



**Australian Government**

**Australian Institute of  
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# Improving dementia data in Australia

Supplement to *Dementia in Australia 2012*





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*Authoritative information and statistics  
to promote better health and wellbeing*

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*Dementia in Australia 2012***

Australian Institute of Health and Welfare  
Canberra

Cat. no. AGE 76

**The Australian Institute of Health and Welfare is a major national agency which provides reliable, regular and relevant information and statistics on Australia's health and welfare. The Institute's mission is authoritative information and statistics to promote better health and wellbeing.**

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# Abbreviations

ABS	Australian Bureau of Statistics
ACAM	Australian Centre for Asthma Monitoring
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ACFI	Aged Care Funding Instrument
ADI	Alzheimer's Disease International
AIHW	Australian Institute of Health and Welfare
BEACH	Bettering the Evaluation and Care of Health
CACP	Community Aged Care Package
CCC	Community Care Census
DoHA	Australian Government Department of Health and Ageing
DOMS	Dementia Outcomes Measurement Suite
DSS	Australian Government Department of Social Services
DUSC	Drug Utilisation Sub-Committee
DYNOPTA	Dynamic Analyses to Optimise Ageing
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia
GP	general practitioner
HACC	Home and Community Care
HDS	Hospital Dementia Services
ICD-10	International Statistical Classification of Diseases and Related Health
ICD-10-AM	International Statistical Classification of Diseases and Related Health, 10th revision, Australian Modification
ICPC-2	International Classification of Primary Care, 2nd edition
MDS	Minimum Data Set
NCMCD	National Centre for Monitoring Cardiovascular Disease
NCMC	National Centre for Monitoring Cancer
NDI	National Death Index
NDIS	National Disability Insurance Scheme
NHMD	National Hospital Morbidity Database
NHPA	National Health Priority Area
NMDS	National Minimum Data Set
PBS	Pharmaceutical Benefits Scheme
PIAC	Pathways in Aged Care
RPBS	Repatriation Pharmaceutical Benefits Scheme
SAND	Supplementary Analysis of Nominated Data

SDAC  
WHO

Survey of Disability, Ageing and Carers  
World Health Organisation



# 1 Introduction

The purpose of this paper is to provide an overview of the status of dementia data at the time of preparing the report *Dementia in Australia* (AIHW 2012a), and to suggest ways in which the availability, consistency and quality of these data could be improved.

This paper was borne out of the process of compiling the dementia report, and is therefore largely the result of a 'bottom up' analysis of dementia data in Australia, rather than a comprehensive 'top down' process, and should be read in conjunction with the *Dementia in Australia* report. It aims to inform and provide direction for collaborative efforts to improve dementia data.

Rich and robust data are needed for policy makers and practitioners to facilitate the prevention, early detection, diagnosis and treatment of dementia, as well as improving support for people with dementia and those who care for them. This is consistent with the goals of the designation of dementia as the ninth National Health Priority Area (SCoH 2012) and the need to monitor the effectiveness of treatments, programs and other activities to deal with the challenges of this condition.

## 1.1 Importance of dementia data in Australia

### Dementia in Australia

Based on projections of population growth and ageing, the prevalence of dementia in Australia is expected to increase from around 322,000 people in 2013 to about 900,000 in 2050 (AIHW 2012a). Dementia was the third leading cause of death in 2010, accounting for 6% of all deaths in that year. In 2011, dementia was responsible for an estimated 4% of the total disease burden, making it the fourth leading cause of burden of disease (AIHW 2012a). Among older people (aged 65 and over), dementia was estimated to be the second leading cause of overall burden of disease, and the leading cause of disability burden (AIHW 2012a).

Effective dementia management and treatment programs must be informed by an accessible, reliable and relevant evidence base. Building such an evidence base requires well-targeted and supported research and the development, collection and reporting of sound dementia data. This will permit a better understanding of:

- trends in dementia prevalence and burden of disease
- how dementia can be prevented, with more conclusive evidence in relation to risk and protective factors
- how differing types of dementia can be detected; for example, with the development of more sensitive diagnostic tests
- how dementia can be treated better, in relation to both pharmacological and non-pharmacological approaches
- what services are needed for people with dementia, their families and carers, where these services are most appropriately located, and how effective these services are.

## **Dementia as a National Health Priority Area**

In August 2012, dementia was designated as the ninth National Health Priority Area (NHPA). In making the designation, the decision makers recognised the potential benefits of early diagnosis and improved services for people with dementia and their carers and families, as well as the potential to reduce the prevalence of dementia by considering modifiable risk factors such as physical inactivity, smoking, body weight, and diet and alcohol consumption (SCoH 2012).

The value of the national focus and whole of government support that is associated with designation of a condition as a National Health Priority is evident from the changes and improvements in practice, service and policy in relation to other NHPA conditions. Examples include reductions in tobacco smoking, increases in the uptake of health screening programs and in the levels of physical activity among adults (Briggs & Buchbinder 2009). Monitoring NHPAs can also provide useful information about the effectiveness of activities to target these conditions, and about the health of the nation more generally (NHPAC 2005).

## **Development of this document**

The AIHW has released 2 national reports on dementia in Australia – *Dementia in Australia* (AIHW 2012a) and *Dementia in Australia: national data development and analysis* (AIHW 2007a). Each of these reports has presented the best available data about the prevalence and incidence of dementia, mortality and burden of disease due to dementia, the use of health and aged care services by people with dementia and expenditure on these services by government. The reports also included data about those who care for people with dementia. There were some improvements in Australian data about dementia in the period between the 2 reports. However, significant gaps and limitations remain in these data.

Improving dementia data was a major focus of the AIHW's 2007 report, with advice provided by the report's Reference Group (National Dementia Data Analysis and Development Reference Group). The report made detailed recommendations in relation to improving dementia data, but few of these have been implemented. A number of the recommendations are still relevant – in this paper, we update these in light of data and policy developments subsequent to the earlier report.

For context, Chapter 2 of this paper first provides information on the main data sources drawn on for the 2012 *Dementia in Australia* report. Chapter 3 then discusses data gaps and issues in existing collections in relation to key areas of dementia information. Chapter 4 presents options to inform and provide direction for a collaborative effort to improve dementia data.

## 2 Dementia data in Australia: sources

Data collection and reporting are essential for measuring need for interventions and support and the effectiveness of treatment and programs at all points along the pathway of people with the condition, their families and carers. Improved dementia data can enable closer monitoring of outcomes and the impact of policies at different points, including how these differ across population subgroups and over time.

Australia has a considerable amount of data about people with dementia and their carers, and a number of established data sources are available to draw on for the above topics. These sources can be grouped into the following broad categories:

- national survey data
- administrative data
- longitudinal data
- data integration.

A summary of the main sources of information about people with dementia, which were used in the 2012 AIHW report *Dementia in Australia*, is provided below. It is important to note that this summary is not intended to be a comprehensive list of all data sources available. More information about data sources is available in *Dementia in Australia* (AIHW 2012a).

### 2.1 National survey data

#### Survey of disability, ageing and carers (SDAC)

The SDAC is a national survey conducted by the Australian Bureau of Statistics (ABS) that collects information about people with disability, older people and their carers. Now conducted every 3 years, the SDAC is the most important source of national data about the health and functioning of older people, including those in cared accommodation, as well as the characteristics and activities of carers of older people living in the community.

The strengths of this survey for dementia reporting arise from: (i) collection of data about long-term health conditions such as dementia; (ii) inclusion of people living in cared accommodation (including residential aged care); and (iii) relatively high rate of sampling of households with older residents.

There are 2 main weaknesses of this survey for dementia reporting. First, the survey appears to under-report milder dementia, with 93% of people with dementia found to be severely or profoundly limited in their core activities (AIHW 2012a). Note, however, that this level of activity limitation may be associated with conditions other than dementia, and not represent direct evidence of under-reporting of mild dementia. Second, people in *Very remote* areas and Indigenous communities were excluded, and although this is consistent with the design parameters of the survey, and accounts for only around 2% of the overall population in scope for the survey, it does mean that there is suboptimal information on these important population subgroups.

The most recent data available for the 2012 *Dementia in Australia* report was from the 2009 SDAC. A number of changes to the 2009 survey enhanced the robustness of the survey data

and increased the usefulness of this source for dementia reporting. These included an increased sample size, and the interviewing of primary carers identified by the care recipient in addition to those identified by 'another adult in the household'. These changes facilitated the derivation of population estimates of carers and primary carers of people with dementia for the 2012 *Dementia in Australia* report. Recent government funding decisions will further support expansion of the survey and increase its frequency to every 3 years.

