# Section 1: Dementia definition, classifications and data sources

# 1 Introduction

## 1.1 Background

Dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. Dementia is not a single specific disease. It affects people differently, and the impact on their carers and families also varies. Dementia is not a natural part of ageing, although most people with dementia are older. After the age of 65 the likelihood of living with dementia doubles every five years and it affects 24% of those aged 85 and over (Henderson & Jorm 1998).

Dementia is the most significant neurological disorder experienced by those over 80. It is the greatest single contributor to burden of disease due to disability at older ages as well as the second greatest single contributor to the cost of care in residential aged care after incontinence. The service needs experienced by someone with dementia may vary greatly with the severity of the cognitive impairments (AIHW 2004f). People with dementia eventually become dependent on their care providers in most or all areas of daily living placing considerable strain on those who care for them.

Because Australia's population is ageing, there has been growing recognition that dementia represents a significant challenge to health, aged care and social policy. In the 20 years to 2024, the proportion of the population aged over 65 is projected to increase from 13% to 20%. The number and proportion of people in the 'older old' age groups (85 years and over) are expected to rise even more rapidly, more than doubling from 298,300 (1.5%) to 725,300 (2.9%) (AIHW 2005b:138).

The number of people with dementia will grow correspondingly from over 175,000 in 2003 to almost 465,000 in 2031, assuming the continuation of current dementia prevalence rates. In recognition of the challenges this presents to governments, families and health and care providers, the Australian Government introduced the *Helping Australians with dementia, and their carers – making dementia a National Health Priority* in the 2005 Federal Budget. This $320.6 million over five years funding package will support people with dementia and their carers through three measures:

- *Dementia – A National Health Priority* – for additional research, improved care initiatives and early intervention programs for people with dementia
- *Extended Aged Care at Home (EACH) Dementia Packages* – for 2,000 new EACH community care places dedicated to helping people with dementia remain at home and in their community
- *Training to Care for People with Dementia* – for dementia-specific training for aged care workers and community workers.

Caring for people with dementia is a responsibility and a challenge for all levels of government. Looking to the future, Australian health ministers noted that within 10 years dementia is predicted to be the major cause of disability for Australians, overtaking cardiovascular disease, cancer and depression. Ministers agreed that an action program is necessary to address this health problem and endorsed a *National Framework for Action on Dementia* in April 2006. The development of the framework was guided by a nation-wide

consultation that included the combined input of governments, health care providers, peak bodies, and people with dementia, their families and carers. The framework focuses on outcomes that can best be achieved nationally, with the cooperation of the Australian, state and territory governments. Consultations culminated in a national forum attended by around 70 stakeholders. This forum supported five key priority areas for action which health ministers had previously identified:

- research
- information and education
- access and equity
- quality, integration and continuum of care
- workforce and training.

## 1.2 Purpose of this report

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

This report supports work undertaken in relation to the Key Priority Area of Research in the *National Framework for Action on Dementia*. Among the priorities for action are to research the projected prevalence of dementia, including prevalence among groups with diverse needs, and to design and implement uniform and effective data standards and systems which can be used in all jurisdictions and which ensure dementia data elements are included in key minimum data sets (MDS). The data analysis included in this report is, however, undertaken at the national level only.

The report will also support and complement Australian Government initiatives in respect of dementia research and data development activity occurring in community aged care and residential aged care programs. This work has been conducted alongside comparable work in relation to incontinence (AIHW 2006a) and community care data alignment to ensure cross-fertilisation and comparable outcomes.

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, for example 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.

## 1.3 Structure of this report

The **introductory section** includes this introduction and Chapters 2 and 3:

- Chapter 2 describes the definitions and classifications of dementia used in clinical and epidemiological research settings. It also discusses some of the problems encountered in identifying people with dementia.
- Chapter 3 reviews the available data sources and summarises their scope, purpose and content, together with a brief description of data elements related to dementia.

