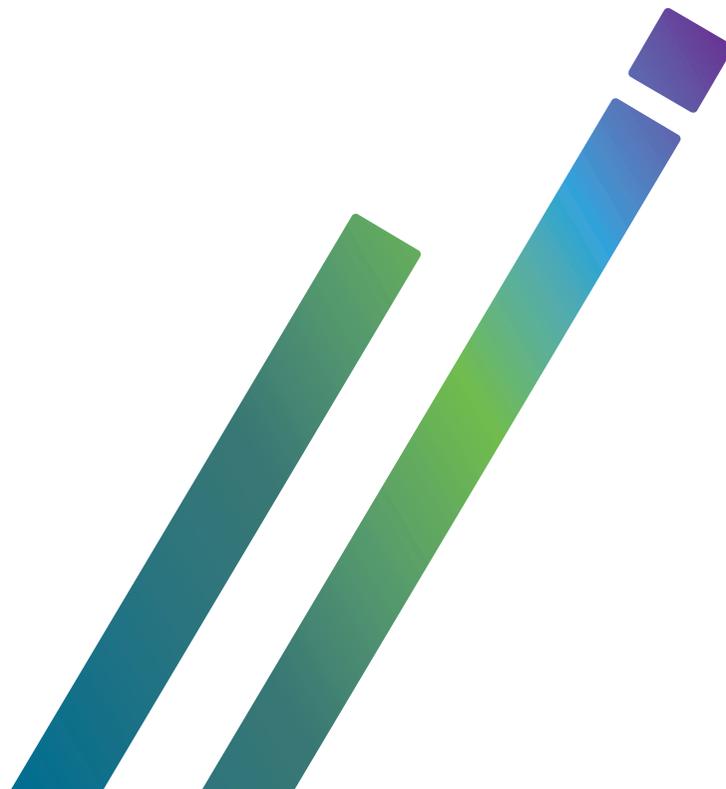




**Australian Government**  
**Australian Institute of  
Health and Welfare**



# **Dementia data gaps and opportunities**



**AIHW**



# Dementia data gaps and opportunities



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ISBN 978-1-76054-749-3 (Online)

ISBN 978-1-76054-750-9 (Print)

DOI 10.25816/xmer-mr26

#### **Suggested citation**

Australian Institute of Health and Welfare 2020. Dementia data gaps and opportunities. Cat. no. AGE 105. Canberra: AIHW.

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Published by the Australian Institute of Health and Welfare.

Please note that there is the potential for minor revisions of data in this report.

Please check the online version at [www.aihw.gov.au](http://www.aihw.gov.au) for any amendment.

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# Summary

The Australian Institute of Health and Welfare (AIHW) has produced 2 comprehensive reports on dementia in Australia (in 2007 and 2012) and in 2021 will release a third compendium on this major public health issue. The earlier reports were hampered by a lack of Australian prevalence data and other limitations in health and aged care data for addressing key policy questions about the extent and impacts of dementia on the Australian community and service systems.

This report takes a fresh look at the dementia data landscape in the light of changes in the health and aged care policy and data environments in recent years. It finds that some key data gaps persist—in particular, a lack of data on the diagnosis and management of dementia by general practitioners and other medical specialists—and that the My Aged Care system introduced in 2015 will only begin to deliver this year the data needed to support analysis of older peoples' assessed care needs.

Clinical information systems and electronic health records offer the opportunity to address long-standing gaps in health system information on dementia. However, the literature depicts a fragmented service system for people with dementia that can be a barrier to obtaining a diagnosis and accessing early support, suggesting that this is not merely a 'data gap' issue. By addressing the service gaps, key data gaps could also be addressed with minimal additional outlay. Sweden and some other European Union countries have taken a clinical quality registry approach and this would appear to offer the best prospects for addressing the needs of Australians living with dementia and, at the same time, generating purposeful data for national dementia monitoring. Australia has established disease registries for many other health conditions and procedures—the expertise to establish a dementia registry most certainly exists here—but with no cure and limited treatment options, dementia may present challenges to participation in a national registry. The Australian Dementia Network's current trial of a clinical quality registry for dementia is an important step in demonstrating the feasibility of this approach in the Australian context.

Linking existing administrative data from across the health and aged care systems appears to be the most feasible approach to dementia monitoring in the short to medium term. Data integration technology is proven, existing administrative data sets are generally of good quality, and the Australian Government's Boosting Dementia Research Initiative has invested in improving dementia data and methods, including through data integration, over the period 2019 to 2021.

To support these and future efforts towards a fit-for-purpose Australian dementia evidence base, this report advocates for a national dementia data framework to be established. The framework would contain objectives and strategies for improving dementia data, through national cooperation. Ideally, this would exist not as a stand-alone framework but as an integral element of the next national dementia strategy. Beneath the data framework would sit a data development plan for dementia detailing governance and resourcing arrangements to ensure that the objectives of the national data framework could be achieved.

Complementing these dementia-specific data initiatives, an aged care data improvement plan is recommended to elevate data governance for aged care data to the level currently afforded to national health system data, ensure the integrity and continuity of data through periods of aged care policy and systems reform, and link aged care data governance with the proposed new national dementia data development plan.

# 1 Introduction

This assessment of national data on dementia is part of the Australian Institute of Health and Welfare's (AIHW) Monitoring Dementia in Australia project commissioned by the Department of Health in June 2019.

The purpose is to review and assess data sources for reporting on dementia, including identifying gaps and opportunities for data improvements pertaining to the topics of interest:

- prevalence, mortality and burden of disease
- risk factors for dementia
- disease expenditure and cost to individuals and society
- health and aged care services
- carers
- capturing data on specific population groups of interest
- recent developments in Australian linked health data assets.

Table 1.1 summarises key dementia data gaps and opportunities discussed throughout the report.

**Table 1.1: Key dementia data gaps and opportunities discussed in this report**

<b>Key data gaps</b>	Lack of primary and secondary care data with dementia diagnosis
	Under-reporting and/or inconsistent coding of dementia in key data sets
	Missing data on dementia diagnosis for some aged care programs
	Sample size issues that limit dementia-specific analysis in national surveys
	Lack of information on patient experiences of people with dementia and their carers
	Missing comprehensive data on dementia in the Aboriginal and Torres Strait Islander population
	Lack of timely data on dementia disease expenditure
	Lack of robust data on dementia among culturally and linguistically diverse communities, people with intellectual disabilities and other vulnerable populations
	Lack of comprehensive data by small geographical areas and in Very Remote areas
	Limited information on younger-onset dementia
	Lack of information on dementia types and severity information in key data sets
<b>Potential future opportunities</b>	Development of a national data development plan for dementia
	Development of an aged care data improvement plan, with immediate priorities to: <ul style="list-style-type: none"> <li>• assess the need for information on clients' health conditions as part of existing and future aged care administrative data collections</li> <li>• review and assess information collected on the new National Screening and Assessment Form</li> </ul>
	Continued integration of data sets to improve dementia ascertainment and aim for these to be enduring integrated data sets (as opposed to one-off linkages)
	Use of electronic medical records and My Health Record
	Development of a dementia clinical quality registry
	Implementation of national policy and programs for timely diagnosis, treatment and management of dementia in the community and support of data collection
	Introduction of dementia-specific Medicare Benefits Schedule (MBS) items/incentives
	Exploitation of supplementary codes for chronic conditions in hospital admitted patient data; with potential extension to emergency department data
	Collection of larger sample sizes in national surveys for health-risk-factor-level analysis by population groups of interest, and use of specific codes for dementia
	Introduction of new data items on date of diagnosis/onset of long-term conditions of care recipients in the Survey of Disability, Ageing and Carers
	Development of dementia research targeted at the Aboriginal and Torres Strait Islander population and other culturally and linguistically diverse groups
	Administration of more frequent National Aboriginal and Torres Strait Islander Health Surveys (NATSIHSs), and the inclusion of dementia as a long-term condition in future NATSIHS
	Investment in a more regular schedule of disease expenditure analysis and reporting
Inclusion of income support data in data integration and analysis	

An updated assessment of the data currently available for monitoring the number of people with dementia, their characteristics and use of services is needed. The assessment should also examine the availability and scope of data about carers of people with dementia. This information is essential to evidence-based policy for an ageing population and can inform the data developments that will be needed for dementia-monitoring activities and reporting into the future.

Previous AIHW assessments of dementia data found that data gaps and other issues were limiting our ability to know the full extent and impacts of dementia. The reports made detailed recommendations for improving the consistency, coverage and quality of national dementia data (AIHW 2007, 2014a). Some of the identified problems relate to the nature of the dementia care pathway itself: under-diagnosis of dementia in general practice settings (and under-documentation); under-disclosure and limitations of self-reporting by respondents with cognitive impairment. Other problems were found to stem from inconsistent approaches to the collection of health information in administrative data and surveys.

A solid evidence base for policy making requires the best possible estimates of dementia prevalence. While this is not the only information requirement, without an accurate and reliable method of case ascertainment, many other information requirements cannot be reliably met. It is therefore useful to start with an overview of the data that have been used for estimating dementia prevalence in Australia. Following chapters will consider the Australian data that are currently available for prevalence estimation and the other topic areas listed above, to identify the main data gaps.

The AIHW's previously published dementia prevalence estimates (AIHW 2012) were calculated using prevalence rates published in the *World Alzheimer report 2009* by Alzheimer's Disease International (ADI 2009) for those aged 60 and over (ADI rates), and using a large-scale UK-based study by Harvey et al. (2003) for those aged under 60. The ADI rates for the Australasian region were derived by meta-analysis (pooling data from separate studies) of 4 dementia studies conducted between 1980 and the early 2000s. Those studies did not report age- and sex-specific rates and consequently the meta-analysis could not directly derive dementia prevalence rates for Australasia by age and sex (ADI 2009:36). To overcome this limitation of the original studies, the meta-analysis calculated age-specific dementia prevalence for Australasia using western Europe as the standard population, estimates which are now regarded as out of date because of changes in life expectancy, living conditions, and health profiles (Wu et al. 2016). Rates for those aged under 60 were based on Harvey et al. (2003), which presented rates by sex and age and was considered the best source of information given the lack of Australian-specific estimates for these younger age groups.

Anstey et al. (2010) used a pooled data set of Australian longitudinal studies that collected clinical information on study participants in the Dynamic Analyses to Optimise Ageing project, or DYNOPTA, to estimate national rates of 'probable dementia', indicated by clinical evidence of cognitive impairment. The resulting estimates are comparable to estimates from meta-analyses of European studies but the authors question the finding of some studies that dementia is more prevalent among Australian women than men. They concluded that the DYNOPTA dementia study provided a useful adjunct to clinical studies of dementia prevalence. Anstey and colleagues (2010) further concluded that the 1997 and 2007 Australian Bureau of Statistics (ABS) Surveys of Mental Health and Wellbeing were not suitable for making projections about dementia and cognitive impairment because of the differing pattern of results from these surveys and the limited availability of survey data at finer levels of age disaggregation.

Access Economics (2005) and Deloitte Access Economics (2011) estimated the prevalence of dementia in Australia using age-specific prevalence rates derived from the ABS Survey of Disability, Ageing and Carers (SDAC) and international epidemiological data. They concluded that the international data provided the more robust estimates of total prevalence while the ABS survey was useful for generating Australian age- and sex-specific profiles.

The National Center for Social and Economic Modelling's analysis of the economic cost of dementia in Australia used prevalence rates from the DYNOPTA study for the older population and, for the younger population, under 65 years, used prevalence rates reported in AIHW (2012) (NATSEM 2017).

Australia has no single authoritative source of national dementia prevalence based on clinical diagnosis. To date, the data used to report on the characteristics of people with dementia do not come from the same sources as the data used to estimate prevalence, raising questions of coverage and accuracy. This is not only a concern for dementia policy and research but an impediment to on-the-ground service planning and delivery. Dementia ranks high in the health needs and priorities of communities around Australia yet prevalence data for planning local dementia services are found wanting, typified by remarks in the community needs assessments carried out by Primary Health Networks (PHNs), for example:

The only available data on dementia prevalence and projections is provided by Deloitte Access Economics, and is reported by Federal Electorate Divisions. This is inadequate and inconsistent with other data and information used for planning and reporting purposes. (PHN Hunter New England and Central Coast 2018:5)

PHN level dementia data not available. (PHN Adelaide 2018:23)

A sample of reports by PHNs highlighting dementia as a priority area of need for local communities can be found in the reference list at the end of this report.

It is also important to measure trends in dementia prevalence over time because it is plausible that these will change. In Australia, rates of cardiovascular disease and other chronic conditions that share risk factors with dementia have declined and this could affect rates of dementia. Past projections do not appear to perform well when compared with current estimates of dementia prevalence in Australia and there is a need to develop more accurate dementia prevalence estimates and projections using a robust, repeatable method.

The conclusion of Waller et al. (2017), that routinely collected health data with record linkage and the capture-recapture method can produce plausible estimates for dementia prevalence at a population level, has helped frame this report in terms of readily accessible national data suitable for routine or regular monitoring. We also consider new possibilities emerging from the widespread adoption of electronic medical records and developments in national health surveys.

## Scope and method

Key informants for this report included data custodians at the AIHW, program and data managers from the Health, Social Services, and Veterans' Affairs departments, the National Disability Insurance Agency (NDIA), ABS publications and a working group of clinicians, researchers, policy experts, and consumer representatives established for the Institute's dementia work program.

A number of the data sources used for the 2012 report remain relevant and we review their current utility in the light of any intervening changes in the policy and data environments. For information on the key features of these data sources readers may wish to refer to earlier AIHW dementia reports.

With its focus on national statistics on dementia, *Dementia in Australia* (AIHW 2012) acknowledged, though did not use, data from a number of longitudinal surveys and studies with targeted regional or demographic coverage. This type of study is also out of scope for review and assessment in this report. Nevertheless, studies of dementia in specific population groups and contexts can contribute vital information and methodological approaches, as seen in the Concord Health and Ageing in Men Project (Cumming et al. 2009) and the linking of data from the Australian Longitudinal Study on Women's Health with administrative data to estimate dementia incidence and prevalence among Australian women (Waller et al. 2017).

This report is a review of national data that may be suitable for routine or regular monitoring of dementia. In-scope data sources include those used for *Dementia in Australia* (AIHW 2012) and any additional national data sources identified through consultations. The identified data sources are classified as tier 1 or tier 2 assets. Tier 1 assets are data sources that record reliable dementia diagnosis information and, subject to data quality, have the potential to inform prevalence estimation, particularly if linked with other data. These include established data sources and planned or proposed new data sources for recently implemented programs. Tier 2 assets are data sources that can inform the topics of interest but do not meet the higher criterion of tier 1 because they do not contain reliable dementia diagnosis information and/or, in isolation, are not expected to contribute substantially to dementia identification for the purpose of prevalence estimation.

For tier 1 assets we apply the AIHW's assessment framework for determining the suitability of specific data sources for population health monitoring. Seven elements of data quality are considered, consistent with the *ABS Data Quality Framework*: institutional environment, timeliness, accessibility, interpretability, relevance, accuracy and coherence of the data (AIHW 2014b; ABS 2009a). The weight given to each element is influenced by the intended end use of the data, in this case, for estimating the prevalence of dementia in Australia via data linkage. When assessing data quality, many of the individual elements interrelate with other elements. For example, the age of a data source, an aspect of timeliness, may impact on its applicability, an aspect of relevance. The framework addresses each element in terms of a concept, target population and 'end-user', defined here as, respectively, diagnosed dementia, Australians with diagnosed dementia, and a reasonably skilled approved-user of the data (as represented by the AIHW). The assessment might yield different results for differently defined uses and end-users of the data.

Assessment is a 3-step process:

1. Collect information about the data source.
2. Identify the potential to inform dementia monitoring based on the available metadata and business intelligence (no direct interrogation of the data).

- Assess the quality of the data using a modified version of the ABS Data Quality Framework (ABS 2009a), to determine its fitness for identifying persons with diagnosed dementia and contributing to the production of dementia prevalence estimates.

The outcomes of this assessment by data source are outlined in Table 1.2.

**Table 1.2: National data sources for dementia monitoring and reporting and assessed quality ratings for reporting on dementia**

Data source	Tier	Quality rating for dementia
Pharmaceutical Benefits Scheme data	1	High
Admitted Patient Care National Minimum Data Set (NMDS)	1	High
Non-admitted Patient Emergency Department Care NMDS	1	High
National Mortality Database and National Death Index	1	High
Income support and allowances data <sup>(a)</sup>	1	High
National Aged Care Data Clearinghouse (NACDC) – Aged Care Assessment Program Minimum Data Set (MDS)	1	Medium
NACDC – Aged Care Funding Instrument	1	Low
Dementia Behaviour Management Advisory Service data and Severe Behaviour Response Teams Program data	1	Low
Specialist Dementia Care Program data	1	Low
National Integrated Health Services Information Analysis Asset	1	Low
National Screening and Assessment Form (NSAF)/Aged Care Client Record	1	Unable to assess <sup>(b)</sup>
My Health Record	1	Unable to assess
National Disability Insurance Scheme data	1	Unable to assess
Multi-Agency Data Integration Project	1	Unable to assess
Medicare Benefits Schedule data	2	—
National Hospital Cost Data Collection	2	—
Residential Mental Health Care NMDS	2	—
Community Mental Health Care NMDS	2	—
NACDC – Community aged care and flexible care programs <sup>(c)</sup>	2	—
AIHW Australian Burden of Disease studies	2	—
AIHW Disease Expenditure studies	2	—
ABS Survey of Disability, Ageing and Carers <sup>(d)</sup>	2	—
ABS National Health Surveys/National Aboriginal and Torres Strait Islander Health Surveys	2	—
ABS Australian Health Survey	2	—
ABS 2016 Survey of Health Care	2	—
ABS Patient Experience Surveys	2	—

(a) Claims and payments data for Disability Support Pension, Carer Payment, and Carer Allowance.

(b) The quality rating of the NSAF will be established once it is available as an analytical data set in the NACDC.

(c) Home Care Packages Program, Commonwealth Home Support Programme, Transition Care Program, Multi-Purpose Services and Flexible Care programs.

(d) Although this data source contains dementia diagnosis information, the SDAC is classified as a Tier 2 asset given known issues with it underestimating dementia prevalence. It is still a key data source for dementia monitoring and reporting, and through data linkage, the SDAC may be able to add substantially to dementia prevalence estimation in the future.

## Report outline

Chapter 2 catalogues the key data sources and provides a 'catch-up' on developments since 2012 that have affected or may affect the utility of these data sources for dementia monitoring and reporting.

Chapter 2 also explains why existing and new data sources are classified as tier 1 or tier 2. As stated previously this is broadly based on the presence (tier 1) or absence (tier 2) of dementia diagnosis information in the data to inform dementia prevalence estimation. However, other factors, such as data quality and suitability for data linkage, also affect the classification.

Chapter 3 presents a detailed quality assessment of the tier 1 assets. This chapter identifies the data quality problems currently limiting the ability to exploit existing data sets for dementia prevalence estimation—gaps that need to be addressed if we are to fully realise the benefits of data integration methods for dementia monitoring. Additional information on the tier 1 quality assessments is presented in Appendix A.

Chapter 4 draws on the detailed assessment in a concluding discussion of data gaps and opportunities that could usefully shape a future dementia data development plan.

## 2 Data sources

The Institute's last comprehensive picture of dementia in Australia drew on a range of administrative data sets, analytical studies and national surveys (Table 2.1). Dementia prevalence estimates for Australia in 2011 and projections to 2050 were calculated by applying dementia rates estimated by AIHW (using published prevalence rates in ADI (2009) for those aged 60 and over, and a UK-based study by Harvey et al. (2003) for those aged under 60) to ABS estimates and projections of the Australian population. Estimates/projections by state and territory were reported between the years 2011 and 2020.

