

Section 3: Dementia data development

10 Developing dementia data standards

10.1 Purpose

This section of the report aims to provide a guide for improving national dementia data in ways that will inform future policy and planning by improving its consistency and comprehensiveness.

This chapter discusses principles and requirements of data development which adhere to recognised data standards. It examines the constraints affecting the collection of data in terms of the context and possible collections methods, including the issue of who provides information, which is of particular relevance for dementia data.

An earlier chapter in the report (Chapter 3) reviewed the scope, purpose and collection context of a number of national data collections, and identified the amount and nature of dementia-relevant data elements included in each collection. Issues associated with existing dementia data were further revealed in the data analysis that comprised section 2 of this report and which were summarised in Chapter 9. Chapter 11 reviews and compares dementia data elements across a selection of relevant data sources in more detail.

Chapter 12 identifies three levels of data elements that would be suitable for inclusion in a range of data collections. The purpose of this report is not to define or prescribe a definitive set of data elements for collection about dementia but to outline key themes and options for potential data elements useable in a wide range of collections. If these data elements are used as a standard 'menu', and if context and purpose are taken into account, this will promote greater consistency and comparability across the field, and improved data quality in many collections.

10.2 Principles of data development

The following policy, planning, provision and performance considerations should guide the development of dementia data elements:

1. Policy considerations: the data elements should reflect and be consistent with policy issues with relation to dementia.
2. Planning considerations: the data elements should also support decisions about the allocation of resources and funding. When fully developed, they should include clear and concise statements about who should deliver what, to whom and where.
3. Provision: data elements should also describe the provision of services that has occurred. These should relate to both policy and planning.
4. Performance: data elements should allow analysis of how well the planning and delivery achieved the policy outcomes. This information should be able to inform policy, evaluation and research.

In determining the type and 'minimum' level of information required to meet reporting requirements about dementia the following principles were considered. These principles guide decisions about whether a data element is recommended for collection and provide a basis for assessing the suitability of elements selected. These principles should also guide the further development of dementia data:

- *Consistency of data specifications with relevant and available national and international standards*
This 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 and reduce data development time and cost. The quality of data, including its consistency and comparability, is enhanced when the proper standards are available for that 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.
- *Minimisation of burden on respondents*
Data development should also support the collection and provision of standardised information as a by-product of service providers' administrative practice. This will also improve data accuracy and completeness. Surveys should also be designed with a view to collecting the required information with minimum impost on respondents.
- *Compatibility of data collection and reporting requirements across settings*
This avoids situations where the same data has to be counted or reported differently for different programs.
- *Data must be relevant and meaningful to respondents including service providers*
Data should provide statistics that support service planning, or provide information necessary for the care and treatment of individuals and the support of their families and carers. They must take account of relevant needs of providers, feasibility and appropriateness of data collection, and current scientific knowledge and technological capacity.
- *Data requirements should take account of usual practice in service delivery*
Where data are collected from service providers, it is important that data collections describe what actually happens in practice. They need to have practical utility (e.g. support client care). Data specifications should not constrain users or force them to operate in a way that does not reflect usual practice. Where possible, data development should be based on data that service providers already want or need to collect about clients and service provision.
- *Privacy and confidentiality provisions should be adhered to*
The data development process must ensure that data that are recommended will be collected, disseminated, secured and used in such a way as to protect the privacy and confidentiality of any individual and/or organisation to which it may refer.

The collection methodology and the context of data capture are other considerations when selecting and specifying data elements. Part 10.4 contains a discussion of the constraints that impact upon the collection of dementia data elements and further explores this theme.

10.3 Data standards

Data standards describe the expected meaning and acceptable representation of data for use within a defined context. Adherence to data standards ensures there is mutual understanding of the meaning of underlying concepts between different parties, and promotes consistency and comparability of data for analysis and interpretation.

Descriptions of data (metadata) are defined in the International Standards Organisation/ International Electrotechnical Commission (ISO/IEC) 11179 standard that includes six parts (Box 10.1) (ISO/IEC 2004). These metadata standards allow information to be consistently defined, so that information can be compared across different service delivery settings and sectors and between service level data and population data. The need for consistency of meaning is vital to facilitate information sharing among primary and secondary users of the data. Much of the work involved in establishing a data collection is in the development of data standards to ensure comparability and consistency of the data collected and produced from the collection. The development of data standards is not something that is done at the end of the data development process. It is part of the data development process and carries on throughout the life of the data collection.

Box 10.1: Component parts of the ISO/IEC 11179 standard

Part 1: Framework – introduces and discusses fundamental ideas of data elements, value domains, data element concepts, conceptual domains, and classification schemes essential to the understanding of this set of standards and provides the context for associating the individual parts of ISO/IEC 11179.

Part 2: Classification – provides a conceptual model for managing classification schemes. There are many structures used to organise classification schemes and there are many subject matter areas that classification schemes describe. So, this Part also provides a two-faceted classification for classification schemes themselves.

Part 3: Registry Metamodel and Basic Attributes – specifies a conceptual model for a metadata registry. It is limited to a set of basic attributes for data elements, data element concepts, value domains, conceptual domains, classification schemes, and other related classes, called administered elements. The basic attributes specified for data elements in ISO/IEC 11179-3:1994 are provided in this revision.

Part 4: Formulation of Data Definitions – provides guidance on how to develop unambiguous data definitions. A number of specific rules and guidelines are presented in ISO/IEC 11179-4 that specify exactly how a data definition should be formed. A precise, well-formed definition is one of the most critical requirements for shared understanding of an administered element; well-formed definitions are imperative for the exchange of information. Only if every user has a common and exact understanding of the data element can it be exchanged trouble-free.

Part 5: Naming and Identification Principles – provides guidance for the identification of administered elements. Identification is a broad term for designating, or identifying, a particular data element. Identification can be accomplished in various ways, depending upon the use of the identifier. Identification includes the assignment of numerical identifiers that have no inherent meanings to humans; icons (graphic symbols to which meaning has been assigned); and names with embedded meaning, usually for human understanding, that are associated with the data element's definition and value domain.

Part 6: Registration – provides instruction on how a registration applicant may register a data element with a central Registration Authority and the allocation of unique identifiers for each data element. Maintenance of administered elements already registered is also specified in this document.

This report uses and refers to national data standards as described in Australian data standards. National health, community services and housing data standards are contained in the National Health Data Dictionary (NHDD) (National Health Data Committee 2004a), the

National Community Services Data Dictionary (NCSDD) (AIHW 2004g) and the National Housing Assistance Data Dictionary (NHADD) respectively (AIHW 2006b). The dictionaries provide a menu of standard data elements, from which a data collection can be specified.

Under the National Health Information Agreement and the National Health Information Standards Plan for Australia, the NHDD is the authoritative source of health data definitions used in Australia where national consistency is required.

The NCSDD is the reference on agreed data definitions and information standards of relevance to the community services sector. The NCSDD is an initiative under the National Community Services Information Agreement and all signatories to the Agreement have agreed to use the NCSDD as the authoritative source of information about endorsed metadata for use in data collections in the community services field.

The NHADD is the authoritative source of housing data definitions where national consistency is required or desired and it sets out agreed data definitions, classifications and standards developed under the National Housing Data Agreement and the Agreement on National Indigenous Housing Information.

These dictionaries contain the agreed specification of the meaning and representation of individual components of data that have been endorsed for use by the relevant national information authority. That is, each metadata element in the national dictionaries has been endorsed as a national data standard. The dictionaries are also intended to assist a much broader audience (e.g. service providers in developing their own data collections, and information systems, and researchers in either analysing data and/or developing surveys).

As part of the data development process, classification schemes such as the International Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) (NCCH 2002b), the International Classification of Functioning and Disability (ICF) (WHO 2001) and the International Classification of Primary Care Version 2, Plus (ICPC-2 Plus) (Britt 1997) can contribute toward semantic interoperability, that is, the ability to exchange data such that there is a mutual understanding of the precise meaning of the data and the context in which that meaning is valid. These are official terminological systems that are used to classify data and that are recognised and endorsed by national or international bodies.

In addition, METeOR, or the Metadata Online Registry, has been developed by the AIHW as the its online registry of nationally endorsed data standards and for the health, community services and housing assistance sectors. Data standards presented in the NCSDD and NHDD have been restructured for METeOR in line with the latest version of the international standard for metadata registries.

10.4 Constraints that impact upon the collection of dementia data elements

The scope of this project has been to identify data elements which are desirable for improving the amount and type of information available about dementia. While this project has attempted to take account of the constraints arising from the data collection context, these considerations will become even more important in the further development and implementation of these data elements in collections.

Both the feasibility and/or appropriateness of introducing new data elements to an existing collection or introducing the same data element across multiple existing collections is

influenced by a number of factors. The development of data elements for inclusion in collections involves a mix of 'top-down' and 'bottom-up' approaches. That is, the inclusion of data elements needs to be driven by management and policy requirements but should also be mindful of the operational constraints on the systems and people who need to record and process data.

Data needed to support secondary (or downstream) information purposes (e.g. reporting, policy, governance, decision support) should be derivable from primary data (point of service delivery data). The challenge for data development is to ensure that operational systems designed to support direct care are also capable of generating standard data as a by-product of the care process, to be used for downstream purposes.

When new data elements are introduced, care should be taken to minimise the burden on data collectors. If the collection of a data element takes significant time or resources, the quality of the data are likely to be compromised if resources and time are limited. This consideration applies not only to service providers but also to population surveys of different types.

To reduce the burden on data recorders in services, and to improve data accuracy, the introduction of data elements should support the collection and provision of standardised information as a by-product of service providers' administrative practice. If the collection of data is used to manage the service it is more likely to be seen as relevant. Data elements that are administrative by-products and can be collected as part of normal processes are more likely to be collected accurately. Data that are not relevant to service delivery or a by-product of service should as far as possible not be collected through routine data collection methods, but through other data collection methods, for example, one-off surveys.

Whether or not a data element can be included in a collection also depends on the scope and purpose of the collection, that is, what population and establishments are included in the collection and what services are provided by the data collector. For example, data elements about type of dementia and type of medications taken are probably not appropriate for collection by a service providing domestic assistance services, but would be relevant for a residential aged care provider or hospital.

The timing and the frequency of data collection can also influence the appropriateness of including some data elements. The data may be collected continuously as a by-product of administrative processes or as part of a one-off survey. In order to monitor change over time it is necessary to collect the same data concerning a person of interest at intervals. The interval of time should be enough that changes can be detected without the need to collect the element too frequently. In addition, some data elements may not be appropriately collected through an initial contact or needs assessment, but may be better collected at a later stage in the service process.

The amount of time needed to collect the data is an important consideration. A data collector who is experiencing time pressures may not be able to dedicate enough time to glean accurate information. The use of closed-end questions, clear question wording and useful instructions are all common ways of ensuring that data collection can occur efficiently.

The physical location where data collection occurs may also have an impact on either the appropriateness of seeking information, or the respondent's ability to respond honestly. For example, collecting information about potentially sensitive topics, such as how a carer is feeling or managing, can be influenced by the level of privacy or intrusion during the collection process.

The skills and knowledge of the data collector may also have a bearing on the quality of the information gathered. If the collection of accurate information is dependent on specific knowledge and skills, the collection of quality information will be compromised if this is missing.

Any data development activity in relation to dementia data needs to recognise that there are very real issues that affect its collection and quality. There is currently no cure for dementia and treatment approaches are few. Diagnosis is difficult, especially since dementia is a secondary complication for a number of other diseases (e.g. stroke and other cardiovascular diseases, diabetes, Parkinson's disease and acquired immunodeficiency syndrome (AIDS)). In this context, and particularly while there continues to be stigma associated with dementia, there may be little incentive to seek and/or provide a diagnosis. A diagnosis may also not be obtained while any problems remain manageable, or the symptoms of dementia are masked by symptoms of comorbid health conditions. While these factors remain, it is possible that the availability and quality of data about early-stage dementia will continue to be poor. In other words, improving dementia data is not simply a technical process, but will also depend on changes in diagnosis and assessment practices.

10.5 Who provides the information?

Practical difficulties can be encountered in recording reliable information about people with cognitive impairment including dementia. Self-reported health and disability data are provided by either the person in scope for the collection or by a professional, family member or caregiver. In either situation, the accuracy and reliability of the information provided may be compromised by factors such as poor memory, misunderstanding of questions or differing perceptions. These problems affect all data collection activities, but are of particular concern for collection of data about dementia:

The nature of dementia as a degenerating condition involving cognitive impairment is perceived as a major barrier, since memory, reasoning and speech and language difficulties militate against understanding and self-report although these may still be appropriate for people in the early stages of dementia (Bond 1999:572).

Cognitive decline, manifest for example in progressive memory loss and/or difficulty in communicating with others, presents a real limitation on the reliability of information provided by the person with dementia, especially during more advanced stages of dementia. As a consequence, professionals and carers are often called on in health and disability surveys to provide proxy information about the health and functional status of people with dementia.

Studies of proxy-reporting have shown that agreement between subjects and caregivers is greater for easily observable, objective elements and less for more subjective measures. Without validity testing it is difficult to know how proxy-reports vary from self-reports; however, a number of factors influence the accuracy of the information collected. A study of differences between elderly subjects with and without dementia and their caregivers revealed that the agreement between self- and caregiver reports decreased with the severity of dementia (Ostbyte et al. 1997). In this study the authors noted that 'some characteristic of the caregivers other than their formal relationship to the subject (e.g. amount of time spent with the subject or even the "quality" of the relationship) could influence agreement more strongly'. The relationship of the reporter, whether the relationship is professional or personal, to the subject of interest can also affect the accuracy of the data collected.

A review of proxy-reporting in the Statistics Canada National Population Health Survey found that the reasons for proxy-reporting fall into two categories, necessity and convenience (Shields 2004). Understanding why the information is collected by proxy is necessary to identify factors that may also influence accuracy. Finally, there may be greater agreement between subjects and proxy reporters where the proxy reporter is careful to understand and present the subject's own responses as far as possible, rather than reporting their own judgements about a subject.

Given the significance of reporter details for dementia data, this report proposes that data elements on self-report or proxy-reporting should be considered for inclusion in relevant data collections, providing an indication of the accuracy and reliability of the data.

11 Comparison and mapping of data items

The scope, purpose and collection context of the data collections described in Chapter 3 in part influences the amount and nature of dementia-related data items included in each collection. This chapter examines these data items in more detail and discusses their comparability between collections.

