

THE HOSPITAL RESEARCH FOUNDATION STATEWIDE COLLABORATIVE PALLIATIVE CARE PROGRAM

MY STORY, OUR JOURNEYS: A PROSPECTIVE, LONGITUDINAL, MIXED-METHODS STUDY

Overview: This prospective longitudinal study will capture behaviours, experiences, and key moments over time that shape how and why people living with a life-limiting illness who need assistance with their care needs, and their chosen carers from underserved South Australian communities make decisions about care at the end-of-life. This will enable the development of resources to ensure timely provision of information to, and support for, patients, families, and carers negotiating and living with decisions about care at the end-of-life.

Where: Participants will be recruited across metropolitan and rural South Australia, with the support from partner organisations, local government and community organisations, and SA Health LHNs. Interviews will typically be held in the participants' home/s, or might include residential aged care facilities and clinical settings.

When: Recruitment is planned to commence in **September 2023** and will be open until **September 2024**. Following participants and their carers for ~18 months, final interviews for this study will be in **March 2026**.

Who:

- A person approaching the end of life (likely to die within the next 12 months), and their chosen carer
- Aged 18 years and above
- English-speaking
- From one of 1) Culturally and Linguistically Diverse, 2) Rural, and 3) Low Socio-Economic populations

How:

A research team from the Palliative Care Research Collaboration will co-ordinate ~three-monthly face-to-face, telephone, or videoconference (e.g., Zoom) interviews, with consenting participants. Through conversations, stories, and a co-created visual map/timeline, we will capture behaviours, experiences and key moments that shape how and why participants and their carers make end-of-life decisions. We will explore changes over time in expectations and experiences, challenges and benefits, needs, expected futures, and other factors that might influence a change in experiences and/or expectations of palliative care. Interviews will be repeated every ~3 months from enrolment to ~3 months following death (bereaved persons only) or March 2026.

FAQs:

What approval processes are in place? The Program is overseen by an Advisory Committee comprising consumers, clinicians, policy-makers, and administrators with relevant expertise and interest in palliative care service delivery. Both consumers and clinicians will be contributing to the design of the study. Ethical approval from the University of Adelaide and SA Health Department of Health and Wellbeing Human Research Ethics Committees (including relevant Site-Specific Approvals) will be in place before recruitment commences.

If needed, what support is available for participants or their carers? As part of the consent process, each participant and their nominated carer will receive a flyer detailing who to contact if they are upset due to participation. Protocols are also in place to direct the research team on how to manage any situations where participants may require clinical intervention, if identified during their contact with them.

How can I find out more information? Contact the below Investigators.

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