**Table 2.1: Key national dementia data sources in 2011**

Data source/collection	Data owner/custodian
<b>Administrative by-product and registration data</b>	
Aged Care Assessment Program data	Department of Health <sup>(a)</sup>
Aged Care Funding Instrument data <sup>(b)</sup>	Department of Health <sup>(a)</sup>
Pharmaceutical Benefits Scheme/Repatriation Pharmaceutical Benefits Scheme data	Department of Health/Department of Veterans' Affairs and Services Australia
Drug Utilisation Sub-Committee database – Pharmacy Guild Survey	Department of Health
Medical Benefits Schedule data	Department of Health
National Mortality Database	Australian Institute of Health and Welfare/ Australian Bureau of Statistics <sup>(c)</sup>
National Hospital Morbidity Database	Australian Institute of Health and Welfare
National Hospital Cost Data Collection	Independent Hospital Pricing Authority <sup>(d)</sup>
Community Mental Health Care National Minimum Data Set (NMDS)	Australian Institute of Health and Welfare
Residential Mental Health Care NMDS	Australian Institute of Health and Welfare
National Respite for Carers Program data	Department of Health
<b>Analytical studies</b>	
Australian Burden of Disease Study	Australian Institute of Health and Welfare
Disease Expenditure Study	Australian Institute of Health and Welfare
<b>National surveys</b>	
Bettering the Evaluation and Care of Health Survey	The University of Sydney
2009 Survey of Disability, Ageing and Carers <sup>(b)</sup>	Australian Bureau of Statistics
2007 National Survey of Mental Health and Wellbeing	Australian Bureau of Statistics
2008 Community Care Census <sup>(b)</sup>	Department of Health

(a) AIHW has had a data custodian role since establishing the National Aged Care Data Clearinghouse in 2013.

(b) New or substantially changed data source since *Dementia in Australia: national data analysis and development* (AIHW 2007).

(c) The National Mortality Database maintained by the AIHW contains cause of death data compiled by the ABS.

(d) In 2011, responsibility for the National Hospital Cost Data Collection passed from the Department of Health to the newly established Independent Hospital Pricing Authority.

Source: AIHW 2012: Appendix B.

Data improvements between the 2007 and 2012 *Dementia in Australia* reports (AIHW 2007, 2012) have included:

- The Aged Care Funding Instrument (ACFI), which in 2008 replaced the Resident Classification Scale (RCS), collects information about the health conditions of people around the time of entry to permanent residential aged care. This information enables the identification of residents with dementia at the time of appraisal whereas the RCS did not. For timing and other reasons, the ACFI is thought to underestimate the prevalence of dementia in aged care homes but the collection of health condition information provides valuable data for an improved understanding of health-related drivers of demand for residential aged care.
- The 2008 Community Care Census increased the coverage of recipients of aged care packages living in the community compared to the 2002 Community Care Census; however, the 2008 data were still thought to underestimate dementia prevalence, especially in areas classified as *Remote* and *Very Remote* and among Indigenous recipients of care packages. The Community Care Census has not been repeated since 2008.
- The 2009 ABS SDAC, a key source of data for the 2012 dementia report, nearly doubled the sample size of the 2003 SDAC for both the household and cared accommodation components (ABS 2003, 2009b). The increased sample substantially improved the robustness of estimates and there was also improved identification of primary carers in the 2009 survey.

AIHW (2012) canvassed options for improving the availability, consistency and overall quality, and extending the use of existing dementia data:

- **data availability**—explore the creation of new data sources, for example, a multistage population survey incorporating appropriate clinical tools or a dementia registry, and ways to make better use of existing data sources for case ascertainment.
- **data consistency and quality**—look for opportunities to improve dementia data when implementing aged care reforms and standardise dementia data collected by the various aged care programs including the Aged Care Assessment Program (ACAP) and the ACFI. Consider collecting health condition information in disability services data.
- **data use**—consider arrangements for ongoing monitoring and reporting on dementia, consistent with other National Health Priority Areas. Strengthen data integration capacity, especially by standardising the identifying information on aged care program data sets to enable data linkage.

The next sections examine the state of dementia coding in currently available data sets, many of which were used for the 2012 report. The discussion highlights developments in Australia's health and aged care systems since 2012 that have implications for our capacity to monitor dementia at the national level, and identifies newly established or potential future data sources that could contribute to dementia monitoring in the future.

## Health system data developments

Table 2.2 lists key national health system administrative, registry and burden of disease data sources currently available for approved secondary (statistical and research) purposes and shows the applicable health condition coding schema used to denote dementia. The current status of each data source and any relevant developments since 2012 are outlined in turn below.

**Table 2.2: In-scope health system, registry and burden of disease data sources**

Data source/collection	Dementia codification	Measurement unit
Medicare Benefits Schedule data	No dementia-specific items	Claim (service)
Pharmaceutical Benefits Scheme data	Anti-dementia medications	Claim (dispensed medication)
Admitted Patient Care National Minimum Data Set (NMDS) <sup>(a),(b)</sup>	ICD-10-AM <sup>(c)</sup> codes	Episode of care <sup>(b)</sup>
Non-admitted Patient Emergency Department Care NMDS <sup>(a)</sup>	ICD-9, ICD-10 and SNOMED codes <sup>(c, d)</sup>	Presentation
National Hospital Cost Data Collection <sup>(e)</sup>	ICD-10-AM codes	Episode of care <sup>(b)</sup> , Establishments
Residential Mental Health Care NMDS	ICD-10-AM codes	Episode
Community Mental Health Care NMDS	ICD-10-AM codes	Patient contact
National Mortality Database and National Death Index	ICD-10-AM codes	Death
AIHW Australian Burden of Disease Studies (ABDS)	ABDS listed condition	Disability-adjusted life year
AIHW Disease Expenditure Studies	ABDS listed condition	Expenditure

(a) Element of the National Hospital Morbidity Database.

(b) Episode of care is a hospital separation, which can be a completed hospital stay, from admission to discharge, transfer or death, or a portion of a hospital stay beginning or ending in a change in care type.

(c) ICD codes refer to the International Classification of Diseases 9th revision (ICD-9), 10th revision (ICD-10) and 10th revision with Australian Modification (ICD-10-AM).

(d) SNOMED is the Systematized Nomenclature of Medicine (<http://www.snomed.org/>).

(e) Collated and maintained by the Independent Hospital Pricing Authority.

## Medicare Benefits Schedule and Pharmaceutical Benefits Scheme

Medicare Benefits Schedule (MBS) data, the data on claims relating to medical services delivered under Australia's system of universal health care, cover medical and related services eligible for Medicare benefits, as listed in the MBS. Diagnosing dementia involves clinicians—general practitioners (GPs) and medical specialists—ordering tests and scans, for which the majority are claimable under the MBS. However, as there are no MBS items specifically for dementia diagnosis and care, Medicare claims for doctor consultations, tests and scans performed as part of diagnostic work-up for dementia are not discernible in the data as relating to dementia.

A range of existing MBS items can be used for the clinical management of dementia, such as health assessments for people aged 75 years and older and Chronic Disease Management items, but in isolation cannot be used to ascertain dementia-related claims in MBS data. While the MBS data have contributed to the picture of health service use and expenditure associated with dementia, to date, this has only been achieved by either integrating MBS data with data from tier 1 assets or using additional information from national general practice surveys. The MBS data are a tier 2 data asset, in this respect, unchanged since 2012.

Two parliamentary inquiries in recent years have considered the question of dementia-specific MBS items. A House of Representatives Committee recommended a comprehensive review of existing MBS items to determine whether it was necessary to expand these or create new items to support the identification, assessment and management of dementia in primary care (for the Australian Government's response, see Department of Health 2017a). A Senate Committee went further in recommending the creation of a new Medicare item number 'to encourage General Practitioners, registered psychologists or other relevant accredited professionals, to undertake longer consultations with a patient and at least 1 family member or carer where the patient has presented with indications of dementia' (for the Australian Government's response, see Department of Health 2017b).

Used in conjunction with other data that contain dementia identifiers, the MBS data provide authoritative information on the medical services used to manage different health conditions, including dementia, and their associated costs. An example is the AIHW's disease expenditure analysis, which has in the past used data from the Bettering the Evaluation and Care of Health (BEACH) survey (The University of Sydney 2016, 2017) to attribute Medicare claims to the Australian Burden of Disease Study health condition list (AIHW 2019a, 2019b). The BEACH survey and the AIHW Disease Expenditure Study are discussed below.

It might be possible to deduce probable dementia from patterns of Medicare service use that indicate clinical work-up for dementia diagnosis. This could be reflected in the sequencing of MBS items over time for an individual patient, including: GP and specialist consultations, brain magnetic resonance imaging and blood tests. It is not known whether this type of longitudinal analysis of MBS items has been attempted for dementia identification. If a method can be validated, this approach could improve case ascertainment, especially for people (who access Medicare services) in the early stages of dementia.

By contrast with MBS data, the Pharmaceutical Benefits Scheme (PBS) data contain dementia-specific information in the form of claims for medications that are prescribed to treat Alzheimer's disease (Donepezil, Galantamine, Rivastigmine and Memantine). While providing only partial coverage of the population with dementia, that is, only people who access medications for Alzheimer's disease under the PBS, the PBS data are a tier 1 data asset. Not only are PBS data

informative about dementia-related health service use in their own right, through data integration they are critically important for identifying people with dementia represented in other data sets. In this context, the PBS data are largely unchanged since 2012.

## National Hospital Morbidity Database

The presence of medical diagnoses in hospital records for admitted patients makes the Admitted Patient Care National Minimum Data Set (NMDS) a tier 1 asset. Dementia can be recorded as the principal diagnosis (the diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care) or additional diagnosis (a condition or complaint either coexisting with the principal diagnosis or arising during the episode of admitted patient care). Principal and additional diagnosis information in admitted patient care data has been found to independently identify around two-thirds of confirmed dementia cases where people have died (AIHW 2020), making these data an essential element in dementia identification through data integration.

Since July 2015, hospitals have been permitted to code dementia as a chronic condition present on admission where the dementia does not meet the criteria for coding as principal or additional diagnosis (Independent Hospital Pricing Authority 2015). For information on the International Statistical Classification of Disease and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) codes for dementia in admitted patient data see AIHW (2019d). In the ICD-10-AM 9th Edition, a new Australian Coding Standard ACS 0003 'Supplementary codes for chronic conditions' was introduced, meaning that from 1 July 2015, where a chronic condition is present on admission and is part of the current health status of the patient but does not meet the criteria for coding as a principal or additional diagnosis, then a corresponding supplementary code, sometimes referred to as a 'U-code', is recorded on the hospital episode regardless of whether the condition influenced the hospital treatment received. Currently, U-codes cover 29 different conditions. Records for admitted patients with diagnosed dementia should have the supplementary code 'U79.1 Dementia (including Alzheimer's disease)' recorded where the dementia does not satisfy the criteria to be recorded as principal or additional diagnosis.

The AIHW collates admitted patient (hospital) data supplied by state and territory health authorities into the Admitted Patient Care NMDS. Supplementary codes for chronic conditions are stored separately in the National Hospital Morbidity Database and require special approval from state and territory health authorities to access.

Routinely collected admitted patient data are known to under-report dementia among admitted patients, based on principal and additional diagnosis codes alone (AIHW 2013; Cappetta et al. 2020; Cummings et al. 2011; Wilkinson et al. 2018). Potentially, ACS 0003 has improved the identification of admitted patients with dementia and increased the utility of the National Hospital Morbidity Database for dementia prevalence estimation, both stand-alone and when linked to other data. An AIHW project is currently evaluating the usefulness of the supplementary codes for ongoing population health reporting using data linkage. Higher sensitivity can also be achieved by combining hospitals data with mortality data (Wilkinson et al. 2018).

Non-admitted Patient Emergency Department Care NMDS data from 2013–14 onwards contains principal diagnosis as well as first and second additional diagnosis, supplied by state and territory health authorities in various formats (ICD-9, ICD-10 and SNOMED), making this a tier 1 asset. However, it is recognised that dementia may not be recorded commonly as a diagnosis in the

emergency department setting as it is often a contributor to an incident, rather than the actual principal diagnosis.

Medical diagnoses are not recorded in the Non-admitted Patient Care NMDS. This data set is important for completing the picture on the use of hospital services by people with dementia and associated health expenditure, making it a tier 2 asset.

## **National Hospital Cost Data Collection**

The National Hospital Cost Data Collection (NHDC) was established in 1996 by the then Commonwealth Department of Health and Family Services with the primary objective of providing Australian governments and the health-care industry with a nationally consistent method of costing all types of hospital activity related to the care of patients.

In 2011, the newly established Independent Hospital Pricing Authority assumed responsibility for governance of the NHDC. A range of developments to the NHDC have been implemented, including data quality controls, the introduction of a submission portal and developments in costing standards designed to increase confidence in the collection for the purpose of national reporting.

The NHDC is an important data source in the estimation of health system expenditure attributable to dementia. It does not itself identify patients with dementia but, rather, uses the Australian Refined Diagnosis Related Group (AR-DRG) recorded for an episode of care to derive average resource utilisation (average length of stay, cost weighted separation, etc.) for admitted patients with a principal diagnosis of dementia. The NHDC is a tier 2 data asset.

## **National mental health-care data**

The Residential Mental Health Care NMDS and Community Mental Health Care NMDS are compiled by the AIHW from data supplied by state and territory health authorities. Inconsistencies in the coding of principal and additional diagnoses across the states and territories makes obtaining person counts by diagnosis from these collections problematic. Neither database supports probabilistic or deterministic linkage with other data.

*Dementia in Australia* used data from these collections for stand-alone descriptive analysis of community mental health service contacts and residential mental health-care episodes for people with a principal diagnosis of dementia, estimated at 1.3% of all service contacts and fewer than 1.6% of episodes in 2009–10, respectively (AIHW 2012). Corresponding figures for 2016–17 are 0.5% and fewer than 1.0%, respectively.

These collections are unlikely to be of great value to national dementia monitoring and reporting but are rated as tier 2 assets.

## **Causes of death data**

The ABS Causes of death collection includes all deaths that occurred and were registered in Australia, including deaths of persons who usually reside overseas. Registration of deaths is the responsibility of each state and territory's Registry of Births, Deaths and Marriages and draws on information in the National Coronial Information System. Cause of death data are collated and coded by the ABS. Since 1997, the coding of cause of death data has been based on ICD-10.

The AIHW maintains a National Mortality Database with records for deaths in Australia from 1964. The data include information about cause of death and other personal characteristics of the deceased such as sex, age at death, area of usual residence and Indigenous status. The National Death Index (NDI) is a database housed at the AIHW that contains records of all deaths occurring in Australia since 1980. The NDI is designed to facilitate the conduct of epidemiological studies; it enables linkage to other data sets and its use is strictly confined to medical research. The National Mortality Database and NDI are tier 1 data assets.

Nonetheless, dementia is known to be under-reported and/or inconsistently recorded in a number of health administrative data collections, including deaths data (Waller et al. 2017). With reference to the coding of dementia-related deaths, the ABS (2015) advises:

There has been an increase in the number of deaths coded to Dementia (F01, F03) when comparing data from pre-2006 to that of 2006 onwards. Updates to the coding instructions in ICD-10 have resulted in the assignment of some deaths to Vascular dementia (F01) where previously they may have been coded to Cerebrovascular diseases (I60-I69). In addition, changes to the *Veterans' Entitlements Act 1986 and Military Rehabilitation and Compensation Act 2004*, and a subsequent promotional campaign targeted at health professionals, now allow for death from vascular dementia of veterans or members of the defence forces to be related to relevant service. This is believed to have had an effect on the number of deaths attributed to dementia.

## Australian burden of disease studies

The latest Australian Burden of Disease Study (AIHW 2019b) provides estimates of the total, non-fatal and fatal burden for the Australian population in 2015, with estimates presented for more than 200 diseases and more than 30 risk factors. It also provides estimates for 2011 and 2003, revised using the same methods as for 2015, to enable direct comparisons. Time series analysis of total and fatal burden attributable to dementia over this period is problematic because of changes to the coding of dementia-related deaths, noted above.

The Australian Burden of Disease Study highlighted a number of data gaps, particularly data on the prevalence of diseases treated in primary health care, data for some risk factors and Australian-specific disease severity measures.

Burden of disease studies use data from multiple sources and generate disease- and health-condition (and risk factor) level results. These results are essential for dementia monitoring but as they are not person-level data and use diagnosis information already existing in the input data sources, the outputs are classified as tier 2.

## AIHW disease expenditure studies

The AIHW periodically conducts studies into the nature of health expenditure, including the analysis of expenditure by the demographic characteristics of the population and by the diseases or conditions being managed by the health system (the AIHW reports annually on overall health expenditure). Expenditure is apportioned to disease expenditure groups according to the Australian Burden of Disease Study conditions (AIHW 2019a, 2019b). Disease expenditure estimates provide a broad picture of the use of health system resources classified by disease groups and conditions, age group and sex, and are a reference point for planners and researchers interested in costs and use patterns for particular diseases.

Updating of disease expenditure estimates is subject to specific funding being made available for the work, which has not occurred in a systematic way in the past. The latest comprehensive update (AIHW 2019c), based on data for financial year 2015–16, follows more than a decade after the previous in-depth report on disease expenditure in 2004–05. The Department of Health has funded the AIHW to repeat disease expenditure along with burden of disease estimates for 2018 (2018–19 for disease expenditure). This will again use the broad scope and scale that was used for the 2015–16 estimates.

Expenditure estimates for 2015–16 were derived by combining information from a wide range of sources, including the National Hospitals Data Collection, National Hospitals Cost Data Collection, MBS, PBS, Private Hospital Data Bureau Collection, the BEACH survey and the AIHW Health Expenditure Database (AIHW 2019a). BEACH data were used as the basis for estimating the conditions that GPs and other medical specialists are treating, and the conditions for which pharmaceuticals are prescribed and diagnostic imaging and pathology are requested. Discontinuation of Australian-Government funding for the BEACH survey program and cessation of the survey in April 2016 means that new approaches must be developed for disease-specific estimates for the 2018–19 report.

In the 2015–16 report, estimates of health expenditure associated with dementia are disaggregated by type of health intervention: allied health and other services; GP services; medical imaging; pathology; pharmaceuticals; private hospital services; public hospital admitted patient care; public hospital emergency department care; public outpatient clinics; specialist services; and dental expenditure (AIHW 2019a). The methodological approach represents the most comprehensive reporting of disease expenditure to date undertaken by the AIHW and includes primary health-care services, hospital emergency department services and hospital outpatient services for the first time. Previous disease expenditure data, including those used in *Dementia in Australia* (AIHW 2012), generally had a more limited scope and scale, for example:

- *Australian health expenditure—demographics and diseases 2004–05 to 2012–13* was limited to hospital admitted patient care (AIHW 2017a)
- *Health system expenditure on disease and injury in Australia 2004–05* did not include primary health-care services, hospital emergency department services or hospital outpatient services (AIHW 2010a).

Due to these changes in scope, as well as changes in estimation methodology, there are challenges with reporting on changes in health expenditure attributable to dementia over time. Nevertheless, the outputs of disease expenditure studies are classified as tier 2.

## Primary care data developments

At the time of the 2007 and 2012 *Dementia in Australia* reports (AIHW 2007, 2012), the BEACH survey (The University of Sydney 2016, 2017) was the only data collection of GP activity with national coverage and a key source of data for examining the use of primary care by patients with dementia. New data sources driven off clinical information systems (CIS) have since become available for use by approved researchers and other clinical data collections are at various stages of development and approval for statistical use. Indicative developments in the primary care data space are outlined below.