11.1 Identifying people with dementia and cognitive impairment

This report has already noted that consistent ways of identifying people with dementia and cognitive impairment is a critical requirement for data development in this area. Section 2 of this report illustrates the limitations of existing data collections in this regard, and the resulting differences that arise in prevalence estimates from the variety of definitions and identification approaches used.

Existing data collections vary with respect to the type and amount of data collected which is used to identify people with dementia (Table 11.1, with more detail in Tables 11.4–11.8). Most collect multiple types of information which could be used to assist with the identification of people with dementia and cognitive impairment, including data about whether there is a confirmed diagnosis (diagnosis status), type of dementia, whether there is evidence of cognitive impairment and/or behavioural symptoms, and whether or which dementia-specific treatments are used. Table 11.1 indicates the amount and nature of the information currently collected.

Table 11.1: Number and type of data items used to identify people with dementia and/or cognitive impairment

Number of data items collected	Collections	Type of data items
1 data item	CACP & EACH census	Diagnosis status
	NHS	Dementia as one of the health conditions classified as <i>organic mental health problems</i>
2 data items	NRCP	Diagnosis status, behavioural symptoms
	ALSWH	Diagnosis of Alzheimer's disease or dementia, cognitive impairment
	Residential aged care (RCS questions), HACC MDS v2	Cognitive impairment, behavioural symptoms
	PBS	Cognitive impairment, prescription of dementia-specific medication
	NHMD, BEACH	Cognitive impairment, type of dementia
3 data items	Residential aged care (trial ACFI), SDAC, ACAP	Cognitive impairment, type of dementia, behavioural symptoms
4 data items	DESP	Cognitive impairment, diagnosis status, type of dementia, behavioural symptoms

ACAP: Aged Care Assessment Program, ACFI: Aged Care Funding Instrument, ALSWH: Australian Longitudinal Study of Women's Health, BEACH: Bettering the Evaluation and Care of Health, CACP: Community Aged Care Packages, DESP: Dementia Education & Support Program, EACH: Extended Aged Care at Home, HACC: Home and Community Care, MDS: Minimum Data Set, NHMD: National Hospital Morbidity Database, NHS: National Health Survey, NRCP: National Respite for Carers Program, PBS: Pharmaceutical Benefits Scheme, RCS: Resident Classification Scale, SDAC: Survey of Disability, Ageing and Carers.

Three collections rely on a single data item to identify people with dementia and cognitive impairment:

- Two of these (CACP and EACH census collections) obtain information about dementia diagnosis only with a simple yes/no response category. One (NHS) obtains information about health conditions including dementia, which assumes or implies there is a diagnosis, although, as already noted, dementia is not coded separately hence precluding identification of people with dementia through the collections.

Seven collections obtain two data items that can be used to identify people with dementia or cognitive impairment:

- In six of these collections, a data item about cognitive impairment is used mostly in combination with data about dementia type (NHMD, BEACH), or behavioural symptoms (RCS questions in residential aged care, HACC MDS Version 2).
- Two collections use information about diagnosis status, combined with data about behavioural symptoms (NRCP) or cognitive impairment (ALSWH).
- Programs designed to provide care for people with dementia are more likely to include data items about behavioural symptoms, since these are usually directly related to the need for and level of care, and have a severe impact on carer stress. As mentioned, the NRCP also obtains information about diagnosis status, while the current RCS questions and HACC MDS v2 also include data items about observed areas of cognitive impairment such as memory problems.
- Data about prescription or use of dementia-specific medication can also be used to identify cases of people with dementia. These data are available through the PBS collection and the BEACH survey.

The current trial version of the ACFI, the Australian Bureau of Statistics (ABS) SDAC and the ACAP include three data items: cognitive impairment, dementia type, and behavioural symptoms.

Alzheimer's Australia DESP data collection includes the most comprehensive suite of items, including diagnosis status, type of dementia, cognitive impairment and challenging behaviour.

The variety of data item types reflects the multi-dimensional nature of the dementia syndrome. At the same time, the primacy of cognitive impairment as the defining feature of dementia is reflected in the use of items about cognitive impairment in nine of the current data collections examined here. Type of dementia is collected in seven collections. While type of dementia implies there is a diagnosis, diagnosis status is separately collected by five collections, as are data about behavioural symptoms.

Cognitive impairment

Although items about cognitive impairment feature heavily, there is no consistent approach across data collections in respect of the type of data collected (see Table 11.6 at end of chapter). The items vary in the domains they cover, the questions used, the response categories and measurements, the temporal context and the assessment environment. As a result of these variations, it is difficult to find a reference point upon which to compare data elements across collections.

Three overall approaches can however be discerned. The first approach involves the collection of data about decline, or evidence of impairment, in specific cognitive domains.

The RCS includes questions on understanding and communication. However, the most common domain reported is memory function (DESP, HACC, ALSWH, ACAP). ALSWH also asks about difficulty concentrating, and ACAP data domains cover a range of mental functions based on the International Classification of Functioning, Disability and Health (ICF).

This general approach is consistent with that used in the ICF Body Functions domain. Chapter 1 on mental functions identifies a range of specific cognitive functions which may be impaired (Box 11.1). Three of these domains are suggested by the ICF for minimum information systems about cognition – attention, memory and high-level cognitive functioning.

Box 11.1: ICF mental functions

Global mental functions

- b110 Consciousness functions*
- b114 Orientation functions*
- b117 Intellectual functions*
- b122 Global psychosocial functions*
- b126 Temperament and personality functions*
- b130 Energy and drive functions*
- b134 Sleep functions*
- b139 Global mental functions, other specified and unspecified*

Specific mental functions

- b140*** *Attention functions (sustaining attention, shifting attention, dividing attention, sharing attention)*
- b144*** *Memory functions (short-term memory, long-term memory, retrieval of memory)*
- b147 Psychomotor functions*
- b152 Emotional functions*
- b156 Perceptual functions*
- b160 Thought functions*
- b164*** *Higher-level cognitive functions (abstraction, organisation and planning, time management, cognitive flexibility, insight, judgement, problem-solving)*
- b167 Mental functions of language*
- b172 Calculation functions*
- b176 Mental function of sequencing complex movements*
- b180 Experience of self and time functions*
- b189 Specific mental functions, other specified and unspecified*
- b198 Mental functions, other specified*
- b199 Mental functions, unspecified*

The second approach involves the collection of data about screening or assessment tools used to identify cognitive impairment and the resulting score:

- This type of data is collected by the PBS which obtains results of the Mini-Mental State Examination (MMSE) or Alzheimer’s Disease Assessment Scale, cognitive subscale (ADAS-Cog) before and after initial therapy. The ACFI is trialling the collection of scores from the Psychogeriatric Assessment Scales, General Practitioner Assessment of

Cognition and the Rowland Universal Dementia Assessment Scale. Data about scores from the MMSE are also sometimes available from the ACAT Aged Care Client Record, although not reported as part of the MDS.

The third general approach consists of constructing categories that describe the manifestations or outcomes of cognitive impairment across a range of activities, for example, *'needs cues or prompting to make decisions – short-term memory loss'* or *'disorientation to time and place is likely'* (ACFI).

- This approach is used by the current trial ACFI. It is also used by the SDAC which collects data on whether assistance is needed with:
 - cognitive or emotional skills
 - making decisions and problem solving
 - coping with feelings or emotions.

Dementia diagnosis status

As already noted in this report, there is a lack of consistency between major classification tools in the definition of dementia and the operationalised diagnostic criteria. However, obtaining an accurate diagnosis of dementia and dementia-related conditions is important for people with dementia and their family and carers. Difficulties in obtaining a diagnosis can lead to complications in the provision of care and delays in obtaining appropriate treatment. A data item about dementia diagnosis status (i.e. whether the person of concern has a confirmed diagnosis) represents an efficient and relatively straightforward way for collections to identify people with dementia.

Table 11.4 describes the diagnosis status data items which are included in five collections, three of which are community care data sets (EACH and CACP census collections and NRCP). The two census collections record the service provider's knowledge about whether the client has been diagnosed with dementia by an ACAT or medical practitioner. NRCP data are based on a report by the carer that a medical practitioner has diagnosed the care recipient as having dementia. All three collections use the same value domains (yes, no, not stated/inadequately described).

The ALSWH also includes a question about whether the respondent had been diagnosed with or treated for Alzheimer's disease or dementia in the last three years, with response options consisting of 'yes' or 'no response'.

The most comprehensive type of diagnostic information is collected by the DESP data collection. The data item about dementia diagnosis status includes value domains which indicate whether or not the person of concern is being assessed for dementia, or has not been assessed but shows symptoms of dementia or memory loss. It therefore combines diagnostic status information and some information about the possible presence of cognitive impairment. Further information is also collected by DESP about the profession which provided the diagnosis and the date of the diagnosis.

Type of dementia

Information about type of dementia is usually collected in lieu of information about diagnosis status. If type of dementia is known, then it can be assumed that there is a confirmed diagnosis. This item is described consistently across the data collections and the

value domains are mostly based on ICD-10. The BEACH data are classified using ICPC-2 Plus (see Table 11.5).

However, the level of detail among the value domains used varies. The NHS collects information about dementia as a long-term health condition, but collapses it into the category of '*organic mental health problems*' under '*mental and behavioural problems*'. This results in a significant loss of information. The SDAC also collapses categories of long-term health condition so that only 'dementia' and 'Alzheimer's disease' are clearly and unambiguously identified, again reducing information available about other types of dementia.

Administrative data sets collect information about type of dementia in order to serve the purposes of the service or program, so that the data items have different meanings:

- as a principal or additional diagnosis contributing to the cost of a hospital episode (NHMD)
- as a primary health condition or other health condition that has an impact on the person's need for assistance with activities of daily living and social participation (ACAP)
- a documented diagnosis that is relevant to current care needs (ACFI)
- reasons for general practitioner (GP) encounter and diagnosis or problems managed by the GP (BEACH).

11.2 Severity of dementia and cognitive impairment

There are no data items in these collections that directly report on the concept of severity of dementia. *Date of diagnosis* collected in the DESP dataset provides an indication of the length of time the person of concern has known they have the condition, and may provide an indication of the stage of dementia they are likely to have reached.

However, the main way in which severity can be assessed is through information about the functional and behavioural outcomes for the person of concern. Functional outcomes include both cognitive functioning and functioning in daily activities. These outcomes are interrelated. Dementia is characterised by cognitive decline, the extent of which will impact over time on the affected person's ability to perform daily activities and to participate in family and community life. In a significant proportion of people with dementia, cognitive impairment also affects their emotional and psychological wellbeing, and their capacity to communicate and interact with others and to regulate their behaviour. These declines manifest as behavioural disturbances and, with functional and cognitive decline, are indicators of severity of the syndrome.

Extent of cognitive impairment

There are a number of ways in which the extent or severity of cognitive impairment is collected in the collections reviewed in this chapter (see Table 11.6). A common approach is to rely on scales of self- or proxy-reported assessments of severity. However, the scales are based on different concepts:

- ALSWH is based on **frequency of occurrence** (never, rarely, sometimes, often).
- ACFI records a scale of **degree of impairment** (no, mild, moderate, severe), which is based on observations about difficulty and/or independence and/or symptoms of cognitive decline.

- DESP records a scale of **degree of memory impairment** (no, minor, moderate, major, severe), which is based on problems experienced compared to previous levels of memory.
- The RCS uses a four-point scale to denote the **level of supervision and care required** because of the impairment.
- **Scores on cognitive screening or assessment tools** are collected by the PBS and the trial ACFI.
- Binary responses are used to simply denote the presence of cognitive impairment by HACC (yes/no in respect of memory problems or confusion). The SDAC also uses a binary response, but in this case about whether the person needs assistance with cognitive skills. Needing assistance denotes a higher level of severity than simply the presence of the impairment.

Extent of behavioural and psychological symptoms of dementia

Six collections include some data items about the behavioural and psychological symptoms of dementia (BPSD) (see Table 11.7 at end of chapter). There is substantial evidence that the presence of BPSD contributes significantly to carer stress and the cost of care and supervision in residential settings.

Once again there is little consistency in how the data are collected. The DESP contact data set identifies particular types of challenging behaviours which may be identified through contact discussions (e.g. anxiety, repetitive speech, depression, wandering). Information about the frequency or severity of these behaviours is not collected.

The RCS questions similarly list a number of BPSDs, but also indicate how much care is required because of the behaviours. The behaviours included in the list are less comprehensive than for DESP but are mappable to the latter (Table 11.2). This is also the case for the ACFI which focuses on three domains – problem wandering, physical and verbal behaviour, and depression and anxiety; and the ACAP which allows unhappiness, irritability and anger, restlessness and agitation, physical violence and hostility to be recorded as one of ten health conditions. The ACFI records information about the frequency with which the behaviour occurs.

Both NRCP and HACC report information only at a broad level in relation to behavioural problems (HACC) or challenging behaviour (NRCP). For NRCP the definition requires that the behaviour is aggressive, disruptive, agitated or offensive and hence leads to a requirement for support. The data domains describe the level of support required because of the behavioural problems.

Only three collections include items to measure the severity of BPSD, all on a different basis. The ACFI collects information about the frequency with which the problem behaviour occurs. NRCP and RCS scales are based on self- or proxy-reports about the level of care or support required because of the behaviours. HACC and DESP only record the presence of behaviours, while the SDAC again records whether the person needs assistance to manage behaviour, feelings or emotions. ACAP only records the behaviours as health conditions if they have an impact on the person's need for assistance with activities of daily living and social participation.

Table 11.2: Comparison of BPSD across relevant data collections

DESP	RCS	ACAP	ACFI	SDAC	HACC MDS v2	NRCP
Anxiety/panic/phobias	Emotional dependence	Unhappiness (worries nos)	Depression & anxiety	Manage own behaviour Cope with feelings & emotions	Behavioural problems	Challenging behaviour
Depression/hopelessness						
Constantly complaining/irritability/demanding		Irritability & anger				
Wandering & disruptive	Problem wandering or intrusive behaviour		Problem wandering			
Generally agitated/unsettled/restless		Restlessness & agitation				
Inappropriate dress/disrobing						
Repetitive speech/repetitious mannerisms						
Threatened or actual physical aggression	Physically aggressive	Physical violence	Physical & verbal behaviour			
Verbally noisy/screeching/screaming	Verbally disruptive or noisy	Hostility				
Resistive to personal care help						
Hiding/hoarding things						
Inappropriate sexual behaviour						
Delusional behaviour/imaginary voices/noises						
Excessively suspicious/paranoid behaviour						
Substance abuse						
Threats of self-harm	Danger to self or others					
	Other behaviour					

Extent of functional limitation

The extent of limitation experienced by the person of concern in performing daily activities is collected by a number of existing collections (Table 11.9). These measures are indicative of an individual's capacity for independent living, their need for assistance and support, the type of support required and the possible impact on carers and service providers.