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

The Bettering the Evaluation and Care of Health (BEACH) survey is a national, cross-sectional survey of general practice activity in Australia, involving a random sample of about 1,000 practising GPs each year (Britt et al. 2011). Each responding GP provides details of around 100 doctor-patient encounters of all types, resulting in a data set containing details of about 100,000 GP-patient encounters per year. Each survey form collects information about the consultations, the patient, the problems managed and the way in which each problem was managed.

Health conditions, such as dementia, can be recorded by the GP as 1 of 3 reasons for a patient encounter, or as 1 of 4 diagnoses or problems managed. These are coded using the International Classification of Primary Care, version 2 (ICPC-2), which is the standard for data classification in primary care (see Britt et al. 2011 for more information about ICPC-2). Additional questions about risk factors or special interest topics may be asked of patients in subsamples of encounters, as part of the Supplementary Analysis of Nominated Data (SAND). In SAND, a section on each recording form investigates aspects of patient health or health-care delivery in general practice not covered by the consultation-based information (see Britt et al. 2011 for further information).

With the exception of data collected about GP activity through the BEACH survey, there is very little information on primary health care activity (such as public and private allied health services, state-funded community health).

While the BEACH Survey is the only current routinely collected information about GP activity, it is a sample survey and subject to the inherent limitations of a survey methodology, including concerns about how representative the survey is of the target population. Results based on BEACH analysis therefore need to be interpreted cautiously.

## **2.2 Administrative data**

### **Hospital use**

The National Hospital Morbidity Database (NHMD), which is compiled and maintained by the AIHW, pertains to episodes of care for admitted patients in public and private hospitals in Australia. As part of the collection of data in Australian hospitals, a principal diagnosis is assigned to each episode of admitted patient care, and 1 or more additional diagnoses may also be assigned. People who are admitted to hospital may have dementia recorded either as the principal diagnosis or as an additional diagnosis. The coding rules specify that only those conditions that were significant in terms of treatment required, investigations needed and resources used during the 'episode of care' are to be coded as an additional diagnosis (NCCH 2010). For this reason, the number of hospitalisations with a principal or additional diagnosis of dementia may not capture everyone with dementia who was hospitalised in a

particular year. Nevertheless, this source provides a significant amount of information available about the hospitalisations of people with a recorded diagnosis of dementia, including care type, procedures and length of stay. Diagnoses are recorded in the NHMD using the ICD-10-AM (see AIHW 2012a for more detail).

## **Aged care assessment and use**

The main sources of regular reporting about the dementia status of aged care program clients are the Aged Care Assessment Program Minimum Data Set (ACAP MDS) and the Aged Care Funding Instrument (ACFI). The 2008 Community Care Census is an ad hoc collection that provides information about people with dementia receiving assistance through 3 types of community age care packages, as well as through the National Respite for Carers Program.

### **Aged Care Assessment Program (ACAP)**

The ACAP is funded to assess comprehensively the care needs of frail older people and assist them to gain access to the types of available services most appropriate to their care needs. These services include Home and Community Care (HACC), Residential Aged Care, Community Aged Care Package (CACP), Extended Aged Care at Home (EACH), Extended Aged Care at Home Dementia (EACHD) and the Transition Care Program. As part of the assessment, up to 10 'diagnosed diseases or disorders that have an impact on the person's need for assistance with activities of daily living and social participation' can be recorded (DoHA 2013). The condition with the greatest impact on the person's need for assistance is designated the 'main health condition'. Reported conditions are coded using the ACAP Data Dictionary Health Condition Code List, which is based on the ICD-10-AM (DoHA 2013). Given the difficulties associated with obtaining a formal diagnosis of dementia, dementia may be under-identified using the ACAP.

### **Aged Care Funding Instrument (ACFI)**

People living permanently in residential aged care have their care needs assessed using the ACFI, which was introduced by the Australian Government in March 2008. The ACFI includes 12 questions about assessed care needs, with these questions falling into 1 of 3 funding domains: 'Activities of daily living', 'Behaviour characteristics' and 'Complex health care needs'. The responses to the questions are used to determine the classification for funding and the overall classification as a 'low-care' or 'high-care' resident. Note that, under the Aged Care Reform Package, there will be some changes to the ACFI, and the distinction between low- and high-level residential care will be removed. 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. In both cases, for conditions to be recorded, the instructions indicate that they must be documented and diagnosed and that they must have an impact on the resident's care needs. The number of people with dementia may be underestimated using ACFI data, but whether this is the case and the extent of any such underestimation is unknown (AIHW 2012a).

ACFI appraisals are undertaken within a specified time period after entry to residential care. There are a number of circumstances that may prompt a reappraisal, including when there has been a major change in care needs or when the resident has experienced an extended hospital stay (AIHW 2011a). Over time, the practice of undertaking these reappraisals may

result in data that provide evidence about the changes in functional limitations and care needs of those with dementia as the underlying condition progresses.

### **Community Care Census (CCC)**

In the 2012 *Dementia in Australia* report, the main data source used to describe the use of CACP, EACH and EACHD packages was the 2008 CCC, with these data describing care recipients who were accessing packaged care during a 7-day period (referred to as census week) in early 2008. In the 2008 CCC, people with dementia were identified in 2 steps. First, the survey asked the service provider to indicate if the care recipient needed assistance with tasks requiring memory and/or organisational skills, or in managing behaviour such as aggression, wandering or agitation. If the recipient needed such assistance, then the reason for needing assistance was requested, with a number of response options available, including 'diagnosed disability', 'diagnosed dementia or related condition', 'early stage undiagnosed dementia', 'other diagnosed condition' and 'other condition'. In cases where more than 1 response applied, respondents were asked to select the primary reason for the need for assistance. As a result of the way in which dementia is identified, the number of care recipients with dementia is likely under-estimated, but the degree to which this is the case is not known. Even so, the 2008 CCC is a valuable source of information about people with dementia, particularly as the routine administrative collections on community aged care packages do not include information on dementia status.

### **Dementia-specific medications**

Data on prescriptions dispensed for dementia-specific medications are available from the Pharmaceutical Benefits Scheme (PBS), Repatriation Pharmaceutical Benefits Scheme (RPBS) and the Drug Utilisation Sub-Committee (DUSC) database. Note that these data do not capture all medications used by people with dementia, nor do they capture drugs that may have been prescribed specifically to manage a person's dementia but can also be used to treat other diseases – these data are not available.

Medicare Australia collects data on dementia-specific medications *dispensed* (as distinct from all medications *prescribed*) for the treatment of dementia, which are covered by the PBS or RPBS, and government subsidies were paid because the medication cost more than the amount the consumer must pay (the 'copayment' amount). Items on the PBS and RPBS are classified according to their site of action, and therapeutic and chemical characteristics using the Anatomical Therapeutic Chemical classification (WHO Collaborating Centre for Drug Statistics Methodology 2011). Information about dementia-specific medications subsidised by the PBS and RPBS can be found in the Schedule of Pharmaceutical Benefits (DoHA 2012). Medicines dispensed to inpatients in public hospitals and those dispensed from remote area Aboriginal Health Services are excluded.

The DUSC database contains estimates of non-subsidised prescriptions dispensed, including private prescriptions and those that cost the patient less than the copayment amount required under the PBS or RPBS. These estimates are based on data collected through a monthly Pharmacy Guild survey of a stratified random sample of about 370 pharmacies throughout Australia.

## Deaths

Data about deaths with an underlying cause of dementia can be obtained from causes of death data compiled by the ABS and from the AIHW National Mortality Database (see AIHW 2012a: Appendix B for more detail).

Registration of death is a legal requirement in Australia. The death must be certified either by a medical practitioner using the Medical Certificate of Cause of Death or by a coroner. As part of the registration process, information about the cause of death is supplied and subsequently provided to the ABS for coding and compilation into aggregate statistics. The ICD-10 is currently used by the ABS for the coding of causes of death statistics. All diseases, morbid conditions and injuries that either resulted in or contributed to the death are entered on the death certificate, with these conditions coded as either the underlying cause of death or an associated cause. The 'underlying cause' of death is defined to be 'the disease or injury which initiated the train of morbid events leading directly to a person's death or the circumstances of the accident or violence which produced the fatal injury, as represented by a code' (WHO 2004). All other causes are considered 'associated causes' of death.

## 2.3 Longitudinal data

A number of longitudinal studies in Australia are contributing to an improved understanding of dementia. Longitudinal studies follow the same group of people (cohort) for a period of time. Advantages of this study design include its ability to examine multiple exposures, determinants and outcomes, and to measure time relationships. Such data are particularly valuable when considering questions pertaining to, for example, the effect of the type of dementia, treatments given or timing of diagnosis upon subsequent disease progression and outcomes. Examples of longitudinal studies of relevance to dementia include the Dynamic Analyses to Optimise Ageing (DYNOPTA) project (ANU 2009), the Australian Longitudinal Study on Women's Health (University of Newcastle 2014), and the 45 and Up Study (Sax Institute n.d.).

