



National Dementia Data Improvement Plan 2023-2033

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About

This *National Dementia Data Improvement Plan 2023-2033* (the 'plan') outlines activities to improve national dementia data over the next 10 years to monitor dementia and provide an evidence base for effective policy development, service provision and planning.

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Findings from this report:

- The aim is to deliver better data to improve outcomes for people with dementia and their carers
 - Goal 2: National dementia data available and reported regularly in key monitoring areas
 - The plan has 5 ambitious goals to aspire to over the 10-year plan
 - Goal 4: Harmonised dementia data collected across sources
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Summary

Dementia is a significant and growing health and aged care issue in Australia. High quality and comprehensive dementia data are needed to monitor dementia in Australia and inform evidence-based policy, service provision and planning.

The aim of this *National Dementia Data Improvement Plan 2023-2033* (the 'plan') is to deliver better data to improve outcomes for people with dementia and their carers in Australia by improving national dementia data for population-level monitoring, research, and reporting. The plan outlines activities to improve national dementia data over the next 10 years to monitor dementia and provide an evidence base for effective policy development, service provision and planning.

Specific goals of the plan are that by 2033, Australia will have:

- robust dementia prevalence and incidence data
- national dementia data available and reported regularly in key monitoring areas
- improved dementia data in priority population groups
- dementia data within wider national data linkages
- harmonised dementia data collected across sources.

Achieving one or more of the above goals would greatly improve data available to effectively deliver and evaluate policies and services aimed at improving the lives of people with dementia and their carers in Australia.

The data improvement activities outlined in the plan involve changes to prioritisation, collection, interoperability and reporting of national dementia data by governments, researchers, service providers and other national data custodians. The plan will also guide activities to be undertaken by the AIHW National Centre for Monitoring Dementia, and activities required to assess the performance of the National Dementia Action Plan.

Proposed activities to improve dementia data in Australia are prioritised using 4 criteria: alignment to fill dementia data needs for monitoring and informing policy and planning, providing foundational data, dependencies on the development or availability of other data and whether it can advance data for priority groups. The plan also details the level of investment and timeframes required to complete each activity.

High-priority data improvement activities include:

- conduct nationally representative survey/s of dementia awareness, risks and attitudes in the Australian community
- collect representative data on dementia awareness and attitudes among priority groups (including First Nations people and culturally and linguistically diverse (CALD) groups)
- collect data on the experiences of people living with dementia and their carers (including experience of stigma and discrimination, diagnosis and management, and interactions with service providers)
- collect data on experiences of people with dementia and their carers among priority groups (including First Nations people and CALD groups)
- investigate known and emerging risk and protective factors for dementia and their impacts
- link dementia onset data to clinical records containing date of dementia diagnosis and calculate timeliness of diagnosis
- create guidelines for collecting dementia data in aged care assessments and include training information on dementia data collection in assessor training
- incorporate dementia diagnosis information in national aged care data collections
- develop dementia identifiers and incorporate into existing data sets
- explore availability and quality of data on people with dementia accessing First Nations-specific primary health care services
- explore patterns of service use, transitions of care and access of services relative to need for people living with dementia using linked data
- collect data on the knowledge of dementia, risk factors, risk reduction strategies, and capability among the workforce caring for and supporting people with dementia
- incorporate dementia data in enduring linked data assets to meet the needs of dementia monitoring
- increase coverage of existing data for national dementia incidence monitoring
- investigate approaches to estimate the national prevalence of dementia
- assess new self-reported dementia data in the 2021 Census
- estimate dementia prevalence in priority population groups
- ensure dementia data are consistently collected in core data sets.

The plan is designed to be flexible and evolve with changes in dementia data sources, progression of the National Dementia Action Plan, new analysis methods, consultations, and improvements in key sector data and Australia's broader data infrastructure.



Introduction

On this page:

- [What are the aims and goals of the plan?](#)
- [What are the objectives of the plan?](#)
- [What is the scope of the data improvement activities?](#)
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- [How has the plan been developed?](#)
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Dementia is a significant and growing health and aged care issue in Australia that has a substantial impact on the health and quality of life of people with the condition, as well as for their carers, family and friends. The number of people with dementia is expected to double by 2058 (AIHW 2023) due to growth and ageing of Australia's population. This will create many challenges for Australia's health, aged care, disability and social support systems in delivering high-quality services to the growing numbers of people with dementia and their carers, providing relevant training for the aged-care workforce, and funding dementia research.

Dementia is a multifaceted condition that impacts people in different ways. Data can help understand these impacts, highlight areas requiring improvement and monitor changes over time, and inform decision-making by government and service providers. Australia's understanding of the impact of dementia on its population and health and aged care systems has been largely based on international studies and bringing together data from multiple Australian sources established for administrative or other purposes. This is a problem, as information from international research may not reflect the Australian experience, and often data sources used to monitor dementia are not designed for this purpose.

What are the aims and goals of the plan?

The aim of the *National Dementia Data Improvement Plan 2023-2033* ('the plan') is to deliver better data to improve outcomes for people with dementia and their carers in Australia by improving national dementia data for population-level monitoring, research, and reporting. The plan will enhance and add to the data available for monitoring and reporting on dementia in Australia over the next 10 years to provide an evidence base for effective policy development, research, service provision and planning.

Specific goals of the plan are that by 2033, Australia will have:

- robust dementia prevalence and incidence data
- national dementia data available and reported regularly in key monitoring areas*
- improved dementia data in priority population groups
- dementia data within wider national data linkages
- harmonised dementia data collected across sources.

Achieving one or more of the above goals would greatly improve data available to effectively deliver and evaluate policies and services aimed at improving the lives of people with dementia and their carers in Australia.

*Key dementia monitoring areas include the data gaps listed in the next section.

What are the objectives of the plan?

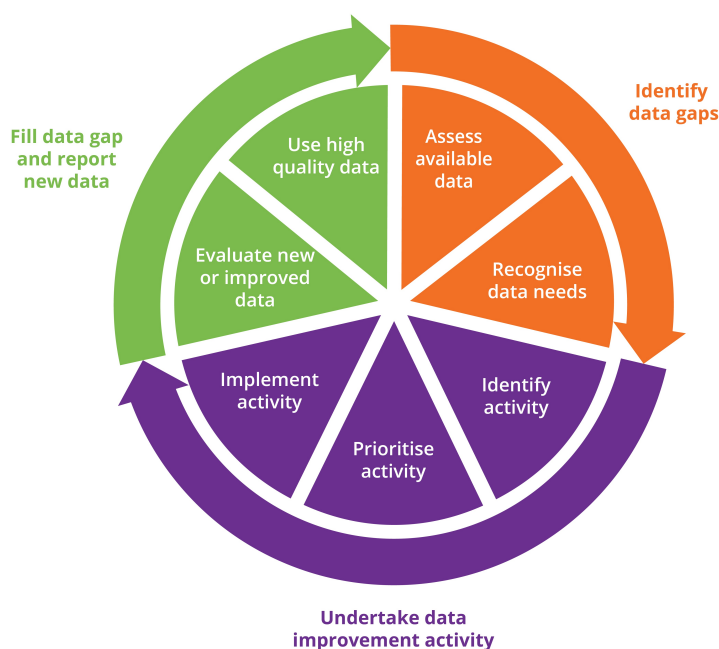
The objectives of the plan are to fill data gaps across 14 identified areas to meet the needs of the AIHW National Centre for Monitoring Dementia (NCMD) and data development needed to assess the performance of the National Dementia Action Plan (NDAP). These objectives will be met through performing several identified activities which will be updated over time and prioritised based on the ability to fill data gaps, provide foundational data, manage dependencies, and improve data on priority populations.

The key data gaps and activities cover the following areas:

1. Risk and protective factors for dementia
2. Dementia awareness and stigma
3. Dementia prevalence and incidence
4. Timeliness of dementia diagnosis
5. Dementia type
6. Dementia severity and progression
7. Dementia diagnosis and management
8. Collection and reporting of dementia and other health conditions in aged care data
9. First Nations people-specific health care data on dementia
10. Other care and support services used by people with dementia and their carers
11. The workforce treating and caring for people with dementia
12. Comorbidities in people with dementia
13. Informal carers of people with dementia, including their needs and outcomes
14. Direct and indirect costs of dementia to the Australian economy.

The overarching elements of a data improvement cycle are shown in Figure 1.1. The first step is identifying data gaps, which has been undertaken already for dementia in the AIHW report: *Dementia data gaps and opportunities* (AIHW 2020). This improvement plan addresses the next step in the improvement cycle, by identifying data improvement activities and assessing their priority. The ability of new data stemming from activities proposed in this plan to meet the goals of the plan will be reviewed and evaluated over the next 10 years. See [Future reviews](#) for more detail.

Figure 1.1: Data improvement cycle



The data improvement activities outlined in the plan should improve the reliability, accuracy, validity, availability and/or timeliness of dementia data. Improvements may involve the scope, coverage, collection tools, methods, integration, accessibility and/or harmonisation of data, and provide potential measures needed for monitoring the NDAP.

The plan builds on recommendations made in the 2020 AIHW report *Dementia data gaps and opportunities*, and incorporates anticipated data needs for:

- measuring dementia system improvements, based on the [consultation paper](#) for the National Dementia Action Plan (DoHAC 2022a)
- the [government response](#) (DoH 2021) to findings of the [Royal Commission into Aged Care Quality and Safety](#) (Royal Commission 2021)
- health, aged care and disability reforms such as from the [National Health Reform Agreement \(2020-25\)](#) (DoH 2020), the [National Aged Care Data Strategy](#) (AIHW 2022) and the Australia's Disability Strategy 2021-2031 (DSS 2021)
- contributing to the Closing the gap data priority
- filling gaps in Australia's international dementia reporting, in particular reporting for the World Health Organization [Global Dementia Observatory](#) (WHO 2023)
- developments in the dementia data landscape, including data linkage
- addressing additional data gaps and initiatives identified through consultation with key stakeholders.

Many of these data needs have occurred in response to aged care reforms and government strategies across health, welfare and best practice use of data, and can be considered as enablers for this plan.

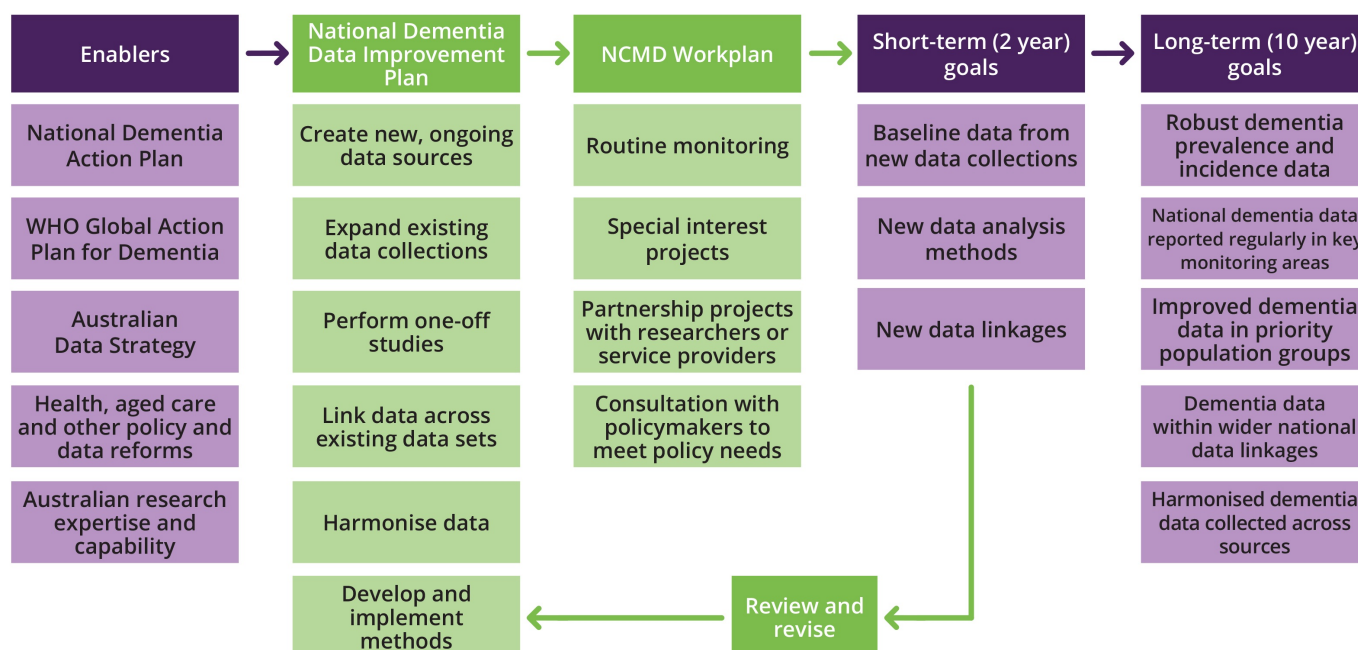
What is the scope of the data improvement activities?

This plan describes a broad scope of national dementia data improvement activities for the purposes of population-level monitoring, research, and reporting. It includes the following types of data improvement activities:

- create new, ongoing data sources - including collecting new administrative data or electronic health data, or conducting new surveys
- expand existing data collections - for example, by including dementia data items in an administrative collection or survey, or by increasing the sample size of an existing survey to facilitate analysis and reporting on people with dementia
- perform one-off studies to provide data to fill a key data gap or quality issue
- link data across existing data sets to expand and enhance dementia data resources and facilitate validation of dementia estimates
- harmonise data to improve dementia data coherence across data sets by implementing standard concepts and classifications
- develop and implement methods to improve dementia monitoring and reporting, especially for the NDAP.

The scope may change over the 10-year plan and include learnings from dementia research and consultation, the evolution of new data sources and methods, the NDAP, the National Aged Care Data Strategy, the National Disability Strategy, the National Preventive Health Strategy and the National Health Reform Agreement. Figure 1.2 shows the relationship of these strategies to this plan, the NCMD and short- (2-year) and long-term (10-year) goals.

Figure 1.2: Relationship of enablers, this National Dementia Data Improvement Plan, and the NCMD with the short- and long-term goals of the plan



Who is the intended audience for the plan?

This plan is for policy makers, researchers, health, disability, aged care and social support service providers, and national data custodians who play a key role in the collection, management and/or reporting of data on dementia in Australia and who use data to inform dementia policy, service provision and planning.

How has the plan been developed?

The AIHW has developed this plan in consultation with the Australian Government Department of Health and Aged Care (DoHAC), the AIHW Dementia Expert Advisory Group and the DoHAC Dementia Expert Reference Group (DoHAC 2022b). These groups include dementia researchers, clinicians, peak bodies for dementia, carers and First Nations aged care, key providers for health, aged care and dementia-specific support services, people with lived experience of dementia, data custodians and subject matter experts. The plan has also undergone wider consultation with a range of data custodians and expert advisors of individual sectors to inform the development of individual data improvement activities.

Future reviews

Plan reviews will occur following the NDAP release and evaluations. Proposed dates for release and/or evaluation of the NDAP and the NCMD are outlined in Table 1.1.

Table 1.1: Key milestones and plan reviews

Key milestones	Data improvement plan
2024	Review of data gaps and priorities following the release of the NDAP to ensure the plan is aligned to meet NDAP data reporting needs.

2025	Review of data gaps and priorities to meet policy, program and reporting needs. Review of progress towards achieving the 2-year goals and adjust milestones to meet the 10-year goals.
2028	Review of data gaps and priorities following the mid-term review of the NDAP to ensure the plan is aligned to meet new NDAP data reporting needs. Review of progress towards achieving the mid-term goals and adjust milestones to meet the 10-year goals.
2032	Review of data gaps and priorities to meet policy, program and reporting needs. Review of progress towards achieving the 10-year goals.

Plan reviews will reflect improvements in data access and integration and dementia knowledge to update the data gaps and activities, list any new dementia data improvement activities required and progress to date in improving dementia data to meet the plan goals.

It should be noted that the data gaps and the proposed activities will evolve over time as new data or data needs arise. The understanding of the most appropriate activities to obtain data from different populations, sources or data types may also evolve and require changes to the proposed activities.

References

AIHW (Australian Institute of Health and Welfare) (2020) *Dementia data gaps and opportunities*, AIHW, Australian Government, accessed 27 July 2023.

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AIHW (2023) *Dementia in Australia*, AIHW, Australian Government, accessed 27 July 2023.

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DoH (2021) *Australian Government Response to the Final Report of the Royal Commission into Aged Care Quality and Safety*, DoH, Australian Government, accessed 27 July 2023.

DoHAC (Department of Health and Aged Care) (2022a) *National Dementia Action Plan Public Consultation Paper*, DoHAC website, accessed 27 July 2023.

DoHAC (2022b) *Dementia Expert Reference Group (DERG)*, DoHAC website, accessed 27 July 2023.

DSS (Department of Social Services) (2021) *Australia's Disability Strategy 2021-2031*, DSS website, accessed 27 July 2023.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2021) *Final Report: Care, Dignity and Respect: Volume 1 Summary and recommendations*, Australian Government, accessed 27 July 2023.

WHO (World Health Organization) (2023) *Global Dementia Observatory*, WHO website, accessed 27 July 2023.





Enablers to support success of this plan

Dementia data gaps and opportunities (AIHW 2020) summarised the 2020 data landscape and suggested improvements, which include this data improvement plan, an aged care data improvement plan and elevated governance. Since 2020, developments across the policy and data landscape make improving data even more relevant, with 2 key developments directly aimed to improve dementia data in Australia - consultation on a draft, new National Dementia Action Plan 2024-34 (expected to be finalised in early 2024) and the establishment of the AIHW National Centre for Monitoring Dementia.

The following pages present information on the:

- [National Dementia Action Plan](#)
- [AIHW National Centre for Monitoring Dementia](#)
- [Enablers for the National Dementia Data Improvement Plan](#) including:
 - Dementia data and research
 - Aged care sector
 - Health sector
 - Primary Health care initiatives
 - Disability sector
 - Other Government agreements and commitments
 - Data specific enablers

References

AIHW (Australian Institute of Health and Welfare) (2020) *Dementia data gaps and opportunities*, AIHW, Australian Government, accessed 27 July 2023.

Enablers to support success of this plan

The [National Dementia Action Plan](#) (NDAP) is a 10-year policy initiative from Commonwealth and state and territory governments with a vision that Australians understand dementia, and people living with dementia and their carers have the best quality of life possible and have support (DoHAC 2022).

The draft plan includes 7 objectives with focus areas under each objective (Table 2.1). Objective 7 specifically covers improving dementia data and maximising impact through focus areas of research and innovation, translation of research into practice, improving data and data systems, and collection of data for monitoring improvement. Improving data collections, intelligence and monitoring systems is an immediate priority of the NDAP.

This data improvement plan will address focus areas 7.3 and 7.4 of the draft NDAP by improving data and information systems and regularly reporting data. The effectiveness of the NDAP will be assessed through regular monitoring and reporting against performance measures to indicate progress in focus areas of the objectives. The performance measures were developed with dementia experts, peak bodies, state and territory governments and public consultation.

Table 2.1: Objectives and focus areas of the draft National Dementia Action Plan

Objective	Focus Area
 1: Tackling stigma and discrimination	1.1 Expanding dementia awareness and reducing stigma 1.2 Creating inclusive communities and environments for people living with dementia, their carers and families
 2: Minimising risk, delaying onset and progression	2.1 Risk factors for dementia are well understood 2.2 People are aware of what they can do to delay the onset and slow the progression
 3: Improving dementia diagnosis and post-diagnostic care and support	3.1 Recognising and acting on early signs and symptoms 3.2 Quality and timely diagnostic services 3.3 Post diagnostic care and support
 4: Improving treatment, coordination and support along the dementia journey	4.1 Quality care and ongoing support as a person's needs change 4.2 Care and support during and after hospital care 4.3 End of life and palliative care
 5: Supporting people caring for those living with dementia	5.1 Recognising carers and assisting carers in their role 5.2 Increasing access to carer respite services
 6: Building dementia capability in the workforce	6.1 A skilled dementia aware health and aged care workforce 6.2 Organisational culture supports quality dementia care
 7: Improving dementia data and maximising the impact of dementia research and innovation	7.1 Advancing dementia research and innovation 7.2 Translating dementia research into practice 7.3 Improving dementia data and information systems 7.4 Collection of data for monitoring improvement

Source: [National Dementia Action Plan consultation paper](#).

Enablers to support success of this plan

The AIHW [National Centre for Monitoring Dementia](#) (NCMD) was established in 2021 to provide accessible, policy-relevant, and timely national dementia data to build the evidence base for the Australian population and health, aged care and disability sectors. This information is critical to prioritise resources and provide effective and efficient dementia-related policies, services and interventions, streamline dementia research and improve the lives of Australians living with dementia or caring for a person with dementia. The Department of Health and Aged Care funds the NCMD.

The primary goal of the NCMD is to be the leading authority on, and comprehensive resource for, national dementia data in Australia. This will be achieved through undertaking work aimed at:

- *Providing timely, accessible and policy-relevant statistics on dementia in Australia:* through systematic analysis and regular reporting of available dementia data that relate to key policy areas across key dementia monitoring areas, as well as special interest or thematic projects that explore particular priority topics in more detail. See [Dementia data gaps and improvement activities](#) for the list of key data for monitoring and policy.
- *Improving dementia data in Australia:* through dedicated efforts in collaborating and consulting with data custodians, policy makers, researchers and other key stakeholders to improve the collection and quality of dementia data, the availability of linked data assets and by developing new analytical approaches to filling existing data gaps. This also includes the NCMD's role in undertaking data improvement projects with external parties where specific expertise or data are required. See [Dementia data partnership projects](#) for more information.

The development of the NCMD allows for an integrated system to effectively and efficiently monitor and report on dementia in Australia.

A Dementia Expert Advisory Group provide expert advice on the NCMD's work program and direction. The group consists of policymakers, clinicians, academics, people with lived experience of dementia, and experts in dementia and related research.

This plan will guide work undertaken by the NCMD to improve dementia data in Australia. The NCMD will also regularly monitor and report performance measures over the 10-year plan for the National Dementia Action Plan (NDAP). The NDAP scope is broad and baseline data may not be available for some new performance measures at its commencement. This plan specifies the data improvement activities that will be undertaken to help measure the progress and performance of the new NDAP, particularly as dementia data access and integration advances.

The NCMD is a leader in developing and reporting national dementia data in Australia. In addition, many of the NCMD's activities rely on close collaboration with key stakeholders across a range of sectors and will be informed by broader reforms across the aged care and other sectors. The role of the NCMD in the improvement plan activities, and in relation to the 10-year goals, is shown in [Figure 1.2](#).

Enablers to support success of this plan

In addition to the National Dementia Action Plan (NDAP) and National Centre for Monitoring Dementia (NCMD), several other developments are enablers for the plan as they support better data collection, sharing and reporting across dementia-specific, aged care, health, disability and data sectors.

Dementia data and research

Dementia research and registries

The National Health and Medical Research Council (NHMRC) [National Institute for Dementia Research](#) (NNIDR) was established in 2015. The NNIDR led a [Boosting Dementia Research Initiative](#) to improve dementia data and methods over 2019-2021, and developed an Aboriginal and Torres Strait Islander Dementia Research Roadmap and a Culturally and Linguistically Diverse Dementia Research Action Plan. While the NNIDR closed on 30 June 2020, dementia remains a research priority for the NHMRC and it funds dementia research on prevention, early diagnosis, quality care and treatments (NHMRC 2023).

In 2015 the Australian Government set up the [Medical Research Future Fund \(MRFF\)](#) to fund important health and medical research projects. Part of this funding will be used for the [Research Data Infrastructure initiative](#) to provide \$100 million over 10 years from 2022-23 to invest in national research data infrastructure (such as data registries, biobanks and data linkage platforms). The initiative will support Australian health and medical research by helping medical researchers collect, share and analyse data more widely (DoHAC 2022a), which may lead to improvements in dementia data.

The Australian Dementia Network's (ADNeT) [Clinical Quality Registry](#) was established through the NNIDR [Boosting Dementia Research Initiative](#). The registry aims to track, benchmark and report on the clinical care of people with dementia or mild cognitive impairment including significant memory loss without the loss of other cognitive functions such as reasoning and judgement (Dementia Australia 2022). The goal is to register all Australians newly diagnosed with either dementia or mild cognitive impairment, to drive improvements in quality of care and patient outcomes. The registry is being piloted in memory clinics and dementia diagnostic services across Australia but does not include all diagnosing clinicians (ADNeT 2023). Further funding for the ADNeT Clinical Quality Registry was announced in the 2023-24 budget (DoHAC 2023), which may increase the registry's coverage and ability to consistently collect data on newly diagnosed dementia in Australia in the future.

International reporting requirements

The World Health Organization's [Global Dementia Observatory](#) (WHO 2023) is the monitoring and accountability mechanism for the [Global action plan on the public response to dementia 2017-25](#), and includes indicator themes of: risk reduction; policy and legislation; diagnosis, care and treatment; research; carer support; awareness and friendliness; and information systems. It is anticipated that many data improvement activities proposed in this plan will contribute to international reporting obligations.

Aged care sector

The Royal Commission into Aged Care Quality and Safety

[The Royal Commission into Aged Care Quality and Safety](#) (the Royal Commission) led to several recommendations (Royal Commission 2021) and a [government response](#) (DoH 2021a). The recommendations sought improvements to:

- fragmented and incomplete data
- lack of common data definitions
- limited interoperability between systems
- use of electronic records and interoperability with My Health Record
- limited integration and analysis of data to inform a person-centred view across sectors
- limited access to data.

Specific Royal Commission recommendations regarding **dementia** include:

- **Recommendation 15: Establishment of a dementia support pathway** that provides information, support, education and planning for care and respite.
- **Recommendation 16: Specialist dementia care services** and reviewing and publicly reporting on whether the number of [Specialist Dementia Care Units](#) established or planned to be established is sufficient to address need within the areas and populations they are designed to cover.
- **Recommendation 80: Dementia and palliative care training for workers** and implementing **mandatory dementia care training** for workers engaged in residential aged care and in care at home (Royal Commission 2021).

Specific Royal Commission recommendations regarding all **data** include:

- **Recommendation 67: Improving data on the interaction between the health and aged care systems.** This includes provision of aged care national minimum data sets (NMDSs) to the AIHW and a legislative framework for health and aged care data to be linked, shared and analysed to understand the burden of disease of current and prospective people receiving aged care and their current and future health needs.
- **Recommendation 68: Universal adoption by the aged care sector of digital technology and My Health Record.** Requirements for approved providers relating to digital technology and My Health Record will be included in the new Aged Care Act. The Australian Digital Health Agency would support aged care providers to adopt My Health Record.
- **Recommendation 108: Data governance and a National Aged Care Data Asset.**

Following the Royal Commission, the DoHAC funded the AIHW to lead a program of work over 4 years from 2021 to improve aged care data. This includes the development of the:

- National Aged Care Data Strategy
- Aged Care NMDS
- National Aged Care Data Asset.

