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Engaging under-represented oldest old in research: An approach for inclusive recruitment

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Abstract

Introduction: Those aged 80 years and over are the fastest-growing sector of the Australian population but are often excluded from research. Oldest old people living alone, in disadvantaged neighbourhoods, and with ill health or dementia, face additional barriers that may hinder their participation in research.

Methods: This paper contributes timely critical commentary on methodological and ethical approaches to engaging under-represented people in research. We draw on our experiences and reflections from a study of social exclusion of people aged 80 years and older living alone in government housing in Melbourne, Australia.

Results and Discussion: We suggest key factors to facilitate representation of this population group in future research. These factors include using door-knocking to gain access, cultivating trust with participants and gatekeepers, and conducting face-to-face home interviews. We also interrogate ethical and safety issues for researchers and oldest old participants including the potential for informed consent protocols to exclude this population group.

Conclusion: To avoid unintentionally excluding the oldest old, researchers need to consider older persons' self-determination and advocate for methods that ensure oldest old perspectives inform future healthy ageing planning and reduce possible health and well-being inequities.

KEYWORDS

80 and older, aged, ageism, ethics, research, social marginalisation

1 | INTRODUCTION

People aged 80 and older are often referred to as the oldest old[1] and may still continue live for over a decade, especially in high-income countries.[2] Little is known about the complex needs and skills of the oldest population, partly due to their omission from research.[3,4] This underrepresentation is unjust from a social equity perspective[5] and may lead to inaccurate conclusions about either the negative or positive experiences of ageing. Thus, it is important to identify ways to increase participation of the oldest old in research.

Barriers that prevent oldest populations from participating in research include deteriorating health, difficulty accessing services (e.g. due to transport, cost and time)

or poor understanding of written materials.[6] Mistrust of researchers may also discourage those from socio-economically disadvantaged backgrounds.[6] Additionally, barriers to including older populations in research may also stem from researchers' decisions associated with ethical or practical considerations, such as perceived difficulty obtaining informed consent, systemic ageism, unconscious bias and concerns about safety.

Often, research studies with older people impose an unjustified upper age limit primarily because of concerns regarding cognitive impairment and potential difficulties obtaining informed consent.[7] Discrimination or systemic ageism is likely partly responsible for such views about the oldest old as participants.[8] In socio-economically disadvantaged settings, the oldest old may be overlooked as potential research participants due to researchers' and gatekeepers' assumptions about their desire and capacity to participate.[9]

Research protocols and processes can also result in oldest old people being excluded, even if a specific age limit is not applied. How a researcher approaches a community and attempts to gain entry can influence participant recruitment, with inter-personal relationships being key. Direct face-to-face contact,[10–12] partnering with community groups,[9] and in-person recruitment in community settings[13] are suggested as effective strategies for engaging 'underrepresented' populations in research. Connections to the participant community and long-term positive relationships are important assets for working with older people in community research.[14] Agreement to participate is also influenced by the empathy and concern demonstrated by interviewer. Perceived benefit may also promote participation.[12]

Reducing barriers to oldest people participating in research is both a practical and ethical concern. Few studies specifically include strategies for engaging the oldest old, especially those from disadvantaged backgrounds. Specifically, there is little critical discussion of doorknocking recruitment as a method for including the oldest old in research. Therefore, drawing from our research experience, this article contributes critical commentary on practical and ethical approaches to engaging underrepresented older people in research.

Practice Impact

It is possible to include people aged 80 years and older from disadvantaged backgrounds in research by enabling agency of older people. Doorknocking is an ethical and viable recruitment method that could ensure that the oldest people's perspectives inform future healthy ageing planning and help reduce health and well-being inequities.

TABLE 1 Summary of doorknock response of older people public housing.

Doorknock response	Number ($n = 150$)
Non-contact (did not open door)	56
Contact, but ineligible	83
Too young	78
Cognitive difficulties	2
Non-English speaking	3
Potentially eligible	11
Refusal	3
Interviews achieved	8

2 | METHODS

2.1 | The social exclusion study

This article presents experiences of and reflections on a qualitative study as part of a larger project exploring social exclusion among the oldest old, living in single older person public housing in a socio-economically disadvantaged suburb in Melbourne, Victoria, Australia.[15] The specific research questions were—(1) What are the perceived factors that exacerbate or protect against social exclusion? and (2) to what extent does this group perceive themselves to be socially excluded?

As part of a larger study, eight oldest old participants were recruited via doorknocking older person public housing units (see Table 1 for recruitment response). In-depth semi-structured interviews were conducted between March and May 2019 in the participants' residence. Ethics clearance was granted by the Australian Catholic University Human Research Ethics Committee (ethics approval number 2018-280H). Verbal or written consent was sought and received from all participants.