## 2.4 Data integration

Data linkage brings together information about people, places and events from different data collections based on common features while protecting privacy and confidentiality. It is 1 of the most powerful means for adding value to data and there is substantial public benefit to be gained from research using linked data. Another major advantage of linked data is that they can overcome the potential for double counting, because a person who is recorded in more than 1 data collection can be analysed as a single entity. Examples of the use of linked data that are of relevance to dementia include the Pathways in Aged Care (PIAC) project, and the NSW Hospital Dementia Services Project (HDS Project).

The PIAC project involved the linkage of data for 7 aged care programs along with the National Death Index (NDI) (AIHW 2011b). By linking ACAP data, where diagnosed dementia is identified and reported for people whose care needs are affected by it, to administrative data from aged care services, it is possible to examine service use pathways of people with dementia. This provides a new and valuable perspective on individuals' access and use of services. It can also potentially be used to estimate the minimum number of people with dementia using services where that program does not record dementia status, such as numbers of people with diagnosed dementia identified by an Aged Care Assessment Team (ACAT) who subsequently received assistance through a CACP.

The HDS Project is a 3-year National Health and Medical Research Council-funded project conducted by the AIHW in conjunction with the University of New South Wales and the University of Canberra, which is looking at outcomes for people with dementia admitted to hospital. The study population consists of patients aged 50 and over who had at least 1 night in a New South Wales public hospital between 1 July 2006 and 30 June 2007, focusing on patients with dementia (AIHW 2011c). As part of the study, administrative data sets (New South Wales hospital, residential aged care and ACAP data) were linked to obtain information about patient pathways through hospital and post-discharge. By linking hospital episodes of care, the HDS data provide information on the full period of a patient's hospitalisation, rather than individual episodes of care.

A number of longitudinal studies link survey data with registry and administrative data (such as hospital or Medicare data) – for example, the Australian Longitudinal Study on Women's Health, and the 45 and Up Study (AIHW 2012a: Appendix C).



### 3 Dementia data in Australia: current issues and gaps

Although many data collections and sources feature information on dementia, there is currently no national data set specifically designed for monitoring and reporting on dementia in Australia. Information and statistics for people with dementia therefore rely heavily on data sources developed for other, often broader, purposes. This diversity of focus allows these sources to be used for a range of purposes, but also results in information gaps in relation to dementia. In addition, currently available data sources often adopt different approaches and methodologies, resulting in comparability and consistency issues.

It is important to note that the limitations identified here relate specifically to the useability of these sources for reporting on dementia, which falls outside the original intention of these collections. The limitations may not reflect the usefulness of these collections for their stated purpose. There are very real difficulties that can affect the collection of data about people with dementia and their carers (see Box 3.1), and these should be kept in mind when considering the limitations and recommendations presented here.

Five key areas of dementia information and statistics are required for a robust monitoring and reporting framework. These are:

- prevalence, incidence, mortality and burden of disease
- characteristics of people with dementia
- carers of people with dementia
- health and aged care services usage
- expenditure on dementia.

This section summarises the main data limitations and information gaps in Australian dementia data in each area, as identified when compiling the AIHW's 2012 *Dementia in Australia* report.

#### **Box 3.1 Constraints affecting the collection of dementia data**

It is important to recognise that there may be many legitimate reasons for the data gaps and limitations identified in this section. For example, difficulties surrounding the diagnosis of dementia inevitably have an impact on the quality of these data. Data improvement is not only a technical/statistical process, but also one that will depend on changes in diagnosis and assessment practices.

There are also a number of constraints on the systems and people who record and process the data. If the provision of data takes significant time or resources, the quality of the data is likely to be compromised – this applies not only to service providers, but also to respondents to surveys. Data collection requirements must be viewed in context. For example, it would probably be an unnecessary burden for people providing home maintenance services to collect information about type of dementia and medications, and this information (which would also have privacy implications) would not support planning or delivery of this service. In a hospital setting, however, such information is essential for service delivery, and is considerably more feasible to collect.

## 3.1 Prevalence, incidence, mortality and burden of disease data

### Prevalence of dementia

Data on the prevalence of dementia is a major data gap. Australia lacks national epidemiological data that can be used to derive reliable estimates about the number of people in Australia with dementia. For many conditions, such as cancer, cardiovascular disease or diabetes, prevalence is generally determined by the number of people diagnosed with, or reporting, the condition (such as in a population survey). These approaches are inadequate for dementia because the condition is often unrecognised and/or undiagnosed, especially in the earlier stages. The 2012 *Dementia in Australia* report (AIHW 2012a: Chapter 2 and Appendix D) contains detailed analyses of the strengths and weaknesses of potential sources for Australian dementia prevalence estimates, including the National Health Survey, the Survey of Disability, Ageing and Carers, the National Survey of Mental Health and Wellbeing, the Dynamic Analyses to Optimise Ageing (DYNOPTA) project, as well as studies by Deloitte Access Economics (DAE 2011), the European Collaboration on Dementia (EuroCoDe 2009), and Lobo et al (2000).

Accurate prevalence estimates are essential for policy and service planning. Relatively small differences in prevalence rates applied to population estimates have potentially major implications for estimating the need for and cost of services, especially at a state/territory or regional level.

Lack of a systematic assessment for dementia using consistent screening tools and (when relevant) clinical diagnostic assessments represents a key information gap in dementia data. In addition, reliable statistics on younger onset dementia are essential for improving the accuracy of dementia prevalence estimates. There are several options for dealing with these gaps; these are discussed in the final Chapter of this paper.

### Use of meta-analyses

The lack of national data on which to base estimates of dementia prevalence is not unique to Australia. The usual solution is to use rates that have been derived through meta-analyses and apply them to population data. This approach was taken by the AIHW in the first *Dementia in Australia* report (AIHW 2007a) and by Deloitte Access Economics (DAE 2011). The rates used in the 2012 AIHW report to estimate the prevalence of dementia among people aged 60 and over were based on those released by Alzheimer's Disease International (ADI 2009) in the *World Alzheimer Report 2009*. By pooling data from a number of studies, this meta-analysis aimed to produce aggregate rates with better accuracy than any single individual study. These rates, produced by international experts, are the most current and comprehensive rates of dementia prevalence available. ADI's estimated prevalence rates for 3 regions were used: Australasia, Western Europe and North America. The rates for Australasia were based on 2 regional studies in Australia and 1 regional study in New Zealand. Rates for Western Europe and North America (which are similarly high-income regions) were also used to improve the robustness of the estimates.

There is considerable uncertainty about whether actual dementia prevalence rates vary across different countries, not just estimates of them (Seeher et al. 2011). The reliance on estimates of international prevalence rates may therefore introduce error into Australian estimates, the direction and extent of which we are not able to determine. In addition, the

application of international prevalence estimates does not allow for possible differences in prevalence rates among different groups in the Australian population.

### **Prevalence among specific population groups**

As noted above, a further gap in Australian prevalence data concerns dementia rates among specific population subgroups. Subgroups with potentially different prevalence rates include Indigenous communities and Australians born in other countries. Although these differences may make little difference to national estimates, there may well be larger effects at state and territory and regional levels.

**Younger onset dementia** is typically defined as onset before the age of 65. Estimating the prevalence of dementia among those under the age of 65 is difficult using population surveys because dementia is relatively rare in these age groups and thus requires very large samples. The dementia prevalence rates available from the *World Alzheimer Report 2009* (ADI 2009) pertain only to people aged 60 and over. Prevalence in younger age groups are commonly estimated from cases that come to medical attention, with 1 United Kingdom study (Harvey et al. 2003) currently widely relied upon (AIHW, 2007a 2012a; DAE 2011). No similar Australian study has been undertaken. However, a National Health and Medical Research Council-funded Australian Study currently underway – the Inspired Study – may provide some Australian data on the prevalence of younger onset dementia (UNSW Medicine 2012).

Little is currently known about dementia prevalence among Indigenous Australians, particularly those living in large towns and cities (Seeher et al. 2011). The limited evidence available suggests that prevalence rates of dementia in specific Indigenous communities are much higher than in the general population (NeuRA 2013; Smith et al. 2008), but studies to date have been limited in size and location. The SDAC is presently unable to supplement this information, because data on Indigenous status of people with dementia were not released from the 2009 SDAC due to confidentiality constraints. In addition, the 2009 SDAC excluded people living in *Very remote* areas and in Indigenous communities.

Similarly, little is known about whether dementia rates vary among Australians born in other countries, including those born overseas with non-English-speaking backgrounds (Seeher et al. 2011; Low et al. 2009). However, Low and colleagues cite research that indicates that a genetic risk factor for dementia (the Apolipoprotein E  $\epsilon$ 4 allele) differs in prevalence and influence on risk of dementia among people of different races (Low et al. 2009).