The National Aged Care Data Strategy (in development)

In response to the Royal Commission's recommendations to improve aged care data, the AIHW and the DoHAC are partnering to develop the [National Aged Care Data Strategy](#) (AIHW 2022a). The National Aged Care Data Strategy describes the agreed vision for the future national aged care data system, including why data improvements are needed and how they will be implemented. Stakeholder consultation on the strategy occurred in 2022 and 2023, with release of the final version planned for late 2023. The aged care reform activities will be overseen by the DoHAC and the Aged Care Quality and Safety Commission, with aged care data improvement activities undertaken by the AIHW. The data strategy will closely align with other health and aged care strategies, plans and reform activities, such as the draft Aged Care Digital Strategy, Aged Care Quality and Safety Commission Digital Strategy and the ICT strategy 2022-25, which provides direction for how technology will support and shape changes. [Digital transformation for the aged care sector](#) aims to create a better-connected aged care sector by simplifying, digitising and automating points of connection between clients, providers, the software industry, and government (DoHAC 2022b).

Aged Care National Minimum Data Set

A national minimum data set (NMDS) is a core set of standardised data elements agreed for mandatory collection and reporting at a national level. The Aged Care NMDS (AIHW 2022a) should create consistency across the aged care data system, and the use of items from the Dementia National Best Practice Data Set (NBPDS) and other established data standards was considered in its development, along with criteria to include data items in the NMDS, which is proposed to be added to over time (AIHW 2023). The Aged Care NMDS data standards were released in June 2023, to be followed by a 12-month implementation period so that data collectors can modify their current collections and systems in the implementation period (AIHW 2022a). Once implemented, the Aged Care NMDS and the National Aged Care Data Asset have the potential to improve data on people with dementia who interact with the aged care system. The Dementia and Aged Care NMDSs support the National Health Reform Agreement commitment to 'Work towards consistent application/interpretation of data across systems to assist understanding of linkages between data sets, establish sharing practices, explore viability of disability identifier in health data'.

National Aged Care Data Asset

The National Aged Care Data Asset will be a multi-source enduring linked data set at the AIHW (AIHW 2022a) that integrates people-centred data related to aged care from aged care, health and welfare data sets.

Health sector

The National Digital Health Strategy

The National Digital Health Strategy aims to provide data that are safe, seamless and secure to support evolving health and care to meet the needs of modern Australia (ADHA 2022).

The strategic priorities include:

1. Health information that is available whenever and wherever it is needed
2. Health information that can be exchanged securely
3. High-quality data with a commonly understood meaning that can be used with confidence
4. Better availability and access to prescriptions and medicines information
5. Digitally enabled models of care that improve accessibility, quality, safety and efficiency
6. A workforce confidently using digital health technologies to deliver health and care
7. A thriving digital health industry delivering world-class innovation.

This strategy is supported by the Framework for Action - an implementation plan which underpins and coordinates work that is already happening between governments, healthcare providers, consumers, innovators and the technology industry.

Department of Health and Aged Care Data Strategy 2022-25

The [Department of Health and Aged Care Data Strategy 2022-25](#) provides the overarching strategic direction to guide departmental data and analytics activities to ensure that resources are allocated efficiently to activities that will support evidence-based policy, programs and service delivery (DoHAC 2022c). This strategy also reflects the need to maintain public trust by protecting the privacy and confidentiality of individuals and use data in the public interest.

National Preventive Health Strategy 2021-30

The [National Preventive Health Strategy 2021-2030](#) aims to improve the health and wellbeing of all Australians by enhancing the focus on prevention and by building systems-based change over a 10-year period. The strategy aims to address the wider determinants of health, reduce health inequities and decrease the overall burden of disease (DoHAC 2022d). The strategy describes actions to decrease risk factors that are common to many chronic conditions including dementia. These risk factors include tobacco use, healthy diet, reducing alcohol use, increasing physical activity and promoting mental health.

A [National Injury Prevention Strategy](#) is in development and could be an enabler for change as brain injury (from diverse causes from sport-related concussion, through falls and motor vehicle accidents) is a risk factor for dementia.

Primary health care initiatives

Australia's Primary Health Care 10 Year Plan 2022-2032

[Australia's Primary Health Care 10 Year Plan 2022-2032](#) (DoHAC 2022e) aims to strengthen primary health care as part of the health system and to provide an agenda for primary health care reform over a decade. Among the enablers of the plan are research and data, with continued investment in research and data essential to evaluating innovation and targeting investments to where they can deliver the greatest value to support quality, value-based care. Digital health infrastructure is a further foundation for reform and includes shared health records and interoperability.

The AIHW is working to improve primary health care data through the development of a Primary Health Care Information System and a National Primary Health Care Data Collection. This data collection is envisaged to contain reliable, detailed, high-quality data about primary health care (focusing on general practitioner (GP) activity initially but expanding into broader primary care areas such as nursing and allied health) (AIHW 2022b) and aims to fill existing primary care data and information gaps which could help improve reporting on dementia diagnosis and management in primary care within the next decade.

2020-25 National Health Reform Agreement

The [2020-25 National Health Reform Agreement \(NHRA\)](#) is an agreement between the Australian Government and all state and territory governments (DoH 2020). The NHRA includes the following 6 long-term system-wide health reforms, which can be enablers for improvements in dementia care and dementia data:

- empowering people through health literacy - person-centred health information and support will empower people to manage their own health well and engage effectively with health services
- prevention and wellbeing - to reduce the burden of long-term chronic conditions and improve people's quality of life
- paying for value and outcomes - enabling new and flexible ways for governments to pay for health services
- joint planning and funding at a local level - improving the way health services are planned and delivered at the local level
- enhanced health data - integrating data to support better health outcomes and save lives
- nationally cohesive health technology assessment - improving health technology decisions will deliver safe, effective and affordable care.

The [NHRA Long-term Health Reforms - Roadmap](#) (Australian Health Ministers 2021) includes the key areas of reform:

- enhanced health data
- prevention and wellbeing
- interfaces between health, disability and aged care systems.

Interdependencies are recognised for these reforms, and the enhanced health data reform will enable the other long-term, system-wide reforms. Access to linked data that provide an end-to-end view of patient pathways will enable policymakers and governments to develop a more accurate model of the health system, to inform system design, funding and improved patient access and experiences. The focus of prevention should address risk factors associated with the development of dementia and the focus on wellbeing should improve quality of life for persons with dementia and their carers.

Reforms to the interfaces between health, disability and aged care systems will help monitor interface performance, help report on new and existing interface issues, and improve governance mechanisms to resolve issues. The interface reform area is linked to the enhanced health data reform given the need to link data across systems and ensure interoperability.

Australian Digital Health Agency activities and improvements to My Health Record

The Australian Digital Health Agency (ADHA) is the My Health Record system operator responsible for establishing the technical infrastructure required to support adoption and the efficient and secure sharing of My Health Record data for research and public health purposes, while AIHW is the My Health Record data custodian for research and public health purposes. The 2023-24 budget provides \$429 million over 2 years to modernise My Health Record and provide a national repository platform that supports easier, more secure data sharing across all healthcare settings (DoHAC 2023).

The ADHA priorities (DoHAC 2022f) that can enable better dementia-relevant data include:

- respecting and caring for senior Australians - ensuring safe and effective transition of care for aged care recipients
- supporting rural, remote and First Nations communities to connect to their health information and make it available to their healthcare providers
- developing national clinical terminology and interoperability - developing standards and specifications to allow different health systems to work together to share accurate and comprehensive patient information to inform care decisions
- supporting digitally-enabled primary care - supporting effective telehealth and virtual care with real-time information exchange (such as electronic prescriptions and referrals for diagnostic imaging)
- supporting the next generation of My Health Record - working with health-care providers across the continuum of care to increase the sharing of core clinical content so information can be accessed when and where it is needed, including on a mobile phone.

The ADHA also performs activities that enable data improvements in the health and aged care sectors by

- designing, delivering and managing infrastructure, solutions and initiatives that provide access to, and promote adoption of, secure digital health services
- facilitating national digital health interoperability between health-care providers and the systems they use to improve the visibility of health information, leading to better decisions and health outcomes for consumers
- conducting train-the-trainer sessions and capacity-building workshops, to facilitate sustainable national digital health literacy and awareness.

Disability sector

National Disability Strategy

[Australia's Disability Strategy 2021-2031](#) is a national framework that sets out a plan for continuing to improve the lives of people with disability in Australia over the next 10 years (DSS 2022a). Disability sector data improvements may impact how people with younger onset dementia obtain disability services.

Governments are committed to collecting and sharing relevant data to support effective monitoring and reporting of outcomes for people with disability to drive change. Australian state and territory data, for both disability-specific and mainstream service systems, will be essential for measuring outcomes and tracking the degree of change.

The Australian Government invested \$15 million in a pilot of a National Disability Data Asset (NDDA) in partnership with state and territory governments, which showed the value of the NDDA to better understand how people with disability are supported through services, payments, and programs across multiple areas, through the linkage, improvement and sharing of de-identified data. The NDDA also plans to make insights accessible while protecting privacy and safeguarding data.

The AIHW is collaborating with partners to further develop the NDDA to link data relating to people with disability from governments and agencies across Australia, to provide a richer picture of the life experiences of people with disability (DSS 2022b). The NDDA will provide valuable data in the future for reporting on the Outcomes Framework and is also expected to improve the data available on the experiences and outcomes for people with disability who are impacted by dementia.

Other government agreement and commitments

National Agreement on Closing the Gap 2020

The [National Agreement on Closing the Gap 2020](#) outcomes include First Nations-led data, so that First Nations people have access to, and the capability to use, locally relevant data and information to set and monitor the implementation of efforts to close the gap, their priorities and drive their own development (Joint Council on Closing the Gap 2020). This outcome is supported by *Priority Reform Four: Shared access to data and information at a regional level* in the [Closing the Gap Implementation Plan 2023](#). These data also support disaggregation by jurisdiction and Closing the Gap outcome areas. The AIHW supports the 2020 National Agreement on Closing the Gap by ensuring that our reporting includes analyses relating to First Nations peoples where data quality permits.

Data-specific enablers

Data Availability and Transparency Act 2022

The [Data Availability and Transparency Act 2022 \(Cth\)](#) establishes a best-practice DATA scheme for sharing Australian Government data, underpinned by strong safeguards and consistent, efficient processes (ONDC 2022a).

The objectives of the Act are to:

- serve the public interest by promoting better availability of public sector data
- enable the sharing of public sector data consistently with the [Privacy Act 1988 \(Cth\)](#) and use of appropriate security safeguards
- enhance integrity and transparency in sharing public sector data
- build confidence in the use of public sector data
- establish institutional arrangements for sharing public sector data.

The [DATA Scheme](#) has safeguards that specify 3 data-sharing purposes that are relevant to dementia services and data: government service delivery, informing government policies and programs, and research and development (ONDC 2022b). Further safeguards exist around accreditation of users, data-sharing principles, data-sharing agreements, transparency and reporting, regulation and compliance, and privacy protections that work with the Privacy Act to protect personal information.

Other data-specific enablers

Developments in artificial intelligence (AI) techniques applied to electronic health data should enable more comprehensive and efficient coding of data. This should enhance the provision of dementia data from hospitals, primary care and other potential dementia data sources, while reducing the coding burden on health professionals.

Key requirements to improve data

While the above initiatives all provide enabling support for better data collection and sharing, how these are interpreted and applied at places of data collection will be critical to the ability to commence new data collection and improve existing collections.

The monitoring of dementia in Australia is dependent on data from a wide variety of sources across government and the private sector that are collected and managed by numerous parties including: health service providers; individual consumers; health professionals; federal, state and territory governments; private health insurers; Primary Health Networks; statistical agencies; universities and research organisations; and non-government organisations. Therefore, improvements in dementia data require multi-sectorial efforts and collaborations.

The success of this plan (and improving data more broadly) is dependent on dedicated commitment to improve dementia data, systems for collection and storage, and usability of the data. A data collection requires:

- data governance
- systems for data collection that are:
 - secure
 - intuitive and easy to use
 - structured to use common data dictionary terms
 - ideally include mandatory data items
 - staff training resources to ensure consistent collection of data
 - processes to ensure that data are high quality.

These factors complement the critical success factors identified for the [National Digital Health Strategy](#) (ADHA 2022), which include:

- trust and security assurance
- commitment, cooperation and collaboration across all governments
- establishment of legislative, regulatory and policy frameworks
- strong consumer and clinician engagement and governance
- effective governance and leadership.

Data governance

Data governance is the 'exercise of decision-making and authority for data-related matters' (The Data Governance Institute 2022). It includes the processes, standards, policies, responsibilities and measures in place to ensure the efficient and effective management, availability, accessibility and security of data and that privacy is protected. Data governance describes the source of authority for making decisions about data, the roles/structures authorised to make decisions, and the basis upon which those decisions are made (AIHW 2021). Key elements of good data governance include people, policies, process and products.

High-quality data governance improves decision-making and enables collaboration across sectors. The AIHW data governance framework (AIHW 2021) provides specific information regarding data governance at the AIHW and data governance concepts more broadly. To support the AIHW's legal, ethical and safe management of data requires a combination of supporting legislation, roles, policies, practices, standards, tools and technologies to deliver effective data governance arrangements.

Data quality - The Australian Bureau of Statistics framework

To ensure the improvement activities in this plan result in high-quality data for dementia monitoring and reporting, data will be assessed against the Australian Bureau of Statistics' (ABS) [Data quality framework](#) (ABS 2015) prior to implementation in national dementia routine monitoring and reporting by the National Centre for Monitoring Dementia.

The ABS [Data quality framework](#) provides standards for assessing and reporting on data quality as well as the development of high-quality data collections. The Framework consists of 7 quality-related dimensions which should be considered in assessing data quality:

- institutional environment - organisational factors such as professional independence, impartiality and objectivity, resourcing, legislative requirements, quality commitment and data governance arrangements
- relevance - how suitable the data are for their intended purposes, such as their scope and coverage, reference period, classifications, data items, and type of data available
- timeliness - how recent the data capture is compared to when the data can be used
- accuracy - how well the data reflect what is intended to be captured
- coherence - the consistency of the data over time and how they compare to other available data of the same nature
- interpretability - information available to support interpretation of the data
- accessibility - how well the data and their associated information can be accessed by the intended users, and the suitability of the medium in which the data are accessed.

Future potential data sources

The significance of dementia as a health and societal issue has led to significant dementia research investments in Australia and globally, which over time, should lead to benefits for people with dementia and their carers and provide improved data. The broad adoption of electronic medical records, along with standardised ways of collecting and sharing data with strict data governance protocols (as described in the above enablers), should provide improved data for research and reporting over the next decade.

Dementia prevention research may lead to programs and knowledge that delay the onset, decrease the severity, or avoid the development of dementia completely. Investments in Australian dementia research are occurring through the NHMRC and MRFF and other funding organisations.

The publications from research into the causes of dementia may uncover other risk and protective factors to reduce dementia in the general population, and better quantify the effect of known factors. New treatments will be developed which will help understand the cause of different dementia types, and their treatment. These studies often accompany genetic or biomarker tests to identify patients with different risks of disease progression, suitability for different drug treatments, or levels of response to treatment. Should genetic, protein or imaging tests show predictive value, then this pathology data could contribute to dementia reporting. It should be noted that genetic information is sensitive personal information, and sharing of these types of data will require community consultation and trust, along with ensuring privacy and governance mechanisms, as for many other types of health information. This work will evolve alongside the [MRFF Genomics Health Futures Mission](#), community awareness and engagement, and better understanding of the societal and economic value of genomics in health care priority (DoH 2021b).

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Current dementia data sources in Australia

National dementia statistics in Australia come from a variety of data sources. At present this includes administrative data, surveys, program data, expenditure data, burden of disease studies and enduring linked data sets. Figure 3.1 shows an overview of current national data sources and the areas of dementia disease progression captured by each source. Current data sources used for dementia monitoring often collect data relevant to multiple monitoring areas, however, there are limitations. See [Benefits and limitations of main national data sources](#) for more detail.

There is also no single data source to derive dementia prevalence for Australia. Current dementia prevalence estimates for Australia are generated using different methodologies applied to data from international studies and small-scale Australian epidemiological studies.

The following pages present information on the following data sources for national dementia monitoring:

- [Survey data](#)
- [Administrative data](#)
- [Data sources measuring the impact of dementia](#)
- [Benefits and limitations of main national data sources](#)

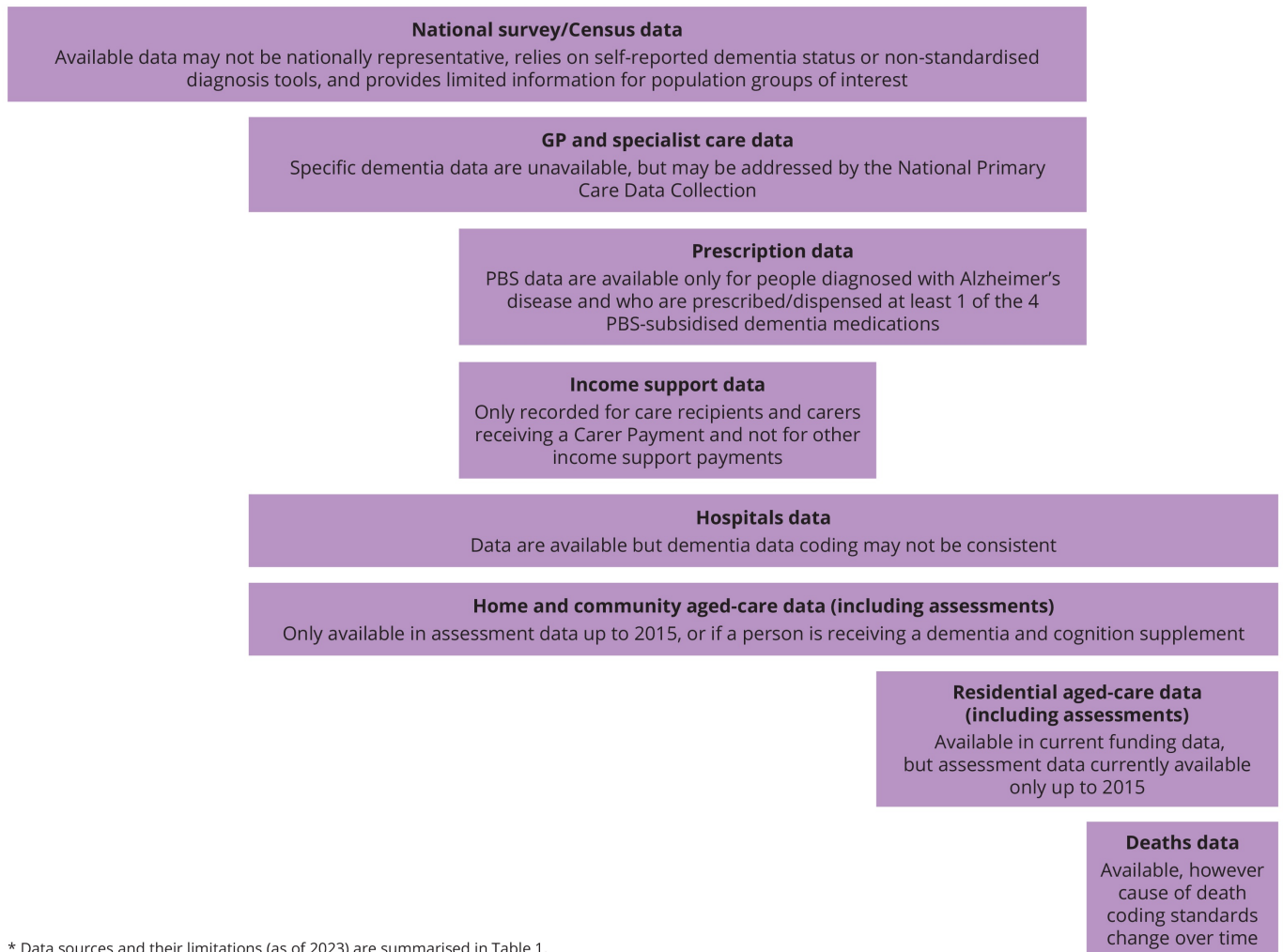
Current data sources and other data sources that could contribute to dementia monitoring in the future (for example, emerging sources that are currently being developed) are summarised in the [Appendix](#). Dementia data sources and issues are also discussed in the following reports: [Dementia data gaps and opportunities](#) (AIHW 2020a), [Australia's health 2020: data insights](#) (Chapter 8: Dementia data in Australia - understanding gaps and opportunities) (AIHW 2020b) and [Dementia in Australia](#) (AIHW 2023).

Figure 3.1. National data collection coverage across dementia disease progression

Dementia disease progression



National data collections and limitations*



* Data sources and their limitations (as of 2023) are summarised in Table 1.

References

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Current dementia data sources in Australia

Survey data that accurately reflect the characteristics of Australia's population are an essential source of data for monitoring the health of a population. Surveys can complement other data sources by capturing people who may not appear in other data collections (for example, those that do not have contact with the health or aged care system). Unlike administrative data that are captured for non-statistical purposes such as administration, operations and service delivery, surveys are designed to collect data for specific research, policy and planning purposes.

The Australian Bureau of Statistics' [Survey of Disability, Ageing and Carers](#) (SDAC) is pivotal for understanding dementia, particularly among people living in the community. The SDAC provides detailed information on the characteristics, health and functional status, experiences of disability and care needs for people aged 65 or over and/or with disability. The SDAC captures data on people living with dementia but as the SDAC does not perform clinical assessment of survey respondents, the survey will underestimate people in the early stages of dementia. Further, some respondents may choose not to disclose their dementia. The SDAC also collects important information on carers of people with dementia, providing rich data on the types of care they provide, the impact of the caring role on a carers' wellbeing, health, finances and employment, as well as information on unmet needs that carers face.

The [National Health Survey](#) and other surveys that collect risk factor data for preventable conditions can inform trends regarding the likelihood of dementia increasing, decreasing or staying the same, and assess if health promotion programs (targeting risk factors) are working in the community. While the National Health Survey collects information on health conditions, it does not adequately capture data on people living with dementia.

A question on the presence of chronic disease, including dementia, was included in the [2021 Census](#), and will be analysed to assess if this can assist to improve the estimate of the prevalence of dementia in Australia.

The use of other survey data for national monitoring of dementia is often challenging. For example, surveys that are not specifically designed for dementia monitoring may not record dementia or if they do, the number of respondents may be too small to report. Other surveys may capture dementia adequately and over time, but do not have national coverage. The cognitive decline that accompanies dementia is expected to limit the self-reporting of dementia, and not all persons with dementia have support to help report their medical conditions, which makes under-reporting more likely.

National administrative and survey data often lack information to monitor dementia among vulnerable groups or groups at higher risk of developing dementia, so smaller-scale Australian research studies also play an important role in providing insights on these groups while the national data landscape improves.

Current dementia data sources in Australia

On this page:

[Administrative data with national coverage](#)

[Limitations of administrative data](#)

[Income support administrative data](#)

Administrative data collected by governments or providers as part of their administration of programs provide valuable information on the characteristics of people with dementia and, if dementia is captured, their use of formal services. People with dementia tend to have increasing health and personal care needs as their condition progresses. The use of formal services by a person with dementia depends on many factors including the number and nature of the person's health conditions, the activities in which assistance is required, the availability of social resources such as informal carers, personal preferences, cultural influences, financial resources, and the accessibility of services. Post-diagnostic support services are also important to help manage dementia.

Health services treat and manage dementia while aged care services provide support and personal care for daily living and manage dementia according to clinical direction within residential respite and residential aged care. Other support services are also available to people with dementia (for example, disability support services through the National Disability Insurance Scheme). National data on health, aged care and other support services data are largely administrative data.

Administrative data with national coverage

Most administrative data are routinely collected and has national widespread coverage, providing rich information about people with dementia on a range of topics. For example:

- hospital admissions are captured in the [National Hospital Morbidity Database \(NHMD\)](#)
- medications dispensed are collected under the [Pharmaceuticals Benefit Scheme \(PBS\)](#) and Repatriation Pharmaceuticals Benefit Scheme (RPBS)
- aged care assessments and residential aged care services from the [National Aged Care Data Clearinghouse \(NACDC\)](#) [Note, this is an incomplete coverage of data on aged care services provided to people with dementia. Gaps exist in the use of home-based services (such as Home Care Packages), and services provided for priority population groups (for example, services under the [National Aboriginal and Torres Strait Islander Flexible Aged Care Program](#) as the [Multi-Purpose Services \(MPS\) Program](#) designed for small regional and remote communities).
- income and disability support and allowances such as that captured under the [National Disability Insurance Scheme \(NDIS\)](#) and Services Australia payment data.

Monitoring the use of health, aged care and other support services and interactions between these services by people with dementia and their carers is essential for service planning. Monitoring can show the use of health and aged care services, patterns of service use and, where linked data are available, links between these services. Linked service and outcome data may also identify opportunities to improve outcomes for people with dementia and their carers.

Limitations of administrative data

However, there are limitations to the use of administrative data for monitoring dementia including under-diagnosis and under-disclosure of dementia, and inconsistent coding of dementia. Aged care reforms have also led to changes in the collection of data on health conditions in aged care data over time. See [Appendix](#) for more detail.

Administrative data sets are largely designed for funding and administration purposes, and accurate recording of dementia and other health conditions is not always a priority. One study of New South Wales public hospitals found that 47% of people with dementia who were admitted to hospital in 2006-07 did not have dementia recorded in their hospital admission (AIHW 2013). Another study found that among women who had died and had a record of dementia in other sources, only 52% had dementia listed as a contributing cause of death and 25% had dementia reported as the main cause of death (Xu et al. 2022).

Dementia may be under-reported and/or inconsistently recorded across administrative data collections for reasons such as:

- changes in clinical guidelines for recording and managing dementia
- variable awareness of dementia among health professionals
- decisions made by health professionals and clinical coders when recording dementia
- past changes to the International Classification of Diseases (ICD-10) instructions for coding deaths data (AIHW 2020).

Income support administrative data

People with dementia and informal carers of people with dementia may be eligible for income support. People with dementia may receive the Age Pension or Disability Support Pension as their main income support. People who provide constant care for a person with a disability or severe medical condition such as dementia may receive the Carer Payment as their main income support. Carer Allowance and Carer Supplement are income-tested supplementary payments for people providing daily care and may be provided to those in or out of the paid

workforce. Income support payments offer insights into people's changing circumstances over time: their capacity to work, levels of disability, and caring responsibilities. These payments, while not specific to dementia, offer the potential to link to a dementia diagnosis in other data sets to better estimate the national cost of dementia.

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Current dementia data sources in Australia

On this page:

[Burden of disease](#)

[Disease expenditure](#)

[Mortality](#)

Dementia can impact individuals, friends and family and health and aged care systems in different ways. Dementia can lead to varying levels of impairment and impact social engagement and access to the community. Access to formal and informal supports and the level of community awareness and stigma will influence the impact of dementia on persons with dementia and their carers.

The health impact of dementia at the national level can be measured objectively by burden of disease analysis and mortality, and the financial impact to the government by disease expenditure analyses. These analyses also provide population-level comparisons across different conditions and over time.

Burden of disease

Burden of disease analysis is valuable for monitoring population health as it measures the combined impact of living with and dying prematurely from disease and injury, allowing comparison between diseases and population groups. The contribution of various risk and protective factors can also be measured.

