



Establishment of a National Mandatory Quality Indicator Program for In Home Aged Care

Dementia Australia Submission

July 2024

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.

The Dementia Australia Policy team can be contacted at policyteam@dementia.org.au. We have dedicated policy and advocacy, consumer engagement and community development staff in South Australia.

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. Dementia is ultimately a terminal condition.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia. This figure is projected to increase to more than 812,500 by 2054.¹ Dementia does not just affect older people. It is estimated that almost 29,000 people in Australia currently live with younger onset dementia - a diagnosis of dementia under the age of 65.²

Dementia is major public health concern and a leading cause of disease burden among Australians aged 65 and over.³ It is the second leading cause of death for Australians and the leading cause of death for women.⁴ In 2023, there were an equivalent of 15 people with dementia per 1,000 Australians.⁵

¹ Dementia Australia (2024) [Dementia in Australia 2024-2054](#).

² Dementia Australia (2024) [Dementia in Australia 2024-2054](#).

³ Australian Institute of Health and Welfare (2024) [Dementia in Australia](#).

⁴ Australian Institute of Health and Welfare (2024) [Dementia in Australia](#).

⁵ Australian Institute of Health and Welfare (2024) [Dementia in Australia](#).

Quality Indicators can improve quality and choice

Dementia Australia supports the introduction of Quality Indicators for in home aged care services and welcomes the opportunity to provide feedback on the proposed Indicators. We are supportive of reforms which improve choice and control for people living with dementia and generate more evidence about the quality of aged care services.

An estimated 67% of people with dementia live in the community.⁶ This will likely increase as more Australians choose to live at home in their older age.⁷ The demand for in home care services is also increasing as more people choose to receive support at home, as demonstrated by the increase of admissions to home care by 267% over the decade to 2022-23.^{8,9}

Dementia has broad social impacts, including being a key factor in the demand for aged care services. Many people living with dementia utilise in aged home care services. The Quality Indicator program will form a critical part of ensuring that these services reflect community expectations for quality care delivered by dementia capable service providers.

There have been significant reforms to the aged care system in the three years since the Final Report of the Aged Care Quality and Safety Commission was released. However, people living with dementia and carers have reported to Dementia Australia that disappointingly, there have been only modest improvements in the quality of their experience of aged care services. They report that most improvements have been made in access to and provision of residential aged care services in major city areas.¹⁰

It remains critical to expand access to quality aged care at home and implement a robust monitoring and regulatory framework for the delivery of care. Dementia Australia is concerned that dementia education of the aged care workforce has still not been made mandatory for all parts of the sector and notes that some in home care providers will not be required to provide dementia capable staff under the new regulatory model and Strengthened Aged Care Quality Standards.

Effective Quality Indicators will be critical to support oversight of quality care and must have built in capability to measure the quality of care delivered to people living with dementia and require dementia capacity in the workforce.

Consultation results

To respond to this consultation opportunity, we worked with our national network of people living with dementia and carers, known as the Dementia Advocates Network. We had 24

⁶ Australian Institute of Health and Welfare (2023) [Dementia in Australia, Prevalence of Dementia.](#)

⁷ Australian Institute of Health and Welfare (2023) [Dementia in Australia, Community Based Aged Care.](#)

⁸ Ratcliffe J. et al (2020) [Australia's aged care system: assessing the views and preferences of the general public for quality of care and future funding.](#) Caring Futures Institute, Flinders University, South Australia.