Finally, there is very limited evidence about the prevalence of different types of dementia in Australia (Seeher et al. 2011). The available international literature is inconsistent in terms of describing how common the various types of dementia are. In part, this is possibly because of the lack of distinct borders between the different types, and because a definitive diagnosis cannot be made unless autopsy evidence is available. The most common type of dementia, Alzheimer disease, is thought to account for about 50–75% of dementia cases worldwide, while the next most-common, vascular dementia, is thought to account for between 20% and 30% (ADI 2009).

In summary, service planning to meet the needs of people with dementia from different backgrounds, and with different types of dementia, is currently hampered by lack of evidence.

## Data used as inputs to prevalence and burden of disease estimates

Sparse Australian data on the following topics affect the derivation of prevalence and burden of disease estimates:

- the prevalence of dementia according to severity level
- the incidence of dementia
- relative risk of mortality due to dementia
- dementia disability weights.

This often necessitates the use of international data for deriving Australian estimates. See Chapter 2 and Appendix D of the 2012 *Dementia in Australia* report (AIHW 2012a) for more information on prevalence, incidence, mortality and burden of disease estimates for people with dementia in Australia.

## 3.2 Characteristics of people with dementia

### Identifying people with dementia

Consistent ways of identifying people with dementia and cognitive impairment is a critical data development requirement. However, existing data collections vary with respect to the type and amount of data collected used to identify people with dementia, and in some cases people with dementia cannot be identified at all. For example, routine administrative data for aged care packages and HACC do not currently collect data on dementia status. In other cases where dementia is identified, the method used (as well as the nature of the condition), can result in under-identification, the extent of which is often difficult to measure. For example, data from the HDS project showed that, for New South Wales, multi-day hospital episodes ending between 1 July 2005 and 30 June 2007, the proportion thought to be for people with dementia ranges from 0.6% if only the principal diagnosis for an episode or stay is used to identify patients with dementia, to 10.2% when a record of dementia in any episode is used to identify a patient as having dementia if dementia was ever recorded on any episode (AIHW 2012b).

People with dementia sometimes receive a service that is mostly unrelated to and unaffected by the presence of dementia – in these cases, collection of dementia identification data may be a lower priority. However, the situation is arguably different where service is sought because the person has dementia or where dementia affects some aspect of service delivery.

In relation to cognitive impairment, there is no consistent approach across data collections in the type of data collected. Scores or results from the use of cognitive screening and assessment tools are not commonly collected or reported in service use data sets.

In addition, reliance on self-report or proxy reporting is particularly problematic for conditions such as dementia, where the individual's cognitive functioning is impaired, where the diagnosis process can be prolonged and uncertain, and where stigma may result in a reluctance to identify. Self-reporting probably contributes to the underestimation of mild and moderate dementia in the household population through the SDAC. As well, where proxy reporting is used, information about the accuracy and reliability of the proxy-reporting elements is currently unavailable.

## People with dementia among specific population groups

Information about people from culturally and linguistically diverse backgrounds is variable in quality, and sparse on selected topics. The 2009 SDAC – which, as already noted, is a key source of information about people with dementia reported in *Dementia in Australia* – collected Indigenous status data, but they were not released at the unit record level due to confidentiality constraints. As well, people living in Indigenous communities were excluded from the scope of this survey (ABS 2011). In relation to people from non-English-speaking backgrounds, the 2009 SDAC collected data about ‘Country of birth’, ‘Main language spoken at home’ and ‘Proficiency in spoken English’.

People living in more inaccessible regions of Australia are often disadvantaged in a number of ways, including access to goods and services. Data about people living in remote areas are often lacking due to the difficulties and cost associated with collection. The SDAC excluded from its scope persons living in *Very remote* areas. Furthermore, small sample sizes affect the ability to present analyses relating to people in *Outer regional* and *Remote* areas. Issues relating to information about people with dementia in the context of health and aged care service use are discussed in Section 3.4.

## Sample sizes

A number of characteristics of current collection methodologies contribute to the limitations of dementia data, including sample size. Sample sizes in national ABS surveys reflect the design parameters of the survey, consistent with its objectives. This may mean that the sample is relatively too small to estimate the numbers and characteristics of people with low-prevalence conditions such as dementia accurately. That is, estimates based on small sample sizes can have high associated errors, limiting the amount of dementia-related information that can be reliably reported (even if it is collected). Over-sampling of older people would improve the reliability of estimates using these sources.

See Chapter 3 and Appendix B of the 2012 *Dementia in Australia* report (AIHW 2012a) for more detailed information on the limitations of major data sources used to describe the characteristics of people with dementia in Australia.

## 3.3 Carers of people with dementia

The availability of a carer greatly influences the ability of a person with dementia to remain at home safely, and carer stress has been found to be a critical factor in decisions to move into the residential care sector. Information about carers, and particularly measures of the impact of the caring role, are therefore important for the delivery of current services and future service planning. The capture of data about carers can be complex, because caring is complex: carers may care for more than 1 person, care recipients may have more than 1 carer, carers may themselves be care recipients, and the experience and characteristics of carers and the people for whom they care are diverse (AIHW 2011d). There is added difficulty in obtaining data about carers of people with dementia due to the relatively low prevalence of dementia in the general population. In addition, people may be reluctant to disclose their status as a carer of someone with dementia because this involves disclosing the dementia status of the care recipient.

The ABS SDAC is the major source of data about carers of people with dementia. The SDAC provides information about the number of Australian carers and their characteristics, the duration and nature of the care provided, the carer’s need for support and the impact of

caring. However, the SDAC provides detailed information only on primary co-resident carers. As well, available SDAC data do not allow for all non-co-resident carers of people with dementia to be identified, as detailed in the 2012 AIHW report (AIHW 2012a). The survey also excludes people living in *Very remote* areas and small sample sizes in *Remote* and *Outer regional* areas mean that information regarding carers in these regions is less reliable than in larger regions.

A number of support programs for people with dementia also collect information about carers. Because programs focus mainly on supporting either clients with frailty or disability, or those who care for them, data on carers varies in level of detail and quality. Several programs have made significant improvements to carer data in recent years (such as the HACC Minimum Data Set) (AIHW 2009). However, many of these do not routinely collect dementia identification data (HACC, EACH and EACHD), and so do not provide information specifically about carers of people with dementia (Table 3.1). The only regular source of program-level data about carers of people with dementia is the ACAP Minimum Dataset. The ACAP MDS provides data about the presence of carers for those people with dementia living in the community at the time of their ACAT assessment. As well, these data can be linked to data from other programs for which an ACAT assessment is required (such as was done in the PIAC project; see Section 2.4), to provide additional information about carers of people with dementia. Data about the availability of carers and the kind of assistance they provide informs recommendations about formal program support.

**Table 3.1: Dementia identification and data about carers in select service use collections**

Data collection	Data about carers	Dementia identification data
ACAP	Yes	Yes
HACC	Yes	No
EACH, EACHD (routine administrative data)	Yes	No
2008 Community Care Census (ad hoc collection)	Yes	Yes

Sources: AIHW 2009, 2012a.

Factors contributing to the fragmentation and comparability of data sources about carers of people with dementia include the use of different definitions of carers (see AIHW 2012a). While there is an agreed definition for use in national health and welfare data collections (AIHW METeOR 2012) its implementation varies across programs (AIHW 2009). Furthermore, collections use different definitions of primary carers. An example of this is the definitions of primary carer in the SDAC and in the 2008 Community Care Census (DoHA 2010) (see Appendix Table A1).

Data about carers from special needs groups are also important for service planning, but are currently lacking. For example, carers born overseas or from non-English-speaking backgrounds may have difficulty accessing services because of language proficiency, culture, religion, family dynamics and lack of awareness of relevant services (Low et al. 2009). Indigenous carers may also face challenges accessing culturally appropriate services and supports, especially in remote areas. Data on the Indigenous status of carers are particularly scarce, as noted in the 2009 *Who cares...? Report on the Inquiry into better support for carers* report (HRSCFCHY 2009).

See Chapter 5 and Appendix D of the 2012 *Dementia in Australia* report (AIHW 2012a) for a more detailed discussion of the availability of data on carers of people with dementia.

## 3.4 Health and aged care services usage

Health and aged care services are a major source of support for people with dementia and their carers. At present, large amounts of service-use data are collected in relation to dementia, but, here again, there is considerable inconsistency in both type of information collected and definitions used. Note that a number of the issues already highlighted in relation to dementia data (for example, identification of people with dementia), are also applicable in the context of health and aged care service use. Some additional issues, not yet explicitly discussed, are presented below.

### Person-focused versus service-focused data

Data collections do not always report activity by individuals, but by other measures such as prescriptions dispensed, episodes of hospital care or contacts by telephone. This means it is difficult to develop an understanding about how many people use some services, frequency of use, and whether the service is actually assisting those who most need its help.

