

# **Dementia in Australia**

**National data analysis and development**

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**National data analysis and development**

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# Abbreviations

|          |  |
|----------|--|
| ABS      | Australian Bureau of Statistics  |
| ACAP     | Aged Care Assessment Program   |
| ACAT     | Aged Care Assessment Team  |
| ACCMIS   | Aged and Community Care Management Information System                              |
| ACFI     | Aged Care Funding Instrument   |
| ADAS-Cog | Alzheimer's Disease Assessment Scale, cognitive subscale                           |
| ADL      | activity of daily living   |
| AGECAT   | Automated Geriatric Examination for Computer Assisted Taxonomy                     |
| AIDS     | acquired immunodeficiency syndrome   |
| AIHW     | Australian Institute of Health and Welfare   |
| ALSWH    | Australian Longitudinal Study on Women's Health                                    |
| ATC      | Anatomical Therapeutic Chemical  |
| BEACH    | Bettering the Evaluation and Care of Health  |
| BPSD     | behavioural and psychological symptoms of dementia                                 |
| CACP     | Community Aged Care Packages   |
| CAMDEX   | Cambridge Examination for Mental Disorders of the Elderly                          |
| CCRC     | Commonwealth Carer Respite Centre  |
| CDR      | Clinical Dementia Rating   |
| CI       | confidence interval  |
| CIBIC    | Clinician's Interview-Based Impression of Change                                   |
| CSHA     | Canadian Study of Health and Aging   |
| CSI      | Caregiver Strain Index   |
| CSTDA    | Commonwealth-State/Territory Disability Agreement                                  |
| CT       | computed tomography  |
| CURF     | confidentialised unit record file  |
| DALY     | disability-adjusted life year  |
| DESP     | Dementia Education and Support Program   |
| DISMOD   | DISease MODels   |
| DoHA     | Australian Government Department of Health and Ageing                              |
| DSM      | Diagnostic and Statistical Manual of Mental Disorders                              |
| EACH     | Extended Aged Care at Home   |
| EURODEM  | European Community Concerted Action on the Epidemiology and Prevention of Dementia |
| fMRI     | functional magnetic resonance imaging  |
| GDS      | Global Deterioration Scale   |

|           |  |
|-----------|--|
| GHQ       | General Health Questionnaire   |
| GP        | general practitioner   |
| GPSCU     | General Practice Statistics and Classification Unit  |
| HACC      | Home and Community Care  |
| HIV       | human immunodeficiency virus   |
| IADL      | instrumental activity of daily living  |
| IAM       | Institute for Algorithmic Medicine   |
| ICD       | International Statistical Classification of Diseases and Related Health Problems   |
| ICD-10-AM | International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification |
| ICF       | International Classification of Functioning, Disability and Health   |
| ICPC-2    | International Classification of Primary Care, 2nd edition  |
| IEC       | International Electrotechnical Commission  |
| ISO       | International Standards Organisation   |
| MBS       | Medicare Benefits Schedule   |
| MCI       | mild cognitive impairment  |
| MDS       | minimum data set   |
| METeOR    | Metadata Online Registry   |
| MMHA      | Mini Mental Health Assessment  |
| MMSE      | Mini-Mental State Examination  |
| MRI       | magnetic resonance imaging   |
| NCCH      | National Centre for Classification in Health   |
| NCSD      | National Community Services Data Dictionary  |
| NHADD     | National Housing Assistance Data Dictionary  |
| NHDD      | National Health Data Dictionary  |
| NHMD      | National Hospital Morbidity Database   |
| NHS       | National Health Survey   |
| NMDS      | national minimum data set  |
| NRCP      | National Respite for Carers Program  |
| OECD      | Organisation for Economic Co-operation and Development   |
| PATH      | Personality and Total Health   |
| PBS       | Pharmaceutical Benefits Scheme   |
| RCS       | Resident Classification Scale  |
| RPBS      | Repatriation Pharmaceutical Benefits Scheme  |
| RSE       | relative standard error  |
| SAND      | Supplementary Analysis of Nominated Data   |
| SDAC      | Survey of Disability, Ageing and Carers  |
| SPECT     | single photon emission computed tomography   |

|     |   |
|-----|---|
| WHO | World Health Organization                       |
| YLD | years lost due to disability                    |
| YLL | years of life lost (due to premature mortality) |