**Section 2** provides a profile of dementia in Australia. This section includes the following chapters:

- Chapter 4 reviews Australian and international prevalence estimates of dementia, and discusses differences in prevalence by age, sex, dementia severity and residential setting. The chapter provides estimates of the incidence of dementia, and also estimates the impact of dementia on the quality of life for people in the community and in residential aged care. These estimates are projected to 2030–31.
- Chapter 5 examines some of the relevant characteristics of people with dementia, including their living arrangements and carer support, their level of disability, behavioural and psychological symptoms and need for assistance.
- Chapter 6 examines the data available about carers of people with dementia, including the impact of their caring role on their physical and social wellbeing.
- Chapter 7 explores use of health and aged care services by people with dementia. It includes newly derived estimates of the dependency profile of people with dementia in residential aged care.
- Chapter 8 discusses the expenditure associated with dementia, including estimates of medical, pharmaceutical, hospital and aged care expenditure. Costs are projected to 2030–31.
- Chapter 9 outlines the strengths and limitations of available data as revealed by the previous chapters.

**Section 3** of the report focuses on developing dementia data standards. It includes the following chapters:

- Chapter 10 discusses principles of data development and describes key data standards that should be adhered to in developing data recommendations.
- Chapter 11 describes and compares dementia-related data elements currently collected in Australian data collections.
- Chapter 12 recommends possible data elements relevant to dementia for inclusion in data collections.

# 2 Definition, diagnosis and classification of dementia

The way in which dementia is defined and classified has implications for the accuracy with which we can estimate the prevalence of dementia in the community. The application of diagnostic guidelines which accompany classificatory systems has consequences for the diagnosis, treatment and care of individuals as well as for statistical measurement, for example through the failure to recognise and identify particular types of dementia. Improving the quality and consistency of dementia data must therefore begin with the use of agreed definitions and classifications. This chapter discusses how dementia and its outcomes are defined and classified within relevant international classifications. It briefly examines some of the complications for defining and classifying dementia and describes some of the common screening tests and assessment tools used to identify and diagnose dementia.

## 2.1 Describing dementia

The term 'dementia' is derived from the Latin word *demens* meaning 'without mind'. Today, dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. These declines[1] in mental function may manifest themselves through different symptoms at various times and often relate to the cause of dementia (see Alzheimer's Australia 2005b). In the early stages of dementia, difficulty may be experienced with familiar tasks such as shopping, driving or handling money. As dementia progresses, more basic or core activities of daily living such as self-care (e.g. eating, bathing, dressing) are affected. More specifically, the cognitive, psychiatric and behavioural manifestations of dementia may include:

- memory problems, especially for recent events (long-term memory usually remains in the early stages)
- communication difficulties through problems with speech and understanding language
- confusion, wandering, getting lost
- personality changes and behaviour changes such as agitation, repetition, following
- depression, delusions, apathy and withdrawal.

There are over 100 illnesses and conditions that can result in dementia—a comprehensive list of these is included in the International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision (WHO 1992a) and the Australian modification (ICD-10-AM) (NCCH 2002b). The most common types of dementia in Australia are:

- dementia in Alzheimer's disease, estimated to be responsible for around 50–70% of dementia cases, involving abnormal plaques and tangles in the brain.

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1 Use of the term 'decline' excludes people with cognitive impairment due to developmental disorders, but includes people with non-progressive forms of dementia (such as dementia caused by head injury) that involve an initial loss of cognitive functioning.

- vascular dementia (formerly known as arteriosclerotic or multi-infarct dementia), resulting from significant brain damage caused by cerebrovascular disease—onset may be sudden, following a stroke, or gradual, following a number of mini-strokes or because of small vessel disease
- dementia with Lewy bodies, in which abnormal brain cells (Lewy bodies) form in all parts of the brain. Progress of the disease is more rapid than for dementia in Alzheimer's disease
- frontotemporal dementia (e.g. Pick's disease), in which damage starts in the front part of the brain, with personality and behavioural symptoms commonly occurring in the early stages
- mixed dementia, in which features of more than one type of dementia are present. For example, many people with dementia have features of both Alzheimer's disease and vascular dementia.