As well, snapshot data (collected at a point in time) do not always provide an adequate picture of how the needs of care recipients and carers change over time – this is particularly relevant in the case of people with degenerative conditions such as dementia.

Data linkage (subject to appropriate ethical and privacy considerations) is 1 strategy that can be used to overcome this limitation. Data linkage is being more and more widely used in health research, and more recently in research in the aged care sector; for example, the HDS and PIAC projects (Draper et al 2011; AIHW 2009). New principles are now in place for the integration (linkage) of Commonwealth data and these high-risk data linkage projects must be carried out by accredited 'integrating authorities' under strict conditions. The AIHW is an integrating authority, which positions the AIHW to play a vital role in bringing together Commonwealth and state data for health and welfare research.

### Service use by specific population groups

Data about characteristics such as Indigenous status, country of birth and English language proficiency is essential for understanding whether patterns of service use vary between subpopulations and whether available services are meeting needs. In relation to aged care, the *Aged Care Act 1997* and *Aged Care Principles* designate some groups of people as 'people with special needs' including Aboriginal and Torres Strait Islander people and people from non-English speaking backgrounds (DSS 2013).

However, the completeness and quality of Indigenous identification data in aged care data sets is variable (AIHW 2007b; Arkles et al. 2010). Furthermore, the reporting requirements from some programs aimed at delivering services to Indigenous people are minimal. For example, the National Aboriginal and Torres Strait Islander Flexible Aged Care Program funds services to deliver culturally appropriate aged care close to home and country, mainly in regional and remote areas. An ACAT assessment is encouraged for each client accessing services provided under this program, but teams may not always be available for these clients given the generally very remote locations of the services they use. An ACFI is also not required for clients accessing the residential aged care stream of the program (AIHW 2012a). The CCC is another example of a data source with incomplete Indigenous identification data – nearly all non-participating outlets were in rural, remote or very remote locations and these service outlets provided assistance to between 300 and 600 Indigenous care recipients

(DoHA 2010). Consequently, the number of Indigenous packaged care recipients is underestimated using this data source.

Although many collections include data elements relevant to the identification of Australians from culturally and linguistically diverse backgrounds, the specific data elements may vary and are rarely fully consistent with the ABS Standards for Statistics on Cultural and Language Diversity (ABS 1999). The standards recommend that the following information should be collected in order to identify people from non-English-speaking backgrounds:

- country of birth of person
- main language other than English spoken at home
- proficiency in spoken English.

The Aged Care Client Record collects 'Country of Birth' and 'Language other than English spoken at home' but only 'Country of birth' is reported as part of the ACAP MDS (DoHA 2013). Certain data elements from the ACAP MDS are imported into the Ageing and Aged Care Data Warehouse. In this instance, only the data element 'Country of birth' is imported.

The 2008 Community Care Census collected both 'Country of birth' and 'Language other than English' (DoHA 2010). Of the package recipients for whom English was not the main language spoken at home, 68% required additional services that specifically dealt with the absence of English, suggesting that this data item could provide useful information for meeting the needs of this group.

The inclusion of the language data item in reporting for the ACAP MDS would enhance information about this client group and make it consistent with other data in the warehouse.

## **Data about people with dementia in a hospital setting**

A wide range of information is currently collected on episodes of admitted patient care in hospitals. Principal and additional diagnosis information can be used to identify episodes of care for which dementia was chiefly responsible for occasioning the patient's episode of care (principal diagnosis), as well as episodes of care for which dementia affected patient management (additional diagnosis). However, not all of a patient's conditions are necessarily coded as an additional diagnosis. The coding rules indicate that only those conditions that were significant in terms of treatment required, investigations needed and resources used during the episode of care are to be coded as an additional diagnosis. Consequently, people with dementia who are hospitalised will only be identifiable in the episode-level data if dementia is considered to have an impact on cost of care. Other factors contributing to the under-identification of dementia in hospitals include constraints on the interactions between patients and doctors, the challenges associated with differential diagnosis and cognitive impairment of dementia patients, and the systemic limitations and issues with documentation and classification practices (Cummings et al. 2011; Phillips et al. 2011). In a recent report, using linked data from the HDS project (see Section 2.4), the AIHW found that about half (47%) the episodes for people with dementia did not have dementia recorded as either a principal or an additional diagnosis (AIHW 2013). Information on outpatient and emergency department care of people with dementia is also limited, because national data on the diagnoses related to such care are not available.

See Chapter 4 and Appendix B of the 2012 *Dementia in Australia* report (AIHW 2012a) for more detailed information on the limitations of service use data for people with dementia.



## 3.5 Expenditure on dementia

Estimates of direct expenditure on caring for people with dementia across the health and aged care sectors are important for policy and planning. As outlined in the 2012 AIHW report, due to the lack of relevant data, not all dementia-related health and aged care system expenditure is available. This includes expenditure for hospital services for non-admitted patients (such as outpatient and emergency department services), for specialised mental health care services and for respite care in residential aged care facilities. At the same time, data available from the numerous programs, packages and services vary widely, so the feasibility of estimating expenditure attributable to dementia (as opposed to expenditure on people with dementia) also varies.

See Chapter 6 and Appendix D of the 2012 *Dementia in Australia* report (AIHW 2012a) for a more detailed discussion of the availability of data on expenditure on dementia in Australia.

## 3.6 Summary

In summary, existing data collections include a wide array of information, which is relevant to the identification, treatment and care of people with dementia, and the support of carers and family members. However, fragmentation and inconsistency are evident across collections in terms of type of data collected, and there is only limited comparability of definitions. In addition, there are key data gaps including a lack of data from which to derive accurate estimates of dementia prevalence. Recent and forthcoming aged care reforms offer a major opportunity to improve the quality and extent of existing dementia data and to fill data gaps. These initiatives are essential for benchmarking and measuring the impact and success of service delivery. Data linkage is also a valuable tool for maximising the use of existing data sets. The next section provides some options to guide continued improvement of dementia data.

## 4 Improving dementia data in Australia

High-quality and timely data and information are essential to support evidence-based policy, drive improvement and provide ongoing monitoring of the accessibility, availability and quality of care and support services for Australians with dementia and their carers. Despite the substantial body of information available about people with dementia and their carers, there are a number of data gaps and issues that have an impact on our ability to monitor and report on the condition.

The purpose and operational context of the data collections often result in varying approaches to the coverage of dementia and cognitive impairment. Data development in this area is also affected by the complexity of the syndrome of dementia, variations in its progression and manifestations among different types of dementia, and developments in clinical research and care practice. The purpose of this section is to present options for data development, and for potential data elements that could be used in a wide range of collections, promoting greater consistency and comparability across the field, and greater quality in many collections. These are summarised in Table 4.1, and discussed below. These options were borne out of the process of compiling the national report *Dementia in Australia* (AIHW 2012a), and are therefore largely the result of a ‘bottom up’ analysis of dementia data in Australia, rather than a comprehensive ‘top down’ process. They should be read in conjunction with both the 2012 *Dementia in Australia* report (AIHW 2012a) and the 2007 *Dementia in Australia* report (AIHW 2007a).

**Table 4.1: Options for the development of dementia data in Australia**

Data source/type	Options
<b>Improving data availability</b>	
Measuring dementia prevalence	Explore with all jurisdictions how more robust dementia prevalence estimates might be obtained, including through the use of existing data sources and/or the creation of new ones such as a multistage population survey (in which participants are systematically assessed for dementia using both screening tools and clinical diagnostic assessments), and a dementia registry.
<b>Improving data consistency and quality</b>	
Aged care collections	<p>Look for opportunities throughout the implementation of aged care reforms to incorporate a focus on improving dementia data in routine aged care data collections, particularly for the new Home Care Packages and Dementia and Veteran’s Supplements.</p> <p>Use the evaluation of aged care reforms to consider the need for regular collection strategies and reporting of dementia data.</p> <p>Consider the recommended tools and guidelines included in the Dementia Outcomes Measurement Suite (DOMS) (a standard suite of the most current instruments and tools for dementia assessment within all environments) in the development of data sets.</p> <p>Standardise the dementia data collected through the ACAP and the ACFI and through other aged care data collections.</p>
ACAP MDS reporting	Revise the ACAP MDS reporting requirements to include ‘Language other than English’ among MDS reporting requirements, to consider whether functional assessment information (already collected) should also be included among MDS reporting requirements.
Disability collections	<p>Consider including ‘Health condition’ as a data element in the Disability Services NMDS specification, enabling dementia to be specifically recorded as the condition causing disability.</p> <p>Consider other ways in which the changing administrative data environment might be leveraged to enhance the collection of information about service clients with dementia.</p>

(continued)

**Table 4.1(continued): Options for the development of dementia data in Australia**

Data source/type	Options
<b>Improving data use</b>	
Monitoring and reporting	Consider arrangements for ongoing monitoring and reporting about dementia, consistent with other National Health Priority Areas.
Strengthening data integration capacity	Standardise the identifying information on aged care program data sets to improve linkage across aged care data sets and between aged care data sets and other administrative collections.

