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Translating policy into practice by
engaging older persons and their carers
as co-researchers

Ms Hannah Beks

E: hannah.beks@deakin.edu.au

Ms Suzanne Clayden^{1,2}

Ms Emma West^{3,4}

Dr Olivia King^{3,4,5}

Dr Laura Alston^{1,6,7}

Ms Sue Williams⁸

Ms Alesha Sayner^{1,9}

AProf Catherine Huggins⁶

AProf Kevin Mc Namara¹

Ms Ellen Gaffy⁸

AProf Anna Wong Shee^{1,9}


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australian healthcare &
hospitals association

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1. Deakin Rural Health, Deakin University,
2. South West Healthcare, Victoria
3. School of Medicine, Deakin University
4. Western Alliance Academic Health Science Centre
5. Monash Centre for Scholarship in Health Education
6. Institute for Health Transformation, Deakin University
7. Research Unit, Colac Area Health, Victoria,
8. National Ageing Research Institute, Victoria
9. Grampians Health, Victoria

Executive Summary

Health care systems are required to be responsive to changing population needs. Globally, the proportion of persons aged 60 years and over is increasing and is set to continue to grow for at least the next two decades. The Australian Government's Royal Commission into Aged Care Quality and Safety (2021) identified the need to improve the delivery of health care to meet the needs of older persons and their carers. A greater involvement of older persons and their carers in research to develop solutions was recommended.

Engagement of older persons and their carers in participatory health research as co-researchers is one such mechanism for this to occur. Whilst there is considerable evidence around older persons and participatory research, little guidance exists for researchers, practitioners, and policy-makers around engaging older persons and their carers in participatory health research.

Guidance identifying strategies to translate the recommendations of the Royal Commission

into practice is imperative to improving the responsiveness of the Australian health care system for older persons and their carers.

To build more responsive systems of health care, it is imperative to optimise the engagement of older persons and their carers and consider the:

- barriers and facilitators to engaging older persons and their carers in health research,
- approaches to optimise the engagement of older persons and their carers as co-researchers in participatory health research, and
- considerations for specific populations, such as First Nations Elders, older persons with multimorbidity and complex conditions including cognitive impairment, older persons and carers from culturally and linguistically diverse backgrounds, and those residing in non-metropolitan settings.

Background

Health care systems are required to be responsive to changing population needs (Mirzoev & Kane, 2017). The Australian Government's Royal Commission into Aged Care Quality and Safety (2021) identified the need to improve the delivery of health care to meet the needs of older persons and their carers (Commonwealth of Australia, 2021). Globally, the proportion of persons aged 60 years and over is rapidly increasing (World Health Organization, 2022).

The United Nations predicts that the proportion of people aged 60 and over will rise from 12.3% to 22% by 2050 (Ageing, 2022). Although definitions of older persons and their carers vary between countries, research studies, and population groups¹ (Sabharwal et al., 2015; Singh & Bajorek; 2014), the importance of involving older persons and their carers in health research to improve health care responsiveness (i.e., the ability for health care systems to meet the health and non-health needs of patients) (Khan et al. 2021) is gaining global traction (Petrovsky et al. 2021). This is particularly important as carers of older persons are often family members who undertake unpaid caring duties (Cameron et al. 2011).

Translating the Australian Government's Royal Commission into Aged Care Quality and Safety recommendations into practice

To achieve a greater involvement of older persons and their carers in decision-making, the Royal Commission recommended research approaches that involve older persons and their carers in generating solutions, be prioritised (Recommendation 107: Aged Care Research and Innovation Fund) (Commonwealth of Australia, 2021). This aligns with other Australian research that identified older persons and their carers want their perspectives regarding health and wellbeing to be heard by decision-makers (National Ageing Research Institute, 2021).

Participatory health research is one such mechanism to elevate the voices of older persons and their carers as co-researchers in research of relevance to them. There has been a surge in the use of participatory approaches in health research undertaken with older persons and their carers (James & Buffel, 2022; Fudge et al. 2007; Schilling & Gerhardus, 2017; Groot & Abma; 2018).

¹ For example, in Australia, government policy identifies non-Indigenous older persons as those over 65 years of age and Aboriginal and Torres

Strait Islander older persons as those over 50 years of age. (Institute of Health and Welfare, 2021)

Participatory approaches to health research appoint end-users of services and programs as co-researchers and can occur in a broad range of study designs (e.g., participatory action research, co-design) (Beks et al. 2022). End-users includes older persons and their carers accessing services and programs.

Examples include appointing carers of older persons as co-researchers to improve support services for older persons such as models of home-based care (Graffigna et al. 2021), and for developing carer support programs (Burnell et al. 2015). Although definitions and the scope of co-researchers vary between studies, we define co-researchers as persons who contribute as members of a research team to all stages of the research process (Marks et al. 2018).