There are also a number of less common types of dementia, including:

- dementia in Parkinson's disease, resulting from the loss of the neurotransmitter, dopamine, in the brain (dopamine is implicated in the control of voluntary movements)—dementia is common in people with Parkinson's but not everyone with Parkinson's develops dementia
- alcohol-induced dementia (e.g. Wernicke/Korsakoff syndrome), in which brain function deterioration is associated with excess alcohol consumption, particularly in conjunction with a diet low in Vitamin B1 (thiamine)
- drug-related dementia, where neurological deficits result from substance abuse, such as petrol sniffing
- head injury dementia, which involves brain damage resulting from head injuries
- Huntington's disease, an inherited disorder of the central nervous system, which is characterised by jerking or twisting movements of the body and is usually eventually accompanied by dementia
- other forms of dementia such as that developing in the course of human immunodeficiency virus (HIV), or Creutzfeldt-Jakob disease
- reversible forms of dementia, such as dementia from B12 deficiency or hypothyroidism, which, although rare, are important to identify.

A definitive diagnosis of many of the diseases associated with the syndrome of dementia is often only possible after death, based on post-mortem examination of the brain, although serial magnetic resonance imaging (MRI) scans show potential in helping diagnose some types of dementia. However, the syndrome of dementia is more amenable to diagnosis and a number of screening tests, assessment and diagnostic tools and international classifications, are available for its diagnosis and classification.

## Cognitive impairment and dementia

Cognitive impairment is generally considered to be the defining feature of dementia, although dementia is also associated with functional impairment and changes in behaviour that result in care and support needs. Additionally, the level of cognitive impairment, including any behavioural manifestations, has an impact on carers of people with dementia. Memory loss, reduced capacity for decision making and problem solving, unacceptable

social behaviour and nocturnal activity all contribute to the labour intensity and distress that can be associated with caring for a person with dementia.

The number of screening tests and neuropsychological assessments that focus on various domains of cognition (see Section 2.2), reflects the large number of specific mental functions that comprise cognition. *Cognitive impairment* is impairment in one or more of these functions, which include short-term memory (learning skills), long-term memory, executive function (abstract thinking, judgement, problem solving) or other higher cortical function (aphasia, apraxia, agnosia, constructional abilities, calculation), among others. Cognitive impairment is generally defined in respect of the disease or condition being discussed, as the specific cognitive domains that are affected may vary.

It is generally accepted that there are states of memory and other cognitive impairments that fall short of criteria for a diagnosis of dementia (Henderson 1994a). The concept of subclinical cognitive impairment has been the focus of intense research, and there are many existing terms that describe this concept, each with different definitions and criteria. Generally, subclinical cognitive impairment has been considered as an intermediate stage between normal ageing and dementia, and the condition has been viewed as either physiological ageing or the beginnings of a pathological process—*mild cognitive impairment* has received the most attention (Peterson 2004, cited in Chong & Sahadevan 2005). Whether a number of these subclinical cognitive impairments progress to dementia, particularly Alzheimer's disease, is still debated. A number of authors, including Ritchie & Touchon (2000), Burns & Zaudig (2002) and Feldman & Jacova (2005) have reviewed the concept of subclinical cognitive impairment, and a significant proportion of the following discussion is drawn from these sources.

Kral (1962) first proposed *benign senescent forgetfulness* which describes a stable impairment commonly featuring depressive symptoms, characterised by an awareness of memory problems, an inability to recall remote rather than recent events and loss of memory for minor details. Crook et al. (1986) developed the notion of *age-associated memory impairment*, quantifying the degree of memory impairment required for diagnosis as at least one standard deviation below the mean for young adults. *Late-life forgetfulness* was defined by Blackford & LaRue (1989) as a more severe form of this concept, requiring a score of between one and two standard deviations below the mean established for age on at least two of at least four tests.

However, Levy (1994) argued that cognitive impairment occurs in domains other than memory, and that memory impairment itself occurs with other impairments. *Ageing-associated cognitive decline* refers to an impairment of one standard deviation below age- and education-corrected norms in one of a wider range of cognitive functions such as attention, memory, learning, thinking, language and visuospatial function. A similar concept, *age-related cognitive decline*, is included in the Diagnostic and Statistical Manual of Mental Disorders (DSM), Fourth Edition, Text Revision, and is defined as a complaint of difficulties in recalling names and appointments or in problem solving, which cannot be related to a specific mental problem or a neurological disorder (American Psychiatric Association 2000). However, strict criteria of deviation from a population norm are not specified for diagnosis.

