative perspective considers zine-making itself to be constitutive of community such that "the zine is made as part of a process of community information, identification or analysis" (ibid). We cannot declare that the process produced a community among participants akin to the making of community (Boellstorff, 2004; Collins, 1999). The academic team brought the group together, and while the group were actively supportive of

our ambitions, and indeed proposed the ideas that drove the design process, the academic team maintained 'control' of the process. Nonetheless, through the production of the zine, we were able to bring individuals together with a shared commitment to understanding and articulating the experiences of those living with dementia as a collective, or at least as a grouping with potentially similar experiences of a shared condition (Eichhorn, 2001; Schilt, 2004; Zobl, 2004). While the group expressed the value in being amongst others who shared their experiences, the key for them was the purposeful nature of the production of the zines (Hagan and Campbell, 2021), and the final product as a material legacy (Facer and Pahl, 2017).

Conclusion

In this chapter, we have outlined a participatory method of dissemination and representation of findings using a visual medium. While engaging with stakeholders and ensuring impactful research is important, we wanted to do more. As qualitative researchers interested in understanding the lived experiences of people with dementia, we were also influenced by the need for more engaged, and engaging, ways of doing research. Additionally, we hoped to better enable that the outputs from the research remained authentic to the voices of those whose experiences we strive to understand. We were also aware of the need for greater reflexivity in how research findings are communicated, and of how in many research outputs those who contribute their experiences to research remain absent from the process of dissemination, save for their occasional appearance via an anonymised quotation (Alcoff, 1991).

The series of zines we produced represent a process as well as a product that enabled a more participatory involvement in research, albeit with constraints. The zines offer a sense of shared ownership and active engagement in the retelling of participant stories. Key here is less the aesthetic appeal of the zine, the more the social context and interactions that produced them. We contend that it is still rare for those who participate in research as the objects of and for data collection to engage in the wider spectrum of activities such as dissemination. In the case of those living with dementia, we suggest this is rarer still, despite many attempts and good intentions, to include participants in the production of research outputs or the co-production of the stories that are told from the work (Swarbrick, 2015). We hope our attempts to engage some participants in a more transparent process of dissemination hold true to the wider principles of participatory research we subscribe to. There is certainly much work to be done on this front, but this chapter presents a contribution to the ongoing debate about the politics of display and representation of other voices, even if this falls short of a truly equal approach to the owning and telling of stories about life with dementia. And in this respect, perhaps we are not too far removed from the efforts of other zine makers who strive to create meaning from the stories of those outside of the mainstream.

Acknowledgements

Note

1 Walking interviews were used as a mechanism to ask people living with dementia and sometimes their family carers to take us on a 'neighbourhood walk' and to show us around their local area. Participants tell us about their memories of living there, and we ask about their different connections to the place. We also asked what people did or did not like about where they lived. In addition, participants living with dementia took us on a 'video tour' or 'photography tour' around their home, telling us about how they spend time at home, and what is important to them about their home. Finally, we asked family carers and sometimes people living with dementia to tell us about the relationships they have in their everyday lives. We asked them to 'map' and describe these relationships and tell us about any support they give and receive.

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18

THE LATER LIFE AUDIO AND RADIO CO-OPERATIVE

Creating sustainable communities from participatory action research

Arlind Reuter and Thomas Scharf

Introduction

Participatory research approaches, such as participatory action research (PAR), are well-suited to support research on older people's civic participation. Civic participation in later life is characterised by older adults' active involvement in creating change in community life (Adler & Goggin, 2005). Similarly, PAR as a research methodology has shown the potential to facilitate meaningful involvement of older adults in shaping public policy and community life (Corrado et al., 2020; Trentham & Neysmith, 2018). Even though traditional forms of civic participation, such as volunteering, often rely on in-person engagement, newer considerations explore how older adults can be civically active in digital spaces (Reuter et al., 2021; Serrat et al., 2022). Supporting these digital forms of civic participation in later life, also referred to as digital citizenship, has become increasingly relevant within the context of the COVID-19 pandemic. The resulting shift of civic life to online spaces requires older adults to develop an additional set of digital skills if they are to pursue their participation in civic discussions online. Drawing on the discourses of later life civic participation and PAR as a methodology to support older adults' digital citizenship, this chapter presents insights from the "Later Life Audio and Radio Co-operative" (LLARC) project. The LLARC project is underpinned by a PAR methodology with a focus on facilitating civic participation and digital citizenship in later life, by supporting older adults to develop the digital skills that enable their civic expression in digital debates.

Participatory action research and civic participation: exploring synergies

PAR represents a collaborative and democratic way of conducting community-based and action-oriented research. The flourishing of communities is a central objective in PAR and, therefore, the research usually addresses a problem field that lies within a community setting, enabling research that is of direct benefit to the communities involved (Kindon et al., 2007). PAR does not claim to be solely a research methodology, but rather a form of social activism that aims to support people's collective praxis and transformation (Rahman & Fals-Borda, 1991). Indeed, through its participatory nature, PAR provides opportunities

for people to reflect and act together and to make their practices more rational, sustainable, and just (Kemmis et al., 2014). Within this context, PAR is characterised by a variety of methodological approaches, referred to by Holstein and Minkler (2007) within the context of methods of inquiry adopted in critical gerontology as "methodological bricolage". When applied to PAR, and reflecting the approach of Kindon et al. (2007), such methodological bricolage can focus on dialogue, such as interviews or group discussions, or they can be creative in nature, by being arts-based or making use of various media, for example, story-telling. All methods aim to support collective action and enable participants to "generate information and share knowledge on their own terms using their own symbols, language or art forms" (Kindon et al., 2007, p. 17). As opposed to more traditional research approaches, PAR methods require the researcher to be flexible and to take on a facilitating role rather than directing the process. Ultimately, when done well, the methods used in PAR will enable reflexivity in both researcher and research participants, enabling them to negotiate the meaning of the knowledge that is generated together (Kindon et al., 2007).

Aligned with PAR's goal to enable transformation in communities, the concept of civic participation has become a growing interest in gerontology research due to its potential to intersect positively with many domains of life, such as community engagement, political participation, and also its association with increased individual benefits in terms of health, wellbeing and life satisfaction (McMunn et al., 2009; Scharf et al., 2016; Serrat et al., 2020). The term civic participation is often used to refer to "voluntary activity focused on helping others, achieving a public good or solving a community problem, including work undertaken either alone or in cooperation with others in order to effect change" (Barrett & Brunton-Smith, 2014, p. 6). Based on a framework developed by Serrat et al. (2020) grounded in a scoping review of older people's civic participation, there are four broad types of civic participation in later life classified into an individual or collective dimension, as well as a social and political dimension. According to Serrat et al., the overwhelming majority of existing gerontological research on civic participation considers collective forms of social participation, with a strong focus on older adults' participation in volunteering activities. By contrast, comparably fewer studies have examined political types of civic participation, reinforcing a conception of social actors sustaining the welfare state, rather than as political agents "whose voices and opinions must be acknowledged in decision-making processes" (Serrat et al., 2020, p. 9).

Drawing these discourses of PAR and civic participation together, there are obvious synergies between the concepts, with the goal of creating change and the inherent notion of facilitating participation in community being paramount. PAR therefore represents a well-suited methodology to not only research but also to facilitate older people's civic participation. Indeed, the use of PAR as a research methodology for projects examining older adults' citizenship can strengthen critical thinking, social change, and reflexivity for both researchers and communities (Ziegler & Scharf, 2014) and can support the development of policy and practice related to ageing (Trentham & Neysmith, 2018; Ziegler & Scharf, 2014).

Digital citizenship

Another under-researched, yet increasingly important aspect within the discourse on civic participation in later life is the engagement of older adults with digitally networked forms of civic participation – or digital citizenship (Mossberger et al., 2007; Theocharis, 2015). The concept of digital citizenship increasingly encompasses digital skills and frequency

associated with the use of digital technologies, considering a digital citizen as somebody who uses the internet regularly and effectively (Mossberger et al., 2007). The need to consider digital citizenship as a form of civic participation in later life became especially evident throughout the COVID-19 pandemic, which required older adults to possess digital skills if they were to continue their participation in civic matters. In the field of Human-Computer Interaction, research studies on ageing and technology use have increased over recent decades. However, the discourse around technology and ageing can be affected by ageist assumptions, with technology primarily viewed as a solution to reduce perceived burdens of old age, such as biomedical or social decline, rather than looking at citizenship opportunities. Indeed, older people's voices are frequently absent, especially in debates around technology use or the design of new technologies (Vines et al., 2015). Even though digital content creation is not referred to in itself as a traditional form of later life civic participation (Serrat et al., 2020), the production of media content can underpin many different types of civic activity. This can range from writing blogs with political content to having a voice in one's community and in digital spaces more generally. The potential of content creation to support civic participation is widely recognised with regard to younger people, including as part of the school curriculum in countries such as the UK (UK Government, 2017) and the USA (Bennett, 2008). However, older adults still tend to be overlooked as active content creators (Waycott et al., 2013). Even the development of new social technologies often prioritises accessibility functions to allow older users to view content produced by others as opposed to creating and sharing their own productions (Waycott et al., 2013). The lack of older people's voices in digital spaces is frequently reinforced by the ways in which older adults are often misrepresented in mainstream media discourse (Ayalon et al., 2020). Indeed, ageism, or the discrimination of people based on their chronological age, has become an established feature of digital platforms which can include design or algorithmic mechanisms that strategically deprioritise, disregard, or exclude older people (Rosales & Fernández-Ardèvol, 2020). Still, research highlights an increasing number of older adults who engage more actively in producing digital content. This content includes blogs (Celdrán et al., 2019, 2022), Instagram posts (McGrath, 2018) or YouTube videos (Harley & Fitzpatrick, 2009). Older content creators often identify social benefits as their main motivation to engage with the production of digital media (Brewer & Piper, 2016), rather than recognising its value for citizenship purposes.

In this chapter, we reflect on the transferability of PAR projects conducted in collaboration with older people into the creation of sustainable communities. We present an example of a PAR project aiming to support older adults' digital citizenship through content creation by facilitating engagement with audio and radio broadcasts. Starting as a PAR project with a focus on civic participation in later life, over the course of four years the project developed into Later Life Audio and Radio Co-operative (LLARC). LLARC is now a growing network of older radio show hosts and age-friendly community radio stations with the civic purpose of promoting older people's voices in radio and audio broadcasting. Our reflections in this chapter encompass how this process of creating a sustainable community initiative from PAR can be driven by older adults themselves. We also highlight the role of digital technologies as facilitators for the process of establishing a self-sustaining co-operative movement from PAR, that supports older adults' civic participation and digital citizenship beyond the end of the research period.

Foundations of a sustainable PAR project

The LLARC project started as a collaboration between the researchers and a group of older adults, who engaged with production of a monthly community radio broadcast. The initial research aim was to explore civic factors that motivate older adults to produce community radio content. Given its participatory nature, community radio offers a voice to different communities, especially those at risk of being ignored or misrepresented in the schedules of national broadcasters. Classified as a 'citizen media' that advocates for citizen empowerment and participation through content creation (Lewis, 2008), community radio has the potential to strengthen civic participation by encouraging people to become more active in their communities and share their voices more widely. Although a range of communities are represented in community radio (e.g. black and minority ethnic communities, rural/urban places, religious communities, and youth communities), older adults are seldom identified in public discourse as producers of community radio shows in the UK. This tends to run counter to high rates of participation by older people in other volunteering activities. Even though civic motivations are shown to drive older adults' engagement with community radio production, for example 'making a contribution to the wider community' (Order & O'Mahony, 2017), these intentions are rarely conceptualised as civic participation or a citizenship contribution by the volunteers themselves. Our project therefore set out to explore in greater depth community radio as a medium for civic participation in later life.

Over the course of four years, we used a PAR approach to engage with older adults who produce community radio broadcasts. Moving through cycles of planning, action, and reflection (Kindon et al., 2007), we were able to explore different models of engaging with (digital) community radio broadcasts in later life before and throughout the COVID-19 pandemic. Even though methodologically PAR cycles are often presented as consecutive, our experience of engaging with PAR was a lot more complex as we engaged simultaneously with several cycles of PAR and different groups of collaborators. Based on this experience, one of the foundations of a successful and sustainable PAR is a continuous engagement with collaborators and the ability to embrace multiple work strands at once. In each of these individual PAR cycles, we employed a combination of methods. We used traditional qualitative research methods, such as interviews, to formally investigate the relationship between radio content creation and civic participation in later life. Additionally, to support a group engagement with our collaborators and at the same time foster our collaborators' agency throughout the research process, we engaged with a range of design methods, such as workshops or research through design. Supporting participation and shaping a research process in collaboration is a necessary requirement for a successful PAR project. Inviting older adults to actively get involved with shaping the research process together by engaging in creative research methods also draws on a skillset needed for many civic activities, such as actively shaping community life by speaking out and advocating on topics of relevance. Structured programmes to develop skills needed for civic participation in later life exist and point to the importance of using media for civic participatory purposes, for example, writing press releases (Scharf et al., 2016). However, in addition to such structured activities, our project provides an explicit example of how engaging older adults with PAR can strengthen the skills needed for civic activities. With the rise of participatory media as a tool to support participation (Vines et al., 2015), the production of grassroots digital and community radio content holds potential for older adults to create their own media narratives.

Using PAR in collaboration with older radio show creators can support their awareness for the civic importance of their activities, but in turn also support the creation of their broadcasts by creating a community of like-minded individuals: LLARC.

In the following section we describe two civic impacts of audio and community radio production in later life: (1) building a civic community network of older community radio broadcasters; and (2) making use of digital technologies within the network to support the members' digital citizenship.

Creating the Later Life Audio and Radio Co-operative

After approximately one year of engaging separately with different groups of older radio creators, we collectively decided to connect the different teams and explore the potential for a future collaboration at a Radio Festival for older adults. This Radio Festival represents a novel methodology of engaging older adults in PAR, by creating a space for data collection as well as facilitating connections and conversations between older content creators, radio stations, researchers, and third-sector organisations. The festival programme included talks, hands-on radio production with live broadcasts, and discussion sessions. Over the course of in-depth discussions, it became clear that there was a collective interest in forming a special interest network as an exchange point for topics related to later life and audio/radio production. In addition to the social benefit of supporting each other as part of a network, the civic relevance of the network was specified in LLARC's aims to:

- Promote positive views and challenge negative views of age and ageing by providing talk-based audio and radio content created by diverse groups of older adults.
- Strengthen the visibility of content created by older adults in media and encourage the expansion of radio programming related to ageing and relationships between the generations.
- Engage older adults in broadcasting, facilitate skill development, and build communities by enabling discussion of a wide range of topics.

Facilitated by the researchers, the various collaborators got together after the Radio Festival with the goal to formalise the creation of this special interest network. Adopting a co-operative approach was identified as a governance model that aligned closely with the principles of community radio in terms of democracy, access, and equity, especially for older adults who might be at higher risk of being excluded from participation in civic activities. Co-operative models are guided by a number of principles that align closely with those of the various stakeholders involved in PAR projects. Specifically, co-operative principles concerning open and voluntary membership, democratic member control, education, training and information, and concern for community (International Co-operative Alliance, n.d.) parallel principles typically associated with PAR; i.e. taking part in research voluntarily; ensuring that PAR is a democratic process driven by the community; working towards sustainable change within a community, which can have an educational component; and PAR being an inherently community-based research process (Manzo & Brightbill, 2007). Having worked with the principles of PAR for nearly two years ahead of establishing LLARC, transitioning the PAR project into a co-operative governance model felt like a natural process to all collaborators. However, throughout the process of establishing a co-operative movement, we also encountered challenges. Whilst the co-operative governance

is a democratic process and therefore aligned with citizenship ideals and well-suited for civic purposes, the implementation of a fully functioning co-operative takes time and represents a considerable learning process. For example, working as part of an intergenerational group we became aware of different life-course experiences in approaching collaborative work, including when conducting meetings. These reflections are especially relevant when considering civic participation in intergenerational settings using a life-course approach. They highlight the ways in which people accumulate contrasting experiences that inform their organisational thinking and collaborative habits across the course of their lives. Such differences in approaching governance within LLARC also reflect the PAR process itself, which entails negotiating different understandings in intergenerational research projects and ultimately finding a collaborative way of achieving a joint goal. Taking time for these reflections within an intergenerational co-operative also allowed us, as PAR researchers, to ensure that ultimately the co-operative's work continues to be driven by its older members. It also imposes upon us the requirement to navigate a path around our own dual roles as researchers and members of the co-operative. Especially with regard to LLARC members' digital participation, which represents the foundation of the co-operative's digital citizenship activities, it is important to consider life-course trajectories of working with digital technologies. Considering people's different life experiences aligns with a need to not only acknowledge but learn from 'local knowledge' in PAR which, as discussed by Ozanne and Saatcioglu (2008), has often evolved from years of experience.

The role of digital technologies throughout Covid-19

Within the context of the COVID-19 pandemic, the first lockdown in the UK began in March 2020 shortly after LLARC decided to adopt a co-operative governance model. With a stronger focus on connecting digitally due to the restrictions placed on in-person meetings, we had the opportunity to gain a new perspective on older adults' digital citizenship activities. As for all other organisations regardless of their size, resources, or longevity, the pandemic posed fundamental challenges for LLARC. However, the nascent co-operative survived and thrived throughout the pandemic, not least because its mission of promoting older adults' voices in broadcasting suddenly gained urgency.

The experience of lockdown had two immediate impacts on LLARC. First, since planned in-person meetings were no longer possible, it became necessary to implement the co-operative's workflows within a digitalised structure. Second, given the considerable impacts of the pandemic on society as a whole and on older people in particular, there was an opportunity for the co-operative to use its online platform to respond to the rapidly changing context. Even before the pandemic, LLARC was exploring ways to facilitate remote working in order to connect as efficiently as possible its members across England. This process was heavily accelerated as part of the restrictions on in-person meetings imposed by the pandemic. Starting in March 2020, LLARC members engaged digitally for two purposes: connecting the members remotely, typically via Zoom, and shifting their content production workflows online. Drawing on peer support within LLARC as part of their Zoom sessions, all members became more proficient in their digital skills throughout the course of 2020. Focusing on digital citizenship, LLARC collaborators demonstrated their enduring commitment to their aim of making the co-operative's civic messages widely available. As a first step, a Mixcloud page (https://www.mixcloud.com/LLARC/) was established to enable content sharing between different radio stations. This Mixcloud page continues to

represent a hub to showcase talk-based content created by older adults that was produced by individual LLARC members or LLARC's member stations. Drawing on the expertise of radio professionals within LLARC, individual LLARC members started using Zoom for remote production activities with the specific civic purpose of representing older adults in broadcasting. Some productions were part of LLARC's public response to COVID-19, as LLARC members felt it was important to address the societal changes on their platform, in particular, what they viewed as an increasingly ageist public discourse. This issue was raised by a collective of researchers and practitioners, who spoke out for greater inclusion of older people in public discourse and the need to be mindful of avoiding ageism in relation to the implementation of policy and practice responses to the pandemic (Ayalon et al., 2020). By creating discussions on COVID-19 with experts from academia, policy, and practice, LLARC members aimed to counteract the predominantly negative representations of older adults in the media throughout the pandemic (Ehni & Wahl, 2020; Søraa et al., 2020). By establishing LLARC and publishing its content on the co-operative's Mixcloud page, it became possible to generate intergenerational conversations in order to broadcast older people's voices in public debates that largely by-passed older age groups. With their work, LLARC members have set an example of how a group of older adults can leverage their peer support system to exploit the prevailing pandemic-related restrictions to their collective benefit. By actively contributing digital content to the LLARC Mixcloud page, participating stakeholders were simultaneously able to extend civic debates and strengthen their digital citizenship, highlighting the need to consider a digital dimension in older adults' civic activities. This civic impact of magnifying older adults' voices to such an extent at a point of crisis would not have been possible without the previous work of establishing LLARC as an overarching body that represents a collaboration of older radio and audio creators. It also demonstrates the success of this type of PAR project. In the case of LLARC, it was possible to facilitate the creation of a considerable amount of digital audio content by older adults at a time when their digital citizenship became a more crucial part of civic life and a lack of digital skills might otherwise have contributed to their exclusion from civic participation.

Disseminating research together with older adults

Beyond the research process itself, thought needs to be given to the dissemination of PAR findings. Aligned with the principle of democracy in PAR, researchers engaged in participatory projects share a responsibility to reflect their position of authority to represent a community's point of view. This highlights the need to disseminate research findings in ways that are valuable in both academic and non-academic contexts. This might entail jointly writing and publishing reports with research partners or disseminating the research in other creative ways, which highlight the action achieved in the PAR through an adequate presentation and interpretation of the research depending on the context of publication and the audience (Cahill & Torre, 2007). Like the research process itself, involving older collaborators more actively in the dissemination of research findings can provide an opportunity to engage with skills needed for civic participation, such as writing statements or creating public visual materials. In the case of LLARC, dissemination activities encompassed mainly the production of digital media content. Throughout the COVID-19 pandemic, LLARC members produced audio recordings which involved inviting gerontology or public health researchers to engage in conversations guided by older LLARC members. Having established

what was regarded as a successful model of engagement and dissemination, LLARC has since been approached by more researchers who are keen to share research findings related to gerontology on the LLARC platform and who are actively seeking conversations with older people through LLARC. In addition to engaging with researchers through the LLARC platform, some LLARC members have become involved with the research community more widely. This has occurred, for example, through participation in symposia at academic conferences on participatory research or through the joint production of an interactive research conference poster with researchers. In 2020, one LLARC member's skills in facilitating discussions were acknowledged by an invitation to chair an online discussion at the annual conference of a learned society based in the UK.

Discussion and conclusion

In this chapter, we set out to highlight synergies and entanglements between PAR and civic participation in later life. We highlighted opportunities to consider digital citizenship activities and skills related to civic participation within PAR projects, not least since they are often grounded in a similar skillset. Using the example of LLARC, we presented findings from our own PAR journey. This involved bringing older community radio content creators together leading to the creation of a larger and more sustainable community in the form of a co-operative organisation. The LLARC journey has been characterised by a series of PAR cycles, beginning with a Radio Festival for older adults and leading to a form of organisation that is able to advocate successfully for strengthening older adults' digital citizenship in broadcasting. In our view, LLARC represents an innovative PAR project that promotes civic participation in later life and is driven by older adults themselves.

The LLARC project demonstrates a trajectory of how a unique community can emerge based on a shared interest in using a specific technology for civic purposes (using community radio broadcasting to advocate for older people), and subsequently lead to the establishment of a broader co-operative movement (connecting age-friendly radio stations and older radio creators). By establishing LLARC as a community and peer network, a major focus of the co-operative's initial efforts was to connect and learn from each other. On this basis, and drawing on the framework developed by Serrat et al. (2020), we would tend to classify LLARC as a collective social type of civic activity. As integral to their work with LLARC, participating members make use of digital and FM audio broadcasts to pursue their civic activism (e.g. addressing political issues such as ageism) with the goal of reaching and engaging other communities and members of the public. This form of civic participation can also be classified as a collective political civic activity (Serrat et al., 2019). LLARC therefore embodies simultaneously both a collective social form and a collective political form of civic participation, suggesting that the real nature of older adults' civic activities can have diverse foci.

The dynamic development of its civic activity as an amalgam of social and political forms of civic participation was largely facilitated through the use of digital technologies. LLARC provides a compelling example not only of how interest and practice with a certain technology can encourage community building but also of how technology can democratise the process of establishing and running a new organisation without the need for a large infrastructure in terms of finances or organisational processes. Building this co-operative entirely online using existing digital technologies, our work with LLARC provides novel insights into the different ways in which communities of older adults operate and interact

digitally when seeking to achieve their civic goals. Working with the LLARC community before and throughout the COVID-19 pandemic, our work implies that the pandemic has accelerated the need to consider digital citizenship activities, as the concept promotes active contributions of older adults in digital spaces and therefore requires a creative digital skill set. Through its central goal of community building, PAR can present opportunities to create intergenerational support networks. In the case of LLARC, participating members were not only socially connected but also used their digital platform to speak up on political topics online. This highlights the potential of using digital technologies to support older adults' social connectedness, whilst simultaneously supporting their civic participatory practices as a part of PAR. The LLARC example also suggests that participatory media can represent a resource to support the goal of encouraging older adults to become more civically and digitally involved, whilst at the same time engaging with creative data collection activities to facilitate research and disseminate research findings.

Against the background of exploring older adults' digital citizenship with regard to content creation activities, PAR researchers can function as catalysts for change in communities. The PAR process is underpinned by a dynamic and processual dimension on multiple levels: the learning process of supporting older adults' civic and digital participation; the process of digitalisation of societies and the associated creation of digital environments; and the process of doing PAR as an active stakeholder within an evolving ecosystem of individuals, organisations, and technologies. The method of PAR can in itself be a factor that facilitates collaborators' engagement with technological innovation in later life and thus heightens levels of civic participation over time. As we reflected on the foundations of a sustainable PAR project, we have to acknowledge the value that lies in time and in participatory methods that embrace the synchronised process of development of research and communities. Recognising the ever-changing nature of digital technologies and contrasting this with the broader digitalisation of societies as an ongoing process, our PAR with LLARC contributes an in-depth local perspective in which communal change is driven by older adults themselves. Taking on such a systemic approach of not only focusing on socio-technical systems but also evolving networks and collaborations between different stakeholders and researchers, can contribute to a sustainable change and use of civic technologies (Klerks et al., 2020). The creation of LLARC in particular is a powerful example of forming a network and leveraging expertise from this community, which secured its future sustainability by scaling up as a co-operative. This focus on nurturing collaborations as part of PAR should be a main concern for researchers and public authorities who aim to support older adults' digital citizenship.

Summary

The research presented in this chapter reflects the expansion of a PAR project from its origins in a local collaboration towards the formation of the UK-wide LLARC. LLARC has now reached the point where it is able to engage in the process of creating international connections. Highlighting synergies between PAR and civic participation based on such values as democracy, equity, and participation, we show that the creation of sustainable PAR communities can be a way to support civic participation in later life that reaches beyond the end of the research period. Bringing together older radio creators and age-friendly community radio stations, LLARC was built entirely within a digital infrastructure due to the COVID-19 pandemic. This emphasises the considerable potential of digital

technologies to support the infrastructure of an emerging co-operative. Indeed, LLARC has advocated for older people throughout the pandemic by broadcasting community radio content, which highlights the urgency of challenging ageism and age discrimination. This demonstrates the potential for PAR projects to engage with participatory media to support older adults' digital citizenship and their inclusion in citizen debates, as well as for research dissemination.

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19

THE LIVING LIBRARY –
A PARTICIPATORY APPROACH
TO SOCIETAL RESEARCH
IMPACT

Bram Vanhoutte and Neil Dymond-Green

Introduction

In an age of increasing digital communication and faceless information digested from screens, the danger of relying on mental shortcuts such as quick first impressions and stereotypes to form opinions is on the rise. While it is natural and spontaneous to categorise individuals into social groups, it is important to understand these cognitive processes are not without consequences. Assumed group characteristics are assigned to individuals who may have none of them and the supposed uniformity of a group is reinforced. The very ageist public discourse during the Covid 19 pandemic depicted all older people as vulnerable and helpless, the loss of their lives as inevitable in natural 'herd' immunity strategies, underlining a general depreciation of the value of a life based on years lived, all illustrating deep-seated prejudices and stereotypes towards older people (Fraser et al., 2020), effectively reinforcing the already established systematic breaching of human rights of older people (McGrath, 2020; Peisah et al., 2020). Combatting ageism therefore is urgently needed on different levels of society, by addressing different targets, not just on the top level by changing ageist policy and ensuring equal rights for people whatever their age, but equally on the ground, by deconstructing established views on the way older people behave, think, and live their lives. One humble, collaborative, and low-key method to address common prejudices is a living (or human) library, which uses the metaphor of people as books to stimulate contact and conversation with a person who belongs to a prejudiced group. In the context of a research project which wishes to reframe ageing as experiencing a limited set of transitions associated with loss, rather than the abstract accumulation of years (Vanhoutte, 2021), we organised a dual event consisting of both a poster presentation and a living library event, with support of the UK's Economic and Social Research Council during the 2018 Festival of Social Science. The living library event, focusing on the narratives and lived experience of several volunteers recruited specifically for the event, was thought of as a more subjective and interactive counterpart to the more objective and fixed poster presentation of research results, both parts underlining three key messages: ageing is highly heterogenous, older people are a very diverse group and age is not a number. This chapter wants to explain what our event entails, focusing mainly on the living library event and

how to organise it, as well as reflect on some key observations made during the event from a perspective of research impact and science communication. In our discussion, we expand on this type of event and their positions in the research life cycle, and the use of living libraries as a method to increase participatory involvement as well as cement partnerships.

What is a living library?

A living library is an event in a public space, where a set of volunteers with one or more prejudiced characteristic, make themselves available for a one-to-one dialogue with a member of the general public to talk about their lived experience. Using the metaphor of people as books, it invites the public not to judge a book by its cover, and the volunteers to be an open book. It was set up for the first time in the year 2000 at the Danish Music Festival Roskilde and in the years since has developed as a format to create safe spaces for conversation about stigmatised or stereotyped characteristics, by the human library organisation (https://humanlibrary.org).

Theoretically we can understand a living library as bringing into practice a classic theory in social psychology, Gordon Allport's intergroup contact hypothesis (Allport, 1954). In the context of racial segregation in the US, Allport hypothesised that contact between different social groups is essential to reduce prejudice and discrimination if it occurs against the background of four conditions, namely equal status, common goals, cooperation, and support by the authorities. Contact works on different levels to reduce prejudice and stereotypes: Next to more rational cognitive mechanisms such as learning about the prejudiced group, and behavioural mechanisms such as opening yourself to future potentially positive contacts, emotions also come into play in how contact stimulates intergroup understanding on an individual level. Negative feelings towards the outgroup such as anxiety are weakened and positive feelings such as empathy are strengthened. A recent meta-analysis of the many studies that tested to what extent intergroup contact reduces prejudice confirmed both that the strategy works, and less prejudice is not just the consequence of selecting interested participants, as well as that it is applicable to wider sets of prejudice outside of racial discrimination (Pettigrew & Tropp, 2006).

Living or human library events as specific tools to combat prejudice have been evaluated by psychologists in experimental settings and are effective ways of reducing prejudice against stigmatised groups (Groyecka et al., 2019; Orosz et al., 2016). A second, less straightforward function of living library events is that they can be gateways to transmit the lived experience of a specific "other", by acting as a discourse forum for participants to foster conversations as humans, instead of objectifying them through our preconceived stereotypes (Sen et al., 2016). The emphasis on direct interpersonal two-way communication in a neutral environment is essential to both functions, with active listening, genuine interest, and looking for a common ground as elements that are reminiscent of building a good rapport in a qualitative in-depth interview setting, to enable a good flow of information.

In the case of later life, it can be argued most of us already have (had) extensive contact with older people, in the form of our ageing (grand)parents. In contrast to other prejudiced groups, it is psychologically easier to project ourselves in the future and imagine what it is like to be older. From this point of view, it is sometimes argued that prejudice against older people is relatively benign and harmless. While it is outside the scope of this chapter to explore why ageism is not harmless, we want to underline two points of relevance to our project: First, old age is mostly seen negatively, to such an extent that ageing often is denied

and many "objectively" older people do not place themselves in that category. Second, the enormous diversity within the group of older people, who may be childless, LGTBQ+, have a different cultural or ethnic background, be a sports instructor, is hidden behind a uniform and stereotypical image of a wrinkled person with a walking stick, rooted in our own memories of grandparents. The loss of individuality that ageist stereotyping entails, as well the emphasis it places on dependency and disability as constitutive of later life are two aspects we believe this project can help to combat.

A living library from a research impact perspective

In our version of the event, a team of colourful volunteers challenged people's preconceptions on ageing, against the background of quantitative research which proposes seeing ageing not as a number, but as experiencing transitions. As such we implemented a specific version of a living library event, with the dual goal of research impact and combatting ageism. The living library event was conceived as the main course, to explore subjective and narrative lived experiences of ageing in a closer more intimate setting of interpersonal exchange, with the more objective, graphical representation of factual data on ageing serving as an introduction that frames the conversations.

Research impact

Research impact is a contested concept that is defined in differing and sometimes contradictory ways (Penfield et al., 2014). It is often summarised as the change academic research can produce in the real world.

From an institutional perspective, the language around impact is usually purposefully vague, so as not to exclude anything. For example, our main partner in this event, the UK Data Service, functions as an access gate to high-quality socio-economic data for researchers from academia, the charity and voluntary sector, national and local government and beyond. Positioned at the interface between data producers and data users, the UK Data Service takes a nuanced approach to identifying and evidencing impact, aligned with that of the Economic and Social Research Council (ESRC). The definition of impact used by the UK Data Service is

> Our focus is on the demonstrable contribution the Service, its data and resources make to the economy, society, culture, public policy and services, health, the environment and quality of life. Our emphasis is on drawing together evidence about the reach and significance of the impact of the use of the data and resources, of the Service as a whole, and on understanding the beneficial effect.

While in principle anything goes and many things can be considered research impact, two main dimensions can be distinguished: A first axis that has to do with the specificity of the impact target and a second with the openness and interactivity of the impact activity. Highly instrumental research impact, such as when a finished result of research is picked up at the end of the research process in parliamentary commissions, by city councils or other institutions scores high on specificity and low on interactivity and openness. More grassroots forms of research impact such as public engagement activities, creative exhibitions, or classroom activities are at the other end of the field, with often a low specificity of the target

group, but high openness to interpret and adapt research results. Placing the living library event we organised in this framework, it clearly addresses a more diffuse audience, and is very adaptable to the context, as the conversations are guided by participants as well as the audience, aligned with the grassroots end of the spectrum.

What is the impact aim of the event, or in other words, what change in society did we target to stimulate or bring about? On a fundamental level, the event was designed to break down communication barriers that may exist between wider society and quantitative research, as well as between generations. On a more applied level, the event engaged attendees with both population-level evidence as well as personal experiences of ageing transitions. Reducing communication barriers by supporting the generation of an emotional, empathic response will supplement breaking down existing stereotypical and established views on ageing.

Research project

The topic of research strongly echoed the dual aims of a living library event, deconstructing ageing and showcasing diversity in ageing, which is why we used it to communicate some of our findings and ideas. Having an open conversation about quantitative research in the form of a poster presentation equally demystifies academic knowledge and quantitative research as distant and only accessible to specialists. Even among academics, strong established opinions on the supposed positivist epistemology underlying quantitative methods often prohibit thorough discussion or engagement with research results so that it is not surprising that a general audience relies mainly on mediatised research findings, which may distort the original research to attract a larger audience or fit a different agenda. A face-to-face poster presentation cuts out all the middle men and creates a training opportunity for the researcher to streamline his research result message, as well as allowing for the audience to share their impressions. The research project which provides an evidence base for the event is exhibited on two banners, with the researcher present to explain and expand on the results of a quantitative analysis of longitudinal panel data on ageing (Figure 19.1). The focus was on how our preconceptions of later life do not always align with objective facts on how people are ageing today. The upward shift in life expectancy, in tandem with profound societal changes makes the way in which current generations are ageing substantially different from earlier ones, and possibly more diverse than ever before.

- A first goal of the project is correcting this misrepresentation by showing some actual data (the English Longitudinal Study on Ageing (Steptoe et al., 2013)) on health, wealth, and partnership to correct a view that equates old age with an inevitable disability, poverty and widowhood. While averages mask a wide variety of realities, more than 75% of those aged 80 years old and living at home in England does not report to have any limitations in daily activities such as dressing, bathing, and so on. A growing proportion of people, around 30% in the younger cohorts, are ageing without a partner, either because they separated or because they never married. Furthermore, while poverty in old age should not be minimised, the share of people living hand to mouth, with less than 1,000 pounds in savings, is larger between 50 and 55 (about 40%) than at older ages.
- A second goal of the project is to redefine ageing as a series of interconnected transitions of loss in health, wealth, and partnership, rather than the number of years lived since

Figure 19.1   Living Library Project meeting.

birth. The research proposes to focus on the wide diversity in ageing by examining the timing of these transitions over the life course, instead of averages over age (Vanhoutte, 2021). This would help to better understand not only the large variability when ageing transitions happen but also help to highlight how these transitions are the gateway through which inequalities over the life course formed by class, gender, ethnic background, and sexualities are translated into different and often unequal ageing pathways.

Living library event

The living library event itself consists of matching people from the audience with our various volunteers to have an informal conversation about ageing transitions (illness, partner loss, financial difficulties) they have lived through (Figure 19.2). The impact of such a conversation works both ways, as it affects both parties. Audience members may adapt their views on ageing transitions, or at least consider the person with whom they have had a conversation as a human being with whom they share similarities, rather than just another older person. In this way, ageing stereotypes are put into context and the uniqueness of each person is highlighted. The older volunteers are also impacted by the event, as they are stimulated and energised by the rapport developed during the interaction, and a genuine interest in how they have experienced their lives is a boost in self-confidence.

The goal of the impact event as such was not to change high level policy, but to provide factual information on the changing realities of ageing, highlighting the diversity in ageing to the general audience, as well as propagating the idea that we are not defined by our age, but rather by the experiences we have lived.

Figure 19.2   Living Library Project discussions.

Methodology and organisation

The living library event was organised by a postdoctoral researcher and a facilitator from the UK Data Service. A small amount of funding (700£) was received from the ESRC in the framework of the festival of social science, and was used to print out two banners with the research results, as well as handouts and materials for the day, provide coffee and cake for a preparatory meeting as well as lunch, refreshments, and reimbursement of transport costs for all the volunteers on the day of the event.

Recruiting volunteers

Key to the success of running a living library event is recruiting volunteers who are both confident and supported to share their life experiences in a psychologically safe environment. The organisers approached a number of organisations such as the Workers' Educational Association (WEA), the University of the Third Age (U3A), Greater Manchester's Combined Authority's Centre for Ageing Better, and 'Ambition for Ageing' at the Greater Manchester Centre for Voluntary Organisations, who were all keen to promote engagement with the event. We promoted the event through social media and our own personal networks as well.

   The timing of the Festival of Social Science event in November put some restrictions on some potential participants who were less keen to take part in an event during the winter. Nevertheless, a small and varied group of eight volunteers was available and willing to participate in the event. While we did not consciously select people, we do feel we should have tried to be more inclusive in our recruitment strategies for working class and less able older people, something which would have come naturally by working closely with established associations. A member of the audience who took part, an older working class woman, made this remark when she took part in the event.

Venue space

A second important aspect of a successful living library event is the venue space, which needs to feel both contained neutral, and safe enough for conversations to flourish, but also be accessible enough that people pass and are drawn in. The organisers were able to work with Manchester Central Library, which has a variety of spaces and runs many different events, to locate and book a suitable space. The chosen area was adjacent to the main lending library and near access points from the entrance. It was, however, also a self-contained space which people would pass by but not through.

Pre-event meeting

As none of the volunteers had taken part in a living library event previously, and most of them had not met each other, it was important to run a pre-event meeting. Here, the structure of the event as well as some more explanation on the background of the living library idea was explained. Furthermore, volunteers were supported to build a temporary, psychologically safe space through careful sharing of experiences, social bonding, and guidance from the organiser on how to get the most out of the event. By having a practice run of the type of conversation that could develop at the event, volunteers were trained in structuring aspects of their life stories around the topic of ageing transitions. They were stimulated to come up with a book name and short descriptive cover text for themselves and a pseudonym if they wanted to. Key guidelines were shared and are reproduced here:

- The focus of this event is 'how it feels to age'. You might choose stories and advice which relate to how your life so far has prepared you (or not!) to be the person you are now. But it's okay if your stories and memories end up following a different path.
- Your life stories are extremely valuable. No matter how exciting or otherwise you think your life has been, people will want to hear.
- Your stories are your own, so you are in complete control of what you choose to share. If a question makes you uncomfortable or is something you don't want to answer, it's okay to say no. To keep the 'book' analogy going, one possible response might be 'Let's skip to the next chapter, shall we?'
- There will be prompt questions available at your spot. These could be used by 'readers' to help them get into your 'book' or you might use them to help you think. They are not compulsory!
- You will have 15 minutes with each 'reader'. You don't have to fill all that time.

Event promotion

The event was promoted through social media, email newsletters, and posters/leaflets distributed to key partners and in relevant venues around the city centre (Figure 19.3). As it was part of a broader ESRC Festival of Social Science, it was also mentioned in the programme guide of the event, which attracted a number of university students. One of the volunteers was a presenter on a community radio station (All FM) and invited us on his weekly radio show to choose some music to play and promote the event.

Figure 19.3   Living Library Project promotion materials.

Various materials were produced to support the event, beyond on-the-day promotion. Pop-up banners were produced and displayed on the day to highlight key elements of the research. For the benefit of 'borrowers' (attendees at the event), simulated book covers were produced, with a title for the 'book' (i.e. volunteer) on the front, a blurb about the 'book' on the rear, and a booking out page for 'borrowers' inside. Each title and blurb was created by the individual volunteer. As part of the work with the volunteers to ensure the event was psychologically safe, they were supported to choose a nom de plume (e.g. Irma Phelps) if they preferred that to their real name. Titles included 'This Rosemary's not for remembrance' and 'And quietly flows the Don' (Figure 19.4).

To support 'borrowers' who might be unsure where to start with their 'book', prompt questions were individually printed and available with the 'books'.

• What advice would you give yourself if you were my age?
• What has been your biggest life change? Was it something you could prepare for?
• Have any changes in health affected how you live?

'They' say that people in their 60s are the happiest and for Rosemary this is certainly true. A single mother of 4 daughters, she worked hard to keep a roof over their heads through her 30s 40s and 50s.

She started a Social Science degree at Manchester Polytechnic on her 37th birthday (so hungover she had to go home at lunchtime - nothing like embracing the student life), completed her degree, took a postgraduate course to become a careers adviser and then worked until she could retire.

In 2011, at the age of 60, Rosemary was offered voluntary redundancy, at the same time as she became an OAP, so decided to put her feet up - literally. She spent the summer of 2011 with her feet up in various poses, training to become a personal fitness trainer. She now has her own company, Over Fifty Fitness, and works mainly on social media with 'virtual clients.'

She's a grandmother with 5 grandchildren and when not with family, she spends her time grabbing opportunities and having a ball.

She's been on Women's Hour and BBC Radio Manchester.

She also supplements her pension by winning money on TV shows and conducting Great Crested Newt Surveys.

Rosemary may be for remembrance, but this Rosemary is for looking forward to an exciting future.

This Rosemary's not for remembrance

Figure 19.4   Living Library Project promotion materials: sample book description.

- When were you happiest? What made you feel that way?
- When were you saddest? Why?