NPS MedicineInsight is a large general practice data set established in 2011 with core funding from the Department of Health. The data consist of de-identified whole-of-practice data extracted from the CIS of participating general practice sites. As at October 2018, participation numbered 555 sites, 8.3% of general practice sites nationally, ranging from 3.3% participation in South Australia to 28.7% in Tasmania (NPS MedicineWise 2018a).

Patient records are assigned a unique identification number at each site, allowing multiple records for the 1 patient to be linked within a site, though not across sites. In addition to practice and provider details, the data include patient basic demographics, selected health risk factors, GP encounters, medical history including diagnoses, prescriptions information, investigations requested and results (NPS MedicineWise 2018b). Researchers may apply to an independent Data Governance Committee (and pay) for access to the data. Projects approved to date that are potentially relevant to dementia include:

- Demonstrating capability of linking MedicineInsight with MBS/PBS data (NPS MedicineWise)—the primary purpose of this project is to demonstrate the technical capability for de-identified MedicineInsight data to be linked successfully to MBS/PBS data.
- Australian Institute of Health and Welfare data evaluation project— the AIHW is using a sample of MedicineInsight data to evaluate the feasibility of using the MedicineInsight data to support and inform national-level reporting in primary care in Australia.
- Optimising quality of care among Australians with dementia (The University of Sydney)—this project is using the MedicineInsight data set to investigate the diagnosis and prescribing patterns for dementia and the subtypes of dementia within Australian general practice.
- Projects using MedicineInsight data to measure the prevalence of specific conditions, for example, chronic kidney disease in people with type 2 diabetes; these studies could provide a template for using this data to improve the estimation of dementia prevalence.

Outcome Health's Population Level Analysis and Reporting tool (POLAR) combines data extraction and reporting for subscribed general practices and PHNs. The system maps free-text and coded GP diagnosis to SNOMED-CT AU and a 'Higher Order Diagnosis' categorisation and generates de-identified patient data (for consenting patients only) for analysis by subscribed users ([www.outcomehealth.org.au](http://www.outcomehealth.org.au)).

NPS MedicineInsight and POLAR are just 2 examples of CIS-generated GP data for statistical and research use. CIS also exist for medical specialist practices.

In the May 2018 Budget, the AIHW was funded to develop a National Primary Health Care Data Asset, envisaged as an enduring data asset that facilitates a better understanding of what happens to patients in the health system, including their diagnoses, treatments and outcomes. The data will likely come from a mixed model of de-identified unit records and aggregate data from health providers and expand to linked health data sets later on. Public consultation was undertaken in 2019 and next steps will include proof-of-concept work and ongoing stakeholder consultation (AIHW 2019e).

The AIHW has been named National Data Custodian for the Practice Incentives Program (PIP) Eligible Data Set arising from the Quality Improvement initiative (PIP QI) funded by the Department of Health. PIP is aimed at supporting general practice activities that encourage continuing improvements and quality care, enhance capacity and improve access and health outcomes for

patients ([www.servicesaustralia.gov.au/organisations/health-professionals/services/medicare/practice-incentives-program](http://www.servicesaustralia.gov.au/organisations/health-professionals/services/medicare/practice-incentives-program)). It is anticipated that, from 1 August 2020, the AIHW will receive the 10 aggregate measures (which do not include dementia) from PHNs arising from eligible practices' participation in PIP QI.

Subject to the establishment of the arrangements to govern the use of de-identified My Health Record data for research and public health purposes, the My Health Record system presents an opportunity for improving dementia prevalence estimation in the future. At the time of writing, around 90% of Australians have a My Health Record following the move in January 2019 to opt-out participation, with eligible Australians having a My Health Record created for them. Data assessment activities are currently underway to understand how representative the My Health Record population is, and which population subgroups are represented. This will form an understanding of whether patients with dementia are well represented in this population. Around 93% of GPs are registered to use the My Health Record (<https://www.myhealthrecord.gov.au/statistics>), however, participation by medical specialists is low. My Health Record stores patient summaries and clinical information uploaded from information systems of participating health service providers across Australia. In essence, it provides both clinician and patient-centric views of a person's longitudinal health data. Pending results of the data assessment and establishment of the data governance arrangements, and as the My Health Record system matures and increases in uptake, a de-identified My Health Record could be an additional data source for a national dementia registry and help address gaps in dementia data—data on the diagnosis and management of dementia by primary and secondary care providers.

# Aged care data developments

## National Aged Care Data Clearinghouse

The AIHW National Aged Care Data Clearinghouse (NACDC), established in 2013, substantially improved the availability and use of existing aged care data and metadata. The NACDC is a centralised repository of national aged care data collected through various portals and government departments, chiefly the Department of Health, and encourages transparency and independence in aged care research and evaluation for a range of stakeholders including policy makers, researchers, service providers and consumers. It contains data on programs administered under the *Aged Care Act 1997*, including aged care assessments, community-based care packages, residential care and a number of flexible care programs, as well as Australian-Government funded entry-level support services for eligible older people living at home. In most cases the data are refreshed annually (in September) via a data supply from the Department of Health. The NACDC may in future expand to include other data sources.

The 2 main sources of dementia identification currently in the NACDC are the Aged Care Assessment Program (ACAP) and Aged Care Funding Instrument (ACFI) data:

- ACAP data contain records of the assessments undertaken by an Aged Care Assessment Team (ACAT) on people referred for government-funded residential and community aged care services; dementia is a common condition prompting an ACAT assessment (Ng & Ward 2019). The NACDC holds ACAP data to 30 June 2015.
- The ACFI is an instrument which has been in use since 2008 to determine the aged care subsidy levels for eligible residents in Australian-Government accredited aged care facilities.

In both cases, dementia is recorded using a version of ICD-10-AM dementia diagnosis codes similar to those used in hospital data. For more information on these 2 sources of data for dementia monitoring please refer to AIHW (2012).

Outside the ACAP and ACFI, dementia is either not identified in aged care program data or the data provide limited coverage of program participants with dementia. Table 2.3 summarises the codification of dementia in NACDC data holdings at the time of writing.

**Table 2.3: National Aged Care Data Clearinghouse, summary of contents**

Data source/collection, temporal coverage	Dementia codification	Measurement unit
<b>Aged care assessment</b>		
Aged Care Assessment Program MDS, 2004–05 to 2014–15 <sup>(a)</sup> (ceased)	ICD-10-AM codes <sup>(b)</sup>	Assessment
<b>Community care – entry-level support</b>		
Commonwealth Home Support Programme data, 1 July 2016 to 30 June 2018 <sup>(c)</sup> (ongoing)	Via use of Dementia Advisory Services (where used)	Client
Home and Community Care Program MDS v2, 2005 to 30 June 2015 (ceased)	Not coded	Client
<b>Community care packages</b>		
Community Aged Care Packages (CACP) data, October 1997 to July 2013 (ceased)	Not coded	Recipient
Extended Aged Care at Home (EACH) data, 2006 to July 2013 (ceased)	Not coded	Recipient
Extended Aged Care at Home Dementia (EACH-D) data, 2008 to July 2013 (ceased)	Identified by package type	Recipient
Home Care Packages Program (HCP) data, August 2013 to 30 June 2018 (ongoing)	Via Dementia and Cognition Supplement (where paid)	Recipient
<b>Flexible Care and Multi-Purpose Services</b>		
Transition Care Program data, 1 July 2005 to 30 June 2018 (ongoing)	Not coded <sup>(d)</sup>	Episode
Short-term Restorative Care data (ongoing)	Not coded	Episode
<b>Residential care</b>		
Resident Classification Scale data, October 1997 to March 2008 (ceased)	Not coded	Appraisal
Aged Care Funding Instrument data, March 2008 to June 2018 (ongoing)	Modified ICD-10-AM codes <sup>(e)</sup>	Appraisal
Permanent Residential Care data (ongoing)	Not coded	Episode
Residential Respite Care data (ongoing)	Not coded	Episode

(a) Assessment level data launched around 2003–04 and implemented nationally in 2004–05 (Aged Care Assessment Program in place since 1994). Associated with the introduction of the My Aged Care system, the ACAP MDS collection ceased on 30 June 2015. There is ongoing work to develop an analytical data set using aged care assessment data captured since 2015 by the National Screening and Assessment Form (NSAF) via the My Aged Care system.

(b) Provision to code up to 10 medical conditions.

(c) Home support services for older people in Western Australia transitioned to the Commonwealth Home Support Programme from 1 July 2018 (Commonwealth Home Support Programme (CHSP) Program Manual 2018, Department of Health). The Australian Government has funded the CHSP to 30 June 2020.

(d) Transition Care services receive an equivalent amount of the Dementia and Cognition Supplement and Veterans' Supplement but this is not reported by individual episode or care recipient.

(e) Provision to record up to 3 disorders on the mental and behavioural disorders checklist (3-digit ICD-10-AM) and up to 3 disorders on the medical diagnosis checklist (4-digit ICD-10-AM).

Since July 2015, dementia case ascertainment using NACDC data, having only ever provided partial coverage, has been further reduced to:

- cases among permanent residents in aged care, identified in ACFI data
- cases indicated by use of Dementia Advisory Services and/or receipt of the Dementia and Cognition Supplement.

Changes which have substantially altered the form and availability of aged care program data since publication of the 2012 *Dementia in Australia* report (AIHW 2012) are discussed below.

## My Aged Care reforms

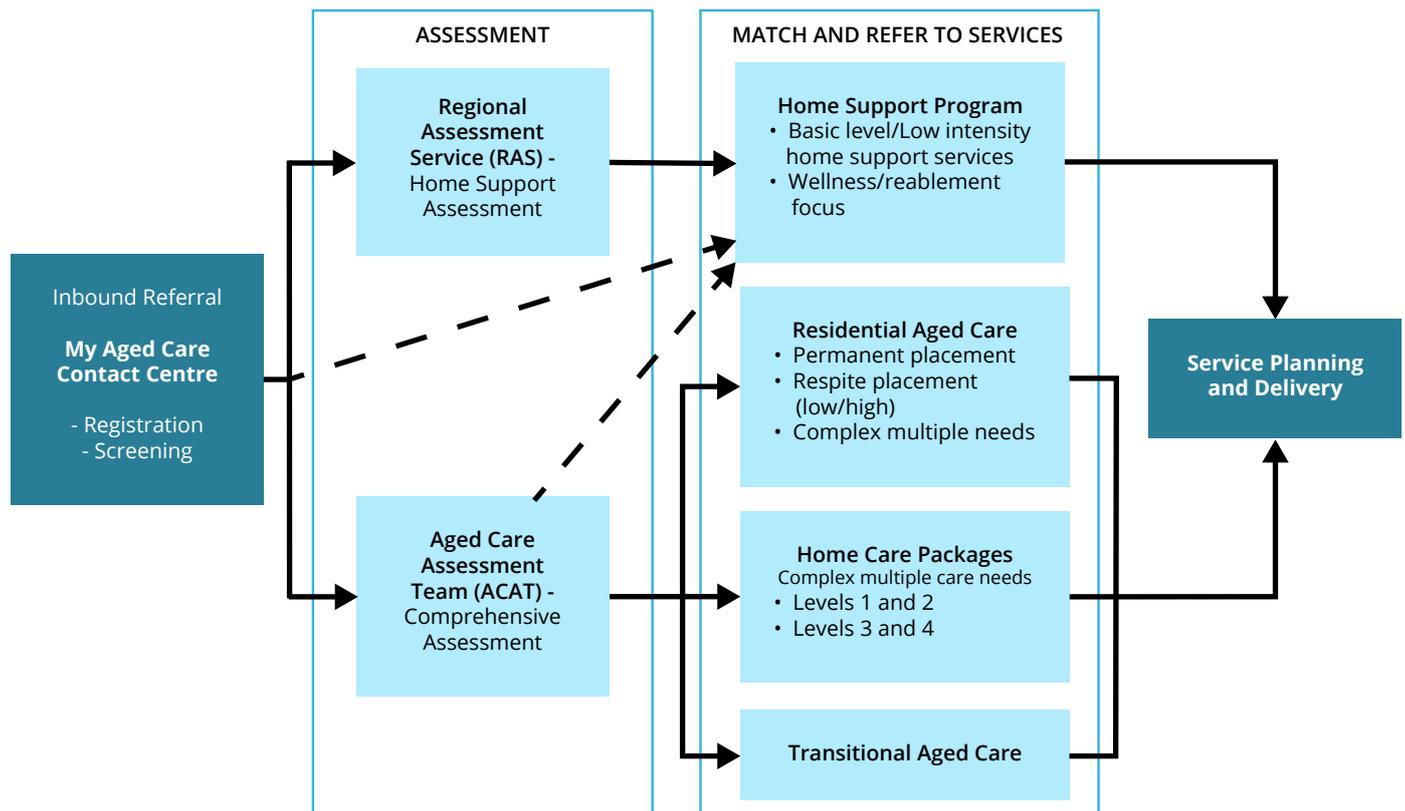
The period since 2013 has seen changes in the way that older Australians connect with Australian-Government funded aged care services and information. A notable change in the context of this report is that, on 1 July 2015, the My Aged Care portal established in July 2013 was expanded to include screening and referral to assessment services (Department of Health 2019; see also Figure 2.1):

- My Aged Care contact centre staff screen callers and make referrals to Regional Assessment Services (RAS) (for Home Support Assessment) and Aged Care Assessment Teams (ACATs) (for Comprehensive Assessment) depending on the person's needs identified through telephone screening questions.
- RAS and ACATs receive referrals and use the National Screening and Assessment Form (NSAF) to conduct Home Support Assessments and Comprehensive Assessments, respectively. Assessments may result in recommendations for entry-level support through the Commonwealth Home Support Programme (CHSP), higher-level support such as a home care package or residential aged care, carer respite, or other type of care.
- A central record, the Aged Care Client Record, and web-based portals for clients, assessors and service providers, are available to view and update client records. New data collection processes and systems using the NSAF replaced those that had operated up to June 2015.

Connected with changes to referral and assessment services have been changes to aged care data collection and handling arrangements. The ACAP continues to be delivered by state and territory-based ACATs that assess clients for home care packages and residential aged care (permanent and respite care). ACATs now carry out assessments using the NSAF and record assessment outcomes in the My Aged Care system. Previously, since 2004, a de-identified subset of ACAT assessment data items, including health condition information, was compiled annually into a national data collection (the ACAP Minimum Data Set, or ACAP MDS), housed in the NACDC since 2013. For more than a decade the ACAP MDS was a premier source of dementia (and other) diagnosis information on people at the gateway to the aged care system and a key source of data for aged care pathways analysis (see, for example, AIHW 2009, 2011a, 2011b, 2019f; Inacio et al. 2019).

Associated with the introduction of the My Aged Care system, the ACAP MDS collection ceased on 30 June 2015.

**Figure 2.1: My Aged Care assessment and service referral pathways**



Source: New South Wales Health 2017

According to the NSAF User Guide – October 2018<sup>1</sup>, the data now recorded by RASs and ACATs assessing people for aged care programs includes information that would assist in ascertaining some cases of dementia among people presenting through the My Aged Care system:

- health conditions—it is mandatory to record at least 1 health condition and there is the ability to record multiple conditions (applicable to both Home Support Assessments and Comprehensive Assessments)
- primary health condition—one health condition may be designated the ‘Primary health condition’ (mandatory for Comprehensive Assessments)
- diagnosis status—for Comprehensive Assessments, assessors are able to record the source of a health diagnosis (e.g. GP, medical specialist)
- supplementary assessment of cognitive and memory function using 1 of 4 validated tools—optional for Comprehensive Assessments. This option is not available for Home Support Assessment as this is a non-clinical assessment of client needs.

The NSAF has potentially improved the health information collected on recipients of entry-level support. A consistent approach to screening and assessment for aged care and alignment of data collection processes for Home Support Assessment and Comprehensive Assessment, should lead to better data—for instance, different approaches across various programs were consolidated into the CHSP, as discussed below.

At the time of writing, aged care assessment data recorded by RASs and ACATs using the NSAF is in the process of being developed by the Department of Health as an analytic data set, with the

<sup>1</sup>See [agedcare.health.gov.au/programs-services/my-aged-care/national-screening-and-assessment-form-user-guide](https://agedcare.health.gov.au/programs-services/my-aged-care/national-screening-and-assessment-form-user-guide).

first phase of the data supply to the AIHW scheduled for the second half of 2020. This supply is expected to only contain the most high-value and accessible data items from the NSAF. Future work is planned to add other information captured in the NSAF into the analytical data set, such as free-text assessor responses. Once available in the NACDC, the new NSAF data will begin to address a near 5-year gap in nationally collated data on aged care assessments. The AIHW and other users of the NACDC will then be able to assess the quality of NSAF data for dementia reporting and monitoring.

### **Community aged care reforms**

Commencing on 1 July 2015, the CHSP replaced the Commonwealth Home and Community Care (HACC) Program. Data for the HACC MDS in the NACDC ends on 30 June 2015. Planned respite under the National Respite for Carers Program, services under Day Therapy Centres, and the Assistance with Care and Housing for the Aged Program were consolidated into the CHSP<sup>2</sup>. These smaller programs incorporated into the CHSP appear as service sub-types in CHSP data. The CHSP has supplied data to the NACDC since December 2016 (the 5 months from July to November 2016 were an amnesty period for CHSP data). Entry-level assessment and support services (previously HACC) for older people in Western Australia were transitioned to the CHSP from 1 July 2018.

Neither the HACC MDS nor CHSP data contain information on clients' health conditions. The only way to identify CHSP clients with dementia is via receipt of Dementia Advisory Services, a sub-type of Specialised Support Services (or by linking to RAS recorded NSAF data, once this becomes available). If a CHSP client with dementia (or their carer) does not make use of the Dementia Advisory Services service sub-type then, without linking to other data sets, the person cannot be identified as having dementia.

The Dementia and Cognition Supplement introduced on 1 August 2013 is available in all levels of the HCP, the Transition Care Program and some other programs currently outside the scope of the NACDC (see below). The supplement provides additional funding to acknowledge the extra costs of caring for people with the moderate or severe cognitive impairment associated with dementia and other conditions.

To be eligible for the Dementia and Cognition Supplement in home care, a care recipient must meet specified assessment criteria in a psychogeriatric assessment performed by a registered nurse, clinical nurse consultant, nurse practitioner, clinical psychologist or medical practitioner trained in the particular cognitive assessment tool. A diagnosis of dementia alone cannot be used as evidence to support a claim for the supplement and care recipients with lower levels of cognitive impairment do not attract the supplement. Note too that if a veteran is eligible for both the Veterans' Supplement and the Dementia and Cognition Supplement in home care, the approved provider will receive only the Veterans' Supplement.

A KPMG (2015) formative evaluation of the HCP highlighted issues surrounding access to the level of assessment required to establish eligibility for the Dementia and Cognition Supplement and suggested that use of the supplement to identify care recipients with dementia will tend to underestimate the number of people with dementia receiving Home Care Packages. Conversely, it is conceivable that a care recipient with cognitive impairment associated with a condition other than dementia may be found eligible for the supplement.

<sup>2</sup>See [agedcare.health.gov.au/programs/commonwealth-home-support-programme](https://agedcare.health.gov.au/programs/commonwealth-home-support-programme).