Burden of disease analysis provides a valuable evidence base for health policy formulation and health service planning. It can highlight which diseases and risk factors cause the most burden, which are increasing or decreasing, and which are causing the greatest health inequalities and gaps. It can indicate the diseases most likely to impact the health system and services and estimate the burden attributable to specific risk and protective factors to target prevention policies.

Disease expenditure

Disease expenditure for dementia includes spending on health and aged care goods and services. It includes spending by governments as well as individuals and other non-government funders, such as private health insurers. Providing goods and services for people with dementia and their carers uses extensive resources in terms of health professionals, hospital services, out-of-hospital services, medications, community support programs, aged care assessments and a range of aged care services. The disease expenditure estimates do not include indirect costs such as loss of productivity or income because of disease.

In addition to disease expenditure data, aged care expenditure estimates are based on government administrative data. Monitoring expenditure for dementia is critical for policy development and service planning as it provides important information on the cost of caring for people with dementia across the health and aged care sectors. It also provides insights into patterns of service use and can be used to evaluate the cost-effectiveness of dementia-related health and aged care policies and interventions.

Mortality

Death estimates are a vital measure of a population's health and inform patterns of diseases that cause death, by population groups and over time. Monitoring the deaths of people with dementia can guide policy development and service planning as it can help explain differences and changes in health status and evaluate population health strategies. The number of people dying with dementia is increasing over time along with increases in population and population ageing. The coding of dementia on death certificates has changed over time and there are differences between state and territory jurisdictions in the recording of causes or contributing factors of death. Dementia is usually a contributing factor when listed as a cause of death. This is unlike other conditions such as cardiovascular diseases (for example, stroke or heart attack) where a single event is responsible. However, it is not unlike cancer where other systems are impacted, leading to other primary causes of death, with dementia being an underlying or contributing cause.

Current dementia data sources in Australia

On this page:

- [Limitations of the main national data sources for monitoring dementia](#)
- [Data linkage](#)
- [Dementia programs data](#)

The benefits and limitations of main national data sources for monitoring dementia are summarised in Table 3.1. Data from these sources have data gaps or limitations that provide caveats to interpreting the results. For more details on each data source below, see [Appendix](#).

Table 3.1: The benefits and limitations of main national data sources for monitoring dementia^(a)

Source	Description	Benefits	Limitations
Survey of Disability, Ageing and Carers (SDAC)	<p>Large survey measuring conditions and causes of disability, and disability-related need for assistance</p> <p>It records dementia along with other health conditions</p>	<p>Nationally representative</p> <p>Comparable methods over time, allowing for time series analysis</p>	<p>Likely underestimates people with dementia</p> <p>Unable to assess subgroups of interest (for example, those with younger onset dementia)</p> <p>No coverage in very remote areas</p>
General practitioners and specialists ^(b)	<p>No national dementia-specific data currently available</p> <p>Dementia diagnoses captured in various practice management systems</p>		<p>Suitability of dementia data from practice management systems still being ascertained</p>
Pharmaceutical Benefits Scheme (PBS)	<p>Information on PBS-listed prescription medications, including those for people with Alzheimer's disease who were prescribed dementia-specific medication</p>	<p>National coverage</p> <p>Routinely collected</p>	<p>Not all people with dementia are prescribed dementia-specific medication</p> <p>The PBS currently subsidises dementia-specific medications only for people diagnosed with Alzheimer's disease</p>
Hospital admissions	<p>Information about admitted patient activity in Australian hospitals and reason for admission</p>	<p>National coverage</p> <p>Routinely collected</p>	<p>Inconsistent coding of dementia</p> <p>Under-diagnosis and under-disclosure of dementia</p>
Emergency department presentations	<p>Information about patient activity in Australian hospital emergency departments and their reason for admission</p>	<p>National coverage of public hospitals with emergency departments</p> <p>Routinely collected</p>	<p>Missing data from private hospitals</p> <p>Inconsistent coding</p> <p>Under-diagnosis and under-disclosure of dementia</p>
Aged care assessments	<p>Information on people assessed by Aged Care Assessment Teams to receive a range of aged care services</p>	<p>More likely to identify mild and moderate dementia</p>	<p>Changes over time in how data are held and reported</p> <p>Detailed health condition and dementia data collection discontinued in transition to AN-ACC^(c)</p> <p>Includes only people who accessed formal aged-care services</p>

Residential aged care	Information relating to the administration of residential aged care subsidies	National coverage of people in permanent residential aged care	May underestimate people with dementia Incomplete coverage in very remote areas
Income support and allowances	Claims and payments data for recipients of certain government income support and allowances with a medical diagnosis of dementia (and their carers)	National coverage Routinely collected	Dementia may not be recorded if claim for payment is based on another medical condition
Deaths	Information on deaths in Australia and their underlying cause of death or associated cause of death	National coverage Routinely collected	Dementia under-reported Unlikely that mild-to-moderate dementia will be recorded

Notes:

(a) There are other data sets, not listed above, that can be used to monitor dementia when linked with the listed databases. However, care must be taken as the limitations listed against each data source are likely to apply to the linked data sets as well.

(b) The Medicare Benefits Schedule (MBS), which captures information on general practitioners (GPs) and specialist services, does not capture dementia diagnosis information. The Bettering the Evaluation and Care of Health (BEACH) program, which captured information on conditions managed by GPs in Australia, ceased in 2016.

(c) AN-ACC is the Australian National Aged Care Classification.

Limitations of the main national data sources for monitoring dementia

Inconsistency in the coding of dementia data items across data sets impacts the quality and comparability of data items such as dementia diagnosis, type and severity. The [Dementia National Best Practice Data Set \(NBPDS\)](#) provides concise and unambiguous definitions for data items related to dementia diagnosis, treatment and management. It aims to standardise the collection of dementia information in Australia across a range of data sets, including those used in clinical practice, clinical registries, epidemiological research and surveys.

Incomplete or consistent coding of electronic medical records may be improved with the use of data mining (using artificial intelligence). AI may also be able to guide assessments to improve diagnostic accuracy.

Inadequate sample size in national surveys, such as the SDAC, limits the analysis that can be undertaken of less common chronic conditions, including analysis by small geographical areas, *Very remote* areas, and by population groups of interest. Dementia is captured in the SDAC, but not other surveys that exclude people living in aged care facilities. Dementia-specific questions may not be included in surveys due to higher priority questions and time limitations for completing surveys. People with cognitive impairment may be under-represented if they opt out of participating in surveys. Survey age limits may also affect the coverage of people with dementia.

Administrative data sets could be improved with appropriate measures of cultural, ethnic and linguistic diversity, informed by the [Standards for Statistics on Cultural and Language Diversity \(ABS 2022\)](#), to better understand culturally and linguistically diverse (CALD) populations and inform health policy and service planning (FECCA 2020). Most studies of dementia in First Nations people and CALD populations come from site-specific epidemiological studies or national surveys such as the SDAC. Site-specific epidemiological studies are irregular, which stop or limit regular comparisons over time (AIHW 2020). Inadequate coverage in national surveys may limit analysis of dementia in priority population groups. Studies and methods of engagement need to be culturally safe and appropriate for priority populations (including First Nations people and CALD populations) in order to obtain representative data to inform dementia service and policy needs.

While improvements to the content and scope of available national data are needed, there are also broader system and policy-level barriers that need to be overcome, such as a lack of technological infrastructure and informatics mapping, and fragmented service navigation (Burkinshaw et al. 2022). Systemic barriers can contribute to a delay of accurate and timely diagnosis, especially in marginalised groups, which can impact reporting in both administrative and other data collections.

Data linkage

Standalone administrative data are particularly powerful for informing dementia monitoring when linked for the same individual or time or across multiple sources. Data linkage can improve dementia identification when dementia records from different sources are captured, as well as allow for a more wholistic, person-centred view of dementia.

Administrative data can also be linked with population-based studies undertaken for specific research purposes and which provide rich, high-quality data that may be difficult to obtain from administrative data (such as self-reported patient experiences or biometric data).

There are different types of linked data assets, and particularly useful for dementia monitoring are enduring linked data assets since they are more efficient than one-off linkages for specific projects and provide a consistent source for different uses. As of June 2023, key enduring linked data assets for dementia monitoring are the:

- [National Integrated Health Services Information Analysis Asset \(NIHSI-AA\)](#), which brings together national data from 2010-11 onwards on various health care data (hospital admissions, emergency department visits, prescriptions under the PBS and Repatriation Pharmaceuticals Benefit Scheme (RPBS), and MBS services), residential aged care data, and mortality data. These data provide better dementia identification than standalone data sets and a wide range of opportunities to better understand the pathways used among people with dementia. This includes the relationship between health and aged care use, reasons for transitioning into residential aged care, and the influence of patterns of care on outcomes.
- [Multi-Agency Data Integration Project \(MADIP\)](#), which links administrative data from a range of Commonwealth agencies covering diverse areas from tax and social security payments to MBS and PBS data. It also has linked national survey data sets, such as the SDAC. MADIP is missing hospitals and key aged care data that capture dementia information but provides insightful information on other understudied groups with dementia, such as people with younger onset dementia.

It is important to note that enduring linked data assets generally take more time to set up and use than standalone data assets and have more complex data governance and access rules.

Dementia programs data

There is a vast body of data captured by non-governmental organisations on the programs they undertake, which are being increasingly used to understand the impact of community services available to people with dementia and their carers, as well as to the broader Australian community:

- [Dementia Australia](#) is the national peak body for people impacted by dementia in Australia and provides a diverse number of activities and support programs, such as education, information, counselling and early-intervention support. Dementia Australia collect rich data on clients accessing their services, but unit record data are not currently available for external analysis.
- [Dementia Support Australia \(DSA\)](#) provides behavioural and clinical support to people living with dementia, their carers and/or health professionals. Services are across metropolitan, regional and remote areas, including tailored First Nations support. DSA collects multifaceted data on their clients. On request, aggregated data sets are available for external analysis.
- [Dementia Training Australia \(DTA\)](#) is a consortium funded by the Australian Government to provide nationwide education and training on the care of people living with dementia. DTA collects data on the numbers of trainings and completions for continuing professional development, [Tailored Training Programs](#) and vocational education and training, by workforce type, setting (aged care, community care, primary care, acute care, mixed care), and whether online or in-person training.

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Dementia data gaps and improvement activities

Specific data improvement activities are required to improve dementia data for Australia.

This section presents a [summary of existing dementia data gaps](#) for Australia and an overview of the type of data improvement activities to address each gap. How activities will be prioritised and who is responsible for undertaking each activity is outlined in [Overview of data improvement activities](#).

The following pages discuss current data gaps and detail specific activities needed to improve key data on:

1. [Risk and protective factors for dementia](#)
2. [Dementia awareness and stigma](#)
3. [Dementia prevalence and incidence](#)
4. [Timeliness of dementia diagnosis](#)
5. [Dementia type](#)
6. [Dementia severity and progression](#)
7. [Dementia diagnosis and management](#)
8. [Collection and reporting of dementia and other health conditions in aged care](#)
9. [First Nations people-specific health care data on dementia](#)
10. [Other care and support services used by people with dementia and their carers](#)
11. [The workforce treating and caring for people with dementia](#)
12. [Comorbidities in people with dementia](#)
13. [Informal carers of people with dementia, including their needs and outcomes](#)
14. [Direct and indirect costs of dementia to the Australian economy](#).

Many activities are dependent on investment in dementia data development and research, national data developments in aged care, palliative care, primary care and the disability sector, advancements in data linkage infrastructure, and collaboration across government, dementia education and service providers.

Implementing these activities are required to meet the following 10-year goals of this plan. The goals are for Australia to have:

- robust dementia prevalence and incidence data
- national dementia data available and reported regularly in key monitoring areas
- improved dementia data in priority population groups
- dementia data within wider national data linkages
- harmonised dementia data collected across sources.

Summary of existing dementia data gaps

Understanding existing dementia data gaps for Australia is the first step in establishing what data improvement activities are needed and the investment required. The magnitude of current data gaps and the extent to which this impacts the ability to improve the lives of people with dementia and their carers informs the key goals of this plan (see [What are the aims and goals of the plan?](#) for more detail).

Overall, there were 14 specific dementia data gaps identified through consultation with the department, the AIHW Dementia Expert Advisory Group, and data monitoring needs for the [National Dementia Action Plan \(NDAP\)](#). See [Enablers to support success of this plan](#) for more information on the NDAP and how this influenced the development of this plan.

Table 4.1: Summary of dementia data gaps and their impact on dementia monitoring

Current data gap	Impact on dementia monitoring
Risk and protective factors for dementia	<p>Incomplete national dementia risk factor data affects our understanding of the contribution of risk factors to dementia incidence and prevalence in Australia and how this impacts trends over time. Having robust and up-to-date information on risk and protective factors is needed to inform primary prevention policies.</p> <p>As there is currently no cure or effective treatment for dementia, reducing lifestyle risk factors in the population is the way to reduce, delay or prevent dementia (Alzheimer's Association 2018). In addition, knowledge in this area will continue to evolve with new research. Therefore, risk and protective factors for dementia is a key area to monitor.</p>

Dementia awareness and stigma	<p>The lack of national data on the Australian community’s knowledge and awareness of dementia, as well as attitudes towards people with dementia, impacts data required to inform and evaluate plans and policies to reduce the risk of dementia and improve outcomes for people with dementia and their carers. National data on how people with dementia and their carers experience stigma are required to inform and evaluate strategies and policies targeted at reducing or eliminating stigma.</p> <p>Better dementia awareness, reduced stigma, and knowing the benefits of seeking early diagnosis, treatment and support can lead to people seeking earlier professional help and improved outcomes for people living with dementia.</p>
Dementia prevalence and incidence	<p>Not knowing the exact number of Australians living with dementia and the number of new cases of dementia each year means we do not truly understand the impact of dementia in Australia. This impacts government and service providers’ ability to plan and evaluate existing services and supports, design and implement new policies, and adequately plan for the future.</p>
Timeliness of dementia diagnosis	<p>Data on timely diagnosis of dementia from onset of symptoms to obtaining a diagnosis in primary or secondary care are important as they may facilitate early intervention, action on modifiable risk factors, better management of symptoms, support for people living with dementia and their carers, maintenance of independence and postponement of entry into residential aged care (WHO 2022).</p>
Dementia type	<p>Data on the different types of dementia will provide information on which types are most prevalent in Australia and where we need more research, policy development or services. Further, understanding dementia types which can be prevented or delayed through lifestyle changes and how outcomes differ by dementia type may lead to different prevention, treatment and service recommendations and planning for those types.</p>
Dementia severity and progression	<p>At present there is a lack of data on people in the early stages of dementia or cognitive impairment, including the diagnosis and early disease management process. Current data sources tend to capture people with more severe dementia, when they engage with hospital and aged care services. This impacts our ability to understand the trajectory of dementia, what interventions lead to reduced severity and how best to plan services for those with increased care needs.</p> <p>Limited data on dementia severity and rate of progression also impacts selecting treatment options, selecting patients into clinical trials and/or assessing responses to treatment (O’Byrant et al. 2008).</p>
Dementia diagnosis and management	<p>A lack of national data on the diagnosis and management of dementia by primary and secondary care providers (in particular, data from general practitioners (GPs) and specialists such as geriatricians) is the biggest single data gap affecting our understanding of dementia in Australia (AIHW 2020a).</p> <p>Existing data are currently unable to capture the complexity of care and support often required for people living with dementia. This includes how they transition between care settings, such as between home, respite, hospital, residential aged care systems and, potentially, palliative care services within community or aged care settings (AIHW 2020b). These transitions are important to understand to improve the quality of care provided to people with dementia.</p>
Collection and reporting of dementia and other health conditions in aged care data	<p>Aged care services are important for supporting older Australians to remain living in their own home for as long as possible, and for providing consistent care and support when a person needs to enter residential aged care. However, there are limited data on dementia in current aged care data. This impacts government and service providers’ ability to plan and evaluate existing aged care services and adequately plan aged care for the future.</p>
First Nations people-specific health care data on dementia	<p>The lack of national data on people with dementia who access culturally appropriate health and aged care services designed for First Nations people is a large gap. This particularly impacts our understanding of the impact of dementia, health outcomes and the use of these services in remote areas where these may be the only accessible services for the local population (AIHW 2016). This impacts government and service providers’ ability to plan and evaluate existing services and adequately plan care for the future.</p>

Other care and support services used by people with dementia and their carers	People with dementia and their carers may access a range of services in addition to primary and aged care, such as dementia-specific support services, disability support services, respite care, and palliative care. Better measures of the types and quality of care services provided is important to better understand support for people recently diagnosed, patient experiences with the health system (including access and barriers), and how variations in care impact health outcomes. Monitoring the patterns of service use by people with dementia and their carers can indicate demand and is essential for service planning. It can also help assess whether services are meeting needs and identify opportunities to improve outcomes for people with dementia and their carers.
The workforce treating and caring for people with dementia	Building a better understanding of the composition of the workforce treating, supporting and caring for people with dementia in and beyond aged care, and their education and training, would provide the necessary information to adequately plan care for the future. This would also help monitor workforce knowledge to provide high-quality, person-centred care for patients and clients with dementia and where greater education is required.
Comorbidities in people with dementia	Understanding the presence of existing health conditions (comorbidities) among people with dementia is important because the presence of comorbidities increases the complexity in managing their co-existing condition/s as well as their dementia. Comorbidities can also be risk factors that impact dementia progression.
Informal carers of people living with dementia, including their needs and outcomes	Information on carers of people with dementia is important for policy development and service planning because dementia not only affects individuals with the condition but also has a substantial impact on their families and carer/s as many of these informal carers help with activities of daily living for people with dementia. Therefore, it is important to measure how many informal carers there are for people with dementia; the characteristics of these carers; the type of assistance that they provide; the impact of their caring role; and areas of unmet support. This can inform the types of programs needed to support informal carers, and how to complement this with formal carers amid a shortage of disability and aged care workers.
Direct and indirect costs of dementia to the Australian economy	There is no single source of data to estimate total expenditure due to dementia. Australia's response to dementia requires regular monitoring and reporting of both the direct costs and the substantial indirect costs, such as informal care, lost productivity, and income support provided to people with dementia and/or their carers.

The lack of comprehensive data on how many Australians are living with dementia and how this differs across Australia is a significant gap. There is no single data source that can provide exactly how many people are living with dementia (prevalence) and the number of people newly diagnosed with dementia each year (incidence). Estimating dementia incidence is difficult because dementia is a gradual evolution of signs and symptoms and requires knowing the date of diagnosis (AIHW 2023). Robust data on dementia prevalence and incidence are essential for monitoring dementia in every aspect, and why improving these data in the next 10 years is a goal of this plan.

As we do not have a great understanding of dementia prevalence at a national level, there are limited data on dementia in people from diverse backgrounds and/or with specific characteristics. These include:

- data on First Nations people
- culturally and linguistically diverse (CALD) populations
- veterans
- people with younger onset dementia
- lesbian, gay, bisexual, transgender, intersex, queer, asexual or sexually or gender diverse (LGBTIQ+) communities
- people living in regional and remote areas
- people with disability
- childhood dementia
- people who are homeless or at risk of homelessness
- people who develop dementia in prisons.

Data are also limited on people living with dementia without support networks or where the support networks are aged under 18, as may be the case in single-parent households where the parent has younger onset dementia. These groups have unique needs and may face barriers to equitable access to services and support. Data on dementia among priority population groups are essential to understand the impact of this condition and whether these groups are receiving the required services and support. This is why improving dementia data in priority population groups in the next 10 years is another key goal of this plan.

Direct improvements to the content and scope of available national data are only one component. There are broader system and policy-level barriers that need to be overcome, such as a lack of technological infrastructure and informatics mapping, and fragmented service navigation (Burkinshaw et al. 2022). See [Enablers for the National Dementia Data Improvement Plan](#) for more detail.

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Dementia data gaps and improvement activities

To address the existing dementia data gaps and achieve the goals of this plan, the following pages outline what data improvement activities need to be undertaken for each data gap. Data improvement activities can be classified by:

- Data activity types (new, expansion, one-off, linkage, harmonisation, methods development or other)
- the activities priority rating (high, medium or low priority, based on selected criteria)
- who will lead the activity

The specific data improvement activities are mapped (in Table 4.2) to fill identified data gaps and will be aligned to the draft National Dementia Action Plan (NDAP) objectives and mapped to NDAP performance measures when these become available to inform policy and program development.

Data activity types

Data activity types can include:

- **creation of a new data source**, such as establishing a collection of new administrative data or conducting a new survey
- **expansion of existing data collections**, for example, by including additional dementia data items in an administrative or survey collection, or through increasing the sample size of an existing survey to facilitate analysis and reporting on people with dementia
- **undertaking a one-off study**, such as a small case study, to provide data that would help fill a key data gap or quality issue
- **data linkage** to integrate data from more than one existing data set to expand and enhance dementia data resources and facilitate validation of dementia estimates
- **data harmonisation** to improve the coherence of dementia data (such as through implementing standard concepts and classifications across data sets)
- **development of data analysis methods** to improve estimates of dementia, including improved estimates of dementia prevalence
- **other** activities that do not fit into the categories above.

Priority criteria and weighting

Activities were ranked according to how they aligned with filling data needs, how they provided foundational data to build from, their level of dependency on external factors, and how they could allow disaggregation by one or more priority population groups. The scoring criteria were:

- **Alignment (0-4)** - how an activity provides data to enable reporting of one or more NDAP performance measures (in development) or the needs for national dementia monitoring by the National Centre for Monitoring Dementia (NCMD) to inform policy, research, consumer or service planning needs
 - 0 - poor
 - 1 - less important gap
 - 2 - moderately important gap
 - 3 - highly important gap (or able to fill 2 data gaps which are individually scored '2')
 - 4 - critical gap (or able to fill 2 data gaps which are individually scored '3').
- **Foundational data (0-3)** - an activity that provides data that are enduring or contribute to quality foundational structured data that can be used within or across data collections via linkages, or over time (as baseline data) for dementia monitoring
 - 0 - not foundational
 - 1 - method development (without foundational data collection)
 - 2 - foundational data but do not provide enduring data and/or not appropriate for linkage or interoperability
 - 3 - foundational and can provide linkage or interoperability.
- **Dependency (0-2)** - the level of dependency the activity has on the finalisation of other data improvement activities, governance, operational or legislative arrangements, or multi-sectorial collaboration
 - 0 - highly dependent on external factors (for example, legislative arrangements, and/or multi-sectorial collaboration for data collection)
 - 1 - intermediate level of dependencies (for example, dependent on one external data source)
 - 2 - minimal dependencies, or provides pre-requisites for other data improvement activities that are needed to achieve the plan goals.
- **Priority group data (0-1)** - whether the activity contributes to improving information on dementia among one or more priority population groups
 - 0 - unlikely
 - 1 - likely.

The above criteria scores were added to provide priority scores from 1-10, with scores ≤ 4 considered 'low' priority, scores of 5-6 considered 'medium' priority, and scores ≥ 7 considered 'high' priority. Note that medium or low priority activities are still considered important for improving dementia data but may occur after higher priority activities or external dependencies have been addressed.

Table 4.2: Criteria and scoring matrix to prioritise dementia data improvement activities

Criteria	Scores				
	0	1	2	3	4
Alignment	Poor	Less important gap	Moderately important gap	Highly important gap (or 2 scored 2)	Critical gap (or 2 scored 3)
Foundational data	No	Method development	Foundational data with limitations	Foundational to provide linkage or interoperability	
Dependency	Highly dependent	Intermediate	Minimal external dependencies, or addresses pre-requisites for other data improvement activities that address plan goals		
Priority group data	Unlikely	Likely			

Other factors that may be considered for implementation are cost and time for completing the activity. All activities will not be able to be commenced at once and activities will be prioritised. Some activities will need to be completed before others and priority activities will be commenced as resourcing allows. Some activities will also vary in duration.

Time - the timeframe for completing the described activity once commenced.

- Short-term - less than 2 years
- Medium-term - 2 to 6 years
- Long-term - 6 years or more.

Time and cost have not been incorporated into the prioritisation matrix as those activities that take significant time and cost need to be considered on their merit before factoring timelines to meet objectives, budget, and value for money considerations.

Any additional activities identified through future consultation and emerging data development opportunities will also be considered, in line with the review points and assessments of data quality arising from the activities.

Who is responsible for undertaking data improvement activities?

The dementia data improvement activities identify a 'responsible stakeholder' that would lead the activity, recognising that multiple stakeholders may be involved in undertaking the activity. Several activities would be led by the AIHW NCMD, but others may be led by other government agencies, service providers and/or organisations that manage existing data collection or service programs, as well as research consortiums or researchers.

The NCMD is well placed to undertake a range of dementia data improvement activities due to their experience in accessing, analysing and reporting on dementia. AIHW houses, and is the data custodian of, many national data sets that can provide national dementia data and is an accredited data integration service provider for data linkage.

Future work under the NCMD data improvement stream will be directly informed by this improvement plan. Projects with an overall high priority rating will be prioritised by the NCMD in consultation with the Department of Health and Aged Care (department) and Dementia Expert Advisory Group and timeframes and funding limitations will be considered to progress this work to address NCMD, NDAP, policy and program needs.

Dementia Data Partnership Projects

The NCMD will administer funding from the department to undertake dementia data improvement activities via the Dementia Data Partnerships Projects program. This program is being established to fund external parties to undertake projects that will lead to tangible and practical steps in addressing key dementia data gaps. A range of projects will be considered for the Dementia Data Partnership Projects program. More detail regarding the guidelines to assess suitability can be found at [Dementia Data Partnership Projects](#).

Department of Health and Aged Care

The [Department of Health and Aged Care](#) (department) is responsible for developing evidence-based dementia and aged care policies, funding dementia initiatives and programs (including the NDAP) and commissioning research to make sure information is available to make better decisions to support people living with dementia, their families and carers.

The department has a leading role in the continuation of funding for dementia monitoring and research, and ensuring dementia remains a policy priority on Australia's health and aged care agenda. However, the department is also responsible for leading specific data improvement activities related to improving data collection in programs they manage. For example, they would be responsible for implementing training for assessors completing aged care assessments to improve capture of dementia in current assessments, any changes to Medicare Benefits Schedule (MBS) items to specify dementia screening or Performance Improvement Program changes to improve reporting.

Key service providers

Key service providers include [Dementia Training Australia \(DTA\)](#), [Dementia Support Australia \(DSA\)](#), [Dementia Australia](#), and providers of care in the disability, community and residential aged care sectors. DTA is a network of dementia specialists that work closely with DSA and Dementia Australia to provide education and training to all people working with or caring for people with dementia. DSA provides key national support services that include the Dementia Behaviour Management Advisory Service, Severe Behaviour Response Teams and a Needs Based Assessment program to determine eligibility for the Specialist Dementia Care Program. Dementia Australia provides the National Dementia Helpline, advocacy, information and events.

Services are also provided through general (non-dementia specific) providers such as carer organisations, medical and health professionals, and social service providers.

Key service providers for people living with dementia and their carers may be responsible for leading specific data improvement activities related to improving data collection in programs they manage.