## Symbols

|      |  |
|------|--|
| *    | estimate has a RSE of 25% to 50% and should be used with caution                     |
| **   | estimate has a RSE greater than 50% and is considered too unreliable for general use |
| —    | when used in a table—nil or rounded to zero (including null cells)                   |
| . .  | when used in a table— not applicable   |
| n.p. | when used in a table— not published by the data source                               |
| nec  | not elsewhere classified   |
| nfd  | not further defined  |
| nos  | not otherwise specified  |

# Overview

Dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. The International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision (WHO 1992a:312) defines dementia as:

*a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.*

Dementia is not a single specific disease and therefore affects people differently and with varying impact of their families and carers. Dementia is not a natural part of ageing, although most people with dementia are older. After the age of 65 the likelihood of living with dementia doubles every five years and it affects 24% of those aged 85 and over (Henderson & Jorm 1998).

Because Australia's population is ageing, there has been growing recognition that dementia represents a significant challenge to health, aged care and social policy. This report estimates that the number of people with dementia will grow from over 175,000 in 2003 to almost 465,000 in 2031, assuming the continuation of current dementia age-specific prevalence rates. Governments at national and state level are developing responses to the challenges posed by dementia, through initiatives such as the Australian Government's *Helping Australians with dementia, and their carers – making dementia a National Health Priority*.

In 2004 the Australian Government Department of Health and Ageing commissioned the Australian Institute of Health and Welfare to undertake the present study to provide a profile of the Australian population who experience dementia and to review the availability and quality of data about dementia. An important objective of the report is to provide a guide for improving national dementia data by identifying possible data elements that would be suitable for inclusion in a range of data collection contexts. Recommendations for these data elements are presented as areas of information and options for potential data element sets that are considered vital to collecting relevant, informative and comparable data on dementia prevalence estimates, management and outcomes.

## Integrating data about dementia

There is no single source of data which can be relied on for estimates about the prevalence of dementia, the characteristics and needs of those with dementia or their carers, and the full range of services and treatments that people with dementia are receiving. A range of data sources has been used in this report to ensure that the most significant and available data was brought to bear on these questions. The multiplicity of data sources gives breadth to the report, and also provides opportunities for confirming findings using data from different sources and from different perspectives. The report draws these data together so that we can achieve a better understanding of dementia in the Australian population than would be possible from any single source.

The major data sources used include:

- Survey of Disability, Ageing and Carers (SDAC)

- National Hospital Morbidity Database
- Aged Care Assessment Program
- Bettering the Evaluation and Care of Health
- Medical Benefits Schedule
- Pharmaceutical Benefits Scheme
- National Respite for Carers Program
- Census data from the Community Aged Care Packages and Extended Aged Care at Home programs
- Dementia Education and Support Program.

## People with dementia and their carers

Almost 175,000 people had dementia in Australia in 2003, of whom 64% were female and 81% were aged 75 or older (see Chapter 4). Since dementia prevalence is strongly age-related, the number of cases of dementia is expected to increase as the population ages to almost 465,000 by 2031. There are about 37,000 new cases of dementia each year of which 23,000 are female and 14,000 male. Alzheimer's disease was the most common diagnosis of dementia, generally followed by vascular dementia.

Dementia may be classified as *mild* in about 96,000 people (55%), *moderate* in 52,000 people (30%) and *severe* in 26,000 (15%). Most people with mild dementia are living in households and most people with moderate or severe dementia are in cared accommodation.

Most of the 'burden of disease' caused by dementia is due to disability rather than premature death, with disability accounting for about three-quarters of the total disease burden in 2003.

## Characteristics of people with dementia (see Chapter 5)

Given the increasing prevalence of dementia with age and longer life expectancy for females, it is not surprising that people with dementia are mostly older women – more than half of the SDAC respondents with dementia, and more than half of people with dementia who sought an aged care assessment or who receive Community Aged Care Packages were women aged 75 years or older. While the majority of people with dementia were born in Australia, a significant minority were born overseas in non-English-speaking countries (16% of SDAC respondents and 18% of clients receiving an aged care assessment).

According to the SDAC, the majority of people with dementia live in cared accommodation including residential aged care facilities. The majority of people with dementia living in households lived with others (usually family) rather than living alone. A smaller proportion of those with dementia lived alone than of those without dementia.

