

## **Submission to the Health Technology Assessment Policy and Methods Review – Consultation 2 options paper**

23/02/2024

Dementia Australia welcomes the opportunity to make a submission to the Health Technology Assessment (HTA) Policy and Methods Review – Consultation 2 options paper.

Dementia Australia commends the efforts detailed in the recent options paper concerning the HTA Policy and Methods Review. The emphasis on elevating the patient voice within this process aligns with our belief in the importance of person-centred care and the value of integrating consumer perspectives into healthcare decision-making.

People living with dementia and their carers face unique challenges and barriers in accessing the treatments and support they need. The options paper's commitment to improving transparency, communication, and stakeholder involvement is crucial for addressing these challenges and enhancing patient outcomes. However, there are still obstacles within the regulatory, evaluation, and funding processes that can delay or restrict access to treatments for people living with dementia.

To ensure that the Review leads to tangible benefits for all Australians, it is necessary to address these barriers. This includes considering the complexities of evaluating and approving treatments for neurological conditions, including dementia, where the measurement of outcomes and benefits may differ from those in other healthcare areas.

We urge the HTA Review committee to:

- Identify and address specific regulatory and assessment barriers that delay the introduction and access to new dementia treatments.
- Enhance mechanisms for patient and carer input, ensuring that their experiences and needs directly inform HTA processes and decisions.
- Implement flexible evaluation criteria for treatments targeting dementia and other neurological conditions, recognising the unique challenges in demonstrating efficacy and value.

- Prioritise the development and funding of innovative therapies that have the potential to significantly improve the quality of life for individuals living with dementia.
- Improve the relationship between Federal and State governments/regulators (possibly through the National Health Reform Agreement (NHRA)) to ensure there is greater clarity regarding data sharing arrangements and timely approval processes and funding arrangements.
- Provide adequate funding and resources for consumer bodies representing people impacted by dementia to engage equitably in the HTA process.
- Support training for consumers to navigate the complex HTA landscape effectively.

Dementia Australia is committed to working collaboratively with healthcare authorities, policymakers, and the wider community to ensure that the HTA review process leads to improvements for people living with dementia, their families and carers. We welcome the opportunity to engage further on these issues.

## Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the more than 421,000 Australians living with dementia and more than 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions. Founded by carers more than 35 years ago, 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 lived 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 neurocognitive disorders which cause a progressive decline in a person's functioning. It is one of the largest health and social challenges facing Australia and the world. There are estimated to be more than 421,000 Australians currently living with dementia and more than 1.6 million people involved in their care. Without a significant medical breakthrough, it is estimated that there will be over 812,500 living with dementia by 2054.<sup>1</sup>

The Dementia Australia Policy team can be contacted at 

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<sup>1</sup> Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare