Flinders University | Research Centre for Palliative Care, Death & Dying

Unpaid Carers Research Roundtable and focus group:

Summary report of discussions

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Prepared by

Research Centre for Palliative Care, Death and Dying (RePaDD)
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Acknowledgment of Country

Flinders University was established on the lands of the Kaurna nation, with the first University campus, Bedford Park, located on the ancestral body of Ngannu near Warriparinga.

Warriparinga is a significant site in the complex and multi-layered Dreaming of the Kaurna ancestor, Tjilbruke. For the Kaurna nation, Tjilbruke was a keeper of the fire and a peace maker/law maker. Tjilbruke is part of the living culture and traditions of the Kaurna people. His spirit lives in the Land and Waters, in the Kaurna people and in the glossy ibis (known as Tjilbruke for the Kaurna). Through Tjilbruke, the Kaurna people continue their creative relationship with their Country, its spirituality, and its stories.

Flinders University acknowledges the Traditional Owners and Custodians, both past and present, of the various locations the University operates on, and recognises their continued relationship and responsibility to these Lands and waters.

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Executive Summary

On 30 April 2025, the Research Centre for Palliative Care, Death and Dying (RePaDD) held a research roundtable at Flinders University City Campus. The aim was to discuss research priorities and key considerations in establishing a research agenda for unpaid carers of older adults, individuals requiring palliative care, and those nearing the end of life. With the support of RePaDD's funding, this event welcomed researchers, carers' advocacy organisations, people involved in policy and planning, and carers with lived experience. It was a productive and collaborative day as ideas were shared and connections were forged.

The event was opened by Prof Jennifer Tieman, Director of RePaDD, who gave an overview of RePaDD's focus and research on carers, ageing and end of life, including CareSearch, CarerHelp and Palliative Care Connect. Dr Sara Javanparast and Dr Tomi Omoya, shared preliminary studies that RePaDD team is currently undertaking. These included a review of Australian carers' policies, an umbrella review of international literature on carers' support models, an environmental scan of Australian initiatives and programs to support carers, and an online survey of key stakeholders to identify research priority areas.

Following the roundtable, we conducted an online focus group (on 12 June 2025) to engage with those who were unable to attend the research roundtable. Five people participated in the focus group, including one carer with lived experience, one university researcher, one health practitioner, a representative from a carers' advocacy organisation and a rural health expert. Dr Sara Javanparast and Prof Jennifer Tieman facilitated the focus group with a similar but shorter format to the roundtable. Participants shared their views on areas of research priority and visions about collaborative carers research.

Research roundtable

Panel discussions

As part of the roundtable, a panel discussion took place, involving representatives from carers advocacy organisations and carers with lived experience, to reflect on carers' involvement in research. The panel included:

- **Annie Dullow**, a past carer with lived experience of caring for her mother with dementia;
- **Imelda Gilmore**, a past carer with lived experience of caring for her husband with early onset Alzheimer's disease;
- **Allison Willis**, Principal Policy & Advocacy Advisor from Carers SA; and
- **Helena Kyriazopoulos**, CEO of Multicultural Community Council of SA.

The key points highlighted from the panel are:

- Carers need to be involved in research about carers

- Sharing carers' stories is a critical part of any carer research. These stories offer a human perspective on the profound nature of caring until the death of the patient and beyond

- Carers are survey fatigued. Early and meaningful engagement in the research process is essential to ensure that carers' voices are heard from the outset of a project, starting with formulating the research question and grant writing and continuing through data collection, analysis, and interpretation

- Carers need to be supported to understand research processes. Researchers should plan for ample time before the research to connect with and introduce research activities to carers.

- Participating in research and sharing their personal and emotional experiences requires an act of courage from carers. Researchers must recognise and respect this by conducting regular wellbeing check-ins, holding one-on-one meetings when necessary, and providing debriefings. These practices are crucial for building trust and relationships. Carers' contributions should also be adequately funded in research

- It is important to recognise and respect the evolving caring responsibilities and therefore provide flexibility regarding when and how much they can contribute to research

- Carers are diverse, and researchers must take the challenging path of engaging with hidden voices, including those who do not speak English and those living in rural and remote areas. This necessitates that researchers consider additional investments and resources for travel and interpreting services. Valuing and gathering diverse stories is what makes the research powerful and capable of making a difference in carers' lives.