The Dementia and Cognition Supplement neither captures all care recipients in the relevant programs who have dementia nor excludes all without dementia. For dementia identification purposes it would ideally be used as an adjunct to other information, noting that HCP and most other aged care programs do not record health diagnoses. As home care is often the first contact with formal services for people with dementia and their carers, there would be value in capturing the data from all psychogeriatric assessments performed for HCP and other home care recipients, regardless of whether or not the person is found eligible for the supplement. Information on care package recipients with mild cognitive impairment and/or dementia, with the prospect of progressing to moderate and severe dementia, would be useful for service planning and funding purposes. Currently, the data in NACDC record payment of the supplement to eligible care recipients but not the assessment outcome.

## **A new funding model for residential aged care**

A new funding model for residential aged care is under development along with an associated proposal to replace the ACFI with a new instrument for classifying residents for funding purposes.

Whereas the ACFI supports the coding of up to 3 disorders on each of the mental and behavioural disorders checklist and medical diagnosis checklist, the new tool does not collect health diagnoses and is not expected to be updated as frequently as the ACFI. The new model separates funding from care planning. While funding assessments may not be as frequent, health condition information, such as dementia diagnoses, may be able to be sourced through residents' care planning documentation rather than the funding instrument.

Notwithstanding concerns about data quality, ACFI data are a tier 1 asset and have been used extensively in the analysis of aged care pathways and demand for residential aged care. The ACFI is a component of the National Integrated Health Services Information Analysis Asset (NIHSI AA), discussed under 'Integrated data' below.

## **Aged care data outside the NACDC**

A number of other programs that deliver services to older (and in some cases younger) people generate administrative data which may include dementia identifiers but these programs do not currently supply data to the NACDC. These include: specialist dementia programs, the Multi-Purpose Services Program, the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, Department of Veterans' Affairs (DVA) assessment agencies, the Veterans' Home Care Program, and other programs that deliver care services to eligible veterans. The Dementia and Cognition Supplement is available in some of these programs.

The AIHW does not have access to the data from these programs to enable it to assess the utility for dementia monitoring and reporting.

### **Specialist dementia programs**

The Australian Government funds a range of programs, services and resources that aim to improve awareness and understanding of dementia and support people experiencing behavioural and psychological symptoms of dementia, and their care givers.

The Dementia Behaviour Management Advisory Service (DBMAS) supports staff and carers in community, residential, acute and primary care settings with information, advice, assessment and short-term case management interventions.

Severe Behaviour Response Teams (SBRT) are a mobile workforce available to provide expertise and advice to Australian-Government approved residential aged care facilities, Multi-Purpose Services, or Flexible Care Services requiring assistance. They include nurse practitioners, nurses, allied health and specialist staff and address the needs of people with severe and very severe behavioural and psychological symptoms of dementia.

Over 80% of referrals to DBMAS and SBRT come from residential aged care providers. GPs and family members may also make referrals.

These grant-based programs are delivered by Dementia Support Australia (for more information see [dementia.com.au/](https://dementia.com.au/)). DBMAS and SBRT do not currently supply data to the NACDC.

A new initiative, the Specialist Dementia Care Program (SDCP) is an additional source of support. Specialist units established within residential aged care services will provide a multidisciplinary approach to care for people exhibiting very severe behavioural and psychological symptoms of dementia who are unable to be appropriately cared for by mainstream aged care services (<https://www.health.gov.au/initiatives-and-programs/specialist-dementia-care-program-sdcp>). The roll-out started in 2019 with the program to establish at least 1 specialist dementia care unit in each of the 31 PHN regions. The SDCP is a transition care model that delivers intensive behavioural and psychological intervention in a specialist residential unit followed by a step-down to the person's usual care setting or to a lower-level specialist unit, as appropriate. SBRT provide the Needs Based Assessment for people referred to SDCP.

The Department of Health receives de-identified unit record data for some specialist dementia programs for evaluation purposes. It is reasonable to assume that persons assessed as eligible for these programs would be represented in other, larger, administrative data sets and that dementia case ascertainment would therefore not rely on the data collected in the DBMAS/SBRT/SDCP programs. Nonetheless, data from specialist dementia programs may be able to provide more granular information and contribute to understanding the needs and service use of people with severe behavioural and psychological symptoms of dementia. For example, SDCP data collected for evaluation purposes is expected to include clinical monitoring data, assessment and placement data, activity and financial data, and a review of the physical aspects of the units.

SBRT assessment data would also be useful for analysis of 'turn-aways'—people whose symptoms are assessed as just below the eligibility threshold for these specialist dementia programs—and may provide a useful comparison group for evaluating program performance. However, on the basis that program participants are diagnosed cases of dementia, the data from specialist dementia programs are classified as tier 1. They provide valuable detailed information on a high needs cohort within the dementia population. These data may become more valuable for prevalence estimation if, in future, health condition information were to be dropped from the funding instrument for permanent residential aged care.

### **Programs for veterans and their eligible dependants**

The DVA administers a number of programs that deliver care services to veterans and their eligible spouses, many of whom are older people, including:

- Veterans' Home Care
- DVA Community Nursing Program
- Coordinated Veterans' Care Program.

Veterans' Home Care offers a range of in-home, entry-level, support services. Eligibility for Veterans' Home Care is determined by Veterans' Home Care Assessment Agencies. Assessments are usually conducted by telephone and any data on dementia status, if disclosed, would be via self or proxy identification rather than clinical diagnosis.

DVA Community Nursing delivers nursing care to eligible veterans at home. To access Community Nursing, individuals must be referred by a GP or other medical officer, nurse practitioner, hospital treating doctor or discharge planner, or a Veterans' Home Care Assessment Agency and be found eligible by a clinical assessment conducted by a registered nurse.

The Coordinated Veterans' Care Program is a program for Gold Card holders with a chronic condition and complex care needs who are most at risk of unplanned hospitalisation. The Program promotes health literacy and self-management and emphasises best practice coordination of care through a person-centred approach.

The AIHW does not currently receive data on these programs from DVA.

## National Disability Insurance Scheme data

Data on National Disability Insurance Scheme (NDIS) participants collected and managed by the National Disability Insurance Agency (NDIA) are a potential source of data on younger onset dementia. The NDIA collects data and reports on the disability-related health conditions of NDIS participants, based on evidence of medically diagnosed conditions. The AIHW understands that this forms part of a person's evidence of functional impairment, evaluated during the NDIS eligibility assessment process.

Dementia is captured under the publicly reported health condition category, 'Other Neurological'. This category includes 2 specific conditions for dementia: 'Alzheimer's disease' and 'Unspecified dementia'. Other diseases and conditions that can manifest in dementia, for example, Huntington's disease and Parkinson's disease, are also reported under 'Other Neurological'.

From December 2019, the NDIA is expected to make data available at the lowest level of disability-related health condition recorded in NDIS data, noting that small cell counts will be suppressed and the NDIA only routinely captures disability-related health conditions where they relate to functional impairment.

NDIS data are tier 1 data for dementia monitoring (not yet available for detailed assessment).

## Income support data

Looking beyond the service system, eligibility for a number of Australian Government pensions and benefits requires claimants to submit documentary evidence that can result in the recording of health conditions relevant to administrative decision making. Via this mechanism, the Disability Support Pension (DSP), Carer Payment and Carer Allowance, DVA Invalidity service pension, Veteran payment (for eligible persons under the Age Pension age with very limited work capacity) and DVA Health Card (Gold Card and White Card) programs are potential sources of dementia data.

Where supported by evidence, a medical condition of dementia is coded in Department of Social Services administrative data as 'Senile Dementia' under the medical condition category, 'Nervous System'<sup>3</sup>. Administrative data on claims and payments for DSP, Carer Payment and Carer Allowance can include this code.

<sup>3</sup>Advice provided by Department of Social Services.

Income support and allowances data are therefore considered tier 1.

Consistent with the eligibility age for DSP being under the Age Pension age, a claim for DSP by a person with a Primary Medical Condition or Any Medical Condition of 'Senile Dementia' can be assumed to be associated with younger-onset dementia. Where dementia is identified as the Primary Medical Condition, it is likely to be moderate-to-severe dementia, reflecting program eligibility criteria.

The health conditions of people being cared for by a person in receipt of Carer Payment or Carer Allowance are recorded in the administrative data. Carer Payment and Carer Allowance administrative data are a potential way to enumerate people with dementia who might not be represented in other data sets.

## National surveys

### Survey of Disability, Ageing and Carers

The ABS Survey of Disability, Ageing and Carers (SDAC) is a large survey designed to measure the entire spectrum of disability, the underlying conditions and causes of disability, and disability-related need for assistance. It gives the most comprehensive measure of disability of any national survey and is the most important source of national data about the long-term health conditions and functioning of older people as well as the characteristics and activities of unpaid carers of older people and people with disability.

As the prevalence of dementia in the general population is quite low and concentrated in older age groups, in a general population survey it is difficult to ensure that there are sufficient cases for reasonable analysis. Oversampling of the older population, a strategy used by the SDAC, generates more robust estimates for age-related conditions, but there are still issues with the SDAC probably underestimating the number of people with dementia in Australia (AIHW 2012).

The SDAC is the only national survey to collect data about people living in cared accommodation, an important consideration when conducting research on older Australians and dementia. For the cared accommodation component, survey forms are completed by staff on behalf of participating residents using information from medical, nursing and administrative records.

The SDAC has been conducted 10 times since 1981, on a triennial timetable from 2009. The last six surveys (1998, 2003, 2009, 2012, 2015, and 2018) have used broadly comparable methods for identifying people with disability, long-term health conditions and carers, and produced data suitable for trend analysis. Sample sizes for both the household and cared accommodation components were increased substantially for the 2009 and later surveys—overall sample around 80% or higher than the 2003 survey. This has improved the robustness of estimates from the SDAC, especially important for analysis of data on people living in cared accommodation (for this component, in 2015 there were 11,696 fully responding individuals, compared to 5,145 in the 2003 SDAC). Higher sample sizes support the analysis of specific health conditions, or condition categories, and other in-depth analyses, though they are not necessarily large enough for small area analysis.

AIHW (2007) based its estimates of dementia prevalence for Australia on meta-analyses in preference to the 2003 SDAC and used the SDAC for estimates of dementia prevalence by residency (living in a household or cared accommodation)—the only reliable source of information

on dementia by residency at that time. The assessment was that the 2003 and earlier SDACs probably under-reported dementia in the household population, and, to a lesser extent, in the cared accommodation population.

Soon after the AIHW published its 2007 *Dementia in Australia* report (AIHW 2007), 2 things happened that are likely to have improved SDAC data on dementia. First, the decision (and funding) to increase the SDAC sample size, beginning with the 2009 survey, and, second, the introduction of the ACFI in 2008 generated administrative data on new entrants to permanent residential aged care that included information on diagnosed health conditions. It is reasonable to assume that the ACFI improved the information available to staff in aged care homes completing the SDAC survey form on behalf of residents.

*Dementia in Australia* (AIHW 2012) used 2009 SDAC data to:

- estimate the prevalence of dementia by residency, finding that, in 2011, around 30% of people with dementia lived in cared accommodation and 70% lived in the community. The report assessed that data collected through the ACFI and the 2009 SDAC were the best available data on which to estimate dementia prevalence by residency
- estimate the number of carers of people with dementia.

Deloitte Access Economics (2011) used the SDAC to estimate the prevalence of dementia in Australia by age and sex, preferring this source to the age-sex specific rates of dementia published in the *World Alzheimer report 2009* (ADI 2009).

First results from the 2018 SDAC were released in October 2019.

To the extent that staff completing the survey source information on residents' medical conditions from their ACFI records, any replacement of ACFI with a tool that does not collect information would require staff to source information from residents' care planning documentation.

The SDAC receives a tier 2 ranking because although it contains dementia diagnosis information, its utility in determining dementia prevalence at a national level is considered limited owing to limitations in the survey design (including scope, coverage and the lack of clinical assessment of survey respondents), resulting in probable underestimates of dementia in the community. In addition, its utility in data linkage studies is untested. Nevertheless, the SDAC is a valuable source for reporting and monitoring of dementia in Australia that may, with improvements to the survey currently in train, be able to add substantially to dementia prevalence estimation in years to come.

## National health surveys

The ABS' National Health Survey (NHS) collects information on the health status—current and long-term health conditions—of Australians living in households and the health-related aspects of their lifestyles. Importantly, the NHS covers the major risk factors for dementia (which are also common to many other chronic conditions). Information on the use of health services was not collected in the 2017–18 NHS but may be considered for future NHSs (the 2014–15 NHS collected information on actions taken in relation to one's health, including information on health service use). The NHS excludes non-private dwellings and therefore does not sample hospitalised persons and people living in cared accommodation, which is a drawback for research on the older population and age-related health conditions.

The NHS was most recently in the field in 2017–18. From 2020, the NHS will move to a continuous collection methodology, rather than a 3-yearly cycle.

Broadly speaking, the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) collects the same data items as the NHS. Data from the 2018–19 NATSIHS were released in December 2019. Prior to this, the NATSIHS was conducted in 2012–13 with a biomedical component, the National Aboriginal and Torres Strait Islander Health Measures Survey, and in 2004–05.

The Australian Health Survey 2011–13 was the largest, most comprehensive health survey ever conducted in Australia. It combined the existing NHS and the NATSIHS together with 2 new elements—a National Nutrition and Physical Activity Survey and a National Health Measures Survey. *Very Remote* areas of Australia and discrete Aboriginal and Torres Strait Islander communities (and the remainder of the Collection Districts in which these communities were located) were excluded. Data from the Australian Health Survey were released after publication of the 2012 *Dementia in Australia* report (AIHW 2012).

In 2021–23 the ABS will conduct an Intergenerational Health and Mental Health Study. This study will incorporate the suite of national health surveys:

- National Survey of Mental Health and Wellbeing
- NHS and NATSIHS
- National Nutrition and Physical Activity Survey and National Aboriginal and Torres Strait Islander Nutrition and Physical Activity Survey
- National Health Measures Survey and National Aboriginal and Torres Strait Islander Health Measures Survey (voluntary biomedical study).

National health surveys code health conditions to ICD-10-AM, however, Alzheimer’s disease and other dementias are not coded to a separate diagnostic category (Module 24, ‘Mental, behavioural and cognitive conditions’, of the 2017–18 NHS included an item on ‘Dementia, including Alzheimer’s Disease’ but this does not feature in the routine survey output). To date, dementia has not been included in the publicly available microdata from these surveys but the surveys are the most comprehensive sources of information on health risk factors and health-related actions in the general and Aboriginal and Torres Strait Islander household populations. Integrated with tier 1 assets for dementia case ascertainment, national health surveys can potentially provide valuable information on the health status and health-related actions of people with dementia living in households. However, on their own, national health surveys are tier 2 assets.

## Surveys of patient experiences of health care

Recent years have seen the implementation of new national surveys of patient experiences that collect information on respondents’ long-term health conditions.

### Survey of Health Care, 2016

The ABS Survey of Health Care is part of the Coordination of Health Care Study, designed to provide information on patients’ experiences of the health system, with a focus on how care is coordinated across multiple health-care providers. The study is a joint initiative of the AIHW and the ABS, funded by the AIHW.

The Survey of Health Care was a one-off survey which collected nationally consistent and local-level information on respondents' experiences with health-care providers. It surveyed people aged 45 and over who had at least 1 GP visit in the 12 months between November 2014 and November 2015. Sampled persons are more likely than the average Australian to have complex and chronic conditions and to have experiences with multiple providers including hospitals, specialists, and allied health professionals.

The survey covered all states and territories and included:

- people who were registered to receive Medicare benefits at any time prior to November 2015
- people who live in private and non-private dwellings (non-private dwellings include hospitals and aged care homes)
- persons in areas classified as *Very Remote*, and those in discrete Aboriginal and Torres Strait Islander communities
- visitors and diplomats from countries where there is a reciprocal Medicare arrangement.

Around 124,000 people were selected for this survey which generated a response rate of 28.6% (ABS 2017). Aboriginal and Torres Strait Islander people could choose to identify as such on the survey form.

People with low English proficiency, or who had a disability that prevented them from completing the survey on their own, were able to complete the survey over the telephone. People with low English proficiency were offered the option of an interpreter from the Translation and Interpreting Service who could facilitate a phone call with the ABS and translate as an ABS officer provided information or collected the participant's data over the phone.

In this survey it is not possible to distinguish between non-response and sample loss and therefore not possible to estimate the coverage of specific population groups.

The Survey of Health Care has produced statistically robust data for reporting by PHN and can be used to enumerate respondents who self-report dementia as a long-term condition ('Alzheimer's disease or dementia' is a listed condition on the survey form). Where a respondent disclosed that they have dementia it is not possible to discern whether this is based on a formal diagnosis and, while PHN-level reporting is a design feature of the survey, PHN-level analysis of low prevalence conditions such as dementia is not necessarily supported by the sample size.

The Coordination of Health Care Study uses data from the Survey of Health Care linked to MBS, PBS, and data on hospital admissions and emergency department care to look at patient pathways and experiences.

### **Patient Experience Survey**

The ABS Patient Experience Survey is an annual survey (since 2010–11) of people aged 15 and over who are usual residents of private dwellings. Among the exclusions are persons living in non-private dwellings such as hotels, university residences, boarding schools, hospitals, aged care homes, accommodation for people with disabilities, and prisons, as well as persons resident in the Indigenous Community Strata.

It includes data from people aged 15 and over who accessed health services in the last 12 months, as well as from those who did not, and enables the analysis of health service information in relation to particular population groups. Data are collected on aspects of communication between patients and health professionals. The 2017–18 survey had a response rate of 71.1% (ABS 2018).

Respondents can report up to 6 specific long-term health conditions<sup>4</sup> and long-term injury. There is no separate category for dementia or Alzheimer's disease.

## **Bettering the Evaluation and Care of Health Survey**

BEACH (The University of Sydney 2016, 2017) was an annual survey of a nationally representative random sample of general practice selected from Medicare claims data which collected data from April 1998 to 7 April 2016.

BEACH collected data on around 100,000 patient encounters across 1,000 GPs each year. Participating GPs recorded the details for 100 consecutive patient encounters. Information regarding the reason for encounter, types of prescriptions, referrals, imaging and pathology requests made during the encounter, and the associated diagnoses were recorded. GP response rates varied from year to year from a low of 22.9% to a high of 32.6% (The University of Sydney 2016, 2017).

Potentially, BEACH covered a representative sample of all persons with diagnosed dementia who saw GPs in the survey years, including patient age, sex, postcode, concession card type, Indigenous status, non-English speaking background indicator, health problems managed, management action, and selected lifestyle risk factors.

The BEACH survey program closed in April 2016 after The University of Sydney received notification that its BEACH funding agreement with the Australian Government would not be renewed.

## **Integrated data**

Integrating (or linking) data from multiple different sources can open up new types of data analysis. This has been a fertile area for data development over the last 10 years and the return on investment in protocols for building and safeguarding new integrated data assets is beginning to be realised. Two new AIHW projects are utilising integrated data to answer key questions about people with dementia, which cannot be addressed by analysis of individual data sets:

- The first project aims to describe primary care and specialist service use (through MBS item claims) among people newly diagnosed with dementia, and assess the feasibility of using patterns of MBS items claims as an indicator of early dementia and predictor of a dementia diagnosis using the National Integrated Health Services Information Analysis Asset (NIHSI AA).
- The second project aims to describe the socio-demographic characteristics, breadth of health and social welfare service use and pathways to aged care of people with younger-onset dementia, using NIHSI AA and the Multi-Agency Data Integration Project (MADIP).

Both the NIHSI AA and the MADIP are described in further detail below.