The study results produced a narrative that contradicts common assumptions about social exclusion among the oldest old. These findings prompted critical discussions among the authors regarding methodological and ethical choices that enabled or curtailed the inclusion of oldest old participants in research. This article reflects on doorknocking because there is little critical discussion in the literature of this recruitment method as a potential option for greater inclusion of the oldest old.

2.2 | Reflective research approach

The research team undertook reflective research practice, informed by an anti-ageist critical gerontological

approach.[16] The lead researcher, who is a woman, living with her family and half the age of the oldest old, maintained a reflective journal (Tables 2 and 3). Then, the research team discussed suitable and evidence-informed recruitment approaches and de-briefed the recruitment and interview experience and lessons learned. A targeted scoping review of academic texts was conducted to inform analysis of the practical and ethical issues raised and their implications for future research. The following lead researcher account is written in the first person.

3 | RESULTS AND DISCUSSION

3.1 | Doorknocking as a method to find and access marginalised populations

Previous research has recruited people aged 80 years and older through general practitioners and people from disadvantaged backgrounds in collaboration with community organisations.[9] Failing to recruit people who are not connected to services is frequently cited as a major limitation in research with disadvantaged communities.[17]

Our experience from previous community development work with older people showed that doorknocking can aid the recruitment of otherwise socially disconnected older people into community programs. However, doorknocking has been discouraged in disadvantaged neighbourhoods on the grounds of potential safety risks to field researchers and 'the distinct likelihood of failure',[18] as people are unlikely to open their doors to strangers. This view is not supported by the recent literature. For example, in one 2023 study, doorknocking was the most successful recruitment method among public housing residents.[19] A feasibility study investigating dementia prevalence in community also utilised doorknocking to recruit under-represented population groups.[20] However, neither of these studies reflected on the challenges or enablers of their approach.

A potential pitfall of doorknocking is that receiving unsolicited visitors may cause distress to prospective participants. To mitigate the potential for distress, a poster with my photograph, name and brief description of the study was displayed in prominent community settings such as the neighbourhood house and health centre foyer prior to doorknocking commencing. We also informed the local police station, housing estate managers and local community health centre staff of the date of doorknocking, so these authorities could vouch for our authenticity and reassure residents. We received no follow-up calls or correspondence from these services.

Table 1 summarises the recruitment response to doorknocking of older person public housing. We adopted a systematic approach to doorknocking all units in each block and were quickly able to identify eligible participants; people 80 years or older who were living alone. On average, 15 homes were approached per hour. For practical and ethical reasons, such as the time constraints to complete the study and assuming older person agency in their choice to open the door, a decision was made to limit the doorknocks to one attempt. Sixty-three per cent of people opened their doors, but most were ineligible because they were too young, had cognitive difficulties (and had to be excluded as required by the Human Research Ethics Committee [HREC]) or did not understand English. Of 11 eligible persons, 73% agreed to be interviewed.

Although it may seem that doorknocking 150 homes for eight respondents is a low response rate and therefore resource-intensive, six of the eight participants did not engage with community or health services, hence would not have been reached using traditional recruitment methods via community referrals. While eight participants is a small sample, this was enough to provide rich and detailed qualitative data for our study.

The possibility of coercion was a key concern for the research team. To give people time to consider their willingness to participate, the research protocol involved explaining the study verbally to eligible participants during the doorknocking visit. I explained I was 'just a researcher' and in no position to deny or influence any current or future care required. Potential participants were left with an information sheet and I conducted the interview after the consent form had been signed. All consenting participants were given the choice of when they would like to be interviewed and where.

Reflection on participant selection is an important but rarely reported aspect of qualitative research because 'researchers do not just collect and analyse neutral data; they decide who matters as data. Each choice repositions inquiry, closing down some opportunities while creating others'.[21] Therefore, an account of participant characteristics of those who consented and a reflection on the recruitment process is provided below. These participant profiles were formed over the course of recruitment and interviews and were based on my impressions noted in a reflective journal. Along with participants names, some additional details have been slightly amended or omitted to protect anonymity.

3.2 | Tailored recruitment messaging for oldest old

Framing participation requests around our desire to learn from the oldest old experts was instrumental in successful recruitment and reflected a genuine commitment to reciprocity,[22] accepting the inherent wisdom of the research

TABLE 2 Researchers' reflections on participant recruitment.