The panel was followed by questions and comments from the whole group, which provided further insights and recommendations regarding carers’ engagement in research. The complex nature of forms of carer engagement and what constituted the appropriate representation of carers given the diversity of carer experiences was noted. A repository of caregiver stories, including video stories, was suggested as an initial step. There was a consensus that a combination of methods, including online and face-to-face interactions, should be considered to engage with carers.

Carers’ leadership in research (beyond co-design and co-production) was another area highlighted as needing genuine change in research processes and mindsets concerning how research is designed and implemented. Finally, participants emphasised the importance of ethical processes, adequate funding for carers’ inclusion in research, and reassurance regarding risks and sensitivity.

Table discussions

Throughout the roundtable, participants engaged in interactive sessions at five different tables, each comprising researchers, people involved in policy and planning, and carers with lived experience. This format encouraged them to discuss and provide reflections by answering three sets of questions:

1. What does an aged care/end-of-life carer research program look like?
2. What does a carer-researcher partnership look like?
3. What is the roadmap for action for the next 6-9 months (until the end of 2025)?

Responses to each of the questions above offered valuable insights into the future direction of carers' research. Participants shared not only broader priority areas but also specific activities or research projects that could be taken into account for future planning and partnerships. Key themes and recommendations are summarised below:

1. End-of-life carers research program: Key considerations

The roundtable discussions provided valuable insights into key considerations for designing a collaborative research program focused on carers. These included the overall research and engagement strategies that should be taken into account, as well as specific areas that participants regarded as essential.

Applied and participatory research that incorporates implementation science and human rights theories and frameworks was highly recommended. A strength-based approach in research was considered essential. Carers bring unique experience and expertise to research, and this should be appropriately utilised in the design and conduct of research to ensure that carers' needs are addressed.

Research aimed at developing evaluation frameworks and examining the adaptability and scalability of existing services must be prioritised. It was acknowledged that funding to test novel ideas, although challenging, is essential for exploring new models of support services. Carer-led research and qualitative approaches to collect and synthesise narratives were also emphasised. There was a consensus that any research about carers should include sufficient funding to compensate for the contributions of carers with lived experience and carers' advocacy organisations. Meaningful engagement with carers' advocacy organisations facilitates relationship building and an understanding of cultural issues when working with carers. Researchers must appropriately recognise their critical role and contribution.

Participants emphasised the importance of recognising and including diverse groups of carers in research to ensure unheard voices are acknowledged. The necessity of exploring various pathways for carer support, tailoring existing services to accommodate the needs of different carer groups, and considering cultural sensitivity in carers' research were also highlighted.

Several specific areas emerged as particularly significant in the research on carers:

Carers' transition into aged care

Carers encounter significant challenges and changes when transitioning from the community to aged care, including issues related to access to information, involvement in care planning, and shared decision-making. Participants highlighted specific questions that can be explored through research:

- What is the range and nature of support currently offered to carers during the transition period and in the aged care setting? What gaps exist?
- What does the carer-staff partnership entail in the aged care setting?
- How can the aged care staff support carers during and after transition into aged care?
- What training do aged care staff require to effectively communicate with and support carers while enhancing their understanding of the ethics and legalities surrounding carers' engagement? What mechanisms and strategies should be put in place?
- How can we best support carers in managing their grief and emotional challenges during the transition to aged care?
- Transitioning to aged care would free up some time for carers. How can carers be supported to return to employment and address the financial impacts of caring (onsite support as well as ongoing support)?

Workplaces and carers

Another priority area for research identified by the roundtable participants relates to carers' rights and workplace support to help them balance work and caring responsibilities. Potential research questions identified by participants are:

- What tools are available to identify carers and assess their needs in the workplace?
- How aware are employers of the Carers Recognition Act? What measures are in place to support carers' rights?
- Narratives from carers about balancing work and caring responsibilities provide valuable insights. What are the success stories? What are the gaps?
- What are employers' perspectives on carers' support and its impact on productivity, staff satisfaction, and workplace culture? What success stories from employers can be adapted?

Digital technology

Utilising digital technology and AI to support carers has been recognised as an area that requires further exploration and research. This encompasses the use of digital technology to enhance carers' knowledge and skills, as well as providing social and psychological support and remote monitoring.