Evidence supports that collaboration between end-users and researchers has greater potential to improve immediate health-related outcomes (Halvorsrud et al. 2021) and align research with the needs of end-users. In the context of older persons and their carers, other benefits include improving the quality of research, including research questions and methodologies, enhancing the relevance of research, and mitigating research waste (i.e., research not published, translated, or with little impact) (Holroyd-Leduc et al. 2016). Historically, research focusing on older persons has examined the burden of disease

experienced (Nunes et al. 2016; Hughes, Closs, Clark, 2009), and approaches to providing care (e.g., models of care (Barajas-Nava et al. 2022), residential care (Frazer et al. 2021)); much of which has been situated within an illness-based or deficit view of ageing. Older persons have also been subject to inequity in research, including a lower representation in clinical trials when compared with other population groups (Watts, 2012; Krysa et al. 2022).

Embedded in social justice principles, participatory research offers a vehicle to shift the practice of framing older persons and carers as the research subjects, to engaging older persons and carers as co-researchers (International Collaboration for Participatory Health Research, 2013). This would be transformative leading to meaningful solutions to address the complex health and social issues experienced by older persons and their carers (Buffel, 2018). In many cultures, including in Aboriginal and Torres Strait Islander communities in Australia, older persons or Elders, are cultural custodians of lore and language, and are valued as teachers and mentors within their community (Cox, Mond, Hoang, 2022). Therefore, Elders should never be excluded from research concerning issues which affect themselves or their communities.

Moving beyond consultation to transformative engagement

From a methodological viewpoint, participatory approaches establish older persons and their carers as partners in research and privileges their knowledge, experiences, and perspectives in the research process (James & Buffel, 2022; Blair & Minkler, 2009). High quality participatory health research moves beyond consultation with older persons and their carers in a single stage of the research process (e.g., dissemination of study findings) and actively engages older persons and their carers as co-researchers in all stages of the research process (James & Buffel, 2022).

A key issue for participatory health research globally is identifying what constitutes authentic participation and how to measure the quality of participation (Corrado et al. 2020). Scholars have sought to address these issues in the development of quality criteria for participatory health research and international working groups (International Collaboration for Participatory Health Research, 2017). Further, guidelines stipulating the principles of participatory approaches, such as co-production (e.g., sharing of power, inclusiveness, respect, reciprocity, building relationships) (Hickett et al. 2019) and involvement of consumers and community members in research (Miller et al. 2017) that are not specific to older persons and their carers, exist. In addition to these guidelines, researchers undertaking participatory health research are encouraged to be reflexive (Hand et al. 2019; Moll et al. 2020) and share learnings (Beks et al. 2022).

Knowledge gaps around best practice for engaging older persons and their carers as co-researchers

Despite the existence of guidelines for participatory health research, and the identified need for a greater engagement of older persons and their carers in health research, gaps in knowledge persist around what is best practice for engaging older persons and their carers in participatory research (Markle-Reid et al. 2021). Further, there is little guidance from the recommendations of the Royal Commission to enact the participation of older persons and their carers in research (Commonwealth of Australia, 2021).

Previous systematic reviews have broadly examined approaches documented in the peer-reviewed literature for involving older persons in health research (Fudge et al. 2007; Schilling & Gerhardus, 2017; Backhouse et al. 2016; Bethell et al. 2018; Liljas et al. 2017) and social sciences research (Corrado et al. 2020; Baldwin et al. 2018), with little focus on engaging carers.

One systematic review examined co-research with older people in health and non-health settings and identified four strategies for improving research practice which included developing diversified structures of involvement, supporting co-researchers, embedding research rigour, and ensuring co-ownership of change (James & Buffel, 2022). However, that review did not focus on the engagement of carers and only retrieved one study undertaken in a health care setting (James & Buffel, 2022).

One realist review was identified which developed a framework of engaging older adults and carers in healthcare research and planning but did not have a specific focus on participatory research approaches (McNeil et al. 2016). A scoping review of studies using 'co-methodologies' to engage older persons in health care interventional research identified that the contribution of older persons in these peer-reviewed studies was largely around providing data or, to a lesser extent, analysing data, with little focus on research planning or dissemination (Cowdell et al. 2022).

A limitation of that review as discussed by the authors, was the possibility that all participatory health research studies may not have been included in the review given the variation in language around participatory study designs (Cowdell et al. 2022). Further, that review did not include consideration of specific population groups (e.g., First Nations Peoples).

To address these knowledge gaps and guidance for translating policy into practice, this perspectives brief synthesises facilitators and barriers of older person and carer engagement in health research, approaches to optimise engaging older persons and their carers in participatory health research, and considerations for engaging specific population groups, using findings from a broad body of health and social science literature (including systematic reviews, key primary research, and evaluation reports) to provide guidance for researchers undertaking participatory research with older persons and their carers.