Australian Bureau of Statistics

The [Australian Bureau of Statistics \(ABS\)](#) is Australia's national statistical agency, providing trusted official statistics on a wide range of economic, social and population matters. It provides statistics that show variations by geography, sex, age and income and specific surveys such as the [Census](#) of the whole population and representative surveys such as the [National Health Survey and Survey of Disability, Ageing and Carers \(SDAC\)](#). The ABS also has a key role in bringing together a range of data sets through data linkage, such as the [Multi-Agency Data Integration Project \(MADIP\)](#), which is a secure data asset combining information on health, education, government payments, income and taxation, employment and population demographics.

Research community

Australian and international dementia research is being performed by a range of universities and researchers. Many of these are funded through the [National Health and Medical Research Council \(NHMRC\)](#), [Medical Research Future Fund \(MRFF\)](#) or the [Dementia Australia Research Foundation](#).

The following pages present the 14 data gaps and outlines specific data improvement activities under each gap. These activities would improve the available evidence on dementia that is needed to improve the outcomes or experiences of people with dementia and their carers.

Dementia data gaps and improvement activities

On this page:

- [Addressing the data gap and improving data](#)
- [Proposed data improvement activities](#)

Risk factors are attributes or exposures that increase the likelihood of a person developing a health condition. Risk factors can be grouped into 2 broad categories: non-modifiable (meaning they cannot be modified in any way) and modifiable (meaning they can be altered or treated with changes in behaviour). Diseases and injuries can also act as risk factors.

Risk factors for dementia include:

- non-modifiable (Chen et al. 2009, AIHW 2023):
 - advancing age
 - genes associated with dementia (for example, apolipoprotein Eε4)
 - family history
- modifiable (AIHW 2023, Desmarais et al. 2020, Günak et al. 2020):
 - low levels of education in early life
 - obesity in midlife
 - high blood pressure in midlife
 - tobacco smoking
 - excessive alcohol consumption
 - physical inactivity
 - high cholesterol
 - high homocysteine
 - depression
 - social isolation
 - air pollution
 - post-traumatic stress disorder (PTSD)
- diseases and injuries (AIHW 2023):
 - cardiovascular disease (including coronary heart disease stroke, and atrial fibrillation)
 - chronic kidney disease
 - diabetes
 - depression
 - hearing loss in midlife
 - traumatic brain injury.

Several of these diseases are modifiable with treatment and in the case of hearing loss - the use of hearing aids.

There are several other risk factors that may be associated with an increased risk of developing dementia, but more research is needed on these. They include various lifestyle and biomedical factors (such as prolonged stress, diet, inadequate sleep, and various health conditions) and environmental risks (Anstey et al. 2019). Repeated head injuries can lead to chronic traumatic encephalopathy (CTE) which is a type of brain degeneration that is associated with the development of dementia (Alzheimer's association). CTE can only be diagnosed after death by examining microscopic changes in the brain and is often identified in brains donated to brain banks such as the [Australian Sports Brain Bank](#) (Suter et al. 2022).

The [Australian Veterans' Brain Bank](#), a sister organisation to the Australian Sports Bank, commenced in 2023 to examine the effect of head injury in veterans (NSW Health 2023). The Australian Former Elite Level Athlete Brain Health Research Program is a longitudinal study that is evaluating how much modifiable risk factors may contribute to the risk of poor health outcomes (AIS 2023). CTE researchers are still learning about its risk factors, causes, symptoms, progression and prevalence. Investigating data sources that could help better understand CTE and its relationship with dementia in Australia would be an important first step to improve data in this area.

Protective factors decrease the chance of a person developing a health condition or may help slow its progression. Protective factors for dementia include higher levels of education and maintaining a socially and cognitively active lifestyle (ADI 2009; Seeher et al. 2011). Actions to address modifiable risk factors include reducing high blood pressure and high cholesterol, eating a Mediterranean style diet, ceasing smoking, limiting alcohol, ensuring sufficient physical activity, healthy sleep patterns and taking protective actions to minimise head injury (Dementia Australia 2021).

Addressing the data gap and improving data

Monitoring dementia risk and protective factors by demographics such as sex, age, geography and cultural background is crucial to understand a population's risk profile and how this impacts the rate of dementia and trends over time. Having robust and up-to-date information on risk and protective factors is needed to inform primary prevention policies. While effective policies across the entire disease

pathway are important, reducing risk and increasing protective factors can reduce, delay or prevent dementia (Alzheimer's Association 2018).

Improved data on dementia risk factors includes better data on the prevalence of risk factors, the strength of association between the risk factor and development of dementia, and research into new risk factors and how risk factors work together. Potential sources for reporting dementia risk and protective factors at a national level are listed below and further sources may emerge over time.

- The [Australian Bureau of Statistics \(ABS\) National Health Survey](#) collects data on population-level health risk factors, including some risk factors for dementia (such as level of highest educational attainment, obesity, physical inactivity, hypertension, smoking, hearing loss and diabetes). National data on other risk factors such as social isolation, head injuries and genetic risk factors are lacking.
- The [ABS 2021 Census](#) asked questions on long-term health conditions, including dementia, for the first time. The Census also includes some data relating to dementia risk factors, such as highest educational attainment and household composition (a possible indicator of social isolation).
- The Sax Institute's [Analysis of Population Traits and Risk Factors \(ADAPTOR\) study](#) links longitudinal data from over 200,000 participants from the 45 and Up Study with data on their use of prescription medications, and hospital, general practitioner (GP) and other health services. It will identify people with dementia and the risk factors that may have contributed to their dementia.
- The [Centre for Healthy Brain Ageing](#) is leading the establishment of Dementias Platform Australia. This platform aims to facilitate data sharing between dementia researchers to enhance productivity and reusability of data from contributing studies to enable the development of new insights into ageing, ageing-related diseases and dementia risk.

Genetic testing is currently not a routine part of dementia diagnosis and is usually only performed in rare cases where there is a strong family history of younger onset dementia, to assess a person's risk of developing dementia. This may change in the future as the understanding of the association between genes and dementia increases (Dementia Australia 2022).

Genetic tests assessing a person's risk of developing certain types of dementia are not covered under the Medicare Benefits Schedule (MBS), but de-identified data from pathology clinics offering genetic testing could be a potential future data source (subject to relevant privacy provisions) contributing to understanding genetic risk factors and their association with dementia diagnosis, clinical pathways, and outcomes.

Proposed data improvement activities

There are 2 main activities proposed to improve available data on dementia risk and protective factors. These include activities to:

- investigate known and emerging risk and protective factors for dementia and their impacts
- expand dementia risk factors included in Australian Burden of Disease Study analysis.

These activities may involve single projects, or multiple projects aimed at improving data on dementia risk and protective factors. Each activity provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activity 1a: Investigate known and emerging risk and protective factors for dementia and their impacts

This activity involves projects aimed at investigating and analysing dementia risk and protective factors using existing data, and work to develop new data if required. For example, this could include an activity that uses linked data (such as the National Health Survey and 2021 Census within the Multi-Agency Data Integration Product (MADIP) and the ADAPTOR study that capture risk factors that contribute to dementia), existing epidemiological studies and data-sharing platforms (such as [Dementias Platform Australia](#)). Risk and protective factors for dementia incidence and progression would be analysed for different population groups and compared to those from large/pooled international studies to appreciate variability across populations groups within (and across) countries.

Relative risks would be calculated, and prevalence of risk factor exposure estimated. The overall contribution of each risk factor on dementia prevalence and mortality (if applicable) in Australia could be estimated. Work to augment existing data collections and specific data developed to assess dementia risks among priority population groups may also be needed where no data are currently available.

Outcome: More comprehensive estimates of the contribution of each risk factor on dementia prevalence and mortality in Australia and how this may change over time, and enable monitoring of risk factors following preventive health initiatives

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	1	1	7

- Alignment: highly important as provides data on risk and protective factors to estimate the burden of dementia attributable to risk factors in future versions of the Australian Burden of Disease Study (ABDS)
- Foundational data: improves breadth and accuracy of risk factors to improve ABDS and projected prevalence data
- Dependencies: data from external groups and linkage
- Priority group reporting: likely

Level of investment: Low-Medium

Low investment is needed for activities that plan to use existing data. More investment is needed for activities that aim to augment existing data collections, analyse more complex risk factors (such as social determinants of health and diseases-as-risks), or explore risks in priority population groups where greater data development is required.

Timeframe: Short term (<2 years)

Activities could commence now.

Responsible stakeholder: Academic researchers; organisations holding potential sources for reporting dementia risk and protective factors at a national level.

Activity 1b: Expand dementia risk factors included in Australian Burden of Disease Study analysis

The ABDS 2018 estimated the dementia burden attributable to 6 modifiable risk factors (tobacco use, overweight and obesity, physical inactivity, high blood pressure in midlife, high blood plasma glucose, and impaired kidney function). This is not an exhaustive list of risk factors linked to dementia and only includes risk factors that were measured in the ABDS 2018.

To include additional risk factors in the study, risk factor exposure data are required at the Australian population level (or which could be applied to the Australian population), as well as estimates of the additional risk of developing or dying from dementia (relative risks). Only risk factors that have these data available will be able to be included in this study. Where possible, new data and information developed from the previous activity addressing this data gap would be incorporated into this activity.

Undertaking a specific dementia risk factor burden analysis that includes a broader range of established risk factors for dementia (such as low education levels, air pollution and depression), would allow the contribution of modifiable risk factors to dementia burden in Australia to be better understood. This information can be used to prioritise public health efforts to reduce the incidence of dementia. It should be noted that burden of disease analysis has stringent evidence requirements, which means that evidence accepted in other scientific disciplines may not be included in the ABDS. Further, additional work would be required to assess whether the risk factors and available data used for estimating dementia burden due to risk factors in the general population are applicable for estimating this among First Nations people.

Outcome: Greater inclusion of dementia risk and protective factors data in burden of disease studies allowing greater appreciation of burden and avoidable burden to inform policy and prevention programs

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	0	1	6

- Alignment: highly important as provides improved data on the contribution of modifiable risk factors for dementia to disease burden in Australia
- Foundational data: for understanding contribution of risks to burden
- Dependencies: outcomes from the first data improvement activity (Activity 1a) would provide data for this activity; this activity is also dependant on ABDS timing and updates
- Priority group reporting: likely - the ABDS currently provides risk factor information by socioeconomic groups, so this work would impact reporting by these population groups; this work could also improve estimates of dementia burden due to risk factors among First Nations people

Level of investment: Low

This activity requires low investment as it utilises existing data and methods developed by the ABDS.

Timeframe: Short term (<2 years)

This activity could commence now and be updated when more evidence and data become available.

Responsible stakeholder: AIHW (National Centre for Monitoring Dementia and teams undertaking the ABDS).

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Dementia data gaps and improvement activities

On this page:

- [Addressing the data gap and improving data](#)
- [Proposed data improvement activities](#)

Dementia awareness means knowing what dementia is and its symptoms and causes, who it can affect, knowing how to delay its onset or slow its progression, and how it can be treated. The number of Australians living with dementia is projected to double to almost 850,000 by 2058 (AIHW 2023), driving a need for dementia education to raise awareness, encourage preventive actions, address common misconceptions, and reduce stigma. Improving the general public's knowledge and acceptance of dementia may help prevent or delay the onset of dementia, improve the support provided to people with dementia and their carers, improve timeliness of diagnosis and reduce dementia-related stigma.

Dementia is a stigmatised condition. Stigma is a complex social phenomenon where a social difference is identified, devalued, and discriminated against. Stigma involves negative beliefs (stereotypes) that manifest as negative emotional responses (prejudice) and negative behavioural responses (discrimination) (Alzheimer's Disease International 2019). Dementia-related stigma can affect people with or without dementia and can be directed towards people with dementia as well as those close to them, such as carers. Dementia-related stigma can cause significant negative effects, such as low self-esteem, isolation, poor mental health and lower quality of life in people living with dementia (Livingston and Cooper 2013) and increased carer burden (Werner et al. 2012). Stigma is the largest concern for people living with dementia (Alzheimer's Australia WA 2015). Stigma can also prevent people from accessing health services, which delays diagnosis and treatment (Vernooij-Dassen et al. 2005; Alzheimer's Disease International 2019).

Addressing the data gap and improving data

Understanding the Australian community's knowledge and awareness of dementia, as well as attitudes towards people with dementia, will help inform and evaluate plans and policies to reduce the risk of dementia and improve outcomes for people with dementia and their carers. Previous research suggests that many Australians do not recognise dementia as a health priority and have limited understanding of lifestyle behaviours that may reduce the risk of developing dementia (Smith et al. 2014). This includes information on the community's awareness of what dementia is (including the conditions that cause dementia and the range of symptoms that may be present), as well as risk and protective factors for dementia (particularly modifiable factors).

The need and approach for awareness activities may vary for different communities including First Nations people and culturally and linguistically diverse (CALD) communities. The [Let's CHAT \(Community Health Approaches To\) Dementia in Aboriginal and Torres Strait Islander Communities](#) (University of Melbourne 2022) is a co-designed project working with 12 Aboriginal Community Controlled Health Services to improve dementia diagnosis and care and provides information about cultural differences in how dementia is understood, spoken about, experienced and responded to. [Caring for Spirit](#) provides First Nations people with culturally safe online dementia resources (NeuRA 2023).

There is a current lack of national data on dementia awareness and stigma in the population. National data on how people with dementia and their carers experience stigma are required to inform and evaluate strategies and policies aimed at reducing or eliminating stigma. These data are also needed to monitor outcomes of the National Dementia Action Plan (NDAP).

Proposed data improvement activities

There are 4 main activities proposed to improve available data on dementia awareness and stigma in the population. These include activities to:

- conduct nationally representative survey/s of dementia awareness, risks and attitudes in the Australian community
- collect representative data on dementia awareness and attitudes among priority groups (including First Nations people and CALD groups)
- collect data on the experiences of people with dementia and their carers (including experience of stigma and discrimination and interactions with care providers)
- collect data on experiences of people with dementia and their carers among priority groups (including First Nations people and CALD groups)

These activities may involve single projects, or multiple projects to enable monitoring of trends over time or to focus on a specific population group. Each activity description provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activity 2a: Conduct nationally representative survey/s of dementia awareness, risks and attitudes in the Australian community

This activity involves conducting a national survey on the public's awareness of and attitudes towards dementia (including behaviours to reduce risks). Understanding public knowledge and beliefs about dementia is important to inform the design and targeting of national initiatives and provide baseline data for measuring progress. Data from this activity would provide baseline information to monitor the

NDAP's aims of expanding dementia awareness, reducing the stigma and understanding risk factors for dementia. Subsequent surveys would need to be undertaken to provide data over time. This would enable examining trends over time.

Outcomes: Data on community attitudes and knowledge of dementia and risk factors to inform where knowledge gaps are and what types of information needs to be provided; repeated surveys would measure any changes following awareness campaigns and actions implemented from the NDAP

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	2	2	0	8

- Alignment: addresses a critical data gap on awareness, attitudes, and risks
- Foundational data: for baseline data
- Dependencies: none (the initial survey can be implemented to provide the baseline for subsequent surveys)
- Priority group reporting: unlikely

Level of investment: Low

Low investment is needed to conduct a single survey but continuous investment is needed for repeated surveys.

Timeframe: Short term (<2 years)

This activity has commenced and should be conducted every 3-5 years to collect data over time.

Responsible stakeholder: AIHW National Centre for Monitoring Dementia.

Activity 2b: Collect data on dementia awareness and attitudes among priority groups (including First Nations people and CALD groups)

Like the previous activity (Activity 2a), this activity involves collecting information on the awareness of and attitudes towards dementia (including behaviours to reduce risks) among First Nations people and/or CALD groups. The sampling method, design and respondent engagement strategies would need to be designed to be culturally appropriate, recognising that different cultural attitudes around dementia will require different approaches. Activities should be designed to maximise participation and data collection from First Nations people and CALD groups and may involve the use of qualitative rather than quantitative data. For this reason, the activity could involve distinct projects for specific population groups. Data collection at subsequent time intervals would enable data and themes over time to be examined.

Outcomes: Data on attitudes and knowledge of dementia and risk factors among priority groups to inform where knowledge gaps are and what types of information need to be provided; repeated data collections would assess changes following awareness campaigns and actions implemented from the NDAP

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	2	1	1	8

- Alignment: addresses a critical data gap on awareness, attitudes, and risks
- Foundational data: for baseline data
- Dependencies: organisations with cultural expertise, relationships and contacts for priority groups required
- Priority group reporting: likely - specific for CALD or First Nations people

Level of investment: vHigh

CALD and First Nations people-specific data collection requires greater resourcing and consultation.

Timeframe: Medium term (2-6 years)

This activity should be conducted periodically to collect data over time.

Responsible stakeholder: Academic researchers; organisations with experience in collecting data among priority population groups.

Activity 2c: Collect data on the experiences of people with dementia and their carers

This activity involves the collection of data on people with dementia and their carers. This may require multiple activities to understand a range of experiences such as stigma and discrimination related to dementia, post-diagnostic support, interactions with care providers, timeliness and barriers to diagnosis, and experiences of the caring role. Data collection at subsequent time intervals would enable data over time and trends to be examined.

Outcomes: Initial data would provide data on the experiences of people living with dementia and their carers and could identify:

- the types of discrimination experienced, to inform responses in the community, health, disability and aged care sectors
- the magnitude and cause of delays in a timely diagnosis, to inform improvements to diagnosis through both community and general practitioner (GP) awareness and health system factors
- experiences with service providers to inform changes needed to improve care and support for people living with dementia

Repeated data collections would measure changes following actions implemented from the NDAP.

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	2	1	0	7

- Alignment: addresses a critical data gap on awareness, attitudes and risks
- Foundational data: for baseline data
- Dependencies: organisations with dementia and/or carer expertise and contacts required
- Priority group reporting: unlikely - numbers likely too low for disaggregation

Level of investment: Medium-High

The level of investment will depend on the data collection methods. However, this activity will likely require in-person interviews with people with dementia and collection of qualitative data. There may be broader options for collecting data from carers but need to consider preferences for engagement.

Timeframe: Short term (<2 years)

This activity should be conducted periodically to collect data over time.

Responsible stakeholder: Academic researchers; organisations with experience in collecting data from people living with dementia and their carers.

Activity 2d: Collect data on experiences of people with dementia and their carers among priority groups (including First Nations people and CALD groups)

Like the previous activity (Activity 2c), this activity involves the collection of data on people with dementia and their carers. This may require multiple projects to understand a range of experiences such as stigma and discrimination related to dementia, culturally appropriate post-diagnostic support and interactions with care providers, timeliness and barriers to diagnosis, and experiences of the caring role.

The data collection methods and respondent engagement strategies would need to be designed to be culturally appropriate, recognising that different cultural attitudes around dementia will require different approaches. Activities should be designed to maximise participation and data collection. For this reason, the activity would involve distinct projects for specific population groups. Data collection at subsequent time intervals would enable data over time and trends to be examined.

Outcomes: Initial data would provide data on the experiences of people living with dementia and their carers among priority population groups, and could identify:

- the types of discrimination experienced, to inform responses in the community, health and aged care sectors
- the magnitude and cause of delays in a timely diagnosis, to inform improvements to diagnosis through both community and GP awareness and health system factors
- experiences with service providers to inform changes needed to improve care and support for people living with dementia.

Repeated data collections would assess changes following actions implemented from the NDAP.

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	2	1	0	7

- Alignment: addresses data gap on awareness, attitudes and risks
- Foundational data: for baseline data but not incidence/ prevalence
- Dependencies: organisations with dementia and/or carer expertise and contacts required
- Priority group reporting: unlikely - numbers likely too low for disaggregation

Level of investment: Medium-High

The level of investment will depend on the data collection methods. However, this activity will likely require in-person interviews with people with dementia and collection of qualitative data. There may be broader options for collecting data from carers but need to consider preferences for engagement.

Timeframe: Short term (<2 years)

This activity should be conducted periodically to collect data over time.

Responsible stakeholder: Academic researchers; organisations with experience in collecting data from people living with dementia and their carers; organisations with experience in collecting data among priority population groups.

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Dementia data gaps and improvement activities

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Monitoring the number of people living with dementia (prevalence) and the number of new cases of dementia each year (incidence) is required for policy development and service planning for health and aged care systems. Monitoring incidence over time indicates if the rate of diagnoses is increasing, decreasing or stable and whether certain population groups are more affected than others. However, this is difficult given the challenges of obtaining a timely diagnosis and lack of national general practitioner (GP) and specialist data with diagnostic information. See [Timeliness of dementia diagnosis](#) and [Dementia diagnosis and management](#) for more information.

Addressing the data gap and improving data

There is no single authoritative data source for deriving dementia prevalence in Australia, leading to varying estimates of how many people in Australia have dementia. Estimating dementia incidence is difficult because dementia is a gradual evolution of signs and symptoms rather than an acute event, and incidence requires information such as date of diagnosis and whether a diagnosis was made close to symptom onset (AIHW 2023a). There is no comprehensive source of information on dementia diagnosis date, meaning that dementia incidence is currently unmeasurable. National data on dementia incidence would also facilitate the estimation of dementia survival rates in Australia, which are currently not well understood. Accurate information on the number of Australians living with, and dying from, dementia in Australia is critical for monitoring trends and informing dementia policy and service planning (AIHW 2023a). Better data are also needed for the prevalence of different dementia types (for example, Alzheimer's disease, vascular dementia) and severities, as well as people with mild cognitive impairment.

The [Australian Dementia Network \(ADNeT\) Clinical Quality Registry](#), with its goal to register all Australians newly diagnosed with either dementia or mild cognitive impairment (ADNeT 2023), may be a future source of data that can contribute to estimates of dementia incidence at the population level. The ADNet Clinical Quality Registry is described in further detail at [Dementia diagnosis and management](#).

Existing epidemiological studies on healthy ageing, especially when linked with existing administrative data that enable identification of people living with dementia, could also inform better estimates of dementia prevalence and incidence. For example, the Sax Institute's [Analysis of Population Traits and Risk Factors \(ADAPTOR\) study](#) already links longitudinal data from over 200,000 participants from the 45 and Up Study with data on their use of hospitals, GPs, health services and prescription medication. Adding cognitive measures to existing studies could improve measures of dementia prevalence and incidence in Australia. There are challenges with this approach, as many existing surveys use volunteers which are not representative of the general population, where dementia risks and prevalence may be greater in those not participating in voluntary surveys (Brayne and Moffitt 2022).

Bringing together disparate data sources through data linkage would also help overcome some of the limitations associated with estimating the prevalence of dementia in Australia. Linked administrative data sets are currently being used to monitor dementia, and methodologies could be developed and refined using linked data to model estimates of dementia prevalence in Australia. However, data linkage is dependent on the capture of dementia and the quality of information provided in the individual data sets. At present, improvements are needed in available data sets and more types of data linked together. For dementia, available national data often capture people who have used a health, aged care or other type of support service, or people who died with a record of dementia, which skews towards capturing people who access services and/or who have more advanced dementia. Therefore, improvements in existing population-based studies and national surveys, or the development of new studies are needed to inform the estimation of dementia prevalence and mild cognitive impairment in Australia.

Proposed data improvement activities

There are 7 activities proposed to improve available data on dementia prevalence and incidence in the population. Some activities are directly focused on improving dementia prevalence and incidence data overall, while others are focused on improving or developing new data. Further, some activities are dependent on the completion of other activities in this plan.

Activities to improve dementia prevalence and incidence data include:

- incorporate dementia data in enduring linked data assets to meet the needs of dementia monitoring
- increase coverage of existing data for national dementia incidence monitoring
- investigate approaches to estimate the national prevalence of dementia
- assess new self-reported dementia data collected in the 2021 Census
- estimate dementia prevalence in priority population groups
- develop a Regional Insights portal of dementia data for local areas
- assess impact of dementia coding changes in ICD-11 when incorporated in the Australian health system.

These activities may involve single projects, or multiple projects to enable monitoring of trends over time, incorporate improvements in data or to focus on a specific population group. Each activity provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activities aimed at improving dementia diagnosis data in primary and secondary health care data would also improve dementia prevalence and incidence data. See [Dementia diagnosis and management](#) for additional activities.

Activity 3a: Incorporate dementia data in enduring linked data assets to meet the needs of dementia monitoring

There have been substantial developments and progress made with enduring linked data assets in recent years. The Australian Institute of Health and Welfare (AIHW) is aiming to expand an enduring linked data asset, which would allow approved projects to access data sets within the linked data asset using streamlined governance arrangements and pre-existing linkages of widely used health and aged care administrative data.

This activity involves the inclusion of dementia-focused data sources (such as data from Dementia Support Australia and the ADNet Clinical Quality Registry) in existing enduring linked data assets for dementia research and monitoring. Once the linked data asset is established and data governance and approvals are in place, dementia analysis would draw on data sets from the linked data asset including mortality data, hospital data, Pharmaceutical Benefits Scheme (PBS), Medicare Benefits Schedule (MBS), aged care, and any other relevant data sets which would improve dementia monitoring. Other relevant data sets could include data from the Department of Social Services Data On Multiple Individual Occurrences (DOMINO), National Disability Insurance Scheme (NDIS), and Department of Veterans' Affairs (DVA). This would allow for monitoring of people with dementia accessing welfare and disability support services, and services offered by DVA.

The enduring linked data asset could improve available data on a range of priority topics identified in the National Centre for Monitoring Dementia (NCMD) work plan, including culturally and linguistically diverse (CALD) status (for example, country of birth at a minimum), First Nations people, dementia among veterans, younger onset dementia, childhood dementia and rarer causes of dementia.

This activity relies heavily on improvements in existing national data infrastructure and governance arrangements, and ideally would be made available to all researchers.

Outcomes: Better diagnosis, prevalence, cost, services, transitions to aged care and outcomes data for the Australian national population and by priority groups.

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	3	0	1	8

- Alignment: highly important for multiple data gaps including National Dementia Action Plan (NDAP) objectives 4, 5, 6 and 7
- Foundational data: the linked data set would allow a breadth of dementia monitoring and research
- Dependencies: relies on linked data asset funding, infrastructure to support data linkage and appropriate governance, access and approvals from data custodians
- Priority group reporting: likely - would allow improved data on priority groups

Level of investment: Medium-High

The level of investment is dependent on the number of data sets to be linked and the resourcing involved to maintain an enduring linked data set. Work to include a single data source into an enduring linked data set would require medium investment. However, in total this is a high investment activity.

Timeframe: Short term for incorporation of single data set (<2 years); Long term (6+ years) to meet needs of dementia monitoring

Work to include a single data source could commence now and be completed in the short term, however, incorporating multiple data sources to suit dementia monitoring needs and maintaining an enduring linked data set are long-term activities.

Responsible stakeholder: AIHW NCMD

Activity 3b: Increase coverage of existing data for national dementia incidence monitoring

This activity involves investigating potential existing sources of dementia incidence data (such as the ADNeT Clinical Quality Registry, the ADAPTOR study and other epidemiological studies) and determining what work could be undertaken to estimate what coverage is required and how could this be achieved. This activity is focused on reviewing available data from existing studies and registries and recommends activities to expand sources to achieve nationally representative dementia incidence data. Following outcomes from this investigation, this plan would be updated to incorporate new activities.