People with dementia have higher levels of dependence in instrumental activities of daily living (and to a lesser extent, higher dependence in activities of daily living) than those without dementia. Almost all people with dementia required assistance with at least one activity (and with at least one personal activity). Those with dementia experience more activity limitations than those without dementia and a larger proportion of people with dementia require assistance with each type of activity than those without dementia.

The activity with which least assistance is required is communication – however, a larger proportion of those with dementia required this type of assistance compared with those without dementia.

The majority of people with dementia also needed assistance with activities such as making decisions or thinking through problems, coping with feelings or emotions, relationships, managing their behaviour or with cognitive or emotional tasks. Additionally, multiple behavioural symptoms (including aggression) appear to be common; a significant proportion of care recipients with dementia experience moderate to severe behavioural symptoms and a significant proportion of their carers experience distress associated with these symptoms.

Among the older population, dementia is more likely than other health conditions to be associated with a severe or profound limitation in self-care, mobility or communication, to be a main disabling condition and to be associated with multiple health conditions. People with dementia reported the third highest mean number of health conditions (5.3 conditions), after those with depression (5.5 conditions) and those with phobic and anxiety disorders (5.3 conditions).

### **Carers of people with dementia (see Chapter 6)**

Carers are family members or friends who provide support to children or adults who have a disability, mental illness, chronic conditions or are frail aged and unable to look after themselves (DoHA 2002b). This ranges from emotional support through financial and practical assistance to supervision and assistance with personal care and other activities for extended periods.

Informal sources of care provided much of the assistance received by people with dementia living in households. The majority of people with dementia living in households have a carer, particularly those who have a more severe level of disability or dependency. Those with dementia were more likely to have a carer than those without dementia.

The review and analysis of data about carers in this report supports the conclusion of Schofield et al. (1996:160) that 'There is limited knowledge about caregivers in Australia in general. Comprehensive data on the prevalence of caregiving are not yet available. Most studies of carers have tended to be small scale and unrepresentative, with study samples often drawn from a client list of a major service provider'.

The only national survey to collect data about carers (SDAC) underestimates the numbers of people with dementia and consequently the numbers of their carers. According to the 2003 SDAC there were approximately 23,200 carers providing assistance to 25,800 people with dementia living in the same household. The SDAC also indicates that approximately 65% of carers of people with dementia live with the person they are caring for. This suggests that there may be approximately 35,900 carers of people with dementia in Australia identified according to Australian Bureau of Statistics (ABS) definitions of a carer. This equates to about four carers for every three people with dementia living in households who receive informal assistance (who are mostly severely or profoundly disabled).

Carers of people with dementia are mostly older women – however, a significant proportion of care is also provided by men. Around three-quarters of carers were married or in de facto relationships. Carers of people with dementia were more likely to live in the same household with the recipient with dementia: 39% of co-resident carers and 65% of co-resident primary carers were a spouse or partner, and 46% of co-resident carers and 30% of co-resident primary carers were children or children-in-law (SDAC).

Although the majority of carers of people with dementia are born in Australia and mainly speak English at home (or speak English as a first language), there is a significant proportion of carers born overseas in non-English-speaking countries.

Most of the available data indicates that carers of people with dementia were either not working or had reduced their hours of work. This reflects partly the age of carers and partly the demands associated with caring for someone with dementia. Consistent with this, government pensions or allowances were the main source of cash income for the majority (53%) of co-resident carers (SDAC).

All co-resident primary carers provided assistance with one or more core daily activities to their main recipient with dementia – 91% provided assistance with communication, 91% provided assistance with mobility, and 78% provided assistance with self-care (SDAC). Furthermore, all carers provided assistance with health care, paperwork, housework and meal preparation; and a large majority provided assistance with transport (96%); property maintenance (87%); and cognition or emotion (91%).

Some studies noted that over half of the care recipients with dementia were unable to be left alone (Schofield et al. 1998b), and data from the 2003 SDAC show that around 65% of co-resident primary carers spend 40 hours or more each week actively caring for or supervising the care recipient with dementia.

The mean or median duration of care is often reported to be less than five years, reflecting the late age of onset of dementia and the fact that increased carer burden is a risk factor for entry into residential care. Methodological and study design differences mean that published estimates of the duration of the caring role vary widely. Data from the 2003 SDAC show that the majority of co-resident primary carers (52%) had been caring for their main recipient with dementia for between one and four years. However, consistent with Schofield et al. (1998b), over one-fifth (22%) had been caring for their main recipient with dementia for more than 10 years.