Although these concepts are all regarded as falling within the (extreme) limits of normal ageing, Ritchie & Touchon (2000) question whether they may be partly due to underlying disease which may be differentiated from normal ageing-related physiological changes—subjects with objectively demonstrated deficits have been shown to be at increased risk for neurodegenerative disease, and to show quantitative and qualitative differences in cerebral imaging and share common biologic and environmental risk factors. *Mild cognitive disorder*

and *mild neurocognitive disorder,* defined in the ICD and DSM, are examples of conditions due to underlying disease which occur at any age and involve symptoms as well as memory loss (Table 2.1).

**Table 2.1: Definition of mild cognitive disorder in the ICD and age-related cognitive decline and mild neurocognitive disorder in the DSM**

| Classification | Terminology | Definition |
|---|---|---|
| ICD-10 & ICD-10-AM | Mild cognitive disorder | A disorder characterised by impairment of memory, learning difficulties & reduced ability to concentrate on a task for more than brief periods. There is often a marked feeling of mental fatigue when mental tasks are attempted, & new learning is found to be subjectively difficult even when objectively successful. None of these symptoms is so severe that a diagnosis of either dementia (F00–F03) or delirium (F05.–) can be made. This diagnosis should be made only in association with a specified physical disorder, & should not be made in the presence of any of the mental or behavioural disorders classified to F10–F99. The disorder may precede, accompany or follow a wide variety of infections & physical disorders, both cerebral & systemic, but direct evidence of cerebral involvement is not necessarily present. It can be differentiated from postencephalitic syndrome (F07.1) & post-concussional syndrome (F07.2) by its different aetiology, more restricted range of generally milder symptoms & usually shorter duration. |
| DSM-IV-TR | Age-related cognitive decline | This category can be used when the focus of clinical attention is an objectively identified decline in cognitive functioning consequent to the ageing process that is within normal limits given the person's age. Individuals with this condition may report problems remembering names or appointments or may experience difficulty in solving complex problems. This category should be considered only after it has been determined that the cognitive impairment is not attributable to a specific mental disorder or neurological condition. |
| | Mild neurocognitive disorder (included as an example of cognitive disorder not otherwise specified) | The essential feature is the development of impairment in neurocognitive functioning that is due to a general medical condition. By definition, the level of cognitive impairment & the impact on everyday functioning is mild (e.g. the individual is able to partially compensate for cognitive impairment with additional effort). Individuals with this condition have a new onset of deficits in at least two areas of cognitive functioning. These may include disturbances in memory (learning or recalling new information), executive functioning (e.g. planning, reasoning), attention or speed of information processing (e.g. concentration, rapidity of assimilating or analysing information), perceptual motor abilities (e.g. integrating visual, tactile or auditory information with motor activities) or language (e.g. word-finding difficulties, reduced fluency). The report of cognitive impairment must be corroborated by the results of neuropsychological testing or bedside standardised cognitive assessment techniques. Furthermore, the cognitive deficits cause marked distress or interfere with the individual's social, occupational or other important areas of functioning & represent a decline from a previous level of functioning. The cognitive disturbance does not meet the criteria for a delirium, a dementia, or an amnestic disorder & is not better accounted for by another mental disorder (e.g. substance-related disorder, major depressive disorder). |

*Sources:* American Psychiatric Association 2000; NCCH 2002b; WHO 1992a.

The Canadian Study of Health and Aging (Graham et al. 1997) referred to *cognitive impairment no dementia* which, like mild cognitive disorder and mild neurocognitive disorder, is attributable to an underlying physical disorder. This diagnostic grouping includes individuals with problems of memory and/or other areas of cognitive functioning that are insufficient to meet dementia diagnostic criteria—the grouping is the most broad-based and inclusive, as it has virtually no exclusions (Feldman & Jacova 2005). However, there are currently no clear defining criteria for the condition.