Data collected by ACAP and the CACP and EACH census collections are consistent with and mappable to each other and to the SDAC, which is based on the ICF. This consistency facilitates comparison between the client population and the general population.

The CACP and EACH census collections are limited to data about core activity limitations (self-care, mobility and communication). Severity in core activity limitations is measured by how often the person needs assistance with those activities (always, sometimes, never), and where difficulty is experienced and/or aids and equipment used.

ACAP includes a wider range of activity limitations covering both advanced activities of daily living (ADLs) such as transport, health care tasks, domestic assistance, and home

maintenance as well as basic ADLs to do with self-care and mobility. The ACAP data set records activity limitations where the person needs the help or supervision of another person. Where the core activity limitations are recorded, this is interpreted to be equivalent to having a severe or profound limitation comparable with the SDAC measure.

The SDAC itself includes a broad range of activity types, including self-care activities, communication and mobility activities. However, the range of activities also includes instrumental activities of daily living (IADLs) such as paperwork, meal preparation, and household chores. The key measure of severity is how often the person needs the assistance of another person in those activities, along with items about the frequency of the need for assistance.

Concepts of difficulty or problems associated with undertaking daily activities underpin the severity measures used in ALSWH and DESP. The latter collection is restricted to information about personal care support, while the others collect information about a more comprehensive range of activities. ALSWH also measures severity using the concept of needing the help of another person, based variously on how often the help was needed ('occasionally'), needing the help with more difficult tasks, or simply that help was needed in the last month.

The HACC MDS Version 2 includes both IADLs and ADLs in its functional categories, and severity is measured by the extent to which assistance is needed for the performance of those activities. The RCS focuses on activities and tasks which have most bearing on the cost of residential care, (IADLs are not represented), with severity measured by the extent of care or supervision involved. The ACFI is similarly focused on activities and tasks which are of relevance to care in a residential setting, and IADLs such as paperwork, managing money and housework are not included.

NRCP differs from all other collections by using a scale (low, moderate, high) to measure the level of need for support by the care recipient.

11.3 Environmental factors

The recognition of environmental factors as fundamental to functioning and disability is an important development in the conceptualisation of disability in the ICF. Environmental factors 'make up the physical, social and attitudinal environment in which people live and conduct their lives' (WHO 2001:10). Environmental factors can have the effect of improving or hindering an individual's body function (e.g. medications), ability to execute an activity (e.g. with the use of aids), and/or their participation in society. Different environments may have a different impact on the same individual with a given health condition (AIHW 2003c).

Environmental factors are clearly an important element in the extent to which a person with dementia is able to remain living in their home, through the availability of a carer. Certain treatment options may reduce the symptoms of dementia in the early stages. Carer support and training potentially increases the care management approaches available for carers, possibly improving their capacity to respond to challenging behaviour. The design of appropriate physical environments can be used to reduce the possible negative impact of problem wandering or other challenging behaviours.

Carers

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. As a result, a number of support programs for people with dementia are also aimed at supporting carers in their role. Information about carers, and particularly measures of the impact of the caring role, are therefore critical for the delivery of current services and future service planning.

Data items on carer availability or carer status, co-residency status, relationship of carer to care recipient and carer demographics are obviously fundamental to understanding the carer-care recipient dyad. Table 11.3 shows which collections include these data items. The scope of this report is to primarily focus on data items which are specific (or particularly relevant) to dementia: hence this chapter does not compare these data items across collections.

Table 11.3: Comparison of data sources collecting core information about carers

Collection	Carer availability	Carer co-residency status	Relationship of carer to care recipient	Carer status	Carer demographics
CACP	✓	✓	✓		
EACH	✓	✓	✓		
ACAP	✓	✓	✓		
HACC	✓	✓	✓		
NRCP	(all are recipients)	✓	✓	✓	✓
SDAC	(whether receives informal assistance)	✓	✓	✓	✓
ALSWH	✓			✓	✓
DESP	(some)		✓	✓	✓

Alzheimer’s Australia DESP, NRCP, ALSWH and SDAC ask questions directly of the carer and therefore provide demographic information as well as information about impact of the caring role and interaction with the care recipient. Although ALSWH and SDAC also collect a range of information about the health and wellbeing of carers, whether a carer is caring for someone with dementia cannot always be (if at all) determined.

Measures that are relevant to the impact of the caring role are collected by Alzheimer’s Australia DESP, HACC MDS v2, NRCP, ALSWH and SDAC. These measures include number of care recipients, frequency and duration of care provision, overall carer need and measures of the health and wellbeing of the carer. These data items, as well as data items about formal and informal support, are included in Tables 11.10a–11.10e. Tables including further data items about carer health and wellbeing, income and financial situation, paid work, social support and relationships, respite care and assistance provided are included in Tables A11.1–A11.7.

Services and treatments

Many formal services and/or service types available to people with dementia or cognitive decline are not specific to this population. Residential aged care is targeted at frail older people no longer able to live in the community. Service types, such as information, counselling or advocacy which may be provided by organisations such as Alzheimer’s

Australia who target people with (suspected) dementia, are also provided by other programs targeting a wider population (e.g. HACC, NRCP).

The major dementia-specific treatment which is included in this set of data collections is dementia-specific medications which are available through the PBS. The PBS includes information about the nature of these drugs and the number of prescriptions for them. The BEACH survey also reports information about medications prescribed by GPs.

11.4 Conclusion

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, 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. International classifications such as the ICD-10 and ICF have been used as standards in some areas, notably type of dementia and functional impairment. The general picture however is one of fragmentation and inconsistency of approach to identifying people with dementia or cognitive impairment and the severity of the associated impairments.

Table 11.4: Mapping of dementia-related data items in Australian dementia-relevant collections: Dementia diagnosis

DESP	CACP census	EACH census	NRCP	ALSWH
<p>Data item: Dementia diagnostic status</p> <p>Definition: Dementia diagnostic status of the person of concern</p> <p>Data domain: Diagnosed with dementia Being formally assessed for dementia Not assessed but symptoms of dementia/memory loss Assessed—dementia not diagnosed Unknown</p>	<p>Data item: Dementia status</p> <p>Definition: Whether or not the care recipient has been diagnosed with dementia (by an ACAT or medical practitioner) to the knowledge of staff of the service outlet</p> <p>Data domain: Yes No Not stated/inadequately described</p>	<p>Data item: Dementia status</p> <p>Definition: Whether or not the care recipient has been diagnosed with dementia (by an ACAT or medical practitioner) to the knowledge of staff of the service outlet</p> <p>Data domain: Yes No Not stated/inadequately described</p>	<p>Data item: Dementia</p> <p>Definition: A report by the carer that a medical practitioner has diagnosed the person he or she cares for as having dementia.</p> <p>Data domain: Yes No Not stated/inadequately described</p> <p>Data item: Care recipient's primary disability</p> <p>Definition: A record of the primary disability, impairment or condition of the care recipient causing the most difficulty to the person.</p> <p>Data domain includes: Acquired brain injury Neurological (including epilepsy & Alzheimer's disease)</p>	<p>Question: In the last 3 years have you been diagnosed with or treated for...</p> <p>Options include: Alzheimer's disease or dementia</p> <p>Response: Yes (or no response)</p> <p>Notes: Option only exists for older cohort in surveys 2, 3 & 4 although an 'Other—please specify' category exists for the younger & mid-age cohorts</p>
<p>Data item: Diagnosis by whom</p> <p>Definition: Category of professional providing the dementia diagnosis</p> <p>Data domain: General practitioner Psychogeriatric/Aged Psychiatry Services Team Behavioural Support Unit/Behavioural Advisory Service Aged Care Assessment Team/Services Neurologist Psychogeriatrician/Psychiatrist Geriatrician Memory clinic/Cognitive, Dementia & Memory Service/Other diagnostic service Other (specify in notes)</p>				
<p>Data item: Date of dementia diagnosis</p> <p>Definition: This item describes the date on which the person of concern was diagnosed with dementia</p> <p>Data domain: MM/YYYY</p>				

Table 11.5: Mapping of dementia-related data items in Australian dementia-relevant collections: Type of dementia

DESP	NHMD	ACAP	ACFI	BEACH	SDAC	NHS
<p>Data item: Type of dementia</p> <p>Definition: Type of dementia as reported by the carer or person of concern</p> <p>Data domain: Dementia of unspecified type</p> <p>Alzheimer's disease</p> <p>Vascular dementia</p> <p>Mixed dementia</p> <p>Frontal lobe dementia</p> <p>Lewy body dementia</p> <p>Alcoholic dementia (e.g. alcohol-related brain damage)</p> <p>Other dementia (dementia type not described in this list)</p> <p>Unknown</p>	<p>Data items: Principal diagnosis, Additional diagnosis</p> <p>Data domain: Valid codes from ICD-10-AM (4th edition)—</p> <p>Dementia in Alzheimer's disease</p> <p>Vascular dementia</p> <p>Dementia in other diseases classified elsewhere</p> <p>Unspecified dementia</p> <p>Delirium superimposed on dementia</p> <p>Alzheimer's disease</p>	<p>Data items: Primary health condition, Other health condition</p> <p>Definition: The diagnosed disease(s) or disorder(s) that have an impact on the person's need for assistance with ADLs—up to 10 health conditions can be recorded. The condition listed first is the one with the greatest impact on the person's need for assistance with ADLs & social participation. Codes are based on the ICD-10 (modified for Version 2.0 & comparable to the SDAC codes)</p> <p>Data domain includes:</p> <p>Dementia in Alzheimer's disease</p> <p>Dementia in Alzheimer's disease with early onset</p> <p>Dementia in Alzheimer's disease with late onset</p> <p>Dementia in Alzheimer's disease, atypical or mixed type</p> <p>Dementia in Alzheimer's disease, unspecified</p> <p>Vascular dementia</p> <p>Vascular dementia of acute onset</p> <p>Multi-infarct dementia</p> <p>Subcortical vascular dementia</p> <p>Mixed cortical & subcortical vascular dementia</p> <p>Other vascular dementia</p> <p>Vascular dementia—unspecified</p> <p>Dementia in other disease classified elsewhere</p> <p>Dementia in Pick's disease</p> <p>Dementia in Creutzfeldt-Jakob disease</p> <p>Dementia in Huntington's disease</p> <p>Dementia in Parkinson's disease</p> <p>Dementia in human immunodeficiency virus (HIV) disease</p> <p>Dementia in other specified diseases classified elsewhere</p> <p>Other dementia</p> <p>Alcoholic dementia</p> <p>Unspecified dementia (includes presenile & senile dementia)</p> <p>Delirium superimposed on dementia</p>	<p>Data item: Mental & behavioural diagnosis</p> <p>Data domain: No diagnosed disorder currently impacting on functioning</p> <p>Dementia Alzheimer's disease</p> <p>Vascular dementia</p> <p>Dementia in other diseases</p> <p>Other dementias</p> <p>Delirium</p> <p>Psychoses, mood disorders (e.g. depression)</p> <p>Neurotic, stress-related, somatoform disorders</p> <p>Intellectual & developmental disorders</p> <p>Other mental & behavioural disorders</p> <p>Data item: Medical diagnosis</p> <p>Data domain includes:</p> <p>Huntington's disease</p> <p>Parkinson's disease</p> <p>Other diseases of the nervous system</p> <p>Cerebrovascular disease</p> <p>Stroke</p> <p>Amnesia</p>	<p>Data items: Reasons for encounter (up to 3) & Diagnosis/problems managed (up to 4)</p> <p>Data domain: ICPC-2 Plus codes include symptoms & complaints & diagnoses—</p> <p>Dementia</p> <p>Alzheimer's disease</p> <p>Dementia, alcoholic</p> <p>Dementia, senile</p>	<p>Data items: Type of long-term condition reported, Conditions producing main disability, Main condition</p> <p>Data domain: Codes based on ICD-10 & include—</p> <p>Dementia</p> <p>Alzheimer's disease</p>	<p>Data item: Long-term condition</p> <p>Data domain: ABS codes based on ICD-10, ICPC-2 Plus & ICD-9</p> <p>Notes: While the NHS collects information about dementia as a long-term health condition it is collapsed into the category of Organic mental health problems under Mental & behavioural problems</p>

Table 11.6: Mapping of dementia-related data items in Australian dementia-relevant collections: Cognitive impairment

DESP	PBS	NHMD	ACAP	HACC	RCS
<p>Data item: Memory impairment</p> <p>Definition: The level of memory impairment of the person of concern (as compared to previous levels?)</p> <p>Data domain:</p> <p>No discernible problems</p> <p>Minor problems</p> <p>Moderate problems</p> <p>Major problems</p> <p>Severe problems</p>	<p>Data item: Baseline results of the MMSE or ADAS-Cog prior to initial therapy & results of evaluations after initial therapy</p>	<p>Data items: Principal diagnosis, Additional diagnosis</p> <p>Data domain: Valid codes from ICD-10-AM (4th edition)—</p> <p>Cognitive disorder not otherwise specified</p> <p>Age-related cognitive decline</p>	<p>Data item: Body function impairments</p> <p>Definition: The physiological or psychological functions of the person's body where significant deviation from the norm or loss of function is experienced & affects the person's need for assistance with ADLs or social participation—codes based on the ICF</p> <p>Data domain under heading of <i>Mental functions</i> includes:</p> <p>Consciousness functions</p> <p>Orientation functions</p> <p>Intellectual functions</p> <p>Energy & drive functions</p> <p>Sleep functions</p> <p>Memory functions</p> <p>Psychomotor functions</p> <p>Emotional functions</p> <p>Thought functions</p> <p>Other</p> <p>Data items: Primary health condition, Other health condition</p> <p>Definition: The diagnosed disease(s) or disorder(s) that have an impact on the person's need for assistance with ADLs—up to 10 health conditions can be recorded. The condition listed first is the one with the greatest impact on the person's need for assistance with ADLs & social participation. Codes are based on the ICD-10 (modified for Version 2.0 & comparable to the SDAC codes)</p> <p>Data domain includes:</p> <p>Disorientation (confusion)</p> <p>Amnesia (memory disturbance, lack or loss)</p>	<p>Data items: Functional status, Functional status—additional items</p> <p>Definition: The extent to which the person is able to perform selected ADLs; & whether they have memory or behavioural problems</p> <p>Data sub-items: Memory problems or confusion</p> <p>Data domain:</p> <p>Yes</p> <p>No</p> <p>Not stated/inadequately described</p> <p>Data sub-items: Communication</p> <p>Data domain:</p> <p>No</p> <p>Yes, sometimes</p> <p>Yes, always</p> <p>Not stated/inadequately described</p> <p>Notes: The client is asked questions about all activities except Memory problems or confusion & Behavioural problems—ratings for these questions are based on other available information</p>	<p>Data items:</p> <p>Understanding & undertaking living activities</p> <p>Social & human needs—care recipient</p> <p>Social & human needs—family & friends</p> <p>Communication</p> <p>Data domain: A to D, where A means virtually no intervention is required & D indicates extensive care involvement</p>

