



Aged Care Data Strategy Consultation

**A Dementia Australia submission to the Department
of Health and Aged Care and Australian Institute of
Health and Welfare**

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Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the estimated half a million Australians living with dementia and 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 almost a million Australians currently living with dementia and around 1.6 million people involved in their care. Without a significant medical breakthrough, it is estimated that there will be almost 1.1 million people living with dementia by 2058.ⁱ

Introduction

Quality dementia data is critical to a successful aged care data strategy. As over two thirds of people living in permanent residential aged care have dementiaⁱⁱ, it is essential that aged care data includes dementia within the data set. At present, data on dementia is captured inconsistently meaning that we don't have an accurate and clear understanding of diagnosis rates, and the corresponding demand for dementia care and support service. Developing an aged care data strategy that specifically incorporates dementia data will contribute to a more detailed understanding of the prevalence and consequences of dementia. Linking the aged care data strategy to the Australian Institute of Health and Welfare (AIHW) dementia data

monitoring work, and in key dementia data sets, is one example of the way in which dementia-specific data sets could be developed and expanded.

What do you think of the draft Vision, Purpose and Guiding principles?

The draft vision, purpose, and guiding principles cover the essential components of an aged care data strategy. As noted above, given the high prevalence of people with dementia living in residential aged care, we would emphasise again the importance of capturing dementia-related data within the broader aged care data set.

Ensuring trust and safeguarding privacy and security must be the highest priority and the fundamental guiding principle of data collection in this context. Strong safeguards to protect people's information will be critical to the strategy. Individuals should be fully informed in relation to what information will be made available and who will be able to access it, and this includes people living with dementia

Dementia is a progressive condition that causes a change in cognitive ability over time and requires a responsive approach to decision-making, including decisions about health care matters. People living with dementia should be supported to make decisions about their healthcare, including decisions requiring informed consent, for as long as possible. This might involve a supported or substitute decision-making process. It is important that people living with dementia in residential aged care can be included in data collection. If a person with dementia can participate in decision-making, supported decision-making is the preferred approach. If the person is unable to participate in decision-making, a substitute-decision-maker can give informed consent for data collection on their behalf.

How well do the Vision, Purpose and Guiding principles align with your organisation's strategies or objectives?

Dementia Australia broadly supports the vision, purpose and guiding principles of the aged care data strategy. However, we would again reiterate the importance of including both qualitative and quantitative data that captures the lived experience of dementia to demonstrate outcomes and impacts as well as measurable outputs.

Dementia Australia's recent research and data collection includes six-monthly outcomes surveys for clients across all our programs and we have commenced using Power BI, a

business intelligence tool, that allows us to combine client and program data to get a better picture of client journeys. We also have a Client Services Monitoring and Evaluation Framework and Strategy document as well.

Digital literacy for people with dementia is an important consideration in any aged care data strategy. If older people are the audience for this data, they need to be able to easily access and navigate it. While the number of older people using the internet has increased, many would potentially have difficulty navigating online menus and reports and might need additional guidance on these elements to ensure legibility and accessibility. As noted above, involving people with dementia, and gaining informed consent in the most appropriate way, will need to be a key consideration in the collection, storage and use of aged care data.

What do you think of the draft Scope in relation to aged care data?

Specific areas Dementia Australia would like to see included in the scope would be to measure service, social impact and outcomes. Outputs are limited in their ability to convey change and do not tell the whole story. However, outcomes and impacts assess whether positive change is occurring.

What areas and activities would you like to see prioritised in the Roadmap?

Within the roadmap, benchmarking data will allow the comparison of organisations to industry standards and identify the areas where the gap between their standard and that of the industry is the largest. This will also enable organisations to more efficiently prioritise the areas that they need to work on and could encourage innovation. Additionally, ensuring that the National Dementia Support Program (NDSP) data is included in the minimum data set will be essential.