*Mild cognitive impairment* is a term in evolution, seeking precise nosological definition (Burns & Zaudig 2002). Ritchie et al. (2001) describe the difficulties among clinicians in reaching a consensus on diagnostic criteria for mild cognitive impairment. The term was first introduced to denote abnormal cognitive functioning in any domain (Flicker et al. 1991 and Zaudig 1992, cited in Feldman & Jacova 2005). However, Petersen et al. (1999) subsequently refined the term to refer to those with a memory impairment beyond that expected for age

and education (yet are not considered as extreme as 'demented'), to describe the transitional state between normal ageing and early or mild (or clinically probable) Alzheimer's disease. Many (but not all) people with mild cognitive impairment were reported to progress to Alzheimer's disease at an accelerated rate. Diagnostic criteria included memory complaint, normal activities of daily living, normal general cognitive function, abnormal memory for age and not demented.

Recognising that other presentations of mild cognitive impairment exist, Petersen et al. (2001) later used the term *amnestic mild cognitive impairment* to emphasise memory loss, and specified diagnostic criteria that included memory complaint (preferably corroborated by an informant), impaired memory function for age and education, preserved general cognitive function, intact activities of daily living and not demented. Other hypothetical presentations of mild cognitive impairment were also proposed, including *multiple domains slightly impaired* (that may progress to Alzheimer's disease, vascular dementia or is possibly associated with normal ageing) and *single non-memory domain* (that may progress to frontotemporal dementia, Lewy body dementia, vascular dementia, primary progressive aphasia, Parkinson's disease or Alzheimer's disease).

Recently, Winblad et al. (2004) proposed an evolved model of mild cognitive impairment, which specifies that individuals are considered to be neither normal nor demented, there is self- and/or informant report of cognitive decline that is supported by impairment on objective cognitive tasks (with evidence of decline over time) and functional activities are mainly preserved with only minimal impairment (particularly on complex instrumental activities of daily living). Individuals are classified as memory impaired or non-memory impaired, and then subclassified as having a single or multi-domain impairment.

Diagnosticians have also noted the difficulties in diagnosing very early dementia—Pond & Brodaty (2004) have documented issues in the early detection of dementia, noting the similarities in manifestations of mild cognitive impairment, early dementia and cognitive impairment associated with depression. The relatively arbitrary nature of dementia diagnosis is based largely on interference with activities (Burns & Zaudig 2002). The difficulties in identifying and distinguishing between early dementia and mild cognitive impairment have implications for measuring the prevalence of dementia.

The term *mild cognitive impairment* may also be used more broadly (like *cognitive impairment no dementia*) to refer to a number of the subclinical cognitive impairments previously discussed—in this report the term is also used more generally to describe the state of cognitive functioning that falls below defined norms, but falls short of dementia in severity (Feldman & Jacova 2005). This definition captures people with cognitive impairment that may or may not progress to dementia, which is due to conditions that may not be associated with ageing, or is actually an early stage of (undiagnosed) dementia. Defining mild cognitive impairment in this way allows for further investigation where the reliability of disease coding is questionable, or where the care requirements for people with dementia are not easily distinguished from other people with similar symptoms.

## 2.2 Diagnosing dementia

Despite the difficulties associated with diagnosing dementia outlined above, the importance of diagnosing the syndrome as early as possible is becoming more widely accepted. There are a number of benefits of an accurate and early diagnosis of dementia and its causes. Identification and recognition of the problem, as well as involvement of health professionals,

may provide some relief to a person with dementia, their family and carers (Ministerial Task Force on Dementia Services in Victoria 1997, cited in Black et al. 2001).

Early diagnosis allows a person with dementia, their family and carers to plan for future living arrangements and care options, organise their financial affairs, and make decisions relating to power of attorney. A diagnosis of dementia also influences decisions relating to rehabilitation programs and provision of aids and services (Wilkinson 2000, cited in Black et al. 2001). Functional assessment enables identification of strategies to reduce risks, maximise independence in daily tasks and identify necessary modifications of the home environment to maximise function (Patterson et al. 1999, cited in Black et al. 2001). Additionally, a diagnosis of dementia can facilitate access to a number of medications that may reduce the symptoms of dementia—for people in the mild or moderate stages of dementia, medications may improve clear thinking and the ability to carry out daily tasks, as well as reducing hallucinations and delusions (Wilkinson 2000, cited in Black et al. 2001).