Undertaken from a viewpoint which understands older persons and their carers to be a heterogeneous population with inter-generational and cultural differences (Groot & Abma, 2018; Feldman 2008), this brief presents evidence-based strategies for researchers and health services which will be of value to guide participatory health research at a local level.

Barriers and facilitators of engaging older persons and their carers in health research

Barriers and facilitators to engaging older persons in health research, including non-participatory research, such as clinical trials, are well established. However, there has been less focus on factors mediating the engagement of carers in health research. Given that carers of older persons are often spouses who are most likely to be older adults themselves, or adult children, it is likely there are some common mediators (Australian Bureau of Statistics, 2016).

For the purpose of this review, barriers and facilitators for engaging older persons and their carers are discussed for participatory and non-participatory health research to provide a context for strategies to optimise engagement. It is important to note that volunteering as a participant in non-participatory health research, and engagement as a co-researcher in participatory health research, are distinct concepts.

There are numerous barriers that prevent older persons from participating in health research, in addition to their active exclusion from some research (Table 1). These include older people having a lack of familiarity with the research process and negative perceptions of the research process (Fudge et al. 2007; Bethell et al. 2018).

Negative perceptions of research may be attributed to feelings of being 'over-researched', particularly by older persons and their carers from specific population groups (e.g., First Nations Elders from colonised countries such as Australia, where unethical

research practices have occurred) (Bainbridge et al. 2015). Older persons may also experience sensory, mobility, cognitive, communication, or other health challenges that prevent or impede participation (Backhouse et al. 2016; Liljas et al. 2017).

These challenges may also make developing relationships between members of the research team difficult (Schilling & Gerhardus, 2017) and require additional resources and time within a research project which is not always available (James & Buffel, 2022; Backhouse et al. 2016; Bethell et al. 2018; Littlechild et al. 2014; Goins et al. 2011). These factors, both individually or collectively, can lead to poor engagement of older persons and their carers in health research and negatively impact the sustainability of engaging older people in research.

Barriers specific to participatory health research included tokenistic engagement of older persons and their carers (James & Buffel, 2022; Corrado et al. 2020), power imbalances within research teams (Fudge et al. 2007; Backhouse et al. 2016; Bethell et al. 2018; Littlechild et al. 2014), and the failure to position older persons and their carers as full research partners (e.g., co-researchers) with the ability to shape the research process (Corrado et al. 2020; Backhouse et al. 2016).

A lack of capacity building opportunities for older persons as part of the research process, also contributes to this (Corrado et al. 2020)

and has the potential to exclude older persons who do not feel like they have the necessary skills or knowledge to participate as a co-researcher.

Feelings of powerlessness experienced by older persons in the research process may be exacerbated where they hold little influence over the research question (Fudge et al. 2007; Corrado et al. 2020; Backhouse et al. 2016) which is often pre-determined by academic researchers as part of the process of obtaining research funding. Institutional ethical requirements, such as the need to obtain written informed consent for different stages of the participatory process, have also been identified to hinder engagement (Corrado et al. 2020; Hand et al. 2019; Backhouse et al. 2016; Bethell et al. 2018) and compound the resource intensiveness of participatory research.

This has been cited as a key issue in co-design and implementation research more broadly (Goodyear-Smith et al. 2015). For example, research reporting on participatory action research undertaken with an Aboriginal community in Australia examining the determinants of chronic disease management, stated that multiple ethical amendments were required to accommodate for changes to the project and the needs of co-researchers (Beks et al. 2022).

A summary of key facilitators to the engagement of older persons and their carers in participatory health research, and health research more broadly are summarised in Table 1. One type of facilitator shared by studies is the belief of older persons and carers that participation will contribute to positive change for self or others

(Fudge et al. 2007; Fiordelli et al. 2021; Waite et al. 2019). This is of no surprise as older persons tend to be engaged in research of relevance to them (Fudge et al. 2007).

Further, having sufficient resources (e.g., funding, time) to allow for meaningful and personalised engagement with older persons and their carers was also cited as a facilitator (Bethell et al. 2018; Liljas et al. 2017).

In participatory health research, meaningful and personalised engagement can also facilitate the development of trust and rapport between co-researchers within the team (e.g., between older people and academic researchers; or between older people and health service providers) (Hand et al. 2019; Backhouse et al. 2016; Baldwin et al. 2018). Other facilitators specific to participatory research which have promoted engagement include having supportive academic researchers (Fudge et al. 2007; Backhouse et al. 2016) (e.g., who are sensitive to the needs of co-researchers) and opportunities for older persons and their carers to upskill as part of the project (e.g., in data collection) (Daly et al. 2021).