## **National Integrated Health Services Information Analysis Asset**

The AIHW together with the Department of Health and participating state health authorities have created the NIHSI AA. The current version of the asset contains de-identified data from 2010–11 to 2016–17 on admitted patient care services (in all public and, where available, private hospitals), emergency department services and outpatient services in public hospitals for all participating states and territories (New South Wales, Victoria, South Australia and Tasmania). It also includes

<sup>4</sup>'Arthritis or osteoporosis'; 'Asthma'; 'Cancer'; 'Diabetes'; 'Heart or circulatory condition'; 'Mental health condition'.

national data for the same period from the MBS, PBS and Repatriation Pharmaceutical Benefits Scheme as well as Residential Aged Care Services (RACS) data and NDI data.

These data will initially be available to selected analysts nominated by the participating data providers.

Approved purposes for the NIHSI AA are analysis of:

- patterns of use and effectiveness of health and residential aged care services
- quality and safety of services provided
- health risks for particular patient cohorts
- chronic disease management—patterns of service provision
- validation of the current treatment pathways for chronic disease management and care
- defining patient journeys and assessing efficiency and effectiveness of the health and residential aged care systems
- safety and quality of hospital and other services, such as residential aged care services
- accessibility and effectiveness of services contributing to the management of chronic conditions
- policies and programs designed to reduce the incidence and severity of disease and injury.

In the NIHSI AA, dementia case ascertainment will be sourced from codes in several of the component data sources: admitted patient care (diagnosis array DIAG1-DIAG150), PBS (PBS item codes for dementia-specific medications), NDI (cause of death) and RACS data (mental and behavioural disorders checklist items—see ACFI). By linking records across multiple administrative data sets, more cases can be identified. The NIHSI AA can be expected to produce reasonable estimates of dementia among permanent residents in aged care facilities. However, the NIHSI AA does not contain aged care assessment data and does not provide coverage of people with dementia receiving aged care services at home in the community.

The NIHSI AA inherits the tier 1 classification of its tier 1 data sources.

## Multi-Agency Data Integration Project

The MADIP is a partnership of 6 Australian Government agencies to develop a secure and enduring approach for combining information on health care, education, government payments, personal income tax, and population demographics (including the Census) to create a comprehensive picture of Australia over time. Authorised researchers can use unidentified MADIP data to look at patterns and trends in the Australian population, and provide new insights into the development and evaluation of government policies, programs, and services (such as health care) to ensure they are delivering value to the people and communities who need them.

MADIP contains data items from the following data sets (see [www.abs.gov.au](http://www.abs.gov.au) for more information about expansions to MADIP data in 2019):

- Census of Population and Housing: 2011, 2016
- MBS and PBS: 2011–2016
- Medicare Enrolments Database: 2006–2016
- NHS: 2014–15 to 2015–16

- Registries deaths data: 2007–2016
- Personal Income Tax: 2010/11 to 2015/16 (financial years)
- Social Security and Related Information (SSRI): 2009–2016
- Centralised Register of Medical Practitioners Provider Directory: 2011–2016
- Higher Education Management System: 2006–2016 (once-off linkage only for a specific project)
- Australian Apprenticeships Incentive Program and Training Contracts: 2006–2016
- Australian Early Development Census: 2009, 2012, 2015.

The combination of PBS, deaths and SSRI data is a potential source of information on cases of younger-onset dementia (before age 65). MADIP inherits the tier 1 classification of its tier 1 data sources.

## National Disability Data Asset

The AIHW has been tasked with pilot testing an enduring longitudinal National Disability Data Asset to help better understand the services, payments and programs received by people with disability and their carers, and the associated outcomes. The proposed data set will link key administrative data sets, making it a promising development for improving data on people with dementia and their carers.

## Pathways in Aged Care 2014

The AIHW has linked data from aged care programs, the ACAP and the NDI to create the Pathways in Aged Care (PIAC) link map, suitable for person-based analysis of aged care pathways and patterns of program use over time (AIHW 2017b). PIAC 2014 covers aged care assessments and use of key aged care service programs, as well as deaths from 1 July 1997 to 30 June 2014 from the following data sources:

- ACAP MDS
- Residential aged care, including ACFI
- HCP and its predecessor care package programs which operated up to August 2013 (Community Aged Care Packages, Extended Aged Care and Home (EACH), and Extended Aged Care at Home-Dementia (EACH-D))
- Transition Care Program
- Home and Community Care Program
- NDI.

PIAC holds data on 5 million people, noting that data are not complete for all programs in all years (AIHW 2019g). PIAC 2014 contains a person identifier that connects applicable records in the NACDC and the NDI.

Pathways analysis using PIAC has reported on distinct patterns of service use by people with dementia, compared with other older people, made possible by dementia diagnosis information in the ACFI and ACAP source data sets (for example, see AIHW 2010b, 2017c).

The estimation by Waller et al. (2017) of dementia prevalence using multiple linked administrative and longitudinal survey data sets similarly relied on dementia diagnosis information in ACAP and ACFI data and identification via receipt of an EACH-D care package (EACH-D was subsequently consolidated into the CHSP).

### 3 Assessment results

Of the national data sources identified in Chapter 2, just over half (14) are tier 1 assets.

This chapter presents a quality assessment of 10 tier 1 assets for the purpose of dementia identification and prevalence estimation. Four tier 1 assets that are not currently available for secondary use (My Health Record, NSAF/Aged Care Client Record, NDIS data), or only available for use in approved projects (MADIP), were not assessed.

The quality rating is an 'on balance' assessment considering the relative strength of information for dementia prevalence estimation, assuming capability of data linkage at the time of writing, plus any quality issues relating to the data source. It is important to note that the assessment is specifically for this purpose, as outlined in the scope and methods section of Chapter 1. None of the identified data sources were intended or designed for dementia reporting, a secondary use of the data, and the quality assessment here says nothing about the quality of the data for their intended primary purposes.

The quality of dementia identification data in tier 1 assets was found to range from high to low (Table 3.1).

**Table 3.1: National data sources for dementia monitoring and reporting and assessed quality ratings for reporting on dementia**

Data source	Tier	Quality rating for dementia
Pharmaceutical Benefits Scheme data	1	High
Admitted Patient Care National Minimum Data Set (NMDS)	1	High
Non-admitted Patient Emergency Department Care NMDS	1	High
National Mortality Database and National Death Index	1	High
Income support and allowances data <sup>(a)</sup>	1	High
National Aged Care Data Clearinghouse (NACDC) – Aged Care Assessment Program Minimum Data Set (MDS)	1	Medium
NACDC – Aged Care Funding Instrument	1	Low
Dementia Behaviour Management Advisory Service data and Severe Behaviour Response Teams Program data	1	Low
Specialist Dementia Care Program data	1	Low
National Integrated Health Services Information Analysis Asset	1	Low
National Screening and Assessment Form (NSAF)/Aged Care Client Record	1	Unable to assess <sup>(b)</sup>
My Health Record	1	Unable to assess
National Disability Insurance Scheme data	1	Unable to assess
Multi-Agency Data Integration Project	1	Unable to assess
Medicare Benefits Schedule data	2	—
National Hospital Cost Data Collection	2	—
Residential Mental Health Care NMDS	2	—
Community Mental Health Care NMDS	2	—
NACDC – Community aged care and flexible care programs <sup>(c)</sup>	2	—
AIHW Australian Burden of Disease studies	2	—
AIHW Disease Expenditure studies	2	—
ABS Survey of Disability, Ageing and Carers <sup>(d)</sup>	2	—
ABS National Health Surveys/National Aboriginal and Torres Strait Islander Health Surveys	2	—
ABS Australian Health Survey	2	—
ABS 2016 Survey of Health Care	2	—
ABS Patient Experience Surveys	2	—

(a) Claims and payments data for Disability Support Pension, Carer Payment, Carer Allowance.

(b) The quality rating of the NSAF will be established once it is available as an analytical data set in the NACDC.

(c) Home Care Packages Program, Commonwealth Home Support Programme, Transition Care Program, Multi-Purpose Services and Flexible Care programs.

(d) Although this data source contains dementia diagnosis information, the SDAC is classified as a Tier 2 asset given known issues with it underestimating dementia prevalence. It is still a key data source for dementia monitoring and reporting, and through data linkage, the SDAC may be able to add substantially to dementia prevalence estimation in the future.

Supporting detailed assessments against the 7 quality dimensions are presented in Boxes 3.1 to 3.10 (see Appendix A for information about each of the tier 1 data sources). To summarise:

- PBS, Admitted Patient Care NMDS, the National Mortality Database and NDI, and Department of Social Services income support data are high quality data sources. Each provides partial coverage of the population with dementia (Boxes 3.1, 3.2, 3.4 and 3.5, respectively). Similarly, the Non-admitted Patient Emergency Department Care NMDS (Box 3.3) contains health diagnoses, although the diagnosis information in this data set is somewhat less mature than in the admitted patient data, in terms of consistency of collection and coding across state and territory jurisdictions. These data sources are generated and maintained in systems operated by publicly accountable institutions with strong data governance arrangements under Commonwealth and/or state/territory legislation and ethics frameworks.
- The incorporation of aged care data substantially lifts coverage and is critical for any degree of confidence in prevalence estimates of dementia. Currently, however, aged care data suffer from coverage and quality gaps (Boxes 3.6–3.9). ACFI data (Box 3.7) are known to under-report Aboriginal and Torres Strait Islander people in residential aged care settings, for a number of reasons (see Appendix Table A.13).
- Integrated data, such as the NIHSI AA, can potentially improve case ascertainment but they inherit many of the deficiencies of their source data sets. For dementia monitoring, the limitation of the NIHSI AA is its construction around institutional care—hospitals and residential aged care—and exclusion of data on dementia in community settings, where the diagnosis, treatment and management of dementia most commonly occurs. The first release of the NIHSI AA (v0.5) contains hospitals data for 4 states only (New South Wales, Victoria, South Australia and Tasmania). Increased participation in future releases of the NIHSI AA by state and territory jurisdictions would improve its utility for dementia monitoring. The quality assessment of the NIHSI AA v0.5 (Box 3.10) should be read in conjunction with the quality assessments of the component data sources (see Boxes 3.1–3.4 and 3.7).
- Integrated data tend to be less timely than their source data collections because of the time required to establish the infrastructure and governance, carry out the data linkage, set up arrangements for approved access, and so forth. Dementia analysis that relies on integrated administrative data will tend to be more dated than the individual component data collections.
- None of the administrative data sets considered here satisfactorily address the health and lifestyle risk factors for dementia, the experiences of dementia carers, or the costs of dementia to individuals. For data on these topics we must look to improve dementia identification in national surveys and electronic medical records.

**Box 3.1: Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) administrative data**

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	x		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?	x		
	Are there sufficient resources for the collection and production of the data?	x		
	Are there processes, staff and facilities in place to ensure data quality?	x		
	Does the data source comply with privacy and legislative requirements for managing data?	x		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?	x		
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?	x		
	Are there likely to be subsequent surveys or data collections?	x		
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)	x		
	Can the data source be provided in a timeframe suited to the user's requirements?	x		
	Are the data available in suitable formats?	x		
	Are data available at costs affordable for the user's project?	x		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?	x		
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	x		
	Are potential or acknowledged sources of error described?	x		
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?	x		
	Does the data source use methodologies comparable with other data collections?	x		

**Box 3.2: National Hospital Morbidity Database: Admitted Patient Care National Minimum Data Set**

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	x		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?	x		
	Are there sufficient resources for the collection and production of the data?	x		
	Are there processes, staff and facilities in place to ensure data quality?	x		
	Does the data source comply with privacy and legislative requirements for managing data?	x		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?	x		
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?	x		
	Are there likely to be subsequent surveys or data collections?	x		
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)	x		
	Can the data source be provided in a timeframe suited to the user's requirements?	x		
	Are the data available in suitable formats?	x		
	Are data available at costs affordable for the user's project?	x		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?	x		
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	x		
	Are potential or acknowledged sources of error described?	x		
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?	x		
	Does the data source use methodologies comparable with other data collections?	x		

**Box 3.3: Non-admitted Patient Emergency Department Care National Minimum Data Set (NMDS)**

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	x		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?	x		
	Are there sufficient resources for the collection and production of the data?	x		
	Are there processes, staff and facilities in place to ensure data quality?	x		
	Does the data source comply with privacy and legislative requirements for managing data?	x		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?	x		
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?	x		
	Are there likely to be subsequent surveys or data collections?	x		
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)	x		
	Can the data source be provided in a timeframe suited to the user's requirements?	x		
	Are the data available in suitable formats?	x		
	Are data available at costs affordable for the user's project?	x		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?	x		
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	x		
	Are potential or acknowledged sources of error described?	x		
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?	x		
	Does the data source use methodologies comparable with other data collections?	x		

### Box 3.4: National Mortality Database (NMD) and National Death Index (NDI)

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	x		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?	x		
	Are there sufficient resources for the collection and production of the data?	x		
	Are there processes, staff and facilities in place to ensure data quality?	x		
	Does the data source comply with privacy and legislative requirements for managing data?	x		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?	x		
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?	x		
	Are there likely to be subsequent surveys or data collections?	x		
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)	x		
	Can the data source be provided in a timeframe suited to the user's requirements?	x		
	Are the data available in suitable formats?	x		
	Are data available at costs affordable for the user's project?	x		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?	x		
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	x		
	Are potential or acknowledged sources of error described?	x		
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?	x		
	Does the data source use methodologies comparable with other data collections?	x		

**Box 3.5: Department of Social Services income support and allowances data (Disability Support Pension, Carer Payment, Carer Allowance)**

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	x		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?	x		
	Are there sufficient resources for the collection and production of the data?	x		
	Are there processes, staff and facilities in place to ensure data quality?	x		
	Does the data source comply with privacy and legislative requirements for managing data?	x		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?		x	
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?	x		
	Are there likely to be subsequent surveys or data collections?	x		
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)	x		
	Can the data source be provided in a timeframe suited to the user's requirements?	x		
	Are the data available in suitable formats?	x		
	Are data available at costs affordable for the user's project?	x		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?	x		
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	x		
	Are potential or acknowledged sources of error described?	x		
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?		x	
	Does the data source use methodologies comparable with other data collections?	x		

**Box 3.6: National Aged Care Data Clearinghouse (NACDC) – Aged Care Assessment Program (ACAP) Minimum Data Set (MDS)**

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	x		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?	x		
	Are there sufficient resources for the collection and production of the data?		x	
	Are there processes, staff and facilities in place to ensure data quality?		x	
	Does the data source comply with privacy and legislative requirements for managing data?	x		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?	x		
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?			x
	Are there likely to be subsequent surveys or data collections?			x
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)	x		
	Can the data source be provided in a timeframe suited to the user's requirements?	x		
	Are the data available in suitable formats?	x		
	Are data available at costs affordable for the user's project?	x		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?	x		
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	x		
	Are potential or acknowledged sources of error described?	x		
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?	x		
	Does the data source use methodologies comparable with other data collections?	x		

**Box 3.7: National Aged Care Data Clearinghouse (NACDC) – Aged Care Funding Instrument (ACFI) data**

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?		x	
	Is the entity responsible for data collection independent and free from potential conflicts of interest?			x
	Are there sufficient resources for the collection and production of the data?		x	
	Are there processes, staff and facilities in place to ensure data quality?		x	
	Does the data source comply with privacy and legislative requirements for managing data?	x		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?		x	
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?	x		
	Are there likely to be subsequent surveys or data collections?			x
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)	x		
	Can the data source be provided in a timeframe suited to the user's requirements?	x		
	Are the data available in suitable formats?	x		
	Are data available at costs affordable for the user's project?	x		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?	x		
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?		x	
	Are potential or acknowledged sources of error described?			x
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?	x		
	Does the data source use methodologies comparable with other data collections?	x		

**Box 3.8: Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams program data**

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	Unable to assess		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?			x
	Are there sufficient resources for the collection and production of the data?	Unable to assess		
	Are there processes, staff and facilities in place to ensure data quality?	Unable to assess		
	Does the data source comply with privacy and legislative requirements for managing data?	Unable to assess		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?	Unable to assess		
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?	Unable to assess		
	Are there likely to be subsequent surveys or data collections?	x		
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)?			x
	Can the data source be provided in a timeframe suited to the user's requirements?			x
	Are the data available in suitable formats?	Unable to assess		
	Are data available at costs affordable for the user's project?	Unable to assess		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?			x
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	Unable to assess		
	Are potential or acknowledged sources of error described?			x
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?			x
	Does the data source use methodologies comparable with other data collections?			x

*Note:* Assessment is based on information supplied by the Department of Health and AIHW review of routine, published reports for these programs.

### Box 3.9: Specialist Dementia Care Program data

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	Unable to assess		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?			x
	Are there sufficient resources for the collection and production of the data?	Unable to assess		
	Are there processes, staff and facilities in place to ensure data quality?	Unable to assess		
	Does the data source comply with privacy and legislative requirements for managing data?	Unable to assess		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?	x		
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?	Unable to assess		
	Are there likely to be subsequent surveys or data collections?	x		
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)?			x
	Can the data source be provided in a timeframe suited to the user's requirements?			x
	Are the data available in suitable formats?	Unable to assess		
	Are data available at costs affordable for the user's project?	Unable to assess		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?			x
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	Unable to assess		
	Are potential or acknowledged sources of error described?	Unable to assess		
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?			x
	Does the data source use methodologies comparable with other data collections?			x

Note: The Specialist Dementia Care Program was not fully operational at the time of assessment. Assessment is based on information about the planned data collection provided by the Department of Health.

### Box 3.10: National Integrated Health Services Information Analysis Asset (NIHSI AA) v0.5<sup>(a)</sup>

Data quality element	Key question	Yes	Partially	No
<b>Institutional environment</b>	Is the production and dissemination of data undertaken in an objective, professional and transparent manner?	x		
	Is the entity responsible for data collection independent and free from potential conflicts of interest?	x		
	Are there sufficient resources for the collection and production of the data?	x		
	Are there processes, staff and facilities in place to ensure data quality?	x		
	Does the data source comply with privacy and legislative requirements for managing data?	x		
<b>Relevance</b>	Does the data collection measure the concept identified by the end user of the data?		x	
	Is the data source representative of the target population identified by the end user of the data?		x	
<b>Timeliness</b>	Are the data up-to-date and current?		x <sup>(b)</sup>	
	Are there likely to be subsequent surveys or data collections?	x		
<b>Accessibility</b>	Are there processes in place to facilitate data access (e.g. Ethics Committee where appropriate; data transmission arrangements)	x		
	Can the data source be provided in a timeframe suited to the user's requirements?	x		
	Are the data available in suitable formats?	x		
	Are data available at costs affordable for the user's project?	x		
<b>Interpretability</b>	Is metadata available to support correct interpretation of the data?	x		
<b>Accuracy</b>	Do the data reflect the condition or situation it was designed to measure?	x		
	Are potential or acknowledged sources of error described?	x		
<b>Coherence</b>	Does the data source use standard concepts, classifications and target populations?	x		
	Does the data source use methodologies comparable with other data collections?	x		

(a) For the 'Relevance' dimension, this is an assessment of the NIHSI AA (v0.5) for dementia monitoring purposes only and is not an assessment of 'Relevance' for other analytical purposes. For other dimensions this is more of an overall assessment of the asset. This table should be read in conjunction with the quality assessments of the component data sources (see Boxes 3.1–3.4 and 3.7).

(b) Reflects the time lag that is typical of integrated data assets. At any given point in time, the current version of the NIHSI AA (in this case, v0.5) might not contain the most up-to-date edition of 1 or more of the component data sources. For example, v0.5 contains hospitals data up to financial year 2016–17 when hospitals data for financial year 2017–18 and beyond are available outside of NIHSI AA.