Most carers report a sense of duty to care – a large proportion reported that they provide care because they felt an emotional obligation to take on the role (52%) or that it was a family responsibility (48%) (SDAC). Only 26% of co-resident primary carers reported feeling satisfied due to the caring role and a significant proportion (46%) reported at least one adverse effect due to the caring role. These adverse effects included frequently feeling angry or resentful about their caring role, having been diagnosed with a stress-related illness, feeling weary or lacking energy or frequently feeling worried or depressed because of the caring role. Most Australian studies have reported a link between carer burden and the behavioural and psychological symptoms associated with dementia.

The majority (61%) of co-resident primary carers reported that the caring role had at least one adverse main effect on their relationship with other family members and friends resulting from losing touch with friends and having less time to nurture other relationships (SDAC). But over half of co-resident primary carers (52%) considered that their relationship with the care recipient was unaffected by the care recipient's dementia.

Almost half (48%) of co-resident primary carers stated that they did not have a fall-back carer (SDAC). Around 52% of these carers reporting needing or wanting an improvement or more support in areas such as respite care, financial assistance, physical assistance, emotional support, improvement in their own health or other areas of assistance.

## **Service use and expenditure**

People with dementia and their carers use a substantial amount of health and aged care services (Chapter 7).

In 2003, 83,000 Australians experienced dementia of such severity that they always or sometimes needed assistance with basic daily activities.

- Approximately 68,000 permanent residents with dementia in aged care facilities collectively used 24.7 million residential aged care bed-days.
- People with dementia accounted for 1.4 million patient days for 82,800 hospital separations.
- An estimated 450,000 GP-patient encounters, 82,500 GP-ordered pathology services, 42,000 referrals by GPs to other health care providers and 10,000 GP-ordered imaging services in 2003 were for the diagnosis and management of dementia.

Traditionally, expenditure on health and welfare services provided for dementia has reflected the total expenditure incurred for people with dementia as their main health condition, regardless of the cost impact of any other health conditions experienced by the individual. This report presents the results of a different approach to estimating expenditure that takes account of the presence of other health conditions. This approach results in estimates of expenditure that can be attributed to the dementia condition (see Chapter 8). Based on this approach, total health and welfare system expenditure for dementia in 2003 is estimated at \$1.4 billion:

- The majority is in the residential aged care sector where \$993 million is attributed to dementia.
- Admitted patient expenditure of \$149.3 million, pharmaceutical expenditure of \$72.8 million and out-of-hospital medical service expenditure of nearly \$20 million are also attributed to dementia.
- Expenditure for community care use by people with dementia, including Home and Community Care, Extended Aged Care at Home, Veterans' Home Care, Community Aged Care Packages and Aged Care Assessment Program is estimated to be \$135 million.

The total expenditure for dementia is projected to increase by 225% between 2003 and 2030-31.

While service use can be measured and reported, non-use of potentially valuable service support can be more difficult to identify. Yet service non-use can be an important indicator of the need for improvements in aspects of program design and delivery such as information strategies, access points, intervention design, and so on. For example, given the high levels of stress experienced by those caring for people with dementia it is significant that the majority of co-resident primary carers of people with dementia (70%) reported that they had never used respite care (SDAC). Furthermore, 57% of primary carers stated that they had never received respite care and did not need or want it. Similarly, 73% of relevant Aged Care Assessment Program clients with dementia had not used it. Brodaty et al. (2005) found that 84% of carers in their study did not use respite services, and only 35% of those carers reported needing this service. Perceived lack of need was reported by 65% of carers as the principal reason for non-use of respite services, followed by care recipient's resistance to accepting help from services (12%), not having enquired (9.1%) and lack of knowledge (7.6%).