Event organisation

The group of volunteers were brought together early on the day of the event, both for a shared lunch and an opportunity to continue to bond and to give them a last opportunity to ask any questions or share concerns (Figure 19.5). On the day, some volunteers dropped out due to external circumstances, but five volunteers were able to attend. Once in the event space, volunteers were able to choose where they sat and adjust layout to ensure they felt comfortable and safe. A secret sign was agreed that indicated the volunteers would like some assistance from the facilitators. The organisers acted as the facilitators, encouraging passers-by to attend, explaining the process of taking part in the living library event, encouraging borrowers to move on if others were waiting to borrow their book and, importantly, relating the event to the research. Actively approaching people as they passed by, we would ask if they were interested in taking part. After a short outline on what exactly participation entails, those interested were introduced to the theme of the event, ageing transitions, by the facilitating researcher present at the event, in an informal poster presentation, that emphasised the changing nature of ageing and challenged preconceptions on later life. This introductory phase was adaptable in length and functioned as a time buffer in case there was some waiting time before a volunteer was available. The facilitators stimulated

Figure 19.5   Living Library Project promotion materials: book presentation.

volunteers to have a break in between conversation sessions, so as not to exhaust them, but in general, conversations lasted longer than the allocated 15 minutes (easily up to 30 minutes). One facilitator was on the lookout in case any of the volunteers needed assistance to stop a conversation if this did not happen naturally or if it became unpleasant in any way, which could be called for by a pre-agreed secret sign. Refreshments were provided for the volunteers throughout the event (Figure 19.6).

Aftercare

After the event, which went on about an hour longer than originally planned, we gathered with the volunteers to gather feedback from the participants. We have been in touch with them through email and social media after the event.

Event observations

A mixed audience consisting of more than 20 passers-by took part in the event as 'borrowers', and five volunteers took part as 'books'. While we did not conduct a formal evaluation, informal evaluation with participants showed they were engaged and fascinated by the life stories they heard, breaking down communication barriers between generations. Often the conversations were only curtailed because the next borrower was waiting. Some participants expressed relief when hearing about the real data on ageing, counterintuitive to their views on old age.

Figure 19.6   Living Library Project discussions.

For the facilitating researcher, the poster presentation was a great opportunity to communicate research results directly to the public. Communicating factual information based on statistical data and knowledge about ageing processes in a more informal, interactive, and loose manner, was both enjoyable as well as good training in clear and straight communication. A balance was sought between illustrating the progress made in terms of life expectancy and living with chronic conditions for the current older cohorts and the existing inequalities therein on the one hand, and possible challenges in accommodating social, mental, and health care needs in later life on the other hand. The rise of specific profiles that do not fit the mould such as childless, single, LGTBQ+, and Black, Asian and Minority Ethnic (BAME) older people was specifically highlighted, to emphasise the diversity in ageing.

In terms of the content of conversations, both volunteers and audience reported that often quite early in the conversation, a common point or element in the life course was discovered, that created a familiarity and became an anchoring point for the conversation: late timing of starting studies, caring for young children, taking up exercise to name a few. Even when they happened decades apart, and sometimes at different stages of the life course, these events created instant connections between volunteers and audience and highlighted similarities in daily life instead of differences.

Volunteers shared enthusiastic debriefs after the event and were later contacted by email for additional evaluation of their experience. All responded positively to the experience and offered to be participants if the event were to be repeated, mentioning for example "I was so impressed with the curiosity of those people who just happened to be passing and stopped to talk.", or "I think the people who came were intrigued by it". While for the organisers

this event was conceived as a trial run with an open end, most of the volunteers explicitly stated they wanted to repeat the event and be involved with further steps of the research.

Representatives from both Manchester Central Library and Age UK Bolton (the latter having attended as an observer) expressed an interest in running similar living library events in future as stand-alone events, which they meanwhile have done.

Discussion

While there were some limitations to the amount of diversity we captured with our small group of volunteers, everybody involved (volunteers, audience, facilitators, and institutions) was very enthusiastic about the project. One question from our volunteers that kept on coming back in the different stages of the project was "why are we doing this?" Three key observations that arose from our experience as facilitators of this research impacted events on later life, which in essence combined a poster presentation with a living library event, can help us to provide a substantiated answer to this question.

First, there is a need for researchers to democratise access to scientific research, and get out of their office, by finding ways to communicate their research outside of the established channels. The relatively novel and unique emphasis put on research impact in the UK is all too often seen as an additional burden to make a press release that may or may not be picked up by the media, which networks you into the circles of power and digests results into policy recommendations. While that is one way to try and foster research impact, which is more suited to established academics, the idea behind it is far more neutral to the level, efficiency, and target of research impact. The relation between (social) science and society works both ways, but the part where the academic community gives back or reports back to the public, outside of the university is often either an afterthought, forgotten, or left to intermediaries. It is healthy for researchers to step off the stage and start an open dialogue with a member of the public about research findings, not only to put things in perspective or enrich the research but also to train different registers of explanation. To reinvigorate public belief in research and trust in science, a more open form of collaboration in the collection of data, production of research, and dissemination of results is needed. In our experience, combing an informal and open setting to illustrate research, casually, through conversation rather than presentation, alongside a different type of event is an effective and interactive means of science communication to small groups of people.

Second, our event illustrated living libraries are a flexible and adaptable methodology that works to create a safe space in which conversations can flow that lead to blurring group-based boundaries. It is an attractive way to set up an intergenerational dialogue with a low threshold for participation. The key to this event is enabling a personal exchange. While we have unprecedented possibilities to communicate with each other, it seems we have become less skilled in doing so outside our direct circle. As social animals, we need to talk to other people, and our event showed us that people are intrigued by individual ageing stories, and immediately try to draw comparisons to their own lives and seek points of alignment, instead of antagonising. Our volunteers were invigorated after the event and beaming with energy, and participants were surprised by the type of conversations they had with total strangers, ranging from their backgrounds to their aspirations in life. Institutions and partners, who hosted us and/or observed what happened, were eager to adopt (and imitative) this innovative type of event that puts everyday people on the stage and facilitates them to be themselves. In a sense living libraries can be seen as filling a gap in terms of

recreating a space for live conversation between citizens in an age of digital communication, in line with initiatives such as deliberative democracy, restorative justice, or peer education, frameworks that seek to connect people through conversation, to solve larger societal issues.

Third and last, we situated our living library events at the end of the research life cycle, as a way to enhance the communication of results. In a classical view on the research life-cycle, you have a question based on your reading of the theory, posit hypotheses on what the answer could be and why, gather evidence and data, research, publish results, and then disseminate your results in the form of research impact events. But our case showed that once you have recruited volunteers, there is a good chance they will be interested in the re-search and might want to participate more. I was actively planning to further engage with some of them by conducting in-depth interviews for a project on resilience in ageing, which for reasons outside the scope of this chapter did not materialise. As such we can easily see a living library event function at a different stage of the research cycle. It could be integrated into the research phase, for example as a more interactive pathway to recruit participants for a qualitative study, as a lay advisory group, or co-researchers in a participatory research setup. It has a clear potential as a way of screening and recruiting members of the community under investigation, with the added advantage of being less individualistic, as people can decide to come and take part with a friend. It can also be a part of research training, as a first event where prospective and inexperienced researchers or interviewers approach the group under focus in a more informal manner, and learn to create rapport with motivated interviewees that are eager to talk. A last potential coupling of living libraries with other activities is in an educational context, to give students (for example nursing, social work, gerontology, or sociology) a point of connection to social groups they might have studied about but with whom they have little practical interactional experience.

In conclusion, a living library is a versatile tool to bridge boundaries between people that showed potential as a way to contextualise quantitative research findings. While it is easy and straightforward to implement, it is labour intensive as it does require planning, recruit-ment of a set of volunteers that need some guidance on the researched topic, as well as host-ing on the day. From our event, it was clear that all parties involved (audience, volunteers, organisers, and hosting institution) were very motivated by the event, and eager to repeat it, which is convincing evidence of the way in which it fills a gap in (science) communication.

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PART 6

Doing the whole research process together

20

THE BELGIAN AGEING STUDIES

Peer research as an instrument to empower older people

Nico De Witte, Dominique Verté and Emily Verté

Introduction

Globally, a rise in life expectancy is noted (United Nations, 2019). In Europe, this longer lifespan has led to an ageing population where in 2019, the year before the covid pandemic, more than one-fifth was 65 years or over. Moreover, the segment of the oldest old in Europe is growing even more rapidly than other age segments, as it is expected to increase from 5.6% to 14.6% by 2100 (Eurostat, 2019). As a consequence, concerns about the sustainability of existing social welfare are a hot topic on the political agenda and are often debated, which is also the case in Belgium. Although a constitutional monarchy, Belgium can be seen as a parliamentary democracy. The U.S. President Abraham Lincoln once defined democracy as: "Government of the people, by the people and for the people". Democracy was created as a reaction against power abuse of rulers. In such a governmental form, politicians are elected to represent their voters' rights in all constitutional boards, which is also the case in Belgium. In the context of an ageing population, however, it remains the question to what degree the voice of this growing group is heard in politics. In this matter, Alan Walker calls this the paradox of old age, where a large number of older people coexist with a lack of political influence (Walker, 2007) In other words, political participation did not follow the demographic changes of an increasingly older population. Moreover, care for the aged was, from a political point of view, often approached with a focus on public pension and health care arrangements (van Groezen & Meijdam, 2005) thereby neglecting other needs of older people for instance, social cohesion and participation (De Witte et al., 2013), safety and security (De Donder et al., 2012), cultural participation (Verté et al., 2007), etc. This is astonishing because as in most European countries, an ageing-in-place policy was chosen in order to cope with the challenges of an ageing population. Within this policy, older people are encouraged to stay in their own home/environment for as long as possible. Enabling older people to age in place entails an involvement of them in decision-making concerning the environment they live in. Moreover, the narrow approach neglects initiatives like the "active ageing policy" from the World Health Organization and the European Commission. Within an Active ageing policy, older people are seen as active contributors to society (Reed et al., 2008). The Belgian Ageing Studies (BAS), which is elaborated in detail in this chapter,

starts from the premises of active ageing and participation in decision-making. This study mostly took place in Flanders, which is the Dutch-speaking part of Belgium. Without going into too much detail concerning Belgium's complex governmental structure, we can say that on the first of January 2022, Belgium counted 11,584,008 inhabitants, of which 6,698,876 live in Flanders, 3,662,495 in Wallonia and 1,222,637 in Brussels. Each of these regions has its own governmental structure (parliament, prime ministers, minister) and there is also an overarching government with its own parliament, prime minister, and ministers.

Background and history

Governmental political participation of older people

In Belgium, the pyramid of the unitary state made way for a more complex three-level structure. At the top level, there is the Federal State. Next, there are the Regional Governments (Flanders, Brussels-Capital, Walloon) and then the localities. For all those governmental levels, compulsory elections are organised on a regular basis (Portal Belgium, 2013). Elections can be seen as formal processes of selecting persons for public office (Encyclopedia Britannica, 2022). In other words, they give people the opportunity to vote for politicians who can stand up for their rights. Although older people are protected by a prohibition of discrimination on grounds of age and their rights for a dignified and independent life are recognised (Treaty of Lisbon, art 25), they often cannot vote for older people. Indeed, the case of Lisel Heise, a 100-year-old woman, who was elected to the town council in Kirchheimbolandes in Germany, is a rare counterexample. Like in many other European countries, there is a lack of older people's representation in the political decision-making bodies in Belgium. Compared with other groups, the voice of older people is hardly heard. Lacking a representative in the central political structure is problematic because policy decision-making is less likely to be influenced. According to some scholars, older people are often viewed as powerless on a political level, which is not the result of their age, but a socially constructed problem (Kam, 2000). They are large in numbers, but small in power (Walker, 2007). Indeed, in Belgium, political participation of older people is restricted to mandatory voting, membership of consultative bodies and advisory boards (Falanga et al., 2020), and party affiliation. Although this sounds good at first sight, reality is quite different. Older people's consultative bodies and advisory boards are often just tolerated, mostly without even taking into account their comments and advices. In political parties, the buzzword is rejuvenation, whereby older people are pushed into the background to stay there as quiet as possible. Next to this, political participation is undermined by stereotyping of old age which is called ageism. Butler was the first to use the word ageism in 1969 to describe the process of the systematic stereotyping of people because they are old. Ageism allows other generations to see older people as different from themselves (Butler, 1975, p. 12). "Ageism is negative attitudes towards older persons that stem from myths (assumptions and stereotypes) about aging, the aging process and being old" (Kelchner, 1999, p. 88). Not only are older people over-generalised, but this process is also accompanied by a "rigidity of thoughts that imprisons others in a role" (Vincent, 2004, p. 87). Thus, older people are often solely assessed on their appearance. They are approached not only as sweet, helpless, harmless, sometimes incompetent, but also as suspicious or stubborn (Kristofferson, 2006). These stereotypes, however, do not correspond with the real situation but have far-reaching consequences for participation of older people in society.

Neighbourhood participation of older people

The aforementioned, negative stereotyping is also found in neighbourhood participation, which is regrettable because, in later life, place and locality become more and more important. Indeed, the older population will highly depend on the suitability of their own housing conditions (Costa-Font et al., 2009). Because of population ageing and an ageing-in-place policy, the reorganisation of older people's living arrangements will become unavoidable. Local consultative bodies and neighbourhood participation are the means for older people to express their opinion (Falanga et al., 2020). In this matter, however, another paradox is observed. Although older people tend to spend a lot of time in their neighbourhood, they are often among the first to be ignored when it comes to decision-making processes and participation. According to some researchers (Buffel et al., 2012), there is still a great potential for involving older people and senior organisations as participants in social policy-making, not only in relation to health- and care-related matters but also as for matters that operate locally such as housing associations, design and liveability of the neighbourhood. One of the aims of the BAS is to empower older people to engage in local decision-making. In this project, older people are seen as key stakeholders in the development of local senior policy plans.

Involving older people in evidence-based policy: the Belgian ageing studies

Historical ground of the BAS

By the year 2000, some policymakers in Flanders became aware of the problem of low participation of older people. As a consequence, a new Flemish decree was proposed in 2002. This decree stipulated that local municipalities had to develop a "local senior policy plan". Most municipalities had already some experience in developing policy plans for youth or cultural participation but lacked experience for senior policy plans. Moreover, like the decree requested both facilitation of the participation of older people in local policy and the prevention of discrimination and social exclusion of older people, municipalities realised they were lacking expertise and insights into the needs of the older population. Altogether, the municipality needed an environmental analysis, which sought to reveal the needs of older people (Flemish Government, 2004). Implementing an environmental analysis was found to be difficult by the local authorities as many municipalities did not know how to deal with this task. In mid-2002, the BAS team, two researchers from de Vrije Universiteit Brussel (VUB) and University College Ghent (HoGent), developed a research project called the BAS. Within this project, besides the creation of evidence-based knowledge, an increasing social and political involvement of older people was obtained. This was realised by a methodology which emphasises active involvement of older people at all levels of the research project, co-creation, and a multi-stakeholders approach. Indeed, there is increased recognition that the best research outcomes are achieved when researchers collaborate with the community members and gain input from those who are living the phenomena under study, that is, older people themselves (Quine & Kendig, 1999; Warburton et al., 2009, Boffi et al., 2021). In doing so, empowering effects towards improvement of their political engagement can be found (Fudge et al., 2007). In the next paragraphs, the development of the BAS, in close cooperation with all stakeholders, is elaborated.

Development of the Belgian ageing studies

Objectives of the bas

The BAS project's objectives can be divided into three groups. First, there are the objectives towards local policy. With this study, we aim to:

- Promote evidence-based policy at the local level by providing input and mobilising knowledge for planning and inclusive policy programmes;
- Provide a tool for evidence-based policy on the local level;
- Examine trends in particular municipalities by conducting follow-up studies;
- Monitoring local challenges, progress, and trends;Monitoring the impact of local policy plans.

Next to this, the BAS project also aims to contribute to society. In concrete terms, the objectives towards society are:

- Support the process of creating age-friendly communities;
- Assessing quality of life and living conditions of senior citizens;
- Provide a tool for supporting the process of creating inclusive, age-friendly communities and promoting active ageing;
- Provide research as a tool for empowerment.

In the end, there are the research objectives as follows:

- Provide an instrument to measure the living conditions and quality of life of older people and their needs;
- Provide benchmarking (results of a municipality are projected against regional, provincial, and Flemish results);
- Generate a large dataset for fundamental research.

Communities decide by themselves whether to participate in the project or not. When the project in a community is finished, we present some of the results to older people, local stakeholders, and policymakers during a press conference. These are well attended, also by people from other municipalities. Because we do not advertise this research project, this must be one of the decisive factors based on which other municipalities decide to participate.

Developing standardised research and educational tools

In order to achieve the objectives, different research and educational tools needed to be developed. As aforementioned, the Flemish decree of 2002 was the onset of the BAS. The whole project was developed in close cooperation with all stakeholders including older people who could take up different roles in the project. Older people could play the role of active subjects participating in the project, advisors in the development of the topics for the questionnaire, research practitioners distributing and collecting questionnaires, or as members of commissions debating on the results.

For the development of the questionnaire, two types of focus groups were created. Focus group 1 consisted exclusively of older people. Participants of this group were: members of senior organisations and members of local or provincial senior advisory boards. Indeed, research provides evidence that the involvement of older people results in greater understanding of the needs and the identification of research questions that otherwise would not have been considered (Fudge et al., 2007). In focus group 2, professional stakeholders like members of local authorities, local political stakeholders, and members of the government participated. In a first round of meetings the topics of the questionnaire were determined. In a second round, consensus about the topics to include was sought. Only the BAS research team was responsible for the scientific quality of the questions to be added to the international validated survey. Scientific measurements were found or developed. Next to this, the BAS research team developed the research methodology. By the end of 2003, standardised tools to perform the study were ready. These tools included (Verté et al., 2007):

- A scientific standardised questionnaire which includes a variety of topics
  The final questionnaire, which was realised after an intensive process of negotiation in focus groups, contained 24 pages. The topics are: socio-demographic variables, physical health, care, housing conditions, public space, feelings of unsafety, psychological wellbeing, loneliness, social networks (quantity, satisfaction, and support), social participation, cultural participation, political participation, political satisfaction, mobility, retirement, etc.
- A research process scenario
  In order to standardise the study over different municipalities, a research scenario was developed. In this scenario, a detailed overview and instructions for every phase in the research process are given. Moreover, all PowerPoint presentations, templates for every letter of invitation, and every document needed in this project were prepared and added to the research scenario.
- Software
  In order to register the results of the questionnaire, a Microsoft Access database was developed to facilitate data entry. This database can be easily used by volunteers or by staff members of the local authorities. Moreover, it significantly reduced encoding errors.
- educational training for volunteers
  In order to let the research project proceed smoothly, training was developed for the research supervisors, for the staff of the municipality, and for the interviewers.
- Data management tool
  In order to control the data flow, a data management tool was developed. Using this tool enables the BAS research team to generate standardised reports for each participating municipality. In these reports, the results of the municipality are compared with provincial and Flemish benchmarks. More specifically, this report focusses on topics of living and housing conditions, health, wellbeing, multidimensional frailty, loneliness, participation of older people, and many more.

Peer research methodology

The BAS make use of a participatory methodology, named peer research. More and more, researchers are aware that the involvement of older people in research will improve the quality and applicability of their research (Warburton et al., 2009). Moreover, in a recent
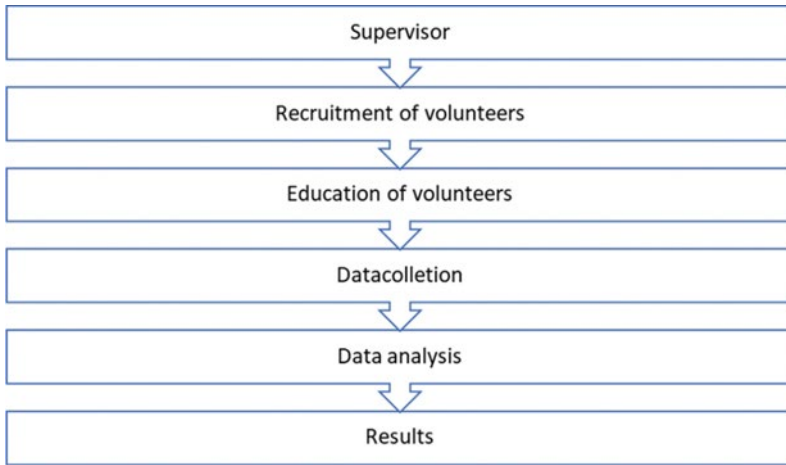
Figure 20.1 The BAS research project

review on this matter, it was shown that the involvement of older people improved their political engagement (Fudge et al., 2007).

The target group of this research project, older adults themselves, not only participated in the development of the project but are essential partners within the ongoing project in a municipality. Indeed, in every municipality, the project is monitored by a local supervisor, often someone from the administrative staff of the community. This person is trained by the BAS research team and afterwards, takes responsibility for monitoring the research process in a municipality. The supervisor gathers all local stakeholders, helps with recruiting older volunteers, and trains the voluntary interviewers who will distribute the questionnaires (Figure 20.1).

By the end of 2021, more than 200 municipalities in Belgium, The Netherlands, Italy, and Curaçao participated in the BAS project. In each municipality, between 30 and 100 volunteers were recruited to participate in the project. This recruitment was realised through an intensive recruitment campaign, which is identical in every municipality. After training by the supervisor, those older volunteers conducted several survey interviews. Although the questionnaire is self-administered, volunteers were trained to help clarify questions to the respondents, but only when respondents requested one. During the research phase, the volunteers could appeal to the supervisor at the municipality, at any time.

Finally, the data are analysed by the BAS research team. First, the strata of the sample were checked against previously provided stratification. If the sample did not meet the requirements, communities were asked to complement the deficits. Next, data cleaning was performed and scales were constructed. In the end, the results are presented to the local authority, the older volunteers, members of the local senior advisory board, local stakeholders, regional authorities, and older people. Thereupon municipalities were stimulated to involve older people in interpreting the data and the development of a local senior policy plan.

This peer research methodology has some advantages. First, it results in a high first response rate (between 60% and -85%) and more complete questionnaires. Second, it generates a "sense of ownership". Indeed, older people identify themselves within the project.

Third, it stimulates political participation and involvement among older people. As a consequence, policy for older people comes on the political agenda. Finally, it counteracts the stereotypical approach of older people by giving visibility to research and involvement of older people at the local level.

Bas: participants

The aim of the BAS is to collect information on community-dwelling people aged 60 years or older. In other words, older people living in institutions like nursing homes were excluded. In each municipality a proportionally stratified sample was drawn, using quota for gender and age (60–69, 70–79 and 80+). Each sample matched the makeup of the underlying population of the community. As a consequence, the most vulnerable age group (80+) is proportionally represented. The sampling size depended on the size of the municipality and varied between $N = 420$ and $N = 1592$, although in one small community, the sample size was 182, as there were less than 400 older people aged 60 and over living in that community. In each municipality, addresses were randomly selected from population registers. Moreover, the potential bias of non-response was also tackled. When respondents refused or were hampered to fill in the questionnaire, volunteers received replacement addresses in the same quota category. Respondents had the right to decline their participation and their privacy was guaranteed.

Bas: participating municipalities

In 2004, which was a pilot year, 11 municipalities engaged themselves to carry out the project. Based on these pilot studies, the standardised tools were refined. From 2005 until 2021, the BAS was executed in more than 200 municipalities in Flanders. In total, over 80,000 older people were questioned, and more than 8,000 older volunteers have taken part. Besides this, the capital of Belgium, Brussels, also participated. Finally, four Walloon municipalities also took part in this project. In addition, on an international level, municipalities in the Netherlands (15 municipalities), Italy (two municipalities) and Curaçao participated.

Outcomes

In this section, the participating municipalities of the BAS and the outcomes are discussed. The outcomes of the BAS project are situated on three levels. First, the project has effects within the participating municipalities. Second, as provincial governments were essential partners from the development stages on, the project has resulted in meso-level outcomes. Finally, macro-level results were obtained (Verté et al., 2007)

Micro-level

Within a municipality, the local results are situated within regional and Flemish contexts in a written report. Therefore, we print the results of the community and add the calculated regional and Flemish benchmarks for each topic. Therefore, our own BAS database, where data of all communities who participated are included, is used. Indeed, giving the research methodology is standardised for all participating communities and 2/3 of all

Flemish communities participated, we are able to calculate benchmarks on both the Flemish and regional levels. The benchmarks help to situate the results of a community. For instance, the feelings of severe loneliness in a community are 16.2%. Knowing that the regional prevalence is 12.9% and the prevalence in Flanders is 12.7% can guide policymakers towards prioritisation. Next, these local results and the benchmarks are discussed in a number of forums which are organised by the stakeholder's network and the older volunteers, who were involved in the study. Finally, based on these results, local action plans are developed.

Another micro-level result of the BAS is that each municipality has its own profile, its own municipality-specific results. The differences in results between municipalities could often be explained by local differences like for instance urbanisation, presence of associations, history, etc.

Meso-level

The results of different municipalities are aggregated on a regional and Flemish level. Regional results are presented to regional stakeholders. On the Flemish level, differences between regions were found although less distinct than between municipalities.

Macro-level

The fact that the BAS study generated a large quantitative dataset, resulted in multiple academic research projects and studies. For instance: "*Social Capital and Feelings of Unsafety in Later Life*", "*the Role of Neighborhood Perceptions on Social Participation among Older Adults Living in Medium Sized Cities*", "*Individual and Contextual Determinants of Care Shortages*", "a *new holistic instrument for the detection of multidimensional frailty*,[1]" "*Housing and Older People*", "*Volunteering and Older People*", etc.

Next to this, additional qualitative studies have been performed. These studies were built on initial analysis, in which the quantitative data were used to guide purposeful selection of the study areas. For instance, two municipalities with low levels of feelings of social cohesion and two municipalities with high levels were selected. In this example, in-depth interviews were used to fully explore all local determinants. The quantitative data have also been used for the promotion of accessibility of meeting places for older people and the organisation of introductory internet courses in community centres which resulted in the creation of "neighborhood websites", or "development of local action plans focusing on initiatives to promote community cohesion". These projects were supported by the local authorities who provided funding and support for these local community initiatives.

Trend research

Several municipalities participated in the research more than once, often with an interval of six years in between, as this is the interval of elections on a local level. The results are used to prepare the policy plan towards older people for the next legislature, prior to elections. In doing so, this policy plan is safeguarded and secured, regardless of the results of the elections. When the BAS was executed once again, the same standardised educational tools,

the same peer research methodology, and the same questionnaire were used. The results of this trend research are summarised in a report where the results of the trend analysis were printed together with the provincial and Flemish benchmarks. This trend research allows municipalities to determine trends and changes between the two measures. In doing so, municipalities can evaluate their policy over time and place.

From research data towards policy

Between 2010 and 2012, the BAS team developed a methodology to translate a municipality's research data into policy. In this project, older people are once again involved as stakeholders. The other stakeholders are professionals (e.g., from care services, government). This project starts with an in-depth discussion of the local results by a member of the BAS team. Next, two focus groups are created. Members of local senior advisory boards, members of local senior organisations, or older people are invited to discuss the results during four meetings in focus group 1. The professionals reside in focus group 2. During these meetings the results are discussed, contextualisation is given and priorities are determined. At the end of the four meetings, each group realises a report with findings, recommendations, and advice. Next, these are discussed during a meeting with the members of all focus groups included. The purpose of this meeting is to reach a consensus about what advices must be addressed to politicians.

Conclusion

The BAS research project demonstrates the political empowerment of older people. Indeed, the peer research methodology has generated a sense of solidarity between older people in a community. Moreover, thanks to this project, older people became more involved in policy making and community practice. The recruitment process of older volunteers was applied in other projects where older volunteers were needed. In the end, the BAS project created a continuous cooperation between a network of partners: local authorities, local senior advisory boards, local senior associations, and older people.

Strenghts and limitations

Despite the strengths of the BAS project and its methodological approach, some limitations have to be considered. First, the decision of whether a municipality participates or not is dependent on the political engagement within the municipality. In other words, if older people, for instance, members of the local senior advisory board are interested and policymakers are not, the project often does not start. Second, although we cover more than 50% of the Flemish municipalities and large cities like Ghent, Bruges, Genk, Hasselt, and Turnhout are included, we do not cover the whole of Flanders.

Note

1 The Comprehensive Frailty Assessment Instrument (CFAI) which assess the physical, psychological, social and environmental domain of frailty.

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21

A SERVICE PROVIDER APPROACH TO RIGHTS-BASED RESEARCH

Meg Polacsek and Tabitha Porter

Introduction

Across countries and service settings, there is an increased commitment to providing systems of aged care that support older adults to live active, meaningful lives, and promote each person's choice and control, dignity, and autonomy. In essence, the design and implementation of these systems should reflect the basic human rights principles of participation, accountability, non-discrimination, equality, and empowerment. This 'rights-based' approach to services is relatively well established in the social work, disability, and mental health contexts (Joyce, 2019). In the aged care sector, however, many service providers still operate under old-style models of care that restrict older adults' voices and choices. The evolution of policy and practice is dependent on research that is relevant, translatable, and measurable in real world settings. By giving voice to older adults, rights-based approaches to research strengthen the potential for building an evidence base that is inclusive and responsive to their experiences, needs, and preferences (James & Buffel, 2022).

We work for a leading not-for-profit service provider based in the state of Victoria, Australia. The aim of this chapter is to present a service provider's approach to rights-based research on ageing. It begins with an overview of the broader human right to age well, before focusing on the principles of rights-based research. The importance of embedding research at the service provider level is explained, followed by a description of the approaches used by this service provider to invite older adults, their families, staff, and other stakeholders to identify research opportunities, co-develop solutions, and contribute to data collection, analysis, and reporting. An approach to research translation, implementation, and continuous improvement of evidence-informed practice in the service provider setting is then presented. This is followed by a description of how rights-based research is used to advocate for long-term change in the aged care system, improvement of community attitudes towards ageing, and to anticipate future challenges and opportunities in the sector. We illustrate our approach through two case studies.

The right to age well

Before we focus on the specific issue of rights-based research on ageing, we should consider the broader context of older adults' right to age well. Global ageing and a growing interest in quality of life in older age have heightened interest in understanding what it means to age well. Of course, the natural experience of ageing is multidimensional: physical changes occur in a particular setting and are influenced by factors such as gender, ethnicity, and the broader social and political climate.

Internationally, the propensity for ageism remains a significant challenge to the experience of ageing (Peisah et al., 2020). While a discussion on ageism is beyond the scope of this chapter, we encourage all researchers in ageing to recognise and reject ageism in all settings. As such, it is incumbent on researchers to overcome negative stereotypes that may prevent the active participation of older adults in planning, conducting, and participating in research (Jacelon, 2007).

Several international instruments provide a framework for protecting the human rights of older adults. Some 30 years ago, the United Nations Principles for Older Persons (1991) articulated a 'rights' approach through 18 entitlements for older adults relating to independence, participation, care, self-fulfilment, and dignity. In 1992, the United Nations adopted a proclamation on ageing, including the declaration of 1999 as the International Year of Older Persons (www.un.org). While these raised the need to improve global approaches to ageing, their influence on research, policy, or social impacts is unclear (Kendig et al., 2013).

Fast forward several years, and the United Nations' Decade of Healthy Ageing (2021–2030) is again bringing together communities, governments, international agencies, professionals, academics, and the media to improve the lives of older adults. This time, one of its strategic priorities is to strengthen research, data, and innovation. This commitment highlights the crucial relationship between fundamental human rights and research, policy, and practice: the principles of each include dignity, equality, fairness, non-discrimination, and mutual respect. Thus, rights-based research has the potential to enable the actual realisation of rights (Arstein-Kerslake et al., 2019).

In Australia, a Royal Commission into Aged Care Quality and Safety was established in 2018, to investigate the quality of aged care services. Over two years, more than 10,500 submissions and 600 witnesses presented evidence of a system in crisis. In its final report of 148 recommendations, the Commission called for a new aged care system based on a 'rights-based Act' (Royal Commission into Aged Care Quality and Safety, 2021). This rights-based approach should guarantee access to a system of high-quality, safe, and timely support, in which older adults can exercise choice and control. Of particular relevance to this chapter, the report recommends that high-quality care, continuous improvement, and innovation should be 'informed by the best available evidence from research and the means to apply it to the everyday practice of aged care' (Royal Commission into Aged Care Quality and Safety, 2021, p. 42). It is clear that the experiences of age and ageing cannot be separated from research on ageing.

A rights-based approach to research

A rights-based approach to research supports each person's right to dignity, agency, inclusion, and equality through research that is meaningful. For research to be meaningful, it should be valued by the researchers and participants, feel worthwhile, and have a positive impact (Helmer et al., 2020).

A global shift towards person-centred aged care is driving rights-based research in the sector, as providers seek to better understand and meet the needs of those using their services (Gardner, 2021; Naidu, 2019). In addition to informing practice, research is one of the ways service providers can assess and monitor their engagement with their clients, and ensure the strongest possible alignment with their needs and preferences. The insights gathered through research inform changes to policies and procedures that lead to improved service provision and client satisfaction. Studies have also shown the positive impact that user involvement can have on the project, the individual, and outcomes for service providers (Aase et al., 2021).

However, as providers respond to growing community expectations of a rights-based approach to aged care, the theory and practice of rights-based research in ageing lag behind (James & Buffel, 2022). In January 2022, a search of a reputable healthcare database resulted in only two items that matched keyword variations related to 'rights-based approach', 'research', and 'aged care'. Removing 'aged care' from the search terms brought up 116 results, most of which related to public, mental, and children's health. A more refined search for variations of 'human right', 'research participation', and 'ageing' revealed one result. In policy and practice, it appears that 'participation' in research may often be (mis) applied as inviting participants to provide data, and later sending them a summary of the findings (Morrison & Dearden, 2013). That said, it is also likely that published studies had not described the participatory approach, while inconsistent terminology relating to research participation may have excluded some results.

Consistent use of terminology is important in any research context but is arguably most critical when the aim is to bridge the gap between evidence and practice in 'real world' settings. As our research involves colleagues who provide services ranging from direct care to hospitality, human resources to maintenance, as well as older adults and their families, we suggest – perhaps contentiously – that the choice of preferred term is less important than its consistent use. In other words, whether you refer to 'participatory research', 'co-design', or 'rights-based research', what matters is that you use the term consistently. This suggestion in no way ignores the theories and frameworks behind the different approaches but prefers the consistent use of language to facilitate understanding and engagement of all stakeholders.

Embedding research at the service provider level

As a service provider, our organisation's mission is to provide older adults with high-quality services and environments that respect their individuality and independence (www.benetas. com.au). Integral to this mission is an agenda for rights-based research that guides innovative, evidence-informed programmes and activities, and a commitment to supporting and enabling the implementation of evidence into practice. Rights-based research also presents opportunities for authentic, meaningful engagement, whereby older adults are recognised as expert contributors to service improvement (Thompson et al., 2020). We would add that participation should be free.

For a provider of aged care services, involving older adults in research processes and learning from their experiences not only provides different insights but also helps guide the research, ensuring it aligns with their needs. Within many healthcare settings, increased 'user activism' is evident in consumer participation in service evaluation and design (Morrison & Dearden, 2013; Romsland et al., 2019). However, this involvement has primarily revolved around one's own care and treatment or focused on the quality and safety of services. As approaches to user involvement evolve, researchers and healthcare professionals are exploring the various ways they can participate in research (Aase et al., 2021).

Depending on the research project, there are different levels at which older adults can be involved (Fischer et al., 2020). At a low level, they may assist the project by completing surveys or trialling new equipment. Involvement at an intermediate level would entail a more active role where older adults may, from time to time, provide feedback on the project's design. Those involved at a higher level may be viewed as partners in the project and potentially provide input on all design aspects.

Nolan's (2006) 'senses framework' outlines several key determinants for maintaining optimal quality of life for older adults, particularly when it relates to care and support. For older adults, involvement in a research project can fulfil several of these 'senses' (Nolan et al., 2006), including:

- Continuity: Recognising, valuing, and using their knowledge and experiences to help bring context to a situation;
- Belonging: Feeling part of a group or community, with opportunities for meaningful relationships;
- Purpose: Being able to engage in activities that have meaning and purpose, and to have the opportunity to pursue goals and desires;
- Fulfilment: Being able to accomplish goals and feel satisfied with one's efforts;
- Significance: To be recognised and valued for making relevant and important contributions to the work.

A rights-based research strategy

As researchers who are employed by an aged care service provider, we are accountable to a board and executive group, our colleagues, the broad range of clients and residents who receive our services, and their families. Our research strategy articulates our commitment to a rights-based approach to research. In practice, we do this by:

- Taking an empathic approach to research, which involves shared language, collaboration, and empathy, respects participants' individuality and integrates their insights as experts in their own care to develop solutions;
- Fostering the multi-faceted concept of dignity, which includes older adults' independence, privacy, autonomy, and right to authentic inclusion;
- Inviting older adults, their families, staff, and other stakeholders to identify research topics, co-develop solutions, and contribute to data collection, analysis, and reporting;
- Enlisting the support of senior managers, team leaders, and direct care staff, to ensure that the aims and process of the research are relevant, acceptable, and feasible;
- Involving a range of internal stakeholders and participants in the transfer of knowledge into practice;

- Conducting our research in a way that is transparent, participatory, accessible, and responsive to the needs of older adults;
- Producing disaggregated ('broken down') data that allow understanding and comparison of population groups and the situations of specific groups;
- Sharing and disseminating our findings through a range of channels, to maximise their potential to inform policy and practice, and to support our advocacy in the aged care sector.

Rather than promoting a particular model, we use a participatory approach that involves close collaboration with our internal and external stakeholders, to co-create knowledge and facilitate implementation that is feasible and sustainable (Aase et al., 2021). At the most fundamental level, we acknowledge that older adults are 'experts by experience' (Thompson et al., 2020).

Practical strategies for embedding a rights-based approach to research

Applied to ageing research, a rights-based approach to research should as a minimum involve older adults in planning, data collection and analysis, and dissemination of findings. This fundamental level of participation should see older adults engage actively and meaningfully, with researchers honouring their experiences and contributions (Smith, 2018; Wolverson et al., 2021). In this way, a rights-based approach focuses not only on the outcome of the research but also on how it is achieved.

Basic principles

Notwithstanding growing interest, we are unaware of any step-by-step guides for the practical realisation of a rights-based approach to research in ageing. In the fields of social work and disability services, several guidelines exist to support rights-based research. The six theme-based strategies described by Maschi (2015), for example, have clear applicability to ageing research:

- Understanding and applying a human rights framework;
- Research and evaluation that makes a difference;
- Informed decision-making, multiple perspectives, approaches, and methods;
- Social contexts, meaningful participation, relational communication;
- Holistic analysis, discerning meaning from narrative and numeric data;
- Thoughtful sharing (dissemination) and action.

Principles of rights-based disability research can also be adapted to the aged care context. Researchers in ageing could modify the requirements listed by Arstein-Kerslake et al. (2020) to ensure that the proposed research:

- Enables equality and is free from paternalism;
- Challenges and confronts cultural attitudes towards older adults;
- Employs processes for design, implementation, and dissemination that are accessible to and include older adults;
- Will be translated into actions that aim to benefit older adults.

If we were to follow these useful principles, it could be argued that a model specific to rights-based research in ageing may not be necessary at all. However, there are several factors that require attention in order to strengthen the experience and outcomes of ageing research.

Recognising and supporting diversity

As with the broader community, it is important to recognise and support older adults' individual characteristics when planning and providing services. While we caution researchers to avoid making assumptions about older adults' needs and preferences, there are several groups who are at higher risk of disadvantage, vulnerability, or marginalisation. More likely to be represented in these groups are First Nations peoples, those from culturally and linguistically diverse communities, and those with diverse gender and/or sexual identities. Diversity also relates to people who live in rural and remote regions, are experiencing financial disadvantage, and are homeless or at risk of homelessness. It also applies to older adults living with dementia.

While service providers are increasingly supportive of diversity in their clients, these 'hard to reach' older adult populations are often under-represented in ageing research (Perkins et al., 2019). To operationalise rights-based research, additional support may be needed to provide equitable access and participation (Appannah et al., 2017; Perkins et al., 2019). As a first step, we recommend that researchers refer to peak organisations in their (or other) countries, to learn best practice approaches regarding inclusive practice for diverse groups of people. Guidance is also available from the current literature. Collins et al. (2022), for example, have reported meaningful ways to communicate with individuals with moderate to severe dementia and promote their inclusion in research and service evaluation. In suggesting that these strategies could be applied more broadly to the diverse range of participants, researchers' creativity and flexibility should be evident in their efforts to (Collins et al., 2022):

• Develop fundamental awareness, knowledge, and experience of the person;
• Show humanity and compassion in their communication and interaction;
• Develop rapport through a person-centred approach;
• Understand the person's cultural and social context;
• Personalise the research environment and setting.

Depending on the context, adopting approaches from other fields of study may be useful. For example, tangible techniques involving activity-based methods and items such as pictures or photographs, can support older adults with a range of needs to participate in research (Collins et al., 2022). Regardless of the methods and tools used, it is clear that these should meet the needs of participants. In addition to meeting the fundamental requirements for rights-based research, the investment in supporting inclusion in this way is borne out in data that are more representative, relevant, and meaningful for researchers, individuals, and communities, and thus more likely to bridge the gap between theory and practice (Aase et al., 2021).

Rights-based research requires careful construction of inclusion strategies that enable the fundamental elements of shared language, agreed goals, clear roles and responsibilities, and removal or reduction of impediments to participation (Jacelon, 2007;

Morrison & Dearden, 2013). At any level of involvement, it is crucial to ensure that participation is not tokenistic (Romsland et al., 2019). In this context, tokenism refers to the false appearance of inclusiveness, without actually giving participants much real influence (Morrison & Dearden, 2013; Romsland et al., 2019).

Experts by experience

As experts by experience (Thompson et al., 2020), the in-depth insights of older adults made possible by rights-based research should form the foundation of service design and delivery. An increased focus on the quality of life above years of living highlights the need to understand the needs and preferences of older adults (Van Leeuwen et al., 2019). Accordingly, research topics and priorities should be set by older adults and those who care for them. This approach improves the potential of research to be relevant and valuable 'on the ground'.

In line with our commitment to a rights-based approach to research, in 2021 we established the organisation's first Research Advisory Group. Through this group, the research team invited community-based clients and aged care residents and their families, to join us in identifying priority research topics, determining the most suitable approaches to data collection, and informing the transfer of knowledge into practice. Intended to be a collaborative, respectful, and enjoyable experience for all members, participation in the group is entirely voluntary. Although participation has been limited by COVID restrictions, the research team has met with each member of the group, to share their interests, suggest priority research topics, determine the most suitable approaches to data collection, and inform the translation of research into practice. This initial engagement involved a semi-structured interview. Perhaps unsurprisingly, all members preferenced qualitative over quantitative data collection, highlighting the importance of hearing older adults' voices and 'putting ourselves in their shoes'.

Striking in their simplicity, several suggestions by those living in residential care provided clear examples of the 'know-do gap'. For example, someone might need to use a walking frame to support their mobility. This typically involves assessment by a physiotherapist, adjustment of the walking frame to suit the individual, and guidance on how to use it. What was lacking, according to the Research Advisory Group, was a poster that could be displayed in a resident's room, with reminders (in text or diagram format) of how and when to use the walking frame. These posters could be tailored to the individuals: some needed to use the walking frame inside their room, including to get from the bed to the bathroom; others needed it only when walking further. Some residents left too much space between themselves and the frame, while others walked too closely. While this example may not reflect research as such, it is through the Research Advisory Group that we have learned the issue and can seek to address it by reviewing best practice evidence for improving the use of walking frames and transferring that knowledge into the real world setting.

The importance of data disaggregation

For data to be meaningful, they should be disaggregated to a level that improves understanding of the experience of and influences on ageing. In 2018, the United Nations released a set of principles and recommendations for a 'human rights-based approach to data'. The

principles of self-identification, transparency, privacy, and accountability (United Nations, 2018) are perhaps more familiar than that of data disaggregation.