The diagnostic process may in involve the use of initial screening and/or assessment tools, followed by more comprehensive assessment by a specialist, culminating in a differential diagnosis of dementia. The general practitioner may become aware of the possibility of dementia in their patients in three ways: presenting problems, noting early pointers when treating other conditions, or screening. A significant number of cases of dementia may only become apparent when the individual's carer dies or becomes unable to cope (Bridges-Webb & Wolk 2003:10).

## Initial screening and assessment

The purpose of initial screening is to identify people who may benefit from more intense assessment—it has the dual purpose of identifying potential need and also minimising the potential drain on resources caused by unnecessary intense assessment processes. Screening is different from case-finding as it refers to action to determine the presence of likely or possible disease in a person without problems or symptoms pointing to the possibility of dementia (Bridges-Webb & Wolk 2003:31). An assessment of dementia not only aims to determine the condition causing the symptoms (whether to rule out dementia, or determine which disease is causing dementia), but also to assess the needs of the person with dementia and their family and carers.

Barriers to early diagnosis include a lack of routine screening for dementia and a lack of access to specialty consultative services (Shores et al. 2004). However, many experts are reluctant to advocate a population-based screening program, arguing that there is currently insufficient evidence to justify the resources that would be required to implement routine screening for dementia of people who do not display symptoms using existing standardised assessment tools (Bridges-Webb & Wolk 2003:31). Further arguments against the implementation of a screening program are that there does not currently exist a screening test that can reliably detect dementia in a cost-effective manner before patients develop noticeable symptoms, and secondly that, even if such a test did exist, there is no treatment available that can cure dementia if applied in the pre-symptomatic phase (refer to Box 2.1 for characteristics of an effective population-based screening program).

Thus, initial screening and assessment for dementia is generally initiated when a patient or his/her family expresses concern about symptoms, or when the clinician notices changes or signs which may be associated with a dementing illness in the course of their contact with the patient (Bridges-Webb & Wolk 2003:31). This requires that clinicians, in particular general practitioners (GPs), are aware of signs and symptoms that may be associated with

dementia and are open to identifying and discussing these with patients and their families if and when they become apparent.

**Box 2.1: Criteria for an effective population-based screening program**

*A screening program must meet certain criteria before it can be considered useful. Important factors influencing the usefulness of a screening program include disease factors, testing factors and therapeutic factors.*

*The disease being screened for must:*

1. *occur in an asymptomatic phase that lasts for a significant length of time*
2. *represent a significant burden to the population*
3. *lead to a bad outcome if left untreated.*

*A screening test must be available that is:*

1. *able to detect the disease during the asymptomatic phase*
2. *acceptable to patients and practitioners*
3. *cost-effective*
4. *highly sensitive and reasonably specific for the target disease.*

*In addition, there must be value in identifying the disease in the asymptomatic phase, that is:*

1. *There must be an effective treatment available that can cure or improve the outcome.*
2. *The outcome for the disease must be better if the treatment is applied during the asymptomatic period than later in the course of the disease. Ideally there should be a chance for cure if treatment is given at an early stage of disease.*

*Source:* Adapted from IAM 2006.

## Assessment and screening instruments

A variety of assessment tools exist which may be helpful in screening for, diagnosing and/or monitoring dementia. In the context of dementia, assessment tools are employed for two basic purposes:

1. to screen people for the likely presence/absence of cognitive impairment which may be indicative of dementia
2. for in-depth assessment for the purposes of formal diagnosis, care planning, and monitoring of disease progression or treatment efficacy.

As dementia is a syndrome with several characteristic features (not all of which may be present in any one case), most assessment instruments include separate components, subscales or domains. Few tests are capable of discriminating across all types and levels of dementia. For example, tests that are capable of identifying mild cognitive impairment may not be suitable for differentiating among more advanced stages of dementia and vice versa. Thus, assessment tools are often best used in combination and in the context of other forms of assessment such as clinical interview, informant interview and biological testing (McDowell & Newell 1996:289; Meade & Bowden 2005). A combination of screening tests may be used to increase the rate of diagnosis for those who have dementia, and reduce the likelihood of falsely diagnosing dementia (Flicker et al. 1997, cited in Black et al. 2001), and clinicians are generally encouraged to look for other evidence of symptoms or functional change in everyday life (Meade & Bowden 2005).