Having distributed benefits of research (e.g., reciprocity) for co-researchers (Fudge et al. 2007; Backhouse et al. 2016) and localised approaches to undertaking research (Bendien et al. 2022) which promotes the flexibility of participation (Fudge et al. 2007; Backhouse et al. 2016; Bethell et al. 2018; Goins et al. 2011), is key.

Table 1. Barriers and facilitators to engaging older persons and their carers in health research –:

Engagement of older persons and their carers in :	
Barriers	<p>Non-participatory health research</p> <ul style="list-style-type: none"> • Difficulty in developing a relationship between older persons as research participants and researchers (e.g., due to cognitive impairment) (Schilling & Gerhardus, 2017) • Sensory, mobility, communication, cognitive or other health challenges experienced by older persons as research participants (Fudge et al. 2007; Backhouse et al. 2016; Liljas et al. 2017) • Older persons may hold a negative perception of research (Fudge et al. 2007) or lack of familiarity with the research process (Fudge et al. 2007; Bethell et al. 2018) • Time-intensiveness and resource heavy nature of research participation (James & Buffel, 2022; Backhouse et al. 2016; Bethell et al. 2018; Littlechild et al. 2014; Goins et al. 2011)
	<p>Participatory health research</p> <ul style="list-style-type: none"> • Older persons not positioned as full research partners (e.g., tokenistic engagement) with little opportunity to shape the research question, approach, or influence change (Corrado et al. 2020; Markle-Reid et al. 2021; Backhouse et al. 2016) • Lack of capacity building opportunities for older persons as co-researchers as part of the research project (Corrado et al. 2020) • Constraints of funding and the need to have a defined research question pre-engagement (Fudge et al. 2007; Corrado et al. 2020; Backhouse et al. 2016) • Constraints of institutional ethical approval and consent forms to participatory process (Corrado et al. 2020; Hickey et al. 2019; Backhouse et al. 2016; Bethell et al. 2018) • Power imbalances between academic researchers and older persons as co-researchers (Fudge et al. 2007; Backhouse et al. 2016; Bethell et al. 2018; Littlechild et al. 2014)

Facilitators	Non-participatory health research*
	<ul style="list-style-type: none"> • Perception that research participation will contribute to positive change, either for themselves or others (Fudge et al. 2007; Fiordelli et al. 2021; Waite et al. 2019) • Having sufficient resources for meaningful research participation (Liljas et al. 2017) • Tailored support to facilitate research participation of older persons and their carers (Baldwin et al. 2018)
	Participatory health research
	<ul style="list-style-type: none"> • Supportive academic research team (Fudge et al. 2007; Backhouse et al. 2016) • Opportunities for older person to upskill in the processes of research (Daly et al. 2021) • Reciprocity in engagement (e.g., benefits for older persons as co-researchers as well as other members of the research team) (Fudge et al. 2007; Backhouse et al. 2016) • Trust and rapport developed between co-researchers and other members of the research team (Hand et al. 2019; Backhouse et al. 2016; Baldwin et al. 2018; Tanner, 2012) • Localised approaches to engagement with co-researchers (Bendien et al. 2022) • Flexibility of researchers to accommodate for the individualised nature of co-researcher participation (Fudge et al. 2007; Backhouse et al. 2016; Bethell et al. 2018; Goins et al. 2011)

*Documented barriers and facilitators for non-participatory health research are of relevance to participatory health research

Approaches to optimising engagement of older persons and carers in participatory health research

Approaches to optimise the engagement of older persons as co-researchers in participatory health research have been broadly examined in systematic reviews and primary research studies (Table 2). However, there has been little focus on approaches to optimising the engagement of carers.

All of the studies identified that had a focus on engaging carers as co-researchers were undertaken in the dementia care context (Burnell et al. 2015; Goeman et al. 2016; Miah et al. 2020). Although there is likely to be shared approaches to optimising the engagement of older persons and their carers as co-researchers, it is important to reiterate that older persons and carers are a heterogeneous population with inter-generational and cultural differences (Groot & Abma, 2018). This heterogeneity is examined in greater detail in the following section.

Approaches described in the peer-reviewed literature largely focused on ways to accommodate the engagement of older persons as co-researchers and address known barriers. Having an emergent study design (Backhouse et al. 2016) with clarification around the role and functions of co-researchers, was widely cited (Schilling & Gerhardus, 2018; Markle-Reid et al. 2021; McNeil et al. 2016).

For example, an emergent study design can include co-researchers deciding on a project title and guiding the research question (James & Buffel, 2022), or the development of an intervention (Burnell et al. 2015). An

important component of defining co-researcher roles was the need to support these roles through training in research methods, terminology, skills, and other project training at the commencement of the research project (James & Buffel, 2022; Fudge et al. 2007; Schilling & Gerhardus, 2017; Blair & Minkler, 2009; Daly et al. 2021) and providing opportunities throughout the project to practice these skills (Daly et al. 2021).