In short, data disaggregation is the process by which information is broken down into smaller units, to understand specific groups and underlying trends. The importance of data disaggregation is particularly relevant to ageing research, because of the common practice of grouping older adults into one large category of '65+ years'. The paucity of age-disaggregated and age-related data prevents a refined discourse on age and ageing, and delays understanding of the broad range of disparities and inequalities experienced by older adults (and, indeed, all population groups; Gardner, 2021). In its declaration of the Decade of Healthy Ageing 2021–2030, the United Nations specifically addresses the need for improved statistics and disaggregated data to make older adults more visible. In a call for standardised age disaggregation, Diaz et al. (2021) recommend five-year groupings for those aged 60 years and over, and a separate category for those aged over 100 years. These changes would increase the potential of data to inform and drive action to facilitate the experience of ageing.

Research dissemination

In rights-based research, the dissemination of findings aims to increase public awareness, improve practice and inform advocacy. However, in academic circles, most researchers tend to publish their findings in peer-reviewed journals (Yeo et al., 2021). Often referred to as 'publish or perish', there is implicit and explicit pressure to publish in academic journals (Miller et al., 2011). However, we suggest that presenting the process and results of a research study in plain language and on easily accessible platforms increases its potential reach, based on shared understanding and application. Through 'shared conversations' in everyday practice, for example, improved understanding can enhance a sense of agency in older adults and service providers (Muurinen & Kääriäinen, 2022). This enhanced agency, in turn, promotes the transfer of knowledge into practice, whereby participants inform the development of policies and procedures, workplace learning, and evidence-based practice.

In rights-based research, it would be reasonable to expect that findings would be shared in community and industry journals or forums. In our organisation, for example, industry magazines left in staff rooms or residential lounges are often read by those who are most affected by the findings: older adults and those who care for them.

For participants, follow-up communication that 'closes the loop' should occur as a matter of course, regardless of a participant's level of involvement. This may take the form of a report, infographic, or presentation that shares with participants the process, findings, and outcomes of the study. At the least a courtesy, communicating the conclusion of a study also builds positive relationships with participants, making it more likely for them to opt into future studies. It also provides an opportunity to 'check in' with participants, who might want to share their experiences of participation (Boothroyd, 2000).

Finally, dissemination supports the aim of rights-based research to make a positive difference in real world settings (Dearing & Singhal, 2020). While sharing the findings is vital, we encourage the open publication of the process of rights-based research, in ways that can further inform the refinement of a rights-based approach to research that is tailored to research in ageing. In this way, an explicit aim of using the findings to advocate, influence policy, inform practice, and develop capacity in real world settings rounds off a rights-based approach.

From evidence to practice

Evidence-based practice is a well-known concept in the aged care sector in Australia and internationally. However, less attention has been given to understanding how that evidence is actually implemented, monitored, and evaluated (Masso et al., 2014). Without a shared understanding of its purpose, process, and intended application, there is a risk that the full potential of research is diminished or even lost. As a result, the potential benefits of innovative evidence-based practices are too often limited by poor implementation. Evaluation is also an important, but often neglected, part of the process. The understanding gained through thorough evaluation of the implementation process strengthens the uptake and sustainability of changes and improvements to practice. These factors are directly related to a rights-based approach to research.

As researchers working for a service provider, we use the term 'knowledge transfer' to describe how we take evidence (knowledge) and put it into practice (that is, transfer the knowledge into a real world setting). We reiterate the importance of consistent terminology in this context. As mentioned previously, the choice of the label matters less than its consistent use: whether you choose to call it 'research translation', 'knowledge transfer', or 'implementation', what matters is that you use the term consistently. For us, knowledge transfer may be done in the form of new or refined policies and procedures, staff education, clinical application, targeted client information, and sector advocacy. Again, this reflects our rights-based approach to research, whereby meaningful change depends on evidence-based interventions that aim to improve the experiences of those who are most affected by our services. This is, of course, easier said than done.

Although we refer to 'knowledge transfer' when seeking to operationalise our research findings, the relatively new study of implementation science provides valuable guidance on systematically bridging the gap between what we know and what we do ('the know-do gap').

The iterative nature of implementation aligns with the well-known philosophy of continuous quality improvement in health and aged care. For residential and community aged care providers in Australia, for example, it is a regulatory requirement to document their plans for continuous improvement (see www.agedcarequality.gov.au). Service providers' efforts to improve the safety and quality of care must be demonstrated through outputs and outcomes, which requires the systematic collection and analysis of qualitative and quantitative data. To this end, Rubenstein et al. (2013, p. 13) suggest that the essential features of continuous quality improvement are to use 'systematic data guided activities' to articulate the aims and measures for improvement, 'designing with local conditions in mind' and using 'an iterative development and testing process'. It follows, then, that the principles of successful implementation frequently align with well-known models of behaviour change, whereby fundamental influences on the success and sustainability of implementation include individual, leadership, and organisational motivation; system design, supports and processes; the perceived value of the intervention; and individual and organisational readiness for change (Michie et al., 2011; Moullin et al., 2019).

Where a particular model is not applied, the fundamental influences on adoption should still be considered, including:

• Taking an organisational and participant perspective that supports acceptance and translation into practice, including support for the project from senior operational managers;

- Building partnerships across the business, to demonstrate how we can build a bridge between research and practice;
- Communicating and demonstrating to frontline staff that the new resources are evidence-based and were co-developed with residents, subject matter experts, and colleagues;
- Highlighting the individual perspective, which increases readiness for adoption by older adults and staff;
- Maximising opportunities to disseminate findings with internal and external stakeholders.

In practice, one of the strategies we used to support implementation was to group the results into 'operational' categories, which allowed us to prioritise actions, identify the target group and people responsible, and assess the level of investment. Together with colleagues from our residential services, we incorporated our findings into a quality improvement project on the residential admission process. This shared focus on improving the critical experiences of admission and transition has strengthened the appropriateness, adoption, feasibility, and sustainability of both projects' outcomes.

Unlikely to be limited to ageing research, one challenge is that descriptions of research frequently focus on the findings and not on how they were implemented. For service providers, this means that they can access evidence, but not guidance on the most effective and sustainable approach to its implementation ('transfer'). Without describing and evaluating the different components of implementation in non-research, real world settings, the potential benefits of an intervention are limited. For us, specific research projects will not be undertaken without the explicit support of a range of internal stakeholders at multiple levels, including senior managers, team leaders, and direct care staff.

However, even a basic logic model can inform the selection of resources and activities. In reality, this might involve a relatively straightforward 'if-then' assessment: if resources are made available in the residential aged care setting, then the programme can be implemented; if activities are implemented, certain outputs and outcomes should be achieved. Together, these enable the overarching research goal to be met. There is also potential to extend this to include advocacy within and beyond the service provider context.

Research-informed advocacy

Advocacy relates to the act of representing and defending another's welfare through speaking, acting, or writing. Advocates support or represent older adults in standing up for their rights.

As a service provider, our research strategy aligns with key advocacy priorities, is based on accurate and timely evidence, and leads to advocacy that is evidence-informed. Built on rights-based research, advocacy to improve and change policies and procedures represents the voices of older adults. To this end, as a natural extension of rights-based research, evidence should be used by researchers and participants to advocate collaboratively for meaningful change. This maximises the potential of research to inform policy and guide continuous improvement of evidence-based practice, and to support broader advocacy in the aged care sector.

An explicit commitment to using research findings to inform and foster change should involve older adults in co-creating and leading advocacy efforts (James & Buffel, 2022). While sector-specific guidance on advocacy is available, Hoefer (2019) offers a clear, six-step approach to planning and implementing advocacy. Guided by these steps, rights-based researchers can strengthen their efforts to link their work with advocacy from the outset:

- Get involved: Agree to begin or take part in a project;
- Understand the issue: Conduct background literature searches;
- Plan: Project design and planning;
- Advocate: Justification and reasoning;
- Evaluate: Collect and analyse data;
- Monitor: Repeat projects and follow up.

These steps can, of course, be followed by anyone in a position to advocate for another. In health and aged care, it is often family members or close friends who take on the role of advocate, as they seek the best outcome for their loved one (Fetherstonhaugh et al., 2021; Peisah et al., 2020). In many countries, information and support can also be sought from advocacy services and networks, which offer free and confidential education and services to older adults, their families, friends, and representatives.

Conclusion

Global efforts are required to meet the needs of ageing populations. Structures and resources to support older adults to age well should be based on research that represents those who are most affected by the findings. In this chapter, a service provider approach to embedding rights-based research has been presented. Practical strategies to guide research in this context are provided. By weaving the close connection between research and advocacy through each stage, we demonstrate the importance of involving older adults in setting the research agenda, building the evidence, and transferring knowledge into practice. Even where resources are limited, we encourage researchers to take the first steps towards enabling the authentic, meaningful contribution of older adults to the processes of planning, conducting, delivering, and evaluating research.

**Case study: smoothing the way: a co-design approach
to improving aged care transitions**

The aim of 'the transitions study' was to facilitate older adults' transition from home into residential aged care, with a view to supporting their mental health (Polacsek & Woolford, 2022). Originally, our intention was to use a co-design approach, whereby residents from different homes would be brought together to inform the overarching research questions, discuss strategies for data collection and co-develop new resources to support the transition. Subsequent co-design workshops with a range of resident and staff participants would inform the development of resources. However, just as the study started, COVID-19 struck. For most of 2021, lockdowns and visitor restrictions to residential homes brought us to a standstill. After postponing our plans several times, we decided to adopt a 'hybrid' approach, whereby we conducted individual in-person interviews with residents (when permitted) and staff (online or in person), before drafting strategies and resources, based

on the interview data. We then re-visited the individual resident participants, giving each the opportunity to review and comment on the proposed material and their preferred format of the new resources. Staff could provide feedback online or by email. This shared approach allowed us to overcome some of the challenges posed by COVID restrictions, thereby strengthening the potential for developing a set of meaningful, effective, and feasible resources. The most significant – and unexpected – outcome of the study was the development of two short films, featuring current residents and staff speaking about the transition into aged care and sharing strategies to support residents' mental health. These films reflect participants' preferences for the format and content of resources and are now freely available on the organisation's website. Participants also informed the development of new information documents, process maps, and guidelines to improve practice in this area. This case study demonstrates that even a compromised version of participatory research can be effective.

Case study: measuring the quality of life in older adults with a cognitive impairment

A substantial number of aged care residents live with dementia. To improve the support they receive, we need a way to measure and monitor their quality of life (QoL). The ideal measure is by self-report. While several dementia-specific tools exist, many standard measurements of QoL are not suitable for people with dementia, particularly advanced dementia. In this research project, we involved older adults with dementia, paid and unpaid carers, and subject matter experts to determine the most suitable approach for people with dementia to self-report their QoL. Overall, we found that those with mild cognitive impairment and moderate dementia could self-report their QoL effectively through existing patient-reported outcome measures, such as the DEMQOL and DEMQOL-Proxy (Chua et al., 2016). However, a simpler tool was needed to enable those with advanced dementia to answer for themselves whether they were happy or sad, as a fundamental measure of QoL. Participation of residents with dementia required a significant amount of time for the dedicated researcher to get to know the person, learn their history and how to best communicate, and use their input and responses to co-develop and test a simpler tool to enable self-reporting of QoL. Through this co-development process, we found that QoL from the perspective of a person with dementia could be represented as 'connectedness'. The 'Simple QoL tool' contains nine items with the response options of 'Agree', 'Neither', or 'Disagree'. A global score question of 'happy' or 'sad' represents the overall outcome. While work on the 'Simple QoL tool' is still in its early stages and requires validation, the active, meaningful participation of those who are most affected by the measure will underpin its successful implementation.

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22

PATIENT PARTNER ENGAGEMENT IN DEMENTIA RESEARCH DURING THE COVID-19 PANDEMIC AND BEYOND

Lillian Hung and Mario Gregorio

Introduction

The COVID-19 pandemic reality in long-term care

The COVID-19 pandemic has significantly impacted Long-Term Care (LTC) homes in Canada and globally. In Canada, LTC refers to facilities for people with complex physical needs and mental health disabilities who require 24-hour nursing care (Canadian Institute for Health Information, 2020). Older people have a particularly elevated risk of infection and death due to COVID-19, especially those living in LTC homes (Aranda et al., 2021). Moreover, heightened isolation during the pandemic has exacerbated the stress, anxiety, and adverse consequences of losing connections with families that older people experience in LTC. As COVID-19 infection control measures were implemented, many residents were confined to their rooms for several weeks and months (Kotwal et al., 2021) and families reported they lost contact with their loved ones (Hung et al., 2022). Due to visiting restrictions, LTC residents reported adverse effects such as weight loss, depression, anxiety, and declines in physical and cognitive functions (Masterson-Algar et al., 2022; Yeh et al., 2020).

Further, public health orders and surging infection case numbers during the pandemic created challenges for conducting research with patient partners (Leese et al., 2021). "Patient partners" are individuals with lived experience who assume co-researcher roles to conduct research "with" academic scholars (CIHR, 2014). Patient partners in our research team provide valuable inputs during various stages of a research study, including design, priority setting, gathering and analyzing data, and helping distribute research results. On the other hand, "patient participants" are recruited to be interviewed or observed in research as a subject of a study after obtaining informed consent. Along with the patient advocacy movement, reports that demonstrate people with dementia doing research "with" academic scholars have emerged in recent years. Research funding agencies in some countries (e.g.,

the United Kingdom) require patient and public involvement (PPI) in the research grant application (Rolfe et al., 2018). Knowledge about the effective engagement of people with dementia as co-researchers (patient partners) is needed.

The involvement of older people in research can help identify inequity issues and advocate for change. For example, residents with dementia who are visible minorities often rely on families for emotional comfort and practical support. During the pandemic, when families were not allowed to visit, many residents with dementia were left to feel confused and abandoned. Despite the apparent importance of including the voices of older people in dementia research, LTC residents with disabilities and cognitive impairment or those of racial, ethnic, sexual, and gender minority groups are typically not included in the research. The COVID-19 infection control measures forced any patient engagement activities that existed to stop. During COVID-19 outbreaks, researchers were not allowed to enter LTC. In the first few months of the pandemic, a UK Health Authority study reported a sharp decrease in patient involvement in research from 80% to 22% (NHS, 2021). In addition, healthcare organizations reported more consultation and less partnership in patient engagement activities during the pandemic (Cadel et al., 2021). Canada reported a significant reduction in patient engagement activities (Tripp et al., 2022). In France, patient partners were not included on committees or consulted about lockdown measures (Casassus, 2020). Similarly, many patients and public engagement activities in Australia were canceled (Dimopoulos-Bick et al., 2021).

Subsequently, researchers had to adopt unprecedented strategies to continue engaging with patient partners. Researchers tried to apply flexibility to modify and adapt to changing policies and the uncertainty that COVID-19 brought us (Hung et al., 2022; Yong et al., 2022). Patient engagement research activities almost entirely shifted to virtual platforms during the COVID-19 outbreak. Although many sections of society embraced this shift, it was incredibly challenging for people with low technology familiarity or cognitive impairment and were disadvantaged in the drastic switch to virtual platforms. Research has shown that video conferencing brings mixed experiences with positive and negative aspects (Oliffe et al., 2021), and the move to technology-based activities can be helpful and burdensome for patient partners. Therefore, remote work with patient partners has been a learning process that encompassed addressing novel challenges as and when they emerged but also tailoring the support for patient partners depending on their individual needs.

Engage patient partners in LTC research

In this chapter, "patient partners" are individuals living with dementia in the community, and "family partners" as individuals who have or had a family member with dementia. Internationally, there is increased recognition that patient partners have the right to provide input to research, and researchers have a moral duty to ensure their engagement (Tscherning et al., 2021). Meaningful involvement contributes to the quality, relevance, and ethical conduct of research (Gove et al., 2018). While including patient partners in research help reveal real-world situations and identify priority strategies, concerns have been raised about tokenism (Bombak & Hanson, 2017). Meaningful patient involvement in research requires a collaborative approach with trust, reflexive practice, and collaborative relationships (Roche et al., 2020).

Under the socially distanced pandemic environment, people living with dementia experienced further exclusion, disadvantages, stigma, and stereotyping in research involvement. Therefore, flexible and creative ways are needed to engage older people with disabilities in research. In Canada, patient partner engagement in research is called patient-oriented research (POR)—it is when people with lived experience in partnership with research teams contribute to the design, planning, analysis, and dissemination of research. In Australia, the United Kingdom, and other countries, it is called PPI. According to the Canadian Institutes of Health Research, the perspectives of patient partners should be integrated into every step of the research project for robust results (CIHR, 2020).

The first author (Lillian) has worked with Mario (the second author, a patient partner) for six years in research. Along with a few other patient partners and clinicians, we co-research the use of technology in care settings to improve patient outcomes. We use a Collaborative Action Research (CAR) approach in our research work (Traynor et al., 2006). Positive collaboration and reflexive practice are two main core principles that guide our ways of working together. Even though the COVID-19 pandemic exacerbates the challenges of POR, we have evolved and adapted to maintain our commitment to co-research.

The Alzheimer Society of Canada (2017) has developed principles for the meaningful involvement of people with dementia. However, reports documenting the experience of people with dementia who took part in research as equal partners to make change are scarce. Our work explores the role and value of people with dementia in taking an active lead to influence research for care improvement. This chapter describes the challenges we faced and our actions to continue working together in research. We tell stories about our partnerships with stakeholders (LTC residents and frontline healthcare workers) to stimulate conversations about patient engagement in research. We hope our lessons learned help expand possibilities for POR in the field of dementia studies (Figure 22.1).

The researchers

I (Mario) was diagnosed with dementia at the age of 57. After several instances of memory loss issues in my work at a telecommunications company, I decided to retire. However, as I continued to have trouble remembering things and missed appointments, I was referred to a neurologist. Within one year of being subjected to a barrage of tests, I was diagnosed with dementia. Now I focus my remaining years in advocacy work on creating awareness and reducing the stigma associated with the disease. In 2016, Lillian invited me to be a co-researcher on the social robot PARO project, which involved using a baby seal robot for the therapeutic care of patients with dementia in hospital wards. We had research meetings over breakfast at the Vancouver General Hospital every Friday morning. Subsequently, I was involved in several research initiatives involving technologies in treating and caring for people living with dementia. Since then, I have given presentations at public forums and was invited to speak with students at universities. I am encouraged by students' enthusiastic response and their willingness to understand the disease from a person who is living with it. I feel energized by being treated as a full member of a research team of eager minds finding ways to alleviate the challenges of daily living for persons living with dementia. The research work kept me connected with academics, clinicians, and students. Social connection is often mentioned as a protective factor to prevent the progression of the disease. I believe that the research connection I have with the students gives me the added benefit

Figure 22.1 Lillian and Mario worked with students together during the COVID-19 pandemic. First row, from left to right: Mario, Paris, and Lillian. Second row: Erika, Charlie Ali, Ahmed.

of stimulating the brain, thus slowing the progression of the disease. Now, I am actively involved in community-based projects with health agencies and charitable organizations. For example, I joined the Translink Universal Access Committee (TUAC) to help address some of the needs of people living with dementia in using public transportation. In addition, I am on a local Patient and Family Engagement Committee to create a newsletter for the new hospital. The guidelines developed by institutions that cater to the regular population do not address the challenges of people with disabilities as consumers of medical care, so we need to make sure their voices are heard. In the past, I have served as a citizen reviewer in the grant review panel for the Alzheimer Society Research Program (ASRP) in Canada. Citizen review adds value to the funding selection process because it addresses some essential key points for a person living with dementia that may not be apparent to researchers.

I (Lillian) am a nurse researcher and lead the research team in the Innovation in Dementia and Aging (IDEA) lab conducting POR. I bring patient partners, frontline healthcare workers, and students from different disciplines (i.e., Engineering, Nursing, Medicine, Food and Nutrition, Chemistry, and Kinesiology) together to make a collaborative contribution

to dementia care. In the IDEA lab, everyone is valued; the relationship is the foundation for everything we do in research. Patient partners are co-researchers and equal members of our team and are important, among many things, to help us understand their priorities and ensure the study serves them. Our patient partners are older people living well with various dementias and family members who have lived experience in dementia caregiving. As the President of the Gerontological Nurses Association of British Columbia, I also collaborate with nurses, healthcare workers, organizational leaders in hospitals, and LTC to advocate for senior care. My research draws attention to innovation in LTC while keeping residents' needs at the core, which aims to help attract and retain a passionate and resilient workforce in senior care. I believe a good way to help people solve problems is to work with them to co-develop practical knowledge relevant and applicable to them.

Our approach – Collaborative Action Research

CAR builds capacity and empowers people through their participation in a research project because it emphasizes that research is conducted "with" rather than "on" people. As Traynor et al. (2006) suggested, CAR is more powerful when done with a group of people invested in the research outcomes. Positive collaboration and reflexive practice, which align with CAR, are at the heart of our approach to improving dementia care and quality of life. It is important to note that reflexive practice is more than just reflection. Reflection is about thinking back to see what worked and what did not. Reflexive practice requires us to critically reflect on why things are the way they are, consider our role as individual researchers in the research team, and take actions for positive outcomes (Hung, 2017). McNiff and Whitehead (2011) highlighted that CAR emphasizes relational values, and its key ontological assumptions are value-laden and morally committed. Importantly, we focus on social justice, a key component of CAR. Our patient partners (people living with dementia) are not to be treated as objects or the means to an end; instead, they are active agents who seek to make changes to improve dementia care. Our research team is tasked with finding positive practical strategies to foster change in care delivery.

The overcoming loneliness study: methods and process

Older people living in care settings experience exacerbated feelings of loneliness compared to those who live in the community (Huang et al., 2022; Simard, 2020). Our overcoming loneliness study investigates the social isolation experience of LTC residents and identifies priority strategies. We underscored the need to involve and empower different voices to be part of the conversation, work together to shape research questions and adapt methods for robust results. The collaborative methods enabled a dynamic approach sensitive to context, participants, and conditions during the COVID-19 pandemic.

The study took place in two large urban Canadian LTC homes with large outbreaks and fatalities during the COVID-19 pandemic. The study was approved by the Research Ethics Board at the University of British Columbia and the local health authority. Lillian and Mario met with the research team, including other patient partners, weekly on Saturday mornings by Zoom to plan the research and discuss progress. In between, we used emails and phone conversations to communicate and work on the research documents. Mario offered his expert perspective as an advocate for people living with dementia in the project. Lillian brought related literature on research methodologies. Healthcare workers working

in the frontline provided practical insights into the clinical context and evolving situations, such as the implementation of a new public health policy, staffing availability and shortage situation, leadership changeover, political wills, and local capacity to support the research. We talked about challenges that emerged in the research and possible opportunities to overcome barriers during our team meetings. The patient partners helped us focus on priorities, such as safety and quality of life in LTC.

Evaluating meaningful engagement of patient partners in research

To assess our quality of interactions and relationships in the research process, we applied the Patient Engagement In Research Scale (PEIRS) (Hamilton et al., 2018). PEIRS contains 22 questions with a 5-point Likert scale (from strongly agree to strongly disagree) to evaluate meaningful engagement in research. For example, the items include "I had sufficient opportunities to contribute to the project" and "Communication within the research team was clear throughout the project." To optimize the PEIRS tool for people with dementia, Mario worked with students to add emojis to the ratings. In addition, we provided extra space for the qualitative elaboration of experience. PEIRS allowed our patient partners to explain what worked well for them and what was useful. They also shared their stories about their involvement and desires for areas of improvement.

While there are complex challenges to conducting research in LTC, we must continue to recognize the value of involving patient partners in research and the benefits of achieving a deeper understanding of the experiences of the people who were affected, their opinions, and their perceptions. From time to time, Lillian and Mario had phone conversations and met over Zoom to reflect on our practice in engaging patient partners in the overcoming loneliness project. Based on our critical reflection, field notes, team discussion, and the PEIRS results, Lillian developed a preliminary summary of analysis about patient partner engagement by using thematic analysis (Braun & Clarke, 2006). We exchanged perspectives and gathered feedback from everyone in our regular research team meeting. The research team members voiced appreciation for the opportunity to reflect on our experiences collectively. Following a reflexive and iterative process, our analysis identified five broad themes of lessons learned.

Lessons learned

Avoid assumptions about the switch to virtual meeting

Our patient partners highlighted how wrong assumptions hindered their involvement as partners in research. When the pandemic began in 2020, Lillian was unsure about the willingness of patient partners to continue contributing to research. Lillian did not want to burden the patient partners, so she paused the research meetings. A patient partner told us, "It felt like everything was put on hold for I don't know how long. My calendar was just empty. I was cut off from research." As our usual ways of working together in regular in-person meetings stopped, patient partners waited for Lillian to reach out to them at home. Like many other researchers, we gradually adopted virtual methods. It turned out that our patients' commitment to making valuable research contributions had not changed. Lillian hired university students to provide individualized assistance for patient partners to set up virtual equipment and give ongoing support. In our team, patient partners and frontline

staff have diverse backgrounds. Some had access to equipment for virtual calls and adapted quickly. Others did not own technology equipment such as computers or headphones and required support. Although the virtual meeting technology saved travel time and allowed us to conduct virtual interviews and focus groups, videoconferencing was a new skill to be learned for many people involved in the research.

Wi-Fi availability was the main barrier to video calls in the LTC homes. Wi-Fi connections were slow and inconsistent in different LTC sites. Also, in the virtual call, researchers could not observe participants' non-verbal cues such as body gestures and actions. Moreover, most computers in LTC homes did not have a good speaker. The microphone was a significant issue for focus groups in care homes. The researcher could not hear the voice of staff gathered in front of a computer at the nursing station of the care home. The majority of staff was unfamiliar with Zoom login and audio connection. Tablet PCs were often difficult for residents (with or without cognitive impairment) to handle, and they tend to have limited audio quality and insufficient volume for older people (residents). The research team had to adapt their research methods to meet people's needs to address frustration and support research engagement.

Support people to do their best by using a telepresence robot

Creative technology-based strategies evolved during the pandemic to overcome difficulties in conducting research. Our patient partners used a telepresence robot for conducting interviews because they could not enter the LTC sites. The patient partner (interviewer) can remotely control the robot. The interviewer could "call-in" the telepresence robot using laptops, smartphones, or tablets. The interviewers' faces would appear on the robot's screen. In addition, the interviewers could see the resident in the room. As telepresence robots have a wide-angle view compared to other video teleconferencing interfaces, the visual access allows observation of the resident interacting with the environment in real time. With residents' consent, the interviews were recorded for professional transcription. The telepresence robot technology allowed our participatory research to take place that would otherwise be inaccessible during a pandemic. The robot was successfully used in LTC homes to conduct interviews with the residents, serving as a viable alternative to in-person interviews, which were unavailable due to the restrictions of the COVID-19 pandemic. This was especially important for high-risk communities such as LTC homes and allowed us to continue to involve patient partners who would not have been able to hold in-person interviews safely.

The residents' acceptance of using the telepresence robots for data collection initially worried us. The residents in the study often made initial curious comments about the robot. As success was evident in the early interviews, residents in the study responded positively to the robot, and the stories spread like wildfire. We emphasized that we wanted to be inclusive in recruitment because everyone's experience mattered. LTC staff then got interested in the interviews and wanted to contribute their stories and perspectives. Furthermore, many residents took advantage of the broad view of the robot to show off objects in their room and discuss them with interviewers. In this way, seeing more of the environment contributed positively to the engagement of residents in the interviews. Having an additional option to follow residents around and observe their environments further open opportunities to better engage with residents. It would also allow other opportunities in research that would otherwise be unavailable with a stationary/handheld device. Our researchers were

Table 22.1 Five lessons learned: ASK ME

A – Avoid assumptions about the switch to a virtual meeting
S – Support people to do their best by using a telepresence robot
K – Know that the contribution will have an impact
M – Meet regularly and stay connected
E – Ethical sensitivity and responsibility

less apprehensive about talking to residents through the robot than they would have been approaching them in person. In-person data gathering would require everyone to wear personal protective equipment, making it impossible to see facial responses behind the mask. Our patient partners felt the robot was the closest alternative to an in-person meeting (Table 22.1).

Our patient partners also showed themselves to be adept at overcoming the challenges to continue collaborating with academic research partners and frontline staff. To ensure continuous communication and engagement, we did weekly check-in by phone, and provided a one-page summary of each person's role, a reminder of tasks to be completed, newsletters, and emails to ensure everyone was clear about the research progress and procedures. In addition, patient partners commented that feeling welcome and a friendly and comfortable atmosphere in the virtual meetings were important for the new way of working together. For example, one patient partner wrote, *"I like I felt all my comments were valued in the team meeting with everyone, regardless of how well they were articulated or not."* Another patient partner remarked, *"I always left the meetings with a sense of optimism and 'can do' spirit."*

Know that the contribution will have an impact.

Patient partners valued opportunities to contribute to the healthcare system in a way they felt was important. For example, they appreciated being involved in writing policy with clinicians, knowing that it will impact practice and outcomes. It was clear that feeling confident that their contributions would be taken seriously was helpful for their involvement in our research. Both groups of the patient partners and the healthcare workers emphasized the importance of authentic congruence between the research effort and the timing of the project. One patient partner indicated that the shared purpose for developing practical strategies to address loneliness among residents ensured the research direction aligned with meaningful motivators for the individuals involved. One person stated, *"I just wanted to be involved if it could help the people in LTC homes. If it can help the folks in the homes, then I'm all for it."* Another patient partner said, *"I appreciate so much to be able to see the shared proud moments, the things we have accomplished. It's so nice to work with the students to co-author papers and conference presentations."*

Based on the literature and our experiences, we know researchers should take all necessary measures to ensure the safety and well-being of people with dementia who contribute to research. However, we know we should also avoid being over-protective and paternalistic. Mario underscored the importance of advocating for meaningful involvement and questioning problematic stereotyping of dementia. We used a "stop and go" approach to accommodate and support people to cope with competing demands. For example, when the COVID-19 cases were high, we stopped data collection and instead prepared for the next step. Digital connection offers complementary support for engagement. Developing relationships and rapport among the research team from a distance required dedication

from all members. In the meetings, we (Lillian & Mario) acknowledged every milestone achievement (e.g., ethics approval, focus group, and interview successes, abstract acceptance for a conference, and manuscript submission for publication), which helped motivate commitment and momentum to keep moving the project forward.

Meet regularly and stay connected

All of our patient partners stated they missed in-person contacts during the pandemic. Small treats like cookies and beverages were sent to patient partners to boost our team spirits. Grocery gift cards were also sent to support patient partners during lockdowns. Our regular meetings allowed for ongoing discussion and exchange of ideas to achieve mutual understanding among patient partners, clinical staff, and academic researchers who contributed to the decision-making in the research process. After a year of regular meetings, our patient partners and clinicians found the virtual experience convenient. They expressed that it would be valuable to continue to have virtual meetings as a supplement to in-person meetings. Video conferencing, telepresence robots, phones, and email are helpful platforms for connecting with patient partners and clinicians. One researcher said, *"Despite restrictions, the virtual platforms gave us a safe and accessible opportunity to be involved in regular and frequent meetings and remain connected."* Another researcher noted the challenges of focusing on research in LTC at times: *"During the pandemic, there was so much going on in LTC. There were constant changes in the directives from the government, leadership, staffing shortages, outbreaks, etc. The journey has been like a crazy roller coaster ride."* To recognize partners' contributions, one individual highlighted the appreciation of gift cards given for respecting their time spent in the research.

Ethical sensitivity and responsibility

In our research, we believed it was vital to have positive collaboration and reflexive practice as well as mutual respect, trust, and power-sharing as a part of our everyday ethics. Everyday ethics involves moral values and beliefs about how we should interact with one another on a daily basis (Banks et al., 2013). Acknowledging the complexities and potential conflicts in values and beliefs of the people involved in the research, everyday ethics recognizes that a better understanding of protection requires the engagement of the patients' perspective. Therefore, the development of an empowering partnership between all research team members was emphasized from the study's inception and throughout the research process. For us, empowering partnership means meaningful involvement of people with dementia (the under-represented, disadvantaged groups) in research as equal partners and value their experiential knowledge. We embrace shared ownership of the research and have respectful collaboration among patient partners, academic researchers, and clinical team members.

Challenges

Lack of infrastructure and resources

As indicated earlier, the lack of Wi-Fi standards and availability in different LTC sites led to difficulties in holding some of our interviews. Wi-Fi was not adequate in some of the residents' rooms, so we used alternative locations in the LTC facility. Moreover, scheduling

conflicts often arose due to limited space in LTC homes, and planning interviews was even more difficult due to staff shortages in LTC during the pandemic (White et al., 2021). Although the diverse perspectives made data collection and analysis more effective, team members voiced concerns about feeling uncertain about their roles and the research steps. There was so much competing time pressure with clinical work, leading to disruption in research meetings and cancellation. It was essential to learn, accommodate, and adjust according to the needs and preferences of each party. Booking team meetings to fit everyone's schedule was challenging at times. Effective engagement requires thoughtful considerations of team dynamics and processes, a patient and family-centered attitude, and competent knowledge and skills in project management.

Fair and timely compensation is essential for showing respect to the patient partners and clinicians for their contributions. However, the processing time for compensation claims in academic and research institutions can be slow. There is a need to improve the compensation process for people involved in research to promptly acknowledge patient partners' value and significant contributions.

Further, leadership turnover also made research planning challenging. Each time a manager left the position, we had to take time to re-establish trust and relationships with the new person. It was challenging to clarify expectations around timelines of the research and deliverables when leadership was unstable in the care homes. We needed leadership support for resources required for the research (e.g., protected time and space for staff participation), champion involvement, and positive endorsement to enable research activities in each LTC home.

Training & technical obstacles

Another challenge in using telepresence robots for interviews was the novelty of the robot to interviewers, residents, and LTC staff. Only a few residents were initially comfortable with it. We had to train staff at LTC homes to ensure safety and trust. Interviewers also required training on how to use the robot. Feedback in our interviews showed that researchers who received more training with the robot felt more comfortable and viewed their interviews as more successful. Training residents and researchers required time before the interviews could be held, and scheduling conflicts often slowed down the research progress. Other interview methods such as virtual video interviews through platforms like Zoom, were challenging for many staff due to unfamiliarity with the technology and poor equipment set up in care homes. Although the telepresence robots made it easy for the residents to connect, staff sometimes forget to plug in the robot for charging. We experienced some cancellation due to low battery in robots.

Staff in LTC often expressed apprehensions about privacy issues regarding data storage security. Training provided at staff huddles at the sites helped alleviate this concern, allowing our research to support more staff promptly. In addition, we made flexible accommodations to ensure support from staff. For example, we provided one-to-one demonstration training for everyone who wanted to learn how to use the robot. We provided covers for the cameras when the robots were not in use. In addition, we created videos, posters, newsletters, and a one-pager summary to help people in the care homes learn about the functions of the robots - what they do and do not do. Clear communication allowed staff to feel more confident about protecting privacy and safety with the use of technology.

Practical strategies

It takes a lot of passion, time, effort, and commitment from each co-researcher to work together in POR. Our team reflection and collaboration were undoubtedly constrained by virtual communication. Active involvement demands an open mindset to listen to diverse opinions and time to build relationships. At times, there were uncertainties, limited time to build trust, and anxiety, especially at the beginning of the research. Team members needed to be courageous to voice different opinions and question each other perspectives to challenge the traditional power relationship and mistrust between groups. In an earlier pre-pandemic study (Hung et al., 2019), we articulated five practical tips to involve patient partners in dementia research: (a) address the needs of team members, (b) build trust and respect to enable effective partnership in all phases of the project, (c) center on shared purpose and collective commitment, (d) demonstrate openness to learn together, and (e) ensure that research findings get into the hands of those who can use them.

Below, we offer some coping strategies based on the recent actions we took in the overcoming loneliness study to address the research challenges posed by the pandemic. As we are proud of using a novice technology, a telepresence robot, to facilitate patient partner engagement in research, we frame the summary of our practical strategies in an acronym – ROBOT: Realign to adapt, Organize with staff champions, Blend Strategies, Offer timely technical assistance, Tailor communication for clarity.

Realign to adapt

We adapted our research methods based on site-specific needs. Given how virtual technology is new to many staff and residents, we listened to all stakeholder groups (researchers, patient and family partners, residents, and staff) to realign the research methods to meet local needs. One patient partner commented that his way of participating in engagement activities would never be the same as pre-pandemic:

> Now I am able to be involved in many more activities than prior to the pandemic because everything is done virtually. I used to go to one meeting maximum a day. Taking the bus to the city took a lot of time and energy. Now I can attend several meetings a day at home.

Organize with staff champions

Our experience demonstrated the value of working collaboratively with staff champions. We worked closely with patient partners and frontline healthcare workers from the beginning. Due to staffing shortages, it was challenging to book focus groups and staff interviews. Not meeting with staff and residents in person made it hard to build trust and rapport. Therefore, we recruited frontline healthcare worker champions (specific staff members that support the research) at the study site. The champion helped us introduce the research, explained the study's purpose and procedures, and acted as a bridge between the research team and the study site. It was vital to have conversations with champions to stay connected and keep pace with the research.

Blend strategies

To accommodate people's diverse and changing needs at the LTC home, we blended different research methods to provide creative solutions to generate data to answer research questions. Staff working closely with residents came up with creative ways to use technologies. For example, families were invited to be involved through the telepresence robots. We used phones, laptops, and various virtual platforms to connect. We promote the intrinsic reward of co-producing actionable knowledge to improve residents' quality of life. Posters were shared in visible common areas. We also remotely spoke with staff in huddles and sent out information by email. To compensate for time for participation, we provided local grocery gift cards for staff and residents.

Offer timely technical assistance

We had several technical issues at the beginning of the research and during data collection. However, we provided ongoing, timely support when required. Without support, our patient partners in the team could have become frustrated with technical issues associated with the telepresence robot and other remote communication. One patient partner remarked,

> It is important that I could contribute to the project. To be able to feel confident in using the robot to conduct interviews made me feel I could perform my tasks to help. It feels good to hear the team members value my contribution.

Tailor communication for clarity

The power of patient involvement in research relies on the communication methods used to include the voice of patient partners in the project. We tailored communication to meet the needs of specific sites and researchers. Each of our research sites had unique team culture, varied operating schedules, workflow, and different preferred communication styles. Every researcher in our team has unique background and familiarity with technology. Some require additional one-to-one conversations to clarify the expected task and procedures; others prefer just an email with a link for remote meetings (Table 22.2). A patient partner expressed, *"I appreciate the regular updates and the support I got. It makes me feel valued. It's nice to see my opinion and feedback are heard. My contribution matters."*

Table 22.2 Five key strategies: ROBOT

R – Realign to adapt
O – Organize with staff champions
B – Blend Strategies
O – Offer timely technical assistance
T – Tailor communication for clarity

Conclusion

Our experience has demonstrated that patient engagement is possible via technology during the COVID-19 pandemic. The lessons learned and actions taken during the pandemic provided helpful insights into the complexity of active involvement of people with dementia in research for change in LTC. The use of telepresence robots allowed us to involve our patient and family partners in research through virtual interviews, which would not have been possible otherwise due to in-person barriers. Our collaborative approach ensured that the project proceeded with a consistent patient-centered perspective.

This chapter offers a unique contribution to the literature on POR by adding evidence related to population- and context-specific needs and related perspectives from patient partners. In the past, research related to dementia care and technology was often conducted by scientists and academic researchers, while patients' perceptions remain unrecognized or misunderstood. More studies are needed to understand better what facilitates patient engagement in research beyond the pandemic. Future reports should include detailed descriptions of patient partners' authentic active engagement experience and the conditions that supported and hindered the engagement. Researchers need to include patient partners to evaluate the impact, benefits, and barriers to their involvement. We encourage researchers and healthcare practitioners to include more direct patient voices in research. People with dementia are diverse populations that require tailored support to maximize the benefit of patient engagement in research for robust outcomes.

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PART 7

Voices and experiences of older co-researchers

23

WORKING *TOGETHER* TO RESEARCH THE EVERYDAY LIVES OF PEOPLE LIVING WITH DEMENTIA AND THOSE SUPPORTING THEM

Diane Seddon, Teresa (Dory) Davies and Hannah Jelley

Introduction

The Dementia Services Development Centre Wales (http://dsdc.bangor.ac.uk/research.php. en) is a UK research centre driven by a strong commitment to co-create research alongside experts by experience. Here we showcase a project that seeks to co-create a resilience-building framework for people living with dementia and those supporting them. We reflect on the experiences of two people involved in the research and highlight the ways they are working together:

- Teresa (Dory) Davies, a co-researcher, and expert by experience research co-supervisor who is living with Alzheimer's disease and vascular dementia.
- Hannah Jelley, an early career researcher in dementia care.

Taking the reader on a journey through the co-creative research process, we highlight how co-creation leads to synergistic relationships that benefit everyone. We illustrate that meaningful co-creation requires a strong commitment to:

- Building and sustaining co-creative relationships.
- Providing opportunities for meaningful dialogue.
- Working toward a common purpose.
- Learning from one another.
- Offering choice and flexibility.
- Embracing diversity.
- Evidencing the contribution co-creation makes, for people affected by dementia and for researchers.

We offer insights to inform future co-creative research activity.

The project and the people involved

The Empowerment Project[1] is a mixed methods PhD study seeking to co-create a resilience-building framework to empower people living with dementia and those supporting them to live as well as possible and achieve positive outcomes. It involves researchers and experts by experience working together. Experts by experience include people living with a diagnosis of dementia and those supporting them include unpaid carers.

With its emphasis on inclusive opportunities, working together, and co-learning, the Empowerment Project implements into practice the UK National Standards for Public Involvement in Research (National Institute for Health Research, 2019). These standards provide benchmarks for effective public involvement and for improving the purpose, quality and consistency of involving members of the public in health and social care research (https://www.nihr.ac.uk/news/nihr-announces-new-standards-for-public-involvement-in-research/23830). The Empowerment Project aligns with the Welsh Government's policy commitment to co-production and to ensuring people with care and support needs have greater voice and control, including greater voice and control in research (Welsh Government, 2018).

The importance of co-creative research activities

The Empowerment Project is underpinned by a co-creative approach to research that meaningfully involves people at all stages of the research process. This grounds the research in the everyday lives of people who are affected by dementia:

> *We've turned research on its head [....] The people with dementia are in the driving seat [....] Learn from the experts by experience [....] Put together, you know, professionals and the experts by experience we are a masterpiece.*
>
> *Teresa*

> *Co-research is a really important part of it, and we decided we wanted not just the usual academic supervisors, but some experts by experience to supervise it [....] really bringing that personal experience in [....] And it's making the research, you know, more real and practical because, you know, we're being led by the expert.*
>
> *Hannah*

The quality of research evidence is only as good as the research questions we ask. Working together ensures that research addresses the questions that are most important to people affected by dementia, rather than those considered most important by researchers.

Reflecting on her experiences of grassroots research development activity, Teresa firmly believes that people must be consulted about and involved in research that affects them – people who might benefit from research should have the opportunity for maximum possible involvement in it. People bring their unique and personal perspectives to research, especially in relation to the ways we explore sensitive topics, such as living with a diagnosis of dementia or caring for someone. This can help to cut through the noise of traditional research development activity straight to what matters, i.e., collaborative, co-creative research focusing on improving care and support for people affected by dementia and finding real solutions to the challenges they face. This raises exciting new possibilities.