*Note:* Authorised users of the NIHSI AA include nominated staff from the Department of Health, participating state and territory health authorities (including contractors and consultants), and the AIHW. For the purpose of this data quality assessment, 'end-user' is defined as an authorised user of the NIHSI AA who is using the data for dementia analysis.

## 4 Data gaps and opportunities

There is no system for monitoring dementia in the Australian community as there is for cancer, diabetes, chronic kidney disease and a number of communicable diseases.

According to the Global Dementia Observatory, few countries operate national dementia surveillance systems and there are varied approaches, including clinical records, administrative data, and facility surveys (WHO 2019a). In a systematic review of dementia registries worldwide, Kyrinska et al. (2017) examined the features of 31 dementia registries of various types and levels of coverage operating between 1986 and 2016. Three leading examples employing alternative approaches to dementia monitoring are the Swedish Dementia Registry (SveDem), Canada's Chronic Disease Surveillance System and the United Kingdom's dementia-specific primary care data collection and Quality and Outcomes Framework.

- **Sweden** has a long tradition of quality of care registries for medical and health services, and since 2007 the SveDem dementia quality of care registry has been at the heart of Swedish dementia diagnosis and care services (Religa et al. 2015). The internet-based registry was established initially with specialist memory clinics and primary care units, joined by nursing homes in 2012. In 2010, the Swedish Board of Welfare published national guidelines for dementia and presented 7 clinical indicators that can be followed-up in SveDem. Patients are registered when a dementia diagnosis is established with the aim of annual follow-up. Each patient has to be informed about the registration and has a right to opt out. A written consent is not required, however, each patient has the right to obtain a copy of the information that is registered, if requested. The patient also has the right to have their data removed from the registry. Approval is needed from a regional ethics committee for each research project where SveDem data will be used.
- The Public Health Agency of **Canada** established the Canadian Chronic Disease Surveillance System (CCDSS) in 2009 to facilitate standardised, national estimates of chronic disease prevalence, incidence, and outcomes across all Canadian provinces and territories (Lix et al. 2018). The CCDSS is a linked administrative data system that integrates health insurance registration files, physician billing claims (including patient and physician identifiers and diagnosis codes), and hospital discharge abstracts. Chronic disease case definitions are a key component of the CCDSS. Case definition for 'Dementia, including Alzheimer's disease' is based on hospitalisation or physician claims coded with ICD-9 or ICD-10 codes for dementia or the use of dementia-specific prescription medications. The CCDSS can be used to generate national and subnational incidence and prevalence estimates using a standardised methodology and longitudinal estimates of disease incidence, prevalence and mortality. There are challenges with using CCDSS given the varied quality and consistency of the data submitted by different provinces. Because of this, studies of dementia prevalence and incidence (as well as other key areas of interest like risk factors and health-care service use) tend to use provincial administrative data, often limited to a specific province (Jaakkimainen et al. 2016).
- In the **United Kingdom (UK)**, the Quality and Outcomes Framework (QOF) under the National Health Service is an incentive payment scheme that encourages general practices to establish and maintain registers for patients with eligible conditions, including dementia, and deliver services that attract QOF payments (NHS Digital 2019). Participation in this voluntary scheme is

high (94.8% in financial year 1 April 2017 to 31 March 2018). As a result, the best source of data on the number of people diagnosed with dementia comes from primary care (Knapp et al. 2014). The UK cause of death data are considered too unreliable for dementia prevalence estimation because of changing 'fashion' in attribution of cause of death rather than changes in real prevalence (Knapp et al. 2014). QOF dementia data are published at national and local levels to inform service planning. The data encompass prevalence, diagnosis incidence rate, and quality indicators (for example, 'DEM004: The percentage of patients diagnosed with dementia whose care plan has been reviewed in a face-to-face review in the preceding 12 months'; NHS Digital 2018).

In order to inform policy making on dementia cure and care, researchers and policy makers must have 3 types of knowledge (OECD, cited in Anderson & Oderkirk 2015):

- knowledge from research—evidence-based care
- knowledge from analysis of routinely collected or audit data 'statistics' or 'information'
- knowledge harvested from the patient experience.

While 'the interconnectedness of the policy issues in dementia means that dementia problems can only be fully understood by examining data from multiple data sources' (Anderson & Oderkirk 2015) the Swedish, Canadian and UK examples underscore the critical importance of primary and secondary health-care data for dementia monitoring.

Australia is not alone in lacking a national surveillance system for dementia but is a long way from international best practice. Our understanding of the community and system impacts of dementia is largely based on international research and the bringing together of records from multiple disparate data sources established for other, mainly administrative rather than clinical, purposes. Earlier chapters identified coverage and data quality gaps that limit the utility of existing individual and linked data assets for dementia monitoring. Dementia prevalence estimates are potentially improved by linking records across multiple data sets but linked data inherit many of the deficiencies of the source records. And, as exemplified by the NIHSI AA, integrated data not designed with dementia identification in mind might not draw on all the data sources that are available for this particular purpose, for instance, primary and secondary care data that include dementia diagnosis information.

A multifaceted strategy is needed to address the breadth and depth of Australian dementia data gaps (Table 4.1). With a strategic, staged approach, good gains and some relatively quick wins appear possible. However, choices may be required between resourcing patchwork solutions and investing in a sound monitoring system to meet long-term public health and dementia research information needs.

**Table 4.1: Data gaps and potential opportunities for dementia policy questions**

Policy interest	Key data gaps	Potential future opportunities
Dementia prevalence & incidence	Missing primary and secondary care data for prevalence and incidence estimation	National policy and programs for timely diagnosis, treatment and management of dementia in the community and supporting data collection
		National data development plan for dementia
		Dementia-specific Medicare Benefit Schedule (MBS) items/incentives
		Electronic medical records and My Health Record
		Clinical quality registry data collection
	Integrate data sets to improve dementia ascertainment	
	Under-reporting of dementia among hospital and deaths data	See entry for 'Use of health and aged care services'
	Missing data on dementia in aged care	See entry for 'Use of health and aged care services'
		Integrate data sets to improve dementia ascertainment
Mortality and burden of disease	Missing primary and secondary care data	See entry for 'Dementia prevalence & incidence'
	Dementia typing in deaths data	National data development plan for dementia
	Australian-specific severity measures	
Risk factors for dementia	Missing primary care data	See entry for 'Dementia prevalence & incidence'
	Sample size in national health surveys	Adequate sample size for health-risk-factor-level analysis by population groups of interest
Disease expenditure, cost to individuals and society	Missing primary and secondary care data	See entry for 'Dementia prevalence & incidence'
	Lack of timely data on disease expenditure	Invest in a more regular schedule of disease expenditure analysis and reporting
Use of health and aged care services	Missing primary and secondary care data	See entry for 'Dementia prevalence & incidence'
	Missing aged care data on dementia	Development of an aged care data improvement plan, with immediate priorities to: <ul style="list-style-type: none"> <li>• assess the need for information on clients' health conditions as part of existing and future aged care administrative data collections</li> <li>• review and assess information collected on the new National Screening and Assessment Form</li> <li>• National data development plan for dementia implemented across aged care data collections</li> </ul>
	Under-reporting of dementia among hospital and deaths data	Exploit supplementary codes for chronic conditions in hospital admitted patient data; potentially extend to emergency department data
	Lack information on patient experiences of people with dementia	Include dementia in long-term condition code frame Increase the sample size of patient experience surveys to support analysis by long-term condition

Carers	Missing data on carers of people with early-stage dementia	Include income support data in data integration and analysis New data items on date of diagnosis/onset of long-term conditions of care recipients in the Survey of Disability, Ageing and Carers
	Lack information on the experiences of dementia carers	Where necessary, increase the sample size of Survey of Disability, Ageing and Carers to support analysis of carer data by main condition of care recipient
Specific population groups of interest	Missing data on dementia in the Aboriginal and Torres Strait Islander population	Include dementia as a long-term condition in future National Aboriginal and Torres Strait Islander Health Surveys (NATSIHS), subject to cognitive and cultural acceptance testing
	Lack of timely data on risk factors in the Aboriginal and Torres Strait Islander population	More frequent NATSIHS
	Lack of robust data on dementia in <i>Very Remote</i> areas, discrete Aboriginal and Torres Strait Islander communities, specific culturally and linguistically diverse communities, people with intellectual disabilities and data for PHN-level and small-area analysis	Invest in PHN-level dementia data collection and dementia research targeted at the Aboriginal and Torres Strait Islander population and other culturally and linguistically diverse groups
	Missing data on younger-onset dementia	Include income support data in data integration and analysis
	Lack of information on veterans with dementia	Include DVA program data in data integration and analysis

## Opportunities for health system data

'Primary health care plays a key role in early detection and diagnosis of dementia, and in regular assessment, support and referral for people with dementia and their families.' (PHN Hunter New England and Central Coast 2018)

Dementia is most commonly diagnosed, treated and managed in the community. The biggest single data gap affecting our knowledge of, and responses to, dementia in Australia is the lack of data capture at or around the time of diagnosis and in post-diagnosis early support, that is, data on dementia in primary and secondary care.

Addressing this single gap will improve the data for informing a range of dementia policy questions.

The lack of data on dementia in primary and secondary care is not only a data gap but symptomatic of a fragmented service system compounded by poor community awareness of dementia as a public health, not just an ageing, issue (Ng & Ward 2019). Greater penetration of specialised dementia assessment services (including through ACATs) and stronger linkages of these services to general practice have been proposed for addressing the service gap (Rozsa & Flicker 2019; Rozsa et al. 2016). In turn, this would provide a solid foundation for addressing the data gap.

Decisions on how to detect dementia in primary and secondary care data will be needed. The MBS data do not contain diagnosis codes and there are no dementia-specific MBS items. As a result, for too long we have relied on hospitals, aged care and cause of death data, which most likely give a picture skewed towards moderate and severe dementia and leave many important questions unanswered. Arguably, the quickest 'win' for Australian dementia data could come from introducing dementia-specific items under the MBS or, alternatively, a Quality Improvement Measure for dementia care that attracts an incentive payment under the PIP, along the lines of the UK QOF system—provided these were adopted by GPs (see Ng & Ward (2019) for a discussion of the reasons for under-documentation of dementia).

As well as the potential benefits for patients, data generated by such measures would increase the coverage of dementia in existing administrative data collections and flow through to integrated data assets such as the NIHSI AA, predicated on the suitability of the approach and take-up of new items by GPs and medical specialists.

It must still be acknowledged that prevalence estimation based on health service use and death certificates is a compromise solution vulnerable to changes in the prevailing practices of coding and attribution.

Estimation of occurrence from population-based epidemiological studies is crucial for planning and costing of health services and economic burdens, and therefore robust, relevant and up-to-date estimates are needed to support the creation of useful dementia policies. (Wu et al. 2016)

Provided there is consistency in the recording and extraction of data on dementia, electronic medical records and My Health Record are potentially rich sources of clinical data across multiple health-care settings. In our assessment, this offers the best longer-term solution to addressing dementia data gaps and, if well designed, estimating prevalence according to consistent diagnostic criteria. The anticipated establishment of a governance framework for the secondary (statistical and research) use of My Health Record data will be an important development. Conceivably,

with adequate clinical involvement, machine-learning algorithms could be developed to extract dementia diagnosis information from My Health Record summaries. Combining this with data from clinical information systems, a national dementia registry becomes a real possibility for driving the analysis of dementia prevalence and incidence, service needs and disease expenditure.

Better use can be made of existing data on hospital admitted patient care by streamlining access to supplementary codes on chronic conditions. Consideration could also be given to the feasibility of expanding hospital emergency department data to include some or all supplementary codes on chronic conditions. This would benefit dementia data and data on 28 other chronic conditions.

Most reports on the economic cost of dementia to the Australian community draw heavily on AIHW disease expenditure studies. The analysis of disease expenditure is complex and resource intensive and, when undertaken for some 200 diseases and 30 risk factors, would be prohibitive to undertake on a frequent basis. The AIHW disease expenditure analysis program has suffered from sporadic investment and while the next disease expenditure study has been funded, consideration could be given to the need for timely information on dementia expenditure and how this might be achieved into the future.

## Opportunities for aged care data

More than any other health condition, dementia sits at the intersection of the health and aged care sectors and brings into sharp relief the comprehensiveness and quality of health-care data and aged care data. The health data landscape has benefited from very large programs, high public awareness, strong governance and widespread use of the data by diverse stakeholders. For a number of decades, health administrative data have been a foundation for intergovernmental financing arrangements and public accountability. By contrast, aged care service delivery involves a large number of non-government and community organisations which can complicate data collection and governance. Aged care also appears to suffer from a less systematic approach to ensuring data continuity in periods of significant policy and system reform. This is reflected in the break in aged care assessment data holdings of the NACDC and shifting positions on the perceived policy importance of health information in key aged care data collections.

The development of new techniques for estimating dementia prevalence (and any other areas of interest to policy makers) using integrated health and aged care data could be wasted if, by the time methods are validated, the required data items are no longer collected and recorded, or made readily accessible.

Australian aged care data have always been a weak link in analytical studies on dementia because of the case ascertainment problem. Ironically, and perhaps because of this, it is in the area of aged care data analysis and research that some of the earliest systematic efforts at large-scale data linkage and pathways analysis have occurred (see, for example, AIHW 2010b, 2011a, 2017c). The establishment of the NACDC in 2013 to bring together national community and residential aged care data collections was a major step forward. Since 2015 this appears to have been hampered by an aged care policy agenda without adequate attention to the importance of ensuring the availability of quality aged care data for secondary analysis to support evidenced-based policy making. There is now a prospect to address this gap through the ongoing development of an analytical data set of aged care assessment information captured since 2015 using the NSAF.

The value of data for informing policy needs to be recognised, championed and appropriately resourced through a comprehensive aged care data improvement plan that can endure through

the not-infrequent machinery of government changes affecting this policy area, including likely further changes in response to the current Royal Commission into Aged Care Quality and Safety. Priority should be given to:

- generating data on aged care assessments and supplying these data to the NACDC (work currently underway by the Department of Health); and ensuring the continued collection and quality of dementia data items in this data asset
- continuing to collect health condition information on new entrants to permanent residential aged care, and regularly re-assessing residents as their health changes
- to the greatest extent possible, achieving consistency in health diagnosis information collected by the NSAF for all individuals presenting for assessment, across all levels of assessment
- identifying all 'touch points' in the aged care system and optimising the collection of health condition information at assessment for services and service delivery and the recording of this information in My Aged Care, in a form that is accessible for secondary analysis
- over time, harmonising all aged care data collections with a (proposed) national data development plan for dementia.

## Opportunities for national surveys

Dementia risk reduction is 1 of 7 strategic action areas in the *Global action plan on the public health response to dementia 2017–2025* (WHO 2017). The World Health Organization recommends a public health approach, citing evidence on the effectiveness of health and lifestyle interventions to reduce modifiable risk factors for dementia (WHO 2019b). This underscores the importance of data, including data from national health surveys, for ongoing monitoring of health literacy, health risk factors for dementia, and health-seeking behaviours of older and younger Australians.

Presently, the rich data collected in national health and patient experience surveys only partially contribute to the picture on dementia. It is recommended that the long-term condition coding schema for dementia in the ABS Survey of Disability, Ageing and Carers (or similar schema) be replicated in the NHS, NATSIHS, the Intergenerational Health and Mental Health Study and the Patient Experience Survey. If feasible, cognitive assessment data for people aged 40 and over would be a valuable addition to health measures surveys.

Information on dementia in the Aboriginal and Torres Strait Islander population would be improved by more frequent NATSIHSs (currently 6-yearly) and the use of culturally appropriate tools for measuring cognitive function.

The benefits of dementia data items in national surveys and risk-factor-level analysis will only be realised if sample sizes are adequate to support health-condition-level analysis in the relevant age groups. An investigation of the robustness of estimates from the Survey of Disability, Ageing and Carers and Patient Experience Survey relating specifically to people with dementia (and their carers, where applicable) is recommended to inform possible future survey improvements. Sample size for the older population will be an important consideration for national health surveys that will potentially collect data on dementia.

The ABS will collect new high-level information on long-term health conditions in the 2021 Census. The health conditions topic relates to conditions that have a long-term impact on the health of individuals and have been diagnosed by a doctor or nurse, including dementia. The forthcoming

Census therefore is likely to provide important data for estimating the prevalence of dementia and will enable other exploration of key sociodemographic factors associated with dementia.

## Conclusion

### *Global action plan on the public health response to dementia 2017–2025*

#### **Action area 6: Information systems for dementia, proposed actions for member states**

'Develop, implement and improve, as needed, national surveillance and monitoring systems, including registers that are integrated into existing health information systems, in order to improve availability of high-quality, multisectoral data on dementia. Enable access to health and social care data and map available services and resources at national and regional levels in order to improve service delivery and coverage across the care continuum from prevention through risk reduction to the end of life.' (WHO 2017)

Little of what is said here is new. Previous AIHW assessments have highlighted persistent gaps in national dementia data and now is a critical and opportune time for making the right investments in a dementia evidence base for the future.

A Strategic Roadmap for Dementia Research and Translation developed by the National Health and Medical Research Council National Institute for Dementia Research (NNIDR) recognises the importance of population data as underpinning dementia research infrastructure—vital for the generation of evidence-based reforms to clinical practice and care. Enacting the Roadmap, NNIDR has driven the Boosting Dementia Research Initiative of targeted investment in improving dementia research over the period 2015 to 2020 (NNIDR 2019). Under this initiative, funding has been allocated to support partnerships of multidisciplinary, national teams to strengthen Australia's national dementia data assets and capabilities to deliver high quality information and analytic methods for dementia research. Funded projects include:

- using data linked by the AIHW, investigators at the University of Queensland will develop methodologies and test the utility of routinely collected administrative data for measuring national dementia prevalence
- investigators at Monash University are leveraging electronic medical records and routine administrative data towards a population approach for monitoring dementia frequency, risk factors and management.

The Australian Dementia Network (ADNeT) will provide new capability for the early and accurate diagnosis of dementia via a national network of memory clinics, harmonisation of diagnostic standards and development of a clinical quality registry (CQR). The ADNeT CQR is being designed to track, benchmark and report on the quality of clinical care of people with dementia and mild cognitive impairment to drive quality improvement, identify suitable and willing persons for clinical trials, and systematically collect longitudinal data for research on the determinants, epidemiology and trajectory of cognitive decline. Similar to Sweden's SveDem registry and dementia CQRs operating in several other European Union countries, data collected by the ADNeT CQR will be directly generated by clinical processes for the diagnosis and management of dementia.

Completion of these and similar projects will enable an assessment of data sources and methods that can best support an ongoing national dementia monitoring program.

While we await the findings, the integration of data sources across the health and aged care sectors looks to be the best approach to dementia monitoring in the near term. This will require sustained effort to improve the quality of dementia data in administrative and survey data collections. However, as long as the diagnosis and early support gap exists there will continue to be concerns about the level of coverage of the dementia population afforded by integrating administrative data not specifically designed for this purpose. The risk to accurate and reliable results would increase further if health information were not readily available from residential aged care data.

Longer term, a national dementia registry could deliver a world-class monitoring program, subject to public acceptance of the concept and considerable financial investment. A dementia registry could potentially draw on multiple different data sources including clinical quality registry data, electronic health records and administrative by-product data. Well-designed disease registries offer a number of benefits, including purposefully collected data that can support national and international dementia benchmarking.

The ultimate proof of any new method of estimating disease prevalence is the gold standard benchmark set by epidemiological study. A national epidemiological study of dementia prevalence conducted within the next 2 to 3 years would provide an objective basis for comparing alternative approaches to dementia prevalence estimation. This type of study could be repeated (for example, every 15 years) for benchmarking purposes.