It should be noted that many of the data gaps and limitations described in the previous sections are not new and have been identified by AIHW and others in the past. A number of the suggestions made in this section have also been presented in the past in the 2007 *Dementia in Australia* report, but these are still of relevance. However, the current policy environment presents new opportunities to enhance the availability and quality of dementia data, and the predicted increase in numbers of people requiring services underlines the importance of these proposed improvements.

## 4.1 Improving data availability

### Dementia prevalence data

In light of critiques of Australian dementia prevalence data (ADI 2009; AIHW 2007a, 2012a; Anstey 2010), it is timely for Australia to give greater attention to developing and obtaining robust epidemiological data in order to inform dementia policy and service planning. Key questions in this regard are: what is the ‘gold standard’ for such data? Moreover, can we improve existing data sources to provide data that are more robust or do we need to consider development of a new collection (or some combination of these)?

Multistage surveys in which participants are systematically assessed for dementia using both screening tools and clinical diagnostic assessments may be of most value in deriving comprehensive estimates of how common dementia is, because they are more likely to detect mild and moderate cases of dementia, and cases are clinically established. This approach was taken in Canada, for example, where a national study of the prevalence of dementia among those aged 65 and over was conducted in the early 1990s (CSHAWG 1994). In Australia, no such national study has been undertaken.

Reliable estimates of the number of people with younger onset dementia – that is, onset under the age of 65 – are particularly important for improving the accuracy of dementia prevalence estimates. Reliable estimates are difficult to obtain from population surveys because dementia is relatively rare in these age groups and thus very large samples would be required. As a result, estimates are derived from cases that come to medical attention, by establishing dementia registries. Although results from a study (not yet published) in Eastern Sydney will provide some more information about the number and experiences of Australians diagnosed with younger onset dementia (Withall et al., forthcoming), no such Australian dementia registry exists.

In addition, there is limited information about the number and characteristics of people with dementia from several important population groups, including people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people and people living in more inaccessible regions of Australia. In the absence of new data sources, beginning to collect dementia information in existing data sources, such as the Census, or

improving dementia information collection, such as in the SDAC or national health surveys, may lead to some reliable data on these specific subpopulations.

#### **Options for improving dementia prevalence data**

- Explore with all jurisdictions how more robust dementia prevalence estimates might be obtained, including through the use of existing data sources and/or the creation of new ones such as a multistage population survey (in which participants are systematically assessed for dementia using both screening tools and clinical diagnostic assessments), and a dementia registry.

## **4.2 Improving data consistency and quality**

### **Dementia data in routine aged care collections**

Aged care programs are a major source of support for people with dementia and their carers. Expanding the capacity of their related data collections to identify people with dementia should be a high priority for data development. At present, a substantial quantity of service-use data are collected in relation to dementia, but there is also considerable inconsistency in the type of information collected and the definitions used. A thorough review of the data presently collected (and reported) in the context of service delivery, as well as a determination of data requirements, would facilitate more efficient collection of data and improve quality. Agreement about the extent of information to be collected, taking into account the purpose and context of data collection activity is also important. Data that are not relevant to service delivery or a by-product of service should if possible not be collected through routine data collection methods, but rather by other means, such as one-off surveys. This reduces burden on data recorders in services and improves data accuracy.

Consistency of data specifications with available and relevant national and international standards is important in order to avoid duplication of effort and the development of conflicting standards. Data sets that are based on a single set of agreed definitions and standards are more likely to have a high degree of consistency with each other, reducing data development time and cost. The quality of data, including consistency and comparability, is enhanced when clear and appropriate standards are available for these data. The cost of not creating data standards may be high and can include loss of information with staff changes, data redundancy, data conflicts, liability, misapplications and decisions based upon poorly documented data.

The establishment of national agreed data elements – particularly in relation to identifying people with dementia – would greatly assist with dementia reporting and monitoring. Previous work in relation to dementia data development may provide a useful basis for further work. The National Dementia Data Analysis and Development Reference Group, which guided the preparation of the 2007 report *Dementia in Australia: national data development and analysis* (AIHW 2007a), developed potential data elements that could be used in a wide range of collections. The current policy context and changes to the aged care system present a major opportunity for renewed consideration and implementation of the proposed data elements. These data elements, if used as a standard ‘menu’, and if context and purpose are taken into account, will promote greater consistency and comparability across the field, and greater quality in many collections.

The proposed data elements are grouped within the following categories:

- identification of cognitive impairment and dementia
- cognitive impairment and dementia diagnosis information
- current behaviour related to dementia and its impact on care
- coexisting health conditions
- impact of caring
- reporter details.

Data elements were recommended at 3 collection levels – essential, highly desirable and desirable. These collection levels differ in terms of the amount and complexity of elements included. The categorisation of elements into levels is not intended to be prescriptive, but provides an indication of how information collected about people with dementia and their carers can be structured. Categorisation to any of the levels depends primarily on the underlying purpose and nature of the collection and the extent to which people with dementia and/or their carers are a significant proportion of the population of interest. Each data element stands alone to provide information on an aspect of dementia, but together the elements offer a more detailed account of the experience of people with dementia and their carers. The data elements may be collected on 1 occasion only, such as when a person accesses an emergency service, or at intervals depending on the nature and purpose of the collection. Table 4.2 summarises the framework for the proposed data elements – see Appendix B for definitions, value domains, and other information about each of the proposed data elements, and AIHW (2007a) for further details.

**Table 4.2: Framework for proposed dementia data elements**

	<b>1 Identification of cognitive impairment and dementia</b>	
	1.1: Identification of cognitive impairment (essential)	
	1.2: Identification of a diagnosis of dementia (essential)	
<b>6 Reporter details</b> 6.1: Reporter status (essential) 6.2: Relationship of proxy reporter to person of interest (essential)	<b>2 Cognitive impairment and dementia diagnosis information</b>	<b>3 Current behaviour related to dementia and its impact on care</b>
	2.1: Type of dementia (highly desirable)	3.1: Nature of current challenging behaviour (desirable)
	2.2: Date of first formal diagnosis (highly desirable)	3.2: Frequency of occurrence of current challenging behaviour (desirable)
	2.3: Professional occupation of the person who first identified cognitive impairment or diagnosed dementia (highly desirable)	3.3: Duration of episodes of current challenging behaviour (desirable)
	2.4: Severity of dementia (highly desirable)	3.4: Disruption due to current challenging behaviour (desirable)
	2.5: Treatment with medication for cognitive impairment due to dementia (desirable)	3.5: Stress experienced as a result of current challenging behaviour (desirable)
	<b>4 Coexisting health conditions</b>	
	4.1: Coexisting health conditions (desirable)	
	<b>5 Impact of caring</b>	
	5.1: Impact of care measure (desirable)	

Source: AIHW 2007a: 244–247.

### **Options for improving dementia data in aged care collections**

- Look for opportunities throughout the implementation of aged care reforms to incorporate a focus on improving dementia data in routine aged care data collections, particularly for the new Home Care Packages and Dementia and Veteran's Supplements.
- Use the evaluation of aged care reforms to consider the need for regular collection strategies and reporting of dementia data.
- Consider the recommended tools and guidelines included in the Dementia Outcomes Measurement Suite (DOMS) (a standard suite of the most current instruments and tools for dementia assessment within all environments) in the development of data sets.
- Standardise the dementia data collected through the ACAP and the ACFI and through other aged care data collections.

## **ACAP MDS**

ACAP data are an important source of information about dementia among clients seeking assessment and support through aged care programs. In addition, AIHW's data linkage capacity has produced information about the dementia status of people who take up aged care packages following assessment. As part of the Aged Care Reform Package, work will be undertaken to standardise assessment processes for the new Commonwealth Home Support program and the comprehensive ACAT assessment for Home Care Packages and residential aged care.

### **Options for ACAP MDS reporting**

- Revise the ACAP MDS reporting requirements to include 'Language other than English' among MDS reporting requirements, to consider whether functional assessment information (already collected) should also be included among MDS reporting requirements.

## **Dementia data in disability collections**

Data collection for disability services is undergoing a transition as the National Disability Insurance Scheme (NDIS) is implemented. However, until the NDIS is fully implemented, the well-established Disability Services National Minimum Dataset (NMDS) remains the main source for reporting on services used by people with disability, and is likely to be a continuing source of important 'benchmark' and other data informing the implementation of the NDIS. Hence, there would be value in improving this collection by including 'health condition' in the NMDS specification, in addition to the current data item on broad disability group. This would enable the recording of dementia as a specific condition causing disability, rather than the current grouping of dementia with other neurological conditions. An alternative to a new data item is an expansion of the value domain for the current item Person – primary disability group, NDA code N[N], to separate out dementia from other neurological conditions.