Activities aimed at improving dementia diagnosis data in primary and secondary health care data would also improve dementia incidence data (see [Dementia diagnosis and management](#) for additional activities).

Outcome: Recommendations on activities to expand existing data sources to achieve nationally representative dementia incidence data

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	1	1	7

- Alignment: highly important to inform incidence monitoring
- Foundational data: needed to inform better incidence data
- Dependencies: relies on continued funding for existing registries and studies
- Priority group reporting: likely - however, this is dependent on data on priority groups available in existing sources

Level of investment: Low

The level of investment to undertake initial work to investigate potential sources and what coverage is required to improve national estimates of dementia incidence is low. Work to expand existing data to improve capture of dementia incidence and monitor this on an ongoing basis would be a high investment activity.

Timeframe: Short term (<2 years)

Responsible stakeholder: AIHW NCMD; academic researchers

Activity 3c: Investigate approaches to estimate the national prevalence of dementia

This activity involves a systematic investigation of different options (and combinations) to better estimate the prevalence of dementia. This would involve a review of international and national surveys and population-based studies used to estimate dementia prevalence and determine if these are appropriate for the current Australian context.

This activity would examine pre-existing nationally representative surveys, such as the ABS National Health Survey, and large population-based studies. The need for a new Australian population-based study, like the longitudinal [Cognitive Function and Ageing Studies](#) in the UK, would also be assessed if there are limitations with expanding or augmenting existing national surveys or population-based studies.

This assessment should consider and propose methodologies to sample participants and undertake cognitive screening to permit robust national estimates of the prevalence of dementia and mild cognitive impairment by key demographics. This activity should also consider priority populations and provide recommendations for collecting data in key priority groups. Completion of this activity would result in recommendations for estimating national prevalence of dementia through cognitive screening in population-based studies.

This investigation should evaluate the benefits of better prevalence data for reporting, policy and programs, and the anticipated benefits of screening or other methods to identify persons with dementia in a population that does not have a dementia diagnosis. Participants in such a study would need to be informed about the potential for a diagnosis of dementia according to the tool being used, and the risks of overdiagnosis harms associated with this (such as misdiagnosis) and consider any psychological harms of a diagnosis provided without a program of support offered in conjunction.

Following this investigation, this plan would be updated to incorporate new activities to implement the recommendations. Suitable data sources identified in this activity could also be used to compare and validate existing and emerging prevalence estimates from national enduring linked data sets.

Outcome: Recommendations to develop national estimates of dementia in Australia through population-based studies

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	2	1	8

- Alignment: highly important to improve prevalence data
- Foundational data: prevalence data
- Dependencies: investigation provides a pre-requisite to inform subsequent data collection
- Priority group reporting: likely - this study would inform data collection methods for priority groups

Level of investment: Low

The level of investment to develop a strategy for capturing national dementia prevalence through screening tests in population-based studies is low. Subsequent work to implement the activity would require high investment.

Timeframe Short term (<2 years)

Responsible stakeholder: AIHW NCMD in collaboration with input from academic researchers and experts in population-based studies.

Activity 3d: Assess new self-reported dementia data collected in the 2021 Census

The 2021 Census included a question on [long-term health conditions including dementia](#) for the first time. A current project under the NCMD aims to compare self-reported dementia records in the 2021 Census with dementia records in other data sets available in the Multi-Agency Data Integration Product (MADIP).

While there is potential that the 2021 Census data could capture people with mild to moderate dementia who have not yet had contact with hospital or aged care services (and thus be a valuable source for capturing additional cases), there is also potential that the public are not willing to share health information in the Census and lead to under-reporting. Analysis of the current Census data on dementia and other chronic conditions will inform the value of the Census data and any corrections to estimates required and the value for advocating for the inclusion of dementia as a long-term health condition in subsequent Censuses.

Outcome: Inform the use of Census data for monitoring dementia and estimating dementia prevalence in Australia; provide evidence to support the inclusion of a question on dementia in future Censuses

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	1	1	7

- Alignment: highly important gap
- Foundational data: may inform data methods and associations with self-reporting, and may allow comparisons with subsequent Censuses if this question is repeated
- Dependencies: data custodian and ethics approvals, repeating Census question
- Priority group reporting: likely

Level of investment: Low

Timeframe: Short term (<2 years)

Responsible stakeholder: AIHW NCMD (this activity is currently underway)

Activity 3e: Estimate dementia prevalence in priority population groups

This activity involves establishing methods and implementing studies to estimate dementia prevalence in priority populations. This may involve undertaking new dementia prevalence studies, expanding existing studies to improve the capture of dementia or using linked data to estimate dementia in priority population groups (if considered appropriate). The data collection methods would need to be designed to be culturally appropriate, recognising that different cultural attitudes around dementia will require different approaches. Activities should be designed to maximise participation and data collection. For this reason, the activity would involve distinct projects for specific population groups.

Outcome: Improved methods and data to estimate prevalence of dementia among priority groups

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	2	1	8

- Alignment: highly important data gap
- Foundational data: may inform prevalence data
- Dependencies: minimal
- Priority group reporting: likely

Level of investment: Low-Medium

The level of investment is dependent on the type of activity being undertaken. Development of new methodologies using existing data would require low investment, but new studies would require more investment.

Timeframe: Short term (<2 years) to Medium term (2-6 years)

Responsible stakeholder: Academic researchers; organisations with experience in collecting data among priority population groups; AIHW (for linked data projects).

Activity 3f: Develop a Regional Insights portal of dementia data for local areas

A Regional Insights portal for dementia would bring together dementia statistics across a range of topics at a local level, allowing users to easily access and compare dementia statistics for geographic areas. This would include estimates for dementia prevalence of dementia, health and aged care service use and other key statistics. This would be a similar design to the [Regional Insights for Indigenous Communities](#)

(RIFIC) website. This activity could build on the current project exploring the geographical variation in health service use by people with dementia currently underway under the NCMD. This activity supports the National Health Reform Agreement commitment to regular reporting on services in regional, rural, and remote communities.

Consideration would be needed on how to best report dementia statistics across a range of topics at a local level and the quality of the data by smaller geographies, and among priority population groups. For example, for data on dementia among First Nations people this could be the incorporation of dementia data into the existing RIFIC website. This would support *Priority Reform Four: Shared access to data and information at a regional level* in the [Closing the Gap Implementation Plan 2023](#). However, sufficient data needs to be available at the local level for this population group.

Outcome: Easy access to local geographic and comparator dementia statistics

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	2	0	1	5

- Alignment: moderately important data gap
- Foundational data: prevalence data at smaller geographies
- Dependencies: highly dependent on developments in availability of primary health care data to report on local geographies for data such as dementia prevalence, services, workforce
- Priority group reporting: likely - improves data on dementia in rural and remote populations and potentially on priority populations

Level of investment: Medium-High

Investment in the development and usability of a web-based portal is required. Maintenance of this website over several years would lead to this activity overall being a high investment activity.

Timeframe: Medium term (2-6 years)

Responsible stakeholder: AIHW NCMD; academic researchers; organisations with experience in collecting data among priority population groups.

Activity 3g: Assess impact of dementia coding changes in ICD-11 when incorporated in the Australian health system

The [International Classification of Diseases \(ICD\)](#) is a global health classification system and forms the basis for the recording of health data and production of health-related statistics. The ICD is revised every 10-20 years to ensure its currency and utility. ICD-11 represents a significant advance on the 10th revision of ICD, currently in use in Australia and internationally. In addition to updated scientific content, ICD-11 has been developed for use in electronic environments and is linked to other relevant classifications and terminologies (AIHW 2023b). The Australian ICD-11 Task Force was established in 2022 to develop a roadmap of activities regarding the implementation of the ICD-11 in Australia (AIHW 2023b).

This activity will monitor the implementation of ICD-11 in Australia and assess its impact on dementia coding across a range of contexts, including morbidity and mortality coding, as well as adaptations for clinical use in primary care, specialty care and research.

Outcome: Known impact of coding changes for dementia in ICD-11 and more rapid adaptations to existing routine monitoring of dementia using ICD coded data

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	3	0	1	6

- Alignment: moderately important data gap
- Foundational data: yes (interoperability)
- Dependencies: highly dependent on when and if the ICD-11 is implemented in Australia
- Priority group reporting: likely

Level of investment: Low

Timeframe: Short term (<2 years)

This activity could only commence after the ICD-11 has been implemented in Australia.

Responsible stakeholder: AIHW NCMD.

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Dementia data gaps and improvement activities

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Dementia is often diagnosed months or years after initial symptoms present. Early symptoms of dementia may not be recognised or are dismissed as a ‘normal’ part of ageing. The possibility of dementia may also be denied by the person experiencing symptoms or denied by their family and carers.

When professional help is sought, obtaining an accurate dementia diagnosis involves comprehensive cognitive and medical assessments and is often a long process that can be lengthened by access issues, especially in regional and remote areas. The time taken to receive a confirmed diagnosis may vary according to the person’s symptoms and who is conducting the assessments (AIHW 2023). An initial misdiagnosis of depression, bipolar disorder or schizophrenia may occur for those with younger onset dementia and may take a long period before a differential diagnosis of younger onset dementia is explored (Burkinshaw et al. 2022; Draper et al. 2016). In younger onset dementia, a multiyear diagnostic period has been attributed to system and policy-level barriers, including a fractured health system that is difficult to navigate and has inequitable access (Burkinshaw et al. 2022).

The Australian Dementia Network (ADNeT) Clinical Quality Registry [Annual Report](#) publishes on average times from general practitioner (GP) referral to a memory clinic to a dementia diagnosis, and will collect information on when symptoms were first observed. National data are not currently available on the time taken from symptom onset to a GP presentation for investigation of cognitive impairment through to a dementia diagnosis.

Timely diagnosis of dementia is important as it may facilitate early intervention, action on modifiable risk factors, better management of symptoms, initiation of care and support services for people living with dementia and their carers, maintenance of independence, and postponement of entry into residential aged care (WHO 2022).

Timely diagnosis of mild cognitive impairment (MCI) can be challenging as it is difficult to determine how much memory impairment is ‘more than normal’ (Dementia Australia 2022) for that individual, and more difficult for those with poor support networks. MCI is usually diagnosed through similar assessments as for dementia. Studies suggest that people with MCI are more likely to develop dementia (especially Alzheimer’s disease) - but MCI does not always lead to dementia (Dementia Australia 2022).

Proposed data improvement activities

There are 2 main activities proposed to improve available data on timeliness diagnosis. These include activities to:

- collect data on the experiences of people with dementia and their carers (Activity 2c described already under [Dementia awareness and stigma](#))
- link dementia onset data (collected through lived experience data collection) to clinical records containing dementia diagnosis data information to calculate timeliness of diagnosis.

Each activity description provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activity 4a: Link dementia onset data to clinical records containing date of dementia diagnosis and calculate timeliness of diagnosis

This activity involves the linkage of data on dementia onset (collected through lived experience data collection) to clinical records that contain date of dementia diagnosis, and subsequent analysis of the linked data to estimate timeliness of diagnosis. Initial linkage will not be nationally representative as there are no comprehensive national data containing date of dementia diagnosis. Consideration should be made over time on whether the lived experience data collection could be incorporated into enduring data linkages planned under Activity 3a.

Outcome: Data available on time between onset of dementia symptoms and diagnosis made; subsequent data collections and linkages would allow examination of trends in time to diagnosis, over time.

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	1	1	1	7

- Alignment: high importance for multiple areas of National Dementia Action Plan (NDAP) objective 3
- Foundational data: method development
- Dependencies: dependent on the collection of dementia onset data

- Priority group reporting: likely - if sufficient data on priority groups in both data collections

Level of investment: Low

Timeframe: Medium term (2-6 years) for incorporation of single data set and analysis; Long term (6+ years) for subsequent analysis of changes in timeliness of diagnosis over time

Responsible stakeholder: Academic researchers; AIHW National Centre for Monitoring Dementia (for data linkage).

References

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Dementia data gaps and improvement activities

People with dementia should be informed about their type of dementia so that they and their family and carers better know the prognosis and appropriate treatment options. However, it can be challenging to correctly diagnose the type of dementia based on a person's symptoms (AIHW 2023), and a confirmation of diagnosis may require post-mortem assessment (Love 2005). A reliable classification of dementia type can also be difficult when a person has more than one type of dementia.

There is a lack of reliable information on dementia type in health and aged care data collections, and those that do collect information on dementia type use different classification systems (AIHW 2020), which is an interoperability issue that can lead to inconsistencies in how dementia data are recorded and reported. The AIHW [Dementia in Australia](#) report currently reports data on dementia type where national data permit.

Addressing the data gap and improving data

Dementia type data will help understand which dementia types need more research, policy development or services. This may lead to different prevention, treatment and service recommendations and planning for those types.

Work has already commenced to harmonise the collection of data on dementia (including by dementia type) in national data collections. The [Dementia National Best Practice Data Set \(NBPDS\)](#) was endorsed for national use in October 2022. A NBPDS is one of several types of metadata sets (known as [data set specifications](#)), that provides recommendations on data collection by organisations. The Dementia NBPDS provides recommendations on how to classify and collect data on dementia type.

Proposed data improvement activity

The main activity proposed to improve data on dementia type in national data collections is to work towards ensuring data are collected in a consistent manner in different national data sets used for dementia monitoring. Information on the intended outcome, priority rating, level of investment required, timeframe for completion and who is responsible for undertaking this activity is detailed below.

Activity 5a: Ensure dementia data are consistently collected in core data sets

This activity would work towards the collection of complete and harmonised dementia national data, including but not exclusive to data on dementia type. There are several components to this activity which would be undertaken sequentially. This includes:

- supporting organisations to transition their data to align with the Dementia NBPDS
- evaluating and refining the Dementia NBPDS based on consultation with organisations who have either attempted to, or have, incorporated recommendations in the Dementia NBPDS in their data collections
- progress to develop a Dementia National Best Endeavours Data Set (NBEDS) or National Minimum Data Set (NMDS). A NBEDS is a metadata set of health data which Australian jurisdictions agree they will make their best effort to collect, while a NMDS is the minimum set of data elements that is mandatory for all Australian jurisdictions to follow when collecting and reporting national data.

The progression to a NMDS would help maximise the use of consistent dementia metadata in key national collections, increasing the quality and consistency of dementia data and facilitating data linkage activities.

In parallel, the National Centre for Monitoring Dementia (NCMD) could promote approaches to include dementia data within sector-specific data sets such as the [Aged Care NMDS](#) and other NMDSs.

Outcome: Dementia data collected consistently and more broadly across sectors

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	3	0	1	8

- Alignment: critical importance
- Foundational data: provides greater interoperability
- Dependencies: high, requires uptake of recommendations in the Dementia NBPDS by organisations; progression to a NBPDS or NMDS require extensive consultation, agreement by federal, state and territory jurisdictions, and endorsement by relevant committees
- Priority group reporting: likely - the current Dementia NBPDS recommends collecting data on First Nations status, veteran status, and culturally and linguistically diverse (CALD) information (country of birth, main language other than English spoken at home, proficiency in spoken English, and year of first arrival in Australia)

Level of investment: Medium-High

As there are several components to this activity, investment is required over the long term. However, significant investment may be required by organisations to change current data collection practices to align to the data developed from this activity.

Timeframe: Long term

Responsible stakeholder: AIHW NCMD.

References

AIHW (Australian Institute of Health and Welfare) (2020) *Dementia data gaps and opportunities*, AIHW, Australian Government, accessed 4 April 2022.

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Dementia data gaps and improvement activities

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[Behavioural and psychological symptoms of dementia](#)

[Proposed data improvement activities](#)

Symptoms of dementia will vary between people and can vary day to day for the same person. However, each person will experience progressive cognitive and physical decline. The rate of decline will vary due to numerous factors such as personal characteristics, dementia type, age at diagnosis, existing health conditions, care and living arrangements and access to health services.

Data on severity and rate of progression will indicate the level of support required, when increases in support are projected to be needed, and may support research into risks for more rapid progression, or eligibility for clinical trials or treatment.

There is no consistent classification of dementia severity and various models are used. In the 3-stage dementia severity model:

- mild dementia is defined by cognitive impairment and poor performance on objective cognitive assessments that represent a decline from the past; however, independence in basic activities of daily living is maintained
- moderate dementia has more distinct symptoms and impacts on activities of daily living
- advanced dementia includes health and functional declines requiring assistance in activities of daily living.

Other classification systems use 7 stages that include stages occurring before a dementia diagnosis (Reisberg et al. 1982).

Data on dementia severity and progression will inform service needs and planning and may assist in assessing the effectiveness of interventions designed to reduce or slow dementia progression, and factors leading to increased severity or progression. Current data focus on functional abilities and level of assistance required to perform tasks across different domains (such as self-care, mobility and communication). These data are currently captured in aged care assessment data and the [Australian Bureau of Statistics' \(ABS\) National Survey of Disability, Ageing and Carers](#). Aged care assessment data also contain some information on current levels of support, daily life, health, behaviours, memory and goals ([My Aged Care](#)).

In addition, there is a lack of information about people in the early stages of dementia or cognitive impairment, including the diagnosis and early disease management process due to poor recognition of symptoms and early assessment (as outlined in [Timeliness of dementia diagnosis](#)). Current data sources tend to capture people with more severe dementia, when they engage with hospital and aged care services.

Behavioural and psychological symptoms of dementia

Behavioural and psychological symptoms of dementia (BPSD) refer to non-cognitive symptoms (such as aggression, agitation, apathy, depression and disinhibited behaviours), that are common across all types of dementia and have no singular cause. The type and severity of symptoms can vary over the course of the illness, and on a day-by-day basis. The symptoms can have a major impact on the person with dementia and their carers (AIHW 2023).

Most people living with dementia will experience at least some level of BPSD as their dementia progresses. BPSD has a range of non-cognitive symptoms and is often associated with complex care needs. The Neuropsychiatric Inventory (NPI) is the primary measure of BPSD within clinical settings in Australia. It assesses a wide range of behaviours, rating severity, frequency, and carer distress for 12 domains. Currently, Dementia Support Australia are the only national data source that collect NPI information for people who experience BPSD, however, these are only of people accessing their services. However, some data on select behaviours are captured in aged care assessment data.

Improved data on BPSD will inform planning for the health and aged care systems including national behaviour support programs currently managed by Dementia Support Australia such as the Dementia Behaviour Management Advisory Service, Severe Behaviour Response Teams, and the Specialist Dementia Care Program (AIHW 2023).

Proposed data improvement activities

There are 4 main activities proposed to improve available data on dementia severity and progression. These include activities to:

- incorporate dementia data in enduring linked data assets to meet the needs of dementia monitoring (Activity 3a detailed under [Dementia prevalence and incidence](#))
- determine outcomes and transitions of care for people with BPSD using linked data
- validate data on select behaviours collected in aged care assessment data
- assess feasibility to incorporate measures of behaviours associated with dementia in existing national surveys or population-based studies.

Each activity provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activity 6a: Determine outcomes and transitions of care for people with BPSD using linked data

Using the enduring linked data assets (detailed under [Dementia prevalence and incidence](#)), key health and welfare statistics for people with BPSD can be identified and reported on by severity level. Hospitalisations, mortality outcomes, service use and interactions with, and transitions of care through, the various care systems can be examined to provide greater understanding on the impact of BPSD, and how this differs across severity levels. The extent to which people experiencing BPSD can be identified is dependent on the data sources included in the enduring linked data asset. The inclusion of data from Dementia Support Australia is a worthy first stage as this allows identification of people who have accessed key national behaviour support programs. Identifying people who have experienced BPSD but who have not accessed these services is more difficult and reliant on identification in other data sources. This is reliant on further data development described in subsequent activities.

Outcome: Better data on outcomes and transitions of care for people with dementia experiencing BPSD

Priority: Low

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	1	0	1	4

- Alignment: moderately important data gap
- Foundational data: methods development
- Dependencies: reliant on external data and data linkage
- Priority group reporting: likely - possible if sufficient numbers and data quality

Level of investment: Low

This activity involves analysis only, therefore this requires low investment.

Timeframe: Short/Medium term

Responsible stakeholder: AIHW National Centre for Monitoring Dementia (NCMD); Dementia Support Australia; academic researchers.

Activity 6b: Validate data on select behaviours collected in aged care assessment data

Using the enduring linked data assets (detailed under [Dementia prevalence and incidence](#)), this activity involves validating data on behaviours collected in aged care assessment data with the gold standard NPI data collected by Dementia Support Australia. Currently, aged care assessments include questions on a range of psychological symptoms, measured by self-reported frequency, that broadly align with the NPI. Linkage can be used to compare data on these psychological variables for Dementia Support Australia clients who have also been formally assessed with the NPI. Validation will provide insight into how the self-reported frequency of psychological symptoms recorded aligns with the NPI's severity, frequency, and carer distress information, and more broadly will evaluate aged care assessments as a data source for capturing BPSD. This may also inform what enhancements could be made to aged care assessments to monitor dementia severity.

Outcome: Better understanding of behaviours data collected in aged care assessment data and their use for national monitoring of BPSD in Australia

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	2	0	1	5

- Alignment: moderately important data gap
- Foundational data: methods development and potentially quality via validation
- Dependencies: reliant on data linkage
- Priority group reporting: likely - possible if sufficient numbers and data quality

Level of investment: Low

This activity involves analysis only therefore this requires low investment.

Timeframe: Short/Medium term

Responsible stakeholder: AIHW NCMD; Dementia Support Australia.

Activity 6c: Assess feasibility to incorporate measures of behaviours associated with dementia in existing national surveys or population-based studies

This activity involves working to incorporate measures of behaviours associated with dementia in existing national surveys or population-based studies. The ABS Survey of Disability, Ageing and Carers has been identified as a possible national source due to its population scope, coverage, capture of people with dementia in community and residential aged care and collection of data from carers. However, other population-based studies may be found suitable stemming from Activity 3c described under [Dementia prevalence and incidence](#). This activity requires extensive consultation on the feasibility of implementing measures to capture behaviours associated with dementia in existing data collections.

Following feasibility assessment and consultation, the next stage would be to implement the new measures in the data collection and assess findings.

Outcome: National data on people with dementia experiencing BPSD, including those who do not currently access behavioural support services

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	2	2	0	6

- Alignment: moderately important data gap
- Foundational data: methods development
- Dependencies: low for feasibility assessment component
- Priority group reporting: unlikely - although could in a subsequent collection phase

Level of investment: Low

This initial feasibility assessment requires low investment.

Timeframe: Short term (<2 years)

Responsible stakeholder: AIHW NCMD.

References

AIHW (2023) *Dementia in Australia*, AIHW, Australian Government, accessed 23 February 2023.

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Dementia data gaps and improvement activities

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There is no single test available to diagnose dementia, and a range of cognitive and medical screening tools and assessments are used to make a diagnosis.

A lack of national data on the diagnosis and management of dementia by primary and secondary care providers (in particular, data from general practitioners (GPs) and specialists such as geriatricians) is the largest data gap affecting our understanding of dementia in Australia (AIHW 2020a). Dementia diagnostic information cannot be inferred from Medicare Benefits Schedule (MBS) data, as it is not possible to distinguish between dementia-specific services and services for the management of other health issues (AIHW 2023).

Currently, services provided under the MBS (such as GP and medical specialist consultations, diagnostic tests and some allied health care) provided to people with dementia at a national level can only be examined through linkage to data sets that include dementia diagnosis information. Important information on dementia diagnosis (such as the date of diagnosis, dementia type, the setting in which dementia is diagnosed, and who made the diagnosis) is captured in various practice management systems, but the capability to report on these for national dementia monitoring has not been determined and they are not available for linkage to other data sets (AIHW 2020b). Better diagnosis data would also allow examination of post-diagnostic care and support for people with dementia.

More secondary care providers of specialised dementia assessment (in memory clinics or other locations), are registering new dementia diagnoses with the [Australian Dementia Network \(ADNeT\) Clinical Quality Registry](#), which aims to measure and drive improvement in quality of care and patient outcomes for people diagnosed with dementia or mild cognitive impairment (Ward et al. 2022).

The [National Primary Health Care Data Collection](#) (under development) will be an important initiative for improving data on the diagnosis and management of dementia in primary care. The [National Primary Health Care Data Collection](#) will fill a long-standing information gap in relation to primary health care data for population health monitoring, research, policy and planning. It will be a key future source of data on dementia that is expected to help fill a range of dementia knowledge gaps.

Importantly, dementia is usually diagnosed, treated and managed in the community, but it may be under-diagnosed in primary care due to lack of symptom recognition, documentation of dementia in medical records and cognitive testing (Ng and Ward 2019). There may also be reluctance to seek medical help due to stigma surrounding dementia or belief that there are no helpful interventions. Poor access to health care providers and a lack of confidence in GPs to diagnose dementia may also contribute to under-diagnosis. Decreasing the stigma around dementia and greater awareness of the benefits from a diagnosis are therefore required to improve diagnosis and capture of dementia in primary care settings.

Proposed data improvement activities

There are several activities proposed to improve primary and secondary care data on dementia diagnosis and management. These include activities to:

- conduct a dementia data demonstration project for the National Primary Health Care Data Collection
- assess utility of future National Primary Health Care Data Collection for monitoring dementia diagnosis and management in primary health care
- undertake a detailed exploration of GP or specialist management software to assess utility and suitability of data for dementia monitoring
- review the MBS to include an item for dementia diagnosis and management
- introduce a dementia measure in the Practice Incentives Program Quality Improvement initiative
- investigate measures of quality of care and quality of life outcomes for hospital patients and aged care residents living with dementia.

Each activity description provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activity 7a: National Primary Health Care Data Collection dementia data demonstration project

As part of the development of a National Primary Health Care Data Collection, AIHW's Primary Health Care Data Development Unit will conduct several data demonstration projects using Primary Health Insights (PHI), a storage and analytics platform that can host de-identified general practice data and other primary health data for Primary Health Networks (PHNs) across Australia. This platform has already been established for this purpose.

The demonstration projects aim to demonstrate the value and utility of compiling general practice data from a selected sample of PHNs, as well as testing governance, data transformation and data flow arrangements with PHNs, within the PHI platform. Subject to PHN endorsement, dementia management in GP clinical settings will be used as a demonstration project.

The activity will gain insights into how patient management software is used to record and extract information on patients with dementia, to better understand how these data could improve dementia monitoring.

Outcome: Understand the value and utility of compiling dementia data from a small sample of GPs; this will also inform processes for the development of a National Primary Health Care Data Collection

Priority: Low

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	1	0	0	3

- Alignment: moderately important data gap
- Foundational data: methods (including governance) development
- Dependencies: requires consultation and agreement to access to de-identified patient electronic medical records from GP practices
- Priority group reporting: unlikely

Level of investment: High

Timeframe: Short/Medium term

Responsible stakeholder: AIHW National Centre for Monitoring Dementia (NCMD) and AIHW Primary Health Care Data Development Unit.

Following completion of the National Primary Health Care Data Collection dementia demonstration project and the data shown to have sufficient utility and quality to add value to dementia monitoring, governance and other arrangements for ongoing reporting will be investigated, with a view to allow public reporting of aggregated data and, over the longer term, potential projects involving data linkage.