## **Review of dementia data in Australian collections**

In Australia, information about people with dementia, their carers and their use of health and care services, is collected through a number of administrative (or service by-product)

data collections and population and client surveys. The report briefly describes 19 relevant data sources and the type of data collected which is relevant to dementia (see Chapter 3):

| <b>Administrative data collections</b>  | <b>Surveys</b>   |
|---|--|
| <ul style="list-style-type: none"> <li>• Dementia Education and Support Program</li> <li>• Medicare Benefits Schedule</li> <li>• Pharmaceutical Benefits Scheme</li> <li>• National Hospital Morbidity Database</li> <li>• Aged Care Assessment Program</li> <li>• Home and Community Care</li> <li>• Community Aged Care Packages</li> <li>• Extended Aged Care at Home</li> <li>• Residential Aged Care</li> <li>• National Respite for Carers Program</li> </ul> | <ul style="list-style-type: none"> <li>• National Health Survey</li> <li>• Survey of Disability Ageing and Carers</li> <li>• Bettering the Evaluation and Care of Health</li> <li>• The Australian Longitudinal Study on Women's Health</li> <li>• Australian Longitudinal Study of Ageing</li> <li>• Sydney Older Person's Study</li> <li>• Canberra Longitudinal Study of Ageing</li> <li>• PATH Through Life Project</li> <li>• Dubbo Study of the Health of the Elderly</li> </ul> |

Chapter 11 examines and compares dementia-relevant data items in more detail across the major relevant collections. These data items cover the following themes:

- How people with dementia and cognitive impairment are identified (e.g. through data items such as diagnosis status and dementia type)
- Severity of dementia and cognitive impairment
- Extent of behavioural and psychological symptoms of dementia
- Environmental factors (e.g. presence and availability of carers, services and treatments).

Existing national 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, in many areas there is inconsistency between collections in terms of what type of data is collected, and there is only limited comparability of definitions and value domains.

Based on the analysis undertaken for this report, the limitations and strengths of the data analysed in respect of dementia are summarised (Chapter 9):

| <b>Limitations</b>  | <b>Strengths</b>   |
|---|--|
| <ul style="list-style-type: none"> <li>• Poor or inconsistent identification of dementia in a number of relevant collections</li> <li>• Non-reporting of collected data</li> <li>• Non-collection of some relevant data</li> <li>• Little national longitudinal or linked data</li> <li>• Study design issues such as sample size and self- or proxy-reporting</li> <li>• Limited national data about carers of people with dementia</li> </ul> | <ul style="list-style-type: none"> <li>• A considerable amount of relevant data is collected</li> <li>• Formal diagnosis or assessment of dementia in a number of collections</li> <li>• The inclusion of cared accommodation in the SDAC contributes strongly to our ability to identify people with dementia in residential aged care</li> </ul> |

### Improving dementia data

Four major strategies would contribute to the improvement of data about dementia in Australia:

- better and earlier diagnosis of dementia

- improved consistency of identification of people diagnosed with dementia in all data collections, including through consistent use of agreed classifications and adherence to data standards
- agreement about the extent of information to be collected
- a change in focus from services-focused data to person-focused data through support and encouragement of data linkage efforts and/or the collection and analysis of longitudinal data.

## Definition and classification of dementia

A number of international classifications assist with identifying and classifying dementia (see Chapter 2). These include the ICD, which approaches dementia from a disease perspective, attempting to identify the underlying aetiology; and the Diagnostic and Statistical Manual of Mental Disorders and International Classification of Functioning, Disability and Health (ICF) which both approach dementia from a perspective of functional outcomes. The International Classification of Primary Care is used as a classification for general practice or primary care, wherever applicable.

Most existing Australian data sources define, diagnose, classify and/or measure dementia using one or more of these classifications. Estimates of the prevalence of dementia in a population are critical for the planning, funding and provision of appropriate treatment and care of people with dementia. Prevalence estimates vary with the definition and diagnostic criteria used by the classification. At the level of the individual, the use of different diagnostic criteria, and the utility and validity of the screening and assessment tools used, affect the likelihood of receiving a diagnosis, and consequently have an impact on the person's access to appropriate information, treatment and care options.

While analysis of currently available data is constrained by the definitions and classifications used in existing data sources, future data development in respect of dementia needs to be supported by the use of common definitions and classifications of dementia and its outcomes.

This report recommends that **both** the ICD and ICF should be used in Australia for this purpose. Both the ICD and ICF belong to the family of international classifications developed by the World Health Organization (WHO) for application to various aspects of health. The WHO family of international classifications provide a framework to code a wide range of information about health (e.g. diagnosis, functioning and disability, reasons for contact with health services) and uses a standardised common language permitting communication about health and health care across the world in various disciplines and sciences (WHO 2001:3).

Health conditions (e.g. diseases, disorders, injuries) are generally classified using the ICD, which provides diagnosis codes for diseases, disorders or other health conditions.