There would also be value in capitalising on the changing administrative data environment to consider other opportunities to improve the collection and recording of information about clients with dementia.

#### **Options for improving dementia data in disability collections**

- Consider including 'Health condition' as a data element in the Disability Services NMDS specification, enabling dementia to be specifically recorded as the condition causing disability.
- Consider other ways in which the changing administrative data environment might be leveraged to enhance the collection of information about service clients with dementia.
- Consider including 'Health condition' as a data element in the Disability Services NMDS specification, enabling dementia to be specifically recorded as the condition causing disability.

### **4.3 Improving data use**

More can be done with the data that are currently collected, and analysis of existing data should be promoted. The establishment of the National Aged Care Data Clearinghouse provides an opportunity to improve data availability, encourage data reporting, and maximise data use.

#### **Monitoring and reporting for dementia as a National Health Priority Area**

Designation of dementia as an NHPA brings with it an expectation that there will be ongoing monitoring of changes in the burden of disease arising from dementia. A robust monitoring system would include reporting in relation to prevalence and incidence, changes in the population profile, risk and protective factors, trends in the effectiveness of treatment and care regimes and in outcomes relating to disability, mortality and quality of life.

A number of other NHPA conditions have established monitoring and reporting arrangements, which can be used to inform discussions. Examples of these models include:

- the National Centre for Monitoring Cancer (NCMC), located and managed within the AIHW, which was established in 2009 to monitor cancer rates and their impact and outcomes, as well as to identify and tackle priority gaps and deficiencies in population-level cancer and related data (AIHW 2012c).
- the Australian Centre for Asthma Monitoring (ACAM), established in 2002 and based at the Woolcock Institute of Medical Research (a collaborating unit of the AIHW), which aims to reduce the burden of asthma in Australia by developing, collating and interpreting data relevant to asthma prevention, management and health policy (ACAM 2002).
- Since 1996, the National Centre for Monitoring Cardiovascular Disease (NCMCD), located at the AIHW, has monitored patterns and trends in cardiovascular disease. The Centre provides data to inform national policies and programs for heart, stroke and vascular health, making the information publicly available. It develops, collates, analyses and disseminates data on cardiovascular disease. It also identifies and tackles gaps and deficiencies in existing data (AIHW 2012d).

In addition to monitoring and reporting, a monitoring centre could also prioritise and tackle gaps and limitations in dementia data. The implementation of the recent Aged Care Reform Package provides an opportunity to enhance the availability and quality of information about aged care clients with dementia. For example, to monitor the dementia supplement for

Home Care Packages successfully, there is a need to identify clients with dementia within existing data collection processes. Similarly, the evaluation of reform measures may require the collection of new data and certainly provides an opportunity to review the adequacy of currently available data.

#### **Options for improving monitoring and reporting on dementia**

- Consider arrangements for ongoing monitoring and reporting about dementia, consistent with other NHPAs.

### **Strengthening data integration capacity**

Combining information across data sets enhances its value, and can also reduce administrative burden. This requires greater standardisation across aged care data sets, which will take time (and resources), but will have long-term benefits in improving the usability of dementia (and other) data.

Data linkage currently offers a powerful tool for understanding service use patterns and pathways within the aged care sector and between the aged care and health sectors. For example, linking service-use data to the NDI and PBS data may be particularly valuable. Data linkage is facilitated by the inclusion of identifying information in source data sets, preferably including full name and date of birth, but at least the statistical linkage key (SLK581) currently included in the ACAP and HACC data sets. Greater use of data linkage (subject to appropriate ethical and privacy considerations) would increase the value of existing data, and shift the focus from service-level to person-level data.

#### **Options to strengthen data integration capacity**

- Standardise the identifying information on aged care program data sets to improve linkage across aged care data sets and between aged care data sets and other administrative collections.



# Appendix A: Additional tables

Table A1: Carer definitions in Australia

AIHW METeOR	2009 ABS SDAC	ACAP	2008 CCC
<p>An informal <b>carer</b> includes any person, such as a family member, friend or neighbour, who is giving regular, ongoing assistance to another person.</p> <p>A <b>primary carer</b> is an informal carer who provides assistance with 1 or more core activities (communication, mobility and self-care.)</p>	<p>A <b>carer</b> is a person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or persons who are elderly (i.e. aged 60 years or over). This assistance has to be ongoing, or likely to be ongoing, for at least 6 months. Assistance to a person in a different household relates to 'everyday types of activities', without specific information on the activities. Where the care recipient lives in the same household, the assistance is for 1 or more of the following activities: cognition or emotion, communication, health care, household chores, meal preparation, mobility, property maintenance, reading or writing, self-care, or transport.</p> <p>A <b>primary carer</b> is a person who provides the most informal assistance, in terms of help or supervision, to a person with 1 or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least 6 months and be provided for 1 or more of the core activities (communication, mobility and self-care). In this survey, primary carers only include persons aged 15 years and over for whom a personal interview was conducted. Persons aged 15 to 17 years were only interviewed personally if parental permission was granted.</p>	<p>A <b>carer</b> is described as someone, such as a family member, friend or neighbour, excluding paid or volunteer carers organised by formal services (including paid staff in funded group houses), who has been identified by the individual, carer or significant other as providing regular and sustained care and assistance to the person without payment other than a pension or benefit. The carer may or may not live with the person for whom they care.</p> <p>Information is only collected about 1 carer in this collection, who is referred to as the <b>main carer</b>. The main carer is the person who is identified by the client and/or a carer as providing the most significant amount and type of care and assistance related to the client's capacity to remain living at home.</p>	<p>A <b>carer</b> was defined as a person such as a family member, friend or neighbour who provided regular and sustained care and assistance to another person, without receiving payment other than a pension or benefit. Formal care services such as care or assistance provided by paid workers or volunteers arranged by formal services were excluded.</p> <p>A <b>primary carer</b> was the person who provided the most informal (unpaid) care on an ongoing basis to the care recipient. This could include coordination of formal care but excluded formal care services such as care or assistance provided by paid workers or volunteers arranged by formal services.</p>

Sources: AIHW 2012a, AIHW METeOR 2012.

## Appendix B: Proposed dementia data elements

### **Data element 1.1: Identification of cognitive impairment**

*Definition:* The presence of cognitive impairment in the person of interest.

*Value domains:*

- definite
- probable
- none
- unknown.

*Guide for use:* Cognitive impairment is impairment in 1 or more mental functions that comprise cognition. These functions include short-term memory (learning skills) or long-term memory, executive function (abstract thinking, judgement, problem solving) or other higher cortical function (aphasia, apraxia, agnosia, constructional abilities, calculation).

If the person of interest has dementia, the code 'Yes' should be selected and dementia diagnosis should also be collected.

*Inclusions:* Any person whose cognitive functioning has been impaired as a result of acquired brain injury due to events such as accidents, stroke, brain tumours, infection, poisoning, lack of oxygen or degenerative neurological disease. This includes a person with pre-existing impairment of cognitive functioning, which had been stable and can be due to any cause, who has experienced a decline from a previous level of cognitive functioning.

*Exclusions:* Any person with cognitive impairment who has not experienced a decline from a previous level of cognitive functioning, including people with intellectual disabilities.

*Value meanings:*

- **Definite:** Presence should be coded where evidence of cognitive impairment is available based on the results of an assessment conducted by a medical practitioner.
- **Probable:** The person of interest has not been assessed and the presence of cognitive impairment has not been definitively established but observations of behaviour and capacity in the person of interest by another person with a long-standing close relationship with the person of interest suggest impairment of cognitive functioning.
- **None:** There is no suggestion of cognitive impairment based on the result of an assessment or the observed behaviour or capacity in the person of interest by another person with a long-standing close relationship with the person of interest.
- **Unknown:** No information about cognitive impairment is available.

*Source:* National Dementia Data Analysis and Development Reference Group.

### **Data element 1.2: Identification of a diagnosis of dementia**

*Definition:* The presence of a diagnosis of dementia in the person of interest.

*Value domains:*

- yes
- no
- unknown.

*Guide for use:* Presence should be coded where a diagnosis of dementia is confirmed by a medical practitioner.

*Source:* National Dementia Data Analysis and Development Reference Group.

### **Data element 2.1: Type of dementia**

*Definition:* A code set representing the aetiology of dementia.