(continued)

Table 11.6 (continued): Mapping of dementia-related data items in Australian dementia-relevant collections: Cognitive impairment

ACFI	BEACH	SDAC	NHS	ALSWH
<p>Data item: Cognitive skills</p> <p>Data domain:</p> <p>No impairment</p> <p>Mild impairment</p> <p>Moderate impairment</p> <p>Severe impairment</p>	<p>Data items: Reasons for encounter (up to 3) & Diagnosis/problems managed (up to 4)</p> <p>Data domain: ICPC-2 Plus codes include symptoms & complaints & diagnoses under 17 chapters including— Psychological (includes dementia, memory disturbance & limited function/disability)</p>	<p>Data item: Whether needs assistance or has difficulty with cognitive or emotional skills</p> <p>Data domain:</p> <p>Not applicable</p> <p>Needs assistance or has difficulty with cognitive or emotional tasks</p> <p>Does not need assistance or have difficulty with cognitive or emotional tasks</p> <p>Assessment of cognitive or emotional tasks not performed (establishments only) or too young to assess</p> <hr/> <p>Data item: Whether needs assistance to make decisions or think through problems because of disability</p> <p>Data domain:</p> <p>Not applicable</p> <p>Needs assistance to make decisions or think through problems</p> <p>Does not need assistance to make decisions or think through problems</p> <p>Activity not performed (establishments only)</p> <hr/> <p>Data item: Whether needs assistance to cope with feelings or emotions because of disability</p> <p>Data domain:</p> <p>Not applicable</p> <p>Needs assistance to cope with emotions</p> <p>Does not need assistance to cope with emotions or too young to measure</p> <p>Activity not performed (establishments only)</p> <hr/> <p>Data item: Number of cognitive/emotion tasks for which assistance is needed because of disability</p> <p>Data domain: 0→ 6, Not applicable</p> <p>Notes: Above data items asked of people with a disability (excluding people with a non-restricting disfigurement or deformity only)</p>	<p>Data item: Long-term condition</p> <p>Data domain: ABS codes based on ICD-10, ICPC-2 Plus & ICD-9—</p> <p>Symptoms & signs involving cognition, perceptions, emotional state & behaviour</p>	<p>Question: In the last 12 months have you had any of the following?</p> <p>Options include: Poor memory, Difficulty concentrating</p> <p>Response: Never, Rarely, Sometimes, Often</p> <p>Notes: Asked of the older cohort in survey 1 (similar questions asked in surveys 2, 3 & 4)</p> <hr/> <p>Question: Compared with when you were in your twenties, how good are you at...</p> <p>Options include:</p> <p>Remembering the name of a person just introduced to you?</p> <p>Recalling the telephone numbers or other numbers that you use on a daily or weekly basis?</p> <p>Recalling where you put objects (such as keys) in your home?</p> <p>Remembering specific facts from a newspaper or magazine article you have just finished reading?</p> <p>Remembering the item(s) you intend to buy when you arrive at the shops?</p> <p>In general, how would you describe your memory compared to when you were in your 20s?</p> <p>Response:</p> <p>Much better now</p> <p>Somewhat better now</p> <p>About the same</p> <p>Somewhat worse now</p> <p>Much worse now</p> <p>Notes: Asked of the older cohort in surveys 3 & 4 & the mid age cohort in survey 4</p>

Table 11.7: Mapping of dementia-related data items in Australian dementia-relevant collections: Behaviour

DESP	ACAP	HACC	RCS	ACFI	NRCP	BEACH	SDAC
<p>Data item: Key issues & discussion areas</p> <p>Definition: Service provided (by whatever approach) to the client</p> <p>Data sub-items include:</p> <p>Challenging behaviour</p> <p>Data domain:</p> <p>Anxiety/panic/phobias</p> <p>Depression/hopelessness</p> <p>Constantly complaining/irritability/demanding</p> <p>Wandering & disruptive</p> <p>Generally agitated/unsettled/restless</p> <p>Inappropriate dress/disrobing</p> <p>Repetitive speech/repetitious mannerisms</p> <p>Threatened or actual physical aggression</p> <p>Verbally noisy/screaming/screaming</p> <p>Resistive to personal care help</p> <p>Hiding/hoarding things</p> <p>Inappropriate sexual behaviour</p> <p>Delusional behaviour/imaginary voices/noises</p> <p>Excessively suspicious/paranoid behaviour</p> <p>Substance abuse</p> <p>Threats of self-harm</p>	<p>Data items: Primary health condition, Other health condition</p> <p>Definition: The diagnosed disease(s) or disorder(s) that have an impact on the person's need for assistance with ADLs —up to 10 health conditions can be recorded. The condition listed first is the one with the greatest impact on the person's need for assistance with ADLs & social participation. Codes are based on the ICD-10 (modified for Version 2.0 & comparable to the SDAC codes)</p> <p>Data domain includes:</p> <p>Restlessness & agitation</p> <p>Unhappiness (worries not otherwise specified)</p> <p>Irritability & anger</p> <p>Hostility</p> <p>Physical violence</p>	<p>Data item: Functional status</p> <p>Definition: The extent to which the person is able to perform selected ADLs; & whether they have memory or behavioural problems</p> <p>Data sub-items:</p> <p>Behavioural problems</p> <p>Data domain:</p> <p>Yes</p> <p>No</p> <p>Not stated/inadequately described</p> <p>Notes: The client is asked questions about all activities except Memory confusion & Behavioural problems—ratings for these questions are based on other available information</p>	<p>Data items:</p> <p>Verbally disruptive or noisy</p> <p>Problem wandering or intrusive behaviour</p> <p>Emotional dependence</p> <p>Physically aggressive</p> <p>Other behaviour</p> <p>Danger to self or others</p> <p>Data domain: A to D, where A means virtually no intervention is required & D indicates extensive care involvement</p>	<p>Data items: Problem wandering, Physical & verbal behaviour</p> <p>Data domain:</p> <p>Does not occur</p> <p>Occurred at least once in a week</p> <p>Occurred daily</p> <p>Occurred daily & with more than one episode in any one day of a week</p>	<p>Data item: Challenging behaviour</p> <p>Definition: A report by the carer concerning the level of support that is required because the type of behaviour exhibited by the care recipient is aggressive, disruptive, agitated or offensive</p> <p>Data domain:</p> <p>High level of support required for behaviour</p> <p>Medium level of support required for behaviour</p> <p>Low level of support required for behaviour</p> <p>No level of support required for behaviour</p> <p>No challenging behaviour</p> <p>Not stated/inadequately described</p>	<p>Data items: Reasons for encounter (up to 3) & Diagnosis/problems managed (up to 4)</p> <p>Data domain: ICPC-2 Plus codes include symptoms & complaints & diagnoses under 17 chapters including—Social problems</p>	<p>Data item: Whether needs assistance to manage own behaviour because of disability</p> <p>Data domain:</p> <p>Not applicable</p> <p>Needs assistance to manage behaviour</p> <p>Does not need assistance to manage behaviour or too young to measure</p> <p>Activity not performed (establishments only)</p> <p>Notes: Asked of people aged 0–14 with a disability living in households (excluding people with a non-restricting disfigurement or deformity only) & persons with a disability living in health establishments</p> <p>Data item: Whether primary carer usually assists or guides main recipient of care to manage behaviour</p> <p>Data domain:</p> <p>Not applicable</p> <p>Usually assists or guides with management of behaviour</p> <p>Does not usually assist or guide with management of behaviour</p> <p>Not stated</p> <p>Data item: Reasons for inability to use some or all forms of public transport</p> <p>Data domain includes:</p> <p>Cognitive difficulties</p> <p>Behavioural problems</p> <p>Notes: Asked of people aged 5 or over with a disability (excluding people with a non-restricting disfigurement or deformity only) or aged 60 years or over living in households</p>

Table 11.8: Mapping of dementia-related data items in Australian dementia-relevant collections: Treatments

PBS
Data item: Alzheimer's disease identified by the prescription of PBS-funded antidementia medications
Data domain: Donepezil Hydrochloride Galantamine Hydrobromide Rivastigmine Hydrogen tartrate

Table 11.9: Mapping of dementia-related data items in Australian dementia-relevant collections: Functional impairment (excluding cognitive impairment or changes in behaviour)

DESP	ACAP	HACC	CACP census	EACH census
<p>Data item: Personal care assistance</p> <p>Definition: The degree of personal care support provided to the person of concern (as compared to previous levels?)</p> <p>Data domain: No discernable problems Minor problems Moderate problems Major problems Severe problems</p>	<p>Data item: Activity limitations</p> <p>Definition: The activities in which the help or supervision of another individual is needed by the person, as assessed by the ACAT</p> <p>Data domain: Self-care Movement activities Moving around places at or away from home Communication Health care tasks Transport Activities involved in social & community participation Domestic assistance Meals Home maintenance Other None Unable to determine Not stated/inadequately described</p> <p>Data item: Body function impairments</p> <p>Definition: The physiological or psychological functions of the person's body where significant deviation from the norm or loss of function is experienced & affects the person's need for assistance with ADLs or social participation—includes 63 codes based on the ICF</p> <p>Data domain headings: Mental functions Sensory functions Voice & speech functions Functions of the cardiovascular, haematological, immunological & respiratory systems Functions of the digestive, metabolic & endocrine systems Genitourinary & reproductive functions Neuromusculoskeletal & movement-related functions Functions of the skin & related structures</p>	<p>Data items: Functional status, Functional status—additional items</p> <p>Definition: The extent to which the person is able to perform selected ADLs</p> <p>Data sub-items: Housework, Transport, Shopping, Medication, Money, Walking, Bathing/showering, Dressing, Eating, Toileting</p> <p>Data domain: Without help With some help Completely unable Not stated/inadequately described</p> <p>Data sub-items: Communication, Getting out of bed/moving around</p> <p>Data domain: No Yes, sometimes Yes, always Not stated/inadequately described</p>	<p>Data item: Core activity limitations</p> <p>Definition: The core activities in which the help or supervision of another individual is needed by the person, as assessed by staff of the service outlet</p> <p>Data domain: Eating Showering/bathing Dressing Toileting Managing incontinence Maintaining or changing body position Carrying, moving or manipulating objects related to the tasks of daily living Getting in or out of bed or chair Walking & related activities Using public transport (e.g. buses, trains) Understanding or making oneself understood by others None Not stated/inadequately described</p>	<p>Data item: Core activity limitations</p> <p>Definition: The core activities in which the help or supervision of another individual is needed by the person, as assessed by staff of the service outlet</p> <p>Data domain: Eating Showering/bathing Dressing Toileting Managing incontinence Maintaining or changing body position Carrying, moving or manipulating objects related to the tasks of daily living Getting in or out of bed or chair Walking & related activities Using public transport (e.g. buses, trains) Understanding or making oneself understood by others No assistance needed from another person in any of these areas Not stated/inadequately described</p>

(continued)

Table 11.9 (continued): Mapping of dementia-related data items in Australian dementia-relevant collections: Functional impairment (excluding cognitive impairment or changes in behaviour)

RCS	ACFI	NRCP	SDAC	ALSWH
<p>Data items:</p> <p>Personal hygiene</p> <p>Toileting</p> <p>Medication</p> <p>Technical & complex nursing procedures</p> <p>Therapy</p> <p>Bowel management</p> <p>Bladder management</p> <p>Social & human needs—care recipient</p> <p>Other services</p> <p>Meals & drinks</p> <p>Mobility</p> <p>Social & human needs—family & friends</p> <p>Communication</p> <p>Data domain: A to D, where A means virtually no intervention is required & D indicates extensive care involvement</p>	<p>Data items:</p> <p>Eating & drinking</p> <p>Mobility</p> <p>Personal hygiene</p> <p>Toileting</p> <p>Data domain:</p> <p>Independent</p> <p>Supervision</p> <p>Physical assistance</p> <hr/> <p>Data item:</p> <p>Continence</p> <p>Data domain:</p> <p>Frequency</p> <p>Management program</p> <hr/> <p>Data item:</p> <p>Medication</p> <p>Data domain:</p> <p>Supervision</p> <p>Physical assistance</p> <p>Daily administer controlled drug</p> <p>Daily administer injection</p> <hr/> <p>Data item:</p> <p>Technical & complex nursing procedures</p> <p>Data domain:</p> <p>Number & frequency of procedures</p>	<p>Data item: Care recipient's level of need</p> <p>Definition: A statement depicting the level of need for, & type of support required by the care recipient</p> <p>Data domain:</p> <p>High (no additional factors)</p> <p>High (plus additional factors)</p> <p>Moderate (no additional factors)</p> <p>Moderate (plus additional factors)</p> <p>Low (no additional factors)</p> <p>Low (plus additional factors)</p> <p>Not stated/ inadequately described</p>	<p>Many data items on functional impairment— examples are below</p> <p>Data item: Broad activity groups— Mobility, Self-care, Oral communication, Health care, Cognitive or emotional tasks, Household chores, Home maintenance or gardening, Meal preparation, Paperwork, Private transport</p> <p>Data sub-item: Broad area of activity where assistance is required or difficulty is experienced</p> <p>Data domain: Yes, No</p> <p>Data sub-item: Grouped frequency of need for assistance or supervision</p> <p>Data domain:</p> <p>Not applicable</p> <p>Less than once a month</p> <p>One to three times a month</p> <p>Once a week</p> <p>Two to six times a week</p> <p>Once a day</p> <p>Twice a day</p> <p>Three to five times a day</p> <p>Six or more times a day</p> <p>Not known</p> <p>Data sub-item: Number of times per day, week or month needs assistance or supervision</p> <p>Data domain: Continuous</p>	<p>Question: Do you regularly need help with daily tasks because of long-term illness, disability or frailty (e.g. personal care, getting around, preparing meals etc)?</p> <p>Response: Yes, No</p> <p>Notes: Asked of the mid age & older cohorts (similar question asked of the younger cohort)</p> <hr/> <p>Questions: In the last month have you needed help from another person to carry out any of these activities?</p> <p>In the last month have you had any difficulty (for example, needing to take extra time, changing the activity or using a device to help you) in completing any of these activities?</p> <p>Options:</p> <p>Grooming (e.g. brushing hair, applying make-up)</p> <p>Eating (e.g. cutting meat, lifting glass or cup, opening milk carton)</p> <p>Bathing or taking a shower</p> <p>Dressing your upper body</p> <p>Dressing your lower body</p> <p>Getting up from a chair</p> <p>Walking inside the house</p> <p>Using the toilet</p> <p>Shopping for personal items or groceries</p> <p>Doing light housework (e.g. cleaning, washing-up)</p> <p>Doing heavy housework (e.g. vacuuming, yard work)</p> <p>Managing money (e.g. writing cheques or keeping accounts)</p> <p>Preparing meals</p> <p>Taking medications</p> <p>Using the telephone</p> <p>Doing leisure activities or hobbies</p> <p>Response: Yes, No</p> <p>No difficulty, Some difficulty, Unable to do</p> <p>Notes: Asked of the older cohort in survey 4</p>

