

# What do older First Nations people from Adelaide, South Australia and Hamilton, Aotearoa New Zealand need to receive culturally safe palliative care using telehealth?



Yitpi Yartapuultiku, Aboriginal Cultural Centre

## Project Overview

Right now, telehealth palliative care in South Australia and Aotearoa New Zealand may not meet cultural needs. This means Aboriginal people in South Australia and Māori in Aotearoa New Zealand might not get the right care at the end of life.

This project was started by a group of service providers, community members, and researchers. We come from the Northern Adelaide Local Health Network, the University of Auckland, Flinders University, the University of Leeds, the Rauawaawa Kaumātua Charitable Trust in Hamilton, Aotearoa New Zealand and the National Aboriginal and Torres Strait Islander Palliative Care Association, Australia.

## The Team

Dr Rosemary Frey (NZ) is leading this whole project. A/Prof Aileen Collier is leading the work in South Australia, and A/Prof Matthew Allsop is leading it in the United Kingdom. Ms. Toni Shearing (Executive Director, Aboriginal Health, and Northern Adelaide Local Health Network), Ms Cindy Paardekooper (National Aboriginal and Torres Strait Islander Palliative Care Association) and Mrs. Rangimahora Reddy (CEO, Rauawaawa Kaumātua Charitable Trust) have supported this project from the beginning. We want to learn how to make palliative care safe and respectful when using telehealth. To do this, we aim to:

1. Create a group to support research about culturally safe palliative care and telehealth
2. Find practical steps to make palliative care safer for older First Nations people
3. Work with key people in South Australia and Aotearoa New Zealand to create a shared research plan.

## Why a roundtable?

We hosted a half-day roundtable event in Adelaide bringing together consumers, services, researchers and health and care professionals in the context of ageing, caring, palliative care needs and end of life. The aim for this roundtable was to talk about what research First Nations People want, practical actions to improve care, future partnerships, and funding ideas for healthcare and research. Two researchers led the discussions. Over 50 people participated.

The questions posed included:

1. What are the practical actions we can take now to improve culturally safe palliative care for older people and their communities?
2. What are the new combined knowledges and /or understandings we need to promote culturally safe palliative care for older people and their communities?



## Who spoke at the round table?

To get us all thinking about the yarn we started the day with several presentations. **Alex Houthuysen (Hill)** kicked things off. Alex is a proud Aboriginal Yamatji Burringurrah man from the Central Western Desert of the Pilbara region of Western Australia who introduced our day. When Alex resigned from the aviation industry, he began a lifelong journey of discovering his true cultural identity, as a Stolen Generations survivor. Alex is currently working within St John's Youth Service Senior Management as the Aboriginal Culture Broke. He supports Aboriginal & Torres Strait Islander young people to break the cycle of homelessness, to move to a place they can call home, a transition to independence and to reconnect with community.

Alex also retains a position as an active board member of the Aboriginal Veterans SA and the Veterans Advisory Council to SA Government. He serves as Chair of the Governance and Performance Committee for Aged Rights Advocacy Service. He also holds the position of Deputy Chair of Aboriginal Family Support Services. Alex is also deputy Chair of Port Adelaide Enfield Council Aboriginal Advisory Panel and an active board member of Turkindi Aboriginal & Torres Strait information service. He told us about the history of Yitpi Yartapuultiku, Aboriginal Cultural Centre and the significance of the building and its spaces for Aboriginal and Torres Strait Islanders in Adelaide.

After Alex we heard from **Kathy Pearce and Cindy Paardekooper** from The National Aboriginal and Torres Strait Islander Palliative Care Association Inc. (NATSIPCA) about their model of Comfort Care to promote culturally responsive, safe, and compassionate support at the end of life. Then we heard from **Dr Ariana Parella and James Bevan** from SAHMRI's Wardliparingga Aboriginal Health Equity unit. Adriana and James provided an overview of the breadth and depth of work the team are doing to support Aboriginal and Torres Strait Islanders to age well. Adriana and James' presentation showed how important the SA Aboriginal health research accord is in doing research WITH older people. It highlighted how culturally safe care for older people is critical at all stages, including the end of life. Their presentation provided a great segway into the final presentation by **Zena Bonney** (Aboriginal Cultural Advisor, Northern Adelaide Local Health Network) and **Dr Sheree Cross** (palliative care doctor). They shared a project called "My Journey Needs Rounds." Co-designed with the community, the needs rounds are multidisciplinary meetings that identify residents nearing the end of life, ensuring that care plans are in place and the drugs that will be needed are prescribed.



