

Health Technology Assessment Policy and Methods Review

Dementia Australia Submission

6 June 2023

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

Our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the living experience of dementia across Australia.

Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

In 2023, it is estimated there are more than 400,000 people living with all forms of dementia in Australia. This number will continue to grow to more than 800,000 by 2058¹.

In February, the Australian Institute of Health and Welfare released data showing dementia is now the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women².

¹ AIHW (2023) *Dementia in Australia*. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

² AIHW (2023) *Dementia in Australia, Summary, Impact* <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

Dementia Australia's feedback

Dementia Australia appreciates the opportunity to contribute to the Health Technology Assessment policy and methods review, being overseen by the Reference Committee.

Dementia Australia understands that the review is considering how health technologies are assessed and funded, including the value of health technologies from the perspective of patients and communities, how people with lived experience are involved in evaluations, and the equitable distribution of health technologies.

Dementia Australia supports reforms which improve equity of access to health technologies, and effective targeting of medicines.

Consumer participation

Dementia Australia supports increased transparency, communication and engagement of consumers, in all phases of decision-making during Health Technology Assessment. This involvement should be appropriately supported so that people with cognitive impairment, including those living with dementia, are able to meaningfully participate.

We recommend consulting with [Half the Story – A Guide to Meaningful Consultation with People Living with Dementia, Families and Carers](#), when considering opportunities to improve consumer engagement.

A national neurological diseases patient registry

Many people with neurological diseases, including dementia, access therapies through experimental clinical trials. Dementia Australia recommends the creation of a unified patient registry for neurological and neuromuscular diseases, which would include all types of dementia and mild cognitive impairment.

Currently, the system is not geared to capturing people early enough in disease stage, which means that there are no clinical trial-ready cohorts, infrastructure in place to identify early cognitive change, or common outcome measures.

A patient registry with provision for clinical trial recruitment would enable increased participation of people with early cognitive impairment or dementia to participate in clinical trials for new medicines and technologies and access greater post-diagnosis support. This may be especially important as new disease modifying treatments for dementia are developed which are targeted to early disease stage.

If you would like to discuss any aspect of our submission further, please feel free to contact the Dementia Australia Policy team on policyteam@dementia.org.au.