Table 11.10a: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (number of care recipients)

HACC MDS v2	NRCP	SDAC	ALSWH
<p>Data item: Carer for more than one person</p> <p>Definition: Whether or not a primary carer is providing assistance on a regular & sustained basis to more than one care recipient</p> <p>Data domain: Yes No Not stated/inadequately described</p>	<p>Data item: Number of care recipients</p> <p>Definition: A record of those carers who are caring for more than one person who requires help (with self-care, mobility or communication) due to a disability or with a disability as a consequence of ageing or illness</p> <p>Data domain: Carer of one person Carer of two people Carer of three people Carer of more than three people Not stated/inadequately described</p>	<p>Data item: Number of recipients of care</p> <p>Data domain: Not applicable One care recipient Two care recipients Three or more care recipients</p> <p>Data item: <i>Carer status</i></p> <p>Data domain: <i>Not applicable</i> <i>Primary & other carer</i> <i>Primary carer only</i> <i>Unconfirmed primary carer</i> <i>Carer, but not primary carer</i> <i>Principal carer only</i> <i>Not a carer</i></p> <p>Data item: <i>Place of residence of recipient(s) of care</i></p> <p>Data domain: <i>Not applicable</i> <i>Carer lives with each recipient of care</i> <i>Carer does not live with any recipient of care</i> <i>Carer lives with at least one recipient of care & does not live with at least one recipient of care</i></p>	<p>Question: How many people with a long-term illness, disability or frailty do you regularly provide care for?</p> <p>Response: One person Two people More than two people</p> <p>Notes: Asked of the mid age cohort in surveys 2, 3 & 4 & the older cohort in survey 2</p> <p>Question: <i>Do you regularly provide care or assistance (e.g. personal care, transport) to any other person because of their long-term illness, disability or frailty?</i></p> <p>Options: <i>Yes, for someone who lives with me</i> <i>Yes, for someone who lives elsewhere</i> <i>No, I do not provide care</i></p> <p>Response: <i>Yes (or no response)</i></p> <p>Notes: <i>Asked of the older cohort in surveys 2, 3 & 4 (similar question asked of the mid age cohort in surveys 2, 3 & 4)</i></p>

Table 11.10b: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*frequency and duration of care*)

DESP	NRCP	SDAC	ALSWH	
Information collected on date care commenced	<p>Data item: Time spent caring</p> <p>Definition: An indicator of the average amount of time the carer spends caring each week</p> <p>Data domain: Less than 20 hours per week 20 to 39 hours per week 40 hours or more per week Not stated/inadequately described</p> <p>Data item: Date caring role commenced</p> <p>Definition: The date on which the carer's role as primary carer or other carer, commenced</p> <p>Data domain: Valid month/year date</p>	<p>Data item: Number of hours per week primary carer spends actively caring or supervising</p> <p>Data domain: Not applicable Less than 20 hours 20 to less than 40 hours 40 hours or more Not stated</p> <p>Data item: Weekly hours of care main recipient of care receives from primary carer</p> <p>Data domain: Not applicable Less than 20 hours 20 to less than 40 hours 40 hours or more Not stated</p> <p>Data item: Duration of care provision (number of years primary carer provided to main recipient of care)</p> <p>Data domain: Not applicable Does not know Less than one year 1–4 years 5–9 years 10–14 years 15–19 years 20–24 years 25–29 years 30–34 years 35 years or more</p>	<p>Data item: Length of time caring because of condition</p> <p>Data domain: Not applicable 1 year 2 years 3 years 4 years 5 years 6 years 7 years 8 to 9 years 10 years 11 to 15 years 16 to 20 years 21 to 30 years 31 years or more Less than one year</p> <p>Notes: Asked of primary carers</p> <p>Data item: Whether main recipient of care needs episodic or continuous care from primary carer</p> <p>Data domain: Not applicable Needs continuous care Needs episodic care</p>	<p>Question: How often do you provide this care or assistance?</p> <p>Response: Every day Several times a week Once a week Once every few weeks Less often</p> <p>Notes: Asked of the mid age cohort in surveys 2, 3 & 4 & the older cohort in survey 2</p> <p>Question: How much time do you usually spend providing such care or assistance on each occasion?</p> <p>Response: All day & night All day All night Several hours About an hour</p> <p>Notes: Asked of the mid age cohort in surveys 3 & 4 & the older cohort in survey 2 (similar question asked of the mid age cohort in survey 2)</p>

Table 11.10c: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*overall carer need*)

DESP	NRCP	SDAC	
<p>Data item: Carer overall need</p> <p>Data domain:</p> <p>Low</p> <p>Moderate</p> <p>High</p> <hr/> <p>Data item: Emergency contact</p> <p>Definition: The nature of the contact made by the client, whether by telephone or in person, in terms of urgency</p> <p>Data domain:</p> <p>Emergency contact (or no response)</p>	<p>Data item: Carer need</p> <p>Definition: The level of need for support at the time of contact, experienced by the carer in terms of the vulnerability of the carer</p> <p>Data domain:</p> <p>High need</p> <p>Moderate need</p> <p>Low need</p> <p>Not stated/inadequately described</p>	<p>Data item: Whether primary carer needs improvement or more support to assist in caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Needs an improvement or more support</p> <p>Does not need an improvement or more support</p> <p>Not stated</p> <hr/> <p>Data item: Type of support or improvement most desired by primary carer to assist in carer role</p> <p>Data domain:</p> <p>Not applicable</p> <p>More respite care</p> <p>More financial assistance</p> <p>More physical assistance</p> <p>More emotional support</p> <p>Improvement in own health</p> <p>Other</p> <p>Does not need an improvement or more support</p> <p>Not stated</p> <hr/> <p>Data item: Primary carer need & receipt of assistance to care for main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>Receives assistance & does not need further assistance</p> <p>Receives assistance & needs further assistance</p> <p>Does not receive assistance & needs assistance</p> <p>Does not receive assistance & does not need assistance</p>	<p>Data item: Whether primary carer has unmet need for assistance on weekdays</p> <p>Data domain:</p> <p>Not applicable</p> <p>Unmet need for assistance on weekdays</p> <p>No unmet need for assistance on weekdays</p> <hr/> <p>Data item: Whether primary carer has unmet need for assistance on weekends</p> <p>Data domain:</p> <p>Not applicable</p> <p>Unmet need for assistance on weekends</p> <p>No unmet need for assistance on weekends</p> <hr/> <p>Data item: Whether primary carer has unmet need for assistance on weeknights</p> <p>Data domain:</p> <p>Not applicable</p> <p>Unmet need for assistance on weeknights</p> <p>No unmet need for assistance on weeknights</p>

Table 11.10d: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (*carer health and wellbeing*)

DESP	SDAC		ALSWH	
<p>Data item: Key issues & discussion areas</p> <p>Definition: Service provided) by whatever approach) to the client</p> <p>Data sub-items include:</p> <p>Coping & mental health</p> <p>Data domain:</p> <p>Stress/anxiety</p> <p>Feelings of anger/frustration/aggression</p> <p>Symptoms of depression</p> <p>Loss & grief issues</p> <p>Spirituality</p> <p>No time for leisure pursuits/pleasant events</p>	<p>Data item: Whether primary carer feels satisfied due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Feels satisfied due to caring role</p> <p>Does not feel satisfied due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer's physical or emotional wellbeing has changed due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Physical or emotional wellbeing has changed due to caring role</p> <p>Physical or emotional wellbeing has not changed due to caring role</p> <p>Not stated</p>	<p>Question: How much of the time during the past 4 weeks...</p> <p>Options:</p> <p>Did you feel full of life?</p> <p>Have you been a very nervous person?</p> <p>Have you felt so down in the dumps that nothing could cheer you up?</p> <p>Have you felt calm & peaceful?</p> <p>Did you have a lot of energy?</p> <p>Have you felt down?</p> <p>Did you feel worn out?</p> <p>Have you been a happy person?</p> <p>Did you feel tired?</p> <p>Response:</p> <p>All of the time</p> <p>Most of the time</p> <p>A good bit of the time</p> <p>Some of the time</p> <p>A little of the time</p> <p>None of the time</p>	
	<p>Data item: Whether primary carer feels weary or lacks energy due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Feels weary or lacks energy due to caring role</p> <p>Does not feel weary or lack energy due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer's sleep is interrupted frequently or occasionally due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Sleep interrupted frequently due to caring role</p> <p>Sleep interrupted occasionally due to caring role</p> <p>Sleep is not interrupted due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer's interrupted sleep frequently or occasionally due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Sleep interrupted frequently due to caring role</p> <p>Sleep interrupted occasionally due to caring role</p> <p>Sleep is not interrupted due to caring role</p> <p>Not stated</p>	<p>Response:</p> <p>All of the time</p> <p>Most of the time</p> <p>A good bit of the time</p> <p>Some of the time</p> <p>A little of the time</p> <p>None of the time</p>
	<p>Data item: Whether primary carer frequently feels angry or resentful due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Frequently feels angry or resentful due to caring role</p> <p>Does not frequently feel angry or resentful due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer frequently feels angry or resentful due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Frequently feels angry or resentful due to caring role</p> <p>Does not frequently feel angry or resentful due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer's interrupted sleep interferes with normal daily activities</p> <p>Data domain:</p> <p>Not applicable</p> <p>Sleep interrupted frequently interferes with normal daily activities</p> <p>Sleep interrupted frequently does not interfere with normal daily activities</p> <p>Sleep interrupted frequently interference with normal daily activities not stated</p>	<p>Question: Do you have any of these sleeping problems?</p> <p>Options:</p> <p>Waking up in the early hours of the morning</p> <p>Lying awake for most of the night</p> <p>Taking a long time to get to sleep</p> <p>Worry keeping you awake at night</p> <p>Sleeping badly at night</p> <p>None of these problems</p> <p>Response: Yes (or no response)</p>
	<p>Data item: Whether primary carer frequently feels worried or depressed due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Frequently feels worried or depressed due to caring role</p> <p>Does not frequently feel worried or depressed due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer frequently feels worried or depressed due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Frequently feels worried or depressed due to caring role</p> <p>Does not frequently feel worried or depressed due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer's interrupted sleep interferes with normal daily activities</p> <p>Data domain:</p> <p>Not applicable</p> <p>Sleep interrupted frequently interferes with normal daily activities</p> <p>Sleep interrupted frequently does not interfere with normal daily activities</p> <p>Sleep interrupted frequently interference with normal daily activities not stated</p>	<p>Notes: Asked of the older cohort in surveys 2, 3 & 4 & the mid age cohort in survey 4</p>
	<p>Data item: Whether primary carer has had a stress-related illness due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Has been diagnosed with a stress-related illness due to caring role</p> <p>Has not been diagnosed with a stress-related illness due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer has had a stress-related illness due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Has been diagnosed with a stress-related illness due to caring role</p> <p>Has not been diagnosed with a stress-related illness due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer's interrupted sleep interferes with normal daily activities</p> <p>Data domain:</p> <p>Not applicable</p> <p>Sleep interrupted occasionally interferes with normal daily activities</p> <p>Sleep interrupted occasionally does not interfere with normal daily activities</p> <p>Sleep interrupted occasionally interference with normal daily activities not stated</p> <p>Sleep interrupted but frequency or interference not stated</p> <p>Sleep is not interrupted</p> <p>Not stated</p>	<p>Question: In general, would you say your health is...</p> <p>Response:</p> <p>Excellent</p> <p>Very good</p> <p>Good</p> <p>Fair</p> <p>Poor</p>
	<p>Data item: Whether primary carer has had a stress-related illness due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Has been diagnosed with a stress-related illness due to caring role</p> <p>Has not been diagnosed with a stress-related illness due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer has had a stress-related illness due to caring role</p> <p>Data domain:</p> <p>Not applicable</p> <p>Has been diagnosed with a stress-related illness due to caring role</p> <p>Has not been diagnosed with a stress-related illness due to caring role</p> <p>Not stated</p>	<p>Data item: Whether primary carer's interrupted sleep interferes with normal daily activities</p> <p>Data domain:</p> <p>Not applicable</p> <p>Sleep interrupted occasionally interferes with normal daily activities</p> <p>Sleep interrupted occasionally does not interfere with normal daily activities</p> <p>Sleep interrupted occasionally interference with normal daily activities not stated</p> <p>Sleep interrupted but frequency or interference not stated</p> <p>Sleep is not interrupted</p> <p>Not stated</p>	<p>Question: Compared to one year ago, how would you rate your health in general now?</p> <p>Response:</p> <p>Much better now than one year ago</p> <p>Somewhat better now than one year ago</p> <p>About the same as one year ago</p> <p>Somewhat worse now than one year ago</p> <p>Much worse now than one year ago</p>