Activity 7b: Assess utility of future National Primary Health Care Data Collection for monitoring dementia diagnosis and management in primary health care

This activity would occur after Activity 7a (National Primary Health Care Data Collection dementia data demonstration project) had shown the value of GP dementia data and a National Primary Health Care Data Collection was established. The activity would involve assessing utility of the collection to monitor dementia diagnosis and management in primary care and could assess variation in diagnosis or management across PHNs or other demographic variables. If successful, this could allow monitoring of changes over time, to observe any changes in diagnosis and management with different work force education, community awareness programs, or other program changes (for example, those suggested in activities 7d and 7e).

Outcome: Understand the utility of dementia data and management reporting from the National Primary Health Care Data Collection

Priority: Low

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	1	0	0	3

- Alignment: moderately important data gap
- Foundational data: methods (including governance) development
- Dependencies: Activity 7a and establishment of a National Primary Health Care Data Collection
- Priority group reporting: unlikely

Level of investment: High

Timeframe: Short/Medium term

Responsible stakeholder: AIHW NCMD and AIHW Primary Health Care Data Development Unit.

Activity 7c: Detailed exploration of GP or specialist management software to assess utility and suitability of data for dementia monitoring

Separate to the National Primary Health Care Data Collection dementia demonstration project (Activity 7a), using PHN data hosted on the PHI platform, a case study would be performed with a GP or specialist practice to examine de-identified records to explore opportunities and limitations of (de-identified) dementia data available from patient management software. It would obtain insights into how patient management software is used in practice to record and extract information on patients with dementia, to better understand how data could contribute to improving future dementia monitoring.

This activity could explore recording of symptoms of dementia, testing for mild cognitive impairment (MCI) and dementia, referrals for assessment, other tests to rule out differential diagnoses, diagnosis within the practice or by specialty memory clinics or specialists, and whether dementia was flagged by the categories provided by the medical software.

Outcome: Understand how patient management software is used in practice to record and extract information on patients with dementia to inform improvements

Priority: Low

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	1	1	0	4

- Alignment: moderately important data gap
- Foundational data: methods (including governance) development
- Dependencies: access to de-identified patient electronic medical records, quality, and completeness of free text data
- Priority group reporting: unlikely

Level of investment: High

Timeframe: Short/Medium term

Responsible stakeholder: AIHW NCMD; academic researchers.

Activity 7d: Review Medicare Benefits Schedule (MBS) items to improve information on dementia diagnosis and management

The MBS Review Taskforce undertook the [MBS Review](#) between 2015 and 2020 to assess how MBS items could be better aligned with contemporary clinical evidence and practice to improve health outcomes. This included recommendations on items that needed to be amended, removed or created, as well as broader structural changes to the MBS (DoHA 2021a). A review of existing MBS items relevant to dementia would inform recommendations for new dementia-specific MBS items or amendments to existing items to support the identification, assessment and management of dementia in primary care data.

Outcome: Understand the need for new dementia-specific MBS items or amendments to existing items to support the identification, assessment and management of dementia in primary care data

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	1	0	1	5

- Alignment: highly important data gap
- Foundational data: ability to inform prevalence or incidence would be dependent on specificity of the new MBS item and uptake of this new item by medical professionals
- Dependencies: high
- Priority group reporting: likely - the MBS data currently captures data on select priority populations

Level of investment: High

Timeframe: Medium/Long term

Responsible stakeholder: Department of Health and Aged Care

Activity 7e: Introduce a dementia measure in the Practice Incentives Program Quality Improvement initiative

The Practice Incentives Program (PIP) Quality Improvement (QI) Incentive is a payment to general practices for activities that support quality improvement in patient outcomes and deliver best practice care. General practices enrolled in the PIP-QI commit to participating in continuous quality improvement activities and submitting de-identified general practice data via the PIP Eligible Data Set (DoH 2021b). The [PIP Eligible Data Set](#) collects data against 10 key [Quality Improvement Measures](#).

The introduction of a new QI measure for dementia care that attracts an incentive payment under the PIP-QI initiative could not only benefit patients but would represent an important dementia data improvement initiative by encouraging reporting of dementia status. This could help generate data at the practice level on reporting of dementia, which could also flow through the better reporting of dementia in clinical records to support Activity 7b and potential reporting of dementia in My Health Record summaries.

Any changes to the PIP-QI measures would be completed over the long term.

Outcome: Improved dementia recording

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	0	0	5

- Alignment: moderately important data gap
- Foundational data: yes, but with limitations for interoperability
- Dependencies: high as relies on the development, agreement and implementation of a new PIP item
- Priority group reporting: unlikely

Level of investment: High

Timeframe: Long term

Responsible stakeholder: Department of Health and Aged Care.

Activity 7f: Investigate measures of quality of care and quality of life outcomes for hospital patients and aged care residents living with dementia

Options for the regular monitoring of quality of care and quality of life measurements for people with dementia in the health and aged care sectors are important to understanding outcomes. Quality of life will be required to be collected by residential aged care services as part of the expanded [National Mandatory Aged Care QI program](#) from 1 April 2023, reported at the service level on the GEN Aged Care Data website. The Residents' Experience Survey (formerly the Consumer Experience Interviews) also samples over 10% of residents across Commonwealth aged care homes to generate a Resident Experience Report and 'star rating' for each home.

This activity may include investigating options for dementia-specific analysis of existing hospital Patient Experience Surveys, other existing quality measures developed by university or health service providers, and the recently funded Australian Consortium for Aged Care Quality Measurement Toolbox (QMET).

Outcome: Report on quality of life and consumer experience measures for people with and without dementia living in residential aged care facilities and who are admitted to hospital

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	1	1	0	5

- Alignment: highly important data gap (National Dementia Action Plan (NDAP) objective 4)
- Foundational data: method development
- Dependencies: existing data collection across care and quality of life measures in hospital and aged care
- Priority group reporting: unlikely - based on existing data

Level of investment: Low investment required to examine existing data; any additional activities stemming from this work would require higher investment

Timeframe: Medium term

Responsible stakeholder: AIHW NCMD.

Activity 7g: Collect data on lived experience of dementia diagnosis and management

The activity relates to activity 2c on [Collect data on experiences of people with dementia and their carers](#) by collecting data on the experience of dementia diagnosis and management by people with dementia and their carers from the general population.

This activity may involve additional questions in a lived experience survey, or if the size of the survey is too large, a separate module specific for the experiences of diagnosis and management. This collection would aim to provide data on when symptoms were observed, what prompted seeking a diagnosis, experience in obtaining a diagnosis (including what factors supported, delayed or made a diagnosis more difficult), and experience of dementia management in the health, aged care or disability sectors.

Outcomes: Initial data on the experiences of people living with dementia could identify:

- the magnitude and cause of delays in a timely diagnosis, to inform improvements to diagnosis through both community and GP awareness and health system factors
- experiences with service providers to inform changes needed to improve care and support for people living with dementia
- Repeated data collections would measure changes following actions implemented from the NDAP.

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	2	1	0	7

- Alignment: multiple highly important data gaps (NDAP objectives 3 and 4)
- Foundational: for baseline data
- Dependencies: organisations with dementia and/or carer expertise and contacts required
- Priority group reporting: no (numbers likely too low for disaggregation)

Level of investment: Medium-High

The level of investment will depend on the data collection methods. However, this activity may require in-person interviews with people with dementia and collection of qualitative and quantitative data. There may be broader options for collecting data from carers but will need to consider preferences for engagement.

Timeframe: Short-term (<2 years)

This activity should be conducted periodically to collect data over time.

Responsible stakeholder: Academic researchers; Organisations with experience in collecting data from people living with dementia and their carers.

References

AIHW (Australian Institute of Health and Welfare) (2020a) *Dementia data gaps and opportunities*, AIHW, Australian Government, accessed 19 July 2023.

AIHW (2020b) *Australia's health 2020: data insights*, AIHW, Australian Government, accessed 19 July 2023.

AIHW (2023) *Dementia in Australia*, AIHW, Australian Government, accessed 23 February 2023.

DoH (2021a) *MBS Review - Final taskforce reports, findings and recommendations*, DoHAC website, accessed 31 July 2023.

DoH (2021b) *PIP QI Incentive guidance*, DoHAC website, accessed 6 October 2022.

Ng N and Ward S (2019) 'Diagnosis of dementia in Australia: a narrative review of services and models of care', *Australian Health Review*, 43(4):415-424, doi:10.1071/AH17167.

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Dementia data gaps and improvement activities

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While many people with dementia live independently and rely on carers, family and friends for assistance, community-based aged care services are important for supporting older Australians to remain living in their own home for as long as possible. Residential aged care is also important, particularly for those in the advanced stages of dementia who need ongoing care and accessible accommodation.

Aged care data have been subject to change due to aged care reforms. This has impacted the use of aged care data for dementia monitoring purposes. Currently aged care assessment data and residential aged care data are used for national dementia monitoring, providing information on people with dementia seeking access to government-subsidised aged care and people with dementia living in residential aged care. There is very limited data on people with dementia accessing community-based services.

However, these data have changed in recent years and will change in the near future:

- The [National Screening and Assessment Form \(NSAF\)](#) captures information from the initial screening and assessment process to determine a person's need for aged care (coordinated through the [My Aged Care](#) system). People with dementia can be identified from assessment data where dementia is recorded as a health condition impacting their care needs.
- The NSAF is expected to be replaced with the Integrated Assessment Tool (IAT) in 2025. The IAT will be applicable for home care, residential aged care, transitional care and respite, and the IAT is likely to include whether there is a confirmed dementia diagnosis.
- Data from the [Aged Care Funding Instrument \(ACFI\)](#) were previously used to report on people living with dementia in residential aged care as it captured information on health conditions impacting care need. However, the ACFI was replaced with the [Australian National Aged Care Classification \(AN-ACC\)](#) from 1 October 2022 (DoHAC 2022), which no longer collects information on health conditions.

While the AN-ACC assessment will continue providing information on a person's level of cognitive impairment, specific clinical diagnosis information is not provided. This will impact national reporting of dementia in residential aged care and the ability to measure dementia's impact on the aged care system and will under-report people with dementia and their ability to be linked in enduring linked data assets. In the interim, national reporting of dementia among residential aged care facilities would be possible from what is available in the Australian Bureau of Statistics' (ABS) Survey of Disability, Ageing and Carers.

The lack of health condition data collection in the AN-ACC has reduced the data available for understanding specific disease prevalence, and risk factors for other conditions among people living in residential aged care, as well as data to identify persons with dementia in linked data.

Proposed data improvement activities

There are 3 main activities proposed to improve the collection and reporting of dementia and other health conditions in aged care data. These include activities to:

- create guidelines for collecting dementia data in aged care assessments and include training information on dementia data collection in assessor training
- incorporate dementia diagnosis information in national aged care data collections
- develop dementia identifiers and incorporate into existing data sets.

[My Aged Care](#) These activities may involve single projects, or multiple projects to enable monitoring of trends over time, incorporate improvements in data or to focus on a specific population group. Each activity provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activities aimed at improving dementia data through increased national data linkages and ensuring data are collected in a consistent manner in different national data sets would also improve data on people with dementia using aged care. See [Dementia prevalence and incidence](#) and [Dementia type](#) for additional activities.

As described in [Enablers to support success of this plan](#) a broad program of work is underway to improve the quality, coverage and availability of aged care data. This includes government actions in responses to the Royal Commission into Aged Care Quality and Safety, a National Aged Care Data Strategy scheduled for release in June 2024, an Aged Care National Minimum Data Set (NMDS), and a National Aged Care Data Asset. The AIHW Dementia Unit is working with the AIHW Aged Care Data Improvement and Ageing and Aged Care Units to ensure that dementia is included in the Aged Care NMDS. For more on AIHW's aged care data improvement activities, see [Data improvements](#) (AIHW 2022).

Activity 8a: Create guidelines for collecting dementia data in aged care assessments and include training information on dementia data collection in assessor training

Health condition data are collected by different people for different purposes, and most assessors and data collectors do not have clinical coding experience and require training specific to the health conditions and the electronic record systems they are using.

The creation of guidelines for collecting dementia data in aged care assessments would include guidance on what data to collect and how to enter the data. Specific dementia data training information would be developed to incorporate into current assessor training to ensure that the data collection is fit for aged care services and ongoing dementia monitoring, following the data collection and use principle of 'collect once, use multiple times'. This work would involve collaborating with the current assessor trainers to incorporate a dementia flag entry into an intuitive workflow to maximise capture of this data element. These guidelines could be complemented by training developed by training organisations or government agencies promoting the collection of quality systematic electronic data, such as the Australian Digital Health Agency that currently provides free online training to multiple sectors including the aged care sector.

Outcome: Dementia data collected systematically in aged care assessments

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	1	1	7

- Alignment: highly important data gap
- Foundational data: prevalence and aged care service data
- Dependencies: dependent on policies to prioritise assessors training for dementia reporting
- Priority group reporting: likely

Level of investment: Moderate

Timeframe: Short term (<2 years)

This would need to be prioritised as the AN-ACC is already in use.

Responsible stakeholder: Department of Health and Aged Care.

Activity 8b: Incorporate dementia diagnosis information in national aged care data collections

The loss of health condition information from permanent residential aged care data and potential changes to aged care assessment data mean that people with health conditions, including dementia, will no longer be identified in aged care data alone. This will temporarily cease national reporting of many chronic conditions (including dementia) and will impact the data available in the aged care system and limit the number of people being identified with chronic diseases (including dementia) in enduring linked data assets.

Currently, an assessor for the AN-ACC funding model can flag in the assessment whether a person has dementia, but this is not mandatory to collect and is not provided to national aged care data collections, such as the National Aged Care Data Clearinghouse (NACDC). This activity would be a high priority pilot project that involves establishing standard data collection and ICT processes to support the supply of dementia information alongside already supplied data to national aged care data collections. This allows for routine monitoring of dementia among people receiving government-subsidised aged care to recommence and would assist in identifying people with dementia in enduring linked data sets. This activity could provide a pathway to expand to other chronic conditions once mechanisms for reporting are established.

Outcome: Dementia data collected systematically in national aged care data collections

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	3	1	1	8

- Alignment: highly important data gap
- Foundational data: prevalence and aged care service data
- Dependencies: high, dependent on changes to collection of dementia data as part of the AN-ACC
- Priority group reporting: likely - likely to support better reporting across priority groups

Level of investment: Low

Timeframe: Medium term (2-6 years)

The timeframe is dependent on the time taken to implement standard data collection and ICT processes, which are unknown at this stage.

Responsible stakeholder: Department of Health and Aged Care; AIHW.

Following this activity, options for improved dementia data collection should also be explored as the flag option doesn't specify how diagnosis information was collected (whether it is resident/carer reported, assessor reported and/or based on medical records), or type of dementia (aligned with ICD codes), or date of diagnosis. Options for collecting data on behaviour support plans for people with dementia in residential aged care should also be explored. These plans are now mandatory for people in residential aged care who require or may require the use of restrictive practices as part of their care. Any future aged care developments also need to align with the directions outlined in the National Aged Care Data Strategy and should involve consultation with AIHW and other key stakeholders on how potential changes may impact aged care data, including development of the Aged Care NMDS.

Activity 8c: Develop dementia identifiers and incorporate into existing data sets

This activity involves the creation of dementia flags from existing data that identify a person with dementia for use in data that do not have diagnosis information. This activity would be an interim approach until national enduring data linkages have expanded to include a greater number of data sets.

This approach could explore linking dementia flags derived from the National Hospital Morbidity Database (NHMD) and the NACDC to the ABS Multi-Agency Data Integration Project (MADIP) using the AIHW-ABS interoperable spine. These are currently some of the most reliable sources of diagnostic information for these conditions, and together with Pharmaceutical Benefits Schedule (PBS), mortality and 2021 Census data, have the potential to improve the coverage of people with dementia in the MADIP.

This may also provide an interim solution for the loss of dementia diagnosis data in residential aged care data. Incorporating a dementia flag into the [Pathways in Aged Care \(PIAC\)](#) linkage map would allow greater identification of people living with dementia in residential aged care. The PIAC 2020 link map uses the Medicare Consumer Directory (MCD) as the spine for data linkage. The spine is an enduring piece of data infrastructure that improves the efficiency and quality of data linkage projects (AIHW 2023). This activity would occur prior to activities aimed to increase dementia data in enduring national data linkages (described in [Dementia prevalence and incidence](#)).

Outcome: Increased identification of dementia in data assets to provide greater coverage and insights into prevalence and impacts of dementia

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	3	1	1	8

- Alignment: highly important data gap
- Foundational data: identifier to inform linkages
- Dependencies: approvals for supply of dementia flags from existing data and linkage to existing data
- Priority group reporting: likely

Level of investment: Medium

Timeframe: Short/Medium term

Responsible stakeholder: AIHW National Centre for Monitoring Dementia.

References

AIHW (Australian Institute of Health and Welfare) (2022) [Data improvements](#), GEN Aged Care Data website, AIHW, Australian Government, accessed 3 May 2023.

AIHW (2023) [Pathways in Aged Care 2020: technical guide](#), GEN Aged Care Data website, AIHW, Australian Government, accessed 12 July 2023.

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Dementia data gaps and improvement activities

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Under the Indigenous Australians Health Programme, the Australian Government funds First Nations-specific primary health care organisations to provide prevention, diagnosis, and treatment services via Aboriginal Community Controlled Health Organisations (ACCHOs), community clinics and other facilities (DoHAC 2023). The organisations deliver holistic and culturally appropriate primary health services to communities and are often a first point of contact for First Nations people with dementia. The services can also act as a referral point to other available services like specialist and aged care services and are important for managing risk factors for developing dementia (AIHW 2023).

A range of data are collected from First Nations-specific primary health care organisations for national reporting through the Online Services Report (OSR) and the National Key Performance Indicators (nKPIs). The main purpose of nKPIs are to support continuous quality improvement activity at the organisational level, with the indicators for specific aspects of care provided to clients. The nKPIs are not intended to measure prevalence (or diagnosis) of a condition. Indicators are designed to measure aspects of the treatment or management for specific conditions - such as HbA1c testing and levels for those with type 2 diabetes. Data on First Nations people with dementia are not available, as the health conditions of people accessing First Nations-specific primary health care are not included in the OSR and nKPIs are not designed to monitor the prevalence of health conditions.

The lack of national data on people with dementia who use First Nations people-specific primary health care limits understanding of the patterns and outcomes from primary health care service use by First Nations people with dementia. This represents a large gap, particularly in remote areas where First Nations-specific primary health care services may be the only accessible primary health service for the local population (AIHW 2016).

Broadly, there are limited data on management of dementia among First Nations people living with dementia. Dementia is often under-recognised and under-diagnosed in First Nations people (Arkles et al. 2010) and international studies have found that minority populations are under-treated with dementia-specific medications, compared to a non-minority population. In addition, data on First Nations people accessing government-subsidised aged care do not capture people who are in certain specialised residential aged care programs, such as the Multi-Purpose Services Program (for people living in rural and remote areas) and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. This represents a care data gap for First Nations people who live in regional and remote areas.

Proposed data improvement activities

There are 2 main activities proposed to improve data First Nations-specific health care data on dementia. These include activities to:

- explore availability and quality of data on people with dementia accessing First Nations-specific primary health care services
- incorporate dementia data in Regional Insights for Indigenous Communities (RIFIC) website.

Each activity provides information on the intended outcome, priority rating, level of investment required, timeframe for completion and who is responsible for undertaking for the activity.

However, there are several other activities in this plan that would also improve data on First Nations people with dementia, including:

- ensure dementia data are consistently collected in core data sets (Activity 5a detailed under [Dementia type](#))
- incorporate dementia data in enduring national linked data sets to meet the needs of dementia monitoring (Activity 3a detailed under [Dementia prevalence and incidence](#))
- assess new self-reported dementia data in the 2021 Census (Activity 3d detailed under [Dementia prevalence and incidence](#)).

Activity 9a: Explore availability and quality of data on people with dementia accessing First Nations-specific primary health care services

This activity involves working with one or more First Nations-specific primary health care services to explore the availability and quality of data on people with dementia accessing their services. This may involve the collection of aggregated data on people with dementia (for example, specific services provided and information on diagnosis and management of dementia). The quality and limitations of available data would be explored and would identify opportunities for data improvement.

These data may inform proposals regarding a new key performance indicator on people with dementia managed in First Nations-specific primary health care services.

Outcome: Better data on people with dementia accessing First Nations-specific primary health care

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	1	2	1	7

- Alignment: highly important data gap
- Foundational data: method development and data quality assessment
- Dependencies: low
- Priority group reporting: likely - data directly on First Nations people with dementia

Level of investment: Medium

Timeframe: Short term (<2 years)

Responsible stakeholder: AIHW National Centre for Monitoring Dementia (NCMD) and external

Activity 9b: Incorporate dementia data in Regional Insights for Indigenous Communities (RIFIC) website

This activity involves working with the AIHW Indigenous Group to add national dementia statistics to the [Regional Insights for Indigenous Communities](#) (RIFIC) website, including data at smaller geographies where feasible. Currently, data on health conditions among First Nations people aged 50 and over in the RIFIC website are reported from the [Australian Bureau of Statistics' National Aboriginal and Torres Strait Islander Health Survey](#) and the AIHW National Mortality Database. This activity is dependent on dementia data developments in other data sources, and for enough to allow for reporting.

Outcome: Better data available on dementia among First Nations people

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	2	0	1	6

- Alignment: highly important data gap
- Foundational data: prevalence, health outcomes data
- Dependencies: high, this activity is dependent on developments in other data sources
- Priority group reporting: likely - data directly on First Nations people with dementia

Level of investment: Low

Timeframe: Short term (<2 years)

Responsible stakeholder: AIHW NCMD; AIHW Indigenous Group

References

AIHW (Australian Institute of Health and Welfare) (2016) [Australia's health 2016](#), AIHW, Australian Government, accessed 30 August 2023.

AIHW (2023) [Dementia in Australia](#), AIHW, Australian Government, accessed 23 February 2023.

Arkles RS, Jackson Pulver LR, Robertson H, Draper B, Chalkley S and Broe A (2010) [Ageing, Cognition and Dementia in Australian Aboriginal and Torres Strait Islander Peoples: A Life Cycle Approach](#), Neuroscience Research Australia and Muru Marri Indigenous Health Unit, University of New South Wales, accessed 30 May 2023.

DoHAC (Department of Health and Aged Care) (2023) [Indigenous Australians' Health Programme](#), DoHAC, Australian Government, accessed 19 July 2023.



Dementia data gaps and improvement activities

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People with dementia and their carers may access a range of services in addition to health and aged care, such as dementia-specific support services, disability support services, respite care and palliative care. Understanding the types and quality of care services provided is important for monitoring post-diagnosis support for people recently diagnosed, patient experiences with the health system (including access and barriers), and how variations in care impact health outcomes. Monitoring the patterns of service use by people with dementia and their carers can indicate demand and is essential for service planning. It can also help assess whether services are meeting needs and identify opportunities to improve outcomes for people with dementia and their carers.

Carers can access information, resources and support services through the [Carer Gateway](#) and [Dementia Australia](#) (Australian Government 2023). Services can include counselling, networking forums, coaching, skills courses, links to financial support and respite services. The use of respite services by people with dementia is an example of a care type where there is currently a lack of national data in a useable format. The Australian Government subsidises community-based and residential respite care to provide a person and their carer with a break from their usual care arrangements. Carers can also access emergency respite through the [Carer Gateway](#) and there may be future opportunities to use these data to improve monitoring on the use of respite care by people with dementia and their carers.

National palliative care-related services are published biannually in the [Palliative Care Services in Australia](#) report (AIHW 2023). However, there are significant data gaps, particularly information on when palliative care has been provided and who provided it, especially in community, primary care and residential aged care settings. Improving data on priority populations, such as those with cognitive impairment (including dementia) was identified as a key priority in the National Palliative Care Information Priorities Report, which is an aspirational vision for palliative care reporting over the next decade (AIHW 2023).

The needs and care requirements of people with younger onset dementia and childhood dementia, are different from those of older people. Younger onset dementia may occur at an age when the demands of family and work are at a peak, placing a severe strain on family and carer dynamics and finances (Alzheimer's Australia 2015). There are limited national statistics on people with younger onset dementia and their carers, and children with childhood dementia who may be supported by the National Disability Insurance Scheme (NDIS). Examining this source, in conjunction with other health service use data will provide opportunities for improving data on people with younger onset dementia, as well as on childhood dementia.

Proposed data improvement activity

There are 4 main activities proposed to improve data on care and support services for people with dementia and their carers. These include activities to:

- explore patterns of service use, transitions of care and access of services relative to need for people living with dementia using linked data
- incorporate dementia data in enduring linked data assets to meet the needs of dementia monitoring (Activity 3a detailed under [Dementia prevalence and incidence](#))
- collect data on the experiences of people with dementia and their carers (Activity 2c detailed under [Dementia awareness and stigma](#))
- collect data on experiences of people with dementia and their carers among priority groups (Activity 2d detailed under [Dementia awareness and stigma](#)).

Each activity provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

This list of data improvement activities may be revised stemming from concurrent data development work, for example:

- The AIHW Palliative Care Workplan (funded by the Department of Health and Aged Care) aims to build comprehensive, accurate and publicly available data that will improve our understanding on the needs of people requiring palliative care to inform improvements in the palliative care system and implementation of the Palliative Care Strategy.
- The new [National Disability Data Asset](#) being established will bring together data from different government agencies about Australians with disability and without disability. This asset may provide greater insights on the use of NDIS services provided to people with younger onset dementia and childhood dementia, as well as people with dementia who have other disability.

There is an opportunity to leverage the above work to improve national reporting on people living with dementia and data across settings and services. This plan will be updated in the future to incorporate new activities stemming from these initiatives.

Activity 10a: Explore patterns of service use, transitions of care and access of services relative to need for people living with dementia using linked data

There is potential to use existing enduring linked data sets to gain greater insights on the use of other care and support services for people living with dementia and their carers. For example, the [Pathways in Aged Care](#) (PIAC) linkage map and/or the National Integrated Health Services Information (NIHSI) data sets would currently allow analysis of pathways in and out of respite residential aged care for people with dementia. Depending on the data available, broader patterns on service use, transitions of care and access to these services relative to need can be explored.

The activity would involve multiple projects and better data would become available with improvements in data available in national enduring data linkages.

Outcome: Better data on the use of carer and support services for people living with dementia

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	1	1	1	7

- Alignment: multiple highly important data gaps (National Dementia Action Plan (NDAP) objectives 4 and 5)
- Foundational data: method development
- Dependencies: some, dependent on expansion of national enduring data linkages
- Priority group reporting: likely - likely to enable reporting on priority population groups

Level of investment: Low

Timeframe: Short term (<2 years)

The level and investment and timeframes are for individual projects.

Responsible stakeholder: AIHW National Centre for Monitoring Dementia.

References

AIHW (2023) *Palliative care services in Australia*, AIHW, Australian Government, accessed 19 July 2023.

Alzheimer's Australia (2015) *Quality dementia care: younger onset dementia - A practical guide*, Alzheimer's Australia, accessed 1 June 2023.