Functioning and disability associated with health conditions are classified using the ICF. The ICD and ICF enable consistent collection of information about diagnosis as well as human functioning. The ICD and ICF are therefore complementary, and WHO encourages the use of these classifications together to provide a more meaningful and complete picture of the health needs of people and populations (WHO 2001:4).

## Proposed data elements for data collection about dementia

The development of data about dementia should occur in a way which is consistent with established principles for data development and adheres to recognised data standards (see

Chapter 10). The development of the proposed data elements recommended by this report (see Chapter 12) was overseen and guided by the National Dementia Data Analysis and Development Reference Group. The Reference Group considered the relative importance of the data elements for supporting policy and practice designed to assist people with dementia and their carers. In addition, the Reference Group took account of other data development criteria such as feasibility of collection and consistency with existing data standards. The recommended data elements were developed with reference to both existing data elements collected in Australia and priorities in dementia research.

The menu of data elements is focused on elements of relevance to dementia or cognitive decline. The proposed data elements are grouped within the following categories:

1. Identification of cognitive impairment and dementia
2. Cognitive impairment and dementia diagnosis information
3. Current behaviour related to dementia and its impact on care
4. Coexisting health conditions
5. Impact of caring
6. Reporter details.

Elements about the sociodemographic characteristics of people with dementia and their carers are assumed to be already included in relevant collections and they are not proposed here. Similarly, data elements about activity and participation limitations (e.g. mobility, self-care, shopping) are clearly critical for assessing the care and support needs of people with dementia and their family and carers. However, the scope of this project did not extend to this area of data collection and the report does not propose specific data elements. The ICF provides a well-developed classificatory framework for the collection of data items about functioning.

**Framework for proposed dementia data elements**

|   |   |   |
|---|---|---|
| <p><b>6 Reporter details</b></p> <p>6.1: Reporter status</p> <p>6.2: Relationship of proxy reporter to person of interest</p> | <p><b>1 Identification of cognitive impairment and dementia</b></p> <p>1.1: Identification of cognitive impairment</p> <p>1.2: Identification of a diagnosis of dementia</p>  |   |
|   | <p><b>2 Cognitive impairment and dementia diagnosis information</b></p> <p>2.1: Type of dementia</p> <p>2.2: Date of first formal diagnosis</p> <p>2.3: Medical professional who first identified cognitive impairment or diagnosed dementia</p> <p>2.4: Severity of dementia</p> <p>2.5: Treatment with medication for cognitive impairment due to dementia</p> <p>2.6: Treatment with medication for behavioural and psychological symptoms of dementia</p> | <p><b>3 Current behaviour related to dementia and its impact on care</b></p> <p>3.1: Nature of current challenging behaviour</p> <p>3.2: Frequency of occurrence of current challenging behaviour</p> <p>3.3: Duration of episodes of current challenging behaviour</p> <p>3.4: Disruption due to current challenging behaviour</p> <p>3.5: Stress experienced as a result of current challenging behaviour</p> |
|   | <p><b>4 Coexisting health conditions</b></p> <p>4.1: Coexisting health conditions</p>   |   |
|   | <p><b>5 Impact of caring</b></p> <p>5.1: Impact of care measure</p>   |   |

Three dementia data collection levels are proposed, which differ in terms of the amount and complexity of elements included:

1. **Essential data elements:** to provide an estimate of the number of people with dementia or cognitive impairment. This level is appropriate for collections or surveys that do not necessarily focus on dementia, include only a relatively small number of people with dementia, or do not require more detailed information about the dementia syndrome for effective and appropriate service delivery.
2. **Highly desirable data elements:** to provide more detailed information about people with dementia, which may be required for appropriate treatment, care and services. This level is appropriate for collections which require more detailed information about the condition, for example programs that provide services to a population that includes a proportion of people with dementia such as the Aged Care Assessment Program and the National Respite for Carers Program.
3. **Desirable data elements:** to provide more detailed information about people with dementia and their carers, which may be required for appropriate treatment and care management. This level is appropriate for collections focusing on the population of Australians with dementia, for example programs that deliver dementia-specific services or deliver services to a population that includes a significant proportion of people with dementia.

The use of any of the levels depends on the underlying purpose, nature and context of the collection. For a comprehensive picture of the population experiencing dementia, it is recommended that the whole suite of elements be used.