Table 11.10e: Mapping of dementia-related data items in Australian dementia-relevant collections: Impact of caring role (formal and informal support)

DESP	NRCP	SDAC	ALSWH
<p>Data item: Current services</p> <p>Definition: The primary type of assistance received in the last 2 weeks by the principal carer or person of concern from Commonwealth, state, local government or private services</p> <p>Data domain:</p> <p>No formal services</p> <p>Home-based supports</p> <ul style="list-style-type: none"> Home nursing care/domiciliary nursing Personal care Allied health care/paramedical Food services Delivered meals Domestic assistance Maintenance/modification Social support <p>Day supports</p> <ul style="list-style-type: none"> Day hospital/rehabilitation centre Centre-based day care <p>Respite support</p> <ul style="list-style-type: none"> Respite—home Respite—residential <p>Community packages</p> <ul style="list-style-type: none"> Community options/Linkages/COPS Aged care packages <p>Community teams</p> <ul style="list-style-type: none"> Aged Care Assessment Team/Service Aged Psychiatry/Psychogeriatric Team <p>Alzheimer's Association service</p> <ul style="list-style-type: none"> Support Group Counselling Education/training Other service <p>Carer's Association service</p> <ul style="list-style-type: none"> Support group/counselling/other <p>Home modifications</p> <ul style="list-style-type: none"> Home modification/security Other service 	<p>Data item: Current use of formal services</p> <p>Definition: The current pattern of formal service used by the carer</p> <p>Data domain:</p> <p>Is receiving one or more formal services (on a regular, intermittent or occasional basis) that are primarily focused on meeting the needs of the carer</p> <p>Is receiving one or more formal services (on a regular, intermittent or occasional basis) that are primarily focused on meeting the needs of the care recipient</p> <p>Is receiving a 'package' of formal services—more than one service (case managed or coordinated) which is primarily focused on meeting the carer's needs</p> <p>Is receiving a 'package' of formal services—more than one service (case managed or coordinated) which is primarily focused on meeting the care recipient's needs</p> <p>Is not receiving services that are either focused on meeting the needs of the carer or the care recipient</p> <p>Not stated/inadequately described</p> <p>Data item: Informal support</p> <p>Definition: The informal support provided to the carer by people outside the carer/care recipient relationship</p> <p>Data domain:</p> <p>Wife/female partner</p> <p>Husband/male partner</p> <p>Mother</p> <p>Father</p> <p>Daughter</p> <p>Son</p> <p>Daughter-in-law</p> <p>Son-in-law</p> <p>Other relative—female</p> <p>Other relative—male</p> <p>Friend/neighbour—female</p> <p>Friend/neighbour—male</p> <p>No informal support</p> <p>Not stated/inadequately described</p>	<p>Data item: Whether main recipient of care has a fall-back informal carer</p> <p>Data domain:</p> <p>Not applicable</p> <p>Has a fall-back informal carer</p> <p>Does not have a fall-back informal carer</p> <p>Don't know</p> <p>Data item: Whether fall-back carer lives with main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>Fall-back carer lives with main recipient</p> <p>Fall-back carer does not live with main recipient</p> <p>Does not have a fall-back carer/does not know</p> <p>Data item: Relationship of fall-back carer to main recipient of care</p> <p>Data domain:</p> <p>Not applicable</p> <p>Spouse or partner</p> <p>Father</p> <p>Mother</p> <p>Son</p> <p>Daughter</p> <p>Son-in-law</p> <p>Daughter-in-law</p> <p>Other male relative</p> <p>Other female relative</p> <p>Friend or neighbour (male)</p> <p>Friend or neighbour (female)</p> <p>Does not have a fall-back carer or does not know</p> <p>Data item: Relationship of main source of assistance to primary carer</p> <p>Data domain:</p> <p>Not applicable</p> <p>Spouse or partner</p> <p>Father</p> <p>Mother</p> <p>Son</p> <p>Daughter</p> <p>Father-in-law</p> <p>Mother-in-law</p> <p>Other male relative</p> <p>Other female relative</p> <p>Friend or neighbour (male)</p> <p>Friend or neighbour (female)</p> <p>Formal provider</p> <p>Has no main source of assistance</p> <p>Data item: Whether primary carer's main source of assistance is a co-resident</p> <p>Data domain:</p> <p>Not applicable</p> <p>Co-resident</p> <p>Not a co-resident</p> <p>Has no main source of assistance</p>	<p>Question: Which of the following groups have you sought advice or help from in the last 6 months?</p> <p>Options:</p> <p>Food services (e.g. Meals on Wheels)</p> <p>Nursing or community health services</p> <p>Respite services (in-home, day centre or inpatient)</p> <p>Homemaking services (e.g. home care service, laundry service)</p> <p>Home maintenance services (e.g. odd jobs, gardening)</p> <p>Counselling or other mental health services</p> <p>Ambulance service</p> <p>Social groups (e.g. CWA, Senior Citizen's Centre, craft or exercise groups, church groups)</p> <p>Support & advisory groups (e.g. Arthritis Foundation, Pensioner Advisory Service, Older Women's network)</p> <p>None of the groups</p> <p>Response: Yes (or no response)</p> <p>Notes: Asked of the older cohort in survey 3 (similar questions asked of the older cohort in surveys 2 & 4)</p> <p>Question: Do you have any paid help with domestic work (e.g. housework, ironing)?</p> <p>Response: Yes, No</p> <p>Notes: Asked of the mid age cohort in survey 2</p>
<p>Data item: Counselling support summary</p> <p>Definition: Describing the level of counselling support provided</p> <p>Data domain:</p> <p>Information, advice & support—practical aspects</p> <p>Empathetic listening & emotional support</p> <p>Counselling</p> <p>Structured therapy</p>	<p>Daughter</p> <p>Son</p> <p>Daughter-in-law</p> <p>Son-in-law</p> <p>Other relative—female</p> <p>Other relative—male</p> <p>Friend/neighbour—female</p> <p>Friend/neighbour—male</p> <p>No informal support</p> <p>Not stated/inadequately described</p>	<p>Not applicable</p> <p>Co-resident</p> <p>Not a co-resident</p> <p>Has no main source of assistance</p>	

12 Improving dementia data

The differences in purpose and operational context of the data collections reviewed in Chapter 11 have produced varying approaches to the collection of data about dementia and cognitive impairment. Data development in this area also reflects 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 report is not to define or prescribe a definitive set of data elements for collection about dementia, but to present options for potential data elements that could be used in a wide range of collections. If these elements are used as a standard 'menu', and if context and purpose are taken into account, this will promote greater consistency and comparability across the field, and greater quality in many collections.

12.1 Data development methodology

Data development concerns the building and/or improvement of a data collection for a specific purpose, irrespective of how the data are collected. For this project the data development process was overseen and guided by the National Dementia Data Analysis and Development Reference Group.

The Reference Group was guided by considerations of the relative importance of the data element 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. Where possible, existing data elements that are included in collections described in Chapter 11 have been used.

The Reference Group considered the intended applications of the information collected by the data elements, and this guided the selection of value domains for new data elements. The value domains that were included were selected to be exhaustive, mutually exclusive and internally consistent.

The theme concerned with the impact on carers is not only of relevance to dementia data. However, as Chapters 6 and 7 both observe, there is some evidence which suggests that caring for someone with dementia can be a different experience in many respects from caring for people with other types of disabilities or long-term conditions. For this reason, this report makes recommendations about possible data elements in this area.

Elements about 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.

The menu 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.

Table 12.1: Framework for proposed dementia data elements

<p>6 Reporter details</p> <p>6.1: Reporter status</p> <p>6.2: Relationship of proxy reporter to person of interest</p>	<p>1 Identification of cognitive impairment and dementia</p> <p>1.1: Identification of cognitive impairment</p> <p>1.2: Identification of a diagnosis of dementia</p>	
	<p>2 Cognitive impairment and dementia diagnosis information</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>3 Current behaviour related to dementia and its impact on care</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>4 Coexisting health conditions</p> <p>4.1: Coexisting health conditions</p>	
	<p>5 Impact of caring</p> <p>5.1: Impact of care measure</p>	

This report recommends data elements for three dementia data collection levels, which 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. Information about proxy-reporting is an overarching theme that applies to all levels because it can provide an indication of the accuracy of the information at any level.

The data elements may be collected on one occasion only, such as when a person accesses an emergency service, or at intervals depending on the nature and purpose of the collection.

12.2 Dementia data collection levels

Level 1: Essential data elements

In this level not all subjects about whom data are collected will have dementia. This level of dementia data is appropriate for collections or surveys that require an estimate of the population experiencing dementia or cognitive impairment and an indication of the accuracy of the reported data. These collections do not necessarily focus on dementia, and any relevant population may either include only a relatively small number of people with dementia, or more detailed information about the dementia syndrome is not required for effective and appropriate service delivery. Data elements about reporter details are included in this level because of their importance in assessing the accuracy of information. The data elements included in this level are:

- *Identification of cognitive impairment or dementia*
 - 1.1: Identification of cognitive impairment
 - 1.2: Identification of a diagnosis of dementia
- *Reporter details*
 - 6.1: Reporter status
 - 6.2: Relationship of proxy reporter to person of interest

Level 2: Highly desirable data elements

The subjects for these data elements are people with dementia. This level is appropriate for collections which require more detailed information about the syndrome itself. This may be for research reasons, or because a service population includes a significant proportion of people with dementia, and information about their condition is necessary to ensure appropriate treatment, care and services. Examples of such service collections might be the NRCP and ACAP.

Level 2 data elements include those in Level 1, with the addition of:

- *Cognitive impairment or dementia diagnosis information*
 - 2.1: Type of dementia
 - 2.2: Date of first formal diagnosis
 - 2.3: Medical professional who first identified cognitive impairment or diagnosed dementia
 - 2.4: Severity of dementia

Level 3: Desirable data elements

For a comprehensive picture of the population experiencing dementia, it is recommended that the whole suite of elements be used, including data elements at this level and the previous two levels. This level is appropriate for collections focusing on people with dementia, for example researchers or programs who deliver dementia-specific services. They may also be collected in contexts where a significant proportion of the service population

have dementia, or are considered to be at risk of developing dementia, and this more detailed information is required for appropriate treatment and care management.

At the same time, there needs to be discretion in the use of these additional data elements, even in dementia-specific programs. The collection of any suite of data elements must be appropriate for the purpose of the service being provided and the characteristics of the clients, and feasible in the service setting and context.

Level 3 data elements include those in Level 1 and Level 2, with the addition of:

- *Cognitive impairment or dementia diagnosis information*
 - 2.5: Treatment with medication for cognitive impairment due to dementia
 - 2.6: Treatment with medication for behavioural and psychological symptoms of dementia
- *Current behaviour related to dementia and its impact on care*
 - 3.1: Nature of current challenging behaviour
 - 3.2: Frequency of occurrence of current challenging behaviour
 - 3.3: Duration of episodes of current challenging behaviour
 - 3.4: Disruption due to current challenging behaviour
 - 3.5: Stress experienced as a result of current challenging behaviour
- *Coexisting conditions*
 - 4.1: Coexisting health conditions
- *Measuring the impact of caring*
 - 5.1: Impact of care measure

12.3 Proposed data elements

The data elements in this framework can be used to improve the comparability of data collected in existing collections and in epidemiological research. The data elements are based on relevant national data standards where these are available or appropriate. Most importantly, they provide a description of the experience of dementia, which is generally unavailable from most existing national collections, and which is essential for a whole-of-a-person approach to assisting people with dementia.

The proposed data elements aim to be independently valid yet related to each other, and appropriate to the general context and scope of a range of data collection instruments and contexts.

Each data element stands alone to provide crucial information on an aspect of dementia, but the data elements together provide a more detailed account of the experience of people with dementia and their carers. They may also be used to monitor changes, over successive collection periods.

A data element is a basic unit of identifiable and definable information. The data elements in this chapter include a name, a definition, value domains and sometimes a guide for use.

- Each data element has a definition attached that expresses the essential nature of the data element and its differentiation from other data elements.
- A value domain provides a set of permissible values by which a data element can be implemented. Some elements include definitions of the value domains.

- The guide for use includes additional comments or advice on the interpretation or application of the value domains. Not all elements include a guide for use and none include detailed information about collection methodology. This is because the guide for use and the collection methodology are specific to the collection in which the element is included.

In this chapter, existing scales used by clinicians have been used as the basis of value domains for some data elements. The advantage of this approach is that the value domains are consistent with existing practice. However, this approach can be problematic.

The settings that scales are used in, and the experience and qualification of the users, can influence the accuracy of the information collected. If these scales are to provide the basis for data element value domains, it may be necessary to ensure that people collecting this data have adequate training in the use of the scales. Similarly if other information or tools are required to calculate the score, these should be available to anyone using the data element. This is especially important if the data element is used as part of a research study.

Scales can provide a starting point for measurement but users should be mindful that scales may be updated. If an update results in a change to the value domains or the essential meaning of the data element, the data element should be updated with a new version number and the commencement date of the new version should be recorded.

Many scales originate overseas and the language may not be 'Australian English'. For example, the Cohen Mansfield Agitation Inventory refers to 'Inappropriate robing/disrobing' which are not terms used in Australia. Terms can be substituted as long as the essential meaning is not compromised.

Identification of cognitive impairment or dementia

The following data elements are proposed to capture the range of information relevant to the identification of dementia and cognitive impairment.

Cognitive impairment is an indicator of possible dementia, particularly when the diagnostic process has not been undertaken or completed or is not conclusive. It is recognised that there are states of memory and other cognitive impairments that fall short of criteria for a diagnosis of dementia (Henderson 1994b). The criteria for cognitive impairment and dementia are closely linked, and there can be similar behavioural and functional outcomes.

Cognitive impairment is also associated with conditions other than dementia, including intellectual disability, closed head injury and discrete brain injury which is not progressive, as well as with depression or other reversible health conditions.

Cases of cognitive impairment due to intellectual disability should be excluded from collection. Intellectual disability is associated with impairment of intellectual functions, with limitations in a range of daily activities and with restriction in participation in various life areas. *Support may be needed throughout life, the level of support tending to be consistent over a period of time but may change in association with changes in life circumstances* (AIHW 2004g, italics added).