Some of the key gaps and opportunities from The AIHW Dementia Data Gaps and Opportunities report are outlined belowⁱⁱⁱ:

Gaps:

- Lack of primary and secondary care data with dementia diagnosis
- Under-reporting and/or inconsistent coding of dementia in key data sets
- Missing data on dementia diagnosis for some aged care programs

- Sample size issues that limit dementia-specific analysis in national surveys
- Lack of information on patient experiences of people with dementia and their carers
- Missing comprehensive data on dementia in the Aboriginal and Torres Strait Islander population
- Lack of timely data on dementia disease expenditure
- Lack of robust data on dementia among culturally and linguistically diverse communities, people with intellectual disabilities and other vulnerable populations
- Lack of comprehensive data by small geographical areas and in Very Remote areas
- Limited information on younger-onset dementia
- Lack of information on dementia types and severity information in key data sets

Opportunities:

- Development of a national data development plan for dementia
- Development of an aged care data improvement plan, with immediate priorities to:
 - assess the need for information on clients' health conditions as part of existing and future aged care administrative data collections
 - review and assess information collected on the new National Screening and Assessment Form
- Continued integration of data sets to improve dementia ascertainment and aim for these to be enduring integrated data sets (as opposed to one-off linkages)
- Use of electronic medical records and My Health Record
- Development of a dementia clinical quality registry
- Implementation of national policy and programs for timely diagnosis, treatment and management of dementia in the community and support of data collection
- Introduction of dementia-specific Medicare Benefits Schedule (MBS) items/incentives
- Exploitation of supplementary codes for chronic conditions in hospital admitted patient data; with potential extension to emergency department data
- Collection of larger sample sizes in national surveys for health-risk-factor-level analysis by population groups of interest, and use of specific codes for dementia
- Introduction of new data items on date of diagnosis/onset of long-term conditions of care recipients in the Survey of Disability, Ageing and Carers

- Development of dementia research targeted at the Aboriginal and Torres Strait Islander population and other culturally and linguistically diverse groups
- Administration of more frequent National Aboriginal and Torres Strait Islander Health Surveys (NATSIHSs), and the inclusion of dementia as a long-term condition in future NATSIHS

What outcomes do you think are most important to this data strategy?

In terms of the outcomes that are most important to this data strategy, amplifying social impact to better understand how best to target services and programs would be critical. It is essential for data to highlight potential gaps in service provision or where services are not working to full effectiveness. Further, it is important to understand how much social impact can be attributed to an organisation's activities by integrating stakeholder feedback to understand community outcomes over time.

What are the most significant barriers and success factors for the data strategy?

Regarding barriers and success factors for the data strategy, some programs are outreach focused and have limited data. There should be a balance with the need for data and need for outreach with Culturally and Linguistically Diverse (CALD) groups, Aboriginal and Torres Strait Islander people, LGBTIQ+ communities, as some groups may be reluctant to share minimum data or there might be barriers to obtaining it. Issues of stigma associated with dementia may affect the likelihood that a person reports their condition. Additionally, language barriers and cultural practices may affect when people are diagnosed with dementia. This means that people from CALD backgrounds may have greater levels of undiagnosed dementia than other Australians, and data pertaining to these groups is likely an underrepresentation.

The Australian National Aged Care Classification (AN-ACC) doesn't easily identify dementia like the previous Aged Care Funding Instrument (ACFI) did and dementia is inconsistently captured in primary care, acute, death, aged care data. Collaboration with the AIHW to better understand the data gaps and opportunities and to ensure they are built into other aged care data systems is required or dementia will continue to be under-represented.

Conclusion

In summary, the aged care data strategy should incorporate dementia specific data to effectively monitor, evaluate, and improve dementia care, policies, service planning and delivery. Accessibility to data should be considered in its dissemination to ensure data users can easily interpret the data as well as considering informed consent for people living with dementia. Benchmarking data should be included to assist in evaluating industry gaps and opportunities for improvement. Working to reduce barriers in obtaining data from CALD groups, Aboriginal and Torres Strait Islander people and LGBTIQ+ groups should also be a priority to ensure these groups are not forgotten within the aged care system. Identifying gaps and opportunities for collaboration will be essential to the success of this data strategy as well as measuring the social impact of programs and policies.

We thank the Department of Health and Aged Care and Australian Institute of Health and Welfare for considering this submission and would welcome any further opportunities for consultation.

ⁱ *Dementia Australia (2018). Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra*

ⁱⁱ *Royal Commission into Aged Care Quality and Safety, Research Paper 8 - International and National Quality and Safety Indicators for Aged Care, 2020, p161.*

ⁱⁱⁱ *AIHW (2020). Dementia data gaps and opportunities*