Getting involved and working together

Reflecting on her experiences of the Empowerment Project, Hannah believes that the UK National Standards for Public Involvement in Research are helpful in supporting co-creative research activities and helping people from a diverse range of backgrounds to come together to work for a common purpose, with a shared understanding of roles, responsibilities, and goals, and how to practically achieve these goals.

The importance of inclusive opportunities, as set out in the UK National Standards, guided the decision to involve people from a diverse range of backgrounds in shaping the design of the Empowerment Project. This includes people diagnosed with different types of dementia, people of different ages, and people at different stages of the dementia journey. There is mutual respect for peoples' lived experiences, their expertise, and the contributions they bring to the project:

> *Truth is we're all unique and beautiful.*
>
> *Teresa*

Teresa is a member of DEEP, which is the UK Network of Dementia Voices (https://www.dementiavoices.org.uk/) that connects people together to share their experiences and to support one another. The CABAN Group of Bangor University Dementia Educators (https://www.dementiavoices.org.uk/group/north-wales-dementia-network/) is part of the DEEP Network that encourages people affected by dementia to share their lived experiences with researchers and shape the direction of research. In 2020, Teresa was involved in developing the DEEP-Ethics Gold Standards for Dementia Research (https://www.dementiavoices.org.uk/wp-content/uploads/2020/07/The-DEEP-Ethics-Gold-Standards-for-Dementia-Research.pdf), which has been adopted by a number of UK universities. *Teresa* was introduced to the Empowerment Project through her association with DEEP and the CABAN Group:

> *Teresa was the first person I thought of 'cause we were already familiar with each other, and I hope Teresa doesn't mind me saying this, but I consider Teresa a bit of an activist [….] So, she was a natural person to ask really.*
>
> *Hannah*

As a co-researcher and co-supervisor, *Teresa* is involved in all aspects of the research. Following on from her contribution to the initial research design, *Teresa* has contributed to:

- The delivery of:
  - Research supervision sessions.
  - Project advisory group meetings.
  - Research planning workshops to better understand peoples' views on resilience and to inform the initial scope of a literature review.

- The analysis of the literature review findings and how these resonate with the everyday lives of people living with dementia.
- The identification of further lines of inquiry following on from the literature-based work that are now being explored through empirical research.
- The production of research documentation and meaningful research materials, including participant information sheets and interview schedules.

- The pilot testing of interviews.
- The analysis of the primary research data.

Teresa relays her experiential knowledge and acts as a critical friend, actively supporting the development and implementation of the research in a meaningful way, including its governance and leadership. The Empowerment Project commits to joint decision-making.

Approaches to public involvement can be transactional in nature and focus on the scheduling of advisory group meetings and information gathering. Such business-like approaches can be impersonal, they can restrict opportunities for imaginative thinking, and they can leave people feeling disconnected from the research project. By contrast, the Empowerment Project is underpinned by a relational approach to co-creation that prioritizes the building of mutually supportive and trusting relationships over time and commits to addressing potential power imbalances:

> *I think there's something there to say really about building a relationship up as co-researchers [….] I'm not just sort of draining information from her. It's not a one-way thing, you know, we chat to each other. We've built up a relationship, and it does take time to do that. And I think it's important to recognise [….] You know not to be like I'm the researcher or I'll do that, I'll tell you what to do and or this is what I want from you. It works both ways. So, it's a respectful relationship [….] I treat her like an academic supervisor.*
>
> *Hannah*

Working together, the priorities are to:

- Develop meaningful connections and shared values.
- Enable people to define and chose how they engage.
- Communicate in an honest, open, and transparent way.

Working together: lessons learned

Experience gained over the course the Empowerment Project shows that it is important to be clear at the outset about the likely level of commitment to the project, which can be time consuming. A flexible, bespoke approach is key to successful co-creative research activities – this includes flexibility in relation to:

- The nature of peoples' involvement and the contribution(s) people may make.
- The ways people may contribute, such as through project advisory groups, workshops, and research supervision sessions, as well as through providing detailed feedback on research materials and research outputs.
- The means of communication.

The organization of and itinerary for meetings is important:

> *Hosting a co-researcher that has dementia I think you should really take their lead and be directed by them. You know, if they need breaks or if they need to speak so*

that they don't forget what they want to say. You know, if you make them wait, you can't do that. You have to let them, you know, prioritize. You know if they need to interrupt you then they need to interrupt you.

Hannah

The Covid-19 pandemic necessitated a shift in the ways people engage, contribute, and communicate, and it saw the use of virtual co-creative spaces hosted on Zoom and other online platforms. Reflecting on the practical and logistical considerations this raises, Teresa commends the Empowerment Project partners for their support, which has enabled her continued involvement and engagement with the project during the pandemic. The use of "I want to speak cards" (https://www.dementiavoices.org.uk/resource-type/speak-cards/) for online meetings and a clearly identified point of contact for information and support are particularly helpful. The careful sequencing and pacing of online meetings are important to avoid people feeling overloaded and this has been a learning curve:

I mean I can do 2/3 zooms a day. It can get really tiring and you know you become zoomed out [….] Well, when it was face-to-face meetings, I would do one meeting.

Teresa

I started to realize it's actually better to have shorter meetings [….] And I think sometimes there's a bit of a balance of maybe recognising you know, uh, maybe we, we were going on a little bit too long.

Hannah

Accommodating peoples' preferred methods for correspondence, for example, hard copy documents rather than electronic documents attached to email, remains important as we emerge from the pandemic. *Teresa* emphasizes that while some people choose to engage with technology and with social media, this is not for everyone.

Working together: capturing the difference it makes

To drive forward improvement we should capture and share the impact that public involvement has for the people involved and for the research project (UK National Standards for Public Involvement in Research, 2019).

Teresa is exposed to new, inclusive opportunities that are empowering and confidence building, and she is learning new skills. *Teresa* finds the support and insights from her peers beneficial, and she enjoys making a valuable contribution to the research design and implementation. *Teresa* believes that *working together* provides unique opportunities for *learning together*:

I am valued [….] Uh, it gives me purpose. You know when you get a diagnosis, it's like you've got no purpose in life anymore [….] Everything took away from you [….] So, when people ask you to be involved in research you feel valued again [….] I've learned from the professionals [….] I've learned so much myself that I didn't know [….] We all work together and then it will work together [….] Especially if it's took on board what it is you're suggesting [….] You'll get a good outcome hopefully.

Teresa

Involvement in the research gives *Teresa* a sense of purpose and she sees the potential for the research to help improve the future for herself and for others affected by dementia.

Public involvement in research is often criticized for being tokenistic in nature and it can be a tick box exercise. *Teresa* and *Hannah* believe that evidencing the contribution people make is essential to addressing tokenism, encouraging co-productive relationships, and capturing the positive difference working together can make:

> *Feedback [….] Don't let them get away without taking on board what we've said. Otherwise, you do just feel like a tick box and just feel like you've just wasted your time [….] We don't want to get that feeling that we're being used [….] Because why you do it, it's to make a difference.*
>
> *Teresa*

> *I think you're quite right, Teresa, and it's important to show the results just so that you know the person involved, the co-researcher feels valued and that, you know, it's recognising that they've put their time in [….] I wanted them to be involved in all aspects of the project because my concern was, you know, obviously PPI's a sort of very popular thing at the moment. But I didn't want it to be just a tick box exercise [….] I wanted, you know, them to really feel involved. And part of the project.*
>
> *Hannah*

Implementing the UK National Standards for Public Involvement, people working on the Empowerment Project gather, offer, and act on feedback, and then share this with everyone.

Hannah believes that the continuous cycle of reflection and learning at the core of this co-creative project improves the quality, relevance, and accessibility of the research. Working together with experts by experience ensures that information about the research is shared in meaningful, public-friendly formats. This includes participant information sheets:

> *It was such a bonus having Teresa involved, because uhm, you know my writing was very, it was very scientific and probably a bit jargony to begin with [….] Teresa and I were fantastic at making the language more accessible, making sure it's dementia friendly, which actually is so important because, you know, I was wanting people living with dementia, their family carers involved. So, they're actually helping me to recruit.*
>
> *Hannah*

Support and co-learning are underpinned by timely, two-way, and clear communication that helps to demystify research and remove some of the barriers that hinder engagement with research, such as scientific jargon and complex methodologies:

> *To be able to explain it to someone else, someone else in a way that they understand means that you have to really understand it yourself. And so actually it's really helpful, you know, to have to explain the methodology and you know, they tell me if it didn't make sense.*
>
> *Hannah*

Academic researchers are accustomed to writing scientifically. By working together with experts by experience it is possible to adapt writing styles so that other people, including the intended research beneficiaries, are not overwhelmed by complex information.

Teresa highlights the importance of using appropriate language and encourages others to think carefully about the language describing people living with dementia, in particular the term 'service user'. She suggests that 'service user' is an impersonal label that prioritizes services over people and has negative associations with illicit drug use. In a research context, this label fails to recognize the active contribution individuals make to research projects. It foregrounds only one aspect of a person's life (i.e., a diagnosis of dementia leading to contact with services), and it fails to acknowledge the wider context of their life and the many insights they bring:

> *Not using negative language [….] That's one of my pet hates [….] Service users [….] It's not person centred is it [….] you don't see the person you know [….] It's kinda hospital speak the oh, they're a hoister or they're a feeder.*
>
> *Teresa*

Careful use of language applies at all stages of the research process, from the initial co-design to the development of research instruments (for example, interview schedules) and the publication of findings and other research outputs across academic, policy, and practice audiences.

Working together helps to ensure that research is as inclusive as possible. Following advice from *Teresa* and other experts by experience, participant inclusion criteria for the Empowerment Project is kept broad, to reflect the experiences of people living with a diagnosis of dementia(s) from a diverse range of backgrounds and to capture a diverse range of caregiving relationships.

Going forward, co-creative knowledge exchange and knowledge utilization activities will extend the impact and reach of the study to policy and practice audiences. They will support the implementation of the research findings into practice to help bring about positive change for people living with dementia and those supporting them. This includes the implementation of the co-designed resilience-building framework into health and social care practice. As an early career researcher, *Hannah* is inspired by this aspect of working together and the 'real world' research application:

> *You get incredibly inspired when you realise that your research can actually make a real difference to people and that people living with dementia do care about the work that you're doing [….] It really motivates you to want to make a real difference [….] It's the way forward and how all research really should be done right from the very beginning. You know, when you're designing a project and right the way through to output to make it real and practical and make the future better. And I think we can really only do that if we involve experts that have personal experience. Research gives you hope. And I think now, you know, when you've got a co-researcher and you're working together, to me actually that gives you as a researcher hope for the future and that you can change things and make things better.*
>
> *Hannah*

Concluding remarks

The Empowerment Project aims to co-create a resilience-building framework to help people living with a diagnosis of dementia and those supporting them. It is achieving this through successfully working together with experts who share a common purpose to advance scientific improvements that benefit the everyday lives of people affected by dementia. Building meaningful relationships is key, as is an openness to learning from one another. The UK National Standards for Public Involvement in Research provide a helpful reference point to engage people affected by dementia in health and social care research and to maximize the positive opportunities afforded by co-creative research.

Note

1 Full title: Co-creating a resilience-building framework for people living with dementia and their carers. Supervisors: Prof. Gill Windle, Dr. Sion Williams, Dr. Jaci Huws, Teresa Davies and Ann McCallum, School of Medical and Health Sciences, Bangor University. Funder: Wales School for Social Care Research PhD Studentship through Health and Care Research Wales.

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24

CO-CREATING RESEARCH

Co-researchers' parallel conversations with Māori elders

Charles Waldegrave and Monica Mercury

Charles Waldegrave was one of three Principal Investigators in the two co-creation, participatory research projects carried out by the Family Centre Social Policy Research Unit (FCSPRU) Lower Hutt, Wellington, New Zealand, presented in Chapter 7 of this book.

Monica Mercury (Te Iwi Mōrehu, Ngāti Kahungunu, Ngāti Hainamana – Māori tribal and heritage affiliations) is a kaupapa Māori (indigenous to New Zealand) researcher who gathered and facilitated a number of the older Māori hui (meetings/workshops) where the co-creation took place in the second research project referred to in the chapter.

We write from our two perspectives to share aspects of our journey with colleagues.

The project we took part in

In 2014 the New Zealand government established the National Science Challenges with the *"aim to tackle the biggest science-based issues and opportunities facing New Zealand"* They stated that they wanted to *"bring together the country's top scientists to work collaboratively across disciplines, institutions and borders to achieve their objectives"* (Ministry of Business, Innovation, and Employment[1] 2022). They agreed to invest $680 million (NZD – around €426,250,000) of funding over ten years on 11 challenges. They included topics like *"Building Better Homes, Towns and Cities"*, *"Our Land and Water"*, *"Healthier Lives"* and *"Ageing Well"*. We successfully applied under the "Ageing Well" Challenge for a project entitled *"Loneliness and Social Isolation among Older Māori and Pacific People: Critical processes, events and mitigating factors"*. It had a time length of three years 2016–2019.

The aim of this project was to enable early detection of pathways that led to loneliness and social isolation for older Māori and Pacific peoples in New Zealand and the mitigating factors that facilitate social connection and enduring relationships during old age.

Critical processes and events that are consistently associated with loneliness and isolation were explored to learn the differing patterns and influences. These included mobility, communication, social relations, mental health, housing, physical health, and capability. Culturally specific and intra-cultural aspects of loneliness, social isolation, and social connection were given particular focus. A solid base of evidence from the research was sought

to enable older Māori and Pacific peoples to find pathways to participation and social inclusion. These pathways in turn were expected to energise further innovative development of culturally resonant forms of service provision and policy formation.

A major finding in the co-creation process was that the participants (200+ Māori and 200+ Pacific peoples aged 50 years and over) were unhappy with some of the questions in the Loneliness Scale (De Jong Gierveld and Van Tilburg 2017),[2] considering them culturally inappropriate for them. As loneliness was the central focus of this research, we needed to listen to the elders and respond. The process involved seeking their understanding as older Māori and Pacific participants in a range of settings. For the Māori elders, settings included marae-based groups (sacred, traditional gathering places), and for Pacific elders, it was within the local gathering places of the different Island country groups. These meetings led to the co-creation with participants of a Modified Loneliness Scale and a scale we called "Meaning and Purpose", which was composed of alternative questions the participants considered were primary causes of loneliness for them. We administered all three scales and found they tested well for consistency and reliability and also correlated well with each other.

These promising findings enabled us to seek funding for a larger study of older Māori, where we could co-create five other Māori social scales and test them with a national random sample of two waves of 1,500 Māori aged 50 years and older. This sample size, estimates a 20% attrition rate for the second wave of up to 300, while still allowing for sufficient power for statistical analyses. Funding has not yet been made available for a follow-up study with Pacific elders.

This second study referred to in Chapter 7 was entitled *"Tai Kaumātuatanga Older Māori Wellbeing and Participation: Present and Future Focus"* has given us the opportunity to test the scales for statistical reliability and validity with a national random sample of older Māori. The other two Principal Investigators were Professor Chris Cunningham (Ngāti Raukawa, Ngāti Toa, Te Āti Awa, and Te Āti Haunui-a-Pāpārangi – Māori tribal affiliations) and Dr. Catherine Love (Te Ātiawa (Nui Tonu), Taranaki, Ngāti Ruanui, Ngā Ruahine-Rangi – Māori tribal affiliations).

At the stage of writing this chapter, we have completed the co-creation process for the development of the key questions that form the draft older Māori scales of wellbeing, social connection, discrimination, abuse, and neighbourhood quality. A revised Loneliness Scale is also being applied with the ten questions that demonstrated the highest loadings shown in the factor analysis carried out in the earlier loneliness and social isolation study. The administration of the questionnaire began last week.

How we got involved

Charles

I was involved from the beginning. I am a psychologist and spent years working with Māori and Pacific colleagues developing an approach to family therapy that deconstructed the Western/Northern assumptions around individualism, nuclear family units, and silence about spirituality. Over time, the Māori and Pacific sections of the Family Centre developed their own approaches to whānau (extended family) work that deeply involved their own cultural values, ways of doing things, and spirituality.

Overall, we worked independently and interdependently in cultural sections to develop a range of approaches to family therapy that fundamentally addressed cultural, gender, and socio-economic contexts. This became known as "Just Therapy" (Waldegrave et al. 2003). We published a lot and as well as working in New Zealand and Australia, we were contracted regularly over a period of 15 years to run workshops in every continent, but especially Europe and North America.

In New Zealand, the issues of colonisation are stark. We live in a country where the mainstream majority, including my own ancestors, settled largely from what is now the UK and Ireland. Through mass immigration, war, introduced diseases, legal frameworks, and governance, the white majority systematically confiscated land, endeavoured to obliterate Māori cultural values, and reduced the vast majority of the indigenous population to second-class citizens with lower incomes and poorer socio-economic outcomes.

Māori resilience has been patient, persistent, and continuous. Today there is a renaissance of all things Māori culturally, socially, environmentally, and economically. However, the negative social and economic outcomes remain stubborn.

I became involved in this project, because I think the colonial process continues subtly today through a whole range of social and economic processes that operate out of Western/Northern assumptions which do not reflect the values and ways of doing things among the indigenous people of Aotearoa, New Zealand. These are the same Western/Northern assumptions around individualism, nuclear family units, and silence about spirituality that we deconstructed in the therapeutic work noted above. It is important to me that I, and other non-indigenous researchers, don't replicate the subtle controls and definitions used in social indices now and in the future, as so much current research practice continues to do.

The social scales we use to measure key indices like loneliness, wellbeing, and social connection, for example, provide answers to the questions that are asked. Those questions largely reflect the assumptions and norms of European and North American cultures whose values are substantially different. While they capture the universal aspects of the indices, they do not capture the Māori specific aspects. As such they are blunt instruments for providing high-quality evidence for good policymaking and service provision. Without robust culturally specific solid evidence, policymaking and the resources for the provision of services will continue to be inappropriate and marginalise Māori, while they do the opposite for the Pākehā (New Zealand European) population.

Our co-created research is designed to arrest this trend, deconstruct the assumptions behind the measures and develop authentic culturally congruent measures, in this case, older Māori measures, that will provide authentic data of their experiences for much more appropriate sophisticated policies and services on their own terms. The rationale and examples are set out in Chapter 7.

As a social policy specialist over many years, I know how powerful numbers can be in research results. Through a qualitative methodology of co-creation, we seek to develop questions and scales that produce culturally rich quantitative results that will help decolonise our policymaking and provision of services by providing data that matters most to Māori, rather than the responses to international universal scales which only tell part of the story.

The methodology developed in this research is pertinent not only to Māori in New Zealand but also to any cultural group, whose values and ways of doing things are different from European, North American, Australian, or New Zealand mainstream assumptions and norms. Participatory co-creation research can usefully throw light on the core cultural

values and allow culturally specific scales to be developed. These, in turn, will enable more fine-tuned research instruments to be prepared for more effective policymaking and the provision of services.

Monica

When I first began my new role, the FCSPRU was about to conduct co-creation hui (gatherings, meetings) with older Māori groups. My colleagues, Catherine and Charles, were very experienced in this process and had arranged a co-creation hui with Māori elders at a local marae (traditional Māori community gathering place) in the Wellington region. This particular connection to the marae came about through a Māori member of the Family Centre Trust Board who is the chairperson of one of the local marae. Our small group were welcomed with a mihi whakatau (an informal greeting process), by a Kaumātua (a male elder) in te reo Māori (the Māori language) and in Te Ao Māori (the Māori World). Whenever someone does a whaikōrero (a speech) on behalf of a group, it must be followed with a waiata (a song). Collectively, the Māori elders then stood and sang us a very moving waiata to support what was said. As manuhiri (visitors) we were expected to respond. Charles spoke on our behalf and afterwards we sang a waiata to support his words.

Following that, there was time for whakawhanaungatanga (establishing relationships). Everyone in the room was given the opportunity to introduce themselves one by one. This can be done either in Māori or English or both and is a way to see if there are any connections one might have with someone else. My tribal affiliations are Te Iwi Mōrehu and Ngāti Kahungungu, so I am always interested in finding out if there is someone who might have similar roots to myself and to whom I can introduce myself to later on. Making connections is an important part of being Māori.

It is customary for the Tangata Whenua o te marae (the host people of the marae), to show their hospitality after a pōwhiri (formal welcome) or mihi whakatau by providing nourishment for their guests, and we were able to sit down and have a cup of tea or coffee and something to eat together.

A short time later, we were shown to a private space at the marae to undertake our co-creation hui. Prior to our visit, the Māori elders had been informed about our research and were asked if there was anyone who wanted to volunteer to join as participants. A group of six elders attended the session. I was both excited and nervous at the same time to be involved in this process with them. I thought that my educational background could be of benefit to me because I was very experienced at working with different groups of people and drawing out the information required.

It was an honour to see Catherine and Charles at work and they were excellent in this space. Particular questions had been prepared ahead of time and were designed to draw out in-depth responses. They immediately made everyone feel at ease and provided a culturally safe and comfortable environment which allowed the participants to open up and share their experiences freely.

I felt privileged to be in the room to be able to hear such personal stories from our kaumātua (respected Māori elders). My previous experiences with co-creation had primarily been with children as an educator and oftentimes only with regard to their thinking and ideas on a specific topic. This new experience of co-creation was on a very different level, which was far more revealing and seemed to trigger emotional responses from the elders, which I had not expected. It was then that I realised how crucial co-creation was in an indigenous space.

Many Māori continue to be marginalised in Aotearoa-New Zealand. They are still over-represented in most of the critical social areas; high incarceration rates, poor education outcomes, high unemployment, continued discrimination, ongoing trauma, many forms of abuse, low incomes, and a lack of secure housing opportunities. Stories related to these very concerns came out in the marae hui. This was all the more reason to gather their experiences first-hand.

I often thought of my own father when I started this journey. He was of Māori descent and grew up in 1940s New Zealand, at a time when being Māori was not valued. My dad was told by many of his teachers that he didn't have the intellect to be anything more than a "labourer or factory worker" because Māori were only good for doing "practical tasks". For my father and his siblings, there was no pride in being Māori because you lived in a Pākehā (NZ European) society and had to adapt to your surroundings. My father and all my uncles and aunties did indeed become labourers, factory workers, cleaners, or kitchen-enhands. Dad was actually incredibly smart and was a very good builder and I think that if he had been given the opportunity to attend university, he would have been a fabulous engineer as he was always fascinated with how things worked or were built. He was told many times growing up, even by his own Māori-speaking parents and society in general, that knowing his indigenous culture or language was not going to be relevant to their lives in the future. Thankfully, he didn't listen to them and at the age of 50, he became a Minister in his Māori-speaking Ratana Church (Māori founded and led) and gave comfort to his people through prayer in his native tongue.

Much has also changed for my generation and that of my own children's because our culture and language underwent a transformational revitalisation phase from the 1970s onwards. The rise of total immersion in Māori early childhood centres and schools created more space and opportunities for Māori language, customs and practices to be revived and thrive in urban environments. My daughters are both fluent Māori speakers and now study it at university level.

I think that my father would have been honoured to be asked to participate in the co-creation hui and I do wonder what he might have said in them.

The co-creation hui (meetings)

Monica

My initial experience with Catherine and Charles at the marae had helped me come to the realisation that I could contribute positively as a tangata Māori (Māori person) in the co-creation arena. The realisation about the benefits of co-creation for Māori became much clearer to me and it is essential to do so using an indigenous, kaupapa Māori principles approach (for Māori as Māori by Māori). It was then that I decided to contribute to this co-creation process and make sure that we continued to do it well.

I come from a whānau (family) that highly values our relationships and connections with others. My parents, Hori and Suie Thompson (my New Zealand Māori father and my New Zealand-born Chinese mother), were exceptional examples of how people could build solid and long-lasting relationships across creeds, colours, and races, despite some opposition and prejudice. They did this by involving themselves in sports codes, particularly basketball, as well as volunteering in various other groups in the community. Owning several local businesses in the 1970s and establishing a Māori sports club that became open

to all, and a Māori led church social service organisation in the 1980s were also incredibly beneficial for getting to know and care about people.

As a child of such people, I just carried on with the same relationship-building process as my parents and when I joined The Family Centre, I brought those connections with me.

Charles asked the FCSPRU kaupapa Māori team if we would help to set up more co-creation hui around the country with Māori community groups for our research project. I immediately said, *"kaore he raru"* (not a problem). My Māori colleagues had some people they knew and I had close ties with three particular Māori groups:

- Both of my daughters attended a total immersion (culture and language) Māori school – Te Kura kaupapa Māori o Ngā Mokopuna (TKKMNM).
- I had a very close and dear friend who was a member of a national organisation called The Māori Women's Welfare League (MWWL).
- I had church connections as our whānau belonged to the Ratana Established Church of New Zealand (a Māori faith-based organisation).

Te Kura kaupapa Māori o Ngā Mokopuna is one of 73 total immersion in Māori schools established in Aotearoa-New Zealand to support the revitalisation of Māori language and customs in takiwā (districts) across the country, over a 35-year period from 1985 to 2020. The majority of whānau (extended family) participants in this group of eight were experienced with tikanga Māori (Māori customs and ways of doing things) and fluent te reo Māori (Māori language) speakers in their fifties and sixties. One was a kuia (an older Māori woman) in her seventies, who had never personally learnt te reo Māori, but had grown up on her marae.

The MWWL were the second group I interviewed. The primary focus of MWWL is to empower Māori women as the tuara o Te whānau (backbone of the family). This group consisted of twelve older Māori public servants and professionals from the West of Auckland, Aotearoa-New Zealand's largest city. Most of them were in their early sixties, with two in their early seventies, who were semi-retired, but still worked part-time and volunteered in their community. I felt instantly accepted into the group as a Māori professional. I was on the same level and they trusted me completely. They knew how the government public systems worked in our country and had seen and experienced the discrimination, inequalities, and inequities within the public sector, particularly for Māori people.

The third group was a pāriha (parish) of the Ratana Church, based in Auckland. The followers within the Ratana faith are called Mōrehu (the faithful, remnant few) who represent a broad socio-economic demographic. A majority of Ratana faith services are conducted in the Māori language. Prior to the co-creation hui in Auckland, the parish were going to have whakamoemiti (a praise and worship church service) at 11.00 am, which I attended. Following the service, the congregation normally had lunch together and then we proceeded with the co-creation hui. A group of ten (three in their fifties, five in their sixties, and two in their seventies) had volunteered to participate from a previous whakamoemiti the week before.

The Information and Consent process was similar in all three groups and went very smoothly. Before the hui, I emailed the Information and Consent Forms to the main contact and asked them to show them to the participants prior to meeting with me. This process made it much easier when I arrived and they were happy to sign the forms before we started the hui. We also asked permission from participants to record what they were saying.

The place of "wairuatanga" (spirituality) is fundamentally important for indigenous peoples and occurs in both traditional and contemporary Māori settings. Our connection to our Ātua Māori (Māori Gods – especially those in nature), tūpuna (ancestors), and tikanga and kawa Māori (traditional Māori processes and procedures) are still highly valued. In Te Ao Māori (the Māori world), it is customary to pay respects to something higher than yourself and there is always consistent tikanga to follow at the beginning of any Māori gathering. The use of incantations (mōteatea), karakia, inoi, whakamoemiti (prayers, praise, and worship) are often provided to set a positive and calming tone for the hui.

Once the TKKMNM were all together, one of the parents stood to mihimihi (greeting speech) on behalf of the kura (school). The kura whānau then performed a mōteatea (chant) to acknowledge the mihimihi. Again, I was able to respond in the appropriate way and do my Mōrehu prayer, pepeha (my genealogical introduction), and waiata from my Iwi. The whakawhanaungatanga (establishing relationships) process followed and helped to establish and maintain a safe and caring setting in which to share our kōrero (discussion) safely and respectfully.

There were a wide range of socio-economic backgrounds, perspectives, views, and experiences represented, which shaped their responses. There were many stories of joy, happiness, and positivity and then others of trauma, sadness, and disappointment. I was especially moved by the resilience displayed by many, despite going through hard times.

The kaupapa (philosophy) of TKKMNM is based on Te Aho Matua (philosophical base for Māori education). It is a holistic Māori kaupapa, which encompasses foci on the spiritual, physical, emotional, mental, and cultural wellbeing of Māori as Māori. Respect for the wairuatanga (spirituality) and tūpuna (ancestors) was consistently acknowledged and accepted at TKKMNM. The fact that I was a former dedicated parent for ten years at TKKMNM was an absolute bonus. They knew me and I knew them and we all had the same kaupapa (philosophies) when it came to Māori families and in particular ō tātou tamariki (all of our children). We trusted each other implicitly and this was a fundamental value for us as Māori and TKKMNM whānau.

The MWWL Chairperson spoke a mihimihi (speech) in te reo Māori to me on behalf of the group that was gathered. Following that they stood up to support her by singing a popular MWWL waiata. I had the opportunity to respond and mihimihi in return to those present. I always say my Mōrehu prayer first in any Māori setting as a significant part of who I am and then I state my pepeha. I sang a short waiata Mōrehu to support my introduction. We were fortunate to be in an excellent meeting space and each attendee stood to introduce themselves to the wider group and create another positive whakawhangatanga experience for everyone.

The kōrero from MWWL emphasised that as urban Māori, they chose to continue to engage and gravitate to Te Ao Māori (The Māori World) wherever and whenever possible. This connection allowed them to maintain some traditional aspects in a contemporary environment with particular emphasis on the acknowledgement of their tūpuna (ancestors) and the sacrifices that were made for them to flourish. The MWWL genuinely cared about what could and should happen for their people in the future and were certain they had the capability and capacity to enact change for Māori living in the cities.

At the Ratana Church meeting, the Apotoro Rehita (registered Minister) had spoken a mihimihi (informal acknowledgement) to me during the whakamoemiti and later on, he led an Inoi Whakatuwhera (opening prayer) to set the tone for the parihā co-creation hui.

I then implemented whakawhanaungatanga (the process of establishing relationships) by standing first to introduce myself, firstly with a specific Mōrehu prayer, which we all knew, and then with my pepeha (my genealogical introduction), stating who I was and who I descended from. In this instance, a waiata was not required as we would sing a collective and well-known waiata together towards the end of the hui.

As at the marae in Wellington, time was put aside for the rest of the participants to introduce themselves to the wider group in whatever way they felt comfortable to do so. It allowed each person to find further possible connections with one another and created a safe and comfortable environment for the gathering to progress and share in a positive and open manner. I felt deeply the wairuatanga in the room because we were one in our collective spirit to Ihoa o Ngā Mano (God of the Multitudes).

These processes of engagement enabled us to comfortably address the co-creation subject matter we needed for the research. Here is a brief example of responses to a question about discrimination. I asked, *can you tell us about any experiences you or other older Māori you know have of being discriminated against – I am referring to being treated less well or poorly than others for some reason like because you are Māori, because you are old, because you are a woman or some other reason?*

Two whāea (older Māori women) told us of particular incidences of 'racial profiling' or especially feeling discriminated against because they were Māori and female. Because there had been incidences of petty crime in some stores that had involved some Māori women, there seemed to be an assumption that all Māori women will behave in this way, including older Māori women. Others, men, and women, shared similar types of experiences and a discussion emerged.

The first whāea shared a story related to how she made a cultural decision to get a sacred traditional Māori chin tatoo called a moko kauae last year in honour of her tūpuna wāhine (female ancestors). Prior to receiving the moko kauae, she says that she had always been a 'fair-skinned Māori' and had never had any problems out and about going shopping, but she has noticed a startling consequence since making the change.

> *I recently got my moko kauae (Māori chin tatoo) and I get followed around a shop by a security guard. He followed me to three different spaces. I was so shocked because prior to that, I had never been followed before.*

The second whāea Māori spoke about many instances of where she was followed around different types of stores by store personnel, and really felt that they thought 'she might steal something'. She also shared about a number of occasions where she has considered Pākehā (New Zealand Europeans) reactions to her were different on the phone compared to when they meet her face-to-face.

> *What do they call it...profiling, racial profiling. I have had that happen maybe about eight times. I have felt like I am being watched in a store because I am brown...or the opposite, being ignored for that reason. I also have a Pākehā-sounding name, so the different reactions I get on the phone compared to meeting someone in person is quite obvious.*

Over the course of the discussion the group began to identify the key types of discrimination they experienced as older Māori.

During the discussions about wellbeing perspectives, notions common to indigenous people, but uncommon to Western/Northern people arose. We sought their views on wellness, happiness, and security. Whānau (extended family) and whakapapa (genealogy) were often referred to. A typical quote was noted:

> *Our Whakapapa is our Māori line. Not just our tupuna (ancestors) from the past, but from you to your child to your mokopuna (grandchild), and then your moko-moko (mokopuna tuarua great grandchild), you know and so on and so on. Therefore, we have got to behave in such a manner that is becoming. An example. If I don't show goodness now, I'd hate to see what my whakapapa would look like.*

Genealogy is seen here as an inter-generational organising principle for wellness, happiness, and security as well as a high standard to live by. This is very different from a mainstream European or North American perspective.

Spirituality was also continually referred to and often in relation to whānau:

> *I am gonna call it wairua (spiritual) because we are talking about continuity. Being part of continuity in the wairua channel from your tūpuna (ancestors), to yourself, to your own tamariki (children), rangatahi (youth) to your mokopuna (grandchildren). Passing on the guidance and those teachings from your tūpuna is so important in life.*

The spiritual "channel" from ancestors before you to children and grandchildren in the generations after you, provide the security and teaching about good living and happiness. Quality of life is seen in these terms as being a connector, or passing on the wisdom, within the spiritual channel from the ancestors to the young ones.

These understandings were not peripheral, but consistent in the meetings I facilitated. They reflected an indigenous understanding of the world and what worked best for their sense of fulfilment.

In Te Ao Māori, it is customary to conclude gatherings by singing a waiata together as an entire group and then someone is asked to say a karakia/inoi mutunga (closing prayer) on behalf of those present. Following that, it is important to ensure that those attending are fed properly, so that both the spiritual and physical needs of the people have been fully acknowledged and catered for.

The TKKMNM whānau and I sang our closing waiata and The Tumuaki (leader) of TKKMNM recited a Karakia Mutunga (closing prayer) to complete our hui properly. I had provided some kai (food) for the participants, we said an Inoi mo Te kai (prayer for the food) and ate together. As with all the other participants in each group, a koha (donation) was given to each person for their time before they left to go home.

We concluded the MWWL hui with the Chairperson asking us to stand and sing a well-known waiata, He Honore (An Honour), together, and then she asked me if I would say a prayer for everyone, to finish off the hui, which I was more than happy to do. The participants had been asked to bring a plate of food to share. We said a blessing for the food and were able to eat and continue to kōrero during the meal. I had given a koha (donation) to the Chairperson before the hui to use within their branch as they saw fit.

Once we had completed the final aspects of the co-creation hui with the Mōrehu group, the Apotoro Rehita asked us to stand together and sing a significant closing himene (hymn) in our faith, Ma Te Marie (Be at Peace) and he closed the proceedings with an Inoi

Whakamutunga (closing prayer). We had eaten lunch together before the hui, so a koha (donation) was given to the Secretary of the Church Committee at the conclusion of the hui to use for parihā activities.

The importance of co-creation research

Charles

Monnie's (we call Monica, "Monnie") description is a world away from a standard Pākehā (white European New Zealander) focus group. Although only one of the groups she refers to is a church group, all three gatherings have prayers, songs or chants, speeches of acknowledgement, and statements of genealogy. These ways of doing things are not only different in terms of actions, but they also reflect a fundamentally different view of life, expectations, and ways of interacting from European and North American mainstream cultures. These naturally lead to different experiences and understandings of social phenomena, such as wellbeing and social connection, for example.

In these gatherings and many other meetings with other groups, spirituality was central to wellbeing and genealogy was central to social connection. Neither of these features in standard wellbeing and social connection scales. Participants in the co-creation hui also spoke of the importance of living in, and relating to, the Māori world as it connected them to their ancestors and helped them flourish. Again, these were emphases that don't appear in standard social scales.

Had we not listened to the elders' early concerns about some of the questions in the loneliness scale we planned to use, and pressed on with them, we would have completed our research much earlier. However, we wouldn't have understood loneliness as older Māori experience it. This is true also of the discrimination and wellbeing questions referred to above.

The significant importance of the co-creation hui or workshops were the rich data that emerged about how older Māori experienced indicator domains like neighbourhood quality, social connection, and abuse. There were certain universal aspects of these indicators that are common to most people, but there were also Māori specific aspects that were particular to their ways of doing things and understanding the world.

If relating to the Māori world and connecting to your ancestors makes you flourish, then surely a question about that on a wellbeing scale will provide Māori specific information about quality of life. That addition may also lead to policies that help enable people to connect to that world and services that aid people who have been alienated from it through generations of colonisation. Likewise, if spirituality is central to wellbeing and genealogy is central to social connection, then some appropriate questions concerning these matters would provide improved data for wellbeing and social connection measures. In turn, policies and services could be much more precisely and relevantly prepared for older Māori.

Monica

Co-creation research is particularly important for marginalised or excluded groups. It is crucial to have those who are the recipients of social and economic policies, have a voice in the process. They are the experts of their own knowledge and their perspectives should be part of the challenge and change that inform future policy actions. If we never ask for all perspectives, things are never likely to change or make a difference in the future.

Indigenous values are based on the importance of "collective thinking". What is best for all of us as a whole rather than the individual? How can we improve what is going on so that we can all benefit from this? I have found that co-creation is a significant form of engagement for Māori that brings greater value and richness to the indigenous research experience.

I have learnt a great many things from the co-creation process. Everyone is a product of their own life experiences and their upbringing has shaped their values, beliefs, perspectives, and behaviours. I think I used to assume many things about people prior to my involvement with how co-creation worked, but I have since learnt how important it is to listen to the stories of others that are willing to share them, and to do so without making any assumptions, judgement or prejudice, and to be more open to what is divulged.

In the early stages of assuming my role, I did not initially realise how crucial the co-creation process was going to be in the development of Māori-specific scales for the research. The creation of a culturally safe and responsive environment for our Māori participants was crucial to ensure that they were fully engaged and eager to share their views and perspectives based on questions in particular areas.

Once, we had completed the co-creation hui. I then had the honour and privilege of re-watching video, re-listening to, or re-reading information from the co-creation hui for the thematic analysis process. I used a "coloured-post-it note" approach which I was quite good at (all primary teachers love fun and colour), using a different-coloured post-it for each co-creation group and large A2 sheets of paper. It allowed Catherine, Charles, and I to find common themes very quickly for the next phase. We could synthesise and analyse them easily, which in turn, contributed towards the development of relevant and robust question lines for the research study.

I felt that the co-creation mahi (the work involved) was incredibly important because the perspectives of Māori in social policy realms in Aotearoa-New Zealand had not always been gathered properly or recorded well in the past. However, I do think this is beginning to change.

Charles

The critical contribution co-creation research makes is it that it de-thrones the notion that social scientists "know best". Social scientists know a lot of useful things that can facilitate good policymaking and improved service provision, but they do not know how cultural groups with different norms and assumptions from their own, actually understand and define key social indices like wellbeing, social connection, and loneliness – to simply mention three.

In New Zealand, our Treasury (Ministry of Finance) has been leading a major piece of work on wellbeing (Treasury 2021). It takes a largely Living Standards approach, not dissimilar to the OECD Better Life Index (OECD 2020). However, Māori and Pacific scholars and policy analysts have clarified that their cultural understandings of wellbeing have spirituality and extended family relationship at their heart (Treasury 2022). The Pacific researchers at the Family Centre who led the Pacific elders' project on Loneliness and Social Isolation, were requested by the New Zealand Minister of Finance to write a paper on Pacific Perspective on Wellbeing and the same emphases were expressed (Tamasese and Parsons 2019).

The Treasury struggles to incorporate these values, as it says,

> The Living Standards Framework does not seek to comprehensively incorporate everything that is important ……. from te ao Māori and Pacific perspectives. We have aimed to incorporate some of the most important concepts at a high level, but intend to use the Living Standards Framework (on wellbeing) alongside in-depth frameworks.
>
> *(Treasury 2021)*

referring to the specific cultural reports noted above. However, the report looks much more similar to the OECD Better Life Index.

The struggle is because the Treasury is a largely white, Western trained organisation that is much more comfortable in the secular, individualistic, and nuclear family world of Europe and North America than it is in the warm Polynesian waters of the South Pacific cultural milieu. The Living Standards Framework, despite its important attempts to go beyond GDP and other single measures of financial capability, has not co-created the framework with indigenous and Pacific New Zealanders. The critical parts of their models simply don't feature.

This is why co-creation methods are so important. When carried out responsibly, they involve a surrender of assumptions and norms and facilitate a process for participants to clarify their understandings and world views. It is hugely important in gender research, cultural research, ability/disability research, sexual orientation research, research with poor people, and indeed all research where the assumptions and norms of the researchers are different from those of the research group. And even where the researchers share the assumptions, the same surrender is important to hear the voices of others which often vary within groups.

During the early and middle 20th century, social scientists in a broad range of disciplines introduced important and innovative ways to understand social behaviour and learnt to measure some of it. The insights have been significant, but they have also developed hubris and blind spots of their own as the challenges from women (Gilligan 1982; Goldner 1985), cultural groups (Smith 1999), and disability organisations (Lawson 2001), to name a few, have testified. Their reality was often seen differently, described differently, and written up differently from the way they viewed it themselves.

Co-creation research at its best shows the respect due to participants that demonstrates they are the experts in the knowledge of their own communities and ways of doing things. The researchers' job is to question respectfully, probe, and listen. The analysis of results also needs to be checked back with members of those communities to mitigate any unintentional bias. This involves a longer and more thorough process than is often used, but the results when carried out well, build trust and represent people's lives authentically.

Notes

1 Much of the New Zealand Government's research funding is managed under the Innovation part of the Ministry of Business, Innovation, and Employment.
2 The criticism was not unique to this scale, it was about the assumptions behind universal scales developed in European, North American, Australia or New Zealand countries that are based on western or northern norms.

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CO-CREATING RESEARCH

Co-researchers' parallel conversations from the participatory action research project 'CareComLabs'

Shkumbin Gashi and Erich Kohler

We combine our two perspectives to share relevant aspects of our experiences and our work together in the participatory action research project, CareComLabs.

Carecomlabs project—a brief description

Shkumbin

The CareComLabs project is interdisciplinary in nature, bringing together local actors and academic scholars. This project's objective is to co-design and co-create a caring community. A caring community aims to build the structures that permit and facilitate the sharing of care responsibilities among diverse actors, including family members, neighbors, and local and/or other relevant institutions, and to foster a culture of solidarity interactions among community members.

CareComLabs has three significant pillars: (a) participation, (b) research, and (c) action.

Participation: the whole team (academic researchers and local co-researchers) is involved in the co-design and co-creation/implementation of each activity that leads to the common goal of creating a caring community. The decisions about project activities are taken through the principles of shared decision-making.

Research: the needs of the community are researched/investigated. For example, in Bachhdorf, 21 interviews were conducted (by co-researchers; older adults among them) with older adults and individuals with special needs, aging in place.

Action: initiating and co-creating activities and structures that respond to the needs of the community and/or individuals involved in the project (identified during the research phase).

CareComLabs is active in multiple locations and in each of them the project has adopted a distinct identity based on local resources, involved personnel, etc. In this chapter of the book, we report on Bachhdorf, one of the locations in which the project is active.