This data element is designed to collect information about cognitive impairments that would be considered to be a physical disability. Physical/diverse disability is associated with the presence of an impairment, which may have diverse effects within and among individuals. Included in this broad category is the subcategory *Acquired brain injury* which is used to describe multiple disabilities arising from damage to the brain acquired after birth. It can occur as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen,

degenerative neurological disease, and so on. Effects include deterioration in cognitive, physical, emotional or independent functioning (AIHW 2004g).

These guidelines mean that someone with Down Syndrome would be excluded from the collection, until they subsequently develop dementia which causes a decline in their cognitive functioning beyond what had existed before. The guide for use outlines inclusion and exclusion guidelines to specify the collection criteria.

A number of screening and assessment tools are available to identify the presence of cognitive impairment (see Chapter 2 for a discussion of some of these). The data element capturing information about cognitive impairment simply records whether there is evidence of cognitive impairment. The value domain of a data element does not replace clinical judgement but can record the outcome of the assessment.

Similarly, *Identification of a diagnosis of dementia* allows for the collection of information that reflects the outcome of the process of diagnosing dementia.

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 one 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.

Cognitive impairment or dementia diagnosis and treatment

The following data elements are proposed to capture a wider range of information about the diagnosis of dementia, the type of dementia which the diagnosis reveals, its severity and pharmaceutical treatments being used.

Type of dementia

The inclusion of the data element *Type of dementia* allows for the differentiation of aetiology which can impact on the manifestation, management and progress of the condition. It also reflects the information that the person of interest, family member, carer or friend is given at the time of initial diagnosis.

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.

Date of first formal diagnosis

Date of first formal diagnosis is included to support the estimation of the length of time the person of concern has had dementia. In some circumstances it can also be used to calculate the length of time prior to admission to residential care and the duration of the caring role. Collecting the date of diagnosis is preferable to collecting data about the number of years that have elapsed since diagnosis, which changes yearly. Date only needs to be collected once, and it allows a more precise calculation of time.

A diagnosis is defined as the decision reached, after assessment, of the nature and identity of the disease or condition in a patient (National Health Data Committee 2004b). 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. The diagnostic process results in a formal diagnosis. This does not mean that a definitive diagnosis always results from the diagnostic process but that the process should have been undertaken in order to arrive at a diagnosis.

This data element is intended to be collected for people who have been diagnosed with dementia. It is expected that the amount of information collected about the diagnosis is likely to increase and improve over time. In the past there has been reluctance on the part of some medical practitioners to initiate the diagnostic process because it was felt that there was no benefit in knowing, there was a fear of provoking distress, it was felt that the diagnosis would be difficult for the person to understand or that no benefit could be gained by the person being diagnosed. There is growing recognition of the value of both diagnosing dementia and informing the person and their family carers of their diagnosis, which will improve the amount and reliability of information about dementia diagnosis.

The date of diagnosis may be the date on which a conclusive diagnosis of dementia was determined, but this is not necessarily the date on which the diagnosis was relayed to the person of interest, their family member, carer or friend. The difference between the two dates is unlikely to be great and it is the provision of a diagnosis that is the most relevant to the person and/or another person. In addition, the person and/or other people are unlikely to be provided with the date on which a conclusive diagnosis was achieved and this date could be difficult to identify because of the number of investigations that would occur before a definitive (or close to) diagnosis was achieved.

On some occasions the diagnosis is not conveyed to the person of interest but is provided initially to another person. A survey of carers of people with dementia that was conducted in 1990 revealed that the diagnosis was given to the respondent alone in 65% of cases in the first instances and to the respondent and patient together in 21% of cases (Brodsky et al. 1990). A more recent consumer medication study revealed that the diagnostic information was provided to the carer, the person with dementia or another person (Alzheimer's Australia 2005a). In order to support the collection of accurate and comprehensive information, the date of diagnosis should therefore be the first date on which either the person of interest, their family member, carer or friend was provided with a diagnosis of dementia.

The data element *Date of first formal diagnosis* cannot always be fully completed, with missing information about the day or month of diagnosis. Where possible it is desirable to collect the full date of diagnosis and include guidelines for data collectors about how to deal with missing data (e.g. if the respondent only knows the month and year of diagnosis). When date is an estimated or default value, national health and community services collections typically use 0101 or 0107 or 3006 as the estimate or default for DDMM. Whatever approach is chosen for dealing with missing data, it should be documented and used consistently.

The collection of this information can also be accompanied by an additional data element, *Date accuracy indicator* (METeOR identifier 294429) which is an indicator of the accuracy of the components of a reported date. The concurrent collection of *Date accuracy indicator* would provide an indication of improvement in the accuracy of date of diagnosis information over time.

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.

Medical professional who first identified cognitive impairment or diagnosed dementia

The data element *Medical professional who first identified cognitive impairment or diagnosed dementia* identifies the professional occupation of the person who diagnosed dementia (not the role of the person). This is because the role refers to functions, tasks or responsibilities, whereas the profession refers to the vocation or occupation, which is more appropriate in this case.

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.

Severity of dementia

A data element that collects information about the severity of dementia has been included because of the importance of information about the extent of the condition and the impact it has on the person with dementia and those caring for them. The severity of dementia can be measured using any of a number of severity scales currently in use. For example, the Global Deterioration Scale (GDS) is used to assess severity and comprises part of a clinical rating system called the GDS staging system (Reisberg et al. 1982). There are three independent measures included: the GDS, the Brief Cognitive Rating Scale and the Functional Assessment Staging Measure.

A consistently used severity scale would allow the collection of nationally comparable data about dementia severity. Developing a data element for this concept, however, needs to take account of the diversity of approaches used by clinicians and care providers to ascertain severity. Two options to achieve this include the development of a data element whose value domains are mappable to a range of severity scales, or the development and implementation of a data element based on an agreed nationally consistent standardised approach to measuring severity.

The Clinical Dementia Rating (CDR) scale is an example of a scale that could be used as the basis of a data element. It describes six domains: memory, orientation, judgement and problem solving; community affairs; home and hobbies; and personal care (Hughes et al. 1982, Morris 1993). The severity categories are *Healthy*, *Questionable dementia*, *Mild dementia*, *Moderate dementia* and *Severe dementia*. It is usually administered by clinicians in the setting of detailed knowledge of the individual patient. Clinicians using this tool require training in its use. A scoring algorithm is used to calculate the severity of dementia. The CDR requires that the assessor determine the score only if it is due to cognitive loss, but this could be difficult to determine. If one domain of the score cannot be completed due to characteristics other than cognitive impairment, this would influence the outcome of the score.

Whatever scoring system is used as the basis of a data element, the element is not the assessment tool; it records the result of the assessment or evaluation. The user guide should specify that a value cannot be allocated without the use of the assessment tool and/or calculation of the algorithm used to derive a result.

Data element 2.4 presented below is based on the CDR. There is some research which suggests that there may be value in adding an additional category of *Advanced dementia* (characterised by complete dependence on carers for all aspects of daily living and with no semblance of memory function) (Draper 2004). Further, most dementia severity scales include a value for no dementia – ‘no cognitive decline’ (GDS) or ‘healthy’ (CDR scale). This reflects that the scales are used to detect both the presence and severity of the disorder. The proposed data element below is intended to be collected about people with dementia so no value for normal has been included.

The AIHW considers that this data element should be the subject of further work and consultation with clinicians and care providers in order to determine the most appropriate basis for an agreed national data element.

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.

Treatment with medication

The data elements that describe treatment with medication for dementia are proposed to capture information relevant to medication usage in people with dementia. Pharmacological interventions for people with dementia are most commonly prescribed to manage behavioural and psychological symptoms and other effects of cognitive impairment. These pharmaceuticals are not limited to cholinesterase inhibitors but include antipsychotic medication that is prescribed to manage behavioural problems.

The collection of information about medication for cognitive impairment allows for the analysis of usage of commonly prescribed medication to assist cognition. Because the range of currently available medications is limited, the proposed data element (2.5) names individual medications. Together with the information about *Type of dementia* it would be possible to identify changing prescribing patterns, reflecting the expansion of usage of antidementia medication for vascular and Lewy Body dementia.

The data elements that deal with medication usage include a value domain '*No medication taken*'. This is to ensure the relevance of the data element for the whole population whether or not they are taking medication, and is intended to improve the accuracy of the data and their application. If a decision is made to collect this data element, it should be collected for all people in the collection, not only those taking medication. Collecting the information about the whole population will enable the estimation of medication usage rates for the total population. If the question is only completed for persons who take medication there would be uncertainty about whether those who had not responded were not taking medication, or they chose not to answer or they were not asked the question. The ambiguity of a simple 'no' response (sometimes called the 'flavours of null') can influence the accuracy and completeness of the data collected. The proposed data elements aim to minimise the adverse influences on aggregated data as much as possible.

The wording of the proposed data elements asks about what medication is being taken as opposed to what medication is prescribed. This recognises that although medication can be prescribed, it is not necessarily taken. Similarly, it allows for the inclusion of complementary medications.

The collection of the name of the medication in data element 2.5 ensures that the lowest level of granularity is available. It can then be aggregated for analysis and reporting and could be allocated to classes of the Anatomical Therapeutic Chemical (ATC) classification system if required. If only aggregated information is collected it cannot be disaggregated to identify

specific medications. This approach also supports the most common way in which medication usage is ascertained (i.e. 'What medicines, tablets or drugs are you taking?').

This list only includes currently prescribed medication. As newer medication becomes available it would need to be coded initially to the *Other medication* value. When introducing the data element to a specific collection, the guide for use should specify that this is the approach to be taken. A review of the *Other* category should be undertaken at defined intervals. This category usually comprises 5–10% of responses. Once the percentage of response in this category rises above an agreed level, the specified medications that have been recorded should be reviewed and if necessary the value domains should be updated.

Complementary medications (also known as 'traditional' or 'alternative' medicines) are not separately included in the list of medications, but this does not preclude collection of this information in the *Other* category. The same approach to incorporating this information into changes to the data element can be used.

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 records information about the class of medication rather than the individual trade names of medications. This is because a wider range of possible medications are available for the treatment of behavioural and psychological symptoms. The use of this data element requires allocation of the medication to a category, which can increase time and burden for those who are reporting the data. A list of commonly used medication and the classes they belong too should be included in the guide for use to allow data collectors to allocate medication to a specified class.

The categories that are currently included in the data element 2.6 are restricted to those in the Psycholeptics and Psychoanaleptics levels (pharmacological/therapeutic subgroup) within the Nervous system group of the ATC classification. More detail is available at lower levels of the classification. The ATC has been endorsed by the National Health Information Group for inclusion in the Australian Family of Health and Related Classifications, and as a national health data standard for reporting on therapeutic drug use.

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.

Current behaviour related to dementia and its impact on care

Challenging behaviour is described as ‘any behaviour associated with the dementing illness which causes distress or danger to the person with dementia and/or others’ (Bird 2003). An integral part of the description is the impact the behaviour has on the person with dementia and on others, not only the type of behaviour. A description of current behaviour is insufficient on its own. The person with dementia and care providers will vary in terms of the extent to which behaviours are experienced as disrupting or challenging. Training and support for carers may also increase their capacity to manage some behaviours more effectively, thereby reducing their disruptive effect. At the same time, caregiver attributes and behaviour may contribute to behavioural and psychological symptoms in the person with dementia (Sink et al. 2006).

Quantification of behavioural disturbance is important in determining disease severity and prognosis and has a significant impact on carer stress. It is not known whether changes in behaviour result from disease-related neuro-chemical imbalance, from psychological reactions to the cognitive deficits associated with the dementing process or from concomitant physical or psychiatric illness (Baumgarten et al. 1990). The data element *Nature of current challenging behaviour* (3.1) does not encompass the psychological causes of the behaviour, but the manifestation.

It is recommended that detailed information about the nature of psychological symptoms experienced by the person with dementia, including depression and anxiety, is collected using the data element *Coexisting health conditions* (4.1) that is described later in this chapter.

The goals of managing challenging behaviour are to reduce the disruptive effects of the behaviour and/or amelioration of distress or danger (Bird et al. 2002). Management

strategies include psychosocial approaches, pharmacotherapy, and education and support for carers or nursing staff.

The impact of the behaviour on the person with dementia, family members, carers, friends or other people determines whether it is considered challenging rather than the behaviour itself and may lead to referral to specialist services for help. Additionally the impact of the behaviour depends on the environment and setting in which it occurs; wandering at home into a garden without a secure fence is more likely to cause concern than wandering in a secure facility.

The guide for use for the data element *Nature of current challenging behaviour* defines current behaviour as 'any behaviour occurring over the previous four weeks'. This definition of 'current' could exclude people who manifest challenging behaviour very infrequently but some constraint on the period over which the behaviour is occurring is usually required in order to capture reliable information about behaviour of concern to family members, carers or health and care workers. A further difficulty with this proposed time period is that it may result in the capture of information about behaviours which are occurring in response to significant changes in the person's environment (e.g. entry to residential aged care, or loss of a carer). On the one hand, these behavioural responses may be atypical of the individual's usual pattern and the collected information may not be regarded as useful for understanding the impact of dementia. On the other hand, any such behaviour requires a care and/or treatment response at the time and may be typical of the individual's response to stressful situations.

The primary focus of the data elements below is to collect a range of information about current challenging behaviour from the perspective of those around them, particularly carers. The inclusion of the data elements *Frequency of occurrence of current challenging behaviour* (3.2) and *Duration of episodes of current challenging behaviour* (3.3) reflects that the frequency and duration of challenging behaviour are important indicators of its impact.

It may not be appropriate to collect both *Frequency of occurrence of current challenging behaviour* and *Duration of episodes of current challenging behaviour*. Some types of behaviour may feel disruptive because they occur often (e.g. hiding things, throwing things). Other behaviours are best defined by how long they last when they do occur, as well as how often they occur. Yelling, screaming or pacing are examples. Both data elements are included here. However, the appropriateness of collecting either or both will depend on the nature of the behaviour manifested.

If the appropriate set of data elements is used they can describe the multifaceted nature of challenging behaviour and assist in understanding the reasons why carers and family members find the behaviour distressing and disruptive. This can be used to guide the development and provision of appropriate information, support and assistance to those caring for people with dementia who manifest these behaviours. Collection at different intervals would facilitate monitoring changes in behaviour and its impact over time, although these would not be sufficient for evaluation purposes.

