

THE HOSPITAL RESEARCH FOUNDATION STATEWIDE COLLABORATIVE PALLIATIVE CARE PROGRAM

WORKING WITH COMMUNITIES: LIVING WELL AS LONG AS YOU CAN (DEATH LITERACY INDEX PROJECT)

Overview: This project involves working with communities to determine if providing materials using culturally appropriate and accessible language through culturally acceptable modes of delivery is associated with an increase in death literacy within their communities (i.e., in the language, knowledge, and practical skills needed to make active end-of-life choices). We will support community leaders to undertake various activities sharing information about death, dying, and grief within their community, assessing death literacy before and after these.

Where: Participants will be recruited across metropolitan and rural South Australia from the three population groups described below, with support from our partner organisations (e.g., Palliative Care SA, Multicultural Communities Council of South Australia, local government and community organisations).

1. Culturally and Linguistically Diverse (CALD) communities: Filipino, German, Italian and Vietnamese
2. Rural communities in Berri, Mount Gambier, Port Lincoln, and Whyalla
3. Low socio-economic status (LSES) communities in the City of Playford and the City of Port Adelaide Enfield

When: Recruitment commenced in **March 2023** amongst the CALD communities and will commence in **July 2023** with the Rural and LSES communities.

Who:

- Individuals aged 18 years and above
- From one of 1) CALD, 2) Rural, or 3) LSES community groups

How:

We will conduct a survey (online or paper-based) using the validated Death Literacy Index (DLI) tool within community groups, before and after community-led interventional activities delivered over a 6-month period. We will analyse results to assess the effectiveness of community-led activities regarding discussions about palliative care, death, dying, and grief, accounting for local conditions and cultural factors. This community-led research will strengthen community resources, providing participant communities with the language, knowledge, resourcing, and practical skills to make active end-of-life choices.

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. Ethical approval from the University of Adelaide has been provided for this study. All materials are developed with and approved by community leaders (including translated materials for CALD communities).

If needed, what support is available for participants or their carers? As part of the consent process, each participant will receive a flyer detailing who to contact if they are upset due to participation. These materials have also been translated into the communities' preferred languages.

How can I find out more information? Contact

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Visit the Palliative Care Research Collaboration website