# The voices of First Nations People come first.

## What did people say about palliative care?

### 1. *Building Trust, Rapport, and Connection*

Participants emphasised that care begins with authentic human connection and respect for the person's sense of place and comfort.

"I don't want you to come inside, today's not the right time... I want to sit outside, let's yarn at the front, let's sit down under a tree, you know this is my favourite space, this is where I feel more comfortable." (Aboriginal cultural advisor)

"What do I need to know to care for you? Start by being curious." (Aboriginal researcher)

There was recognition that trust and relationship-building take time, and service delivery must allow for that rather than being constrained by efficiency targets. There was also recognition that mainstream service expectations (e.g., completing multiple home visits) can conflict with culturally appropriate care.

"That's not because I haven't done my job—that's because I've respected time." (Aboriginal cultural advisor)

"You've just found out there's a lot of other stuff to unpack here and that's about culture and that's about safety." (Aboriginal cultural advisor)



## 2. Cultural Safety and Respect for Local Ways of Knowing

Cultural safety involves understanding kinship ties, authority structures, “sorry business,” and local ways of doing things, especially for Aboriginal people from different regions (city vs country).

“Not all Aboriginal people are the same, same as culture.” (Aboriginal researcher)

“Understanding sorry business... who is the authority?” (Aboriginal researcher)

“What happens when an outsider doesn’t understand local ways of doing things—how can you address that challenge?” (Aboriginal researcher)

There was also reflection on how systemic pressures can alienate Aboriginal workers from their heritage:

“Some Aboriginal workers potentially forgetting where they’ve come from... manipulated by white people.” (Aboriginal Elder)

There was acknowledgement of diversity within Aboriginal communities—not all are the same, and mainstream systems often fail to recognise this. There was also concern about Aboriginal workers feeling disconnected from their roots due to systemic pressures or “white governance.” And questioning of whether cultural safety principles translate across countries, and how local adaptations can be made.

## 3. Racism, Power, and Institutional Accountability

There was recognition of ongoing racism in healthcare, with calls for stronger anti-racism strategies and accountability (not just firing individuals but reforming structures).

“It’s very sad to hear about racism... what actually are the strategies that we’re putting in place?” (Advanced nurse manager-palliative care)

This included discussion of ‘institutional bending’—the need for services and policies to adapt to the needs and choices of Aboriginal patients rather than forcing assimilation to mainstream norms.

“Make the service, make the actual institutions bend for our patients that we’re meant to be looking after.” (senior nurse)

There was recognition of the Importance of governance and accountability frameworks that uphold equity and community leadership.



## 4. Access, Language, and Equity in Palliative Care

There was concern that the term “palliative care” may exclude people who need support but don’t identify with that label.

“Who’s missing out on palliative care because of the language that we use? If we call it palliative care, are there people who don’t see themselves as having palliative needs?” (Aboriginal researcher)

There was a desire for a more inclusive and community-led model of care where individuals or families can seek help based on perceived need, not just professional referral.

“Imagine a future where you could access a palliative care service because you think you need it, or your family thinks you need it—not because a doctor or nurse decided.” (Aboriginal researcher)

Alongside this, the term comfort care was preferred, aligned with the National Aboriginal and Torres Strait Islander Palliative Care Association (NATSIPCA) framework for discussing and delivering end-of-life care in a culturally sensitive manner. Issues were highlighting around returning to Country for end-of-life care—including logistics, cost, and responsibility.

## 5. Workforce, Governance, and Leadership

There was recognition of the need for advocacy for greater inclusion of Aboriginal leadership, including Elders as investigators and decision-makers in research and service design.

“What models can we put in place so that we get the right people in charge of projects... and make sure we’ve got tangible outcomes?” (Aboriginal researcher)

“Only for the first time last year did I see a Medical Research Future Fund project that had Elder investigators on it.” (Aboriginal researcher)

There was recognition that funding control and distribution can act as barriers to community-led solutions. And there is a need for clear accountability and governance structures that ensure Aboriginal communities lead and benefit from projects.