Australian Government (2023) *Carer Gateway*, accessed 1 March 2023.

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Dementia data gaps and improvement activities

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Services provided across the health, aged care, disability and community sectors are a major source of support for people with dementia and their carers. This can include health care services (for example, those provided in the community by general practitioners (GPs), specialists and allied health professionals, and health care in hospital settings), pharmaceuticals, aged care assessments, aged care packages, National Disability Insurance Scheme (NDIS) supports, and other community and residential aged care services. Post-diagnostic support services are also important to help manage dementia.

There is an expansive workforce providing treatment, care and support to improve outcomes for people living with dementia. Regular monitoring of this workforce would open avenues to:

- identify workforce gaps and plan for future needs
- target dementia-specific training in current areas of high need
- identify optimal educational contexts for introducing dementia-specific training to ensure maximum coverage of the workforce (such as communities of practice, micro credentials, and sharing of resources regarding effective dementia responses and supports).

However, there is a current lack of national comprehensive data on the formal workforce treating and caring for people with dementia (AIHW 2023).

Addressing the data gap and improving data

The national aged care workforce is monitored and reported on through a 4-yearly census and survey conducted and reported on by the department. The Royal Commission into Aged Care Quality and Safety (the Royal Commission) recommended more regular monitoring of the aged care workforce (Royal Commission 2021). The Aged Care Provider Workforce Survey has replaced the Aged Care Workforce Census, with a survey in 2023. An Aged Care Worker Survey is planned for early 2024 (DoHAC 2023).

The Royal Commission also recommended implementing mandatory dementia care training for workers engaged in residential aged care and in care in the community after finding that staff often lack skills and resources to appropriately care for people with dementia, particularly people experiencing behaviours and psychological symptoms of dementia (Royal Commission 2021). The Australian Government funds the Dementia Training Program to improve workforce skills for those working with people with dementia in the primary, acute, residential and community-based care sectors. This includes personal care workers, as well as GPs, nurses, pharmacists, psychologists, specialists, and allied and other health professionals (DoHAC 2022).

There is evidence that insufficient training among health and aged care workers contributes to the substandard care of people living with dementia (Royal Commission 2021). Better data on dementia education and training among health and aged care providers could be used to monitor care provision and identify where further training is needed. Better data are also needed on knowledge of dementia risks and risk reduction strategies among primary health care professionals.

Building a better understanding of the composition of the workforce treating, supporting and caring for people with dementia beyond aged care, and their training, would improve ongoing dementia-specific workforce monitoring. It would also help monitor workforce knowledge to provide high quality, person-centred care for patients and clients with dementia.

Proposed data improvement activities

There are 2 main activities proposed to improve data on the workforce treating and caring for people living with dementia at a national level. These include activities to:

- collect data on the knowledge of dementia, risk factors, risk reduction strategies, and capability among the workforce caring for and supporting people with dementia
- report data from dementia education and training across Australia.

Each activity provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activity 11a: Collect data on the knowledge of dementia, risk factors, risk reduction strategies, and capability among the workforce caring for and supporting people with dementia

To support a skilled, dementia-aware workforce caring and supporting people with dementia, it is important to know the workforce's current knowledge of dementia. This activity involves collecting data on the knowledge of dementia, including risk factors, risk reduction strategies, use of non-pharma behaviour support, capability and adherence to evidence-based clinical practice among the workforce caring

and supporting people with dementia This would indicate where efforts should be targeted. Data could be collected every 3-4 years to assess the impact of any interventions.

As there are no existing data to comprehensively capture the expansive workforce providing treatment, care and support for people with dementia, a new study will likely be needed to capture knowledge and capabilities of dementia, its risk factors and risk reduction strategies.

Outcome: Data on workforce knowledge of dementia, including risk factors, prevention strategies, capability, and adherence to evidence-based clinical practice, established to inform workforce training and minimum standards

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	2	1	0	7

- Alignment: multiple highly important data gaps (National Dementia Action Plan (NDAP) objectives 2 and 6)
- Foundational data: baseline data to inform educational programs and monitor the impact of actions stemming from the NDAP
- Dependencies: requires healthcare providers or professional groups partnering to support data collection
- Priority group reporting: unlikely

Level of investment: Medium

Timeframe: Medium term (2-6 years) for initial data collection

Responsible stakeholder: AIHW National Centre for Monitoring Dementia (NCMD).

Activity 11b: Report data from dementia education and training across Australia

Building a better understanding of the training undertaken by the unpaid carers and paid workforce caring for people with dementia would provide a step toward monitoring how well-equipped the dementia workforce is with the knowledge to provide high quality, person-centred care for patients and clients with dementia. Regular monitoring of dementia education and training would open avenues to target dementia-specific training to where it is needed and identify optimal educational contexts for introducing dementia-specific training to ensure maximum coverage of the workforce.

This project would aim to explore the sources of workforce training information available (such as, Wicking Centre, Dementia Training Australia, Dementia Australia and possibly universities and Registered Training Organisations that include TAFE and entities approved to deliver specific courses) to determine whether sufficient dementia-specific information is available to routinely monitor the workforce and their training and qualifications. Once feasibility is assessed and reported on as part of the data improvement work program, workforce monitoring would become part of routine monitoring of dementia.

Outcome: Collated national reporting of dementia-specific training and qualification data to monitor dementia workforce capability

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	1	1	0	6

- Alignment: multiple highly important data gaps (NDAP objectives 5 and 6)
- Foundational data: method development
- Dependencies: on dementia workforce training information available from Wicking Centre, Dementia Training Australia, Dementia Australia, TAFEs and universities
- Priority group reporting: unlikely

Level of investment: Medium

Timeframe: Short term (initial) to Long term (once routine)

Responsible stakeholder: AIHW NCMD

References

AIHW (Australian Institute of Health and Welfare) (2023) *Dementia in Australia*, AIHW, Australian Government, accessed 23 February 2023.

DoHAC (Department of Health and Aged Care) (2022) *Dementia Training Program*, DoHAC website, accessed 19 July 2023.

DoHAC (2023) *Aged Care Data Collection*, DoHAC website, accessed 1 June 2023.



Dementia data gaps and improvement activities

Comorbidities (co-existing health conditions) are common in people with dementia, but data on comorbidities are not currently accessible on a large scale for analysis. There are several administrative data sources which capture some data on comorbidities but generally only if the comorbidity affected service provision or for deaths data if it contributed to the cause of death.

Understanding comorbidities is important because the presence of comorbidities in people with dementia increases the complexity in managing their co-existing condition/s as well as their dementia. Certain health conditions can also be risk factors for developing dementia and impact its progression.

Proposed data improvement activity

The main activity proposed to improve data on comorbidities among people with dementia in national data collections is to:

- examine comorbidities among people living with dementia using linked data.

Below provides information on the intended outcome, priority rating, level of investment required, timeframe for completion and who is responsible for undertaking for the activity.

However, there are several other activities in this plan that would also improve data on comorbidities in people with dementia. These include:

- ensure dementia data are consistently collected in core data sets (Activity 5a detailed under [Dementia type](#)).
- incorporate dementia data in enduring national linked data sets to meet the needs of dementia monitoring (Activity 3a detailed under [Dementia prevalence and incidence](#)).
- assess new self-reported dementia data in the 2021 Census (Activity 3d detailed under [Dementia prevalence and incidence](#)).

Activity 12a: Examine comorbidities among people living with dementia using linked data

This activity involves undertaking analysis of comorbidities in people with dementia using data available in enduring linked data sets and exploring demographic characteristics by health condition status. Analysis could focus on issues such as: specific comorbidities (for example, diabetes or cardiovascular conditions), changes in common comorbidities as dementia progresses, or characteristics of hospital stays in people with comorbidities (including expenditure). This may include how comorbidities among people living with dementia are changing over time, how other co-morbid conditions impact the onset and progression of dementia, and how this impacts patterns of health and aged care service use by people living with dementia.

This activity could explore other opportunities for comorbidity analysis in priority populations, for example, in the Australian Bureau of Statistics' Multi-Agency Data Integration Project (MADIP) (using dementia identifiers as described in Activity 8c), the 45 and Up Study and other relevant data sources.

Outcome: Increased data on comorbidities among people living with dementia including impacts on people living with dementia and impacts on health and aged care systems.

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	1	1	1	5

- Alignment: moderately important data gap
- Foundational data: method development
- Dependencies: on linked data and some external data sources
- Priority group reporting: likely

Level of investment: Low

Timeframe: Short term (<2 years)

Responsible stakeholder: AIHW National Centre for Monitoring Dementia

Dementia data gaps and improvement activities

On this page:

- [Introduction](#)
- [Addressing the data gap and improving data](#)
- [Proposed data improvement activities](#)

Carers, both formal (paid) and informal (such as family members and friends), play a vital role in the lives of people with dementia, particularly when the condition has progressed beyond the early stages. They help with the activities of daily living which include personal care, transport, housework and other activities, as well as managing behavioural problems and providing supervision. For people with dementia, access to carers can improve their quality of life and may help to delay or avoid entry into residential aged care services (Dramé et al. 2012).

Information on carers of people with dementia is important for policy development and service planning because dementia not only affects individuals with the condition but also has a substantial impact on their families and carer/s as many of these informal carers help with activities of daily living for people with dementia. Therefore, it is important to measure the number of informal carers for people with dementia; the characteristics of these carers; the type of assistance they provide; the impact of their caring role; and areas of unmet need. This can inform the types of programs needed to support informal carers, and how to complement this with formal carers amid a shortage of disability and aged care workers (JSCNDIS 2022; Royal Commission 2021).

Addressing the data gap and improving data

The Australian Bureau of Statistics' (ABS) Survey of Disability, Ageing and Carers (SDAC) provides national data on people with dementia and their informal carers. It provides information on primary carers living in the same household as their care recipient on factors such as time spent in the caring role, unmet needs, and impacts of the caring role on the carer's physical and emotional wellbeing, relationships, employment and financial situation (AIHW 2023). However, the survey is thought to underestimate the number of people with dementia, particularly people with mild dementia living in the community. Data are also restricted to co-resident carers (AIHW 2023). Availability of the SDAC linked with other data in the ABS Multi-Agency Data Integration Project (MADIP) is a promising data development. Further, the addition of new data on dementia in the 2022 SDAC (to be released in 2024) may provide greater capture of people living with dementia and their carers.

Carers can access information, resources and support services through the Carer Gateway, state and territory-based nongovernment organisations and Dementia Australia (Australian Government 2023). Carers Australia conducted a national [Carer Wellbeing Survey](#) in 2021 and 2022, which provides information on the health, wellbeing and service use of carers, including carers of people with dementia. Carers NSW has also conducted a biennial [Carer Survey](#) since 2002, with the survey conducted nationally in 2020 and 2022. The survey captures information on topics including carers' service use, unmet needs, health, wellbeing and employment impacts, and includes data on carers of people with dementia. Rather than being representative of the Australian population, carers were specifically recruited for these surveys.

More comprehensive nationally representative data on informal carers would provide greater insight on how many Australians provide care for people with dementia, important support mechanisms, unmet needs, and how the prevalence of carers and their needs may change in the future. This will improve the ability to plan and make informed decisions on the magnitude and type of support services needed for carers of people with dementia in the future (AIHW 2023).

Proposed data improvement activities

There are 5 main activities proposed to improve data on informal carers of people with dementia, including their needs and outcomes. These include activities to:

- assess health and welfare of carers of people with dementia using linked data
- explore collection of data on whether care recipient has dementia in existing carer support services data (such as data from Carers Australia, Carers Gateway)
- collect data on the experiences of people with dementia and their carers (Activity 2c detailed under [Dementia awareness and stigma](#))
- collect data on experiences of people with dementia and their carers among priority groups (Activity 2d detailed under [Dementia awareness and stigma](#))
- incorporate dementia data in enduring linked data assets to meet the needs of dementia monitoring (Activity 3a detailed under [Dementia prevalence and incidence](#)).

Each activity description provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activity 13a: Assess health and welfare of carers of people with dementia using linked data

This activity involves undertaking analysis of the health and welfare outcomes of carers, using newly available data from the SDAC, linked with other data in MADIP (such as Census, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), social security, personal income tax and mortality data).

Outcome: Better data on informal carers of people living with dementia and the health and welfare factors that impact sustaining their carer role

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	1	1	0	5

- Alignment: highly important data gap
- Foundational data: method development
- Dependencies: release of the 2022 SDAC
- Priority group reporting: unlikely - based on current dementia reporting from the SDAC

Level of investment: Medium (could require paying for additional questions in current surveys)

Timeframe: Short/Medium term

Responsible stakeholder: AIHW National Centre for Monitoring Dementia (NCMD).

Following the completion of this activity, opportunities for exploring other data sources that capture additional information on carers of people with dementia could be examined. For example, data from Carers Australia, Dementia Australia and the Australian Longitudinal Study on Women's Health, along with other data sets could be examined.

Activity 13b: Explore collection of data on whether care recipient has dementia in existing carer support services data (such as data from Carers Australia, Carers Gateway)

This activity involves assessing what data on people with dementia are available from providers of carer support services (such as Carers Australia and Carers Gateway) and assess the feasibility and potential mechanisms for incorporating identification of carers of people with dementia into existing data. This would involve extensive consultation with providers to encourage the collection of data on whether the care recipient of the person accessing the service has dementia and investigate opportunities for future data linkage.

Outcome: Identify whether improvements can be made in existing carer support services data and whether this is an appropriate avenue for dementia data improvement

Priority: Low

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
3	1	0	0	4

- Alignment: highly important data gap (National Dementia Action Plan (NDAP) objective 5)
- Foundational data: method development
- Dependencies: on dementia carer support services including capture of dementia-specific data
- Priority group reporting: unlikely - although may have potential if these demographics are captured at scale

Level of investment: Low

Timeframe: Short term (<2 years)

The subsequent activity to implement any changes to existing data collections would require greater time and investment.

Responsible stakeholder: AIHW NCMD

Activity 13c: Collect data on lived experience of carers of people with dementia

The activity relates to Activity 2c: Collect data on experiences of people with dementia and their carers and Activity 7g: Collect data on lived experience of dementia diagnosis and management by collecting data on carers' experiences (as opposed to carers providing proxy responses on behalf of the person with dementia).

This activity may involve additional questions in a lived experience survey (Activity 2c), or if the size of the survey is too large, a separate module specifically for the experience of carers of people with dementia. This collection would aim to provide data on carer health, wellbeing, support services, respite for carers of people with dementia and training. This activity may also provide insights relevant to The workforce treating and caring for people with dementia.

Outcomes: Initial data on the experiences of carers of people living with dementia could identify:

- carer health and wellbeing and how this impacts, and is impacted by, caring for a person with dementia
- carer use of and experience with support service providers for both the person living with dementia and for their own wellbeing, including helplines, counselling and respite services
- experience navigating the health, aged care and disability sectors to access service and supports
- dementia training awareness, access and satisfaction

Priority: High

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
4	2	1	0	7

- Alignment: multiple highly important data gaps
- Foundational data: for baseline data
- Dependencies: organisations with carers of people with dementia expertise and contacts required
- Priority group reporting: unlikely

Level of investment: Medium-High

The level of investment will depend on data collection methods.

Timeframe: Short term (<2 years)

This activity should be conducted periodically to collect data over time.

Responsible stakeholder: Academic researchers; organisations with survey experience

References

AIHW (Australian Institute of Health and Welfare) (2023) *Dementia in Australia*, AIHW, Australian Government, accessed 23 February 2023.

Australian Government (2023) *Carer Gateway*, accessed 1 March 2023.

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JSCNDIS (Joint Standing Committee On The National Disability Insurance Scheme) (2022) *NDIS Workforce Final Report*, Commonwealth of Australia, accessed 16 June 2023.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2021) *Final Report: Care, Dignity and Respect: Volume 1 Summary and recommendations*, accessed 16 May 2023.



Dementia data gaps and improvement activities

On this page:

- [Introduction](#)
- [Proposed data improvement activities](#)

There is no single source of data to estimate total health and aged care expenditure due to dementia. Most reports on the economic cost of dementia to the Australian community draw heavily on AIHW disease expenditure studies, which describe the activities and characteristics of Australia's health care system in terms of estimated expenditure for different demographic groups in the population, and expenditure relating to different groups of diseases (based on Australian Burden of Disease Study conditions) (AIHW 2020). The latest expenditure estimates for 2018-19 were derived by combining information from a wide range of sources, including the National Hospital Morbidity Database, Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), Private Hospital Data Bureau Collection, and the AIHW Health Expenditure Database. Due to data availability, allocated spending is skewed towards activities in hospitals (AIHW 2021).

Disease expenditure studies can use different data and estimation methodologies over time, which creates challenges reporting changes in health expenditure attributable to dementia over time (AIHW 2020). The analysis of disease expenditure is complex and resource intensive, which limits the frequency and timeliness of the estimates. *Dementia in Australia* (AIHW 2023) reports health and aged care expenditure estimates that are directly attributable to dementia to avoid including expenditure related to other conditions. Data limitations mean that expenditure estimates exclude costs such as state and territory expenditure on aged care, government payments to support people with dementia and their carers, and indirect expenditure (such as lost wages and productivity) - therefore, the expenditure estimates should be considered conservative (AIHW 2023).

Australia's response to dementia requires regular monitoring and reporting of both the direct costs and the substantial indirect costs, such as informal care, lost productivity, and income support provided to people with dementia and/or their carers. To date, reporting of indirect costs of dementia has been on an ad-hoc basis. The National Centre for Social and Economic Modelling (NATSEM) has recently estimated the economic and societal cost of only one type of dementia (Alzheimer's disease) in Australia (Brown et al. 2022). Consistent investment in estimating both the direct and indirect costs of dementia in Australia is needed, particularly with future changes in dementia policies and program/service delivery.

Proposed data improvement activities

There are 2 main activities proposed to improve data on direct and indirect costs of dementia to the Australian economy. These include activities to:

- expand existing national reporting on the direct expenditure of dementia
- undertake updates on the indirect costs of dementia in Australia.

Each activity provides information on the intended outcome, priority rating, level of investment required, timeframe for completion of the activity and who is responsible for undertaking the activity.

Activity 14a: Expand existing national reporting on the direct expenditure of dementia

This activity would involve expanding current national reporting on the expenditure of dementia to leverage new data being available and include government expenditure on welfare and disability support services.

The Australian Bureau of Statistics' (ABS) Multi-Agency Data Integration Project (MADIP) contains information on income support and other Australian Government payments linked to a range of other national health data sets. The addition of long-term health condition questions in the 2021 Census and the incorporation of other dementia identifiers into MADIP would enable analysis of government expenditure on income support and other payments to people with dementia and their carers. This would expand the information about direct expenditure for caring for people with dementia across the health and aged care sectors in *Dementia in Australia* (AIHW 2023).

The National Disability Insurance Scheme (NDIS) provides funding for disability-related support for people aged under 65, including people with younger onset dementia. The NDIS data held by the National Disability Insurance Agency include primary disability information (and additional diagnoses), which could be used to identify people with dementia for expenditure analysis.

Outcome: Improved data on the direct expenditure on dementia available to support investments in research and prevention initiatives

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	1	1	1	5

- Alignment: moderately important data gap

- Foundational data: method development
- Dependencies: ability to appropriately identify people with dementia in data sets
- Priority group reporting: likely - persons with disability, younger onset dementia

Level of investment: Low

Timeframe: Medium term (2-6 years)

Responsible stakeholder: AIHW National Centre for Monitoring Dementia.

Activity 14b: Undertake updates on the indirect costs of dementia in Australia

To date, there has been ad-hoc reporting on the indirect cost of dementia. In early 2022, the University of Canberra’s NATSEM published *The Economic and Societal Cost of Alzheimer’s disease in Australia, 2021-2041* (Brown et al. 2022). This report (commissioned by Biogen Australia) is an extension of an earlier report produced by NATSEM, *Economic Cost of Dementia in Australia 2016-2056* (Brown et al. 2017). However, the latest report focuses specifically on Alzheimer’s disease rather than all dementia types. The 40-year projection of estimated indirect costs of dementia from the earlier report may not be reliable, particularly with dementia data developments and implementation of the National Dementia Action Plan.

This activity involves investment in studies designed to estimate the indirect costs of dementia in Australia to ensure this is reflective of the current state and to examine how these change over time. Consistent reporting of indirect costs for dementia collectively is needed, particularly to reflect future changes in national dementia policy and program/service delivery. This would require updates to estimated costs.

Outcome: Up-to-date estimates of the indirect costs due to dementia to support investments in service provision, research and so on

Priority: Medium

Alignment	Foundational	Dependency	Priority Group Data	Priority score (Maximum 10)
2	1	1	1	5

- Alignment: moderately important data gap
- Foundational data: method development
- Dependencies: quality of data to inform estimates
- Priority group reporting: likely - potential if demographics captured at scale

Level of investment: Low

Long-term investment would be required for concurrent studies.

Timeframe: Medium term (2-6 years)

Responsible stakeholder: Academic researchers

References

AIHW (Australian Institute of Health and Welfare) (2020) *Dementia data gaps and opportunities*, AIHW, Australian Government, accessed 4 April 2023.

AIHW (2021) *Disease expenditure in Australia 2018-19*, AIHW, Australian Government, accessed 19 July 2023.

AIHW (2023) *Dementia in Australia*, AIHW, Australian Government, accessed 19 July 2023.

Brown L, Hansnata E and La H (2017) *Economic cost of dementia in Australia 2016-2056*, NATSEM, University of Canberra, accessed 9 May 2023.

Brown L, Li J and La H (2022) *The Economic and Societal Cost of Alzheimer’s disease in Australia, 2021-2041*, NATSEM, University of Canberra, accessed 9 May 2023.

Glossary

Abbreviation	Name in full
ABS	Australian Bureau of Statistics
ABDS	Australian Burden of Disease Study
ACCHO	Aboriginal Community Controlled Health Organisation
ACFI	Aged Care Funding Instrument
ADAPTOR	Analysis of Population Traits and Risk Factors
ADHA	Australian Digital Health Agency
ADNeT	Australian Dementia Network
AN-ACC	Australian National Aged Care Classification
BPS	Behavioural and psychological symptoms of dementia
CALD	culturally and linguistically diverse
CTE	chronic traumatic encephalopathy
DA	Dementia Australia
DoHAC	Department of Health and Aged Care
DSA	Dementia Support Australia
DTA	Dementia Training Australia
DOMINO	Data On Multiple INdividual Occurrences
DVA	Department of Veterans' Affairs
GP	general practitioner
IAT	Integrated Assessment Tool
ICD	International Classification of Diseases
MADIP	Multi-Agency Data Integration Project
MBS	Medicare Benefits Schedule
MCI	mild cognitive impairment
MRFF	Medical Research Future Fund
NACDC	National Aged Care Data Clearinghouse
NATSEM	National Centre for Social and Economic Modelling
NBEDS	National Best Endeavours Data Set
NBPDS	National Best Practice Data Set
NCMD	National Centre for Monitoring Dementia
NDAP	National Dementia Action Plan
NDDA	National Disability Data Asset
NDIS	National Disability Insurance Scheme
NHMD	National Hospital Morbidity Database
NHMRC	National Health and Medical Research Council

NHRA	National Health Reform Agreement
NIHSI-AA	National Integrated Health Services Information Analysis Asset
NMDS	national minimum data set
NNIDR	NHMRC National Institute for Dementia Research
NPI	Neuropsychiatric Inventory
NSAF	National Screening and Assessment Form
PBS	Pharmaceuticals Benefit Scheme
PHI	Primary Health Insights
PHN	Primary Health Network
PIAC	Pathways in Aged Care
PIP	Practice Incentives Program
QI	Quality Improvement
RIFIC	Regional Insights for Indigenous Communities
RPBS	Repatriation Pharmaceuticals Benefit Scheme
SDAC	Survey of Disability, Ageing and Carers



Summary of activities ranked by priority

The following 3 tables provide a summary of the high, medium and low ranked activities, organised by the ability to provide monitoring data for the draft National Dementia Action Plan (NDAP) objectives.