An example of this from the United Kingdom, was a research awareness training program developed for older persons with dementia and their carers to promote involvement in research (Miah et al. 2020). The program involved the delivery of six sessions which included: research awareness, understanding the research process, qualitative methods, quantitative methods, developing and evaluating interventions, and health economics and research ethics and governance (Miah et al. 2020).

Qualitative feedback identified that participants were generally satisfied with the program, favoured group work, and appreciated tailored approaches to meet individual needs (Miah et al. 2020). This resonates with other research supporting the need for a tailored and flexible approach to engaging co-researchers (e.g., need for regular breaks during activities to avoid fatigue) (Schilling & Gerhardus, 2017; Hand et al. 2019).

Approaches identified to optimise the recruitment of older persons and carers as co-researchers were the use of a wide range of networks and recruitment strategies to ensure the diversity of experiences and perspectives (Schilling & Gerhardus, 2017; Hand et al. 2019; Markle-Reid et al. 2021; McNeil et al. 2016; Latulippe et al. 2020). Having targeted strategies to recruit older persons from population cohorts that are otherwise under-represented and hard to reach due to health determinants (e.g., socio-economic disadvantage, functional limitations) was supported (Markle-Reid et al. 2021).

For example, research undertaken in Canada with a focus on the older person experience of multimorbidity had four strategies to recruiting research 'patient partners', which included using existing networks, re-connecting with patient partners who had been involved in previous research, developing relationships with key organisations delivering services to older persons with multi-morbidity, and identifying potential older person co-researchers through health care professionals directly (Markle-Reid et al. 2021). As part of recruiting older persons as co-researchers, financial reimbursement for time (James & Buffel, 2022; Backhouse et al. 2016; Bendien et al. 2022; Buffel, 2015), and travel were supported (Buffel, 2015).

One study shared that it was important to discuss arrangements, such as reimbursement through gift cards or salary, with co-researchers, particularly those receiving external financial support (e.g., low-income support, carer support) where additional income may compromise these benefits (Markle-Reid et al. 2021).

Consideration of the research setting was also widely cited by studies as a key factor in optimising engagement. Using a venue that was familiar, accessible, clearly structured, and quiet was recommended, particularly for projects engaging older persons with cognitive impairment, sensory, mobility, or communication challenges (Schilling & Gerhardus, 2017; Backhouse et al. 2016; McNeil et al. 2016).

Accommodating for non-face-to-face participation for older persons who may experience challenges in engaging in face-to-face activities, was identified in one study (Schilling & Gerhardus, 2017) with examples of having written surveys or postal consultation. Flexibility of location, timing, and contributions of co-researchers was discussed as being particularly important for carers who had to manage the changing health needs of themselves or the older person they were caring for (Markle-Reid et al. 2021).

Allocating time and resources to facilitate the development of rapport and trust between co-researchers (e.g., university researchers and older persons and their carers), was foundational (Blair & Minker, 2009; Hand et al. 2019; Markle-Reid et al. 2011; McNeil et al. 2016; Bendien et al. 2022). Examples included allowing for regular contact to support feedback and the establishment of relationships (Markle-Reid et al. 2021) and having a designated research lead to act as a conduit between co-researchers, and to act on the needs of co-researchers through relationship building (Markle-Reid et al. 2021).

In other research, implementing multiple mechanisms of feedback between co-researchers, both informal and formal, was key (e.g., reflective meetings) (Baldwin et al. 2018; Cairns et al. 2022). An example of an approach applied in multiple studies was appointing co-researchers to research advisory groups (e.g., reference group, advisory committee, panel group, working group – terms often used interchangeably) (James & Buffel, 2022; Schilling & Gerhardus, 2017; Backhouse et al. 2016; Buffel, 2015) to facilitate feedback mechanisms.

To optimise co-research engagement in data collection methods, the need to be creative and accommodate for different needs and experiences, was supported. Methods cited were largely qualitative and included photovoice (James & Buffel, 2022; Corrado et al. 2020), surveys (Schilling & Gerhardus, 2017), interviews (Buffel, 2015), visual ethnography, focus groups, and theatrical

improvisation workshops (James & Buffel, 2022; Backhouse et al. 2016). Methods specific for engaging carers included co-design workshop moderated by expert facilitators to organise, interpret, and synthesise emerging issues (Graffigna et al. 2021; Gheduzzi et al. 2020). Few studies provided guidance around the engagement of older persons and their carers as co-researchers in the stage of data analysis. One study reported having older person co-researchers involved in data analysis through workshops (Buffel, 2018), and another described the processes used to engage older persons in qualitative data analysis (e.g., iterative cycles of data coding) (Buffel, 2015). Of studies providing evidence of older person engagement in the dissemination of research findings, approaches used included having co-researchers as co-authors on written outputs and presenting findings at conferences or other dissemination platforms (James & Buffel, 2022; Markle-Reid et al. 2021; Littlechild et al. 2014).