Erich

In Bachhdorf, we divided the project into three phases:

Phase 1: (a) create a team, explore, and document the actual status of the community

Phase 2: (a) Investigate the needs of the community, through a community qualitative study which culminated in 21 interviews.

Our findings from this study are listed in the categories:

a Social engagement, relationships, and networks
b Aspects of well-being and mental health
c Physical limitations and potentials in old age
d Asking for help, being able to accept help, and giving help
e Barriers

Phase 3/Further planning in terms of continuation of idea collection/measure development

a Find further supporters
b Establish this project as a platform within the health and older adults department in the Bachhdorf municipality.

Today's status

It became very clear that even though there are different living service offerings for older adults, it's not given that they are known to each of them. With a "coffee-bike" we are presented since December 2021 on hot spots in the village, to be as close as possible to the people, to listen, to coordinate, to help.

How we got involved?

Erich

Living more than 40 years in Bachdorf, a village close to Zurich and Zug, I was most of the time "on the road" with customer projects throughout Switzerland as well as in the USA. After retirement, I was looking for activities in the older adult market. First at UZH3 (Senior University Zurich) I found an environment which fully supports my targets and also offered opportunities in participative working teams. This Citizen Science opportunities showed me a creative, educational way to develop my skills further.

The CareComLabs Bachhdorf was a project I could live the participatory approach and also bring in my knowledge about the village, and my vision to develop Bachhdorf toward an age-friendly village.

Shkumbin

After I had completed my master's studies in psychology in my country of origin, Kosovo, one of my goals in Switzerland, where I have immigrated for five years now, was to

continue my academic development by pursuing doctoral studies. After conducting sufficient research into my options, I applied as a doctoral student to the CareComLabs project in Switzerland. My position in the project was funded by the Swiss National Scientific Foundation with the idea that I would divide my time during the project between the work I do in the project and my doctoral studies, combining at the same time the synergies of both and creating a symbiotic relationship between project work and doctoral studies. Being new in Switzerland, and knowing the context and the local language very little, the beginning of the project (the first meetings) was one of the times when I was most challenged to go outside my comfort zone. My elementary knowledge of the German language has been an initial obstacle, but over time, through the solitary nature of the team, helping me with the language as well as having an empathic understanding of my situation, I have benefited a lot, and this has been one of the unplanned effects of a "caring community," where I have seen how naturally people can benefit from such structures.

The concept of co-creation was to some extent "foreign" to me, because of my previous experience. My exposure to science has been more quantitative in nature, even though I have worked with qualitative methods (grounded theory) before. Therefore, at first, it required a lot of analysis and adaptation on my part, to understand well the principles of co-creation. But once I understood the basics, the idea of co-creation immediately stuck with me, because I quickly realized its power to get to the core of the problem. In traditional forms of research, groups of interest when the research is conducted are seen only as subjects, while in participatory action research, subjects are also part of solution finding actions. This particular approach enabled through co-creation has fascinated me from the beginning, and I continue to follow it with "open eyes, ears and mind" and learn from it as a process.

The co-creation potentials and pitfalls: lessons learned from CareComLabs

Shkumbin

From my experience and lessons learned in CareComLabs, I think that if done properly, co-creation is not only recommended but necessary, especially in community interventions. At a time when communities are becoming more and more diverse, structures are needed that bring all (or as many) perspectives to one table to create solutions that suit everyone. From what I have observed, co-creation has the power to build structures that last longer and are more useful to the community than when change comes from outside.

Another important aspect, or lesson learned on the co-creation, is the process of expectations management. In CareComLabs, we have seen that managing the expectations of all parties involved in such projects is the biggest/main challenge. It is true that the team has a common goal, but this does not prevent individuals and other interest groups from having other goals, more related to their self-interest or the institution that they represent, which is not wrong, but it should be acknowledged. Therefore, I think that the first step that should be taken in such projects is to understand the expectations of everyone from the beginning, and then during the various phases of the project to try to discuss and meet those expectations. Have they been met? What have been the obstacles, etc.? If this is not addressed, I think each project will have "stones in shoes" that hurt the "walk." Conflicts can arise from members frustrated with not managing expectations.

Erich

Co-creation has several strengths, but one of its main advantages is that it allows for the integration of multiple perspectives and resources, which results in a more sophisticated method of approaching a problem. The co-creation process in PAR combines two perspectives that are complementary to one another. Researchers from academic institutions contribute to the project with their expertise in scientific methodologies, while co-researchers provide their familiarity with the environment, culture, and resources that are found locally. In addition, co-creation bolsters the emancipation of community members, the pursuit of learning throughout one's life, and the dissemination of scientific information.

The combination of lay and academic knowledge is definitely a strength of co-creation, but for this to happen, a challenge should be mastered. And that is that both academic researchers and local team members accept what the other party brings to the project. This means academic researchers accept the lay knowledge, information, and ideas provided by non-academics and local team members accepting the academic world, pace, resources, use of particular methods, etc.

The co-creation CareComLabs: our personal reflexions

Erich

It was a very positive experience for me to be a member of a team like that, which brought together local residents and academics to collaborate on finding answers to issues concerning Bachhdorf. Since the very beginning, the project has been conducted with an attitude in which all of us have operated as members of a team that reviews, discusses, and makes choices in a democratic manner regarding the activities and the project itself. In my opinion, this is a project that showcases the highest levels of collaboration and engagement possible.

Due to the fact that I have a strong interest in the scientific world, being a part of the CareComLabs project has provided me with the chance to expand my knowledge of the scientific world, the spirit and paradigms of participatory action research, and the working relationship between scientists and local actors to effect change. I have gained knowledge not only about the thinking patterns that are used in scientific and academic contexts but also about the use of various programs that make it easier for team members to communicate with one another, such as Miro Board.

At the end of the day, it is a project in which you can contribute to the community but at the same time learn a lot, and that would be how I would describe my experience on the project: learning by contributing.

Shkumbin

I would describe my time at CareComLabs as both demanding and rewarding, as evidenced by the experiences listed below.

In such projects, one learns a lot all the time. For me as a new resident of Switzerland, for example (for five years in Switzerland), engaging in direct contact with different stakeholders has helped me immensely to understand the socio-cultural context and cultural patterns in Switzerland—as a result, it helped my integration in Switzerland.

One change I have noticed in myself because of CareComLabs is, for example, my desire to work in multidisciplinary teams. Through CareComLabs, I have gained knowledge that enables me to work in teams, build synergies, and use resources around me pragmatically. Another change I would mention has to do with my perception of old age. My grandparents died early, so I did not get to know them. I didn't have a "grandpa or ma" figure in my life. As a result, I had prejudices about old age as a gloomy period, but from contacts with members of CareComLabs (older adults), I changed the perception of old age from gloomy to one where dreams are built, where man has and finds space to develop, to contribute to the community, etc.

I also think that I have gained a better perspective on doing science for the common good. "Making a difference" has always been a motivator for me—a strong reason to wake up in the morning. That is why I do science — to change the lives of other people. However, sometimes I had the impression that my science served me and my scientific advancement, but I did not influence others. But through the co-creation process at CareComLabs, I have gained another impression of my scientific work, one that is more than the statistics or scientific papers in impact factor journals. Through co-creation in CareComLabs, I managed to co-build structures that will potentially stay in the community, and that is what I consider to be the main purpose of doing science.

Still, the work was sometimes stressful. This is due to the fact that, methodically, through participatory action research, there is not much room to do proper planning, two to three months in advance, for example. A lot happens ad-hoc, and often decisions about what to do next vary from one meeting to the next. Therefore, my role as a researcher is sometimes reactive, which requires quick decisions and negotiations with parts of my private life.

Two stories that exemplify co-creation in CareComLabs

Shkumbin

We planned a gathering in the neighborhood and invited several people to inform them about the CareComLabs and to invite them to become involved in our project, to join in our caring community initiative. We (all team members) organized the event down to the smallest detail, and we made sure that everything was done "correctly." The response we got from participants was not what we anticipated, and the level of enthusiasm that we imagined would be there in the room was not there. This came as a surprise to us.

Following the conclusion of the event, we regrouped in order to have a conversation regarding what had just taken place. In spite of the fact that there was dissatisfaction felt by all, it did not take very long, and after approximately forty-five minutes of discussion, the group's sense of unity did not diminish; rather, individuals saw the positive aspects of the occurrence, and the community felt a sense of collective pride as a result. As a direct consequence of this development, throughout the subsequent weeks, the group demonstrated an even stronger commitment to cultivating communication bridges with other organizations.

I believe that this is the value of co-creation because it creates a group with an identity, a group in which members invest a lot, and a group in which members are able to go "the extra mile" for the sake of the group and push the work forward with all of their potentials. The process of co-creation "melts" individuals into a group.

Erich

Prior to the first wave of the coronavirus pandemic, we had already established a work routine as well as short- and medium-term research objectives, and we were prepared to begin conducting interviews for the study. COVID-19 posed an unanticipated obstacle to our plans.

As the number of COVID-19 infections increased and the initial lockdown was implemented, we had a three to four week respite. However, it was short-lived, and we resolved not to give up and simply wait, but to keep the project alive. The first course of action was to resume our biweekly meetings. As a result, we determined that the most effective way to host such gatherings would be through online platforms, and we enlisted the aid of researchers to use platforms (i.e., Zoom) that would make this possible. We found a way to keep the project alive and to continue communication and coordination among ourselves, and I see this adaptation in an unusual circumstance as a sign of our determination to advance the caring community and a positive indicator that the initiative will be sustainable.

Due to the pandemic context, numerous plans and adjustments were made. Despite this, we were able to keep the project alive.

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DOING RESEARCH TOGETHER – INSIGHTS FROM THE INTERGENERATIONAL PROJECT "DIGIGEN" IN GERMANY

Anna Wanka, Miranda Leontowitsch,
Friedrich Wolf and Horst Schöberl

This chapter sets out to give voice to the people – both academic and experts by experience – that was part of the research project "DigiGen – Two Generations One Digital Age"[1] based at Goethe University in Frankfurt/Main, Germany. The three-year project was funded by the German BHF-BANK Foundation and started in 2020. It aimed to facilitate a dialogue between two age groups – high school aged students and retired adults – who jointly created knowledge about artificial intelligence and co-created means to disseminate this knowledge through a podcast series.

For the purpose of this chapter, two interviews were conducted in 2022 – one with the two principal investigators of the project, Miranda Leontowitsch (ML) and Friedrich Wolf (FW), and one with Horst Schöberl (HS), one of the retired project participants and co-researcher. Both interviews were guided by the same interview guide, comprising questions around involvement with the project, experiences with the participatory design, and lessons learned. Both interviews were conducted via Zoom and lasted for about one hour. In this chapter, the answers of all three interview partners are presented together to allow readers to capture different perspectives.

Question 1: How did you get involved with the DigiGen project and what is the project's participatory approach?

The two academic researchers and principal investigators of this project answered this question first and foremost with their research interests. As ML put it: "*When Friedrich outlined the idea to me the first time, I knew we needed to do this!*" And, FW adds, "*And then the next step was simply to try it out!*". Horst Schöberl, a non-academic researcher in the project, came to it quite differently – namely through a flyer distributed via the University of the Third Age that he studies at.

> *I'm at the University of the Third Age in Frankfurt, and they always send out a letter when some researchers are looking for test subjects, and then there was this reference*

to the Citizens' University and this project on artificial intelligence or generations shaping digital technology together. That caught my attention...I am interested in artificial intelligence and then I signed up, then there was an interview and then I was selected. That's how I came to the topic. […] And, I think, you don't get any more stupid, and so I said, maybe you'll learn something new.

<div align="right">(HS)</div>

Both academic principal investigators framed the participatory approach of the project as essentially democratic, "*that people of all ages should have the opportunity to learn how digital technologies e.g. artificial intelligence work because many of these technologies affect them in their everyday lives*" and that their voices are heard in the discourses around digitalization. Friedrich found the idea appealing to design a participatory project that would both create knowledge and societal benefit. As researchers at a department for Educational Sciences, Miranda added that participation also aligns with democratic concepts of learning and education, particularly reflexive learning: "[…] *so instead of saying that you somehow prescribe a curriculum, you take as a starting point this interest that is there already*". In this learning process, people want to learn more about something that is relevant to them, not by being taught but by working it out themselves.

And I find this reflexive form of learning, which is also something I implement a lot in my own teaching, of great value in a participatory project. When Friedrich pitched the project idea to me for the first time, I immediately thought it could be set up as a participatory, intergenerational learning project.

<div align="right">(ML)</div>

However, while the project clearly featured participatory elements, both principal investigators framed it as "*not quite a classic participatory research project*" (ML), that is, participants were invited to discuss and learn about a predetermined topic (artificial intelligence), but had a lot of freedom in how to work on it. So questions regarding the level or degree of participation in participatory research designs remained, such as

[…] when is it genuine participation that really comes out of people's interests? […] How much help do I have to give, and when do I let go so that I really get development, and not just (something) that others have already given/said? I actually find that an interesting thought and, yes, I don't have any answers as to whether that is good or bad.

<div align="right">(ML)</div>

Working out how much freedom to give was particularly relevant when working on topics that are controversially debated in the public discourse, such as digitalization and artificial intelligence. For the PIs it is important to try to get everyone to the same level – through the provision of knowledge – before more interactive work can be fruitful.

PIs also found that their project idea provided an opportunity to further develop research on intergenerational learning. In their experience, most intergenerational projects involve older adults and small children (up to the age of 11 years) in projects around emotional bonding (e.g. by meeting up regularly for board game afternoons) The aim of those projects most often is to decrease loneliness in later life. Other intergenerational research

that involves older adults and teenagers, often assumes asymmetrical and stereotypical approaches to intergenerational learning, providing little to no space for self-directed, joint learning about a topic that is new to both age groups:

> *So it's not a particularly reflexive learning process, it's more like this: we have the digital natives and they teach the non-digitised older people and try to compensate for their deficits and that's where we're trying to move away from actually […] Yes, it is possible that the younger ones are somehow even more digitised, but we simply look at how they negotiate this together.*
>
> *(ML)*

Horst Schöberl agrees that digital skills is a topic that concerns older and younger people equally:

> *Everyone has to deal with it, because otherwise they simply can't exist in today's world, or, or can't participate. So, the younger ones, if they don't have these smartphones and are not in any social groups, they are outsiders, right? So they have no chance at all of surviving, right. But I will put it this way, and with the older ones it is amazingly the same!*

Time was another asset of DigiGen compared to existing projects on intergenerational learning as the participants had a whole school year to get to know each other, learn about artificial intelligence, and discuss how they wanted to live in a digitalized world. Other projects on digital skills with high school students and older adults run on a fraction of time:

> *That was one of the points where I thought, that's great and no one has ever done that before, to take so much time. In other projects they are together for a week or a few days over two weeks, and then one of the recurring results is that it should have been longer, participants had just got going.*
>
> *(ML)*

Question 2: Which positive and negative experiences have you made in the course of the project?

Challenges in communication: irritations and intergenerational relations

All persons interviewed agreed that there was a positive dynamic to the group from the start, and the principal investigators made sure to invest a lot of time in getting to know each other and building up relationships:

> *Well, I think what worked well was that we now have a group that is very well connected with each other. We took a lot of time for that at the beginning […] Now you have a very harmonious group, as far as the common attitude, the common work is concerned. That has worked well at this level.*
>
> *(ML)*

Getting to know each other, and working through the respective age-based stereotypes, took some time, as Horst Schöberl remembers:

The first two times you have to, you know get to know each other a bit […] until the younger classmates have […] also granted us the role of classmates, in that we as older ones have then also regarded the younger ones not just as grandchildren or almost grandchildren, but also as classmates, and after that it actually went well.

(HS)

Whereas the interviewees emphasized the value of harmony in attitudes towards shared work and heterogeneity in terms of age, generation, and experiences, both academic and non-academic researchers also sometimes struggled with this. Horst Schöberl explained that he enjoyed the project, but perceived one shortcoming, and that was related to the communication across age groups:

Everyone was talking about artificial intelligence as they understand it and the result was, it was a huge mess […] That was about the only thing that I perceived as a shortcoming in the project. That we didn't ensure a clear terminology right from the start, so that later on we kept running into this problem: one person sees it this way, another understands it that way, and the third has something completely different about it.

(HS)

What he was interested in did not always and necessarily resonate with the others in the group. At times he felt misunderstood. However, he adds that this irritation also contributed to his learning processes:

What I found extremely positive was […] the desire to solve this confusion and to find out for myself what it is all about. So that was an extremely positive aspect of this project, that it stimulated thinking, that it also, if you, as, I wanted to know exactly, then also forced you to act, to deal with it and to question your own position again.

(HS)

The differences between students and older adults did not only concern their knowledge and experiences but also their level of commitment. As much as the school students had been given a choice in what extra subject they could take that year, DigiGen remained a school subject that had to be attended, whereas the older adults came to the project as a result of their intrinsic motivation.

Challenges in the project design and implementation: selection biases and ageism

As in many participatory projects in ageing research, the principal investigators were faced with the challenge of recruiting and motivating a diverse group of people to get involved in the project. As FW put it:

[...] what I think we have to critically reflect is that we yet again have those people with an affinity for education. Not all of them are educated to a high level, but they are very interested in further education and this poses the question: The participatory idea is nice, but if we can only cultivate it with people who are willing to do it and are

also used to getting involved in a certain way, [...] is it then perhaps something that only works for this group?

<div align="right">(FW)</div>

The groups that would "*benefit greatly from having their voices heard*" (FW) are also hardest to reach – a common problem among the research community, as ML also notes:

This remains a big problem. And you hear it a lot . Even in projects where a lot has been invested to somehow get marginalised groups involved, it just doesn't work out so well.

<div align="right">(ML)</div>

Recruitment and retention also proved to be one of the major differences between the age groups involved: While students were recruited through their school and showed no dropouts throughout the whole project duration, older adults were recruited through a more selective pathway, namely via several large, local non-profit organizations providing services for older adults. The mailing lists via which the call was advertised, however, only reached a relatively well connected, active population of older adults (who at least used email). Indeed the call initiated a huge interest and was condensed in a second step when potential participants learned about the requirements for participation: weekly meetings from 9.50 to 11.25 on Mondays for the duration of a school year. In addition, potential participants were asked to submit short answers to four questions: "What interests you about artificial intelligence?", "Which digital devices (e.g. smartphone, voice assistant, PC) do you use and what for?" "What was school like for you?", and "Why would you like to work with high school students?" A group of interested participants were invited to a meeting in which they met the research team and could ask questions. Due to the pandemic, this meeting was held via Zoom. Although this created a selection bias for one of the participants who could not use Zoom it worked for the rest. The person who did not join the Zoom meeting did, however, become one of the older co-researchers.

Beyond recruitment, dropouts proved to be a challenge in the process of the project:

I think dropout is a real issue. It may be due to the pandemic, but I think that's basically a challenge in participatory research, and of course we don't have such a dropout on the student side.

<div align="right">(ML)</div>

Reasons for dropouts included, for example, care obligations, wanting to be careful due to the COVID-19 pandemic, or also feeling overburdened by the learning contents and requirements of the project. One participant, for example, "*wants to do it properly, she wants to be able to read the texts, to be able to prepare herself, and it has all become too much for her now*" (ML). This left her feeling overwhelmed: "*It's simply a complex subject, right? And that's where you lose people.*" (ML) Dealing with a complex topic that includes mathematical language can increase dropouts, particularly among those with low formal educational attainment and/or who have not been in touch with educational organizations

for a long time. The struggle to "keep up" with others who have been involved in educational programmes throughout their lives increases this risk.

> *I think these are precisely the people who have low self-esteem […] they have this feeling that they could catch up on something, but they are also particularly sensitive to feelings such as, 'Oh, I can't keep up. […] I haven't got what it takes.' That is something that is carried along biographically over a long time: as a child, as a young person, someone told you, 'You are not good enough for a higher school education', and somehow you can't completely get rid of that. And that becomes apparent here in this project, too.*
>
> *(ML)*

When Horst Schöberl talked to his former work colleagues about his involvement in research projects, he found them interested, but also sceptical. They would ask: "What are you doing there again? Don't you have anything else to do?" What he found to be more of a barrier to participation, however, was not primarily rooted on the side of potential participants, but in (scientific) ageism. He had the impression that the academic system itself disregards later life when it comes to participatory and non-participatory research.

> *Why bother about older people? They have actually retired from working life. They are only there to bring money to the people, now and then, or to take care of grandchildren, or to do something else, but that they can still achieve something and maybe even want to achieve something, that is not recognized. [...] People simply say: […] Spend your money, be peaceful and make sure that you don't hang around here for too long, so that your pension does not burden us any further. [...] And that's also / my impression is actually that those who are retired are de facto discarded by society.*
>
> *(HS)*

He spoke of "attributed competence" that is withdrawn at the moment that people retire, which makes retired adults also not an interesting group for research. Even though he saw a change in these attitudes, he concluded:

> *I won't live to see it. Maybe that will be the generation after me, or even later, when people say: No! We can no longer afford this age-related phasing out of know-how.*
>
> *(HS)*

Question 3: What are your lessons learned from the project?

Both principal investigators agreed that resources are key – particularly in terms of time (both duration and work hours). They also emphasized that they were lucky to have a student assistant that has worked on the project throughout

> *I think you can scale such a project by investing more time and the more time and involvement you have in it, the more you can develop it.*
>
> *(FW)*

Communication between researchers and participants was particularly time-intense, and also required a high level of social skills:

> *So she [the student assistant] is good with the high school students because she is only slightly older than them, and she is incredibly good with the older ones because she is an incredibly warm, genuinely warm person and they all adore her and she got presents at Christmas and we didn't.*
>
> *(ML)*

The desire for communication was not as pronounced among high school students as it was among older adults. Despite the weekly meetings, the older participants also communicated with the students' researcher, the PIs, and each other via email. During the course of the year, messenger groups were set up in small working groups with younger and older adults, however, the older adults lamented the slow response of younger participants. Time and communication were also of the essence in the first phase, in which participants got to know each other. In DigiGen, this process took four to five weeks.

> *We allowed ourselves so much time to get to know each other that the teacher eventually came to us and said, 'The students should start doing something in terms of content', because they are starting to get restless. But in the end it paid off. If you do have this long time horizon, then really spend time getting to know each other somehow.*
>
> *(FW)*

This time investment in communication and getting to know each other should not merely involve participants and researchers, but should extend to the institution and stakeholders involved (i.e. in this project, the school and teachers). Beyond these lessons learned, non-academic researcher Horst Schöbel summarized, that learning in participatory research is an open-ended process of becoming: *"I'm still in the process of learning!"*

Note

1 DigiGen – Two Generations One Digital Age: tinygu.de/digigen.

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CO-CREATING RESEARCH

Co-researchers' parallel conversations from the project 'SEVEN – Socially Excluded Older Adults: Voices and Experiences'

Charlotte Gruber and Katrin Lehner

This chapter is written on the backdrop of *'SEVEN – Socially Excluded Older Adults: Voices and Experiences'*, a project with an emphasis on co-creation focusing on the exclusion from social relations in old age. The following pages give insights into the research process, encountered obstacles, and learnings from both a citizen scientists' perspective, as well as from the perspective of an academic researcher.

The project: SEVEN – Socially Excluded Older Adults: Voices and Experiences

Katrin

The 'SEVEN' project, realised from 2021 to 2023, explores gendered experiences of the under-researched group of socially excluded older adults (SEOA) aged 65 and older by actively involving them in the research process from beginning to end as citizen scientists.[1] By doing so, the focus of the research, the data collection, and analysis, as well as the presentation of the outcomes is guided by older adults themselves. The approach therefore allows to explicitly capture the diverse voices and experiences of SEOA, reflecting the citizen scientists' diverse life trajectories and the multifaceted effects on their social relations in later life.

SEVEN is the follow-up study of 'GENPATH – A life course perspective on the Gendered Pathways of exclusion from social relations in later life, and its consequences for health and wellbeing' (2020–2022), which investigated older adults' gender-specific differences in social exclusion and compared them across seven European countries – Austria, Sweden, Ireland, the Czech Republic, Israel, Norway, and Spain. Although some of SEVEN's citizen scientists were recruited from GENPATH, most were approached via stakeholders from social organisations.

After two introduction meetings, citizen scientists were introduced to the general objectives of qualitative research. By doing so they acquired the basics of problem-centred interviews, group discussions, photovoice, and autoethnography in the course of several three-hour long workshops. During those workshops inputs were given by the experts by training[2] and the citizen scientists were able to practise the methods in small exercises.

Later on, citizen scientists chose their area of interest within the context of exclusion from social relations in older age, formulated their own research question, and selected an appropriate method. During the following phase of data collection, the experts by training stayed in contact with the citizen scientists by holding bi-weekly online meetings or via phone calls. Thereby emerging challenges could be discussed and advice could be given when needed. When data collection was completed and interviews were transcribed, two more meetings on data analysis were held. In the course of the meetings participants learned to analyse the data themselves. In parallel, the experts by training interpreted the material as well, so that in the following workshop the findings of participants were implemented into the academic researcher's findings and discussed in detail. Further, key findings were decided upon collaboratively so that the preparation for the final presentation to stakeholders could be realised. Two consultative forums, one at the very beginning and one at the end of the project, were conducted and stakeholders, as well as all citizen scientists, were invited. The first forum was held to present the aims of SEVEN to both groups, about a year later the findings were presented by the co-researchers to the stakeholders. For future reports and publications, the involvement of co-researchers is planned likewise.

Charlotte

With project SEVEN, opinions and attitudes of older people should be explored using a participatory approach, i.e., amateur researchers tried to use their everyday environment and their acquaintances to find out what their peers think about ageing and the challenges they face. During this process, they are accompanied by a professional team of researchers who introduce them to different methods of data collection, coding, and analysing the findings from the interviews and other data collections conducted by older people.

How we got involved

Charlotte

The initiating factor to get in contact with the Department of Sociology at the University of Vienna was that I started the newly created master's programme 'Studium Generale', especially addressing retired people. When the Department of Sociology initiated the project GENPATH all participants of this study were contacted and invited to take part in the project. The target group of GENPATH was older people; therefore, the participants of the Studium Generale were the ideal addressees. I decided to participate in this project, and I was interviewed. At that time, I already planned to write a master thesis in sociology – so working together with this department aroused my interest.

Project SEVEN is to some extent a follow-up of GENPATH and since my contact was already known I was again asked to participate. The project start was still during the time of the lockdowns and restricted regulations for meeting in presence caused by the COVID-19 pandemic – so the first meetings were online.

From the very beginning, the topic was interesting for me. It opened a possibility to question my own situation and learn about thoughts, opinions, and attitudes of others about ageing. I immediately thought of a very good friend of mine who is leading a group of older people in a rural area of Austria and invited her to join me.

When the COVID-19 restrictions were eased and meetings in presence were again possible – although while wearing a face mask – a small group of four amateur researchers or co-creators met with the involved experts at the Department of Sociology. In the first meeting, I was the only woman, but one of the men left the group and then another woman took his place. In the beginning, I felt somehow like a stranger in the group, because my life reality was very different from the others. Then I began to see this situation as an opportunity to gain an insight into living conditions that are quite different from mine.

Katrin

Like Charlotte, my involvement in the project started with GENPATH. I was part of the research team at the University of Vienna and as the project almost came to an end, SEVEN got funded. About nine months later – postponed due to the COVID-19 pandemic – we started to work on SEVEN. Generally, SEVEN can be seen as a complementary extension of GENPATH, as it also focusses on SEOA. Through the citizen science approach, SEVEN allows us to exceed some limitations we faced in the more 'classical' research design we approached in GENPATH, due to the active involvement of older adults in the data collection and interpretation. The project itself, as well as my position within it, are granted and financed by the Austrian Science Fund (FWF).

Positive and negative experiences of co-creation

Charlotte

The positive experiences clearly outweigh the negative ones.

The only negative impression for me was that the group of co-creators was so small, and I had the feeling that I do not have much in common with the others. I had hoped for an exchange of ideas with others that have a similar background, like fellow students of the Studium Generale. Until now I still feel somehow superior to the other participants in the project SEVEN as co-creators. I have almost always worked in a context with people less educated than me and/or coming from a very different background, but it makes a difference when you are the boss, the project leader, the project manager. In the project SEVEN there is no hierarchy among the participants, and I had to learn to adapt to the project conditions.

These feelings reflect my attitude towards the people of the village where I live. It is a very small village with less than 500 people; I was not born here but came here more than 30 years ago because, on the outskirts of the village, we found an old house on sale that suited my husband's and my expectations. At that time, I was almost 40 years old and had travelled and worked outside of Europe, and had just become mother of a son. I love the place, the house, and the surrounding property, but until today I do not have friends in the village. I feel there are not many similarities with the people living here – but participating in project SEVEN makes me thoughtful that maybe I should change my attitude of looking at them somehow with arrogance and superiority. Being part of the group of co-creators and making the interviews offered me an opportunity to get a closer look at other life realities and they won my respect. This has strengthened the feeling that I am really privileged, and I have no reason to feel superior. Each life story is unique and shouldn't be compared to others.

The positive experiences are that becoming involved in other people's life realities made me think more thoroughly about my own life and has inspired me to write an autoethnography about the fact of being 70 years old but not feeling like 70 at all – in addition to the interviews and group discussions I conducted within the frame of SEVEN.

Conducting the interviews together with my friend has greatly increased my respect for her engagement of leading a local group of older people and to see how much her activities are appreciated. Without her initiative many of these people would be lonesome and would not have a possibility to meet others and make one-day trips to see interesting places and have fun together during the bus rides she organises regularly and at the meals together in a restaurant. It made me understand that the role of an animator is really important for older people living in rural surroundings.

I consider co-creation a very useful instrument for involving the addressees of a study; in particular, when voices and experiences of older people should be investigated. In the case of SEVEN most academic researchers cannot draw on their own experiences, so they have to rely on the statements of the co-creators. A major challenge is definitely the choice of co-creators and convincing them to participate.

Reflecting on the co-creation process of SEVEN, I come to the conclusion that I acted as a kind of mediator between the university and older people in a rural area of Austria via my friend. I think my friend would not have been contacted by the university without my intermediary role. In fact, it was a double co-creation process – but without contacts and mediators, co-creation processes cannot get started.

The main challenge for me was to define my own role: I belong to the target group of older adults but in the beginning, my main interest was on experiences and voices of other people – that was why I involved my friend to get access to the 'real' target group – but then I realised that the topic of ageing affects also me, albeit in a different way, and I decided to write an autoethnography. By writing down my own thoughts I got much more involved with my own self and could also better understand and classify the arguments of the people interviewed.

Katrin

The first thing I want to mention regarding the positive aspects of the project is the close collaboration between citizen scientists and the experts by training that seemed to have promoted a sense of fellowship. As the phase of joint preparation, data collection, and analysis took several months, all people involved got to know each other increasingly. SEVEN involved regular meetings and an ongoing contact, which had an effect on the level of acquaintance and the trust for each other. In the workshops, the conversations during coffee breaks seemed to go beyond small talk soon and this also reflected onto the co-researcher's projects, as they shared very personal stories in autoethnographies and while discussing results. Further, witnessing the development of the citizen scientists' research projects was an interesting experience for me personally. The citizen scientists' self-chosen research questions displayed their own personal situations, the various experiences they made, and their differing realities of life. Some of the co-researchers really committed themselves to their questions and exhibited great dedication in data collection and while discussing findings in the workshops. Charlotte, for example, conducted several interviews, a group discussion, and even an autoethnography, all aiming at her research question of social relations and place in older age. Her research topic also reflected her reality of life as a person who moved to the country site and does not feel integrated into the local community.

Regarding challenging aspects it has to be mentioned, that the participatory approach of SEVEN required a lot of versatility in planning, as on the one hand we had to structure the process to realise the project objectives, but on the other hand flexibility was required to allow space for co-creation. Also, for SEVEN the group of co-researchers was not set from the beginning. For example, one participant dropped out as his expectations of the project were not met. He was disappointed with the diverging individuals involved and did not see himself contributing productively. However, well into the project a collaboration with a national social organisation emerged, which left us with two groups of citizen scientists in completely different stages of the research process. This also required momentary adjustments in our planning, such as organising additional workshops and timing the research steps of the two groups' collateral to eventually merge them into one.

Another challenging aspect that has to be pointed out is group dynamics. In the workshops and meetings for both groups of citizen scientists, tensions within each group got apparent at some point. This of course comes naturally with every constellation of people, however it required strategic planning of exercises and discussions sometimes. This also made clear, that as academic researchers, compared to qualified mediators, we are not trained to facilitate arising potential of conflicts. However, looking back at the main phase of workshops and joint meetings, it worked out fine and I am confident to say that although this aspect definitely is necessary to consider, it is nothing that should abstain researchers from participatory approaches.

The relevance of co-creation in ageing research

Katrin

Generally, I find co-creation to be a beneficial undertaking. In the field of ageing research especially, it allows us to capture the personal experiences and diverse life situations in older age in an engaging and multifaceted way. In the specific case of SEVEN, co-creation contextualises existing and non-existing social relations of older adults differently than other approaches would have. First of all, this is because the focus of sub-projects was defined by the older adults themselves. This has resulted in a broader spectrum of overall themes and allowed deepened insights into their reality of life. Also, acknowledging older adults as experts of experience takes their needs and ambitions seriously and values their knowledge at the same time. Moreover, since the research process went on for several months, the experts by experience were able to gain competences in research methods, witnessed the development of their own projects, the projects of others, and the overall development of SEVEN – this fuelled a sense of collectiveness among both experts by experience and by training through the shared experiences. Also, contrary to the putative consensus within the scientific community, that only interviews conducted and data collected by trained experts is good data, in SEVEN we perceived the data collected by the citizen scientists as valuable and insightful, as the citizen scientists were able to approach their peers in a different manner than (young) academic researchers could.

Finally, from a gerontological perspective, the several research projects enabled a competence-oriented view upon social relations in older age, as differing types of social relations and their benefits, as well as emotions that are associated with those relations, became apparent, further social practices that are used to facilitate an increase of social exchange in everyday life became apparent. All of this enabled a reflected view on the topic of research throughout the entire research process.

Charlotte

I think co-creation is a very down-to-earth method of exploring people's thinking and attitudes, in particular when the research subject is voices and experiences of older adults. The researchers implementing the study cannot draw on their own experiences, since they usually are still young – so they rely on questioning the target group. And I think it makes a difference for data gathered when, for example, the interviewer is a familiar person of the same age and an amateur researcher than when a professional researcher conducts an interview.

But to get scientifically useful results it is necessary to make the co-researchers familiar with techniques of interviewing, and give them guidance and training. This introduction to research methods is crucial and the time spent in our meetings at the Department of Sociology was very valuable – the knowledge gained there was very helpful, and the online availability of the professional researchers was useful for giving feedback and making suggestions for improvement.

Co-creation does not end with providing information, but we were also involved in analysing and interpreting the gained information and drawing conclusions. In the end, there will be recommendations for stakeholders and policymakers on how older adults' concerns could be heard better. Being established together with the group of those affected the results should be more credible and authentic.

A personal reflection during and after co-creation

Katrin

My participation in a project with an emphasis on co-creation was an instructive experience for me as an academic researcher. Not only did I gain a broader perspective on social exclusion in older age, it also enhanced my knowledge and abilities of conducting workshops, overcoming obstacles along the way, and be delighted by the advantages of the collaborative work of co-creation. Beyond that, I personally enjoyed regular exchange with participants and to get acquainted with them in a way that exceeds the 'classic' interview situation. Thus, the often overlooked approach of participatory research, which rightfully draws the interest of a broad research community, convinced me too and I see myself implementing my knowledge from SEVEN on future co-creation projects.

Charlotte

I have already described my thoughts about other people's life realities that changed during the co-creation process. Participating in the project SEVEN as co-creator has made me more sensitive to the concerns of older adults. I am thankful to my friend that she offered me an opportunity to get an insight into her activities as a leader of a group of older people. My attitude towards such associations has changed; I was somehow looking down on such activities by thinking I do not need others to design and plan events for me – I have so many ideas what I want to do – but I began to better understand that I am privileged. Most people in my surroundings did not have the same chances I had.

One main aspect of the co-creation process was that I realised that many older people in this rural area where I live have little access to internet technologies. They themselves

consider this a dividing and excluding factor from important daily necessities like carrying out bank transactions and deal with local or regional authorities. Many small bank branches in rural areas have closed, only cash dispenser machines are remaining, administrative procedures should be done online, buying train tickets from a machine – all these activities overwhelm many older people. They begin to feel helpless, and their concerns are neglected.

My friend has organised training free of charge for handling a smartphone – but not everybody even owns a smartphone. Our society is changing into an online society, and I see a great danger in excluding the older generation from taking part in many important everyday activities. This fear was clearly expressed by the participants in the group interview.

I was a little surprised by one observation during the interviews: from the ten people we interviewed there was only one man. Although we made the group interview during and after a meeting in a pub for playing cards – and there were also men present – only women took part in the interview. My friend tried to invite also men for the group discussion, but they all found excuses for not taking part. It is a singular observation, but for me, it is significant that women are more interested in their own situation and give more thoughts on their future; and women are more willing to share their thoughts with others.

Discussing the low participation of men with my friend she confirmed my impression. She noticed a great difference between men and women. Women are more engaged in the group; they are more reliable, and they can deal better with being alone. Older men with a rural background are still strongly rooted in old traditions. If they are widowed their strongest argument to join the group is to find a new partner; many of them feel helpless without a wife because until the death of their wives, they never had to worry about organising a household. Widowed women on the contrary are not looking for a new husband to live with – they very often enjoy a new freedom – they may be looking for a partner for doing things together from time to time, but do not want to live in a common household and taking care for a man.

Participating in project SEVEN made me deal with the wide field of the topic of ageing and then realising my personal concern. The professional researchers also encouraged me by appreciating my contributions and gave me a feeling of providing them with useful information. I was very pleased when I was invited to participate in the international conference 'Ageing in Europe' that took place at the University of Vienna in July 2022. This was a wonderful experience for me: the different contributions from researchers from all over the world were very interesting and I greatly enjoyed being part of an international community, speaking English, and talking to people from other countries. I was also surprised to see so many young researchers dealing with questions of ageing delivering useful results. Their studies should be known to a much wider public – so there is still a lot of work to be done. It needs more publicity for the scientific analysis and results, therefore, co-researchers could also play an important role in the future as they can present the results of scientific research more authentic and with more credibility.

The participation in the project SEVEN made me want to celebrate my 70th birthday by inviting the family and a few friends and having a real birthday party. I realised that there are only a few friends that live close to my home, most of my friends are scattered throughout the whole of Austria or even abroad and they are too far away for inviting them for a party. And the family is mostly the brothers and sisters of my husband, since I have only one brother. But they will almost all come and stay for at least two days to celebrate

with me. And there will be my son and my two Afghan foster sons to celebrate with me. It should be a celebration for life and not for the 70th birthday, a life in peace, satisfied, and filled with gratitude.

At the moment I am planning and organising for the party that will take place in three weeks. I want to celebrate that I had a good life so far. I am scanning and printing pictures from my early childhood until now for decorating the place. Looking at the pictures makes me realise how many things I have done, how many places I have seen, and how many people I have met. – I think without becoming part of the project SEVEN I would not have given this birthday celebration such an importance: a celebration of being thankful for a good life, for a happy life.

Notes

1 In this chapter citizen scientists are understood as co-creators of the research process, they are experts by experience.
2 By experts by training I am addressing the academic researchers of the project.

PART 8

Future perspectives in the field of participatory approaches in ageing research

28

PARTICIPATION FOR MISSION-ORIENTED INNOVATION

A governance perspective

Julian Stubbe, Anne Busch-Heizmann and Maxie Lutze

Introduction

The topic of participation is currently receiving a lot of attention in Germany, especially with regard to research and development.[1] A striking example of this is the Science Year 2022 "Nachgefragt" (in English: "Participate!"),[2] with which the German Ministry of Education and Research (BMBF) focuses on the role of the general public and strives for an open dialogue between administration, scientists and people from civil society. This lighthouse activity radiates out to many other activities of ministries and stakeholders that want to bring scientific content closer to the citizens in a communicative way and initiate a dialogue between different groups.[3]

Participatory formats can look back on a long tradition. Not only in relation to scientific issues, event and workshop formats have developed that enable people to exchange their opinions and develop solutions co-creatively. This is also true when it comes to planning or strategic issues related to activities of public and political interest. These participation formats are less focused on scientific research questions, but rather on societal challenges, such as the planning of an urban neighbourhood or the improvement of care and health, and how corresponding solutions oriented to people's lifeworlds can be developed. Demographic change and the ageing of society is also a societal challenge. While knowledge about the form of change is increasingly widespread, the social challenge remains as to which solutions can be used to mitigate or positively influence the effects of change, e.g. in the context of regional structural change or in care.

The current boom of participation in political discourse in some countries and regions goes hand in hand with a changing understanding of politics in many areas of innovation policy. The German research landscape is currently experiencing demands for a reorientation of innovation policy towards a mission orientation. Through this orientation, innovations should be consistently geared towards solving societal challenges. This demand is not fundamentally new; what is added to the current discussion, however, is the focus on societal transformation. The coalition agreement of the current German government, consisting of Social Democrats, Greens and Liberals, commits to this new policy style in the context of its research and development policy (SPD, B90/Die Grünen, FDP, 2021).

It is thus the declared goal of innovation policy and promotion to develop solutions for societal challenges.

This is now accompanied by the need to adequately involve the general public in shaping the very processes of change that are being sought. Participation becomes a prerequisite for innovation policy missions to be accepted by the population and for their transformative potential to unfold in people's lives. However, it remains unclear how exactly the involvement of citizens in the new mission orientation of innovation policy is to be shaped, at which level and on which topics it is to be implemented and to which preconditions it is tied.

This chapter will explore the questions of which challenges for participation go hand in hand with a mission-oriented understanding of politics and how the role of participation can be systematised in this context. Both questions are related to innovation activities that develop solutions for challenges of an ageing society. To this end, the development towards a mission-oriented innovation policy, as already indicated, will be outlined. Building on this, participation is systematised from a governance perspective using a policy cycle model. This is illustrated with selected examples of demographic challenges. Finally, the results are discussed and evaluated.

Mission orientation as a new guiding principle of innovation policy

Systemic transformations come into focus

A mission-oriented innovation policy is increasingly becoming part of the German as well as international innovation systems (Lindner et al., 2021). The approach aims to bundle innovation processes that may be taking place in isolation from each other in the highly differentiated society with highly specialised scientific disciplines, economic sectors and administrative structures, and to focus them on crucial, current, societal issues. This includes a holistic understanding of innovation that encompasses not only the implementation of technical solutions but also societal changes for the solution of complex problems. In contrast to the promotion of selected technology areas, it is about a systemic approach to innovation that enables system transformations (Stubbe et al., 2021).

Not least, the Corona pandemic showed how much society depends on overcoming challenges by applying scientific knowledge. At the same time, it became clear that, above all, the successful transfer of technical and organisational solutions into practice is an indispensable step for overall success. The same applies to other major challenges, such as slowing down climate change and the societal adaptations required for this, or the ageing of society and the structural changes that go along with it. In this respect, innovations – and the societal capacity to produce them – do not only play the role of purely economic accelerators to strengthen the growth and market positions of companies and regions. Rather, the global challenge of the Corona pandemic highlighted the extent to which socio-technical innovations and their systemic coupling of the most diverse fields and sub-fields – from biotechnology and a digital health system to digital learning and public administration – are needed to overcome a challenge of such societal scope. In this respect, governance by state institutions should not be limited to regulating market-based framework conditions and remedying a market failure. Rather, the public sector is called upon to provide impulses in a guiding and proactive manner, to demand innovative services from actors and to enable the achievement of measurable goals.