Smaller-scale epidemiological and social research and longitudinal studies will continue to be important for building the dementia evidence base. Small longitudinal studies can increase our knowledge of dementia incidence and high quality, targeted research is essential for addressing questions about dementia in the Aboriginal and Torres Strait Islander population and other culturally diverse and local communities for which national data and large-scale studies may be less suitable.

A national data development plan for dementia, ideally to sit under the next national dementia framework, could outline Australia's actions to develop and implement national surveillance and monitoring systems for dementia. The plan would set out the goals and strategies for addressing dementia data gaps in the short (within 2 years), medium (5 years) and longer (10 years) term, and provide the authority and resources to enable the responsible agencies to achieve the identified goals. A first priority should be a strategy to implement an accurate and reliable system for measuring the prevalence and distribution of dementia in Australia.

### **Recommendation**

It is recommended that the Department of Health strategically and systematically address dementia data gaps through the development and implementation of:

- a comprehensive aged care data improvement plan
- a national data development plan for dementia.

## Appendix A: Tier 1 quality assessment for dementia data, Steps 1–2

**Table A.1: Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) administrative data: Step 1**

Characteristic	Details
Type of data source	National administrative
Description	Records all claims for PBS/RPBS-listed prescription medications dispensed, and benefits paid, including claims for dementia-specific PBS items
Purpose	Administration of the PBS/RPBS
Collection method	PBS/RPBS claims and payments system
Scope (theoretical coverage of dementia population)	Medications subsidised under the PBS/RPBS for the exclusive treatment of Alzheimer's disease: Donepezil, Galantamine, Rivastigmine and Memantine. Alzheimer's disease is estimated to be responsible for 50%–75% of dementia cases world-wide (ADI 2009: Table 1). Person-level data can be generated by linking PBS/RPBS records.
Coverage (actual)	People with dementia from Alzheimer's disease who are using or have used a dementia-specific PBS/RPBS-listed medication. Not all people with Alzheimer's disease necessarily use or have used these medications.
Geographic coverage	National
Frequency/timing	Ongoing, routine data collection
Basic collection count	PBS/RPBS claim (dispensed medication)
Size	In Quarter 2, 2019, Medicare Australia processed 49.2 million PBS services (Medicare Australia is now known as Services Australia)
Collection management organisation	Services Australia on behalf of Department of Health (PBS) and the Department of Veterans' Affairs (RPBS)
Further information	<a href="http://www.pbs.gov.au/pbs/home">www.pbs.gov.au/pbs/home</a> <a href="http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp">http://medicarestatistics.humanservices.gov.au/statistics/pbs_item.jsp</a>

**Table A.2: Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) administrative data: Step 2**

Priority information area	Details	Data available
Risk factors	May be possible to infer certain risk factors by the range of PBS/RPBS-listed medications used by claimants with Alzheimer's disease	Partial, by inference through record linkage
Prevalence and incidence	Prevalence—partial coverage of people with Alzheimer's dementia	Via data linkage, contributes to prevalence estimation
Dementia type	Alzheimer's disease	Alzheimer's disease
Prevention, treatment and management	Medication use and associated cost to the PBS/RPBS, patient co-payments (if applicable)	<p>Claims for dementia-specific PBS/RPBS-listed medications Donepezil, Galantamine, Rivastigmine and Memantine.</p> <p>Other PBS/RPBS-listed medications dispensed to patients with Alzheimer's disease may be found through record and data linkage.</p> <p>Does not cover medication use by people with other types of dementia, or people with Alzheimer's dementia who do not use dementia-specific PBS/RPBS medications.</p>
Quality of life (QoL)	No QoL measures	No
Disability and death	N/A	N/A
Expenditure, costs	Cost to health system of PBS/RPBS medications for Alzheimer's disease and of overall use of PBS/RPBS-listed medications by claimants with dementia	<p>PBS/RPBS-listed medications only; does not cover costs of non-PBS medications.</p> <p>Excludes costs associated with the use of dementia-specific PBS/RPBS medications where a PBS/RPBS subsidy is not payable.</p>
Population demographics	Age, sex, location (postcode of the mailing address of the patient, as recorded on the Medicare Enrolment File)	Partial

Note: N/A = not applicable

**Table A.3: National Hospital Morbidity Database: Admitted Patient Care National Minimum Data Set: Step 1**

Characteristic	Details
Type of data source	National administrative
Description	Information about admitted patient activity in Australian hospitals
Purpose	National collation of admitted patient data from state and territory health authorities
Collection method	Data are collected at each hospital from patient administrative and clinical record systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (e.g. monthly). From there, state and territory health authorities provide the data (via the secure online platform, Validata) to the AIHW for national collation, on an annual basis.
Scope (theoretical coverage of dementia population)	<p>Codes for principal diagnosis, additional diagnosis and supplementary codes for chronic conditions, which can be used to identify episodes of care (separations) for patients with dementia.</p> <p>Episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, corrections authorities and in Australia's off-shore territories may also be included. Hospitals specialising in dental, ophthalmic aids and other specialised acute medical or surgical care are included.</p>
Coverage (actual)	Hospital patients for whom dementia is assessed after study as chiefly responsible for the admission, or coexisting with the principal diagnosis or arising during the episode of admitted patient care and requiring management during the hospital stay; or otherwise recorded as a chronic condition. Actual coverage is reported to be less than theoretical coverage owing to the under-diagnosis and under-disclosure of dementia.
Geographic coverage	National
Frequency/timing	Annual to financial year 2017–18
Basic collection count	Separations
Size	11.3 million separations in Australia's public and private hospitals in 2017–18
Collection management organisation	Australian Institute of Health and Welfare
Further information	<a href="http://www.aihw.gov.au/">www.aihw.gov.au/</a>

**Table A.4: National Hospital Morbidity Database: Admitted Patient Care National Minimum Data Set: Step 2**

Priority information area	Details	Data available
Risk factors	Health-related risk factors may be coded in the admitted patient data	Principal and additional diagnoses and supplementary codes for chronic conditions (where coded)
Prevalence and incidence	Prevalence—partial	Via data linkage, contributes to prevalence estimation
Dementia type	Underlying disease cause of dementia as indicated by ICD-10-AM codes for dementia recorded as principal or additional diagnosis	Codes for: Alzheimer's disease Vascular dementia Fronto-temporal dementia Dementia in Creutzfeldt-Jakob disease Dementia in Huntington's disease Dementia in Parkinson's disease Dementia in human immunodeficiency virus (HIV) disease Lewy body dementia Dementia in other diseases Dementia due to psychoactive substance use Unspecified dementia Delirium superimposed on dementia
Prevention, treatment and management	Treatment and management delivered in hospital settings	Treatment and management received may also relate to co-morbid conditions and not solely be attributable to dementia
Quality of life (QoL)	No QoL measures	No
Disability and death	Death, if it occurs during episode of admitted patient care	Death as exit reason/discharge status coded on hospital separation
Expenditure, costs	Estimated cost to health system can be calculated using supplementary, activity-based funding data. Difficult to attribute dementia-related costs where dementia is not the principal diagnosis.	Australian Refined Diagnosis Related Group (AR-DRG) classification of episode of care for principal diagnosis of dementia
Population demographics	Age, sex, location, country of birth, Indigenous status, marital status, labour force status, usual accommodation type, personal identifiers for data linkage	Comprehensive

**Table A.5: Non-admitted Patient Emergency Department Care National Minimum Data Set (NMDS): Step 1**

Characteristic	Details
Type of data source	National administrative
Description	Information about patient activity in Australian hospital emergency departments (EDs)
Purpose	To collect information on the care provided (including waiting times for care) for non-admitted patients registered for care in EDs in public hospitals
Collection method	Data are collected at each hospital from patient administrative and clinical record systems. Hospitals forward data to the relevant state or territory health authority on a regular basis (e.g. monthly). From there, state and territory health authorities provide the data (via the secure online platform, Validata) to the AIHW for national collation, on an annual basis.
Scope (theoretical coverage of dementia population)	<p>Codes for principal diagnosis and first and second additional diagnoses can be used to identify ED episodes for patients with dementia.</p> <p>Data cover presentations to EDs where the ED meets the following criteria:</p> <ul style="list-style-type: none"> <li>• a purposely designed and equipped area with designated assessment, treatment, and resuscitation areas</li> <li>• the ability to provide resuscitation, stabilisation, and initial management of all emergencies</li> <li>• availability of medical staff in the hospital 24 hours a day</li> <li>• designated emergency department nursing staff 24 hours per day 7 days per week, and a designated emergency department nursing unit manager.</li> </ul>
Coverage (actual)	<p>For 2017–18, the coverage of the Non-admitted Patient Emergency Department Care NMDS is considered complete for public hospitals which meet the above criteria. The collection does not include all emergency services provided in Australia; for example, emergency service activity provided by private hospitals, or by public hospitals that do not have an emergency department that meets the above criteria are excluded. This should be taken into account, particularly when comparing data by remoteness area and Indigenous status as a greater proportion of Indigenous Australians live in more remote areas (the quality of the data reported for Indigenous status in emergency departments has not been formally assessed).</p> <p>For 2017–18, diagnosis information was not reported using a uniform classification. The majority of records (68%) were reported using various editions of ICD-10-AM. Most states and territories reported patients' diagnoses using a single type of classification. A principal diagnosis was not reported for about 283,000 records (approx. 3.5%). In addition, about 8,000 records had an ICD-9-CM or a SNOMED-CT AU<sup>(a)</sup> diagnosis that did not map to a valid ICD-10-AM diagnosis (AIHW 2018).</p>
Geographic coverage	National
Frequency/timing	Annual to financial year 2017–18
Basic collection count	Presentation
Size	8.0 million presentations in 2017–18
Collection management organisation	Australian Institute of Health and Welfare
Further information	<a href="http://www.aihw.gov.au/">www.aihw.gov.au/</a>

(a) SNOMED-CT AU is the Systematized Nomenclature of Medicine, Clinical Terms Australian Release.

**Table A.6: Non-admitted Patient Emergency Department Care National Minimum Data Set (NMDS): Step 2**

Priority information area	Details	Data available
Risk factors	Risk factors may be coded if relevant to the emergency department (ED) presentation	Principal and additional diagnoses codes (where coded)
Prevalence and incidence	Prevalence—partial	Via data linkage, contributes to prevalence estimation
Dementia type	Underlying disease cause of dementia as indicated by ICD-10-AM codes for dementia recorded as principal or additional diagnosis, depending on the diagnosis coding system used	Diagnosis classification system varies by jurisdiction
Prevention, treatment and management	Treatment delivered in ED settings	Treatment received may also relate to co-morbid conditions, not solely attributable to dementia
Quality of life (QoL)	No QoL measures	No
Disability and death	Death, if it occurs in the ED	Death as discharge status coded on ED record
Expenditure, costs	Estimated cost to health system can be imputed based on certain assumptions. Difficult to attribute dementia-related costs where dementia is not the principal diagnosis occasioning the presentation to ED.	
Population demographics	Age, sex, location, country of birth, Indigenous status, personal identifiers for data linkage	Comprehensive

**Table A.7: National Mortality Database (NMD) and National Death Index (NDI): Step 1**

Characteristic	Details
Type of data source	National registry
Description	The NMD is a national collation of data on deaths in Australia since 1964. The NDI is a database of all deaths occurring in Australia since 1980, designed to facilitate the conduct of epidemiological studies; it enables linkage to other data sets and its use is strictly confined to medical research.
Purpose	To record information on all deaths that occur in Australia, including cause of death information
Collection method	Data is supplied by the Registrars of Births, Deaths and Marriages in each state and territory, the National Coronial Information System and the ABS
Scope (theoretical coverage of dementia population)	All deaths of people with dementia as the underlying cause of death or associated cause of death
Coverage (actual)	Actual coverage should be close to theoretical coverage. Differences between theoretical and actual coverage arise for 3 main reasons: (i) changes over time in the recognition, diagnosis and classification of dementia are likely to affect the frequency with which dementia is recorded as a cause of death; (ii) as dementia is strongly age-related and many older people have multiple comorbidities, it can be difficult to disentangle cause of death in older adults; (iii) under-disclosure of dementia in deaths certificates due to various reasons.
Geographic coverage	National
Frequency/timing	1964–2018, ongoing
Basic collection count	Death
Size	158,493 deaths registered in 2018, including 13,963 with an underlying cause of 'Dementia, including Alzheimer's disease'
Collection management organisation	Australian Institute of Health and Welfare
Further information	<a href="http://www.aihw.gov.au/">www.aihw.gov.au/</a>

**Table A.8: National Mortality Database (NMD) and National Death Index (NDI): Step 2**

Priority information area	Details	Data available
Risk factors	N/A	N/A
Prevalence and incidence	Prevalence—partial. People with dementia can die of causes unrelated to the dementia in which case dementia would not be recorded as a cause of death. Dementia can also be under-reported even when related to death.	Deaths with dementia recorded as a cause of death can contribute to prevalence estimation via data linkage
Dementia type	ICD-10 codes F01, F03, G30	Deaths with cause of death recorded as: Alzheimer’s disease Vascular dementia Unspecified dementia
Prevention, treatment and management	N/A	N/A
Quality of life (QoL)	N/A	N/A
Disability and death	Death, dementia-related fatal burden of disease	Deaths
Expenditure, costs	N/A	N/A
Population demographics	Age, sex, country of birth, years resident in Australia, place of usual residence, Indigenous status, marital status, personal identifiers for data linkage (NDI only)	Comprehensive

Note: N/A = not applicable

**Table A.9: Department of Social Services income support and allowances data (Disability Support Pension, Carer Payment, Carer Allowance): Step 1**

Characteristic	Details
Type of data source	National administrative
Description	Claims and payments data for administering programs under the <i>Social Security Act 1991</i>
Purpose	The provision of financial assistance in the form of income support and allowances to persons who are unable to work because of a disability or caring responsibilities, or persons who incur additional costs associated with caring for a frail older person or a person with a disability
Collection method	Routinely collected administrative data generated by Human Services systems
Scope (theoretical coverage of dementia population)	Recipients of Government income support and allowances with a medical diagnosis of dementia. Disability Support Pension (DSP) recipients are mostly persons under the Age Pension age; Carer Payment/ Carer Allowance recipients may be persons of any age over 16 years.
Coverage (actual)	Actual coverage may be lower than theoretical coverage if claimants with dementia base their claims on other medical conditions, without disclosing dementia. Moreover, dementia may develop/be diagnosed after a claim for payment is made, in which case the dementia is unlikely to be recorded in the income support and allowances data.
Geographic coverage	National
Frequency/timing	Ongoing, routine data collection
Basic collection count	Claim
Size	Total recipients as at December 2018: DSP: 750,045 Carer Payment: 277,376 Carer Allowance: 621,910
Collection management organisation	Department of Social Services
Further information	<a href="http://www.humanservices.gov.au">www.humanservices.gov.au</a> <a href="http://www.dss.gov.au">www.dss.gov.au</a> <a href="https://data.gov.au/">https://data.gov.au/</a>

**Table A.10: Department of Social Services income support and allowances data (Disability Support Pension, Carer Payment, Carer Allowance): Step 2**

Priority information area	Details	Data available
Risk factors	N/A	N/A
Prevalence and incidence	Can potentially contribute to prevalence estimates via data linkage	Primary medical condition or any medical conditions coded to 'Senile dementia', based on medical evidence
Dementia type	N/A	N/A
Prevention, treatment and management	N/A <sup>(a)</sup>	N/A
Quality of life (QoL)	No QoL measures	No
Disability and death	Relate to payment eligibility criteria (disability)	For Disability Support Pension (DSP), data contain impairment ratings across a number of medical condition domains. Death is one of a number of possible reasons for exit from payment.
Expenditure, costs	Costs to social security system of income support and allowances paid to persons with dementia who are unable to work and people who are unable to work because of caring for a person with dementia	Income support and allowances payment amounts
Population demographics	Age, sex, location, Indigenous status, marital status, living arrangements, labour force status, etc., personal identifiers for data linkage	Comprehensive

(a) Not applicable, but receiving any of these payments may allow carers and people with dementia to access other payments and services.

Note: N/A = not applicable

**Table A.11: National Aged Care Data Clearinghouse (NACDC) – Aged Care Assessment Program (ACAP) Minimum Data Set (MDS): Step 1**

Characteristic	Details
Type of data source	National administrative
Description	Collect information on the activity of Aged Care Assessment Teams (ACAT)
Purpose	<p>To:</p> <ul style="list-style-type: none"> <li>• provide ACAP program managers, both Commonwealth and state/territory, with access to data for policy and program development, strategic planning and performance monitoring against agreed outcomes</li> <li>• assist ACATs to provide high quality services to their clients by facilitating improved internal management and local/regional area planning and coordinated service delivery</li> <li>• facilitate consistency and comparability of ACAP data with other relevant information in the health and community services fields.</li> </ul> <p>One of the few sources of detailed data on diagnosed dementia in the community-dwelling population. Captures data on people at the ACAT gateway to a range of community-based and residential care programs, including respite care.</p> <p>ACAP is more likely than other programs to identify cases of mild-to-moderate dementia, particularly among people who live alone, and to identify people with moderate-to-severe dementia who have a family carer and may have been able to delay accessing formal care—this information is highly valuable for dementia monitoring via linkage with other data sources.</p>
Collection method	Administrative data submitted by the Department of Health to the National Aged Care Data Clearinghouse
Scope (theoretical coverage of dementia population)	Community-dwelling older persons with dementia in need of formal assistance and younger people with disability and dementia (also eligible for ACAT assessment). Referral to ACAT may also be related to a carer's need for respite.
Coverage (actual)	Older persons with dementia and young people with disabilities and dementia referred to ACATs for comprehensive assessment of care needs
Geographic coverage	National
Frequency/timing	<p>Annual collation (financial year) from 2004–05 to 2014–15.</p> <p>State and territory-based ACATs have continued to operate but, since June 2015, the Department of Health has not supplied usable data on ACAT activities to the National Aged Care Data Clearinghouse.</p> <p>Analytical data from the National Screening and Assessment Form for comprehensive assessments performed by ACATs (2015–16 onwards) are being developed for inclusion in the NACDC.</p>
Basic collection count	ACAT assessment
Size	Around 182,000 completed ACAT assessments in 2014–15, corresponding to around 167,000 individuals who had at least 1 assessment.
Collection management organisation	Department of Health
Further information	<a href="http://www.health.gov.au/">www.health.gov.au/</a>

**Table A.12: National Aged Care Data Clearinghouse (NACDC) – Aged Care Assessment Program (ACAP) Minimum Data Set (MDS): Step 2**

Priority information area	Details	Data available
Risk factors	Not known	May have been collected at Aged Care Assessment Team (ACAT) assessment but were not part of the ACAP MDS
Prevalence and incidence	Prevalence —partial, contributes to dementia prevalence estimation via data linkage. A unique source of dementia identification in the community-dwelling population as it captures older people with dementia and young people with disabilities and dementia (and their carers) at the ACAT gateway to formal assistance through government programs, (including community, residential and respite care).	Dementia could be coded as 1 of up to 10 health conditions, using ACAP health condition codes, mappable to ICD-10-AM diagnosis codes
Dementia type	0500 Dementia in Alzheimer’s disease 0501 Dementia in Alzheimer’s disease with early onset (<65 years) 0502 Dementia in Alzheimer’s disease with late onset (>65 years) 0503 Dementia in Alzheimer’s disease, atypical or mixed type 0504 Dementia in Alzheimer’s disease, unspecified 0510 Vascular dementia 0511 Vascular dementia of acute onset 0512 Multi-infarct dementia 0513 Subcortical vascular dementia 0514 Mixed cortical & subcortical vascular dementia 0515 Other vascular dementia 0516 Vascular dementia—unspecified 0520 Dementia in other diseases classified elsewhere 0521 Dementia in Pick’s disease 0522 Dementia in Creutzfeldt-Jakob disease 0523 Dementia in Huntington’s disease 0524 Dementia in Parkinson’s disease 0525 Dementia in human immunodeficiency virus (HIV) disease 0526 Dementia in other specified diseases classified elsewhere 0530 Other dementia 0531 Alcoholic dementia 0532 Unspecified dementia (includes pre-senile & senile dementia) 0542 Delirium superimposed on dementia	Dementia can be coded as 1 of up to 10 health conditions, using ACAP health condition codes that are mappable to ICD-10-AM diagnosis codes