Table 2. Approaches to optimise engagement of older persons and their carers as co-researchers in participatory health research

Research Processes	Approaches to optimise older persons and carers engagement in participatory health research as co-researchers
Study design	<ul style="list-style-type: none"> • Have an emergent study design (Backhouse et al. 2016) (e.g., engage co-researchers in deciding on project title and promotional materials (James & Buffel, 2022)) • Allow flexible participation tailored to individual needs (e.g., lots of breaks to avoid fatigue, small groups combined with larger group discussions) (Schilling & Gerhardus, 2017; Hand et al. 2019; Markle-Reid, 2021) • Provide clarification around what being a co-researcher involves and roles (Schilling & Gerhardus, 2017; Markle-Reid, 2021; McNeil et al. 2016) • Allow time for development of rapport and trust between co-researchers, including opportunities for regular feedback (Blair & Minker, 2009; Hand et al. 2019; Markle-Reid, 2021; McNeil et al. 2016; Bendien et al. 2022) • Provide training in research methods, terms, skills, and other relevant project training at the beginning of the project (James & Buffel, 2022; Fudge et al. 2007; Schilling & Gerhardus, 2017; Buffel, 2018; Blair & Minkler, 2009; Markle-Reid, 2021; Daly et al. 2021; Miah et al. 2020) • Providing opportunities to refine skills (e.g., undertaking interviews with peers) (Daly et al. 2021) • Use of reference groups, advisory committees, panel groups, and working groups (James & Buffel, 2022; Schilling & Gerhardus, 2017; Backhouse et al. 2016; Buffel, 2015) with co-researcher involvement to guide research
Recruitment of co-researchers	<ul style="list-style-type: none"> • Use of wide networks (e.g., primary care health professionals or peak organisations) (Liljas et al. 2017; Lord et al. 2022; Kirk et al. 2021) and multiple strategies to ensure diversity in recruitment of older persons and carers as co-researchers (Schilling & Gerhardus, 2017; Buffel, 2018; Hand et al. 2019; Markle-Reid, 2021; McNeil et al. 2016; Latulippe et al. 2020) • Framing co-researcher title using positive language (Buffel, 2018) • Reimbursement for co-researcher time (James & Buffel, 2022; Markle-Reid, 2021; Backhouse et al. 2016; Bendien et al. 2022) using preferred remuneration means (e.g., voucher, salary)

<p>Setting</p>	<ul style="list-style-type: none"> • Use a venue which is familiar, accessible, clearly structured, and quiet, particularly for co-researchers with cognitive or sensory impairments (Schilling & Gerhardus, 2017; Backhouse et al. 2016; McNeil et al. 2016) • Flexibility in location, timing, and role for individual needs (e.g., accommodate for non-face-to-face participation (e.g., postal consultation, surveys (Schilling & Gerhardus, 2017)) and for the needs of family caregivers) (Markle-Reid, 2021)
<p>Data collection methods</p>	<ul style="list-style-type: none"> • Having co-researchers support participant recruitment and data collection with other older persons (e.g., conduct interviews) (Buffel, 2018) • Use of specific activities and data collection methods for older people with different conditions and experiences (Schilling & Gerhardus, 2017) (e.g., methods used include photovoice (James & Buffel, 2022; Corrado et al. 2020; Sebastiao et al. 2014), surveys, and postal consultations (Schilling & Gerhardus, 2017)) • Use of interactive data collection methods e.g., narrative interpretive interviews, visual ethnography, focus groups, and theatrical improvisation workshops (Schilling & Gerhardus, 2017; Backhouse et al. 2016) • Co-design workshops or consensus building methods (e.g., Delphi process) for carers with expert facilitators to organise, interpret, and synthesise emerging issues (Graffigna et al. 2021 Burnell et al. 2015; Gheduzzi et al. 2020) • Frequent reflective meetings and feedback to co-researchers (Buffel, 2018; Markle-Reid, 2021; Baldwin et al. 2018), including informal and formal feedback mechanisms through the research process (Tanner, 2012; Cairns et al. 2022) (e.g., how their feedback has been used) (Markle-Reid, 2021) • Having skilled facilitators to engage with perspectives of co-researchers (Markle-Reid, 2021)
<p>Data analysis</p>	<ul style="list-style-type: none"> • Involvement of co-researchers in data analysis through workshops (Buffel, 2018) (e.g., coding qualitative data in pairs (Buffel, 2015)), discussion of data interpretation (Bindels et al. 2014), or individual reflective processes (e.g., diaries) (Di Lorito et al. 2020), followed by data analysis undertaken by academic researchers (Fang et al. 2016)
<p>Research dissemination</p>	<ul style="list-style-type: none"> • Having participants as co-authors on research outputs^{12, 38, 66} • Having co-researchers present research findings at conferences and public engagement events (James & Buffel, 2022; Markle-Reid, 2021; Littlechild et al. 2014)