Participant	Reflections
Mary	As I approached Mary's unit a man with many tattoos (including one around his neck) and walking a pit-bull terrier wanted to know 'what's going on here?'. Fighting back nerves (he looked intimidating) I told him my reason for being there and then he introduced me to his mother. Turned out looks can be deceiving, as he was a loving and caring son. Mary had been very sick and was just out of hospital, hence her son's visit. Mary was 91 and had lived in public housing all her life. Born with polio, she had to develop resilience from a young age. Her grief over the death of several of her children was palpable and she did not get out of her house because 'maybe I'm not quite over the deaths yet'. Mary recognised she was going blind but was determined to do things herself, 'even if it takes all day'. About 20 years ago, when she first moved to her unit, she wanted to help older people and had established a social group. It lasted a few years (until she got too sick herself). She said she was not lonely herself
Edith	My understanding and non-intruding approach paid off with Edith. She let me into her house on my third visit. On the first and second visit she said she felt too sick (but she said I could come and try again). On the third time, she had home-help cleaning her bathroom. I imagine her change of mind was something to do with safety in numbers. Edith was 82 and had lived in public housing in the area since the break-up of her marriage. She had no choice on where she was housed, and she ended up in a neighbourhood she never warmed to. Edith raised four children and then one grandson on her own. She did not have much to do with her kids anymore because of difficult family relationships. Edith had a nasty car accident a few years ago and was still in a neck brace. She needed a walker to get around her flat. She was annoyed that her prescriptions were no longer delivered to her door. She said walking to the letter box was too painful. Her brother came about once a week and took her out for a drive and some shopping. She looked forward to that. She was adamant that she did not want to join a social group. She loved her cat
Holly	Holly was 81. As I arrived at her house, I met her daughter in the driveway. She was about to take her mother to a medical appointment (Holly had had a fall and broken her wrist). Holly's daughter agreed I could try and speak to her mum the next day. Holly usually got out of bed at 2 pm but she had made a special effort to get up early on the day of the interview. Holly had lived in her current unit for about 20 years. She had to find somewhere to live after her husband died, as she could not afford anything on her own. Sometimes her son lived with her. Before her stroke, she used to drive him to his Centrelink (welfare) appointments. Holly liked going to the pokies (gaming venues); she met friends there
Andrew	Andrew was 89 and had lived in his unit for about 9 years. He absolutely loved his home and was proud of how neat and tidy he kept it. He told me he had a disability, and because of that he got fantastic help from the council. He had lived with his son previously, but things did not work out. He was divorced and had four children, two of whom were adopted. Andrew had a lady friend who had died 4 years ago. He missed her – 'She was the best woman I ever had' he reminisced. Andrew's daughter had undergone an operation recently and he hoped she would be well enough to visit him soon. He did not get any other visitors. He had a pet bird and felt content with the way things were
Geoff	Geoff was 88 and had been the main carer for his disabled son. He moved to his current unit after his son died. Geoff's daughter came over regularly to check in on him and was there when I doorknocked. She helped facilitate the discussion between myself and her dad, but he seemed reserved throughout the interview. As a way of explaining his curt replies, his daughter divulged to me that her dad had been raised in an orphanage and that the death of his wife had gutted him. Geoff seemed more engaged in our conversation when we talked about his dog and footy team
Tom	Tom was 85 and born in the British Isles. When I knocked on his door, I had interrupted his cleaning; 'My carer is about to come over you see' he explained, but he was more than happy to stop and talk to me. Things did not work out with his marriage and he had no children. He had lived in public housing more or less since he arrived in Australia, and his current home for 11 years. He had a dog for company. He was treated for cancer, and when discharged from hospital he had a carer assigned to help him. He looked forward to outings with his carer. Apart from that he did not go out socially, but he was fine with that
Chris	Chris was 81 and born in Mediterranean Europe. He was divorced and had one son. Facing bankruptcy in his later years (aged about 70), he was relieved to be offered a home in public housing. Chris said after he retired (aged 78) it was hard for him to find something to do. He loved gardening. He planned to grow food that he can give to his neighbours. Chris was the only person in the sample who had a car. He drove to the shops, and to watch his granddaughter and grandson play basketball. He would like to re-partner, because he missed the romantic company of women
Clifford	Clifford was 82 and born in south-eastern Europe. He was initially very suspicious of my research motives. He did not trust the government and described *My Aged Care* (Australian Government aged care service) as the 'Mafia'. He had had several turbulent relationships with women and had one son who was removed from his custody. Clifford felt helpless when his son was in prison. Clifford had a heart condition and a serious back injury. At work, he had lifted a frozen cow carcass that had severely injured him. That is what led him to public housing. He liked this public housing estate much more than the previous one because it was safe, and he could grow some fruit trees. He might consider going to a social group, if someone he knew went with him, or was there. He felt embarrassed to go by himself

Note: Pseudonyms and accounts have been altered to protect anonymity.

participants.[23] For example, the original recruitment message was changed from one of hoping to 'better support' older people to one of hoping to 'learn from' older people and their experiences. This minimised the anxiety that potential participants may have had around needing support, and the loss of independence that this signifies.[15]

TABLE 3 Reflections on ethical considerations impacting recruitment, extracted from reflective journal.

