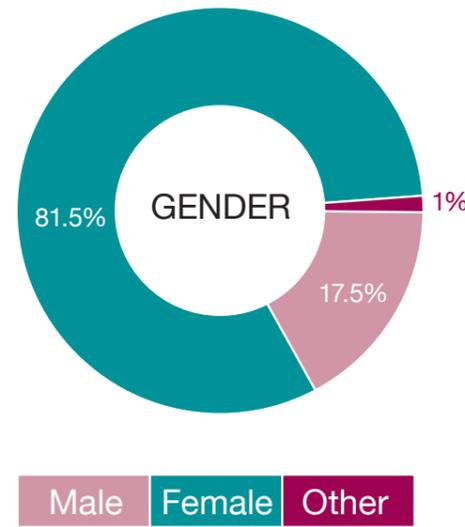
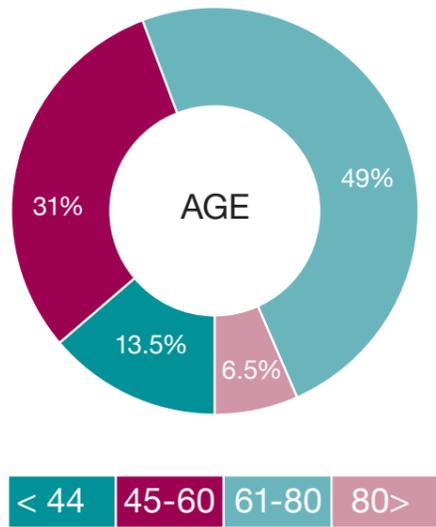
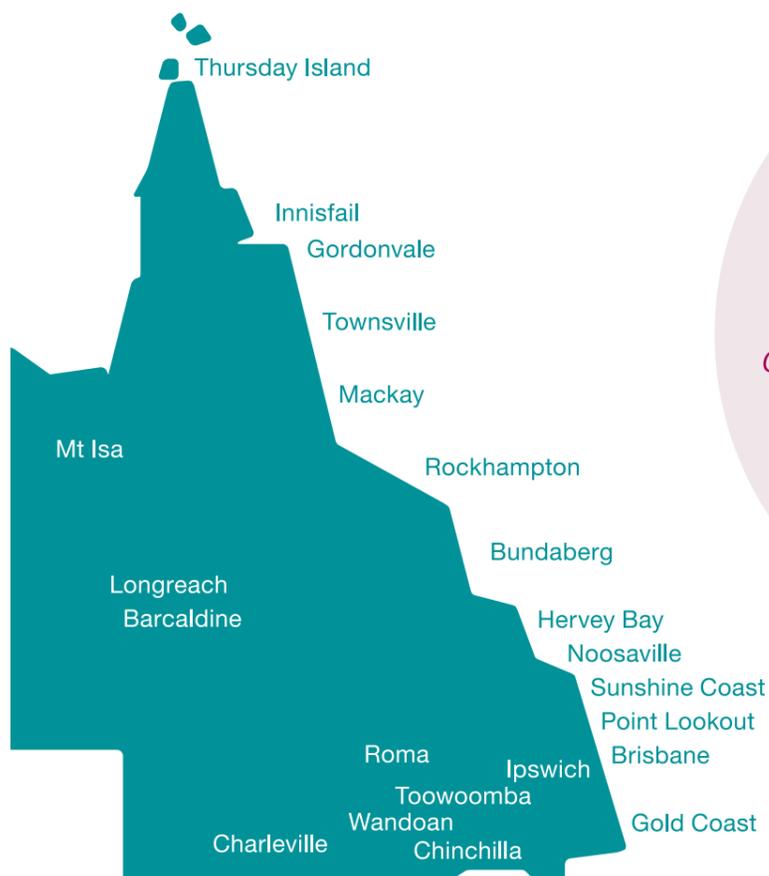


Who We Spoke With



Where We Went



We can't say we can't cope in our culture when caring for loved ones. We look after our own but for this to work we adapt, we manage, we do as we do what's needed for a loved one.

Consumer, Thursday Island



Talking about what matters to you in relation to ageing, end-of-life care and dying

CONSULTATION SUMMARY

Consultation Purpose

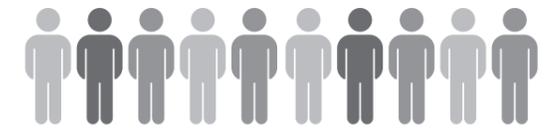
Health Consumers Queensland with COTA Queensland, Palliative Care Queensland and Carers Queensland have collaborated with Clinical Excellence Queensland to facilitate a targeted process of engagement and consultation on “What Matters to you in relation to ageing, end-of-life care and dying. We utilized proven engagement methods to support and enable:

- Reach to a significant number of consumers, carers and community members with varying levels of health literacy and those who are not engaged with health services to inform Queensland Health projects and committees on what community identifies as their priorities.
- Inclusive consultation by hearing the voice of people including rural and remote, Aboriginal and Torres Strait Islander, culturally and linguistically diverse, hard-to-reach and LGBTIQ people.
- Opportunity for informed health consumers and carers to lead the consultation process by facilitating sessions with less-informed community members.

What We Did



400 Queenslanders consulted



Two phases of consultation:

Phase 1: Kitchen Table Discussions



Phase 2: Focus Groups



What We Asked

Kitchen Table Discussions and Focus Groups

- 1 Have you had direct experience engaging with the aged care, health and social sector with a loved one or significant other?
- 2 How does that influence you in terms of the future of your own care i.e. what did you think was good about that care and what did you think was terrible?
- 3 How would you like to see that changed?

Focus Groups

- 1 What's important to you as you grow older, and how can the health system support you?
- 2 Of the answers given to the previous question, which did you think were the 3 most important to you personally?
- 3 If you are unable to fully care for yourself in the future, what kind of support would you want, and where would you like to receive it?

What we heard: key themes

Kitchen Table Discussions

Stay at home	Workforce (carers/health professionals)
Access to quality and timely care and support	Palliative Care
Better information and knowledge, better navigation and choice	Emotional burden and support
Voluntary assisted dying	Financial burden and support
Care choice (choice around what I need/individualised)	Communication
Informal Support system (family carers, volunteers, community)	Transport
	Housing



Focus Groups

- 1 **Support Us**
 - Support to stay at home
 - Care of the Carer
 - Aged Care
 - Palliative Care
 - Hospice Care
 - Dementia Care
 - Navigation and Advocacy
 - Transport
- 2 **Involve us**
 - Communication
 - Respect and listening
- 3 **Empower Us**
 - Choice, Dignity and Rights
 - End-of-life Planning
 - Information
 - Training and Education

How does Queensland Health support consumers and ensure the checks and balances are in place in aged care to ease people feeling fearful of the aged care system?

The chance to support oneself, preserving identity and integrity for as long and as well as possible. Support should extend to friends, family who are engaged in keeping that alive.