Despite the documentation of approaches to engaging older persons and their carers in participatory health research, there was little information available regarding ethical considerations of engagement (Schilling & Gerhardus, 2017). Scholars working with older persons living with frailty and their carers identified ethical challenges around navigating institutional ethics arrangements for engaging with older persons with cognitive impairment, and what to do if researchers encounter older persons who are at risk, such as those experiencing physical, emotional, or financial

abuse (Holroyd-Leduc et al. 2016). For specific population groups (e.g., First Nations Elders), guidance exists in the form of an international synthesis of ethical guidelines for engaging First Nations Peoples in health research (e.g., Consolidated Criteria for strengthening the reporting of health research involving Indigenous Peoples) (Huria et al. 2019). To our knowledge, no such guidance exists for the engagement of older persons and their carers in participatory health research which synthesises international ethical guidelines.

Considerations for engaging specific population groups

As older persons and their carers are not a homogenous population, considerations for specific population groups are presented in Table 3. These considerations are largely determined by the scope and focus of the research. However, diversity has been cited as a goal of recruitment of older persons and carers as co-researchers (Schilling & Gerhardus, 2017; Buffel, 2018; Hand et al. 2019; Markle-Reid, 2021; McNeil et al. 2016; Latulippe et al. 2020).

Underpinning considerations for the listed population groups (Table 3), should also be considered, including the inter-generational differences of older persons and their carers which are shaped by social and political experiences (Groot & Abma, 2018), and how this mediates relationships established between co-researchers (e.g., younger co-researchers, like generation X (born from 1965 to 1980)) within the research team.

For example, participatory health research undertaken in the Netherlands grouped co-researchers according to historical events (e.g., war generation (born 1901-1930), the silent generation (born 1930-1940), the protest generation (born 1940-1955)) (Groot & Abma, 2018) to account for differences in experiences and perspectives. Having a breadth of experience and perspectives in co-researchers not only allows maximum variation, but also has the potential to enrich the research. Considerations specific for co-researchers with dementia and their carers

that expand on approaches to optimising engagement discussed earlier, include promoting the visualisation of research materials and processes (Schilling & Gerhardus, 2017; Lord et al. 2022), and providing additional time throughout the research process for all co-researchers to develop rapport (James & Buffel, 2022; Schilling & Gerhardus, 2017; Waite et al. 2019).

For older persons with comorbidities or complex conditions, the need to accommodate for flexible participation which allows for individual limitations (e.g., mobility), and a lack of continuity in participation (e.g., due to illness) was reiterated (Schilling & Gerhardus, 2017; Holroyd-Leduc et al. 2016). One study discussed an approach of supporting carers to facilitate the participation of older persons experiencing frailty and highlighted that for this cohort the role of carers was crucial to engagement (Holroyd-Leduc et al. 2016).

Participatory research undertaken with First Nations Elders in colonised countries offers valuable insights into strategies to engage with older persons as co-researchers. These include using Indigenous theories, research methodologies (e.g., Kaupapa Māori (Simpson et al. 2021), Tribal Participatory Research (Goins et al. 2011; Webkamigad et al. 2020), and methods (e.g., yarning (Cox et al. 2022; Cairns et al. 2022; Smith et al. 2021)) as part of the participatory research process.

Examples of an Indigenous theory applied in research undertaken in New Zealand is Kaupapa Māori (Simpson et al. 2021) which holds Māori ways of doing and being as central to the research process. In Australian Aboriginal and Torres Strait Islander health research, yarning has been applied as an Indigenous method to obtaining in-depth qualitative insights from Elders (Cox et al. 2022; Cairns et al. 2022; Smith et al. 2021). Further, participatory health research undertaken with Elders has identified the importance of being guided by local cultural knowledge (Cairns et al. 2022) and adhering to ethical guidelines concerning the conduct of research, specifically the relationship between community members and researchers (Beks et al. 2022). Evidence around considerations for engaging older persons and carers from culturally and linguistically diverse communities is sparse. Strategies specific to engaging older persons from culturally and linguistically diverse communities include the importance of having other co-researchers with a shared language

and culture to facilitate a culturally safe and comfortable environment (James & Buffel, 2022; McMurdo et al. 2011), and translating plain language statements and letters of invitation into relevant community languages (Feldman et al. 2008).

For older persons residing in non-metropolitan settings who may experience geographical barriers to engaging in face-to-face activities, there was little evidence available. One study reported using online co-design methods (e.g., through a videoconferencing platform), however, this particular study was limited to the involvement of carers residing in remote locations that were not otherwise described (Latulippe et al. 2020). Examining strategies to optimise the engagement of older persons and their carers residing in non-metropolitan settings, is an area for future research.

