

Guest editorial

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Exploring participatory approaches with older adults in health and care research

Participatory approaches with older adults

As societies age and life expectancies increase, the study of older adults becomes increasingly important. Research in gerontology and related fields not only advances our understanding of the aging process but also informs policies, health-care practices and social interventions. In this context, participatory approaches in research with older adults have emerged as a transformative paradigm, shifting the traditional researcher-subject dynamic towards a more collaborative and inclusive framework ([Raymond et al., 2022](#)). These approaches recognize the experiences and unique perspectives of older individuals, allowing them to actively contribute to the research process. The importance of participatory research in this context cannot be overstated, as it not only enhances the quality and relevance of findings but also empowers older adults, promotes social inclusion and addresses complex challenges associated with aging ([Burns et al., 2014](#)).

Participatory approaches also have the potential to bridge the gap between research and practice. Older adults bring a wealth of experiential knowledge that cannot be gleaned from textbooks or academic literature alone ([Albert et al., 2023](#); [Littlechild et al., 2014](#)). Engaging them in the research process enables researchers to tap into this knowledge, gaining insights that enrich the interpretation of findings and guide the development of practical interventions. As older adults actively contribute to the formulation of recommendations and strategies, the resulting outcomes are not only evidence-based but also reflective of real-world challenges and opportunities ([Fudge et al., 2007](#)). This synergy between research and practice facilitates a more holistic approach to addressing the diverse needs of older adults.

Three of the central tenets of participatory research are co-creation, inclusion and transformation. By involving older adults as partners in the research process, their voices are amplified and their insights are acknowledged ([James and Buffel, 2022](#)). This collaborative engagement empowers older adults to shape the research agenda, determine research questions and participate in study design. This sense of ownership cultivates a deeper connection between researchers and older adults, fostering a shared commitment to the research goals ([Clough et al., 2006](#)). Such engagement ensures that research questions are meaningful and pertinent to the lived experiences of older adults, leading to findings that are more applicable and actionable ([Moser et al., 2021](#)).

Furthermore, participatory research promotes social inclusion and challenges ageism ([Corrado et al., 2020](#); [Fraser et al., 2014](#)). In the realm of academic research, participatory approaches compel researchers to reassess preconceived notions about aging and actively engage with older adults as equal partners in knowledge generation. This process fosters a profound sense of agency and relevance among older adults, dispelling notions of passivity and dependency that are often perpetuated by ageist attitudes ([Ayalon et al., 2021](#); [Fraser et al., 2020](#)). Through their active involvement, older adults demonstrate that their contributions are valuable and their insights meaningful, discrediting the idea of diminished involvement in older age.

Incorporating participatory approaches in research with older adults also enhances the ethical dimension of the research process. Respect for autonomy and dignity is paramount

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when working with vulnerable populations, and participatory methods promote ethical research by empowering older adults to actively shape the research that concerns them (Lenette, 2022). This approach ensures that research endeavours prioritize the well-being and preferences of older adults, aligning with the principles of beneficence and justice (Medina, 2017).

Finally, the integration of these voices into research outputs and public discourse serves as a catalyst for a broader cultural transformation. By challenging negative perceptions of aging and showcasing the diverse, vibrant experiences of older adults, participatory research contributes to a shift in societal attitudes. Academic researchers gain an opportunity to become agents of change, facilitating a transition from ageism to a more positive, respectful and inclusive perception of aging (Blair and Minkler, 2009; Corrado *et al.*, 2020).

In this relationship, academic researchers are not merely recipients of older adults' insights; they might also become advocates for a more equitable and empathetic society. Participatory research compels researchers to confront their own biases and assumptions, fostering a deeper understanding of the heterogeneity and complexity of aging experiences (Corrado *et al.*, 2020; Urbaniak, 2023). As researchers collaborate with older adults, they might work towards bridging generational gaps and facilitating cross-cross-fertilisation of bodies of knowledge gathered by experts-by-experience with knowledge gathered by experts-by-training (Richardson, 2021).

Participatory approaches with older adults in health and care research

In the realm of research on health and care, participatory approaches with older adults assume an even greater significance (Andrews *et al.*, 2021; Slattery *et al.*, 2020; Poland *et al.*, 2019). As we confront the multifaceted challenges of an aging population, it becomes imperative to involve older individuals as active collaborators in the research process. The incorporation of participatory methods not only enriches the quality and relevance of studies but also empowers older adults to actively contribute to the enhancement of their own health and well-being (Backhouse *et al.*, 2016).