Diagnosis cannot be made purely on the basis of screening. People who screen positive for cognitive impairment must undergo further clinical evaluation to confirm or reject a

differential diagnosis of dementia (Black et al. 2001). Thus, though GPs may often be the first port of call for people who are worried about their own or a loved one's cognitive functioning, the final diagnosis of dementia is usually made by a neurologist, geriatrician or psychogeriatrician (Wilkinson et al. 2004, cited in Brodaty et al. 2006).

Initial assessment/screening tools must achieve a balance between comprehensiveness and clinical utility. Many standardised tools were initially intended to be a component of a battery of tests in the full assessment and diagnosis of dementia. In applying such items and subscales to initial assessment and screening rather than to diagnosis, a balance must be found between minimising test length and complexity, evaluating total cognitive function and maintaining test accuracy (Boustani et al. 2003). In their entirety, these instruments have more in common with diagnostic protocols (discussed below) than screening instruments.

**Box 2.2: Requirement for use of MMSE and/or ADAS-Cog and CIBIC to access subsidised anticholinesterase medication through the PBS**

*The use of some standard assessment tools is enshrined in administrative requirements of some aspects of Australia's health and aged care systems. For example, some anticholinesterase medication used in the treatment of mild to moderate dementia, donepezil hydrochloride (Aricept), rivastigmine hydrogen tartate (Exelon), and galantamine hydrobromide (Remilyn), are approved for listing on the Pharmaceutical Benefits Scheme (PBS) for people with Alzheimer's disease who meet specific criteria (Alzheimer's Australia 2004).*

*People who have a diagnosis of mild to moderately severe Alzheimer's disease are able to access Aricept, Exelon or Remilyn at a subsidised cost through the PBS provided that certain criteria are met. In order to establish eligibility for this subsidy, the client must have a diagnosis of mild to moderately severe Alzheimer's disease confirmed by a neurologist, psychogeriatrician, psychiatrist, geriatrician or consultant physician, and a written application for subsidised treatment must be made to Medicare Australia. This application must include the results of a baseline Mini-Mental State Examination (MMSE) test, and to be eligible the client must score 10 or higher, and if the score is 25 points or above, the results of a baseline Alzheimer's Disease Assessment Scale, cognitive subscale (ADAS-Cog), must also be specified. In order to receive continuing subsidised access to the medication beyond the initial six month treatment period, it must be demonstrated that the client has benefited from the pharmacotherapy. The requisite proof of improvement in cognitive function is an increase of at least 2 points from baseline on the MMSE or a decrease of at least 4 points from baseline on the ADAS-Cog for patients with an MMSE baseline score of 25 points or higher (DoHA 2006).*

*Access to subsidised Aricept, Exelon or Remilyn may be granted to people who score lower than 10 points on the MMSE under the following circumstances, which are non-cognitive factors accepted as limiting the person's ability to complete the MMSE. These are where the patient (DoHA 2006):*

- *is from a culturally and linguistically diverse background and has limited English language skills*
- *has less than six years of formal education, and/or is illiterate or innumerate*
- *is an Aboriginal or Torres Strait Islander*
- *has an intellectual disability (developmental or acquired), e.g. Down's syndrome*
- *has significant sensory impairment, despite best correction, which precludes completion of an MMSE test and/or*
- *has prominent dysphasia, out of proportion to other cognitive and functional impairment.*

*In such cases, access to continuing subsidised pharmacotherapy requires demonstration of improvement in cognitive function, based on a rating of 'very much improved' or 'much improved' on the Clinician's Interview-Based Impression of Change (CIBIC) scale, which must be completed by the same clinician who initiated treatment (DoHA 2006).*

*As at April 2006, other tests cannot be used to demonstrate initial or ongoing eligibility for PBS-subsidised pharmacotherapy.*

The most widely used cognitive assessment tool in primary care settings is the MMSE (Folstein et al. 1975). The extent to which the MMSE is an effective screening tool depends on the prevalence of dementia within the target population and the cut-off points at which the screening result is determined to be positive or negative (Boustani et al. 2003). Despite its shortcomings (see Table 2.3), the MMSE remains the best-studied clinically feasible cognitive assessment for screening purposes (Boustani et al. 2003), is often incorporated in diagnostic assessments, and is recognised as a method of demonstrating treatment efficacy by the Australian Government (see Box 2.2).

