Aged Care Data and Reporting Review – Phase 2 Consultation

April 2026

Dementia in Australia

Dementia Australia is the peak body representing the estimated 446,500 people living with dementia and their carers across Australia. Dementia prevalence in Australia is set to increase to more than a million people by 2065[1, 2].

Dementia is the leading cause of death for all Australians, as well as a leading contributor to disease burden[3].

Introduction

Dementia Australia welcomes the opportunity to contribute to Phase 2 of the Aged Care Data and Reporting Review. Phase 2's focus on clinical, care needs, quality and service delivery information is directly relevant to people living with dementia and their carers, given the prevalence of dementia amongst aged care recipients and the complexity of care pathways over time.

Although dementia-relevant information is collected across multiple parts of the aged care system, it is not captured in a consistent or structured way. As a result, there is limited visibility of people living with dementia within core aged care datasets and increasing reliance on indirect estimation of the size of this cohort and their care outcomes through linked data that can be out of date and misaligned with the current policy landscape.

Unfortunately, aged care reforms appear to have inadvertently reduced dementia cohort visibility, making it harder to understand experience, outcomes, and carer impacts in real time. For example, changes to aged care funding and program settings have reduced the availability of clear condition-level identifiers within aged care data, making it more difficult to consistently identify people living with dementia or cognitive impairment.

When dementia status is not consistently identifiable for people using aged care services, governments and service providers have reduced ability to plan, price and evaluate services, design and implement dementia appropriate policy and monitor care outcomes. These gaps also make it harder to understand how people affected by dementia experience aged care

services, identify good practice and areas for improvement, understand how care needs change as dementia progresses and recognise and respond to the needs of carers.

Dementia provides a clear example of how improving the structure, standardisation and reuse of existing data could strengthen the aged care data system without increasing reporting burden in line with the current review's term of reference.

Key Issues

Impact of recent reforms on dementia data

Recent reforms, including the transition from the Aged Care Funding Instrument (ACFI) to the Australian National Aged Care Classification (AN-ACC) in residential aged care, have aligned funding with functional care needs. However, the shift away from diagnosis-related data previously captured has reduced the visibility of conditions such as dementia within aged care datasets. Under previous arrangements, condition-related information contributed to identifying cohorts within the system. The current residential aged care funding model does not capture diagnosis in a structured way, meaning dementia is no longer consistently identifiable within core aged care data.

Similarly, under the previous Home Care Packages program, the Dementia and Cognition Supplement (DACS) provided a data flag for dementia within the home care system. Although not everyone with dementia receiving a home care package received the supplement, it provided an indicator. With the introduction of the Support at Home program and the removal of the DACS, there is no equivalent data point in home care.

These changes have increased reliance on proxy identification through linked datasets and reinforce the importance of strengthening condition data capture in other parts of the aged care system, including assessments and reporting frameworks.

These changes have consequences beyond aged care planning. The National Dementia Action Plan (NDAP) is monitored through an AIHW indicators dashboard, which reports baseline data for 53 indicators and notes that data development is still required in key areas. The NDAP's first Collective Priority Framework (2025–2027) agreed by the Commonwealth and all state and territory health Ministers in February 2026, identified improving dementia data (Action 8) as one of three priority actions for urgent attention. This is recognition that that limited data on prevalence, service use and outcomes for people living with dementia constrains governments' ability to plan, invest and deliver improvements for people living with dementia now and in the future.

Some critical aged care–relevant NDAP measures cannot currently be reported against due to data gaps. For example, there is currently no data available to measure and report on inappropriate use of restrictive practices for people living with dementia in aged care. With the AIHW noting that linked-data development is underway but further work is needed to enable more direct measurement. Similarly, the cognitive status of a person impacted by a Serious Incident was previously reported by the Aged Care Quality and Safety Commission as part of public SIRS reporting. However, reporting by cognitive status has ceased due to a lack of reliable data.

Inconsistent identification of dementia across aged care datasets

Dementia is captured in various ways across aged care data, including assessments, program-level reporting and linkage with health datasets. However, there is no consistent, standardised approach to identifying people living with dementia across these sources. As a result, individuals may be recorded differently across systems, recorded inconsistently within the same dataset, or not identified at all. This limits the ability to define a reliable dementia cohort for analysis.

Reliance on proxy identification through linked data

Due to inconsistent capture in primary datasets, national reporting often relies on proxy indicators such as MBS, PBS and hospitalisation data to identify dementia. This approach may miss people in earlier stages of dementia or with rarer forms of dementia, may exclude those not interacting with hospital systems, and introduces variability depending on the data sources used. Reliance on proxy measures with extended lookback periods also limits the timeliness of insights and reduces the system's ability to respond to contemporary policy and service delivery challenges and priorities.