Table 3. Consideration for engaging older persons and their carers from specific population groups.

Population group	Considerations for engaging older persons and/or their carers
Older persons with cognitive impairment	<ul style="list-style-type: none"> • Ensuring accessibility of information and adapting the information and activities to the group (Schilling & Gerhardus, 2017) and individual needs (Waite et al. 2019; Lord et al. 2022) • Having frequent knowledge refreshers of research progress (Schilling & Gerhardus, 2017) • Setting a pace which is appropriate for all co-researchers (Schilling & Gerhardus, 2017; Waite et al. 2019) • Using visualisation of research materials and processes (Schilling & Gerhardus, 2017; Lord et al. 2022) • Providing time for all co-researchers to develop rapport (e.g., for older persons with dementia) and mutually supportive relationships ((James & Buffel, 2022; Schilling & Gerhardus, 2017; Waite et al. 2019) • Being in a familiar place (Waite et al. 2019)
Older persons with comorbidities and/or complex conditions, including mental illness and disability, and/or frailty	<ul style="list-style-type: none"> • Flexible participation that allows for limitations in continuity of individual participation (e.g., due to morbidity, frailty, or death) (Schilling & Gerhardus, 2017; Holroyd-Leduc et al. 2016) • Recruit a diverse range of older persons with multimorbidity, particularly those who are otherwise hard to reach and under-represented (Markle-Reid et al. 2021) • Support carers to assist in engaging older persons experiencing frailty (Holroyd-Leduc et al. 2016)
First Nations Peoples	<ul style="list-style-type: none"> • Yarning in interviews and yarning circles with Elders (Cox et al. 2022; Cairns et al. 2022; Smith et al. 2021) • Using Indigenous research theory to guide participatory processes (e.g., Kaupapa Māori (Webkamigad et al. 2020), Tribal Participatory Research (Goins et al. 2011, Webkamigad et al. 2020) • Adhere to ethical guidelines concerning Indigenous research (Beks et al. 2022) • Being guided by local Indigenous knowledge (Cairns et al. 2022)

<p>Older persons from culturally and linguistically diverse communities</p>	<ul style="list-style-type: none"> • Having other researchers with shared language (bilingual) and culture (James & Buffel, 2022; McMurdo et al. 2011) to engage with and conduct interviews with (Feldman et al. 2008) • Translate plain language statements, letters of invitation and other project materials into relevant community languages (Feldman et al. 2008)
<p>Older persons residing in non-metropolitan settings</p>	<ul style="list-style-type: none"> • Online co-design methods using videoconferencing platforms (Latulippe et al. 2020)

Conclusion and recommendations

Barriers and facilitators to research participation and engagement specifically experienced by older persons and their carers were identified. Approaches to optimise the participation of older persons and carers in participatory health research were synthesised, with considerations for specific population groups.

A greater focus is required for these specific population groups, particularly older persons and carers residing in non-metropolitan settings.

Although undertaking rigorous participatory health research with older persons and their carers is resource intensive, the process has the potential to be transformative because of the ability to generate outputs of relevance to older persons and their carers, aligning with the recommendations of the Australian Government's Royal Commission into Aged Care Quality and Safety.

Review findings are of value to researchers, health services, and policy makers seeking to translate policy recommendations into practice by promoting the transformative participation of older persons and their carers to build more responsive systems of health care.

Three recommendations are provided to translate the Royal Commission

recommendation to involve older people and their carers in research into practice.

- It is necessary for policy-makers and practitioners to consider the barriers and enablers of engaging older people and their carers in health research, and as co-researchers when implementing calls for research funding, and designing research projects.
- To optimise engagement of older persons and their carers as co-researchers and move beyond consultation, targeted strategies need to be implemented through all stages of the research process. These strategies may require additional resources (e.g., funding, personnel) and time to allow for engagement.
- Targeted strategies are required to optimise the engagement of older persons and their carers as co-researchers from specific population groups. These specific population groups include older persons with cognitive impairment, older persons with comorbidities and/or complex conditions, including mental illness and disability, and/or frailty, First Nations Peoples, older persons from culturally and linguistically diverse communities, and older persons residing in non-metropolitan settings.

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Contact:

Adj AProf Rebecca Haddock
Executive Director Knowledge Exchange
Australian Healthcare and Hospitals Association.
Email: rhaddock@ahha.asn.au

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AHHA acknowledge the Aboriginal and Torres Strait Islander peoples as Australia's First Nation Peoples and the Traditional Custodians of this land. We respect their continued connection to land and sea, country, kin, and community. AHHA also pays our respect to their Elders past, present, and emerging as the custodians of knowledge and lore.