Participation is crucial for such a mission-oriented understanding of policy. It coordinates the symbiotic relationship between the state's targeted innovation policy and the participation of the social actors who are to be the driving force as well as the compass of this change. In addition, it shows the multi-layered interlocking of innovations in their societal sub-areas when, for example, new digital administrative processes or learning methods meet people's practical lifeworlds. The discussions of the science and health system as well as democratic structures that emerged in the wake of the Corona pandemic also mark a need for communication and participation that bring people into exchange and negotiation of future developments. The participation of people in change and the new missions of innovation policy generates co-responsibility – an essential prerequisite for political goals and interventions to unfold a transformative effect as well. At the same time, however, this presents innovation policy institutions with the challenge of involving people constructively and finding ways to implement participation in innovation policy decision-making processes.

The mission orientation approach is not a product of the Corona pandemic, but it is gaining attention and importance as a result. Most recently, it was prominently called for in Germany by the High-Tech Forum and the Commission of Experts for Research and Innovation (Expertenkommission Forschung und Innovation – EFI) in their report on research, innovation and Germany's technological performance as a new policy style (Expertenkommission Forschung und Innovation [EFI], 2021, 2022; Hightech-Forum, 2021). In the report, the authors suggest a transformation orientation of innovation policy. At the same time, they advocate the creation of structures that enable public actors to act in an agile and forward-looking manner. Economist and advisor to the European Commission Mariana Mazzucato defines this as missions aimed at solving complex societal problems ("wicked problems") that initiate transformative systemic change (Mazzucato, 2021). In the context of innovation policy, this means focusing promotional and steering activities, impulses and impacts on a predefined major societal goal.

Although the implementation of this mission orientation is a more recent development, it is no longer just pie in the sky or a theoretical guiding principle but has already been tested several times in various innovation programmes (Dachs et al., 2015). For example, the Federal Government of Germany implemented the cross-departmental research agenda "The New Future of Old Age" within the years 2011–2016. With a total volume of around 189 million euros, research programmes of the ministries were bundled and consistently oriented towards the challenges and opportunities of a society of longer life (Federal Ministry of Education and Research [BMBF], 2011). The Federal Government's High-Tech Strategy 2025 is similarly characterised by a mission orientation, although here the focus is on technological progress, which in turn is oriented towards socially relevant areas of application – for example, medical care (BMBF, 2014). A particularly ambitious concept of a mission-oriented innovation policy is the European Commission's "Horizon Europe" research framework programme, which was launched in 2021. This programme contains five missions: "Adaptation to Climate Change, including Societal Change", "Beating Cancer", "Healthy Oceans, Seas, Coastal and Inland Waters" as well as "Climate Neutral and Smart Cities" and finally "Soil Health and Nutrition".[4]

The ageing of society is not a topic that is conceptually at the forefront of current innovation policy discourse. The political discourse in Germany peaked at the beginning of the 2010s, also caused and mirrored by the Science Year 2013 "The Demographic

Opportunity".[5] These and other measures led to the dissemination of knowledge about demographic structures and processes of change, including their social science laws. In current political programmes, demography is often included as a relevant background in other thematic areas, e.g. in topics such as health, shortage of skilled workers or regional structural change (EFI, 2022), which are of great social significance.[6]

The role of participation and governance challenges

Participation has a central role to play here: it should turn the new mission orientation into a democratic innovation policy. It is intended to inform participating citizens and stakeholders about relevant issues, to communicate democratic approaches and to disclose a variety of points of view. With the focus on public participation, today's missions differ from missions such as the moon landing in the 1960s. This mission was implemented entirely from the top down by the US government and accordingly drew strong social criticism. In contrast, the new missions of research and innovation policy should be consistently oriented towards societal challenges and involve the population. In this respect, Mazzucato demands that participation be part of the development and articulation of missions from the very beginning: "Participation requires reimagining the future together" (Mazzucato, 2021). Participation should not be reserved for committed elites but should be distributed across all levels of an innovation system. This approach would then also involve economic actors and, above all, the broad population. This requires openness as well as the ability to learn and adapt in the decision-making processes of institutions so that feedback from the groups involved does not only have a marketing effect but that transformations are also actively shaped (Mazzucato, 2018).

The call for more participation is not new. Related innovation policy approaches, such as "Responsible Research and Innovation" (RRI), aim to ensure participation not only in concrete research projects but already in innovation policy decision-making processes. With regard to institutional implementation and the associated legitimisation of a policy change, an important critique also begins: In their comparative analysis of institutional implementations of mission-oriented approaches, Frahm et al. show that these are often based on a "deficit logic" (Frahm et al., 2022). If the change is acknowledged, this could at the same time be used as confirmation that innovation policy has lacked acceptance in the past. In other words, so the possible reproach, innovation policy could not have had the desired economic and prosperity-promoting effect in the past, and implementation of participation would be "proof" of lacking efficiency. At the level of the Organisation for Economic Co-operation and Development (OECD), for example, the authors show that societal involvement in the management and regulation (governance) of innovation was only given institutional legitimacy by helping to increase acceptance among the population and to deal with uncertainties in demand. The authors' criticism is that participation is legitimised less from a democratic self-understanding than as a solution to problematic governance. Taking up this criticism, such a narrow understanding of participation – solely as an instrument to increase acceptance among the population – bears the danger that participation will fail. This is because it is not seen as a source of newness and as a force for co-design but as a downstream fulfilment of duty.

Another point of criticism is the failure so far of participatory formats to achieve broad participation. All too often, the implementation of participation only reaches certain population groups and individuals, that is, for example, highly educated, privileged,

middle-aged and politically interested people, while, for example, groups that have no relation to science or people with low digital literacy, including older people, are not reached. The EU project "PRO-Ethics" points out the challenge that successful implementation of participation must include creating low-threshold access. This is the only way to involve those groups that have a legitimate interest in having a say. According to the project's findings, this also means involving actors who are not traditionally part of the innovation system. These include citizens or civil society organisations (PRO-Ethics, 2021). This criticism does not mean that entire social groups cannot be represented by individual representatives of those groups. Rather, the criticism draws attention to the fact that the implementation of participatory formats is associated with its own ethical tasks. These factors, such as low-threshold access, generally understandable communication as well as regional diversity and target-group-specific channels, must be taken into account and translated into appropriate solutions. This may require considerable effort from innovation policy institutions and organisations.

Against the backdrop of this criticism, participation requires a reformed self-understanding of innovation policy organisations as well as coordinated efforts to constructively put the values and promises associated with it into practice. The organisations, whose strategic and practical efforts influence new mission orientations and thus at the same time the quality of participation, include not only the governmental and non-governmental institutions that promote innovations in a medium-effective way but also the advisory and implementing organisations, such as project management agencies, research institutions, innovation agencies and economic as well as civil society actors, which are also part of the governance structure of innovations.

To support the practical implementation of participation in these governance structures, successful examples of participation along three phases of the innovation policy decision-making process are presented below. A special focus is placed on examples in the context of age-related issues.

Policy cycle approach on participation in innovation governance

Innovation policy decision-making processes can be described on the basis of a policy cycle (Schubert & Klein, 2020).[7] In this model cycle, a problem is identified (problem definition) and, if necessary, placed on the political agenda (agenda setting). Policy measures are then developed and decided upon (policy formulation) so that they can be implemented in the next phase (policy implementation). In the evaluation phase, the achievement of objectives, efficiency and effectiveness are examined (policy evaluation), after which the policy closes the process (policy termination) in order to obtain capacities for a new problem definition. The fields of application of participation listed below already support decision-making processes and can each be structured in the sense of co-production. While the model basically shows five phases (Figure 28.1), the following text is reduced to three phases (agenda setting, implementation and realisation of research) and two illustrative practical examples for reasons of space.

Co-design: participation for agenda and topic development

In innovation policy agenda setting, a specific political goal or problem is put on the agenda. Such a societal problem can be, for example, the demographic change with the accompanying ageing of society – with a simultaneous increase in the burden on care staff
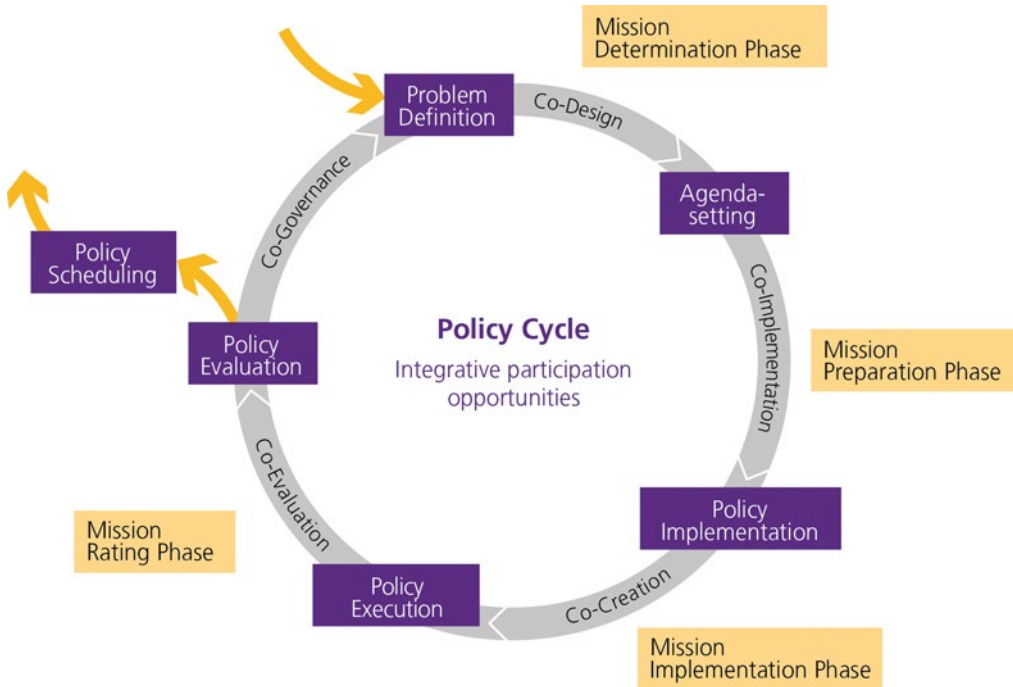
Figure 28.1 Phases of the policy cycle

(Lutze et al., 2021). A resulting political goal could be to formulate and implement innovative (also technological) requirements for age-appropriate care while at the same time improving working conditions.

In principle, democracies are characterised by a multitude of politically relevant and possibly competing issues, as well as by a multitude of actors involved in agenda setting: for example, by the separation of powers of government and parliament or by consultative processes of scientists, experts or other stakeholders.

Participatory activities here have a forward-looking as well as lifeworld-related character. Varieties of formats that involve citizens from different backgrounds in addition to the traditional actors of the innovation system have already been successfully implemented for many years. One example of this is future workshops, in which people develop a vision of the future for a social challenge such as demographic change and the increasing ageing of society. These have certainly had an impact on innovation policy in the past. For example, the Demography Workshop Talks of the Federal Ministry of Education and Research (BMBF) in 2013 brought together older people and experts and resulted in the very successful funding measures of the "Senioren-Technik-Botschafter" (in English: senior technology ambassadors) and municipal advice centres ("Kommunale Beratungsstellen") (2014–2016). A forward-looking perspective for citizens is also provided by technological test environments and experience spaces, so-called "living labs". Engels et al. point out that these can also be places for jointly developing socio-technical futures (Engels et al., 2019). Instead of being mere enablers of technology, test environments could serve as real societal tests for the desirability of certain transformations, the authors argue, based on

a comparative case analysis. This, they argue, requires rethinking notions of success and failure, planning with reversibility in mind, and a closer examination of the distribution of power in such environments.[8] They argue that test environments should not only be viewed as zones of low technical regulation to drive innovation but should also be used strategically to develop socially desirable governance frameworks associated with emerging technologies in real time.

All in all, when considering the problems and possible innovative solutions for dealing with the increasing ageing of society, it is important to systematically include the groups of people who are directly affected by this (older people, caregivers, family caregivers, care communities, etc.) in the research processes from the very beginning – i.e. already when setting the agenda. Only in this way can innovation research oriented towards the needs of those affected succeed in the long term. If this is only taken into account at a later point in time, the innovation process runs the risk of missing the needs and only generating supposed acceptance afterwards. To be more concrete, if participation takes place at a later point in time, there is the danger that the general need for a certain technology (e.g., a certain assistance technology for persons in need of care) is not questioned itself, and that participation is for the sole purpose of confirming the benefits of the technology. In the worst case, stereotypes are reproduced here. In contrast, when the group of people for whom this technology is being developed is included from the beginning, questions of real needs and system requirements (and the question of whether this technology is even needed at all) can be revealed systematically from the beginning on.

Box 1: Case I – The path from demonstration of technology to participation in research and innovation

Under the motto "Forschung für mich – Forschung mit mir" (in English: Research for me – Research with me), the VDI/VDE Innovation + Technology GmbH initiated a dialogue between the older generation and science and research for the Federal Ministry of Education and Research back in 2011. Since then, a series of measures have taken place in which older people were asked about their requirements for new technical possibilities and were able to engage with them.

Within the format of Senior Technology Day (within the framework of the AAL Congress), the focus was on trying out and evaluating exhibits and products. For this purpose, older people were invited to get to know ideas from research projects that developed ideas to address requirements of demographic change. Guided groups visited various stands of an industrial exhibition and discussed with researchers and developers how they would like to see age-appropriate technology, whereby the suitability of the systems for everyday use proved to be particularly important. In the course of an additional evaluation of the visited stands according to three criteria (expected benefit of the presented technology, comprehensibility of the stand presentation and own interest in use), the iHomeLab of the Lucerne University of Applied Sciences and Arts was awarded a prize by the participants. In a repetition of the format, older people visited research projects of the BMBF funding measure "Altersgerechte Assistenzsysteme für ein gesundes und unabhängiges Leben" (in English: Age-appropriate assistance systems for a healthy and independent life), where they intensively tried out, tested and evaluated the

technical developments. In the process, the researchers and developers received feedback and suggestions on their technical developments, which also provided information about needs and perceptions.

To continue the dialogue, the format "Research for me – Research with me" was further developed to strengthen the involvement of the user perspective at an earlier stage. The concern here was to readjust the role of older people and turn them from "affected to involved" (Source: Federal Ministry of Education and Research (2012): Forschung für mich - Forschung mit mir: Ergebnisse der Senioren-Werkstattgespräche zur Forschungsagenda der Bundesregierung für den demografischen Wandel "Das Alter hat Zukunft". Berlin, Bonn).

With this claim, older people were given the opportunity to contribute their suggestions to research, development and innovation as early as the formulation of the "research questions of tomorrow". Thus, the format of the Seniors' Workshop Talks was born in 2012, in which older people from different regions of Germany discussed the contents of the Federal Government's research agenda for demographic change. In cooperation with the German National Association of Senior Citizens' Organisations (BAGSO), four locations were selected in northern, southern, eastern and western Germany. Through dialogue with the older generation, the aim was to identify feedback, new ideas and pioneering impulses for age-appropriate innovations. The central insight thereby included criteria that defined the participants in the design of new technologies:

- Maintain and support independence,
- Strengthen personal responsibility,
- Promote physical and mental well-being,
- Take into account the heterogeneity in the older generation,
- Address the social and inclusive aspects,
- Involve the user groups from the beginning,
- Integrate the intergenerational aspects,
- Enable products and services that benefit all generations,
- Affordability for broad sections of the population and
- Putting people at the centre

In 2013, the dialogue format was taken up with the so-called "Demography Workshop Talks" and expanded to include actors from academia, with older people and researchers jointly discussing research needs, access routes and new methods. The six "Demography Workshop Talks" were dedicated to one research field and took place between March and July 2013 at a research institution with an appropriate thematic focus. In a concluding expert discussion, the findings were brought together and discussed across research fields.

Results of the formats

In the senior citizens' workshop discussions, a need for information about current and new technical developments in the older generation was called for. Compared to younger age groups, who are often introduced to new technologies through school, training and work, older people

come into contact with them much less frequently. There is a lack of own or mediated experience; especially from the same age group. It also became clear that the desire for knowledge transfer by people of the same age is often preferred. The BMBF initiative "Senioren-Technik-Botschafter" (in English: "senior citizens-technology-ambassador"), also launched in 2013, addressed this issue: Older people with technical experience acquire and impart knowledge and experience with new information and communication technologies. Low-threshold and practice-oriented approaches that also reach very old people were in demand (including the internet, mobile devices, assistance systems for living, mobility and care, ICT applications to promote or maintain health, and consumer electronics).

Conclusion

Research has a key role to play in successfully shaping demographic change: it analyses the needs of an ageing society and designs concepts for adapted system solutions consisting of technology and services for a society of the advancing years. The central task is to involve addressees and users in the research and development processes at an early stage and to bring the results of research more quickly into practice and thus also more quickly to the people.

Sources

- Homepage of the aforementioned project "iHomeLab: www.hslu.ch/de-ch/technik-architektur/ueber-uns/organisation/kompetenzzentren-und-forschungsgruppen/technik/ihomelab/)
- Homepage of the co-designed funding measure: https://www.interaktive-technologien.de/foerderung/bekanntmachungen/senioren-technik-botschafter)

Co-implementation: implementation of innovation programmes and selection of projects

The implementation of agendas within the framework of innovation programmes essentially determines how the transformation potential of a topic can be exploited in terms of impact for a desired goal in concrete projects. It is a matter of preparing and making decisions about which approach, which project idea or which partner constellations have the best chances of making a constructive contribution to achieving the programmatic goal. So if the agenda setting formulated in the previous phase was, for example, the political goal of researching innovative (also technological) needs for age(ing) appropriate care while at the same time improving working conditions, the task now is to implement this political goal in a participatory manner by means of suitable measures.

These decisions are part of the substantive translation of laws, ordinances or – quite essential for innovation policy – budget titles into concrete material benefits such as project funding. In the context of funding, this process presupposes that goals have been defined and ideas exist as to which research and development work can be used to achieve these goals.

The majority of these processes have so far been carried out by institutions, sometimes with the participation of experts. These are, for example, consultations on the priorities of funding calls and jury processes in which project proposals are evaluated on the basis of outlines or competitive idea presentations (so-called "pitches") and thus given a chance to receive funding. Currently, these processes are definitely evolving: there is less selection behind closed doors; transparency and diversity of the jury are gaining in importance. For example, the juries of the "Kreativpiloten" (in English: creative pilots) and "Innovation Programme for Business Models and Pioneering Solutions" programmes of the Federal Ministry for Economic Affairs and Climate Action (BMWK) are made up of people who bring not only scientific expertise but also experiential knowledge from entrepreneurial and professional practice. Another example in which the participation of affected groups of people is already systematically included in the project selection phase is the BMBF's announcement of the guideline for funding projects on the topic of "Technologiegestützte Innovationen für Sorgegemeinschaften zur Verbesserung von Lebensqualität und Gesundheit informell Pflegender" (in English: Technology-supported innovations for care communities to improve the quality of life and health of informal caregivers) (BMBF, 2021). Here, the selection of suitable project outlines was not only carried out by a scientific review panel but also by a citizens' advisory board made up of stakeholders with a connection to informal care (see Box 2).

This experiential knowledge enriches the selection process by linking the novelty value of a project to its practical impact. However, such a broad participation of different groups or citizens in these processes has so far been the exception rather than the rule.

Box 2: Case II - Integration of a citizens' advisory board in the BMBF call for project proposals "technology-based innovations for care communities to improve the quality of life and health of informal caregivers"

The call "Technology-supported innovations for care communities to improve the quality of life and health of informal carers" of the Federal Ministry of Education and Research (BMBF) is an example of research funding in which participation is actively pursued from the outset. The announcement focuses on the growing group of informal carers and aims to promote research and development of socio-technical innovations for care communities. Care communities include the network of informal caregivers and other actors (e.g. associations) as well as professional carers, if available. Innovative technologies should improve the quality of life and health of informal caregivers by facilitating their everyday life and strengthening their self-help and competence to act. The announcement results from the BMBF research programme "Miteinander durch Innovationen – Interaktive Technologien für Gesundheit und Lebensqualität" (in English: Together through Innovation – Interactive Technologies for Health and Quality of Life) and is assigned to the topic area "Digitally Supported Health and Care".

 Participatory research and development is at the heart of the measure in two ways:

• Involvement of a citizens' advisory board: The implementation of the announcement is actively accompanied by a citizens' advisory board from the beginning. This consists of representatives of informal caregivers in Germany. The assumption is that the members of the

advisory board, who have a corresponding background of experience as informal caregivers, can contribute this experience through their participation to the research and development of technologies that are intended to relieve the everyday life of this group of people. This makes a decisive contribution to the later successful use of the technologies to be developed and to their acceptance by the target group. Interested persons could apply to participate in the citizens' advisory council, and the council was composed in such a way that it was as heterogeneous as possible with regard to various criteria (e.g. gender, type of care situation). The citizens' advisory council was involved in the selection of suitable projects alongside a scientific expert panel and accompanies the selected projects during the project period. The task of the citizens' advisory board members here is to actively contribute their perspective as informal carers, to evaluate the research results with regard to the needs of informal carers and to make recommendations to the project members.

- Participatory research and development: The funded projects should explicitly implement participatory methods; the research results should result from participatory development. The evaluation of the participatory research approach was one of the essential criteria in the selection of suitable projects. In order to implement participatory methods, funding is provided not only for content-related collaborative projects but also for an accompanying project whose task is to support the participatory research and development processes. For this purpose, a Participation Lab is to be set up, which is to serve the exchange of information between the collaborative projects and in which participation methods can be "tried out". Furthermore, it is the task of the accompanying project to advance the theoretical foundations of participation research, to contribute to the corresponding theory formation and to integrate these into the research field.

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Co-creation: participatory implementation of innovation activities in projects

The participation of citizens and users in research and development projects has advanced considerably in recent years. Approaches such as user-centred design, "responsible research and innovation" or integrated research have already been implemented in research programmes and calls for projects to involve future users in the development process from the very beginning of the research. This development also applies in particular to research into innovative technologies for dealing with demographically induced new demands on care (BMBF, 2021).

Subsequently, a variety of methodological approaches was developed on how impulses, suggestions and experiential knowledge from everyday life worlds can be absorbed and processed. This development is being continued: In the new EU research framework

programme "Horizon Europe", the implementation of open science principles is an important selection criterion for funding research and innovation projects. In the new BMBF programme "Together through Innovation", too, integrated research is a central cross-sectional task and a requirement for the research attitude of the projects (BMBF, 2020). The aspect of the demographically changing society with the resulting new needs for health and quality of life takes a central place in this programme with the topic area "Digitally supported health and care". The inclusion of all relevant knowledge carriers, especially citizens, users and civil society in the sense of "citizen science", continues to be an integral part of the co-creation of project content.

The participation of citizens in research designs, such as citizen science projects, can make scientific activities in research and innovation programmes more transparent. Citizens can contribute to penetrating global societal challenges ("Grand Challenges") such as demographic change at the local level (Chicot & Domini, 2019). In turn, public research and development becomes more transparent. Irvin and Stansbury see a high degree of information sharing from day one, transparent rules for decision-making processes and dialogical mediation as fundamental framework conditions for resolving conflicts that may arise within participatory processes and for accelerating decision-making processes (Irvin & Stansbury, 2004).

In the orientation of this programmatic call, it has become apparent that although it should be clearly articulated as a requirement, methods should not be strictly prescribed. At this point, research and development thrive on being open and experimental. In addition to the diversity of methodological approaches, this also implies that project goals can change due to impulses from participatory activities and that a project can take a different direction than initially planned. If programmes do not allow this openness of projects, they will not be able to open up to participation in the long term, because participants would become vicarious agents of the experts. Here it is necessary to strengthen an open culture of innovation so that new solutions can emerge from the experience of citizens and be implemented for specific problems.

Concluding remarks

The examples compiled show how diverse and constructive participation is already being implemented today, especially with the constructive participation of older people. They show that participatory instruments can be creative, forward-looking and effective as well as a source and guide for innovation. They can thus be an essential element for a mission-oriented innovation policy. The policy cycle approach used here can be used to better systematise participation and integrate it into innovation policy decision-making processes.

For the systemic participation of older people, it is particularly important to recognise that demographic issues are no longer dealt with in isolation, in terms of age issues. Rather, the ageing of society has become a background issue for a whole range of topics that concern innovation policy. In the examples presented, these were in particular health topics or technologies of human-technology interaction. Other topics in which the ageing of society forms an essential background are, for example, regional structural change or education. In all these topics, the label "concerns older people" does not come first, but they are topics in which generational issues play an essential role and should therefore be discussed and constructively shaped by young and old together.

Missions, which are already being defined today and will be defined even more in the future within the framework of innovation programmes, affect people across age groups. This insight must also be reflected in the form of participation, which should not isolate age groups so much as connect and integrate them. For participation to be implemented with integrity and credibility, creating a culture of openness and willingness is necessary – and this from all actors and age groups. In mission-oriented participation, the creation of something new is not reserved for institutions or researchers. Rather, citizens are involved in their creative competences and their experiential knowledge. Learning from the experiential knowledge is an important goal for creating innovative technologies that are really sustainable and useful for the affected group of people. As the examples have shown, this can work in all phases of the innovation policy decision-making process: from the articulation of new thematic priorities to their implementation and the participatory implementation of research.

In order to gain impetus from these processes, a very substantial effort is needed not only to allow people who are already in a privileged position to participate. Enormous efforts are needed by all stakeholders to create a culture of innovation in which all segments of the population are given the opportunity to participate in innovation and thus in fulfilling the mission of equal participation for all – without reproducing discrimination and stereotypes. With regard to older people, this means that the governance of innovations as well as the actors involved should not integrate older people from a deficit perspective, but rather constructively transfer their experiential knowledge to new topics. Conversely, this means that older people also need to be empowered to participate, to build skills and to break down barriers. This concerns, for example, finding a common language, which can be a particular barrier in innovation topics.

For the governance of innovation, this also involves structural challenges. For the implementation of a mission-oriented innovation policy, the role of state institutions must be reflected and, if necessary, rethought. For this, it is necessary to create the necessary capacities. On the one hand, these consist of competencies that include reflexive methodological approaches as well as transfer knowledge and must be anchored in institutions. On the other hand, the innovation and funding policy instruments must be in place to enable participation and constructively embed it in the innovation process, as well as to strengthen the necessary innovation culture. This includes instruments that specifically enable participatory formats, such as citizens' councils or open foresight processes, and instruments that call for constructive participation in research and create the experimental space for it. Innovation policy organisations should also live out their openness in the sense of experimental governance and openly develop capacities.

Notes

1 Parts of this text have been published elsewhere (see Stubbe et al., 2021). That is in particular, parts explaining the developed policy cycle of mission-oriented participation. The text presented here is a transfer of this approach to demographic issues of innovation policy and in this respect is an original contribution to the debate.
2 https://www.wissenschaftsjahr.de/2022/english
3 An overview of the Year of Science activities and resources can be found on the homepage of the Federal Ministry of Education and Research (BMBF), including current research programmes with a participatory focus: https://www.bmbf.de/bmbf/de/ueber-uns/wissenschaftskommunikation-und-buergerbeteiligung/buergerbeteiligung/buergerbeteiligung.html

4 Five missions from Horizon Europe: https://ec.europa.eu/info/research-and-innovation/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe/eu-missions-horizon-europe_en

5 The German Ministry of Education's Science Year 2013: https://www.wissenschaftsjahr.de/2013/

6 To support this statement, the Federal Government's funding database can be consulted: https://www.foerderdatenbank.de/

7 This differentiation of participatory formats along a policy cycle can be understood as a complement to other forms of differentiation of participatory formats, for example levels of participatory formats according to their depth of intervention. cf. Unger (2014). A differentiation along the policy cycle lends itself to the focus pursued here on participation in the context of a mission-oriented innovation policy, in order to clarify in which phases of mission implementation participation can be relevant.

8 Power imbalances in test environments can occur for example if people with different communicative skills and personality traits come together: self-confident, extroverted people and those who are able to formulate their arguments in a convincing way will have higher chances to assert their interests.

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29

EMPLOYING CITIZEN SCIENCE TO UNDERSTAND THE CONTEMPORARY NEEDS OF OLDER ADULTS ACCESSING AND USING TECHNOLOGY IN A PANDEMIC

Hannah R. Marston, Deborah Jane Morgan, Gemma Wilson-Menzfeld, Jessica Gates, Carol Ann Maddock, Elisabeth J., Jenny Philips, Gavin Bailey, and Julie Nicholson

Introduction

The reliance on technology during the COVID-19 pandemic grew considerably, with digital technology being a fundamental tool for education, work, social connection, and civic participation, to name a few. However, the inequitable access of technology use for those citizens who can access and use online support tools, and those citizens who are excluded from this support, heightens existing inequalities, including health inequalities.

The digital divide, or digital exclusion, is the gap between those who are fully connected to technology and those who are not. Historically, this gap was considered as being simply around lack of access to technology, but this understanding has grown, and there are now three recognised levels of the digital divide: access, skills and usage, and the offline tangible outcomes of internet use, i.e. both the personal and civic benefits that individuals derive from being online (Blank & Groselj, 2014; Scheerder et al., 2017; van Deursen & Helsper, 2015). Therefore, digital exclusion may not only relate to access and digital skills but also its possible associations with the lack of interest or understanding of the advantages of use (Yu et al., 2016).

It is imperative to consider digital inclusion as being multifaceted, as even among users with some digital skills, difficulties remain. A recent study completed by some members of the research team highlighted the complexity of digital exclusion, as even older adults who owned smart devices and regularly used social media technology experienced barriers which negatively influenced technology use (Wilson et al., 2021). Several biopsychosocial barriers impacted use of technology; physical functioning (dexterity and visual issues), self-efficacy, fear, culture and communication, and lack of social capital. It is essential to

address the barriers to technology use to reduce this digital divide and increase inclusiveness of the use of technology.

The pandemic brought the 'digital divide' to the fore, further widening the divide between those with and without digital technology access or skills. Organisations across the UK responded to this crisis with initiatives aiming to provide digital technology to those without access and to connect them to the internet (e.g., Livingstone, 2021; Vodaphone, 2021) and to promote digital learning remotely (e.g., Good Things Foundation, 2020; Livingstone, 2021). This short-term reliance on technology as a direct outcome of the COVID-19 pandemic will almost inevitably continue to cause longer-term issues. There is now an urgency to continue promoting digital access, and to also develop digital confidence and digital skills, to enable individuals to independently access online content and support.

One solution to address these factors is through inclusive design – co-designing digital devices/social applications with older people. Smartphones and tablets provide an affordable, accessible entry route to the digital world. However, the interfaces are not user intuitive and can be off putting for individuals who lack basic digital skills (Nurgalieva et al., 2019; Williams & Shekhar, 2019). Although there are apps which simplify smartphone interfaces (e.g., Grand Launcher), these have limited functionality: e.g., SOS button, SMS text, and flashlight, and are not representative of the needs of older people. There is an urgent need to co-develop an application that has the functionality to reflect their needs and build digital confidence.

The project

The purpose of the 'Adapt Tech, Accessibly Technology' (ATAT) project (2020) was to explore and understand the needs, barriers, and challenges of smartphones and mobile apps experienced by older adults. ATAT aimed to identify, from new user perspectives, by employing a citizen science (Haklay, 2015; Riesch & Potter, 2014) approach with older adults and stakeholders to understand what basic adjustments are needed or should be considered to existing, affordable technology to support digital confidence and literacy among adults who are over the age of 50 years. Continuing with a citizen science approach, the second aim of this study was to identify what technological innovations and prototype applications enable new users to confidently access digital platforms.

Ethical approval and informed consent

Prior to participant recruitment and execution of workshops, ethical approval was sought initially from the research ethics board at Swansea University [22021b] and once approved, enabled respective submissions to be submitted at Northumbria University [2887] and The Open University [HREC/3869/Marston].

Aim of the book chapter

This book chapter describes the research design and findings from the study ATAT (2020) and contributes to the fields of gerontology, social sciences, gerontechnology, health psychology, human computer interaction (HCI), and research methods. Case exemplars are provided throughout the chapter to illustrate findings from the ATAT project.

Older adults' experiences of digital exclusion

There is a growing body of literature surrounding experiences of the digital divide, and the impact it can have on citizens both young and old, who are residing in various communities such as rural, urban, and metropolitan environments (DiMaggio et al., 2011; Freeman et al., 2020; Marston, 2019; Marston et al., 2021, 2020a; White et al., 2020; Wilson et al., 2021). Yet, older adults still use the internet to a lesser extent than younger generations, despite the sharp rise in internet use from those over 75 in the last decade (Eurostat, 2017; Office for National Statistics, 2018), and as a result, are more likely to be considered as being digitally excluded (Age UK, 2018). Ihm and Hsieh (2015) note how old age can be a predictor of the lack of access to technology, which in turn may mean that they do not experience the same potential benefits as younger cohorts. It is of course equally important not to consider older adults as one homogenous cohort with the same attitudes to technology, the same digital needs, or having the same digital barriers (van Deursen & Helsper, 2015).

Digital poverty is a further factor associated with digital exclusion, connected to the financial constraints that many citizens experience and plays a pivotal role in the digital divide, coupled with digital literacy varying across age cohorts, with some older adults lacking the digital skills needed to execute basic activities (Nimrod, 2016; Schumacher & Kent, 2020). Son et al. (2021) explore the challenges of reaching vulnerable citizens who do not have access to digital technologies to access resources; Schumacher and Kent (2020) categorise vulnerable citizens as older adults who are the oldest, and who have low incomes, and low education. It is vital to consider this intersectionality of existing inequalities, and its role in digital inequality, which in turn further exacerbates inequalities through lack of digital access.

In some instances, digital inequalities play a key role in older adults being socially excluded, from technology-related leisure activities and access to services because of having limited or no digital literacy skills (Hebblethwaite, 2017). Increasingly digital forms of exclusion are being recognised within conceptualisations of wider forms of social exclusion (Leppiman et al., 2021). Although many citizens had engaged and used various forms of digital devices, and platforms to virtually connect to, and receive social (Gabbiadini et al., 2020) and health-related support (Fisk et al., 2020), many others were excluded, and this added a new dimension to inequality (Seah, 2020).

While cost and access to digital devices/technologies are significant issues, other factors such as perceived usability, and usefulness can impact uptake (Heinz et al., 2013). It could be argued that designing technology with and for older people may overcome some of these barriers. Throughout the pandemic many citizens have been using various forms of digital devices, and platforms to virtually connect to, and receive social support (Gabbiadini et al., 2020) and health-related support (Fisk et al., 2020).

During the ATAT workshops, the older co-designers were encouraged to share their experiences about the different types of barriers, challenges, and concerns that they have encountered with technology and include,

> I've got a laptop which I'm using at the moment, and I've also got a smartphone recently err but it's far too small and I don't like using it at all, I much prefer to have a keyboard in front of me.
>
> I predominately use a laptop and I have also got a smartphone and I get lost on it, why, because it is different, why cannot we not have consistency across platforms?

[…] the tablet I think I could use if it didn't have these millions of things on it

I've been going back and forth to hospital from surgery etc. and they've been asking for selfies of the condition that I've got, erm so I've had to use my phone for that and send them pictures, but I couldn't' do it on the laptop. So, I can do certain things with WhatsApp that I can't do on in an email and so I've got to go between them all, and there's WhatsApp and Messenger, but I'm never quite sure which is the best one to use.

I think one of the disadvantages is cost. Because you have to buy a device but then you have to sign up to a broadband package erm that is really a barrier.

These statements illustrate a wide breadth of concerns experienced by the older co-designers ranging from several apps (pre-installed) onto devices, to the cost of accessing broadband and switching between different platforms, which for many people can be confusing, and irritating. The cost of monthly broadband services is unaffordable for some on a fixed income, resulting in them being categorised as in 'digital poverty'. Digital poverty not only hinders individuals from being able to connect with friends and family members but limits their opportunities of being able to access services and garner important information, (e.g., health and government; Marston et al., 2021).

Co-production

User-centred design is not new, it is however a more passive form of participation, one that older adults are not often engaged in, and as such technology is developed without them in mind (Ivan & Cutler, 2021). This may be because involving older adults in technology design can be perceived as challenging by designers because they are a heterogeneous group with regard to their needs and the way they use and engage with technology (Grates et al., 2019). Alternatively, power imbalances between designers, and older people may mean that the voice of the older person is not prioritised. Even when older people are the focus of technological design, there is often a disconnect between what older adults want and what designers think they need (Mannheim et al., 2019). Often the functionality of applications aimed specifically at older adults is based on stereotypical ageist assumptions of how older people use technology and what they use it for (Mannheim et al., 2019).

The reason for this is twofold. First, as with any form of design, the idea is based on a premise of who the end-user is and how they will use the prototype (Ivan & Cutler, 2021). Second, designers of technology are typically younger and therefore are less likely to design features that facilitate older people's interaction with technology (Ivan & Cutler, 2021). Furthermore, technological innovation is being driven by feasibility rather than the needs of the end-user (Rießenberger, 2021) thus contributing to the digital divide, and creating a self-fulling prophecy through product design and marketing aimed at younger cohorts.

One approach to overcoming issues such as usability, lack of confidence in technology, and low digital literacy is for technology design to adopt a participatory or co-design approach with 'older end-users'. Participatory or co-design is a democratic approach to design where older adults or other end-users are central to the design process. Participatory design is on a continuum, which ranges from doing to (informing and educating) through doing for (engaging and consulting) and ending up with doing with (co-production and co-design) (Slay & Stephens, 2013). It has been argued that to date participatory co-design has been overly paternalistic (Peine et al., 2014; Rießenberger, 2021) and focused at the

'doing to' end of the continuum. Indeed, Peine and colleagues (2014) argue that too often older adults have been assigned the role of object rather than subject, as is the case with user-centred design.

Yet participatory design when undertaken at the 'doing with' end of the continuum, where older adults are equal partners in the process can overcome many of the issues experienced with technology, instilling confidence in the older person. However, care is needed even within participatory approaches to design to ensure that the participatory approach is neither paternalistic, ageist, or stigmatising for the older adults involved in the co-design (Rießenberger, 2021). This is something the ATAT research team were conscious of during the planning of the co-design workshops.

How we embedded citizen science and participation throughout the ATAT project

Embedded throughout the different phases of the ATAT project was active participation and citizen science approaches. Such approaches relating to citizen science related to the engagement of and with the project partners (Digital VOICE for Communities and Digital Communities Wales), to facilitate the recruitment of older people with limited digital skills and who had an interest in co-design. During the online workshops, the older co-designers shared their experiences of using digital technology, which included exploring and understanding the barriers, challenges, and more importantly their needs and expectations from technology.

After each online workshop, members of the research team were able to proceed with the development phase, and in Workshop 3, the continuum of employing citizen science by involving the older co-designers to visualise the design and development of a mobile app launcher and to suggest changes that would overall benefit the design/development phase. This iterative design process enabled the computer scientists to address the challenges and barriers the older co-designers themselves had encountered when using digital technologies such as mobile/smartphones. Such challenges and barriers identified were the font style, the ease of navigation, and ability the to understand the different icons available (and installed) on a phone. Employing citizen science approaches further, the older co-designers were able to visualise the prototype during the workshop (through a demonstration); they were also able to engage with the prototype (in their own time) via a link provided by the research team to facilitate additional feedback to the developers. Taking this citizen science approach between the older co-designers and the prototype facilitated the basis and fundamental ethos to the study outcomes, and to participation (with older co-designers), as rather than being passive receivers of this information, (older) co-designers were actively engaged and were able to directly inform the study through citizen science approaches.

Further citizen science approaches were applied in the ATAT by primarily engaging with two project partners and older co-designers in two separate regions of the UK. We were fortunate to engage with a third partner – Age Northern Ireland which resulted in a fourth workshop. The purpose of Workshop 4 was to build on the previous workshops and to demonstrate the prototype, instilling active feedback and engagement, to facilitate the research team to garner more feedback about the barriers and challenges encountered by older people who use mobile/smartphones. Participants received reimbursement of a £25 gift voucher.

Feedback on the citizen science approach from older adults

The ATAT project ensured citizen science was integral in the project ethos by positioning older adults as the experts while employing and weaving citizen science approaches throughout the different phases of the project. For example, employing citizen science

from the offset of the project was key to the dissemination activities, as illustrated in the co-developed 'Icon Booklet' (https://www.open.ac.uk/health-wellbeing/projects/adjust-tech-accessible-technology-atat) and podcast 'Design for Age – Doing Co-Design Better' (Morgan, 2021). Briefly, the workshops were recorded, and additional interviews were conducted with the stakeholders and older co-designers to explore how they found engaging with the project and what benefits, challenges, and positives they experienced. These recordings were placed into the design and development of a podcast by an external company, and by listening to the content, listeners can understand the value of citizen science.

Additional insight can be found through the lens of the older co-designers who for some identified their confidence was a barrier to using and engaging more so with technology,

> I feel it has enriched things for me because, I'm looking at it now and feeling just more capable with it all and I think, like, I am able to do it, it's just that, confidence certainly wasn't there before, and I just felt like… the group gave me that really, and the people running it, it was all very interesting
>
> I felt comfortable with them I didn't expect that initially, because I thought, […] I didn't know what level I'd feel at, […] I enjoyed learning more about terminology and hearing what the other participants comments were, because we could all discuss what the issues were, what we found difficult
>
> I was confident about using technology to a certain point, but technology changes and you have to move with the times

This positivity is supported by feedback from Digital Communities Wales who note the co-designers,

> […] felt good about their part in the process and felt they left with more confidence, not only in their digital skills, but in general. That was fantastic to hear.

Another older co-designer describes how she felt her workshop involvement, was not only beneficial to herself, by learning from other attendees, but also knowing the information that she was sharing was going to benefit other people:

> What interest me about the project was a new way of doing things, learning new technology, learning how to live to other people, and to connect with a much wider audience, and you know learning from each other […] reconnecting, reducing social isolation, because, when you reconnect with people, especially for us in rural worlds we are really isolated, you know. And when you get to speak to people, and people come back to you, and you learn from one another, it's fantastic, its fabulous participating in something which would be beneficial to others was great, because we was able to share our ideas, and say what was good, what was bad what was accessible to other people, […] taking part in something that would meet individual peoples' needs […]

Being made to feel valued and respected as part of the wider research team was important to one individual, knowing that mutual respect was integral to the participatory approach and ethos of the project afforded this older member of the co-design team to realise the value of her contribution,

[T]here wasn't this assumption that we you know, they won't know anything, […] the respect of the team, […] our ideas were valued that was very important

Benefits of citizen science approaches

Fostering a positive relationship with stakeholders is one of the critical factors to employing participatory approaches, and, embedding early engagement, coupled with direct involvement from project partners and older co-designers themselves in the context of technology.

Digital VOICE for communities in Newcastle describes the benefits they perceive in co-design by directly involving older adults early on to ensure the design of the product will meet the needs of the participants. Implementing a citizen science approach can add benefits to older adults being co-designers, facilitating greater understanding of how the technology and/or product can benefit them, and relate to them specifically in their day-to-day lives.