Excluded participant	Reflections
Nicole	Upon introducing myself to Nicole (pseudonym), she gripped my arm and ushered me inside her home. Nicole appeared distressed and was difficult to understand. I spent some time with Nicole, reassured her, and later made enquires at the local health centre for a welfare check. Nicole was known at the health centre, and a visit from a dementia support worker was arranged. The decision to not interview her seemed warranted. However, politely declining to talk to her (as set out in the protocol) and then leaving was deemed inappropriate, as I considered it an ethical duty to alleviate her distress
Lana	It was not immediately obvious that Lana (pseudonym) may have had cognitive decline and after gaining consent, I proceeded with audio recording an interview. Lana was able to demonstrate good communication skills and answer in detail as to what she had been doing recently. Her 'don't know' and 'can't remember' seemed initially plausible. Only after further probing, repetitive stories, concern for her missing sister (who I suspected may have been deceased) and noticing visual clues such as a calendar with marked visits from a nurse and a locked medicine case, did I suspect that Lana was cognitively impaired. At that point, I ceased asking interview questions and engaged in a conversation that was of interest to Lana – the much-loved neighbourhood cat. I checked with staff at the local health centre, and they confirmed that Lana came to a dementia-specific support group, and in their opinion was well and safe. This interview was not transcribed nor included in the analysis due to the ethical concern of potential cognitive incapacity to consent. However, as Lana was able to communicate and express her wish to participate, the choice to exclude her interview was a difficult one

Note: Pseudonyms and accounts have been altered to protect anonymity.

The non-threatening emphasis on 'telling your story' aligns with successful research recruitment among other excluded populations.[5]

3.3 | Consider using family gatekeepers to enable participation but be aware of the potential for coercion

In our study, it is possible that trusted others, referred to as *gatekeepers*, facilitated access to some participants. For five participants, it soon became apparent by their comments that they required assurance from a trusted other (e.g. 'I'll get my daughter to read over it [the participant information sheet], to see if it's important'). In this study, *gatekeepers* were participants' children or grandchildren. Some gatekeepers were visiting the participants because they were caring for their relatives or were about to take them to an appointment. That these gatekeepers were in the house when the researcher doorknocked could be the reason the door was opened.

The initial intention was to interview participants one-on-one. However, in some cases, a gatekeeper was present during the interview. While gatekeepers may facilitate participation of oldest old people in research due to their role in 'protecting the older adult from unnecessary, inappropriate, or unsafe intrusion by strangers',[24] attention must be paid to the potential for gatekeepers to influence the interview.

In one instance, I felt that one gatekeeper was influencing participant well-being during the interview by encouraging discussion of things that made the participant uncomfortable, such as the exclusionary experience of being removed from family as a young child to live in a state-run boys' home. My decision to prematurely conclude that interview was made to minimise gatekeeper influence in the production of knowledge and possible coercion or power imbalances. The imperative to find, interview and hear the voices of hardly reached older people tests researchers to carefully weigh the ethics related to the potential benefits and risks of gatekeepers being present on a case-by-case basis.[8]

3.4 | Inclusion of people living with Dementia

Given the high proportion (one-third) of the oldest old having some degree of cognitive impairment,[25] excluding them from research may represent ageism embedded in research practice. From an anti-ageist and human rights viewpoint, people in their 80s and 90s should be seen beyond vulnerability, and their exclusion from research due to cognitive capacity needs rectifying.[26,27] Indeed, some researchers argue that, for people who are cognitively impaired, the benefits of being included in the research far outweigh the potential risk of participant discomfort, as dignity is enhanced by their inclusion.[27]

Following the standard HREC approval processes, the consent protocol for our study stated that if a potential participant was confused, for example, having difficulty finding a word, not making sense when speaking, interrupting or ignoring the researcher, the researcher would not proceed with recruitment. In practice, however, the

recruitment process and subsequent exclusion of participants with suspected cognitive impairment was not predictable and raised some ethical concerns. This was evident in two cases described in Table 3.