Older adults possess a wealth of experiential knowledge that is indispensable in the realm of health and care research. Traditional research methodologies often fall short in capturing the intricate nuances of daily experiences, challenges and coping mechanisms that older individuals encounter (Parveen *et al.*, 2018). Participatory approaches bridge this gap by directly involving older adults in the research process, enabling them to share their insights, preferences and concerns. By integrating these perspectives, researchers gain a more holistic understanding of the factors influencing health and well-being, leading to more informed decision-making and targeted interventions. For instance, a participatory approach could involve older adults in co-designing health interventions tailored to their unique needs, thereby enhancing the interventions' efficacy and relevance (Moser *et al.*, 2021).

Furthermore, research on health and care for older adults often deals with complex and sensitive topics, such as chronic illness management, end-of-life care and mental health (Baldwin *et al.*, 2018; Ludwig *et al.*, 2021; Slattery *et al.*, 2020). Participatory approaches offer a safe and inclusive space for older adults to discuss these matters openly and honestly. Through participatory approaches, older individuals can share their experiences, preferences and concerns, fostering a deeper understanding of their needs and ways they wish to communicate them. This open dialogue not only generates richer data but also empowers older adults to break the silence surrounding these topics (Bendien *et al.*, 2020), ultimately paving the way for more adequate and improved health-care practices and policies.

Participatory approaches also align with the principles of patient-centred care, which advocate for tailoring health-care services to the preferences and values of individual patients (Brett *et al.*, 2014). In the context of older adults, this becomes even more crucial, as

their health needs are often intertwined with their life histories, social contexts and personal aspirations. Engaging older adults in the research process enables researchers and health-care practitioners to adopt a more personalized approach, aligning treatment plans with patients' goals and priorities. This patient-centred perspective promotes better health outcomes and enhances the overall quality of care.

Another compelling reason for using participatory approaches in health and care research for older adults is the potential to reduce health-care disparities (Walsh *et al.*, 2022). Older individuals from marginalized backgrounds, such as minority communities or those with limited access to resources, often face unique challenges that can impact their health outcomes (Parveen *et al.*, 2018). Participatory research allows these individuals to voice their concerns and contribute to solutions that are culturally sensitive and inclusive. This approach can lead to the development of interventions that are more effective in addressing the specific needs of marginalized older adults, what in long turn might be contributing to the reduction of health disparities.

Participatory approaches with older adults in research on health and care hold a pivotal role in shaping the trajectory of this field. By actively involving older individuals in the research process, these approaches harness their experiential knowledge, foster open dialogue on sensitive topics and promote patient-centred care (Backhouse *et al.*, 2016; Pii *et al.*, 2019; Modigh *et al.*, 2021). Furthermore, participatory methods empower older adults to actively shape the research agenda and contribute to the development of interventions that align with their unique needs and preferences. In an era marked by unprecedented demographic shifts, the adoption of participatory approaches not only enhances the quality and relevance of research but also paves the way for a more inclusive, effective and compassionate approach to health and care for older adults.

Challenges in the participatory approaches with older adults in health and care research

While participatory approaches hold immense promise, challenges are inherent in their implementation, especially within the domain of health and care research (Andrews *et al.*, 2021). Engaging older individuals as active partners in the research process requires careful consideration of various factors to ensure meaningful and effective collaboration. As we explore the complexities involved, it becomes evident that addressing these challenges is essential to harness the full potential of participatory research in this context:

- ***Diverse health needs and experiences:*** Older adults are heterogenous group that cover a diverse spectrum of health needs, experiences and backgrounds. Tailoring participatory research to accommodate this diversity can be challenging. Researchers should pay a special attention to creating inclusive spaces that respect the unique perspectives of older adults, ensuring that their voices are equally valued and integrated into the research process. Adequately addressing the range of health conditions, cultural nuances and socioeconomic factors demands flexibility and a willingness to adapt research methodologies.
- ***Health literacy and cognitive abilities:*** Variability in health literacy and cognitive abilities among older adults can impact their ability to fully engage in the research process. Complex medical terminology, abstract concepts or intricate research protocols may pose barriers to effective collaboration. Researchers should use clear and accessible communication strategies, using visual aids, simplified language and interactive methods to ensure that all can contribute meaningfully.
- ***Time and commitment:*** Participatory research requires a significant time commitment from all involved. Older adults may have competing priorities, such as health-care appointments, caregiving responsibilities or social engagements, which can limit their

availability. Striking a balance between meaningful engagement and accommodating participants' schedules is crucial. Researchers should be flexible and considerate, providing options for participation that suit diverse lifestyles.