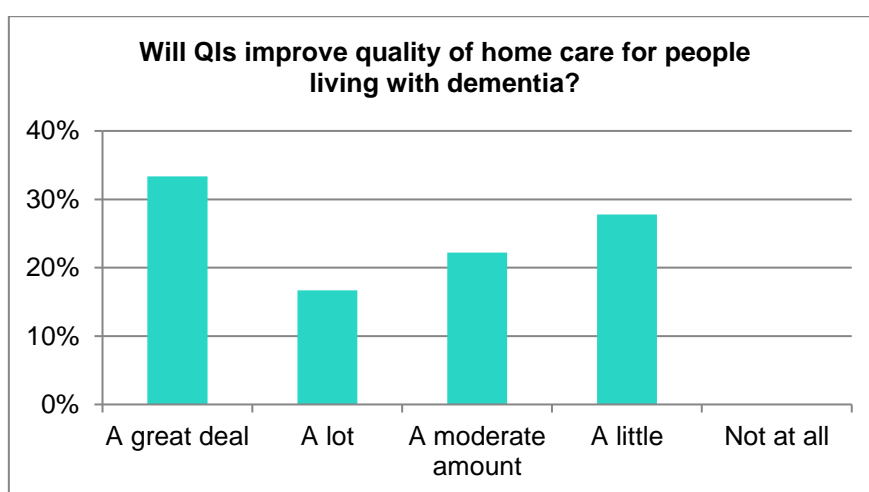
⁹ Australian Institute of Health and Welfare, National Aged Care Data Clearinghouse (2024) [Admissions into Aged care.](#)

¹⁰ Dementia Australia (2024) [Progress Report on Implementation of Aged Care Royal Commission Recommendations.](#)

responses to a survey, consisting of four people living with dementia and 20 carers or former carers. We also consulted through email and phone interview with an additional three people.

Survey responses were received across all states and territories other than Tasmania. There were no responses from First Nations people and most respondents did not identify as culturally or linguistically diverse (92%). Respondents were aged between 56 and 85 years of age, with 46% aged between 66 and 75. Most respondents were female (67%) and none identified as LGBTI. Respondents lived in major cities (46%) and regional areas (54%).

A large proportion of respondents to our survey said that it was likely or very likely that they would use Quality Indicators to inform their decisions about in-home care. There were mixed views about the extent to which Quality Indicators would improve the quality of in-home care for people living with dementia and carers, as indicated below:



A carer observed that “there have to be incentives for in-home care providers to improve and maintain their standards of care and there has to be a valid guide to assist clients, families and carers find the best or most appropriate services to meet their needs”.

While another carer noted that “not having staff or people who commit and show up or notify if unable to attend is one of the biggest issues and this is unlikely to fix those issues”.

Almost all respondents said that Quality Indicators should apply to all in-home care service types, with one noting that they should start with some service types to begin with to determine if they are worthwhile and finesse implementation.

We asked survey respondents what the most important things are that contribute to a positive experience of in-home care for them. Many people emphasised the need for home care workers to be trained in understanding dementia and how to deliver person-centred care to people living with dementia.

Themes in the responses included relationships, actions, compassion, professionalism, communication, understanding of dementia, kindness, understanding, reliability, training, individualised care and consistency.

Some comments included:

“Reliability in carers, having consistency, a good care plan that identifies what support is required, sufficiently trained and motivated staff to complete the care for which they are employed, level of dementia knowledge in carers”

“Good, sensitive, appropriate care tailored to a person's needs”.

We asked survey respondents to rank the proposed Quality Indicators. The top three Quality Indicators were:

1. Quality of Life – how satisfied a person is with their life, including emotional, physical, material and social wellbeing.
2. Consumer Experience – the perspective of the person receiving care on the quality of care and services they receive.
3. Service Delivery/ Care Planning – whether care is planned and individualised for each aged care recipient.

When asked whether there should be any additional Quality Indicators included, many of the respondents emphasised that dementia education was a high priority:

“Training would definitely be high on my list for anybody being asked to give care to a person with dementia...”.

“A thorough understanding of different types of dementia and how to interact”.

“Carers of people living with dementia must have thorough, specialist training in working with people living with dementia and their families”.

“Every carer attending to someone living with dementia must have quality specialist training...”.

“Documentation and reporting of observable changes in a client's cognition, behaviour or physical capabilities”.