Collecting information about the frequency of behaviour is most useful if it can be collected in respect of each behaviour. The matrix in Table A12.1 is an example of how this could be achieved.

Data element 3.1 is based on the Cohen-Mansfield Agitation Inventory. Other scales and inventories of challenging behaviours also exist, such as the Dementia Behaviour Disturbance Scale (Baumgarten et al. 1990) and the Problem Behaviour Checklist (Brodaty & Hadzi-Pavlovic 1990). No single existing scale was considered by the National Dementia Data Analysis and Development Reference Group to be completely satisfactory. The Cohen-

Mansfield Agitation Inventory is widely used, including by the trial ACFI, and hence has been proposed as the basis of data element 3.1. One limitation of the Cohen-Mansfield inventory is that it doesn't give any measure of severity or impact. Further work is required to develop this data element, including issues associated with interpretation and weighting of responses to individual items.

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 (Bird 2003).*

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

Source: National Dementia Data Analysis and Development Reference Group.

The above data elements can be used to describe the characteristics of challenging behaviour. However, the extent to which such behaviour contributes to distress for the person with dementia, family members and carers is highly variable. The impact of this behaviour cannot be simply explained by differences in frequency or the apparently less disruptive behaviour of pacing compared with screaming. The impact of challenging behaviours is also affected by personal factors, the extent to which modifications to the physical environment have facilitated the management of the behaviour, the development of effective strategies for managing the behaviour, and the nature and type of support and education available for the carer.

In order to understand the impact of challenging behaviours, it is also necessary to collect data which specifically focus on the extent to which the carer finds the behaviour stressful or disruptive (Caldwell & Bird 2004). As discussed earlier, these data elements record subjective measures of the impact.

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 which causes distress or danger to the person with dementia and/or others (Bird 2003).*

Current behaviour includes any behaviour occurring over the previous four 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 which causes distress or danger to the person with dementia and/or others (Bird 2003).*

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

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

Coexisting health conditions

Chapter 5 reported data which reveal that people with disabilities and dementia have a higher average number of comorbidities compared with others. The existence of comorbid conditions has implications for the diagnosis, treatment and care management of people with dementia.

A coexisting condition is one that exists at a point in time, usually the time when the information is collected. These conditions include pre-existing conditions, conditions that have become evident after the diagnosis and conditions that have arisen because of dementia or the care received for dementia.

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.

The presence of a coexisting health condition may indicate a need to engage other clinical support. The list of health conditions that are included in the data element that is proposed is not extensive or detailed enough to reflect the intricacies of clinical management but merely provides an indication of the need for additional care, not the specific nature of that care. Although the list includes some conditions that are risk factors for dementia, accurate identification of risk factors is more suited to the collection of detailed medical histories rather than by the use of this data element.

Health conditions can be either self-diagnosed or diagnosed by a clinician. In this data element self-reported health conditions are excluded to enhance the reliability of the information collected. Health conditions are included if they are currently being treated, and excluded if they occurred in the past and are no longer current or being treated, for example, postnatal depression.

The coexisting conditions are grouped into the chapter headings of the ICD. This classification was used in order to maximise the comparability of information collected about health conditions across collections. It is used as the basis of health condition collection in the Australian Bureau of Statistics collections.

Only the chapter headings are included in the data element; the suggested list of conditions based on the ACAP code list for *Health condition – short* is included in Table A12.2 (AIHW

2002a). The contents of the list are not exhaustive and may not meet the data needs of all agencies. It can be expanded within the existing chapter structure to meet the needs of individual collections, particularly in respect of conditions and symptoms which are integral to dementia.

For example, anxiety and depression are particularly common amongst people with dementia. Between 30% and 50% of people with Alzheimer's disease have depression and similar rates occur in other types of dementia (Olin et al. 2002). Some symptoms of depression such as sleep disturbance, apathy, lethargy and decreased concentration are common to dementia, and may result in certain types of behaviour (e.g. negativism or general restlessness) which would be captured through the data element *Nature of current challenging behaviours*. These conditions are included in the Mental and Behavioural disorders chapter of the ICD-10 (*psychoses and depression/mood affective disorders; phobic and anxiety disorders*). It is important to collect information about the presence of these conditions at a sufficient level of detail through the data element *Coexisting health conditions*. However, care should be taken to only record depression or anxiety if they have been diagnosed by a medical practitioner, using tools specific to assessing depression in people with dementia such as the Cornell Scale for Depression.

Measuring the impact of caring

The provision of care by the family and friends of people with dementia constitutes the largest care sector for people with dementia. This is not unique to people with dementia. However, there is increasing recognition that the provision of treatment and care for people with dementia needs to acknowledge the part carers play. Service provision needs to include both carers and people with dementia – people in care relationships – and there is growing evidence that support for carers is an essential component in the provision of care and treatment for the person with dementia (AIHW: Hales et al. 2006). Indeed some services, such as those provided by Alzheimer's Australia, initially helped carers; people with dementia became clients in more recent times. Understanding the impact of caring is critical to understanding how carers can be supported.

Although data about the impact of caring is not a dementia-specific data requirement, the inclusion of such data elements is recommended for any level 3 collection. These data elements should go beyond the information collected by data element 3.5 *Stress experienced as a result of current challenging behaviour*, which does not capture the overall impact of the caring role. This would particularly be the case where behavioural disturbances are either absent or infrequent (which may be the case in 'advanced' stages of dementia as described by Draper 2004:66). Similarly, if the behaviours occur but do not cause the carer to feel stress, other aspects of their caring role such as feelings of isolation or financial disadvantage may contribute to carer stress.

Chapter 6 discussed research suggesting that caregivers of those with an intellectual disability reported significantly more positive components of caregiving than the caregivers of those with a dementia-related disorder, and carers of those with dementia or undiagnosed memory loss were more likely to express anger and resentment than carers of those with a physical impairment. Research in the United States by Clipp & George (1993) (cited in Parks & Novielli 2000) suggests that caring for someone with dementia is associated with a higher level of stress than caring for someone with functional impairment from another type of chronic illness. Data collected through the inclusion of these data elements will contribute to

better understanding whether and in what ways the needs of this group of carers differ from those of other carers (e.g. carers of people with an intellectual disability).

Caring for a person with dementia can cause adverse impacts on the carer although not all carers experience caring negatively. 'Carer burden' is a term that has been used to describe the negative impacts on carers and been defined as 'the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for impaired older adults' (George & Gwyther 1986:253, cited in Vitaliano et al. 1991:67). The impact of caring is not restricted to family members but includes anyone who provides care. The stress of caring is a widely recognised risk factor for entry to a long-term residential aged care facility and for formal service use in general. The stress that can arise from caring is recognised as causing psychiatric and physical consequences. Depression and anxiety are the most commonly observed psychiatric conditions observed in carers, whilst activation of the hypothalamic-pituitary-adrenal axis and impaired immune function in older caregivers, and increased systolic blood pressure in carers who had ceased employment, were observed. In addition carers are at an increased risk of injury due to the physical demands of caring (Volicer 2005).

Amongst carers who experience stress, the impact has been defined as both objective burden (e.g. disruption of family life) and subjective burden (e.g. caregiver response to the situation). Objective burden reflects disruption to finances, role, family life, supervision and neighbour relations, whilst subjective burden refers to feeling embarrassed, overloaded, trapped and resentful and excluded (Thompson & Doll 1982, cited in Vitaliano et al. 1991). Not all caregivers experience both types of burden nor would they necessarily use the word burden to define the impact of their role, but measures that capture the impact of caring should ideally be able to capture both objective and subjective burden. Subjective measures are harder to collect even when collected with a standardised measurement tool (AIHW 2003a).

Predictors of an adverse carer impact identified in a multinational review include the care recipient characteristics such as severity of the dementia, behavioural disturbance, the gender and age of the care recipient at disease onset and the hours of care required. Carer characteristics include the gender and age of the carer, the duration of caregiving, the relationship to the patient, the socioeconomic status of the care and their self-rated competence or self-efficiency (Torti et al. 2004).

There are a number of possible scales of carer stress or carer burden which would be appropriate for use in collecting such information. This project does not recommend any particular scale for use. Its recommendations are limited to the following:

- Data elements about the impact of care should be included at least in Level 3 collections.
- The data element(s) should be based on a reputable and validated instrument that covers a range of possible impacts.
- The data element(s) should be mappable to the ABS SDAC, thus facilitating comparison with the general population of carers.
- Reporting should include an overall score of carer stress, along with scores on individual items making up the scale or instrument used.
- The same scale should be used for repeat measures as appropriate to monitor change over time.

Two widely used scales used for measuring caregiver burden are the Zarit Burden Interview and the Caregiver Strain Index (CSI).

The Zarit Burden Interview is a 22-element self-reported inventory that examines burden associated with functional and behavioural impairments and the home care situation, and includes questions such as: ‘Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?’ and ‘Do you feel your health has suffered because of your involvement with your relative?’ (Zarit et al. 1980). The elements are worded subjectively focusing on the affective response of the caregiver (Vitaliano et al. 1991). A high score correlates with higher level of burden.

The CSI was developed using responses from 85 individual carers of older patients who had returned home after hospitalisation for a major episode of illness or surgery (Robinson 1983). In this 13-element self-report scale, scoring is dichotomous and subjective burden can be inferred through the endorsement of certain elements (Vitaliano et al. 1991). It is included in the Australian Government Department of Veterans’ Affairs outcome measurement guidelines and in the Queensland Ongoing Needs Identification assessment guidelines.

Experience in the Aged Care Innovative Pool dementia and disability services evaluation conducted by the AIHW suggested that service providers often feel more comfortable requesting caregivers to complete the CSI than the Zarit Burden Interview (AIHW: Hales et al. 2006). A positive screen (7 or more elements positive) on the CSI indicates a need for more in-depth assessment to facilitate appropriate intervention.

Table 12.2: Caregiver Strain Index

Here is a list of things that other people have found to be difficult when caring for someone who needs support. Please circle YES if they apply to you or NO if they do not apply to you.	
1. My sleep is disturbed (e.g. because the person I care for is in and out of bed or wanders around all night)	YES / NO
2. It is inconvenient (e.g. because helping takes so much time or it’s a long drive over to help)	YES / NO
3. It is a physical strain (e.g. because of lifting in and out of chair; effort of concentration is required)	YES / NO
4. It is confining (e.g. helping restricts my free time or I cannot go visiting)	YES / NO
5. There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)	YES / NO
6. There have been changes in personal plans (e.g. had to turn down a job; could not go on holiday)	YES / NO
7. There have been other demands on my time (e.g. from other family members)	YES / NO
8. There have been emotional adjustments (e.g. because of severe arguments)	YES / NO
9. Some behaviour is upsetting (e.g. incontinence, trouble remembering things, or accusing people of taking things)	YES / NO
10. It is upsetting to find the person I care for has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)	YES / NO
11. There have been work adjustments (e.g. because of having to take time off)	YES / NO
12. It is a financial strain	YES / NO
13. Feeling completely overwhelmed (e.g. because of worry about the person I care for; concerns about how I will manage)	YES / NO
Total score (count YES responses)	

Source: Robinson 1983.

A data item on the effect of the caring role on carer wellbeing was proposed in a related project (*Australian incontinence data analysis and development*) (AIHW 2006a). The item is modelled on selected relevant data items collected in the ABS SDAC. Each of the values in the value domain is drawn from questions directed to primary carers in the SDAC, and concern the carer's physical and emotional response to the caring role, and the effect of the caring role on their relationship with the person being cared for, other family members and friends.

A similar data element might also be considered for the collection of information about the impact of caring for a person with dementia with the inclusion of additional value domains:

- No effect of caring role (to cater for carers who do not experience effects on their physical and emotional wellbeing)
- Other effect of caring role on physical and emotional wellbeing
- Not stated/inadequately described.

Box 12.1: Dementia – effects on carer physical and emotional wellbeing

Definition: *The effects on a carer's physical and emotional wellbeing associated with assisting a person to manage their dementia.*

Example value domains:

Feels weary or lacks energy due to caring role

Sleep frequently interrupted due to caring role

Feels worried or depressed due to caring role

Feels angry or resentful due to caring role

Relationship with person being cared for affected due to caring role

Relationships with other family members affected due to caring role

Relationships with friends affected due to caring role

Other effects

No effect due to caring role

Not stated/inadequately described

Source: Based on ABS Survey of Disability, Ageing and Carers.

Finally, screening tools such as the 28-item General Health Questionnaire (e.g. GHQ-28) could be used to collect data on the mental health of carers. However, this tool is focused on subjective aspects of carer stress and does not include items relating to disruptions to work, relationships and family life.

The AIHW considers that a data element to collect information about the effect of the caring role on carers of people with dementia should be the subject of further work and consultation with care providers and clinicians in order to determine the most appropriate basis for an agreed national data element.

Reporter details

As discussed earlier, understanding the source of reported information provides an indication of the accuracy of the information collected. Gradual decline is a key characteristic

of dementia and the nature and extent of the decline can only be appreciated if the proxy reporter has known and been able to observe the person with dementia for some time.

In addition to the data element *Reporter status* (6.1), one other element is proposed: *Relationship of proxy reporter to person of interest* (6.2). This element captures information that can provide an indication of the accuracy of the reported information based on the nature of the relationship between the reporter and the person of interest.

Data element 6.1: Reporter status

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

Example 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.*

Example 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.

12.4 Recommendations for future data development

This report reviewed Australian data collections to determine the nature and extent of data about dementia that are currently collected in Australia, and to guide the development of draft data elements for possible inclusion in future collections.

This chapter proposes 14 data elements that may be used to collect information on the prevalence, type, severity, behavioural manifestations and impact of dementia among Australians, and the types of medications they use to manage their dementia. The chapter also recommends that data about the impact of caring should be included in collections. Data about functional limitations is clearly also of importance. However, the focus of this project was on dementia-specific data. It is assumed that data about functional impairment and other relevant sociodemographic characteristics are already (or will be) collected.

Further work is required to develop these data elements, particularly in respect of dementia severity and impact on carers. As research, treatment and management modalities and the provision of care in the field of dementia change, new information needs may also become evident. These might include the capacity to collect the outcomes of screening and assessment tools and information about new medications or psychosocial interventions. The project to develop the Dementia Outcomes Measurement Suite being undertaken over the next year will be an important part of the next stage of developments in this area.