Post-caring phase

Carers need continued support after the death of the person they cared for. This support includes grief and bereavement assistance, as well as financial and employment aid, to help carers cope with personal loss and the loss of identity and purpose. Death literacy is particularly important for end-of-life carers, enabling them to navigate the complexities of death and dying, understand the end-of-life options available, make informed decisions, and address the practicalities surrounding death and dying. Research can examine the coping mechanisms of carers during grief and bereavement, the psychological impact, social support, and financial assistance after the caring phase.

2. Carer-researcher partnership: Enablers and barriers

Participants discussed the panel's key points regarding carers' involvement in research, what a carer-researcher partnership should entail, and the factors that enable or hinder meaningful collaboration in research. Participants reaffirmed the reflections shared by panel members and offered additional comments on the carer-research partnership:

Training for carers and researchers

It was agreed that both researchers and carers require training to ensure meaningful dialogue and engagement. For carers, training should be provided in a format that is understandable and meets their needs, covering areas such as research processes, ethics, and co-authorship. Consumer training courses are already designed and can be offered to empower carers with the research knowledge and skills they need. One example is the consumer training course offered by the Cancer Council, which was very useful, as one carer stated.

Researchers must also possess human communication skills, cultural awareness, and the ability to navigate different perspectives and potential conflicts between researchers and carers with lived experience. A participant provided an example of linking early career researchers and research students with consumers during their studies to maximise learning and, in the long term, enhance research culture.

Flexibility in carers' contribution

Carers, particularly current carers, are time-poor. Participants commented on the need for flexibility to allow carers to adjust the nature and level of their involvement based on their changing circumstances (e.g., being a Chief Investigator on a project through to providing more occasional input at different stages of research).

Times and modes of communication

The key points raised by participants regarding time and methods of communication in research are:

- Early and ongoing engagement is vital
- Allocating sufficient time to build relationships and trust is necessary
- Engaging with community leaders, community organisations, and carers advocacy organisations helps identify the best strategies for communication. For instance, using flyers in various languages or providing spaces where carers feel more comfortable

- Face-to-face interaction, online communication methods, surveys, and diaries for reflecting on experiences are just a few of the strategies that should be utilised and tailored to ensure maximum engagement and response from carers and consumers.

Acknowledging carers' contribution

Aligned with points raised by the panel members, participants emphasised the need for appropriate compensation for carers' time and contribution.

3. Roadmap for action

In the final exercise, participants were asked to share their thoughts on a roadmap for action for the next 6-8 months that the RePaDD team should consider. Three main areas for consideration, as recommended by participants, are:

- ***Policy alignment:*** ensuring that research aligns with policy priorities (e.g., carers, aged care and disability policies) and exploring related research opportunities

- ***Funding opportunities:*** exploring potential funding sources, including philanthropic and social science field funding, community funding, and major government funding schemes

- ***Establishing and maintaining relationships with researchers, carers and carers advocacy organisations:*** exploring funding sources to enable ongoing engagement and contribution, examining different payment schemas for carers involved in research at state and national level, approaching community organisations, investigating existing registers of carers and consumers, and calling for expressions of interest to gather a pool of potential carers interested in research, including their area of interest and level of participation.

Participants also shared two specific research ideas for consideration:

- A feasibility study exploring carers support during the transition from community to aged care; forming partnerships, examining service gaps for two groups of carers (one about to transition to aged care and the second after transitioning to aged care), co-designing and mapping out support models, and conducting an economic analysis to explore the viability of the support model

- Stakeholders' interviews to follow up with the 33 initiatives identified in the environmental scan to further examine their alignment with policy priorities and how service gaps have been met.

Focus group discussions

Focus group participants shared their views on carers' research priorities, which generally aligned with those of the roundtable participants. However, some additional and specific areas were discussed in more detail.

Undertaking research that is carer-centred was particularly emphasised. Research with a primary focus on carers' needs, support, and wellbeing, rather than viewing them as secondary to the person receiving care or as incidental research targets, was considered crucial. This approach will help shift the culture within health, aged, and palliative care systems, where carers' needs and support are often overlooked. In line with roundtable discussions, early recognition of carers, self-identification, and the use of tools to assess carers independently from patients were identified as key priorities for research and action.