*Value domains:*

- Alzheimer's disease
- vascular dementia
- mixed dementia
- Lewy body dementia
- frontal lobe dementia (includes Pick's disease)
- dementia in alcohol abuse (e.g. alcohol-related brain damage)
- dementia in other substance abuse
- dementia in Huntington's disease
- dementia in Parkinson's disease
- dementia in HIV disease
- dementia in Creutzfeldt-Jakob disease
- dementia of unspecified type
- other dementia of a type not listed above
- unknown type.

*Source:* National Dementia Data Analysis and Development Reference Group, based on ICD-10-AM.

### **Data element 2.2: Date of first formal diagnosis**

*Definition:* The date on which a person of interest, family member, carer or friend is first provided with a diagnosis of dementia.

*Value domains:*

- DDMMYYYY.

*Guide for use:* The date of the first formal diagnosis marks the occasion when a medical practitioner first provides a diagnosis of dementia to a person, family member, carer or friend based on the outcome of a formal diagnostic process.

A formal diagnosis is defined as a 'decision reached, after assessment, of the nature and identity of the disease or condition in a patient'. The diagnostic process includes the use of recognised and accepted assessment or diagnostic tools by a medical practitioner who is experienced in their use and interpretation.

If a medical practitioner subsequently revises the type of dementia, this does not influence the date of the first formal diagnosis.

*Source:* National Dementia Data Analysis and Development Reference Group, based on METeOR identifier 270544 .

### **Data element 2.3: Medical professional who first identified cognitive impairment or diagnosed dementia**

*Definition:* The professional occupation of the person that identified cognitive impairment or diagnosed dementia in the person of interest.

*Value domains:*

- general practitioner
- specialist physician
- geriatrician
- psychogeriatrician or psychiatrist
- neurologist
- other
- unknown.

*Guide for use:* A formal diagnosis is defined as the decision reached, after assessment, of the nature and identity of the disease or condition in a patient. The diagnostic process includes the use of recognised and accepted assessment and diagnostic tools by a medical practitioner who is experienced in their use and interpretation.

*Source:* National Dementia Data Analysis and Development Reference Group.

#### **Data element 2.4: Severity of dementia**

*Definition:* A code set representing the extent of the dementia.

*Value domains:*

- very mild
- mild
- moderate
- severe.

*Guide for use:* This data element should be based on the assessment of a clinician who has had training in the use of the Clinical Dementia Rating scale based on a detailed knowledge of the person of interest.

*Source:* Based on Hughes et al. 1982 and Morris 1993.

#### **Data element 2.5: Treatment with medication for cognitive impairment due to dementia**

*Definition:* The medication, if any, the person of interest is currently taking to manage cognitive impairment.

*Value domains:*

- no medication taken
- donepezil (Aricept)
- galantamine hydrobromide (Reminyl)
- rivastigmine (Exelon)
- memantine (Ebixa)
- other medication (please specify)
- not stated/inadequately described.

*Source:* National Dementia Data Analysis and Development Reference Group.

**Data element 2.6: Treatment with medication for behavioural and psychological symptoms related to dementia**

*Definition:* The class of medication, if any, the person of interest is currently taking to manage behavioural and psychological symptoms of dementia.

*Value domains:*

- no medication taken
- psycholeptic
- antipsychotics (typical and atypical)
- anxiolytics
- hypnotics and sedatives
- psychoanaleptics
- antidepressants
- psychostimulants and nootropics
- psycholeptics and psychoanaleptics in combination
- antidementia drugs
- other medication (please specify)
- not stated/inadequately described.

*Source:* ATC classification.

### **Data element 3.1: Nature of current challenging behaviour**

*Definition:* The challenging behaviour the person exhibits.

*Value domains:*

- does not exhibit challenging behaviour
- verbal aggression
- hitting
- grabbing
- tearing things
- pushing
- biting
- spitting
- physical sexual advances
- pacing
- inappropriate robing/disrobing
- performing repetitive mannerisms
- trying to get to a different place
- handling things inappropriately
- throwing things
- general restlessness
- constant requests for attention
- repetitious sentences/questions
- complaining
- negativism
- making strange noises
- screaming
- verbal sexual advances
- hiding things
- hoarding things
- other
- not stated/inadequately described.

*Guide for use:* Challenging behaviour is any behaviour associated with dementia which causes distress or danger to the person with dementia and/or others.

Current behaviour includes any behaviour occurring over the previous 4 weeks.

*Source:* National Dementia Data Analysis and Development Reference Group, based on Cohen-Mansfield Agitation Inventory.

### **Data element 3.2: Frequency of occurrence of current challenging behaviour**

*Definition:* How often a person exhibits challenging behaviour due to dementia.

*Value domains:*

- not applicable
- less than once a week, but still occurring
- once or twice a week
- several times a week (three or more)
- once or twice a day
- several times a day (three or more)
- several times an hour (two or more)
- other
- not stated/inadequately described.

*Guide for use:* Challenging behaviour is any behaviour associated with dementia which causes distress or danger to the person with dementia and/or others (Bird 2003).

Current behaviour includes any behaviour occurring over the previous 4 weeks.

*Source:* National Dementia Data Analysis and Development Reference Group, based on Cohen-Mansfield Agitation Inventory.

### **Data element 3.3: Duration of episodes of current challenging behaviour**

*Definition:* The average number of minutes, from start to finish, that a person exhibits challenging behaviour due to dementia.

*Value domains:*

- not applicable
- number (MMMM)
- not stated/inadequately described.

*Guide for use:* Challenging behaviour is any behaviour associated with dementia which causes distress or danger to the person with dementia and/or others (Bird 2003).

Current behaviour includes any behaviour occurring over the previous 4 weeks.

*Source:* National Dementia Data Analysis and Development Reference Group.



#### **Data element 3.4: Disruption due to current challenging behaviour**

*Definition:* The extent of disruption to usual activities that results from the challenging behaviour.

*Value domains:*

- not disruptive
- mildly disruptive
- moderately disruptive
- very disruptive
- extremely disruptive.

*Guide for use:* Challenging behaviour is any behaviour associated with dementia that causes distress or danger to the person with dementia and/or others (Bird 2003).

Current behaviour includes any behaviour occurring over the previous 4 weeks.

*Source:* National Dementia Data Analysis and Development Reference Group, based on Caldwell & Bird 2004.

#### **Data element 3.5: Stress experienced as a result of current challenging behaviour**

*Definition:* The extent of stress experienced by a family member, carer, friend or other person in response to challenging behaviour.

*Value domains:*

- no stress
- little stress
- moderate stress
- high stress
- extreme stress.

*Guide for use:* Challenging behaviour is any behaviour associated with dementia that causes distress or danger to the person with dementia and/or others (Bird 2003).

Current behaviour includes any behaviour occurring over the previous weeks.

*Source:* National Dementia Data Analysis and Development Reference Group, based on Caldwell & Bird 2004.

#### **Data item 4.1: Coexisting health conditions**

*Definition:* Coexisting diseases and conditions that have been diagnosed by a clinician and are currently being treated, including mental health conditions, and other diseases, illnesses or conditions.

*Value domains:*

- no coexisting health condition
- certain infectious and parasitic diseases
- neoplasms
- diseases of the blood and blood-forming organs and certain disorders involving the immune system
- endocrine, nutritional and metabolic disorders
- mental and behavioural disorders
- diseases of the nervous system
- diseases of the eye and adnexa
- diseases of the ear and mastoid process
- diseases of the circulatory system
- diseases of the respiratory system
- diseases of the digestive system
- diseases of the skin and subcutaneous tissue
- diseases of the musculoskeletal system and connective tissue
- diseases of the genitourinary system
- certain conditions originating in the perinatal period
- symptoms, signs and abnormal clinical and laboratory findings not otherwise specified
- injury, poisoning and certain other consequences of external causes.

*Guide for use:* The presence of a coexisting health condition may indicate a need to engage other clinical support.

*Source:* Based on ICD-10-AM.

#### **Data element 6.1: Reporter status**

*Definition:* The source of reported information regarding the person of interest.

*Value domains:*

- self-reported
- reported by another person (proxy reporter)
- not stated/inadequately described.

*Guide for use:* If another person reports on behalf of the person of interest, that person is a proxy reporter.

*Source:* National Dementia Data Analysis and Development Reference Group.

**Data element 6.2: Relationship of proxy reporter to person of interest**

*Definition:* The nature of the relationship between the proxy reporter and the person of interest.

*Value domains:*

- clinician/medical practitioner
- care worker
- spouse or partner
- family member other than spouse or partner
- friend or neighbour
- other
- not stated/inadequately described.

*Source:* National Dementia Data Analysis and Development Reference Group.

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Rich and robust data are needed for policy makers and practitioners to facilitate the prevention, early detection, diagnosis and treatment of dementia, as well as improving support for people with dementia and those who care for them. This paper provides an overview of the status of dementia data at the time of preparing the report *Dementia in Australia* (AIHW 2012a), and suggests ways in which the availability, consistency and quality of these data could be improved.