- *Technological barriers:* The digital divide poses a challenge in modern participatory research, where technology may be an essential tool for communication and collaboration. Older adults who are not comfortable with or do not have access to technology may be excluded from certain aspects of the research process. To address this challenge, researchers should offer alternative communication methods and ensure that technology does not create additional barriers.
- *Power dynamics and decision-making:* Participatory research aims to shift power dynamics, but challenges can arise in ensuring that older adults genuinely have a voice in decision-making during the research process. Researchers should navigate the fine line between facilitation and control, fostering an environment where older participants feel empowered to express their perspectives without feeling overwhelmed or marginalized. Strategies such as co-creation of research questions and co-analysis of data can help address this challenge.
- *Ethical considerations:* Ethical concerns are amplified when working with populations like older adults, who sometimes are considered as more vulnerable. Researchers should prioritize informed consent, protect participants' privacy and ensure that the research process does not cause emotional distress. Addressing ethical challenges requires clear communication, transparency and a commitment to safeguarding the well-being of all involved (older adults and academics alike).
- *Heterogeneity:* Achieving diversity in participatory research can be challenging, especially when working with older adults who may face mobility limitations or live in isolated communities. Researchers should use adequate techniques to ensure diverse representation and consider collaborating with community organizations to facilitate access to a broader range of participants.
- *Skill and training:* Participatory research requires a skill set that extends beyond traditional research methods. Researchers must possess strong facilitation, communication and interpersonal skills to foster effective collaboration and engagement with older adults. Adequate training and ongoing support for both researchers and older adults are essential to ensure a successful participatory research endeavour.
- *Resource constraints:* Participatory research can be resource-intensive, requiring funding for training, materials and logistical support. Securing adequate resources may be challenging, particularly for researchers working within limited budgets. Collaboration with community organizations, seeking grant funding and leveraging partnerships can help alleviate resource constraints.

It is essential to acknowledge and address the challenges inherent in this approach to ensure that older individuals can contribute meaningfully and equitably. By embracing flexibility, clear communication, ethical considerations and innovative strategies, researchers can navigate these challenges and harness the potential of participatory research to enhance understanding of health and care for older adults, leading to more effective interventions and improved quality of life.

Rationale for this special issue and contributions

The rationale for dedicating a special issue to participatory approaches with older adults in health and care research is rooted in the imperative to amplify the often-overlooked

perspectives and unique insights of this demographic (Burns *et al.*, 2014; Thoft *et al.*, 2020). Traditional research methods have frequently sidelined the valuable contributions of older adults, resulting in interventions that inadequately address their distinct needs (Lambert and Carr, 2018). In response, this issue aims to rectify this oversight by repositioning older adults as active collaborators within the research process. This aligns with an ethical and humanistic research philosophy, emphasizing the significance of integrating older adults as co-creators and co-analysts of knowledge (Ludwig *et al.*, 2021; Ries *et al.*, 2020). By providing a dedicated platform for their voices, participatory approaches elevate the role of older adults, acknowledge their wealth of experiential wisdom and contribute to interventions that are not only contextually relevant but also highly impactful (Grotz *et al.*, 2020; Kowe *et al.*, 2022). The contributions in this special issue aim to do just that.

In the paper that opens this collection, “Participatory action research and intersectionality: a critical dialogical reflection of a study with older adults” by Barbara Groot *et al.*, the authors draw upon their experiences from a participatory action research (PAR) project conducted with older adults as co-researchers in The Netherlands during 2016–2017. The study engages in a retrospective analysis, focusing on two pivotal turning points within that project. The study also highlights the potential of intersectional reflexivity, extending self-reflection beyond individualized concerns to potentially drive broad social change. It underscores that academics, despite their intentions, sometimes perpetuated harmful power dynamics. Ultimately, this research serves as a valuable resource for learning from past experiences and preventing such situations in the future. Authors show how a case-study approach to ethical dilemmas, coupled with dialogues among peers, can serve as an effective means to unpack the ethical tensions researchers encounter.

