

Submission to the Co-Design Project: Enhanced Consumer Engagement Process

04/04/2024

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 2054.¹

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

Introduction

Dementia Australia's submission to Co-design of an Enhanced Consumer Engagement Process for health technology assessment (HTA) consultation is informed by feedback from Dementia Australia Advocates. Our Advocates are people living with dementia, and former and current carers, who participate in a voluntary advocacy capacity in our Dementia Advocates program. This submission builds upon our prior submissions to the Health Technology Assessment Policy and Methods Review.

Dementia Australia endorses a collaborative approach to reform, ensuring the HTA process is both inclusive and effective. This submission supports the recommendations and implementation considerations outlined in the consultation document.

Feedback received from our Advocates aligns with the recommendations and implementation considerations outlined throughout the consultation document and emphasises the importance of the recommendations outlined below.

Key recommendations

- The inclusion of dementia-specific considerations in the HTA process, recognising the unique challenges and unmet needs of people living with dementia, their families and carers.
- The importance of involving consumers living with dementia and their carers at all stages of the HTA process to ensure their perspectives, preferences and needs are accurately represented.
- HTA information must be communicated in plain English and other languages, and accessible formats (including audio, visual and other flexible formats) to cater to the diverse needs of people living with dementia.
- Policies that prioritise the development of innovative dementia therapies, especially those addressing unmet clinical needs.
- Ensuring the HTA engagement process is inclusive, representing a broad spectrum of people living with dementia at different stages of the condition, and including individuals from culturally and linguistically diverse backgrounds, other minority populations and people living in rural, regional and remote areas.
- An emphasis on the value of and need to consider both quantitative data and the qualitative experiences of people living with dementia in shaping HTA decisions.
- Development of resources and training programs tailored to enable people living with dementia and their carers to make a meaningful contribution.

- Promote consultation and awareness of current research and trials and encourage people living with dementia to trial new medicines that have proven efficacy.

Enhanced consumer engagement

Enhanced consumer engagement, particularly involving people living with dementia and their carers, is essential for ensuring that Health Technology Assessment (HTA) processes are inclusive and reflective of the experiences of those directly affected by the outcomes of these assessments. By integrating the insights and experiences of consumers and their representative bodies into HTA processes, we ensure these evaluations are informed by current best practices, consumer needs, and expectations. This approach significantly contributes to the credibility and quality of both the training provided to healthcare professionals and the services delivered to individuals with dementia, underscoring a genuine commitment to partnership with key stakeholders.

'Half the story' is a guide to meaningful consultation with people living with dementia, families, and carers and can provide a useful tool when consulting consumers. Half the story can be found [here](#). It is important to ensure that people with lived/living experience are given the opportunity to provide meaningful input and have their voices heard. By taking an inclusive and collaborative approach, organisations can ensure that the needs and perspectives of people living with dementia are effectively incorporated into the HTA processes.

Accessibility and communication

Feedback from our Dementia Australia Advocates consistently highlighted the convoluted nature of the current process for individuals wanting to participate in research or access new medications. Suggestions for an improved experience included creating more straightforward pathways for engagement and ensuring local-level links for those interested in participating. These recommendations align with the proposal for a 'one-stop-shop' portal providing consumer engagement resources and regularly updated notifications about activities occurring in the health technology pathway.

Advocates also noted the importance of ensuring information about new research initiatives and the availability of new medications is accessible and communicated through diverse channels. This information must be disseminated widely across media platforms and forums, including through newspapers, social media, and community and advocacy organisations like Dementia Australia. This ensures that individuals living with dementia and their carers have timely access to the most up-to-date research and related information.

"Information should be detailed in newspapers, social media, through Dementia Australia or any other communication available." Carer

"It is important to use all avenues of communication and whatever is most suitable and comfortable for the person living with dementia and their carers." Carer

Effective communication with people living with dementia and their carers involves utilising existing networks, such as newsletters, community programs and support from healthcare providers like geriatricians, GPs, and service providers. The focus should be on maintaining stable, familiar environments and using the communication methods preferred by the person living with dementia or their carer, including but not limited to telehealth, emails, or face-to-face meetings where possible. Ensuring that information is accessible to diverse groups as well as those living in regional, rural and remote areas is also key to ensuring equity in consumer engagement participation.

"Stay connected via telehealth, emails, meetings, Facetime, Zoom or SMS." Carer

Continuous feedback and improvement

Contributions from Dementia Australia Advocates also emphasised the need for a flexible approach to engaging with people living with dementia and their carers. This acknowledges that as research methodologies and technologies evolve, the strategies for engaging the dementia community and implementing new approaches and treatments must be equally responsive.

"As this is an ongoing process all stakeholders need to be aware that often there will be periods of adapt and improve." Carer

Advocates also identified the need for mechanisms that allow continuous feedback from people living with dementia and their carers once a medicine is approved.

"Being able to communicate with the manufacturer of the drug if there is a problem detailing their concerns & reactions." Carer

After a medicine is approved, continuous monitoring and documentation of the patient's status, reactions, and efficacy of the medication are crucial. This process should involve the patient, carers and support people, and medical personnel to ensure any changes or adverse effects are promptly identified and appropriately managed.

"A person's status prior to medication administration must be carefully assessed...reactions, responses and effects must be monitored, reported and documented." Carer

Training and education

High quality dementia education is essential for anyone involved in health treatment decision-making. Anyone involved in supporting a person with dementia in relation to research initiatives including medical treatments, must have the skills and knowledge to provide communicate effectively. They must also be confident and competent in providing compassionate and person-centred care, supporting informed and nuanced decision-making and capable of guiding tailored treatment strategies appropriate for everyone's needs.

Prioritising dementia education is a critical component in enhancing the care and support of people living with dementia in the context of the HTA process and the broader healthcare system.

"Those undertaking health treatment decisions must be educated about the illness the proposed new medicine is proposed for." Carer

"There are different types of dementia requiring different types of treatments and management. Can't create a one fit all approach." Carer

Consumer representation and co-design

Dementia Australia Advocates emphasised the importance of actively seeking out and valuing the contributions from people living with dementia and their carers. Advocates supported the strengthening of the role of 'Consumer Representatives' and the 'Co-design Working Group' throughout the decision-making processes so that the diverse voices of people living with dementia and their carers are heard. Suggestions from Advocates included expanding these groups to include a broad range of representatives living with different forms of dementia and from diverse socio-economic, cultural and geographical backgrounds and dementia types to ensure genuinely inclusive representation.

"All of the questions can be supported through 'Consumer Representatives' and 'Co-design Working Group'." Carer

Conclusion

The contributions from our Dementia Advocates highlighted their strong collective belief in the importance of a more inclusive, transparent, and simplified approach to health technology assessment and the development of new treatments for dementia. Equally importantly, our Advocates emphasised the need for improved communication strategies that cater to the diverse needs of people living with dementia, the proactive inclusion of their living experience and insights, and consideration of their perspectives in relation to decision-making processes. The need for flexibility and responsiveness in the way in which people living with dementia and their carers are engaged with and participate in research and related processes, and evaluation of research initiatives and treatments was also identified as a key priority in the context of health technology assessments.

We appreciate the opportunity to contribute to this Inquiry and welcome the opportunity for further discussion in relation to any of the recommendations or issues raised in this submission.