Table 4.3: High priority dementia data improvement plan activities

NDAP objective ¹	NDDIP #	NDDIP activity	Anticipated outcome	Timeframe ²	Data sources ³	Responsible stakeholder ⁴
Tackling stigma and discrimination	2a	Conduct nationally representative survey/s of dementia awareness, risks and attitudes in the Australian community	Data on community attitudes and knowledge of dementia and risk factors to inform where knowledge gaps are and what types of information needs to be provided	2023 Baseline	Australian Dementia Awareness Survey ⁵	NCMD
			Repeated surveys would measure any changes following awareness campaigns and actions implemented from the NDAP	2028 Wave 2 2033 Wave 3		
	2b	Collect data on dementia awareness and attitudes among priority groups (including First Nations people and culturally and linguistically diverse (CALD) groups)	Data on attitudes and knowledge of dementia and risk factors among priority groups to inform where knowledge gaps are and what types of information needs to be provided	2024 Baseline	New survey ⁵	External partnerships
			Repeated data collections would assess changes following awareness campaigns and actions implemented from the NDAP			
2c		Collect data on the experiences of people with dementia and their carers	Initial data would provide data on the experiences of people living with dementia and their carers and could identify discrimination experienced, diagnosis delays, and experiences with service providers	2024 Baseline	New survey ⁵	External partnerships
			Repeated data collections would measure changes following actions implemented from the NDAP			
2d		Collect data on experiences of people with dementia and their carers among priority groups (including First Nations people and CALD groups)	Initial data would provide data on the experiences of people living with dementia and their carers among priority groups and could identify discrimination experienced, diagnosis delays, and experiences with service providers	2024 Baseline	New survey ⁵	External partnerships
			Repeated data collections would assess changes following actions implemented from the NDAP			

Minimising risk, delaying onset and progression	1a	Investigate known and emerging risk and protective factors for dementia and their impacts	More comprehensive estimates of the contribution of each risk factor on dementia prevalence and mortality in Australia and how this may change over time, and enable monitoring of risk factors following preventive health initiatives	2024 Initial report 2027 Update	New and existing enduring data linkages ⁵	External partnerships
Improving dementia diagnosis and post-diagnostic care and support	4a	Link dementia onset data to clinical records containing date of dementia diagnosis and calculate timeliness of diagnosis	Data available on time between onset of dementia symptoms and diagnosis made Subsequent data collections and linkages would allow examination of trends in time to diagnosis, over time	2024	Lived experience data and clinical records	NCMD External partnerships
	7g	Collect data on lived experience of dementia diagnosis and management	Initial data on the experiences of people living with dementia could identify: the magnitude and cause of delays in a timely diagnosis, to inform improvements to diagnosis through both community and general practitioner (GP) awareness and health system factors; and experiences with service providers to inform changes needed to improve care and support for people living with dementia Repeated data collections would measure changes following actions implemented from the NDAP	2026	New survey ⁵	External partnerships
	8a	Create guidelines for collecting dementia data in aged care assessments and include training information on dementia data collection in current assessor training	Dementia data collected systematically in aged care assessments	TBD	Builds capability for more systematic data collection	Department of Health and Aged Care
	8b	Incorporate dementia diagnosis information in national aged care data collections	Dementia data collected systematically in nationally aged care data collections	TBD	Health, aged care and disability data ⁶	NCMD Department of Health and Aged Care

	8c	Develop dementia identifiers and incorporate into existing data sets	Increased identification of dementia in data assets to provide greater coverage and insights into prevalence and impacts of dementia	2026	Existing data sources	NCMD
	9a	Explore availability and quality of data on people with dementia accessing First Nations-specific primary health care services	Better data on people with dementia accessing First Nations-specific primary health care	2028	Existing data sources	TBD
Improving treatment, coordination, and support along the dementia journey	10a	Explore patterns of service use, transitions of care and access of services relative to need for people living with dementia using linked data	Better data on the use of carer and support services for people living with dementia	2026	Existing data sources	NCMD
Supporting people caring for those living with dementia	13c	Collect data on lived experience of carers of people with dementia	Initial data on the experiences of carers of people living with dementia could identify: carer health and wellbeing and how this impacts, and is impacted by, caring for a person with dementia; carer use of and experience with support service providers for both the person living with dementia and for their own wellbeing, including helplines, counselling and respite services; experience navigating the health, aged care and disability sectors to access service and supports; and dementia training awareness, access and satisfaction	2026	New survey ⁵	External partnerships
Building dementia capability in the workforce	11a	Collect data on the knowledge of dementia, risk factors, risk reduction strategies, and capability in the workforce caring for and supporting people with dementia	Data on workforce knowledge of dementia, including risk factors, prevention strategies, capability, and adherence to evidence-based clinical practice, established to inform workforce training and minimum standards	2033	New survey ⁵	NCMD

Improving dementia data and maximising the impact of dementia research and innovation	3a	Incorporate dementia data in enduring linked data assets to meet the needs of dementia monitoring	Better diagnosis, prevalence, cost, services, transitions to aged care and outcomes data for the Australian national population and by priority groups	TBD	New and existing enduring data linkages ⁵	NCMD
	3b	Increase coverage of existing data for national dementia incidence monitoring	Recommendations on activities to expand existing data sources to achieve nationally representative dementia incidence data	TBD	Existing data sources New and existing enduring data linkages ⁵	NCMD External partnerships
	3c	Investigate approaches to estimate the national prevalence of dementia	Recommendations to develop national estimates of dementia in Australia through population-based studies	TBD	Nationally representative dementia prevalence data	NCMD External partnerships
	3d	Assess new self-reported dementia data collected in the 2021 Census	Inform the use of Census data for monitoring dementia and estimating dementia prevalence in Australia Provide evidence to support the inclusion of a question on dementia in future Censuses	2024	Existing data sources	NCMD
	3e	Estimate dementia prevalence in priority population groups	Improved methods and data to estimate prevalence of dementia among priority groups	2026	Methods developed	AIHW NCMD External partnerships
5a	Ensure dementia data are consistently collected in core data sets	Dementia data collected consistently and more broadly across sectors	2028	All administrative data sets containing dementia information ⁶	NCMD	

Notes

1. All address National Dementia Action Plan (NDAP) Objective 7, Focus areas 7.3 and 7.4.
2. Timeframes assume commencement of National Dementia Data Improvement Plan (NDDIP) activities in 2024. The dates for text in grey are uncertain. TBD is 'To Be Determined'.
3. Further information on current or proposed data sources are included in activity descriptions.
4. The organisation(s) most suitable for completing the activity.
5. New National Centre for Monitoring Dementia (NCMD) or AIHW activities.
6. Includes national and jurisdictional data.

Table 4.4: Medium Priority Dementia Data Improvement Plan Activities

NDAP objective ¹	NDDIP #	NDDIP Activity	Anticipated outcome	Timeframe ²	Data sources ³	Responsible stakeholder ⁴
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Minimising risk, delaying onset and progression	1b	Expand dementia risk factors included in Australian Burden of Disease Study analysis	Greater inclusion of dementia risk and protective factors data in burden of disease studies allowing greater appreciation of burden and avoidable burden to inform policy and prevention programs	2024-2026	Existing data sources	AIHW
Improving dementia diagnosis and post-diagnostic care and support	6b	Validate data on select behaviours collected in aged care assessment data	Better understanding of behaviours data collected in aged care assessment data and their use for national monitoring of behavioural and psychological symptoms of dementia (BPSD) in Australia	2025-2026	Existing data sources New and existing enduring data linkages ⁵	External partnerships
	6c	Assess feasibility to incorporate measures of behaviours associated with dementia in existing national surveys or population-based studies	National data on people with dementia experiencing BPSD, including those who do not currently access behavioural support services	2025	Existing data sources	NCMD
	9a	Explore availability and quality of data on people with dementia accessing First Nations-specific primary health care services	Better data on people with dementia accessing First Nations-specific primary health care	2028	Existing data sources	TBD
	14a	Expand existing national reporting on the direct expenditure of dementia	Improved data on the direct expenditure on dementia available to support investments in research and prevention initiatives	2028-2030	Existing data sources	AIHW
Improving treatment, coordination and support along the dementia journey	7d	Review the Medicare Benefits Schedule (MBS) to include an item for dementia diagnosis and management	Understand the need for new dementia-specific MBS items or amendments to existing items to support the identification, assessment and management of dementia in primary care data	2031	Existing data sources	Department of Health and Aged Care
	7e	Introduce a dementia measure in the Practice Incentives Program Quality Improvement initiative	Improved dementia recording	2026	Aggregate practice data	AIHW

	7f	Investigate measures of quality of care and quality of life outcomes for hospital patients and aged care residents living with dementia	Report on quality of life and consumer experience measures for people with and without dementia living in residential aged care facilities and who are admitted to hospital	2028	Existing data sources	NCMD
	12a	Examine comorbidities among people living with dementia using linked data	Increased data on comorbidities among people living with dementia including impacts on people living with dementia and impacts on health and aged care systems	2025	New and existing enduring data linkages ⁵	NCMD
Supporting people caring for those living with dementia	13a	Assess health and welfare of carers of people with dementia using linked data	Better data on informal carers of people living with dementia and the health and welfare factors that impact sustaining their carer role	2026	New and existing enduring data linkages ⁵	NCMD
Building dementia capability in the workforce	11b	Report data from dementia education and training across Australia	Collated national reporting of dementia-specific training and qualification data to monitor dementia workforce capability	2025	Leverage information from regulators of training providers or perform a new survey ⁵	NCMD
Improving dementia data and maximising the impact of dementia research and innovation	3f	Develop a Regional Insights portal of dementia data for local areas	Easy access to local geographic and comparator dementia statistics	2028	New and existing enduring data linkages ⁵	AIHW NCMD External partnerships
	3g	Assess impact of dementia coding changes in ICD-11 when incorporated in the Australian health system in capture of dementia in administrative data	Known impact of coding changes for dementia in ICD-11 and more rapid adaptations to existing routine monitoring of dementia using ICD coded data	2026 Implementation 2028 Review	Existing data sources New and existing enduring data linkages ⁵	NCMD
	9b	Incorporate dementia data in Regional Insights for Indigenous Communities (RIFIC) website	Better data available on dementia among First Nations people	2026	Existing data sources	AIHW
	14b	Undertake updates of the indirect costs of dementia in Australia	Up-to-date estimates of the indirect costs due to dementia to support investments in service provision, research and so on	2032	Specific studies	NCMD

Notes:

1. All address National Dementia Action Plan (NDAP) Objective 7, Focus areas 7.3 and 7.4.
2. Timeframes assume commencement of National Dementia Data Improvement Plan (NDDIP) activities in 2024. The dates for text in grey are uncertain.
3. Further information on current or proposed data sources are included in activity descriptions.
4. The organisation(s) most suitable for completing the activity. TBD is 'To Be Determined'.
5. New National Centre for Monitoring Dementia (NCMD) or AIHW activities.

Table 4.5: Low Priority Dementia Data Improvement Plan Activities

NDAP objective ¹	NDDIP #	NDDIP Activity	Anticipated outcome	Timeframe ²	Data sources ³	Responsible stakeholder ⁴
Improving dementia diagnosis and post-diagnostic care and support	6a	Determine outcomes and transitions of care for people with behavioural and psychological symptoms of dementia (BPSD) using linked data	Better data on outcomes and transitions of care for people with dementia experiencing BPSD	2028	New and existing enduring data linkages ⁵	TBD
	7a	National Primary Health Care Data Collection dementia data demonstration project	Understand the value and utility of compiling dementia data from a small sample of general practitioners (GPs) This will also inform processes for the development of a National Primary Health Care Data Collection	2024 Initial practice exploration	New and existing enduring data linkages ⁵	AIHW
Supporting people caring for those living with dementia	13b	Explore collection of data on whether care recipient has dementia in existing carer support services data (such as data from Carers Australia, Carers Gateway)	Identify whether improvements can be made in existing carer support services data and whether this is an appropriate avenue for dementia data improvement	2031	Existing data sources	NCMD
Improving dementia data and maximising the impact of dementia research and innovation	7b	Assess utility of future National Primary Health Care Data Collection for monitoring dementia diagnosis and management in primary health care	Understand the utility of dementia data and management reporting from the National Primary Health Care Data Collection	2024-202	New enduring data linkages ⁵	AIHW
	7c	Detailed exploration of GP or specialist management software to assess utility and suitability of data for dementia monitoring	Understand how patient management software is used in practice to record and extract information on patients with dementia to inform improvements	2024-2026	Existing data sources	NCMD

Notes:

1. All address National Dementia Action Plan (NDAP) Objective 7, Focus areas 7.3 and 7.4.
2. Timeframes assume commencement of National Dementia Data Improvement Plan (NDDIP) activities in 2024. The dates for text in grey are uncertain.
3. Further information on current or proposed data sources are included in activity descriptions.
4. The organisation(s) most suitable for completing the activity. TBD is 'To Be Determined'.
5. New National Centre for Monitoring Dementia (NCMD) or AIHW activities.

Appendix: Current and emerging data sources

Dementia Support Australia: referral data for the NBA and data on cases supported by the DBMAS and SBRT.

Table A.1: Main data sources currently used for dementia monitoring

Source	Data source	Description	What it provides	Limitations/other notes
AIHW	Australian Burden of Disease Study (ABDS)	The ABDS provides estimates on the fatal, non-fatal and total burden of over 200 diseases and injuries in Australia, as well as estimates of the disease burden attributable to specific risk factors.	The non-fatal, fatal, and total burden of disease attributable to dementia, and the proportion of dementia burden that is due to specific risk factors that have a causal association with dementia.	Data are not directly linked to dementia diagnosis but are based on study-derived rates rather than actual diagnosis information.
	<i>Ad hoc updates</i>			The quality of the non-fatal burden estimates could be improved if more recent and more generalisable data on dementia prevalence and severity in Australia become available.
	<i>National coverage</i>			
AIHW	Disease Expenditure Database	The Disease Expenditure Database provides data on government, patient and insurance expenditure on disease, estimated using multiple data sources.	Health system expenditure attributable to dementia	Data are not directly linked to dementia diagnosis for primary care data but are based on study-derived rates rather than actual diagnosis information.
	<i>Ad hoc updates</i>			The quality of disease expenditure estimates could be improved if more generalisable data on dementia prevalence and severity in Australia become available.
	<i>National coverage</i>			There is partial funding for the Disease Expenditure Database.

<p>AIHW</p>	<p><u>National Aged Care Data Clearinghouse (NACDC)</u></p> <p><i>Various updates</i></p> <p><i>National coverage</i></p>	<p>The NACDC is a central repository of national aged care data from various sources, mostly related to government-subsidised aged care programs operating under the <i>Aged Care Act 1997</i>. It includes data relevant to dementia status identification collected from:</p> <ul style="list-style-type: none"> • the National Screening and Assessment Form (NSAF) • the Aged Care Funding Instrument (ACFI). <p>The NSAF captures information on people interested in accessing government-subsidised aged care services coordinated through the My Aged Care system. This includes:</p> <ul style="list-style-type: none"> • the initial screening of the interested person over the phone by My Aged Care contact centre staff • information from either a home support assessment conducted by Regional Assessment Services, or a comprehensive assessment conducted by Aged Care Assessment Teams for people who are found eligible to use of government-subsidised aged care services. <p>The Aged Care Funding Instrument (ACFI) is used to allocate government funding to aged care providers based on the day-to-day needs of the people in their care.</p>	<p>The NSAF identifies people with dementia living in the community and their assessed care needs.</p> <p>The ACFI captures up to 3 behavioural or mental conditions, and up to 3 medical conditions impacting care of people in aged-care facilities.</p>	<p>While work is needed to develop the NSAF into a comprehensive resource for statistical reporting, it is expected to be replaced with the Integrated Assessment Tool within the next 12 months. It is unknown what data will be made available for future analysis, or when it will be made available.</p> <p>The ACFI may not capture information on dementia if, at the time of an ACFI assessment, other mental/behavioural conditions had a bigger impact on a person's care needs. It was replaced on 1 October 2022 by the Australian National Aged Care Classification (AN-ACC) and will no longer collect information on health conditions. While the AN-ACC assessment will assess a person's level of cognitive impairment, the absence of specific clinical diagnosis information will be a major barrier for ongoing dementia monitoring.</p> <p>The combination of these upcoming changes creates uncertainty about the utility of these data for routine dementia monitoring.</p>
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AIHW

National
Hospital
Morbidity
Database
(NHMD)

*Annual
updates*

*National
coverage*

The NHMD is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian hospitals. The data supplied are based on the national minimum data set (NMDS) for admitted patient care and include demographic, administrative and length of stay data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning.

Provides information on dementia-related hospitalisations where dementia was recorded as a principal and/or additional diagnosis.

The hospital separations data do not include episodes of non-admitted patient care provided in outpatient clinics or emergency departments.

In 2015 supplementary codes for chronic conditions were introduced to better capture health conditions that impact care but may not be the diagnoses associated with the hospital stay. The introduction of these codes is expected to have had an impact on the use of additional diagnosis codes and may have reduced the capture of dementia diagnosis information. Supplementary code data are not available for monitoring and reporting to date.

As noted in *Dementia data gaps and opportunities* (AIHW 2020), the admitted patient data are known to under-report dementia among admitted patients, based on principal and additional diagnosis codes.

AIHW

National
Integrated
Health
Services
Information
Analysis Asset
(NIHSI-AA)

*National
coverage*

The NIHSI-AA contains de-identified data from 2010-11 to 2020-21 (v2.0) on admitted patient care services (in all public and, where available, private hospitals), emergency department services and outpatient services in public hospitals, and where available private hospitals, for all participating states and territories (New South Wales, Queensland, Victoria, South Australia, the Australian Capital Territory and Tasmania). It also includes national data for the same period from the Medicare Benefits Schedule, Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme as well as Residential Aged Care data, and National Deaths.

Identifies patients with dementia, where:

- dementia was reported as a principal or additional diagnosis in any hospital admission
- dementia was reported as a principal or additional diagnosis in any emergency department presentation
- they had 1 or more prescriptions for a dementia-specific medication
- dementia was recorded on their aged care funding assessment when they used a residential aged care service (either permanent residential aged care and/or respite residential aged care).

As noted in *Dementia data gaps and opportunities* (AIHW 2020), the admitted patient data are known to under-report dementia among admitted patients, based on principal and additional diagnosis codes.

The Northern Territory and Western Australia do not have hospitals data included. The coverage of private hospitals data is incomplete.

AIHW	<p><u>National Mortality Database</u> (NMD)</p> <p><i>Annual updates</i></p> <p><i>National coverage</i></p>	<p>The NMD holds records for deaths in Australia from 1964 and comprises information about causes of death (compiled by the ABS) and other characteristics of the person, such as sex, age at death, area of usual residence and Indigenous status.</p>	<p>Provides information on people who died with dementia, where dementia was recorded as:</p> <ul style="list-style-type: none"> the underlying cause of death an associated cause of death, that significantly contributed to the death. 	<p>The number of people with dementia recorded on their death certificate is unlikely to include every person with dementia, even when dementia contributed to their death.</p>
AIHW	<p><u>Pharmaceutical Benefits Scheme</u> (PBS) Repatriation Pharmaceutical Benefits Scheme (RPBS)</p> <p><i>Daily updates</i></p> <p><i>National coverage</i></p>	<p>The PBS database provides data on medications prescribed and prescriptions dispensed under the PBS and RPBS.</p>	<p>Provides information about claims for Alzheimer's-specific PBS listed medications, including:</p> <ul style="list-style-type: none"> N06DA02 - Donepezil N06DA03 - Rivastigmine N06DA04 - Galantamine N06DX01 - Memantine. 	<p>The PBS provides only partial coverage of the population with dementia as only people who are eligible to access medications for Alzheimer's disease through the PBS are included.</p>
ABS	<p><u>Multi-Agency Data Integration Partnership data asset</u> (MADIP)</p> <p><i>Ad hoc updates</i></p> <p><i>National coverage</i></p>	<p>The MADIP data asset contains linked national survey and administrative data from a range of Commonwealth agencies, including healthcare, Census, social security payments, personal income tax, and mortality to create a comprehensive picture of Australia over time.</p>	<p>Identifies people with a dementia diagnosis recorded on their record in the National Death Index. PBS information can also be used to identify people who were dispensed Alzheimer's-specific PBS-listed medications.</p>	<p>The MADIP does not contain hospital or key aged care data, which limits utility for dementia projects.</p> <p>New 2021 Census data on long-term health conditions (including dementia) may help identify people diagnosed with dementia (subject to further exploration and comparison with other sources).</p>
ABS	<p><u>Survey of Disability, Ageing and Carers</u> (SDAC)</p> <p><i>Updates every 3-4 years</i></p> <p><i>National coverage</i></p>	<p>The SDAC is a national survey that collects detailed information on a sample of people who:</p> <ul style="list-style-type: none"> have a disability that restricts every-day activities are aged 65 or over, or care for individuals with a disability or long-term health condition(s), including dementia, or care for older people. 	<p>Provides sociodemographic details, level of disability, need/ source of assistance, co-existing conditions, carers of people with dementia</p>	<p>The information on dementia collected by the SDAC requires people to be formally diagnosed, and this diagnosis being reported by the respondent.</p> <p>The information collected on carers is restricted to co-resident carers (primary and otherwise) only for people with dementia.</p>

Dementia Australia	<u>The National Dementia Helpline</u> administrative data	Dementia Australia is an organisation that delivers services and supports across Australia through the National Dementia Support Program (NDSP). Data on incoming calls to the National Dementia Helpline, as well as from people who use their services, are collected.	Provides high level information on contacts to the National Dementia Helpline and outcomes of the National Dementia Support Program.	These data relate specifically to Dementia Australia clients and are only available by request through Dementia Australia. Unit record data are not currently available for external analysis or linkage.
	<i>Ad hoc updates</i>			
	<i>National coverage</i>			
Dementia Support Australia	Dementia Behaviour Management Advisory Service (DBMAS); Severe Behaviour Response Teams (SBRTs); Needs Based Assessment (NBA) administrative data	Identifies people receiving specialist dementia care in residential aged care or at home and the services they received. Services are provided in hospitals where appropriate. Data cover a range of cohort trends, demographics, comorbidities, gender, clinical and psychosocial factors.	These data relate specifically to Dementia Support Australia clients and are only available by request. Unit record data are not currently available for external analysis or linkage.	
	<i>Ad hoc updates</i>			
	<i>National coverage</i>			

Reference

AIHW (Australian Institute of Health and Welfare) (2020) *Dementia data gaps and opportunities*, AIHW, Australian Government, accessed 27 July 2023.

Table A.2: Other data sources that may contribute to future national dementia monitoring

Data source	Description	Expected timeframe for data availability ¹	Geographic coverage
Australia Dementia Network (AD-Net) <u>Clinical Quality Registry</u>	A registry of people newly diagnosed with dementia or mild cognitive impairment (MCI) in selected memory clinics and dementia diagnostic services across Australia. Currently being piloted in selected clinics to track, benchmark and report on the clinical care of people with dementia or MCI. The goal is to register the entire population of persons newly diagnosed with dementia or MCI, including in specialist and primary care.	Medium term	State/territory during pilot, with aim to roll out nationally

<p><u>Census of Population and Housing</u></p>	<p>A self-report data collection undertaken by the Australian Bureau of Statistics (ABS) every 5 years to collect comprehensive information on the personal and household circumstances of the Australian population. For the first time, the 2021 Census asked questions about people’s long-term health conditions, including dementia.</p> <p>AIHW is likely to gain access to 2021 Census microdata on long-term health conditions to validate the data against other sources to determine how representative it is of people living with dementia. This is an essential step before Census data can be incorporated into national prevalence estimate models in an informed way.</p>	<p>Short term</p>	<p>National</p>
<p><u>My Health Record</u></p>	<p>My Health Record stores patient summaries and clinical information uploaded from information systems of participating health service providers across Australia, providing both clinician and patient-centric views of a person’s longitudinal health data.</p> <p>As at May 2022, there were more than 23.3 million My Health Care records, with 96% of these (over 22 million records) containing data. 99% of GPs are registered to use My Health Record, but only 23% of medical specialists have registered (ADHD 2022).</p> <p>Data assessment activities are underway to understand how representative the My Health Record population is, and which population subgroups are represented. This will provide information on whether patients with dementia are well represented in this population and whether the data could help improve dementia prevalence estimation in the future (subject to the establishment of the arrangements to govern the use of de-identified My Health Record data for research and public health purposes).</p>	<p>Long term</p>	<p>National</p>
<p><u>National Aged Care Data Asset</u></p>	<p>The AIHW and the Department of Health and Aged Care are partnering to develop a National Aged Care Data Strategy. Two key activities under the data strategy include the development of an Aged Care National Minimum Data Set (NMDS) and a Data Asset. Once implemented, the NMDS and Data Asset have the potential over the medium term to improve data on people with dementia who interact with the aged care system. This includes improving data on the reporting of dementia and other health conditions during a person’s time using aged care services.</p>	<p>Medium term</p>	<p>National</p>
<p><u>National Disability Data Asset</u></p>	<p>The AIHW is working with partners to develop the National Disability Data Asset (NDDA), which will link data relating to people with disability from governments and agencies across Australia, to provide a richer picture of the life experiences of people with disability. The NDDA has been piloted and in the long term the NDDA may provide valuable data on experiences and outcomes for people with disability who are impacted by dementia.</p>	<p>Long term</p>	<p>National</p>

<p><u>National Primary Health Care Data Collection</u></p>	<p>The AIHW is leading the development of a Primary Health Care Information System. A key component of the system will be the Data Collection, envisaged to contain reliable, detailed, high-quality data about primary health care (focusing on general practitioner (GP) activity data initially but expanding into broader primary care data such as nursing and allied health). It aims to fill existing primary care data and information gaps and could help improve reporting on dementia diagnosis and management in primary care within the next decade.</p>	<p>Long term</p>	<p>National</p>
<p><u>NPS MedicineInsight</u></p>	<p>NPS MedicineInsight is a quality improvement program developed and managed by NPS MedicineWise to support quality improvement in Australian primary care and the post-market surveillance of medicines. It is a large general practice data set established in 2011 with core funding from the Department of Health until June 2022.</p> <p>The data consist of de-identified whole-of-practice data extracted from the clinical information systems of participating general practice sites. From July 2019 to June 2020, participation numbered 458 general practices, 5.6% of general practices nationally, ranging from 2.0% in South Australia to 19% in Tasmania (NPS MedicineWise 2021).</p>	<p>Short term</p>	<p>National</p>
<p><u>Pathology laboratory data on genetic testing</u></p>	<p>Subject to adhering to relevant privacy provisions, de-identified data from pathology clinics offering genetic testing to assess a person's risk of developing certain types of dementia could be a potential future data source contributing to understanding patterns and variations in dementia diagnosis, clinical pathways and outcomes. However, as genetic testing is currently not a routine part of dementia diagnosis, its usefulness as a data source for national monitoring is limited unless it becomes more routinely used in the future.</p>	<p>Long term</p>	<p>National</p>
<p><u>Primary Health Insights</u></p>	<p>Operated by the WA Primary Health Alliance, Primary Health Insights is a storage and analytics platform that hosts the de-identified primary health data of 27 of the 31 Primary Health Networks (PHNs) across Australia. It aims to use reporting and analytics of de-identified primary care data to enable general practice, commissioned healthcare service providers and PHNs to make informed decisions about primary health care delivery. Provision of data to other organisations or individuals for research or planning purposes will be strictly controlled by the Primary Health Insights Governance Framework.</p>	<p>Medium term</p>	<p>Participating PHNs</p>

<p><u>Registry of Senior Australians (ROSA)</u></p>	<p>Based at the South Australian Health and Medical Research Institute, the Registry of Senior Australians (ROSA) monitors the health, service utilisation, medication use, mortality, and other important outcomes of people receiving aged care services in Australia. ROSA currently has 2 components:</p> <ol style="list-style-type: none"> 1. A historical nation-wide data set ('Historical ROSA' or the 'Registry of Senior Australians'), containing de-identified data from all Australians who were assessed for and/or received government-subsidised aged care services from 1997-2020. It includes national aged care data and death records from 1997-2020, linked to Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) records for the period 2002-2020. Hospital and emergency department data have been linked from South Australia, Victoria and Queensland, and hospital, emergency department and ambulance service data have been linked from New South Wales. 2. A prospective state-wide registry ('Prospective ROSA' or the 'Registry of Older South Australians'), which from April 2018 onwards, aims to enrol all older South Australians who have an ACAT aged care eligibility assessment across 4 Local Health Networks in the state between April and August 2018. Since August 2018, all older South Australians receiving an ACAT assessment are provided with the ROSA Participant Information Statement for Opt-Out Consent in the ACAT information pack. The registry links Commonwealth aged care data, death records, MBS and PBS data to South Australian hospitalisation and emergency room encounter data sets. 	<p>Short term</p>	<p>National ('Historical ROSA') and State (South Australia) ('Prospective ROSA')</p>
<p><u>45 and Up Study</u></p>	<p>A longitudinal study of over 250,000 people aged 45 and over living in New South Wales. Managed by the Sax Institute, the study follows the health of participants to examine which factors are associated with good or poor health as people age. Survey responses are linked to other health data, allowing a broad view of health service use and outcomes.</p> <p>(Note that the <i>Addressing Dementia through Analysis of Population Traits and Risk Factors</i> (ADAPTOR) project will use 45 and Up data to investigate the incidence of dementia in Australia and the proportion of dementia that is preventable through modifying risk factors.)</p>	<p>Short term</p>	<p>State (New South Wales)</p>
<p><u>Australian Longitudinal Study on Women's Health</u></p>	<p>The Australian Longitudinal Study on Women's Health has been funded continuously since 1995 by the Department of Health and Aged Care. It has national coverage and has more than 50,000 participants across 4 age cohorts. It has linked data across all jurisdictions and multiple data sources. It includes data on more than 4,000 women with records of dementia, and women who are carers of people with dementia.</p>	<p>Short term</p>	<p>National</p>

References

ADHD (Australian Digital Health Agency) (2022) *My health record - the big picture, May 2022*, accessed 11 July 2022.

NPS MedicineWise (2021) *General Practice Insights Report July 2019-June 2020 including analyses related to the impact of COVID-19*. Sydney: NPS MedicineWise, accessed 11 July 2022.



Notes

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