This interactive approach facilitates the research team's understanding of the issues and concerns that older adults' experience to a greater extent. It is seldom we hear how research projects can impact other partners and Digital Communities Wales share their insights into being a partner on the ATAT project,

> I learned a great deal about what co-design means in practice and will use this learning in my future practice as it is a really transferable approach to service design.

From a personal perspective, the ATAT project facilitated individual learning experiences of those who work directly within the community,

> I learned how co-design and co-production can be really inclusive and beneficial to end users, not just in terms of ending up with a better product but also in terms of empowering and giving a voice to people who sometimes don't feel listened to.

Although we have shared the value from the co-designers' perspective, we can also share the value perceived by a research partner, working collegially across different expertise, and maintaining respect throughout; while acknowledging the challenges the rewards for everyone can result in greater outcomes,

> I loved being part of a multi-disciplinary team and felt that it was a perfect example of people being respectful and valuing different areas of expertise (not just academic expertise). I can see how this approach is difficult and presents many challenges but is ultimately both rewarding for the participants and results in better outcomes.

Looking to the future, this two-way approach can inform various actors of the opportunity to learn and implement a different approach to product/service life cycles by hearing direct experiences that can afford a change in behaviour for the better.

Lessons learned

We provide a series of lessons learnt which we hope will afford readers the ability to instil and implement into their projects:

1 Keep it informal and friendly: avoid using PowerPoint if possible- think about the implicit message tools such as PowerPoint can make to older people, by making it too formal -too academic can affect the power balance.

2 Make it your mission: to co-design at the outset and consider what the needs of the end-user might be and how you can enable co-designers to work with you. Think about the language you use – too often we slip into academic speak or acronyms which mean nothing to the people we are working with.

3 Time: having plenty of time at the outset for preparation not just yours but the end-user and in this context the older co-designers who are giving up their time to co-design with you.

4 Time to explain and explore: older adults in the ATAT project had lots of questions and not always directly relevant to the project. It is important to work at the speed of the group- rather than be led by your own agenda.

Start with the older person and how they would like to resolve those issues

1 Partner organisations are a bridge: make sure you have the right partners, and they are part of the team.

2 Keep the same people in multiple sessions: building rapport, helps you dig a little deeper-enabling the participants to feel heard throughout.

3 Listen: we were able to identify something en route (Icon booklet) that we are translating into a resource for the individuals and the partner organisations we worked with – something tangible that they have identified, are proud of and which others will benefit from.

4 Keep it fun: Have fun along the way – research and data collection is a serious activity but you can still have fun with it, and it helps break down those barriers – for all who are participating in the co-production or design.

We chose the Zoom platform because members of the project felt it was the most accessible and familiar platform for the older people and most commonly used during the pandemic (Evans, 2020; Karl et al., 2021; Sherman, 2020). A Zoom link was created to enable older adults to access and familiarise themselves with the platform, ahead of the workshops. Meetings were scheduled for 90 minutes per workshop to reduce the risk of 'Zoom fatigue' (Busby, 2021; Karl et al., 2021), and the same Zoom link was used throughout. Support from project partners ensured that help was on hand for anyone experiencing difficulties before or during the workshops.

Conducting online workshops via a communications platform, facilitated the research team to easily connect with everyone, enabling a diverse group of older adults from different parts of the UK to connect. Employing this approach enabled all attendees (older adults, project partners, and research team) to connect with each other. Whereas had we been in a pre-pandemic society, workshops would have been conducted separately at on-site locations and participants would not have had the opportunity to engage with each other.

Employing a citizen science approach, the older co-designers identified an issue in relation to understanding icons used in technology (e.g., via smartphones). As such we co-designed an Icon booklet with them to help support them and others. During the online workshop conversations, several of the older co-designers expressed how they sometimes found it difficult to understand the meaning of icons on their respective smartphones. The published booklet is a template comprising some of the key icons found on both Android

and iOS platforms. In the booklet, we have included various 'apps' that can be downloaded and installed onto smartphones. While the apps in the booklet may not be directly of interest to all participants the purpose of including them was to illustrate the wide array of apps available for download via the respective app stores. We discussed with the group what would be helpful from their perspective (older people and third-sector charity partners do not often access traditional academic outputs), and this type of output was suggested and received positively. The development and production of outputs such as the podcast 'Design for Age – Doing Co-Design Better' (Morgan, 2021), includes narration by the project lead (Morgan), coupled with sound bites from all members of the research team. We believe this type of output is very rewarding, and tangible because it can be shared and accessed across existing platforms, and audiences. Finally, and more importantly, it continues the participatory approach and demonstrates the citizen science ethos of what we as a research team set out to achieve. Our co-designers (older adults and stakeholders) were invited to share their experiences of being involved coupled with the opportunity of the project partners to share the podcast across their networks in an accessible format.

Conclusions

The ATAT project demonstrates the importance of implementing participatory approaches and citizen science to overcome product design issues from the context of interdisciplinary research teams. To garner beneficial and positive insights relating to participatory discourse and engagement, we believe the ATAT project affords readers with a blueprint for future research projects. Moreover, what is integral to any research project, but specifically interdisciplinary research where inclusion and participatory approaches are central, is trust.

However, from the discourse presented here and via the podcast, we would disagree. The positive feedback about the project from all co-design team members (both stakeholders and participants themselves) demonstrates trust and integrity were achieved. Outputs such as the podcast and the design and development of the 'Icon booklet' are evidence of responding to identified needs and this trust in listening and actioning accordingly. The podcast and booklet are resources which can and are currently being distributed not only to the participants themselves and stakeholders but also to wider communities across the country including researchers, and many others who have an interest and are delivering online services to communities and individuals with limited digital skills.

We are pleased to have been able to share our research with Policy Connect[1] a think tank in the UK and who work closely across different all-party parliamentary groups (APPGs) such as Assistive Technology (Policy Connect). This in turn has led to the ATAT being included in the report 'Smarter Hones for Independent Living Putting People in Control of Their Lives' (Gilbert, 2022) as a case study to demonstrate the gold standard of participatory approaches while bridging various disciplines. This approach is imperative if positive changes and behaviours are to take place for societal benefits now and in the future.

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Note

1 Policy Connect https://www.policyconnect.org.uk/

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CO-PRODUCING KNOWLEDGE

Reflections from a community-based participatory research project on caring communities to strengthen ageing in place

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Introduction

In the bulk of ageing research, roles between research subjects and researchers are incisive and coined by distinctive power imbalances (Chen et al., 2020). Participatory research approaches strive to balance power asymmetries by valuing diverse sets of expertise and shared decision-making. To value diverse sets of expertise, older adults are involved as co-researchers, i.e. as active partners collaborating with academic researchers in generating and disseminating new knowledge. This shifts the operational modus from an "extractive and analytical approach to a more managing, collaborative and action-orientated approach" (Mey & van Hoven, 2019, p. 324). Furthermore, it gives way to what Gibbons et al. (1994) have named the mode 2 of knowledge production, i.e. a way of generating new insights that draws on and benefits from a multi-directional flow of information and inspiration between society and science.

Today, a variety of configurations is labelled as participatory research. Approaches range from involving people as research subjects to people-led research. Common to all participatory approaches that involve non-scientific persons as co-researchers is their focus on establishing equal research partnerships to co-create knowledge and action. The aspiration is to bring together diverse perspectives and sets of knowledge during the research process with the requirement that all groups affected by the research project come together on an equal footing and that all voices are acknowledged. Participatory research collaboration between academic and non-academic partners requires a high degree of reflection regarding possible knowledge and power asymmetries, interpretive authority, and ownership throughout the entire research process, from designing the study to dissemination and implementation of findings.

Fostering empowerment of the co-researchers through learning processes and competence building is another aspect common to the various participatory approaches (James & Buffel, 2022). A third element that characterizes many participatory approaches is the combination of gaining knowledge and developing local interventions to improve

living conditions within the communities of practice involved, as is particularly pursued in approaches to health-related community-based participatory research (von Unger, 2014; Wallerstein et al., 2018b).

With respect to knowledge generation, a dichotomous view of knowledge domains is prevalent. Academic researchers are usually seen as the embodiment of scientific methodological and theoretical knowledge whereas co-researchers are seen as the bearers of experiential knowledge. The common claim in participatory research is to integrate the two sets of knowledge (Behrisch & Wright, 2018). However, we know little about how this integration is (successfully) performed. Few studies provide accounts on how the co-construction of new knowledge unfolds in the respective research phases (James & Buffel, 2022; but see: Bratteteig & Wagner, 2012; Muhammad et al., 2015; Silberberg et al., 2021). This is particularly true for participatory data analysis (but see: Clarke et al., 2018; Flicker & Nixon, 2015; Frisby et al., 2005; Gillard et al., 2012; Pelz et al., 2004; Schaefer et al., 2019).

This paper contributes to closing this gap by providing reflections on the unfolding of co-constructing knowledge in a three-year-long community-building participatory research project to initiate and develop a caring community for the support of older people with care needs in a peri-urban commune in Switzerland. The local partners include representatives of the administration, employees of a non-profit professional home-care provider, and older residents of the village. Our findings provide a nuanced picture on how various sets of knowledges are distributed within the research team and the conditions facilitating the articulation and valuation of specific sets of knowledge.

In the next section, we position participatory research as the establishment of equal research partnerships for which the integration of various sets of knowledge is essential. We introduce the types of knowledge discussed in participatory research literature (Part 2 of this chapter), and set the scene by briefly introducing the project and community (Part 3), and provide an overview of how the collaboration evolved (Part 4). Part 5 elaborates on three exemplary moments of cooperation in the research process to explore how various sets of knowledge surfaced, lingered, clashed, and merged. In Part 6, we synthesize our findings by defining two forms of collaboration: division of tasks and mingling of different sets of knowledge. We conclude (Part 7) by suggesting three issues that merit further attention to advance the field of participatory ageing research: (a) further differentiate types of knowledge and the translation work performed to integrate them, (b) developing a more contingent and precise understanding of roles in research process, and (c) examining the complex positionalities of citizen researchers in more detail.

Partnerships in research

Participatory research is not a coherent body of research practice. It consists of diverse schools and traditions, even just within the field of ageing studies (James & Buffel, 2022) and health research (Andersson, 2018; von Peter et al., 2020). It is a somewhat unreserved umbrella term. One common ground unites participatory research from various backgrounds and fields: "research should be in respectful partnership *with* people; it is not *on*, *for*, or *about* people" (Andersson, 2018, p. 154; original emphasis).

Yet, there is no consensus (or control) about the kind and scope of involvement required to qualify as participatory. Wright et al. (2013) differentiate between participatory research as a *method* and as an *approach* or *style*.[1] Participation as a research method implies endowing study participants with a more active role in research, beyond the provision of

information (Wright et al., 2013). The overall aim of participation as a research *method* is to improve the quality of research. Control over who participates in which research phases or tasks usually remains with scholars or funders (Wright et al., 2013). Participation as a research approach, in contrast, applies participation as a critical principle in all stages of the research process (Bergold & Thomas, 2012; Hartung et al., 2020; Mey & van Hoven, 2019; Wright et al., 2013). Therefore, control over the process of participation is understood as a shared responsibility; it cannot be pre-defined or controlled by academic researchers, solely (Wright et al., 2013).

Research, hence, is the product of an equal partnership, i.e. between partners that are different, yet meet on equal footing. But how is such a partnership achieved and practiced? And what does it take to qualify it as equal? The distinction between collaboration and co-production as elaborated by Williams et al. (2020) is productive here:

> While collaborative (as opposed to co-produced) research may increase knowledge translation and uptake, it does not necessarily share the aim of making the conception of delivery of such research or services – or indeed the design process – more egalitarian, democratic or transparent.
>
> *(William et al., 2020, p. 3)*

In other words, co-production is a form of collaboration in which all involved partners have a say in defining premises, goals, conditions, and processes of the research.[2] Accordingly, key prerequisites to effectively co-produce knowledge are: valuing diverse knowledges, a readiness for mutual learning, sensitivity for shifting positionalities, and an aspiration to balance power asymmetries.

Integrating diverse sets of knowledge

One prominent tactic – or rather requirement – to work towards equal partnerships in participatory research is to see and treat co-researchers as *experts* contributing to the production of knowledge by bringing in sets of knowledge academics might lack. This requires to recognize and work with "multiple ways of knowing" and with "multiple expressions of knowing" (Wallerstein & Duran, 2018, p. 22).

There are various typologies of knowledge. Behrisch and Wright (2018) differentiate between scientific, professional[3], and everyday life knowledge. Others distinguish experiential knowledge (Chen et al., 2020; Gillard et al., 2021; Silberberg et al., 2021) and contextual or local knowledge (Cornwall & Jewkes, 1995). Experiential knowledge can be situated in the field of everyday life or professional practice. Contextual knowledge might include geographical and historical knowledge about places and communities, their evolution, and spatial, social, and political organization. Another set of knowledge referring to the social organization of a place or community is identified as relational knowledge. Figure 30.1 provides an overview of these various sets of knowledge and how they relate to each other.

Differences between sets of knowledge are gradual, rather than categorical; Behrisch and Wright (2018) suggest understanding various sets of knowledge as facets of a continuum (grey area in Figure 30.1). Knowledge that is general and abstract is located at one end of a continuum. It consists of ideas, principles, and concepts and is generated through rational reasoning, conceptual thinking, and in distance to action. Knowledge that is contextual and situational, rich in detail, and concrete is located at the other end of the continuum.
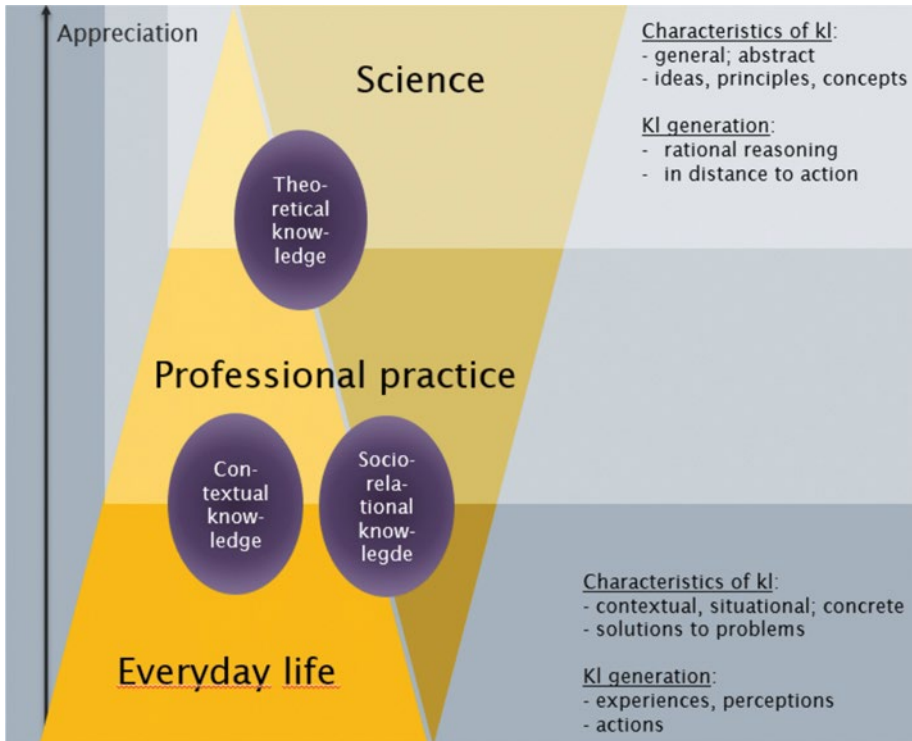
Figure 30.1   Order of sets of knowledge. Illustration based on Behrisch and Wright (2018)

It is "generated in the immediate pressure to act and make decisions" (Behrisch & Wright, 2018, p. 310; translation: hk), i.e. it is produced through (inter-)actions and making and processing experiences.

Participatory research as an approach aspires to integrate knowledge from everyday life, professional practice, and science. Integrating implies bringing the various sets of knowledge into fruitful discussion with each other to co-create novel insights, rather than simply adding and stacking packages of information (Behrisch & Wright, 2018). Yet, connecting various sets of knowledge is challenging.

Challenges to integration: comprehension and hierarchies

Communication is a hurdle. Different sets of knowledge follow different rationales, priorities, and structures. Many voices communicate in different "languages". How can they comprehend each other? – By identifying a common project, defining a common purpose worth investing the effort to learn from the other and co-create a shared "language". Such a project or purpose needs to be situated at the intersection of respective fields, i.e. it must be relevant in everyday life, professional practice, and science to gain the attention and support from representatives of all fields. Star and Griesemer (Star & Griesemer, 1989) work with the notion of "boundary objects" for things or ideas that bear the potential of connecting unconnected fields. Research can work as such a boundary object (Wöhrer & Höcher, 2012; cit. in: Behrisch & Wright 2018, p. 313).

Hierarchy is another hurdle. When researchers make the claim to equally value all sets of knowledge, they work against a common logic. Since the dawn of the modern age, more abstract and general sets of knowledge are ranked top, while other-than-scientific knowledge is devalued; experiential knowledge is viewed as an area to apply scientific knowledge, rather than a (decent) source of knowledge production (Behrisch & Wright, 2018). This modern age – or mode 1 (Gibbons et al., 1994) – production of knowledge is characterized by the clear separation of the spheres of science and society, with knowledge flowing top-down, from science to society, but not the other way. Hierarchy and separation are hurdles because non-academics have been alienated from research. The task of participatory research is to bring people, and professional and everyday life experiences, back in.

Project context: developing caring communities to improve ageing in place

The project Caring Community Living Labs (CareComLabs) is part of the Swiss National Research Programme (NRP) 74 "Smarter Health Care" funded by the Swiss National Science Foundation (SNSF).[4] The project combines the concept of caring communities (Wegleitner & Schuchter, 2018) with the community-based participatory research approach to foster ageing in place. Two Swiss research organizations and a German university partner with four municipalities in German-speaking Switzerland to initialize and develop interventions. The overall research plan consists of the following three phases: (a) exploring and documenting (unmet) care needs, (b) developing and implementing interventions and (c) evaluating and improving interventions.

Community-based participatory research (CBPR) to initiate caring communities: community-building participatory research

The objective of CBPR is to work with communities to explore health-related problems relevant to the community and develop actions to respond to these problems (von Unger, 2014, p. 30). Like other participatory approaches, CBPR is an *orientation* towards research, rather than a research method (Wallerstein et al., 2018a). CBPR is

> A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. It begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.
>
> *(W.K. Kellogg Foundation Community Health Scholars Program, 2001;*
> *cit. in: Wallerstein et al., 2018a, p. 3)*

In each commune, the community we are working with comprises different members, usually including volunteers and local representatives of non-profit organizations and political authorities. Each of these communities has been developing a different approach to (a) explore the status quo, (b) identify a call for action and (c) evaluate and improve their initiatives. As we were initiating the communities to work with, rather than approaching existing communities as common in CBPR, we suggest calling our approach community-*building* participatory research.

Case study: Bachdorf caring community

In this chapter, we focus on Bachdorf.[5] Out of all participating communes, Bachdorf Caring Community puts the most emphasis on the production of knowledge. Bachdorf is a typical Swiss peri-urban commune. With close to 6,000 inhabitants, it is situated close[6] to the city in an agriculturally dominated landscape. There are two restaurants and more than 25 associations. An Age Commission is part of the political structure. It consists of representatives of non-profit organizations (social, health, and spiritual care) and volunteers.

In Bachdorf, a joint research and implementation project has been evolving over three years at the time of writing. In this chapter, we consider the first two years of the collaboration. We retrospectively reflect on the events, processes, activities, and developments of the project, drawing on proceedings and field journals (47 protocols). Over a period of three years, more than 55 exchanges[7] took place in which academic and citizen researchers participated. In the analysis, we explore which different sets of knowledge emerge in moments of cooperation and how they interact.

In the next part, we describe how the partnership between people in Bachdorf and academic researchers has been evolving and then analyze how various kinds of knowledge have been cooperating in the joint effort to develop a caring community. In the subsequent part, we elaborate on exemplary moments of cooperation discussing the interactions between contextual, experiential, and scientific knowledge.

Evolving partnerships with Bachdorf caring community

How did the research partnership in Bachdorf evolve? It is a story of a research project moving step-by-step towards involving the public, from representational to partial public participation. These are the major stations on the journey.

Academy-led development of a joint project proposal with communes

Academic researchers developed the overall research idea and an action research plan to initiate, develop and evaluate caring communities in selected pilot communes deploying a CBPR design. They invited professional non-profit home-care providers in three regions as partners. In the case of Bachdorf, a borough health councillor joined as partner, too. The research proposal was submitted to SNSF and approved.

First steps of assembling local allies: the kick-off meeting

With the councillor in the lead to invite people, academic researchers, and local partners organized a first meeting in the mayor's office. The councillor invited people she had been knowing for their engagement in the village, among others in the Age Commission. It resulted in the formation of a project team comprising of the academic researchers, the counsillor, and local volunteer residents. Those were three female representatives of the Age Commission, all retired, and living in Bachdorf since many decades. In addition, a male retired IT manager, strongly interested in research activities, joined the group. All volunteered in other organizations, too. With the academics preparing a presentation on the project ideas and the suggested methodological approach in CBPR, the counsillor connected to the suggested research ideas through her professional interest. She mobilized the group of residents based on her practical access to those persons. Most importantly, she provided a

leap of trust to the local participants by demonstrating that the project enjoys the government's full support.

The initial projection of the research idea of building caring communities stimulated intensive discussions to which the local participants contributed by reflecting their experiences as older adults living in the commune as well as their experiences of volunteering for the commune. Scientific concepts were well received by the group and successively connected to personal experiences and the local context.

Creating larger awareness of the project and gaining more allies

In the kick-off meeting, the group decided to present the project idea to the public to create larger awareness and to find more participants. To organize this public event, the group developed a workflow in two further meetings. At this point, the lead for deploying the sub-tasks of the workflow (organization and content) lay mainly with the counsillor and the academic researchers, while citizens provided feedback and support. Academics contributed with ideas for the organization of the event, such as the event format, and took the lead in collaborative developing material for publicity work. First suggestions for a newspaper text and a logo were presented and successively refined in joint discussions with the group.

The event programme included two parts: an information part with project presentation by the counsillor and the academic researchers and an interactive part with three thematic workshops, each led by teams with one academic researcher and one local group member. The roles in those partnerships were specifically distributed: the researchers took the main responsibility of the organization and deployment of the workshops, with their knowledge of methods of how to stimulate interactivity and discussion. The local partners' role at that point focused on trust building as a local representative who had approved the project ideas. In fact, they acted as boundary-spanners to the wider local public. With more than 80 visitors, the event was perceived as a great success by all team members.

Preparing and conducting a qualitative interview study with local citizen researchers

Seven people had finally formed a research group with two academic researchers. This included the four local people from the initial meeting as well as three new members: two women in their 50ies, one working in an IT company, the other a mental health professional in a double role, both as interested citizen as well as a representative of the home-care provider. In addition, a male retired teacher and consultant joined the group. Another couple was present at the training sessions but could not participate in the interview series due to family commitments. The counsillor had temporarily pulled out due to her workload and wanted to rejoin the analysis sessions later (but did not because she had accepted another demanding job in the meantime).

The seven local citizen researchers were all very keen to participate intensively in the interview study and to carry out all the steps from interview planning, preparing, and conducting to data analysis. They agreed to meet on-site every two weeks. The organization of the meeting room and amenities was soon handed over from the commune to a member of the group who participates in other organizations and is adept with the local facilities and organizational requirements.

The academics were faced with the challenging task of breaking down complex knowledge about qualitative research to the needs of the group, to dock on to their knowledge and experience and at the same time not to lose sight of quality assurance. The engagement with the methodology also had to be appealing and meaningful for the participants. A training programme was developed that closely connected to the development of the study design and procedure. Topics included an introduction to scientific, particularly qualitative, research and interactive sessions on co-developing the research question; the interview guide; informed consent form; (convenience) sampling; pre- and post-interview checklists; technical details, such as operating the recording equipment. Altogether, 21 interviews were conducted and transcribed by citizen scientists. The analysis workshops took part on-site as well as via Zoom due to the following COVID-19 lockdowns.

On including contextual, experiential, and scientific knowledge: cooperation and tension

How did various types of knowledge cooperate during the project? In this part of the chapter, we shed light on exemplary moments of cooperation along the joint research. We learned from this process that identifying different types of knowledge is not as straightforward as imagined; many things overlap and concur.

Adapting the research question based on contextual knowledge

In the workshop on developing the research question, a discussion arose about the right focus. While discussing the concept of caring communities, citizen researchers' personal experiences yielded aspects that academic researchers had not included in their initial portray of the concept. Citizen researchers expanded the project's initial foci on older people and on comprehensive care needs. Regarding the target group of older people, citizen researchers highlighted that younger generations, too, need support such as with childcare, housekeeping, and gardening. They emphasized the relevance of the latter for Bachdorf, a commune consisting of high portion of houses with gardens. Regarding care needs, citizen researchers highlighted that this is a sensitive issue that older adults in Bachdorf might not feel comfortable to talk about:

> You focus on the older adults and the need for care. But we know that people find it difficult to talk about their problems and it could be unpleasant for us to point them out so directly. Besides, we also want to research more cultural and social needs, shouldn't we put the need for care on the back burner?
>
> *(Anna, 14.11.2019)*

This quote expresses a citizen researcher's worry: A study with a focus on older adults' care needs in Bachdorf might not be feasible. If people are not willing to talk about a key topic, no insights can be gained. Additionally, citizen researchers voiced their own unease in addressing sensitive issues as interviewers.

As a result of this discussion, the research question was jointly defined as follows: What is the living situation of people with presumed need for help? The group deemed this rather broad research question as productive for two reasons: (1) Chances to facilitate interviews

in the first place are intact, while including the opportunity to advance to more sensitive issues during the interview. (2) The question includes adults of all ages and various fields of support. The defined research question hence is adapted to the local context and responds to co-researchers' interests and competences. Citizen researchers expressed that with this question, they felt confident to succeed in conducting a study in Bachdorf.

Academic researchers deemed the broadening of the scope necessary to advance the project in Bachdorf. While adaptions of research foci were generally in line with the participatory research design, there clearly were limits on how far we could divert; (responses to) care needs could not be abandoned as a focus. The defined research question clearly includes this focus. However, it also allows addressing it marginally, only. Therefore, for academic researchers the defined research question entailed the risk of not yielding the quality of data they considered necessary.

Two things helped us tackling this risk. First, systematic sampling: At the beginning, citizen researchers recruited people they knew as study participants (convenience sampling). The initial analysis of first interviews showed that informants were healthy and fit and had little support needs leading to the preliminary conclusion that people in Bachdorf basically are fine. Interviews indicated that informants' health status was related to their financial stability and good housing conditions. It was clear to everyone in the group that not all residents in Bachdorf are wealthy, have a garden and their own house, and that there indeed are people receiving care and that we hence needed to systematically diversify the sampling to achieve the full picture. The sample was complemented with people who depend on caregivers or do not speak the local language.

The second thing that effectively helped us tackle the risk of compromised data quality was citizen researchers' competences. Some citizen researchers were experienced in addressing sensitive issues with strangers or loosely acquainted people based on their professional or volunteering work and successfully did so during the interviews. We assume that these citizen researchers did not share the concern of addressing sensitive issues with study participants expressed when defining the research focus and question. But the disagreement did not surface in the discussion. As a result, academic researchers learned about these competences later, only (see Part 5.2).

"People don't talk about money" – handling sensitive questions in interviews

Citizen researchers consider the need for care, personal hygiene, and financial issues as sensitive issues they find difficult to address in interviews. This became obvious while developing the interview guide. *"You don't talk about money, especially not in Switzerland"*, was a clear opinion of some citizen researchers. A similar reluctance appeared regarding personal body-related topics. However, this time, disagreement surfaced from citizen researchers who are experienced in addressing sensitive issues. *"I manage asking: 'How do you keep up with personal hygiene? Can you still do everything by yourself?'"* (Silke, 14.01.2020).

As the discussion proceeded, strategies became apparent from the more hesitant individuals: on the one hand, Eduard reported from his first interview during the evaluation session with an older couple that he was surprised: *"I was highly uncomfortable with the financial question, so I first asked if I could ask this question at all. But the gentleman answered quite openly and made it easy for me with his announcement: 'Just ask me!'"*.

Eduard assumed a connection between the interviewee's openness and the successfully established rapport in the preparation for the interview. *"In the preliminary telephone conversation, we had already found the first common ground. My interview partner, just like me, for many years during his professional life just slept in Bachdorf, and paid taxes"*. (Eduard, 16.07.2020).

Walter tackled his unease with addressing sensitive issue by handing over control over the issues addressed to the interviewee. Following an ad-hoc idea, he created a card deck with the interview questions. In the interview, he spread it out on the table and the interviewee could see all questions and pick the questions she/he wanted to discuss. This tactic helped Walter to not feel intrusive, while not presuming a taboo where there might be none. In so doing, he maximized the scope of topics for him.

These discussions about appropriate questions suggest that relational and contextual knowledge work both as an advantage and as a disadvantage: It is an advantage that the citizen researchers' contextual knowledge informs the direction of the study; it ensures that the focus of the study is relevant for this community and sensitive to local culture (i.e. do's and don'ts). And citizen researchers' relational knowledge clearly was supportive in recruiting study participants and establishing rapport.

Contextual knowledge, however, simultaneously complicated citizen researchers' role and capacity to obtain information. An interviewer needs to elicit information, in our case, including on sensitive issues. This is a challenging task, even for experienced academic researchers. Discomfort with sensitive questions might be addressed with adequate training. This is the common solution suggested in literature. But unease might last, despite education and training. To date, there is little in literature that would help us here.

As a retrospective reflection, we conclude that this situation would have merited more attention from academic researchers' side. Even though there is little guidance from literature, we could have worked on options. We could have offered more or different training, and/or we could have worked on strategies together. We could have opened more space for mutual inspiration and discussed the pros and cons of tactics. But foremost, we could have looked more closely into the discomfort. Why have we not done so? First, there was time pressure. We were behind schedule, and we felt that we needed to move on. Second, we wanted to take citizen researchers' inputs and concerns seriously. We viewed this as an essential part of sticking to participatory principles. Accepting these concerns appeared as the only option, then. Many months later, we think that we should have worked with the various concerns: of asking sensitive questions, and of not asking them. And we might have worked out better solutions without compromising participatory principles. And we certainly take this with us as a lesson learnt to the next study. Taking time for reflection, even when there seems to be no time, will be productive.

Relational knowledge added further complications. In our case, citizen researchers live in the community they research. This proximity implies that, contrary to academic researchers, citizen researchers are in the field before and remain there after fieldwork; relationships precede and proceed, they have a history and a future. This both supports data collection (and analysis) and limits it. While providing further information beyond the interview, it might also narrow the field of questions deemed appropriate. Furthermore, information citizen researchers obtain might complicate future interactions. In everyday life, citizen researchers might feel not entitled to the information they have received as researchers and find it difficult to handle the information entrusted with them.

"Is this still scientific now?"

"You are the professionals, and we have to learn from you first"

(Eduard, 14.11.2019)

The citizen researchers expressed a pronounced interest in obtaining scientific, especially methodological "correct" knowledge for the study to be conducted. Since most of them were familiar with quantitative studies in different ways due to their (previous) professional activity, they were eager to learn about qualitative research. Academic researchers handed out training materials at the beginning. These were duly read and brought to all workshops. Citizen researchers understood producing relevant and reliable results as a top priority.

Accordingly, the reliability of data was vividly debated. A particularly significant situation arose in one of the first analysis workshops. A theme in an interview text sparked intensive discussions in the group during a data interpretation workshop. Some citizen researchers shared their own experiences. At some point, Anna intervened: *"We want to work scientifically and analyze the interview texts. Don't talk so much about yourselves all the time!"*(Anna, 16.07.2020).

For Anna, the intensive discussion of the text passages and their enrichment with own experiences of group members did not seem appropriate. She blocked it and disqualified it as knowledge irrelevant for analysis. The academic researchers, in contrast, found the discussion rich and constructive, generating further data. This created a tension that had to be negotiated.

The situation presented above revealed a phenomenon of co-production that probably occurs frequently in participatory research but has barely been described. Bergold and Thomas (2012) identify two typical modes of co-production of knowledge: on the one hand, when academic researchers work together with professional practitioners and, on the other hand, in the work of academics with groups directly affected by the research. In our project, experiential knowledge placed citizen researchers in between: Some of them represent knowledge areas of the target group, as they themselves are older residents of the community, or as some of them have professional knowledge, which they have acquired either in professional or voluntary work. Here, the frequently mentioned duality in participatory research is broken down and produces a special configuration of knowledge for which further examination of good strategies for raising this special format of knowledge in participatory analysis settings is needed.

Academic researchers responded with methodological reflections to convince sceptics of the validity of the procedure. Simultaneously, they also looked for a practical solution to address the concerns. The following solution was jointly developed: to mark the group's own experiences, to separate them from the text interpretations, and to include them later in the process.

A similar example: Eduard mentioned that he had forgotten to ask some questions during the interview. As some other citizen researchers also knew his interview partner, they contributed additional information. This was, however, vehemently rejected by Walter saying: *"That's village gossip, but we'd better refrain from that here in the group"*(Walter, 16.07.2020). Again, relational knowledge is introduced and then disqualified. This leads to the more general question of which knowledge is deemed reliable. Two decisive factors come here into play. First, the context of expression. An interview is a confidential situation created especially for this purpose. A street in contrast is a public sphere. Information

provided in public is expected to travel and for this very reason of doubtable validity. Second, the question of representation. Is somebody providing information on her-/himself or on someone else? Walter denies the latter the authority to speak the truth while deeming interviewees' responses as true. This might mirror common sense. However, scholars have highlighted the intricate nature of truth, particularly in interview situations.[8]

Precis: two forms of cooperation

We identify two forms of collaboration between different sets of knowledge in our research partnership: (a) working in parallel on well-defined and clearly assigned tasks and (b) getting into each other to create novel solutions. Both occur as a tactic to achieve a joint goal.

Sets of knowledge working in parallel to achieve a common goal

In some moments of collaboration, tasks were identified and divided among the group members according to their expertise and capacity. Here, different sets of knowledge operated alongside each other. There was no need for translation between the various sets of knowledge because they worked independently, and because there was a shared understanding within the group regarding who would be best equipped with knowledge and resources to complete the task.

Mobilizing allies is an example of various sets of knowledge working in parallel. One citizen researcher organizes the event venue using her contextual knowledge on local facilities and how to access them, another personally invites people using relational knowledge and her position as a political leader, and academic researchers prepare the project introduction using their conceptual and factual knowledge on the topic. It is noteworthy that both academic and citizen researchers benefit from each other to win the interest and trust of the public. Academics profit because practically, it would be laborious to find convenient venues without local support. Academics profit ideologically, too. Citizen researchers work as a warrant and provide credibility. Their presence signals: "This is a local initiative, it concerns us". Similarly, the presence of academics, helps citizen researchers to raise interest and again provide credibility: "This is a serious and professional initiative". Hence, while not touching and altering each other, different sets of knowledge mutually support each other; they join forces to achieve a common goal.

Melding of different sets of knowledge to achieve a common goal

In other – indeed, most – moments of collaboration, various sets of knowledge melded in working towards a joint goal. The melding often was prompted by a request for clarification, or completion, a manifested irritation, an articulated doubt, or discomfort, in other words by an expression of some sort of disagreement with what had been said before. The expressed unease with asking intimate questions when developing the interview guide and the questioning of the value of personal experiences while analyzing data are two examples. These moments required translation and negotiation because not everyone in the room shared the same understanding of the process in question. Here, sets of knowledge touch each other. As a result, individual knowledge is being transformed.

It is important to note that the articulation of some sort of disagreement sparked, indeed facilitated that different sets of knowledge emerged and engaged with each other. In fact,

if there are no tensions, there is no variety of perspectives in the room, or no opportunity where differing views could emerge, such as when people do not feel safe to suggest other views. Therefore, in participatory research, irritation is productive; it is a welcome trouble-maker. The trouble irritation causes elicits knowledge that otherwise would remain tacit.

Hence, we suggest being passionate and considerate about irritations. How can we cultivate divergence, prompt manifestations of disagreement? But of course, we need to be ready to do the translation work. This requires explaining ourselves. It requires listening to others and *working* towards comprehension. In the presented cases, the engagement resulted in solutions that integrate knowledge from various sources. The interview questions card deck is such an invention; it combines the scientific requirement to ask sensitive questions with the reservation based on relational proximity. The questioning of the value of experiential knowledge for data analysis is another example. It is in such moments of cooperation that academic researchers learned most.[9]

Coda

In this study, people were involved as citizen researchers along the entire research process. Most citizen researchers were older adults, though not all. Within the group of older adults, we have included rather privileged individuals. They all are able-bodied and -minded, well-educated, middle-class, and most are well-networked in the commune. Therefore, Mey and van Hoven's (2019) cautionary remark that involved citizen researchers might represent a rather privileged group, applies to this study. Accordingly, the variety of perspectives integrated is not as diverse as we aspired it to be. Diversity regarding the *types* of knowledge is represented: Experiential, contextual, relational, methodological, factual, and conceptual knowledge cooperated in this project to achieve joint goals. But the sources of knowledge represent relatively privileged positions in society. Therefore, regarding the *content* of knowledge, diversity is limited.

Based on the reflections on our own research partnership as well as existing literature, we suggest three observations as issues that merit further exploration. First, further differentiating types of knowledge to provide a more nuanced analytical lens. Literature generally differentiates between experiential and/or contextual knowledge and scientific knowledge. Our analysis would have benefitted from a more nuanced understanding of different kinds of knowledge as a lens to look at our data. Nevertheless, our findings indicate that valuing various sets of knowledge in research partnership implies translation work from all involved parties. We suggest that creating or looking out for boundary objects and cooperative moments during the research project and together with citizen researchers as promising tactics.

Second, developing a more variegated, contingent, and precise understanding of roles in research process. Although there is a continuum rather than a crisp distinction between various sets of knowledge, different sets of knowledge commonly are clearly assigned to people: abstract knowledge to academics, contextual factual and procedural knowledge to professionals and everyday knowledge based on personal experience to citizens. Representatives of these groups are positioned within respective fields: academia, profession, and everyday life. But people hold myriad sets of knowledge, and some transect fields. The clear assignment impedes the emergence of some sets of knowledge. In our case: Academic

researchers were reluctant to share their experience-based knowledge, leaving that field to citizen researchers. Vice versa, citizen researchers might hold conceptual knowledge back to not interfere with academics' expertise.

Third, examining the complex positionalities of citizen researchers. It is commonly distinguished between academic and citizen researchers and their relationship is discussed (e.g. Silberberg et al., 2021). The relationship of citizen researchers with other citizens usually is portrayed as an asset and source of knowledge from which the project benefits. This chapter indicates that the story is more complicated. Citizen researchers' entanglement with the local community might also complicate research. Proximity can be prohibitive for sensitive questions. Furthermore, citizen researchers must handle the information gained in confidential interviews in everyday situations. The acquired information travels with them into situations where it is deemed to not belong.

The chapter indicates that research is not just about thinking, reflecting, pondering, conceptualizing, and developing theories and graphs. Research involves a lot of relational as well as organizational, practical, and hands-on work that shapes the research team and its activities. Scholars agree that in research and even more in participatory research, how things are arranged, organized, articulated, conducted has a great influence on who is how when in what roles included. In Tickett's words: "the specific meaning of community involvement depends on the details on how it is enacted" (Trickett, 2011, p. 1353). Yet, few accounts documenting and reflecting on the practicalities of participatory research exist. Participatory research is well positioned to create momentum for a move from mode 1 to mode 2 production of knowledge, i.e. for a production of new knowledge in which inspiration and information circulate between science and society, rather than flowing unidirectionally, only. But to tap this potential we need to unpack the complex *doing* of co-producing knowledge. On the level of the everyday conceptual, practical, relational work of participatory research, literature provides little guidance on how to effectively integrate various sets of knowledge to the benefit of all involved parties and the project objective, or on how to negotiate positionalities in a way that empowers individuals and the community, or on how to work through situations in which participatory principles appear to contradict scientific quality criteria. The currently re-arising interest in participatory approaches shall be used to spark mutual learning by providing rich reflections on *doing* participatory research.

Acknowledgements

Notes

1 In a similar vein, Trickett (Trickett, 2011) differentiates between community-based participatory research as a *worldview* or as an *instrumental strategy*.
2 However, as Williams et al., point out, notions are often confounded as a result of the increasing "appetite for participatory research practice" (Williams et al., 2020, p. 1).
3 The literal terms in Behrisch and Wright (2018) are «wissenschaftliches Wissen», «Praxiswissen» and «Alltagswissen». The notions «scientific knowledge" and "everyday life knowledge" are verbatim translations. The verbatim translation of "Praxiswissen" is "practice knowledge". We took the liberty to adapt it to "professional knowledge" to avoid confusion. From a praxeological perspective, practice implies action and doing in a more general sense, i.e. in everyday life as well as in science and other professions. We think that this is in line with the authors' intention.
4 The sub-project "Media of Cooperation in Caring Communities" funded by the German Research Foundation (DFG) (SFB 1187 "Media of Cooperation") cooperates with and builds on the CareComLabs research work.
5 All names of places and persons are pseudonyms to protect people's identities.
6 It takes a 45-minutes bus- and train-ride to reach the next city.
7 Exchanges consisted of physical, online and hybrid meetings, and some events with the Bachdorf population and other local organizations such as hosting a booth at the Christmas bazaar.
8 See e.g. the discussion on social desirability (Krumpal, 2013).
9 This might apply for citizen researchers, too, but we lack a solid basis to claim it.

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31

EPISTEMOLOGY AND METHODOLOGY OF PARTICIPATORY RESEARCH WITH OLDER ADULTS

A comparison of four age-friendly city national experiences

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Introduction

The ageing of population has been a major socio-political concern in many countries for almost 30 years. The speed at which societies are ageing is a central issue for the sustainability of public policies. At the dawn of the 21st century, public policies advocate greater inclusion of older adults in social and political life. This is evidenced by an increasing call for older adults' participation in the development of policies and projects where they can feel engaged and recognized by society as a whole. The best example of this is undoubtedly the Age-friendly Cities and Communities (AFCC) projects promoted by the World Health Organization (WHO). Concerned by the rapid growth of the global ageing population, WHO developed in 2005 the concept of age friendly cities age-friendly cities. This initiative essentially aimed to mobilize different stakeholders related to local government's policies on the important trend of their ageing demographics. Cities, with overgrowing urbanization, are the core for bringing local solutions. Therefore, the WHO launched a guide in 2007, which was based on research work carried out in 33 cities around the world. Sherbrooke (Canada) and Geneva (Switzerland) were the only two French-speaking cities of that group. Since then, AFCC projects have multiplied in the French-speaking countries.