The cases in Table 3 demonstrate that while current practices for recruiting people over 80 years old often require rigid assessments of cognitive decline, in practice, ethics protocols need some flexibility to take into account the researcher's ability to aid participation in tandem with an assessment of the persons willingness to participate in the process of informed consent.[27] For Nicole, flexibility in the ethics protocol would allow for the provision of ethics of care that she needed, even if she was not included. For Lana, who wanted to be interviewed, a more flexible protocol may have prevented her exclusion. Nevertheless, allowing more flexible protocols for assessing informed consent requires that researchers are sharp observers and socially attuned, and may not be appropriate in all cases (e.g. where the researcher is inexperienced at working with people living with dementia). Some level of protective ethical standards is valid; however, ethics committees should consider the expertise and skills of the researchers applying for ethical clearance.

Several approaches in the current literature show promise in this regard, such as an inclusionary approach that centres around the person with dementia's interests[28] or the *Evaluation to Sign consent tool*[29] that have been proposed among Australian dementia researchers.[27] However, more work is required to dismantle ageism in research, especially recruitment practices that too rigidly prescribe assessments of cognitive decline as automatic exclusion from participating. Human research committees should go further in considering self-determination to participate to counter potentially ageist views about older peoples' interest in and capacity to participate in research.

3.5 | Consider emotional and physical safety when conducting qualitative research in disadvantaged settings

My (author NP) knowledge of the area and community development employment had built my skills in recognising and mitigating any possible safety risks. One example of a safety risk while doorknocking was when a man came to his door and invited me inside with inappropriate comments that constituted sexual harassment. I relied on the strict inclusion criteria (participants over 80 years) to decline the man's unwanted sexual advances by saying, 'sorry, my research is about people over the age of 80, because you are younger, sorry I can't interview you'. With a formal rationale for declining the invitation, the man's advance was curtailed. Other safety mechanisms used during the interviews included choosing to position myself closest to the door, leaving the door open and declining invitations to tour participants' houses or gardens. Doorknocking occurred during daylight hours and another member of the research team was notified of the location and time of the doorknocking. Recognising that women and ethnic or racial minorities may experience heightened risks during recruitment via doorknocking is imperative for ensuring researcher safety.

When conducting qualitative research among oldest old from disadvantaged backgrounds researchers should be appropriately prepared for potentially traumatic or triggering conversations. For example, in this study, some participants discussed topics that were distressing for them (e.g. family violence), and difficult for me to hear. Specific protocols should be in place for researchers' emotional distress, including debriefing strategies, peer support, buddy systems and self-care,[30] as well as training in trauma-informed qualitative research to support researcher and participant well-being.[31]

Discussing sensitive topics such as social exclusion and then leaving the person alone does pose an ethical and social quandary. The standard practice was to provide information detailing local support; however, some literature points towards the potential therapeutic impact of ongoing interview participation.[32] A one-off doorknocking and a solitary interview could leave the participant feeling disappointed that there was limited opportunity for social engagement.

In some cases, to meet ethical obligations, it may be necessary for the researcher to arrange a welfare check to ensure participants (or prospective participants) have access to care. There was one instance where I was asked while doorknocking 'please help, can you come in?' Upon entry, there was the smell of excrement, and I observed a person living with disability trying to draw attention to a packet of biscuits that they were struggling to open. After opening the biscuits and holding a cup with a straw to their mouth, I enquired and learned that their disability support worker had not come that morning, and this person had been unable to eat or use the toilet since the previous day. Although this person was too young to be included in the study, I felt I had the ethical responsibility to help them. So, I rang the disability support manager to notify them of their client's situation. This example highlights that when conducting research in disadvantaged neighbourhoods, some of the practical advice to limit researcher risk, such as not entering the homes of non-participants during recruitment, may not be realistic, and does not facilitate ethical judgments.

4 | CONCLUSIONS

Methods, as well as ethical and safety considerations when engaging difficult to reach populations in research, are rarely described. By describing these experiences, we enter a dialogue about how some methodological and ethical practices may inadvertently lead to the exclusion of the oldest old from research. Doorknocking is a novel, ethical and effective method of recruiting this under-represented population group.

We did not set out to examine why people did or did not take part in the study and so are cautious about generalising from what we report here. With that caveat, we offer five key recommendations:

- Doorknocking is a key strength in recruiting socially unconnected tenants.
- The recruitment message should be targeted to the sensitivity of the intended audience.
- Flexibility around the presence of gatekeepers such as family carers, should be considered.
- Notwithstanding the ethical dilemma of informed consent, flexibility in ethics protocols may facilitate greater inclusion of people with cognitive decline in research.
- The emotional safety of researchers and participants working in this context should be prioritised.

These efforts and adaptations to recruitment are encouraged to improve the representation of under-represented voices in research.

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