Limited standardisation and reuse of assessment data

Assessment tools such as the Integrated Assessment Tool (IAT) capture some dementia-relevant information, including condition and cognitive data. However, this information is not routinely or consistently captured, structured or sufficiently detailed to support reliable identification for monitoring and reporting. Assessment data is also not routinely reused across other aged care datasets or reporting systems. This reflects the broader "collect once, use often" gap identified in the current Review.

Inability to stratify outcomes by dementia status

Across key datasets, including quality indicators, incident reporting and performance measures, it is not currently possible to reliably analyse outcomes for people living with dementia. This limits the system's ability to understand quality and safety for this cohort, identify variation in outcomes and target improvements.

This is particularly problematic when it is estimated that up to 54% of residential aged care residents have dementia[1], and around two thirds of all people with dementia live in the community[2] and will require access to some form of aged care home support as their condition progresses.

[1] 2021–22 ACFI-based data; no further updates post AN-ACC.
[2] AIHW calculations using prevalence rates from the 2015 World Alzheimer report and Withall et al. 2014, AIHW analysis of ACFI data and the ABS 2022 Survey of Disability, Ageing and Carers confidentialised unit record file

Lack of longitudinal and progression data

Dementia is a progressive and terminal condition; however, current data collections are largely point-in-time and do not capture changes in care needs or outcomes over time. While multiple data points may exist for an individual (for example, assessments, service use and hospital interactions), these are not structured in a way that supports a clear view of progression or changing needs. As a result, it is difficult to track pathways, understand escalation drivers, evaluate interventions, or plan effectively for future demand.

Limited visibility of informal carers

Informal carers play a central role in supporting people living with dementia, yet there is limited and inconsistent carer data captured within aged care datasets. This constrains understanding of carer needs and outcomes, access to supports such as respite, and the broader impacts of caring.

Recommendations

Dementia Australia's recommendations are consistent with the AIHW National Centre for Dementia Monitoring's previous commentary on the need to improve structured dementia identification, standardising clinical and care needs data, and enabling reuse of data for monitoring and reporting.

Dementia Australia recommends that Government:

1) Improve standardisation of condition data within aged care assessments

Introduce consistent, structured approaches to capturing dementia and cognitive impairment condition data within existing tools such as the IAT (e.g., standardised fields with clear definitions), replacing reliance on free text or inconsistent formats.

2) Align aged care data with health system definitions

Support alignment of condition data with recognised clinical classification systems (e.g., ICD, SNOMED) to enable more consistent identification of dementia across aged care, health and disability datasets.

3) Improve reuse of assessment data

Enable data collected through assessments to be more effectively reused to enable better planning, pricing, reporting and monitoring care experience, quality and outcomes for people living with dementia.

4) Reduce reliance on proxy identification

Strengthen the capture of condition data at source, reducing reliance on indirect proxy measures derived through data linkage, which are unnecessarily costly, complex and less inaccurate.

5) Enable stratification across datasets

Ensure key datasets (e.g. quality indicators, incident reporting, use of restrictive practices, care minutes, security of tenure breeches, IHACPA costing) can support analysis by dementia status.

6) Include dementia within the aged care data dictionary

Ensure dementia is clearly defined and included within the development of a national aged care data dictionary, supporting consistency across data collections.

7) Strengthen linkage through improved input data

Improve the consistency and structure of data captured in aged care to enhance the quality and reliability of linked datasets (e.g., the National Aged Care Data Clearinghouse (NACDC) and the National Health Data Hub (NHDH)), supporting NDAP Action 8 priorities to improve health, social and aged care data collection, accessibility and integration for monitoring outcomes and whether interventions are improving outcomes for people living with dementia.

8) Improve visibility of carers

Consider opportunities to incorporate indicators of carer presence and needs within existing data collections, to better understand and support carers of people living with dementia.

Conclusion

Dementia provides a clear example of the broader data challenges identified in this Review, including inconsistent capture of condition data, limited standardisation across collections, and reliance on indirect identification through linked data. These issues have practical implications: it is difficult to accurately identify people living with dementia accessing aged care services, understand pathways through the system, assess outcomes, or recognise and respond to the needs of carers.

There is an opportunity to strengthen the aged care data system by improving the consistency and reuse of existing data through more standardised approaches to condition data and better alignment with health system definitions. This aligns with the NDAP Action 8: Improving dementia data and supporting monitoring of outcomes. Given core aged care datasets and national reporting infrastructure are largely shaped through Commonwealth settings, Commonwealth data enhancement is a key enabler for nationally consistent dementia data improvements and will encourage similar action by states and territories in their areas of responsibility. Dementia Australia would welcome ongoing engagement as this work progresses.

References

1. Dementia Australia, *Commissioned AIHW Dementia Prevalence Data 2024-2054*. 2023, Dementia Australia.
2. Australian Institute of Health and Welfare, *Dementia in Australia*. 2025, Australian Government.
3. Australian Bureau of Statistics, *Causes of Death Australia, 2024*. 2025, Australian Bureau of Statistics.