Challenges related to system-level changes, such as limited capacity, understanding, and awareness, were identified as barriers to adopting research evidence in practice. To address these issues, collaborative research and codesign processes involving meaningful engagement with both consumers and healthcare providers were recommended.

Participants discussed the importance of clearly differentiating between family or friend carers and volunteers, as their roles can often become confused in practice. This is due mainly to the unpaid or informal nature of the care provided by both groups. Acknowledging the significant contribution of volunteers in health and aged care settings, focus group participants emphasised that these are two different concepts that should be recognised in any research involving family or friend carers. The confusion also exists among many carers and various cultural groups, who may see themselves as volunteers rather than carers. Therefore, using a clear definition for carers and the nature of the caring relationship is essential in research, as volunteering is usually organised through an institution or organisation, and volunteers may have different backgrounds, relationships, and experiences from family carers.

The diversity of carers and carers' support in rural and regional areas was particularly emphasised. Carers take on a greater role in these areas, mainly because of limited access to health and aged care services and a lack of awareness about the available services. Aligned with the roundtable discussions, focus group participants highlighted that research on carers should avoid viewing carers as a single, uniform group and instead recognise their varied needs. Additionally, carers caring for a person living with dementia experience considerable emotional adjustment as their loved ones' cognitive abilities decline steadily over time. The lived experience shared in the focus group highlights the unmet needs of dementia carers and the importance of multidisciplinary research to support them in the early stages of their journey.

Grief and bereavement support for carers was another common theme that emerged from the focus group discussions. Participants identified several barriers, including patient-driven funding systems that offer limited support for bereaved carers and difficulties in recruiting carers who are grieving for research purposes.

Community-based initiatives and compassionate communities were emphasised as a key research approach to empower communities as active citizens, bolster social capital, and reduce reliance solely on government, health, and aged care systems. Instead, communities should be empowered to lead grassroots initiatives and support each other. The compassionate community approach is an expanding field and should be integrated into the carers' research agenda to ensure networks are developed around carers who need support during caring and grieving.

Along similar lines to the suggestions from the roundtable participants, focus group attendees stressed the importance of carers being involved in research that's meaningful, respectful, flexible, and properly acknowledged and recognised. A positive comment from one of our participants with lived experience was that there is a growing acceptance and emphasis on consumer involvement in research, research co-design, and acknowledgment of consumers' time and contributions to research.

Next steps for RePaDD

1. We have completed the analysis of the stakeholders' survey and prepared a short report. The report will be shared alongside the roundtable and focus group summary report.
2. We will complete other preliminary works currently underway and prepare related publications. These include a review of carers' policies, an environmental scan of carers' support initiatives in Australia, and an umbrella review of international literature on carers' support models and what works or doesn't work. Publications and reports from these works will be shared with participants.
3. Based on the preliminary works and roundtable/focus group discussions, we will draft a research agenda that includes the top 3-5 areas of research priorities. We will call for expressions of interest to identify who is willing to contribute or lead in these areas. This may lead to the establishment of a working group to further discuss roles and responsibilities, funding opportunities, and action plans.
4. We will develop a plan that identifies and supports ongoing engagement with carers who contributed to the roundtable, as well as those involved in our previous carers' projects, and other carers who are interested in being involved with carer research through RePaDD.
5. We will draft a manuscript for publication based on the process of developing a research agenda (including an online survey, roundtable discussions, and a focus group) and offer co-authorship to those who contributed to this process.

About the Flinders Research Centre for Palliative Care, Death and Dying

The Research Centre for Palliative Care, Death and Dying (RePaDD) is hosted by the College of Nursing and Health Sciences at Flinders University.

The Centre's mission is to make a difference to palliative and end-of-life care by examining issues and challenges experienced by people living with a life-limiting illness, their families and carers, and health and care professionals supporting them.

RePaDD comprises of a multidisciplinary research team with a diverse set of skills and experience in working in a variety of settings. The group has an extensive track record in delivering successful national palliative care projects as well as high impact research and evaluation relating to palliative care, community experience of death and dying, innovative models of palliative care, and the contribution of palliative care to individuals at the end of life, health professionals and health and social care systems.