There were mixed views on the impact of delaying the implementation of Quality Indicators, with many respondents urging immediate action to ensure that quality of life is maintained for people living with dementia in the community. However, some respondents also noted that a progressive implementation would be useful to ensure that the Quality Indicators are fine-tuned.

Respondents emphasised how critical it is to ensure that there is a high-quality in home care system to provide respectful, rights-based care.

“People living with dementia are vulnerable in every case. I will be my partner's principal carer and I expect very high standards of understanding, training, expertise and compassion

to help me maintain her dignity and quality of life over the next few years which she most thoroughly deserves”.

“Until recently, dementia was thought of as a disease that robbed the person living with it of their dignity. Compassionate, appropriate, considered and intelligent care, and carers, will help those living with dementia experience, once again, the dignity at the end of life that everyone deserves”.

“Quality of life is synonymous with high-quality in home care. Good in home care allows frail, disabled older people to stay in the comfort of their homes and stabilises their lives”.

Dementia Australia received additional feedback about the proposed Quality Indicator model through email and phone interview with people living with dementia and carers.

We heard that it is vital that home care responds to the individuality of each care recipient. Measures of service delivery and care planning need to assess the extent to which the person receiving care is at the centre of planning, as well as the appropriate involvement of their carer and health care support team.

Supported decision-making for people with cognitive impairment or dementia is an important part of the best practice model for care planning and should be measurable in the Quality Indicator framework.

Consistent with reform directions across the aged care system, services need to be rights based, trauma informed, responsive to change and flexible to meet individual needs for each person’s emotional and physical wellbeing. Measures need to take account of how well care is delivered to people from a range of cultural backgrounds. Choice of service providers is also important.

The Quality Indicators should also measure the effectiveness of complaints procedures, including for people with cognitive impairment or dementia. Rights, choices and respect need to be the underlying principles.

Some feedback we received suggested that there needs to be a more nuanced analysis of how the proposed indicators would be used to make improvements to the quality of in home care, including how they are linked to the performance of the home care provider.

Quality Indicators need to reflect measurable and quantifiable outcomes which are meaningfully attributable to the care provided. They will have utility to the extent that they are applied consistently and provide insight into how improvement can be made. They need to provide evaluative measurement of outcomes and experiences.

Recommendations

Dementia Australia supports the establishment of a national mandatory Quality Indicator program with the aim of improving quality of care and providing greater transparency. We recommend that:

1. Quality Indicators apply to all service types delivered under the new Support at Home program, to ensure that at a minimum, supported decision-making is implemented and services are delivered according to the care recipient's choices.
2. Quality Indicators for Quality of Life, Consumer Experience and Service Delivery/Care Planning be prioritised and implemented from the start of the new Support at Home program from 1 July 2025. We recognise the complexity of attributing quality of life outcomes to home care service provision and suggest that this Indicator should consider a range of aspects of care stratified by dementia status, for example supported decision-making and care planning practices; social connection; mental health; hospitalisations; and, medication. Data collection should include self-reported consumer experience outcomes by care recipients and carers.
3. Quality Indicators be designed to measure the quality of care delivered to people living with dementia receiving care at home, including by measuring domains relevant to dementia and by stratifying all reporting against Indicators by dementia status
4. The Workforce Quality Indicator include measurement of the dementia capability of the workforce, for example, staff education, training and mentorship; implementation of appropriate communication, planning, decision-making and complaints practices for people with cognitive impairment; extent of appropriate collaboration with carers and health professionals; and, assessment and documentation of cognitive and physical health.

Thank you for the opportunity to share the insights of people living with dementia and carers into the establishment of a new Quality Indicator program for in home aged care services.

Dementia Australia would be happy to facilitate further engagement with people living with dementia and dementia carers as part of the development of this program, if requested. The Dementia Australia Policy Team can be contacted on policyteam@dementia.org.au.