Three papers in the special issue focus on participation in care and caring practices. The paper titled “Participatory Action Research on Webs of Caring in the Digital Age Across Four European Countries” by Miranda Leontowitsch *et al.* offers a comprehensive examination of the potential of participatory approaches in nurturing age-friendly initiatives within the context of the digital era. Grounded in the emancipatory principles of PAR, which seeks to mitigate inequalities through collaborative co-design, the EQualCare project engaged nine teams of co-researchers spanning Finland, Germany, Latvia and Sweden. These teams placed older individuals at the centre of evidence-based policy development, actively participating in shaping research objectives, gathering data, reflecting upon findings and crafting recommendations tailored to local policy stakeholders. This paper exemplifies how participatory approaches involving older adults can be catalysts for transformation within the digital age, steering societies towards more inclusive and co-created futures for older adults who live independently.

Annette Bilfeldt focuses on a public nursing home in Denmark and discusses how PAR can contribute to quality of life in her contribution on “Participatory action research and empowerment of nursing home residents.” Drawing on the method of “future creating workshops”, learning processes were initiated and a democratic knowledge-building process was established – all based on the voices of residents, their relatives and staff alike. They showcase how through the implementation of new democratic practices in nursing homes that have a focus on the residents’ needs built into them, capacity building and mutual learning and understanding can be facilitated. However, they also acknowledge how such implementations need resources, and these resources require a broader policy agenda.

In their contribution “Involving older adults and unpaid carers in the research cycle: reflections on implementing the UK National Standards for Public Involvement into practice”, Catrin Jones and colleagues show how older adults, including those living with dementia, and their caregivers can participate in research, and what prevents them from doing so. They showcase how the UK National Standards for Public Involvement (2020–2023) can be implemented with people who are often excluded from research and how choice, flexibility and active learning from one another are crucial elements in this process. People with a

dementia diagnosis became co-creators that developed three significant outputs: a conceptual model of resilience for people living with dementia, involvement in co-creating a new measure of resilience for people living with dementia and booklets sharing information on useful support and strategies following a diagnosis of dementia. Finally, they discuss challenges that remain in their experiences of participatory approaches.

When we move from care to ageing in place, the paper “Interventions to promote ageing in place: developing the Village model in Manchester” by Patty Doran *et al.* sheds light on the potential of participatory approaches to nurture age-friendly initiatives. The study’s findings showcase how residents have been empowered to create and test seven distinct projects, all aiming at combating social isolation and enhancing aging in place. What sets this paper apart is its exploration of the challenges encountered in co-producing age-friendly solutions with older adults in deprived neighbourhoods. These challenges are thoughtfully categorized into three key dimensions: individual capacity and expectations, collective capacity encompassing communication and knowledge-sharing, and the capacity of the physical environment itself. This paper underscores the significance of inclusion by specifically targeting economically deprived, inner-city neighbourhoods and marginalized individuals and groups in Manchester. It recognizes that participatory approaches have the potential to transform not only the research process but also the well-being and quality of life for older adults in these communities.

Finally, the special issue concludes with a reflexive piece. In his paper “[...] And (epistemic) justice for all: a cautionary tale of knowledge inequality in participatory research”, Andrew Fletcher draws on Miranda Fricker’s concept of “epistemic injustice” as a lens to describe the author’s experience in an interdisciplinary, intersectoral participatory research project on healthy ageing. He reflects upon how different forms of knowledge were negotiated and highlights the cautions and considerations that must be made when navigating, handling and amalgamating “other people’s knowledge” – including older adults and children, researchers and non-academics, as well as stakeholders across health and care, design, business and academia. The paper concludes by suggesting ways that researchers might address epistemic injustice by valuing the range of knowledge types encountered in participatory research.

Conclusions

This special issue offers exploration of participatory approaches with older adults in health and care research. By emphasizing their heterogeneity, acknowledging the significance of participatory methodologies in health and care research, and navigating the challenges inherent in such endeavours, this issue illuminates the transformative potential of collaborative engagement. The diverse range of papers presented herein underscores the importance of amplifying the voices of older adults, both in research and in policy and practice. As we delve into these pages, we are invited to rethink traditional research paradigms, challenge ageism and embrace the power of participatory approaches to shape a more inclusive and empowering future for our aging populations. Through this special issue, we aim to contribute to a growing body of knowledge that redefines the study of aging, enriches health-care practices and enhances the well-being of older adults across the globe.

The papers in this special issue collectively enrich our understanding of participatory research with older adults in the context of health and care. Through nuanced explorations of disparities, technology, ethics, person-centred care and intergenerational dynamics, these papers contribute valuable insights that collectively inform and advance the field. As we navigate the challenges and opportunities of participatory research, these papers serve as beacons of knowledge, guiding us towards a more inclusive, effective and impactful approach to promoting the well-being of older adults in the realm of health and care.

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