## 6. Valuing Lived Experience

There was a strong call to fully recognise and compensate lived experience as legitimate expertise in service design and research.

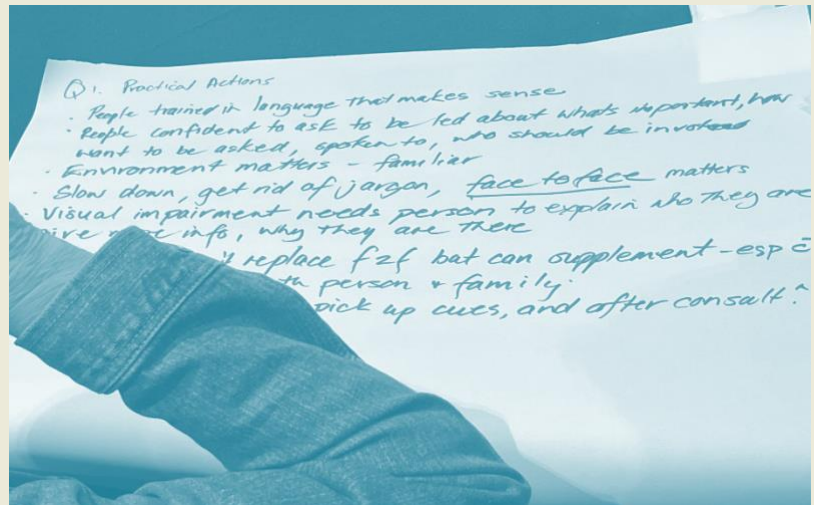
"University of Life—those people providing lived experience getting paid and compensated for that as well." (Advanced nurse manager-palliative care)

Alongside suggestions for a streamlined funding approach to support people with lived experience who contribute to service improvement.

## How might these conversations guide how telehealth is used?

- **Face-to-face first:** Ahead of using telehealth approaches, face-to-face contact should come first to establish relationships and cultural safety. Telehealth could play a supplementary role once trust is built and when distance, mobility, or cost become barriers.
- **Relationship-Centred Design:** Digital interactions must preserve the relational essence of care, allowing people to connect from places of comfort. Telehealth platforms could integrate video or audio options that feel informal and personal, enabling yarning, rather than transactional consultations. Telehealth must also seek to support long-term relationships, not just care based on transactions. Systems should enable follow-ups and consistent provider access to support continuity of care.
- **Flexible Time and Pace:** Scheduling models for telehealth should permit longer, flexible sessions and follow-ups, avoiding strict time limits that undermine culturally respectful dialogue.
- **Inclusion of Liaison Workers and Kinship Networks:** Telehealth systems could enable multi-participant sessions, bringing in family, community liaisons, community-nominated support people, or interpreters as desired—mirroring the kinship-informed approach valued in face-to-face settings.
- **Locally Governed and Culturally Controlled Models:** Digital systems should be community-governed, with Aboriginal organisations leading design, data governance, and implementation, ensuring technology strengthens—not replaces—local authority.

- **Accessible Language and Framing:** Telehealth platforms and educational materials should use clear, culturally resonant language, avoiding medical jargon and framing care around support, family, and wellbeing rather than technical terms that may alienate users.
- **Equity of Access and Return to Country:** Telehealth strategies must address digital inclusion—improving connectivity in remote areas, considering access to devices, and exploring hybrid models that blend virtual care with community-based presence, particularly for those seeking end-of-life care on Country. Whilst telehealth can bridge gaps between city and country communities, it must fit local contexts and resources.
- **Accountability and Evaluation:** Implementation of telehealth should include community-led monitoring and evaluation, ensuring technologies are held accountable to local values, outcomes, and definitions of cultural safety.



## Call to Action

We are committed to improving palliative care delivery via telehealth to ensure that it is culturally safe, respectful, and accessible for all older First Nations people.

- Join us in this journey! Whether you're a health professional, policymaker, researcher, or community member, your voice matters.
- Contact us to collaborate, share your insights, or learn more about our work: [aileen.collier@flinders.edu.au or r.frey@auckland.ac.nz] Stay connected for updates, resources, and opportunities to get involved.
- Together, we can shape a future where every person receives the care they deserve.