The aim of this chapter is to present a comparative approach on participatory methods within four AFCC case studies from different French-speaking contexts.[1] First, the Université de Sherbrooke in Quebec (Canada) is interested in observing older adults' participation

within the management of cities and the older adults' organizations involved in AFCC. Second, the Université catholique de Lille (France) leads a research that consists in supporting older adults of a rural territory to analyze by themselves the different dimensions of their own participatory practices, in order to reinforce collective reflexivity and inclusive process. Third, at the Université de Moncton, in New Brunswick (Canada), participatory research seeks to help a French minority community implement an AFCC's action on community housing for older adults and, in doing so, highlights the challenges of rallying social actors and older adults in a knowledge mobilization process. Fourth, the Université catholique de Louvain in Belgium, through the Age-friendly Wallonia project, challenges the development of a collective conscience and the potential for social change through the empowerment of older adults. Then, a researcher from the Université Grenoble Alpes (France) examines the relationships between these AFCC experiences to highlight common challenges and opportunities through such a rare international comparison.

The comparison of these four case studies presents an opportunity to highlight the challenges, effects, strengths, and limits of participatory methods for older adults. The following issues will be addressed. How do AFCC's methods contribute to older adults' citizenship? How does the programme promote participatory democracy at local and regional levels? Are they paths of social innovation?

AFCC background

What is commonly referred to as "Age-friendly Cities and Communities" (AFCC) is a common narrative from a myriad of projects that are federated by WHO. The WHO definition of AFCC is the most recognized in the literature:

> An age-friendly city encourages ageing by optimizing opportunities for health, participation and security in order to enhance quality of life as people age. In practical terms, an age-friendly city adapts its structures and services to be accessible to and inclusive of older people with varying needs and capacities.
>
> *(WHO, 2007a, p. 1)*

One fact about AFCC is its rapid development since the programme was launched by WHO in 2007. AFCC has come a long way in a short period: publication of the policy framework on active ageing at the Second World Assembly on Ageing in Madrid (WHO, 2002); first sketches of the AFCC programme in 2005 at the 18th World Congress of Gerontology and Geriatrics in Rio de Janeiro (Plouffe and Kalache, 2010); publication of the "Global Age-friendly Cities: a Guide" (WHO, 2007a); establishment of the WHO Global Network for Age-friendly Cities and Communities (AFCC) in 2010 (WHO, 2018); publication of a new "World report on ageing and health" (WHO, 2015) which peculiarity is to have replaced "active ageing" by "healthy ageing", an orientation supported by the UN "Decade of Healthy Ageing, 2020–2030" whose second objective is developing communities in ways that foster the abilities of older people.

From the beginning, WHO's goal was to identify characteristics of social and built environments that support older adults in their pursuit of active and healthy ageing. The first step was to put in place a team of experts from different fields in order to draft the methodological guidelines that would be included in the research protocol submitted to the first participating cities in the AFCC initiative. This protocol, finalized in Vancouver in March 2006, is better known as the "Vancouver Protocol" (WHO, 2007b). In doing so, WHO

ensured that the data collected from various sites around the world could be compared. Between March 2006 and October 2007, WHO coordinated a consultation with 33 cities in 22 countries covering most regions of the world. The results supported the publication of the "Global Age-friendly Cities: a Guide" (WHO, 2007a) and a "Checklist of Essential Features of Age-Friendly Cities" (WHO, 2007c) which defines the basic features of an age-friendly city or community in eight domains considered as social determinants of healthy ageing: housing, social participation, respect, and social inclusion, civic participation and employment, communication and information, community support and health services, outdoor spaces and buildings, and transportation.

With these publications, WHO sought to lay the groundwork for a programme to help cities and communities assess how open they are to older adults and how more inclusive they can be in terms of built and social environments (WHO, 2007a). However, the AFCC programme methodology was still in need of reflection and development, as the guide did not offer guidance on how to achieve an age-friendly city, nor offered sufficient awareness of public policies addressing ageing or even the eight suggested domains.

In 2010, in response to the growing popularity of AFCC, WHO established the Global Network for Age-friendly Cities and Communities (Beard and Montawi, 2015). It was through this network that the AFCC method took shape, including through the work of local and regional projects such as those in Quebec, Canada (Garon et al., 2021). Today, this network plays a coordinating role for AFCC projects by disseminating good practices and proposing guidelines for participating cities.

To this day (July, 2023), the WHO Global Network for AFCC includes 1,445 cities and communities, covering over 300 million people worldwide.[2] It appears, however, that few projects have completed all AFCC's steps. Indeed, the WHO estimated in 2018 that only 31% of projects had completed an action plan (WHO, 2018). These 1,333 cities and communities are located in 51 countries, but the distribution is very unequal geographically. There is a strong north-south cleavage in the number of AFCC projects: Global North countries are overrepresented, while African countries are completely absent from the WHO programme, as mentioned in the first international comparative work on AFCC (Moulaert and Garon, 2016, p. IX).

Four participatory experiences within AFCC

Age-friendly Quebec, Canada

Context

The age-friendly city movement has rapidly developed since the launch of the WHO guidelines in 2007, and this is particularly true for Quebec, a French-speaking province of Canada. There are many reasons for that. First, Quebec is one of the fastest-ageing societies in the world. Second, the same research team (Université de Sherbrooke/Research Center on Ageing) that had worked with the WHO in 2007 received the mandate from the government of Quebec to develop a programme, which started in 2008 with seven pilot projects and counts now more than one thousand cities in 2021. This programme is rooted in a community building approach that fosters a participative methodology. As a consequence, all the stakeholders have a role to play in the process and special attention is paid to the involvement of seniors' organizations. It goes by the motto: "With and by us". One of the

main reasons why the AFCC programme is so popular in Quebec is because of the strength and the large scoop of organizations working for the older adult's rights. There are 17 administrative areas in the province and for each of them, there's a round table of associations dealing with seniors' issues. Moreover, the second larger seniors' association in North America, after the AARP in the United States, is the FADOQ in Quebec with a membership of 5,00,000 people. These are the people who are involved in the AFCC process mainly as stakeholders in the different steps of the programme.

Quebec's AFCC model is recognized around the world, and by WHO, to be at the origin of the four methodological steps that ensure the participation of older adults during the entire process. These steps, with some variations, are also found in each of the cases studied in this chapter.

The participation of older people: steering committee

The steering committee is a central component of the age-friendly cities process because it is where collaborative governance has a chance to occur. The composition of a multi-sectoral steering committee in the municipalities enhances a concerted mobilization of the actors from different perspectives. The presence of individuals from older adults' organizations, the health and social services sector, the municipal administration, and an elected municipal official is heavily solicited by the Seniors' Secretariat. The role of this committee consists of following and facilitating each of the three steps of data collection, collaborating in the implementation of the actions, circulating information, as well as participating in mobilizing the actors and decision-makers of the community.

The planning of the age-friendly cities process: social diagnosis

A social diagnosis is essential to the success of all subsequent steps of the age-friendly cities process. This specific step facilitates the emergence of a vision shared by all actors regarding the living conditions of the older adults in their community. In the Quebec experience, three sources of data gathering ensure the rigour of this social diagnosis.

The socio-demographic portrait of the milieu. This data collection is based on population statistics, available to the public, among others with the help of specialized organizations, public and municipal services, or through the Internet. It includes the proportion of persons aged 65 or older, the evolution of ageing, the social, ethnic, and economic characteristics of different areas (boroughs) of the municipality. Its pertinence exceeds that of a simple technical operation as it may raise awareness among the members of the steering committee and the municipal administration as to the scale of the challenge they have before them.

The consultation on the needs of older adults. The goal of this process is to arrive at a good understanding of the perspectives which older adults have of their needs, and at the same time the solutions which they themselves propose so that they can better live and evolve in their community (be it urban or rural), according to the eight domains identified by the WHO (2007a). To do this, various means are available for municipalities, but the Seniors' Secretariat strongly encourages the use of discussion groups or of a community forum. The Vancouver Protocol is a very useful tool to start with.

The services grid. This information gathering is necessary to measure the services actually offered in a given milieu and their geographic accessibility. Combined with information collected from the discussion groups, the grid makes it possible to gauge the degree of

knowledge about the services offered to older adults. This perception of the availability of services is as important as the actual services offered, as many services are not well known by older adults.

Working together: action plan

After it has appropriated the portrait of its milieu and the needs expressed by the older adults of the community, the steering committee constructs its vision of the entire situation, elaborates ideas for intervention, and shares its preoccupations with the group. Starting with the evidence of the situation in their community as well as their knowledge of the local culture, the practices, and the conditions, they must set priorities among the projects destined to improve the living conditions for older adults. From this, they choose scenarios envisaged for the duration of the age-friendly cities project. This process is carried out within the group and allows its members to arrive at a common vision, even at times a strategic vision, which takes local exigencies into consideration.

Moreover, the process of elaborating the action plan serves to reinforce the capabilities of the group which profits from this exercise to share their values and to better recognize the complementary expertise of its members.

Implementation

The final step consists of planning and organizing the resources necessary to implement the actions and to carry out a follow-up. The implementation must produce the results anticipated by the action plan and contribute to reaching the objectives set by the steering committee. It is important to mention that the financing offered by the Quebec government to municipalities participating in the age-friendly cities programme contributes only to the elaboration of the action plan and not to the financing of projects. This fact explains why such important infrastructure regarding housing or transportation is not enough implemented to meet the needs expressed in the social diagnostic. It's an important limitation of the AFCC approach as it is executed in Quebec. If the programme brings awareness on the challenges of ageing in a community, its limitations also help to open the eyes of the different stakeholders of the restrained tools that local instances have in their hands.

Regarding the participation of older adults in this implementation, a survey of close to 900 municipalities in 2015–2016 showed that 49% of the actions presented in the action plan were going to be done by partners outside of the city's services. It must be emphasized that 78% of those 49% were actions that were going to be done by older adults' organizations. These organizations take very seriously their motto: "With and by us"!

Challenges

Finally, if the AFCC programme in Quebec can claim a real success for improving the awareness of the living conditions of the older adults in the community where the programme was implemented and has brought some solutions, there's still a lot to be done. Moreover, one of its most significant limitations is regarding the most vulnerable older adults. The ones who cannot participate in any of the previous steps mentioned because of their fragility. This group of older adults has no voice, no public recognition, and almost no rights. Among them were the ones who died by thousands in the first wave of Covid-19 in

the spring of 2020. They were living in long-term care facilities where municipalities have no jurisdiction because these facilities are under the provincial government's responsibility (Ministry of Health and Social Services).

Age-friendly Mormal Community, France

Context

In 2016, an AFCC project was initiated by Pays de Mormal across its territory. It is an original initiative since AFCCs generally develop over a municipal territory in France. Besides, Pays de Mormal is a "*communauté de communes*", i.e. a political and administrative institution built up by a set of local governments. The "*Pays de Mormal Communauté de Communes*" (CCPM) was created in 2014 and gathers 53 communes. It is located in the North of France, in a rural territory and near a strongly urbanized area including such cities as Valenciennes or Maubeuge. Around 48,850 inhabitants, 23% of whom are aged over 60, live in this 469 km² large area.

Between 2015 and 2017, various actors played a major part in the launching of this approach: the CCPM's Vice-President, pension funds' representatives, various local partners, and more. Among these actors, people defining themselves as "seniors" (n=5) had already been involved at the time of the development of the AFCC process and of the organization of focus groups whose task was to elaborate a participative territorial diagnosis. These focus groups gather other seniors of the territory (n=141), caregivers (n=7) as well as municipal councillors, private partners, and people concerned by ageing challenges.

On the basis of the initial diagnosis, the mobilization of the various partners into this approach, here called "*Communauté Amie des Aînés*" (CADA), or Age-friendly Community, was formalized in 2017 when a "commitment chart"[3] was signed, mainly by institutional partners; a year later, it was also signed by various associations, many of which include seniors. Therefore, the seniors involved in CADA did not sign it as individuals or as members of the Seniors Assembly. At the same time, the 2017–2019 action plan was organized around seven themes, close to those which were developed by WHO. A working group was set up for each theme. Besides, there were cross-disciplinary governance bodies for each working group.

Seniors' participation examples

In the beginning, the CCPM's Vice-president and the seniors endeavoured to give their AFCC's project a participative character, being thought of as developed not only "for" but also "with" the seniors. Indeed, since 2017, the seniors' participation has adopted various forms within this AFCC's project. First, three seniors who had been strongly involved since the beginning were seen as referring actors by local elected representatives, partners, and the other seniors. They are the seniors' representatives in the governance instances of the AFCC process, which also include CCPM's political and administrative representatives, major partners (mainly financial), and local elected representatives who are the thematic work groups' referring members. Other seniors also participate in these work groups, together with a referring local elected representative (often a mayor), partners, and thematic experts. Second, seniors hold assemblies, meeting two to three times a year. This "Seniors Assembly" includes about 150 members today and constitutes a place to give and share

information concerning the actions implemented by the AFCC's project. Third, in order to link the intercommunal and the communal fields together, the seniors have also organized themselves into a group of "relay-people" whose mission is both to diffuse information about the process on a local level with a top-down reasoning and to mobilize the territory's seniors on the challenges they are concerned with, with a bottom-up reasoning. Fourth, more directly targeted actions are regularly promoted thanks to a participative approach. Finally, the seniors contributed in several ways to the transitional time spent for the preparation of the second cycle of the CADA 2022–2025 process, by participating either in the preparation or the organization of survey approaches, or by playing a "respondent" role.

Intervention research on participation

Between 2019 and 2021, sociological intervention research was conducted, focused on the social and civic participation of seniors across the Pays de Mormal territory. The heart of this research process was the organization of group analysis days (Van Campenhoudt et al., 2005) with 15 seniors involved in the AFCC's process in various capacities and at various levels (Bertillot and Vanneste, 2022). These days offered a reflexive and collective scope of participation experiences. The aim was to study participation practices and to question their concerns, potentialities, and limits. These analyzes were cross-referenced with semi-directive individual interviews held with various seniors (n=15) that were little or not involved in the AFCC's process. The whole work performed was submitted to a discussion during two co-construction days gathering seniors, elected municipal representatives, administrative staff, and partners. In a more cross-disciplinary way, the three referring seniors were eventually associated with the definition of the research objectives, were members of the research steering committee, and were regularly consulted to embark upon the work consisting in disseminating the research conclusions among the seniors. This intervention research is participative in nature but is different from the contributions provided by research teams to the participative diagnosis or the co-research processes on detailed themes. Here, in a perspective that is close to Touraine's sociology (1981), this mainly consists in suggesting a support and a reflexive work on the participation itself, together with the people actually practicing and testing it, i.e. experiencing it. In this way, this approach also echoes Dewey's political philosophy (1927), which sees democracy as anchored in concrete experiences and in the mediation work performed between them.

Principal issues

Among the cross-disciplinary issues brought out by the intervention research, two of them concerning the seniors' place in the AFCC's process can be highlighted.

The first issue is how to deepen the territorial anchoring of the seniors' participation. If the AFCC's process stands out by the large diversity of participation formats which helps anchor it into a plurality of practices and open it to a diversity of profiles, one of the issues for its actors remains the reinforcement of its anchoring by developing a stronger connection with the territory's participative fabric. Indeed, the approach is still little-known to numbers of actors who contribute to various forms of participation: local councillors, care professionals, and dynamics initiated by the volunteer sector. AFCC is sometimes even seen as a competing approach or redundant with existing institutional or voluntary activities. Beyond the seniors participating strongly in one or several of these dynamics, AFCC's

actors, while more easily mobilized, also find it difficult to become acquainted with the seniors, who are the most distant from any social participation.

The second issue is how to connect representative legitimacy and participative legitimacy. Indeed, the AFCC's legitimacy relies on the strongly interdependent relation linking an intercommunal institution (that ensures the political, logistical, and communicational support) and a collective of seniors busy structuring itself (who participate in the setting up of diagnosis and the implementation of actions to adapt the territory to ageing conditions). This governance joins two democratic legitimacy domains which combine their strengths and weaknesses. On the one hand, the "*Communauté de Communes*", as an institution, is granted with a "legal" legitimacy, related to the elective processes of representative democracy. However, the territory's seniors do not all consider as obvious the importance of this intercommunal institution ruled by elected representatives whom they do not elect by direct universal suffrage, nor do they even see the relevance of such a large area across which it extends its action. On the other hand, the legitimacy of the seniors participating in AFCC is less formalized. It belongs more to the participation field and the voluntary charism resulting from the action, driven by the most strongly involved among them. In the absence of any elective or designation process, this "*de facto*" legitimacy brings out the still unsolved question of the way the territory's seniors consider the representativity of the collective.

One may consider that the more seniors participate in AFCC, the more this could lead to questioning or critical proposals regarding public policies currently in place. Isn't it the peculiarity of a process that promotes democratic experimentalism to provide itself with internal mechanisms enabling it to work on disagreements and clarify issues?

Age-friendly Cocagne, Canada

Context

This case study is situated in New Brunswick, a bilingual province located on the East Coast of Canada. In 2017, New Brunswick had a population of 747,101 people, of which two-thirds speak English and one-third speak French. The population is dispersed on a predominantly rural territory, with only nine cities of more than 15,000 residents representing 41.6% of the population living in urban areas. New Brunswick is the Canadian province with the highest proportion of older adults (19.9%). Also, in 2017, the ageing population in the province was more accentuated among French-speaking people (21.6%) than English-speaking people (18.3%). New Brunswick developed an AFCC programme for both official language communities. To this day, there are 33 AFCC projects in the province, of which more than half are in French-speaking communities.

One of them is AFCC Cocagne, a small rural locality of 2,649 inhabitants where 81.9% of the population speaks French and 24.7% are aged 65 and over. A steering committee composed of senior citizens and local representatives (including the mayor and the general manager) started an AFCC project in 2016 with broad consultation of its population. The consultation was a door-to-door survey of more than 700 people aged 55 and over. The results of this consultation offer rich data to develop the AFCC action plan. Among the AFCC domains, housing stood out, with four main findings: 708 respondents (87%) lived at home; almost half (46%) intended to move into rental accommodation if they had to leave their home; almost all respondents (96%) wished to age in Cocagne; and slightly less than half (43%) had an annual income under $25,000. With that in mind, the steering

committee developed a specific action on housing: "Ensure that rental accommodations are built and benefit older adults, for all types of income".

But even with their data from the consultation, with their consensus on the action plan, the steering committee members faced huge challenges during the implementation step. Indeed, the work of the AFCC in Quebec shows (Garon et al., 2021) that housing domain is difficult to develop and implement for local governments.

Participatory research on housing

In 2017, a participatory research project was developed in collaboration with the AFCC Cocagne project with two objectives: to further study the housing needs of older adults living in the community and to offer alternative ideas on housing models. The methodology not only aimed scientific purposes but also concrete data to support the steering committee members in achieving their AFCC action plan.

For the first objective, four focus groups were set up with 34 participants from four specific age groups: people aged 60 to 70; women aged 70 and over; men aged 70 and over; couples aged 60 and over. The data collection and analysis were carried out based on three main housing themes (built, social and organizational frameworks) taken from previous studies on community housing for older adults (CdRV and CAMF, 2016; Masson and Vanneste, 2015). In addition, a "world café" was organized to allow older citizens to take part in a public conversation, in order to establish a global vision on older adults housing in Cocagne. This forum assembled 48 participants for three hours around the three same themes used during the focus groups. All discussions among participants were animated by students in social work and took place around flip charts, illustrations, and coloured pencils to help imagine the "dream" housing project for older adults.

For the second objective, a review of innovative housing projects for seniors was carried out, based on the various findings of the focus groups and the "world café". Out of a total of 61 innovative housing projects identified, six were documented and described to steering committee members so that they have concrete examples to implement in their community. In addition, following the results of this participatory research and the state of knowledge on housing for older adults, a series of recommendations were formulated in a community report.

Moving beyond research

Participatory research has many names: action research, collaborative research, partnership research, and community-based participatory research (Israel, Schulz, and Parker, 2012). Through various epistemologies and methodologies, participatory research projects pursue some specific goals, such as the deconstruction of the traditional relationship between experts and laymen. Often, those projects aim towards a co-construction of knowledge with the social actors who are concerned with the balance of scientific power. It is easy to find participatory research in AFCC scientific literature. Buffel (2019), following a co-research approach embedded in Manchester's AFCC, has found a range of advantages associated with this approach in terms of recruitment of participants, quality of data, and personal benefits.

The experience with the AFCC Cocagne has brought an ethical issue regarding the commitment to the community. Indeed, should participatory research stop after the general cycle of research funding and, it must be said, academic recognition (e.g. published articles,

conferences, etc.)? The answer is rather negative. In order to implement housing for older adults, or, in other words, a social change, it was necessary to take ethical responsibility and change one's relationship with the community. On the one hand, a participatory research project should not be limited to a university timeframe but needs to encompass a community time span. In Cocagne, the researcher's commitment therefore did not stop with the publication of the last research report. The researcher decided to get involved in a non-profit housing organization and became a member of its board of directors in 2019. Today, the planning stage for developing housing for older adults continues and its construction is becoming more and more real for the community's social actors. On the other hand, such kind of commitment provides academic legitimacy to the community approach. But it leads to reflecting on the status of the researcher, who becomes increasingly "native" to the community.

It is often recognized in participatory research that the process is as important as the results. The length of this process might also be lived according to the point of view of social actors and not only from a research standpoint.

Age-friendly Wallonia, Belgium

Context

The Age-friendly Wallonia programme, i.e. *"Wallonie Amie des Aînés"* (WADA), was co-ordinated by the Université catholique de Louvain (Faculty of Architecture, Architectural Engineering, Urban Planning) and the AVIQ (Agency for Quality of Life), with the financial support of the Walloon regional government from 2016 to 2020. AVIQ is responsible for the implementation of major policies in the following three areas: welfare and health, disability, and family.

WADA was participatory action research conducted "by, for and with older adults", with the general aim of supporting healthy ageing. The practical objective was to produce a Walloon age-friendly guide (Leleu and Masson, to be published) in co-construction with older adults. Beyond this objective, this action research was a breeding ground for observations of ageing conditions at different levels: local policies, social and spatial environments, citizen participation, social inclusion, etc.

This research programme involved professional agents, elected officials, volunteers, and seniors from six pilot municipalities situated in Wallonia and chosen for their diversity. A group of ten municipalities attached to a Local Action Group in a rural area joined the project later, in 2018, which allowed for observations of the work and reactions of a community of municipalities and its older adults.

The participation of seniors formulating their aspirations for healthy ageing was observed over four years, thus nearing the five years of an age-friendly city process recommended by WHO (2007a). This process took place in six steps and was based on the eight WHO domains adjusted during the research process to the Walloon context (Masson, Leleu, and Grabczan, 2022). The older adults' aspirations were collected through qualitative interviews realized by older adults themselves with older adults, focus groups, and walking assessments; and all the results were analyzed by and with the older adults. A particular focus was made on the empowerment and self-determination which could result from this AFCC's action, allowing older adults to distance themselves from a disqualifying status generated by a society which tends to see older adults as frail beings rather than politically powerful ones.

Age-friendly Wallonia concerns today more than 60 municipalities, among the 262 municipalities of the Walloon Region.[4] There are important variations in the way the age-friendly process is implemented relative to the coordinators, the profiles of the people involved, the local contexts, etc.

If the perspective of an Age-friendly Wallonia has been opened up, there are still questions about the effectiveness of the participatory mechanisms, the collective awareness developed by seniors invited to participate in a programme which is dedicated to them which they didn't initiate, and the posture of the researcher confronted to the limits of a participatory approach with its uncertainties and the limits of a scientific treatment of data collected by older adults who declare themselves not being researchers.

Steering committees and referent tandems

The six pilot municipalities have set up a steering committee including a majority of senior citizens (ideally), social workers, healthcare workers, volunteers, representatives of associations, administrative agents, and local elected officials, i.e. 10 to 15 people by municipality. The participation evolved according to the tasks, the workload and time required for these tasks, the local support, and the frailty of the older adults who had to retire for health reasons, their own or that of a relative.

Each steering committee was supported by a local facilitator, usually a worker from social support services or from the municipality administration. The six pilot municipalities have also set up a referent tandem, composed of the local facilitator and an older adults' representative. The community of municipalities worked with a referent tandem for each of the ten municipalities and a supra-local steering committee led by a project manager supported by the Local Action Group.

It's important to emphasize the place given to the older adults through the referent tandem including necessarily one senior, as a condition for the implementation of the local WADA process. If a Communal Advisory Council of Seniors[5] exists at the local level, at least one older adult from this Council participates in the steering committee.

Actors' commitment to the WADA process

The local dynamic is based on the relationship between the individuals and the group. At the crossroads of the intensity of the commitment and the cohesion of the group, roles can be distinguished for the individuals. This dynamic is also undoubtedly marked by the role of the researcher.

The following typology reveals the attitudes of seniors, administrative agents or workers, and elected officials towards the participatory research and its objectives. It draws its inspiration from a previous work conducted by Moulaert and Houioux (2016) on the potential of age-friendly cities in Wallonia and source of inspiration for WADA.

- Senior:

  - Committed, creative: developing effective mobilization for social change;
  - Stakeholder, supporter: reinforcing ideas of a movement to which they subscribe;
  - Customer, passive: waiting for services as an institutionalized figure of beneficiary;

Table 31.1 Older adults' commitment levels related to steering committee degrees of cohesion

Cohesion steering committees	Strong	Weak
Commitment older adults		
Strong, regular	Builders	Activators
Moderate, episodic	Executors	Supporters
Low, distant	Customers	Attendees

- Administrative agent, worker:

  - Developer, active: implementing a project seen as a social innovation;
  - Executor, submitted: sustaining a project according to a mandate not chosen, depending on the will of the hierarchy;
  - Obstructer, passive: serving other interests, slowing down the project;

- Elected official, politician:
  - Initiator, supporter: seizing an opportunity to meet the challenge of ageing;
  - User, instrumentalizer: utilizing a project to serve political interests;
  - Distant, sceptical: being not concerned.

Some change their position along the way: from wait-and-see and sceptics or even obstructers, they become stakeholders or defenders of the project, or they give up. Here is supra a proposal for formalization of older adults' levels of commitment as related to the steering committees' degrees of cohesion, which reveals different profiles of actors (Table 31.1).

The Empowerment of People and Communities (Le Bossé, 2012) suggests a meeting between people being supported and people providing support, allowing for a shared expertise. WADA puts the researcher in a peculiar posture, being a "researcher-accompanier" (Bourassa et al., 2017). "Accompanying" is therefore fundamental as it is more about "guiding, walking with" than "directing or deciding for". Wouldn't this posture, which aims to accompany a process of change carried out by local actors, be specific to a participatory action research that recognizes the expertise of older adults?

Being at the same time a facilitator, a mediator, a coach, a guide, and a researcher reveals however a complex posture. These roles are shaped by the level of commitment of the researcher, walking with the steering committees, experiencing emotions, and subjectifying the research by his involvement while objectifying his subjectivity in a constant dialectic movement between commitment and distance, in a kind of "pragmatic epistemology" (Le Moigne and Morin, 2007).

Lessons on participatory approaches

Considering the scarcity of international comparisons on AFCC (Buffel, Handler, and Phillipson, 2018; Moulaert and Garon, 2015; Rémillard, Buffel, and Phillipson, 2017; Woolrych et al., 2021), this comparison of four French-speaking contexts offers an interesting insight on participatory approaches in the AFCC context. It is possible to identify three main lessons from these case studies.

Firstly, while WHO strongly considers AFCC projects as intersectional between elected politicians, administration staff, and older adults' representatives, such projects may not

properly function without a fourth partner, which is the researcher (Moulaert and Garon, 2015). However, the challenge for the researcher is inherent to the AFCC: what is the role of the researcher and how far should he go to support the AFCC process? These questions were raised in the Vancouver Protocol, where a clear answer was given: the research brings only methodological knowledge to consult older adults (construction of a sample of older adults, focus groups conduction, data analysis) and support "solutions" (see the above-mentioned "*Checklist of Essential Features of Age-Friendly Cities*"). Through the four exposed cases, it can be clearly seen that the researcher, whatever the process he takes part in (action research, collaborative research, partnership research, community-based participatory research, or intervention research), is more than a "technical" or "consultant" expert. All researchers raise broader considerations when embarking on such experimentation: about their role at the level of society and the positions of the frailer older adults let in the margins of the AFCC processes, as in the Quebec case; about the contradictory positions and the legitimacy of involved "experts" seniors and the less visible or less concerned ones, as in the Mormal case; about the boundaries of the research facing a concrete action emerging from experimentation, as in the Cocagne case; about the empowerment of older adults generated through such a research process, as in the Wallonia case. Furthermore, all researchers in this chapter face common challenges: When do they have to end their intervention? Should they stop when the funding of their participative research programme stops? How clear are they about the final outcomes with the participants of the project they follow or create? What's their position towards the data collected? How do such researchers deal with public policies on ageing?

Secondly, another challenge is the participative methodology in AFCC: it seems that it is not only limited to a research agenda. Indeed, it is also driven by a political agenda. Such an assertion is based on previous research on AFCC (Moulaert and Garon, 2015). Referring to Michael Burawoy's division of sociological work (professional, critical, policy, and public sociology), a "public sociology" position can be suggested for the AFCC's researchers, that is "a dialogic relation between a social researcher and the public in which the agenda of each is brought to the table, in which each adjusts to the other" (Burawoy, 2005, p. 9). The Mormal case probably illustrates a more balanced situation, with researchers evolving between "public" and "professional" sociologists. By mobilizing well-recognized sociological methodology, this case not only brings a broader view on participative methodologies by recalling some of their historical sources of inspiration, but it also considers that political sociology can learn something from studying the AFCC project. How can such a participative democratic example interact with and adapt to legislative democracy? One of the answers to such a question probably lies in the role played by some mayors or elected officials, often present in the different "local action groups" which exist in the Mormal case. Mayors or elected officials, when they are simultaneously older adults and municipal officials, can play the role of "intermediaries of active ageing", i.e. people or professionals who cross boundaries (of services, communities, levels of public actions, etc.) to link new visions of ageing such as "active or healthy ageing" and "experiences of ageing". All four cases of AFCC experimentations are, in themselves, such laboratories of such mediations. By so doing, these intermediaries question the development of older adults' citizenship, as announced in the initial research questions of this chapter.

Thirdly, the concept of participation is ambiguous and hides the diversity of participatory experiences in different contexts for older adults. AFCC largely relies on volunteer participation, and sometimes civic participation, in its programme model. In all four case

studies, the steering committee and the diagnostic step were the most recognized spaces for participation by the stakeholders. However, participation of older adults should not just be limited to these two categories. Indeed, it is generally widespread to find social participation rooted in the leisure responsibilities of the community. In fact, this other category of participation covers the social life of older adults, but also civic life, in the sense that they benefit from public infrastructure and services. Also, AFCC doesn't seem to cover the participation of older adults in their family life, i.e. family and intergenerational ties. There is another participation category that can be important in the coming years: with the disinformation that abounds in social media, more and more democratic systems are noticing the risk of weakening public institutions in the long term. AFCC projects can constitute an opportunity to "live" democratic participation within the boundary of cities and communities.

Conclusion

The four case studies from different French-speaking settings have demonstrated that participatory approach is at the centre of AFCC. The Quebec and WADA cases have particularly shown how the participation of older adults can be integrated throughout the AFCC project: on the steering committee, with their participation as members, but also with the commitment of seniors' organization representatives; at the diagnosis step, when older adults are consulted by various means to find out their needs and expectations in terms of built and social environments; at the action plan step, where participation generally takes place within specific activities related to AFCC domains and, sometimes, in the way of implementing these activities where their involvement can be central to the success of the AFCC approach.

That being said, this AFCC programme model, as deployed in different French-speaking contexts, is at first theoretical. Like the AFCC cases described in this chapter, several studies have shown the challenges of translating the model into the reality of local communities (Buffel, Handler, and Phillipson, 2018). The position of the researcher is not the least question here, as he is at the same time the producer of a process, a scientific observer of it and of what it can produce, and involved in spite of himself or by choice, in quite a different posture than the academic one. Engaged in a principle of verticality of time in an act occurring here and now, he participates in what he produces by his explicit presence while putting himself at a distance through the synthesis of ideas leading to conceptual structures. Nevertheless, after 15 years of existence, WHO's AFCC has certainly stood the test of time. It has produced a generation of researchers and decision-makers aware of the necessary involvement of older adults in the decisions and actions that affect their daily life.

In all case studies presented, community building plays a central role, as an approach to social change. This kind of participatory approach, which not only promotes individual participation but also community participation, shows once more that AFCC can be a positive means to recognize older adults as equal citizens of the city or community. As Alan Walker said "[…] old age is itself partly a product of public policy" (1999, p. 362). So, it is worth bearing in mind that public policy, such as the AFCC project, can influence not only the ageing process but also representations of old age within society and our relationships with older adults.

Notes

1 A first version of this chapter was presented at the Symposium "Inclusive society and ageing" organized by the International Network on Age, Citizenship and Socio-economic Integration (REIACTIS, February 2020, www.reiactis.com).
2 https://extranet.who.int/agefriendlyworld/who-network/#:~:text=The%20WHO%20Global%20 Network%20for%20Age-friendly%20Cities%20and, community%20a%20great%20place%20 to%20grow%20old%20in.
3 This document formalizes the moral commitment of different partners to cooperate on the issues of ageing in this territory and to recognize and value the experience of older people themselves.
4 The Belgian territory has 581 municipalities.
5 The Council of Seniors is established by the Municipal Council, on the free initiative of the local authorities, as a consultative partner in decisions that concern older adults.

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32

PARTICIPATORY APPROACHES IN AGEING RESEARCH

Future perspectives

Anna Urbaniak and Anna Wanka

The primary objective of this book was to provide an in-depth, multi-disciplinary knowledge base for participatory approaches in ageing research. Drawing on insights from over 25 projects from Australia, Canada, Europe, India, New Zealand, South Africa and the USA, chapters of this book reflect different disciplinary perspectives, a wide variety of applied methods and socio-geographical contexts of participatory approaches in ageing research. The findings drawn from them are highly relevant both for research and practice, ranging from the design of ageing policies to product and service development, urban and landscape planning, health, care and social work.

The key elements of participatory research practice are explored in eight parts that capture the logic of the research process (designing research together with older co-researchers, collecting data together with older co-researchers, analysing and validating results together with older co-researchers, disseminating the results together with older co-researchers, doing the whole research process together with older co-researchers) and cross-cutting themes such as voices of older co-researchers themselves, methodological aspects, and future of participatory approaches in ageing research.

In this final chapter, we want to summarise the main lessons learned from the contributions in this book and encourage readers to think about the potential future(s) of participatory approaches in ageing research. From our perspective, the following aspects play a crucial role in this: heterogeneity of older adults; global transformations in modern societies; participation of older adults in policy-making and products/services' designs; ageism; as well as the need for flexibility and adaptability in order to successfully co-create research.

As suggested by the authors of numerous chapters in this book, **older adults are a heterogenous group** whose diverse perspectives and voices should be captured in a way that goes beyond the role of research subjects. As highlighted in Chapters 3 and 12, this heterogeneity also translates into different motivations for getting involved in (ageing) research in the first place, leaving some older adults more willing to engage than others and some cultural contexts more familiar with this form of research than others. Taking the aim of this book seriously, the heterogeneity of older adults implies reaching out to groups beyond the 'usual suspects' of white, middle-class, able-bodied adults to those whose voices are more likely to be marginalised in society and research, such as indigenous older adults (see Chapter 7)

or older adults living with dementia (see Chapter 17). It also implies the need to challenge participation inequality as highlighted in Chapter 2, as well as the reproduction of social inequalities in applied research as highlighted in Chapter 5. To capture the diversity of experiences and motivations to participate in research, the book includes contributions from the perspective of older co-researchers themselves, as highlighted by older co-researchers and their academic partners in Chapters 23–27.

The need to facilitate social inclusion of marginalised groups in research and beyond becomes even more evident in the context of **transformational worldwide processes** such as e.g. globalisation, urbanisation, climate change, or digitalisation. In Chapter 8, for example, the authors reflect upon two renewable energy research projects in the UK and India and showcase the potential for participatory approaches in unpacking green transitions together with older co-researchers, whereas authors in Chapter 31 showcase the potential of participatory approaches in the domain of age-friendly cities. In Chapter 29, authors address two main global challenges – digitalisation and the COVID-19 pandemic – and showcase a citizen science project exploring what basic adjustments are required to access and use affordable technologies and software. In a similar line of thinking, authors in Chapter 18 demonstrate the potential for PAR projects to engage with participatory media to support older adults' digital citizenship. All these projects show how participatory approaches in ageing research can not only improve our findings but also facilitate social inclusion at the backdrop of recent societal transformation processes.

Hence, the contributions in this book emphasise the value of deepening our knowledge of the ways in which different voices of older adults can be heard and listened to in the design of **research, policy and practice interventions**. In Chapter 21 authors present a service provider's perspective on rights-based research to guide innovative, evidence-informed programmes and activities, whereas in Chapter 28 authors highlight how important it is to better systematise participation and integrate it into innovation policy decision-making processes from the researcher's perspective. Authors in Chapter 11 showcase the process of implementation of participatory approaches in designing food products for older consumers, whereas in Chapter 14 authors reflect on the design of healthcare products together with older co-researchers. In Chapter 20, author presents peer research as a way to political empowerment of older people and aid in developing policy plans on the local level, whereas in Chapter 13 author focuses on the potential of participatory approaches in the development of services.

However, one of the main factors hindering participation of older adults is that we can still observe **ageism** in research, policy making and among older adults themselves. For example, in Chapter 4 authors reflect on power dynamics in the research cycle that might (re-)produce ageism, and authors of Chapter 16 discuss the difficulty in exposing ageism in order to then challenge it, precisely because older people deny being affected by it. At the same time, authors of contributions collected in this book highlight that participatory approaches in ageing research have the potential to challenge ageism and age-related stereotypes, as outlined in Chapter 6. Authors in Chapter 9 showcase how creating a creative platform to collect the urban knowledge of older adults can make the contributions of older adults visible and thus buffer ageism in the local community, whereas authors in Chapter 15 highlight that promoting the participation of older people in research on sexuality might support the development of competencies to counter the stereotypes referring to this sphere of life in older age.

Another factor that can be challenging for designing and implementing participatory approaches in ageing research is the relative lack of **flexibility and adaptability** – which are crucial in harnessing the full potential of participation, as Chapter 30 unpacks – in the academic research system. Chapter 10 highlights for example, how data collection with older co-researchers differs between community-based settings and residential care environments, and hence needs to be adapted according to the context they are applied in. Authors in Chapter 22 captured the potential of flexibility and adaptability of participatory approaches in the context of the COVID-19 pandemic. In Chapter 19, authors reflect on the living library as a flexible research tool that can be applied in participatory approaches in ageing research.

For the future of participatory ageing research, contributions of this book make it apparent that we will be facing an increasing heterogeneity in both older co-researchers as well as in academic researchers. Thinking about current developments in the field of participatory approaches and in academia in general we can expect that future generations of researchers and older adults might develop a more critical approach to traditional ways of knowledge generation and academic institutions. Following the ever-growing trend towards the democratisation of science, we can only assume that the future of participatory approaches with older adults will build more links between research and activism, where power relations will be further questioned and challenged by academic researchers and non-academics alike. As we consider participatory approaches with older adults as a field that will dynamically develop and evolve in the upcoming years, however, we believe that there is no point in predicting the future at this stage. We consider asking questions as a more stimulating way of developing the debate about participatory ageing research further. Therefore in the next part of this chapter, we gathered some questions that researchers, policymakers, representatives of institutions supporting/advocating for older adults and older adults interested in being co-researchers might find inspiring.

Where do we go from here? Open questions in participatory ageing research

As outlined above, we can take some learnings from the contributions in this book. However, what might be the biggest learning is that there is a range of questions that are yet open and must be addressed in order to develop participatory ageing research further. For analytical reasons we can differentiate these open questions by societal level, however acknowledging that all of these levels are strongly entangled.

At the micro level, we can focus our view on the research process itself and how to involve older adults in it. This can be done, first, from the perspective of older co-researchers: How can we ensure to include not only the voices of older adults per se but also engage diverse voices to show the intragenerational difference within this group? How can we find access to and motivate older people in such diverse life situations, for example people with experiences of homelessness, abuse, poverty, forced migration, and/or physical limitations? How can we meaningfully engage them throughout all stages of the research process, from the development of a project proposal and formulation of research questions over data collection, analysis and dissemination? How do we facilitate sustainable participation in such enduring research processes, what can we learn from and how can we prevent drop-outs in the short and the long run? Second, we can shift our focus from the participating older co-researchers to the academic researchers and reflexively ask about our own ageist beliefs

and stereotypes. Are we as researchers 'ready' to accept different positions, approaches and opinions than our own? How much leeway, tinkering with methods or seemingly non-academic conversations do we tolerate, or do we even foster them? How does the scientific community at conferences or reviewers react to such experimental knowledge creation?

Especially the latter question leads us right to the meso level of the research team and the research institutions that are embedded in it. How can we negotiate the diversity of needs and motivations we find on both the sides of the older non-academic researchers, the academic researchers and their research institutions? And, to put it bluntly, what's 'in it' for these different actors – are they looking for prestige, best practice examples, high-ranked publications, or simply pleasure and learning experiences? In analogy to the question posed above, we can also ask: How 'ready' are academic institutions for participatory approaches in ageing research, and how can we make them ready? This applies to, for example, research ethics and ethics committee votings, reimbursement issues, participatory approaches in transnational projects (e.g. language issues), funding programmes and necessary resources for participatory research, as well as ageist structures within academic institutions (institutional ageism). One essential element on the institutional meso level is the provision of much needed methods training for building competencies for participatory approaches among academic and non-academic researchers. This concerns social sciences' primary focus on verbal data as well as the rigidness and orthodox with which some disciplines approach their methodological toolboxes (a circumstance that also differs between countries). When working with non-academic researchers and meeting them at eye level, academic researchers might have to step away from strict methodological guidelines and allow for some creativity in tinkering with methods. Whether or not they are willing to do so also depends on how much the academic system around them approves of such approaches, for example in probability to get such findings published in high-ranked journals.

The questions outlined on the micro and meso levels are all shaped by wider societal developments and debates around knowledge production in ageing societies. The major question to be addressed from a participatory point of view is: How can we move from ageist and paternalist cultures of knowledge production to participatory ones? Digitalisation might not only help to democratise participation in knowledge production for a certain layer of society but also make it more difficult for others. As societies are always in transformation, we can expect future generations of older adults as well as ageing researchers to be different than the ones we are inviting to participate in research today. Hence, we need to think early about how to excite and motivate future ageing generations for research, and contribute to the development of life courses of participation, not only in research but also in social and political life on a more general level.

Concluding remarks

Summarising, the chapters in this book provide a foundation for the emergence of a distinct approach to research, characterised by the meaningful involvement of diverse groups of older adults to contribute their perspectives and experience as co-creators of the research process. In doing so, the book recognises the contributions of scholars across diverse disciplines, applying different methods employed within the emerging field of participatory approaches in ageing research today and proposing new directions for the future. We hope that readers of this book are inspired to contribute further to participatory research practice with older adults and look forward to future developments in this field. In responding to

the challenge of democratisation of science in ageing societies, participatory research practice with older adults might become a prominent way of doing research on ageing. To fully harness the potential of participatory approaches in ageing research it would be required to nurture research capacity and cross-national collaboration across researchers, policy-makers and practitioners. One such initiative is a COST Action CA22167 on Participatory Approaches with Older Adults (PAAR- net) that brings together people committed to developing participatory approaches in ageing research. We, as editors of this book and leaders of PAAR-net, would be delighted if readers of this book decided to join this network and further contribute to developing an understanding of participatory approaches with older adults and shaping debates around the meaningful involvement of older adults in research, policy-making and practice intervention designs.

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