Prevention, treatment and management	Data relating to management of the person in their usual care setting and ACAT recommended long-term care setting, including respite care where applicable	<p>Carer availability and relationship to person with dementia</p> <p>Respite care use</p> <p>Current assistance with activities</p> <p>Source of current assistance with activities (formal/informal)</p> <p>Government program support at assessment</p> <p>Government program support recommended</p> <p>Recommended formal assistance with activities</p> <p>Recommended long-term care setting</p>
Quality of life (QoL)	No QoL measures	No
Disability and death	Disability, death and burden of disease (as a summary measure of these 2 factors combined)	<p>Activity limitations (10 activity areas of daily living)</p> <p>Body function impairments</p>
Expenditure, costs	No	No
Population demographics	Age, sex, location, living arrangements, country of birth, Indigenous status, main language spoken at home, English proficiency, record linkage key (SLK)	Comprehensive

**Table A.13: National Aged Care Data Clearinghouse (NACDC) – Aged Care Funding Instrument (ACFI) data: Step 1**

Characteristic	Details
Type of data source	National administrative
Description	<p>Data relating to the administration of residential aged care subsidies under the Aged Care Act 1997.</p> <p>ACFI data are generated by the appraisal of a person's care needs in 3 functioning (funded) domains around the time of entry to permanent residential aged care using the ACFI tool: (i) Activities of Daily Living, (ii) Behaviour and (iii) Complex Health Care. ACFI data items in the NACDC include demographics; health conditions; and appraisal results (nil, low, medium or high care needs) in each domain.</p> <p>The ACFI form includes a 'Mental and Behavioural Disorders Checklist' which allows for the reporting of up to 3 major mental and behavioural diagnoses for each resident. In addition, a 'Medical Diagnosis Checklist' allows for the reporting of other health conditions.</p> <p>In both cases, for conditions to be recorded, the instructions indicate that they must be documented and diagnosed and that they must be having an impact on the resident's care needs. ACFI identifies a resident with dementia in residential aged care if the ACFI form contains a dementia diagnosis code based on the Aged Care Assessment Program (ACAP) code list (see information on the ACAP MDS, above).</p>
Purpose	The ACFI assesses the relative care needs of residents and is the mechanism for allocating the Government subsidy to aged care providers for delivering care to residents
Collection method	The ACFI form is completed by staff in aged care facilities and transmitted to the Department of Health. The Department of Health supplies ACFI data to the NACDC maintained by the AIHW.
Scope (theoretical coverage of dementia population)	<p>Permanent residents with dementia living in Australian-Government funded aged care facilities. Scope excludes people with dementia:</p> <ul style="list-style-type: none"> <li>• in residential aged care facilities not subsidised by the Australian Government</li> <li>• in residential care places under the Multi-Purpose Service Program or the National Aboriginal and Torres Strait Islander Flexible Aged Care Program</li> <li>• accessing respite care or transition care in residential aged care facilities (i.e. usual accommodation is in the community).</li> </ul> <p>The proportion of Indigenous permanent residents in aged care facilities, and in turn the number reported to have dementia in these facilities, may be under-estimated for a number of reasons. These include that, as noted above, an ACFI appraisal is not required for people accessing programs such as the National Aboriginal and Torres Strait Islander Flexible Aged Care Program and there is no other source of information that provides the dementia status of people using these services. As well, the ACFI data have below full coverage of Australian-Government subsidised operational permanent residential aged care places in Very Remote areas. Indigenous Australians are relatively more likely than other Australians to be living in these areas.</p>
Coverage (actual)	The number of people with dementia may be under-estimated using ACFI data, but whether this is the case and the extent of any such underestimation is unknown. The requirement under the ACFI for a formal medical diagnosis of dementia in order to make a valid claim is problematic for some facilities. In addition, where changes to the funding model have potentially altered the financial incentives for certain data items to be completed, this may have resulted in changes in actual coverage over time.
Geographic coverage	National. Incomplete coverage of Australian-Government subsidised operational permanent residential aged care places in Very Remote areas.
Frequency/timing	<p>March 2008 to financial year 2017–18. Annual (financial year) collection.</p> <p>ACFI reviews generally don't expire and the majority of permanent residents receive only 1 ACFI appraisal during a 12-month reporting period. However, subsequent reviews sometimes occur for reasons such as a major change in care needs.</p>

Basic collection count	ACFI review
Size	1,808 reviews in June quarter 2019
Collection management organisation	State and territory health authorities and the Department of Health
Further information	<a href="https://agedcare.health.gov.au/tools-and-resources/aged-care-funding-instrument-acfi-reports">https://agedcare.health.gov.au/tools-and-resources/aged-care-funding-instrument-acfi-reports</a> The AIHW is aware of concerns that financial incentives may cause some aged care providers to manipulate ACFI reviews, potentially affecting data quality.

**Table A.14: National Aged Care Data Clearinghouse (NACDC) – Aged Care Funding Instrument (ACFI) data: Step 2**

Priority information area	Details	Data available
Risk factors	Records some health conditions	Assessment form allows recording up to 3 mental and behavioural disorders, as well as up to 3 other medical disorders
Prevalence and incidence	Contributes to dementia prevalence estimates via data linkage	Aged Care Assessment Program (ACAP) health condition codes for dementia. See entry for 'Dementia type' under Step 2 of the ACAP MDS table, above
Dementia type	ACAP health condition codes	See entry for 'Dementia type' under Step 2 of the ACAP MDS table, above
Prevention, treatment and management	Items indicate the management of care needs required (and funded) in residential aged care settings, including subsidised complex health-care needs (on the assumption that, where funding, this care is delivered)	Activities of Daily Living-related care needs, Behaviour-related care needs, Complex Health Care-related needs
Quality of life (QoL)	No QoL measures	No
Disability and death	Information on functioning in 3 domains. Death may be recorded as exit reason	Partial
Expenditure, costs	ACFI assessment of care needs used to determine Australian-Government residential aged care subsidy amounts	Partial
Population demographics	Age, sex, facility ID and location, Indigenous status, etc., personal identifiers for data linkage	Comprehensive

**Table A.15: Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams program data: Step 1**

Characteristic	Details
Type of data source	National administrative
Description	Data produced by service providers for grant-based dementia programs targeting people with severe behaviours and psychological symptoms of dementia (BPSD) and their care providers
Purpose	Program management (to meet Department of Health reporting requirements)
Collection method	Service provider systems and processes
Scope (theoretical coverage of dementia population)	People with severe BPSD living in residential aged care whose symptoms of dementia are impacting on care provision. Scope may include a relatively small number of community-dwelling people with BPSD referred by GPs or family carers.
Coverage (actual)	Actual coverage depends on several factors, including the level of awareness and access to the programs in residential aged care facilities and among carers of people with severe BPSD living at home in the community
Geographic coverage	National when fully implemented
Frequency/timing	2015 onwards, reporting frequency varies by program
Basic collection count	Case, client, service
Size	Unable to assess
Collection management organisation	Dementia Support Australia (a partnership led by HammondCare on behalf of the Department of Health)
Further information	<a href="http://www.dementia.com.au">www.dementia.com.au</a> <a href="http://www.health.gov.au/">www.health.gov.au/</a>

**Table A.16: Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams program data: Step 2**

Priority information area	Details	Data available
Risk factors	Not known	Not known
Prevalence and incidence	Potentially, could contribute to prevalence estimates and severity estimates (estimated to be the highest 1% of dementia cases, by severity)	Unknown potential for data linkage
Dementia type	Yes	Unknown coding
Prevention, treatment and management	Prevention, treatment and management of behaviours and psychological symptoms of dementia (BPSD) and treatment outcomes	Unknown coding
Quality of life (QoL)	Not known	Not known
Disability and death	Death, where occurring during episode of care	Discharge reason – unknown coding
Expenditure, costs	Not known	Not known
Population demographics (SBRT data)	Client age, sex, location/address, country of birth, main language spoken, Indigenous status, risk of homelessness indicator, indicator for financial or social disadvantage	Unknown coding

**Table A.17: Specialist Dementia Care Program data: Step 1**

Characteristic	Details
Type of data source	National administrative
Description	Data produced by service providers for the place-based Specialist Dementia Care Program that targets people with severe behaviours and psychological symptoms of dementia (BPSD) and their care providers (this includes Dementia Support Australia)
Purpose	Program management (to meet Department of Health reporting requirements)
Collection method	Service provider systems and processes
Scope (theoretical coverage of dementia population)	People with severe or very severe BPSD (tier 6 or 7 of Brodaty triangle) living in residential aged care, hospital or the community, whose symptoms of dementia are impacting on care provision
Coverage (actual)	Actual coverage depends on several factors, including the level of awareness and access to the programs in residential aged care facilities and among carers of people with severe BPSD living in the community. Actual coverage will also depend on the number of operational places relative to demand and the eligibility and screening processes applied by intake assessment teams.
Geographic coverage	National when fully implemented
Frequency/timing	Data collection commences with program implementation, progressive starting in late 2019.
Basic collection count	Case, client, service
Size	Unable to assess
Collection management organisation	Dementia Support Australia (a partnership led by HammondCare on behalf of Department of Health)
Further information	<a href="http://www.dementia.com.au">www.dementia.com.au</a> <a href="http://www.health.gov.au/">www.health.gov.au/</a>

*Note:* The Specialist Dementia Care Program was not fully operational at the time of assessment. Assessment is based on information about the planned data collection, provided by the Department of Health.

**Table A.18: Specialist Dementia Care Program data: Step 2**

Priority information area	Details	Data available
Risk factors	Not known	Not known
Prevalence and incidence	Potentially, could contribute to prevalence estimates and severity estimates (Specialist Dementia Care Program clients constitute the estimated highest 1% of dementia cases, by severity)	Unknown potential for data linkage
Dementia type	Yes	Unknown coding
Prevention, treatment and management	Prevention, treatment and management of behaviours and psychological symptoms of dementia (BPSD) and treatment outcomes	Unknown coding
Quality of life (QoL)	Not known	Not known
Disability and death	Death, where occurring during episode of care	Discharge reason – unknown coding
Expenditure, costs	Not known	Not known
Population demographics	Not known	Unknown coding

*Note:* The Specialist Dementia Care Program was not fully operational at the time of assessment. Assessment is based on information about the planned data collection, provided by the Department of Health.

**Table A.19: National Integrated Health Services Information Analysis Asset (NIHSI AA) v0.5: Step 1**

Characteristic	Details
Type of data source	Integrated administrative data. National data for Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS)/Repatriation Pharmaceutical Benefits Scheme (RPBS), Residential Aged Care Services (RACS), and National Death Index (NDI). New South Wales, Victoria, South Australia and Tasmania contributed hospitals data to the initial release, NIHSI AA v0.5.
Description	Brings together de-identified data for health services, aged care and deaths into a person-centred data set. Data are sourced from: MBS, PBS, hospitals, aged care (residential aged care) data and the NDI.  Dementia identifiers are contained in the PBS, hospital admitted patient care, RACS, and NDI data. Does not incorporate Aged Care Assessment Program (ACAP) data or data on community aged care services.
Purpose	Can be used for projects consistent with the AIHW Ethics Committee-approved research purposes for the asset, including patterns of use and effectiveness of health and residential aged care services
Collection method	Linkage of existing administrative data holdings
Scope (theoretical coverage of dementia population)	People with dementia who use: Australian hospitals (admitted patients and non-admitted patients); residential aged care facilities; PBS and RPBS anti-dementia medications; Medicare services. Deaths with dementia recorded on the death certificate as a cause of death.
Coverage (actual)	As for theoretical coverage apart from hospitals data, for which NIHSI AA v0.5 covers hospitals in New South Wales, Victoria, South Australia, Tasmania. See 'Coverage' notes for the individual contributory data sources. Where dementia is indicated, assumptions about the date of onset are likely to be required.
Geographic coverage	Geographic coverage varies by collection.  National coverage for MBS, PBS/RPBS, RACS, and NDI. New South Wales, Victoria, South Australia and Tasmania contributed hospitals data for NIHSI AA v0.5.
Frequency/timing	NIHSI AA v0.5 contains data for financial years 2010–11 to 2016–17. NIHSI AA has been developed as an enduring data asset.
Basic collection count	Person
Size	See 'Size' notes for the individual contributory data sources
Collection management organisation	Australian Institute of Health and Welfare
Further information	<a href="http://www.aihw.gov.au/">www.aihw.gov.au/</a>

**Table A.20: National Integrated Health Services Information Analysis Asset (NIHSI AA) v0.5: Step 2**

Priority information area	Details	Data available
Risk factors	Partial, through diagnosis codes in hospitals data and limited health conditions captured in RACS (ACFI) data.	In hospitals, ICD-10-AM principal and additional diagnosis codes for risk factors and external cause codes, where coded.  In RACS, ACFI data capture some health conditions of residents (using ACAP health condition codes).
Prevalence and incidence	Partial. Major limitations of NIHSI AA v0.5 for dementia prevalence estimation are that actual coverage of hospitals data is limited to 4 states and the NIHSI AA does not include aged care assessment (Aged Care Assessment Program (ACAP) data or community aged care data	Codes for dementia in: hospital admitted patient care data (ICD-10-AM); National Death Index (NDI) (ICD-10); RACS (see Aged Care Funding Instrument (ACFI)/ ACAP health condition codes); Pharmaceutical Benefits Scheme (PBS) (dementia medication PBS item numbers
Dementia type	Underlying disease cause of dementia	RACS (ACAP health condition codes).  Principal and additional diagnosis codes in hospital admitted patient care data, where coded.  Limited typing available in ICD-10 codes in the NDI where recorded as a cause of death.
Prevention, treatment and management	Treatment in hospital settings.  PBS medication use.  Subsidised complex health care delivered in residential aged care.	See entries in tables above for Admitted Patient Care National Minimum Data Set (NMDS), Non-admitted Patient Emergency Department Care NMDS, PBS, and ACFI.  Medicare Benefits Schedule (MBS) services.
Quality of life (QoL)	No QoL measures	No
Disability and death	Death.  Disability indicated by ACFI data items on functioning, though these are not necessarily up-to-date.	See entries in tables above for Admitted Patient Care NMDS; Non-admitted Patient Emergency Department Care NMDS; PBS; National Mortality Database and NDI; and ACFI.
Expenditure, costs	Cost of residential aged care subsidies to government.  Cost to health system of PBS/RPBS medications.	See entries in tables above for PBS and ACFI.  Cost of MBS services.
Population demographics	Age, sex, area of usual residence	Partial

# Acknowledgments

This report was prepared by Cathy Hales of the Dementia Unit of the Australian Institute of Health and Welfare (AIHW), with valued input from Fleur de Crespigny, Richard Juckes, Melanie Dunford, Thao Vu, Lilia Arcos Holzinger, George Bodilsen, Conan Liu, Clara Jellie, Melinda Leake, Jenni Joenpera, Jen Mayhew-Larsen, David Braddock, Michelle Gourley, Adrian Webster, Brett Henderson, Gary Hanson, Jason Thomson, Louise York and Navreet Bhattal, also of the AIHW.

Review and valuable input on the final draft was provided by the AIHW Dementia Working Group whose members at February 2020 included: Kaarin Anstey, Janice Besch, Henry Brodaty, Colm Cunningham, Annette Dobson, Linda Fardell, Anthony Hobbs, Verity Jausnik, Marissa Ostuszewski, Velandai Srikanth, Kaele Stokes and Kumar Ujjineni.

The Australian Government Department of Health funded this report.

# Abbreviations

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ACFI	Aged Care Funding Instrument
ACS 0003	Australian Coding Standard Supplementary codes for chronic conditions
ADI	Alzheimer's Disease International
ADNeT	Australian Dementia Network
AIHW	Australian Institute of Health and Welfare
AR-DRG	Australian Refined Diagnosis Related Group
BEACH	Bettering the Evaluation and Care of Health
CCDSS	Canadian Chronic Disease Surveillance System
CHSP	Commonwealth Home Support Programme
CIS	Clinical information systems
CQR	Clinical Quality Registry
DBMAS	Dementia Behaviour Management Advisory Service
DSP	Disability Support Pension
DVA	Department of Veteran Affairs
DYNOPTA	Dynamic Analyses to Optimise Ageing Project
EACH	Extended Aged Care at Home
EACH-D	Extended Aged Care at Home-Dementia
GP	General practitioner
HACC	Commonwealth Home and Community Care Program
HCP	Home Care Packages Program
ICD-9	International Statistical Classification of Disease and Related Health Problems, 9th Revision
ICD-9-AM	International Statistical Classification of Disease and Related Health Problems, 9th Revision, Australian Modification
ICD-10	International Statistical Classification of Disease and Related Health Problems, 10th Revision
ICD-10-AM	International Statistical Classification of Disease and Related Health Problems, 10th Revision, Australian Modification
IHPA	Independent Hospital Pricing Authority
MADIP	Multi-Agency Data Integration Project
MBS	Medicare Benefits Schedule
MDS	Minimum Data Set
NACDC	National Aged Care Data Clearinghouse

NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NDI	National Death Index
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NHCDC	National Hospital Cost Data Collection
NHS	National Health Survey
NIHSI AA	National Integrated Health Services Information Analysis Asset
NMDS	National Minimum Data Set
NNIDR	National Health and Medical Research Council National Institute for Dementia Research
NSAF	National Screening and Assessment Form
OECD	Organisation for Economic Co-operation and Development
PBS	Pharmaceutical Benefits Scheme
PHN	Primary Health Network
PIAC	Pathways in Aged Care
PIP	Practice Incentives Program
PIP QI	Practice Incentives Program Quality Improvement initiative
POLAR	Population Level Analysis and Reporting tool
QOF	Quality and Outcomes Framework
RACS	Residential Aged Care Services
RAS	Regional Assessment Services
RCS	Resident Classification Scale
RPBS	Repatriation Pharmaceutical Benefits Scheme
SBRT	Severe Behaviour Response Teams
SDAC	ABS Survey of Disability, Ageing and Carers
SDCP	Specialist Dementia Care Program
SNOMED	Systematized Nomenclature of Medicine
SNOMED-CT AU	Systematized Nomenclature of Medicine, Clinical Terms Australian Release
SSRI	Social Security and Related Information
SveDem	Swedish Dementia Registry
UK	United Kingdom
WHO	World Health Organization

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## Related publications

The following Australian Institute of Health and Welfare publications relating to dementia and/or health service use in people using aged care services might also be of interest:

- AIHW 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.
- AIHW 2018. Australia's health 2018. Australia's health series no. 16. Cat. no. AUS 221. Canberra: AIHW.
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Persistent gaps in national data limit monitoring and reporting on dementia in Australia. Linking administrative data is helping overcome data limitations associated with determining the prevalence of dementia, and investment in a national dementia registry could deliver a world-class monitoring program over the longer term. The report discusses current dementia data gaps and identifies ways in which these gaps can be systematically and strategically addressed.

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