Table 2.3 includes information about the most commonly used tools in Australia, including their application, strengths and weaknesses. A summary of the applications of these tools is in Table 2.2 below.

**Table 2.2: Type/use of screening test or assessment tool**

| Screening test | Provisional diagnosis | Diagnostic suite | Clinical monitoring |
|---|---|---|---|
| Mini-Mental State Examination | Alzheimer's Disease Assessment Scale | Kimberley Indigenous Cognitive Assessment | MMSE |
| General Practitioner Assessment of Cognition | Informant Questionnaire of Cognitive Decline in the Elderly | Psychogeriatric Assessment Scales Cambridge Mental Disorders of the Elderly Examination | CogHealth |
| CogHealth Memory Monitoring System | Rowland Universal Dementia Assessment Scale | Consortium to Establish a Registry for Alzheimer's Disease | Dementia Rating Scale |
| Clock drawing tests | Kimberley Indigenous Cognitive Assessment | | Clinician's Interview-Based Impression of Change |
| 7 Minute Screen | Psychogeriatric Assessment Scales | | Clinician's Interview-Based Impression of Change with Caregiver Input |
| Mini-Cog | | | |

**Table 2.3: Summary of selected cognitive assessment and screening tools**

| Screening test/ assessment tool | Authors | Purpose & use | Benefits | Limitations |
|---|---|---|---|---|
| Mini-Mental State Examination (MMSE) | Folstein et al. (1975) | Most widely used & widely researched cognitive assessment tool in primary care settings<br>Can be used as a clinical screening instrument<br>A MMSE score is usually required to establish eligibility for access to subsidised anticholinesterases through the PBS<br>Used to screen for entry into dementia research studies | Brief, structured mental status examination, requiring 10–15 minutes to administer<br>Screens orientation, memory, attention, naming, comprehension & praxis<br>Portable—requires only a pen & paper for administration<br>Provides a unitary score which is often used as a basis for classifying severity of cognitive impairment<br>Scoring system is helpful in following change over time<br>Does not require specific qualifications to administer & can therefore be used by a wide variety of personnel in various settings (with some training)<br>Free for research purposes | Insensitive to patients with mild cognitive impairment<br>Lacks diagnostic specificity<br>Lacks frontal lobe domain tests<br>Does not take into account levels of education, premorbid ability & cultural & linguistic diversity<br>Some doubt about the ability to monitor change in individuals over time, due to the relatively high measurement error<br>Influenced by premorbid intelligence, social class, physical disability, age, gender & education—dementia may be missed in some individuals & individuals without dementia may be misclassified<br>10–15 minutes administration time makes the tool impractical for use within a standard GP consultation |
| Alzheimer's Disease Assessment Scale (e.g. ADAS-Cog) | Rosen et al. (1984) | Developed to sample the cognitive functions typically impaired in Alzheimer's disease & to express these as an overall summary score<br>Used as the primary outcome measure in many antidementia drug trials<br>May be used as supplementary evidence to establish eligibility for access to anticholinesterases through the PBS (see Box 2.2) | More thorough than the MMSE<br>Effective, brief examination for study of language & memory skills<br>Assesses cognitive function & non-cognitive features associated with dementia | Shares many of the limitations reported for the MMSE, with similarly variable scores for individuals<br>Takes approximately 30 minutes to administer & is therefore impractical for use as a screening tool within a standard GP consultation<br>Requires purchase of a special kit that costs in excess of $400 |
| Informant Questionnaire of Cognitive Decline in the Elderly (IQCODE) | Jorm & Jacomb (1989) | Designed to elicit information about the elderly person's memory & thinking at the time of screening as compared with 10 years before | Collects structured informant-based information in the context of a quantitative survey instrument<br>Appears to be unaffected by patient's education levels<br>Advantages of informant-based assessments include relevance to everyday life, acceptability by subjects, flexibility to assess difficult-to-evaluate patients, administrative ease, longitudinal perspective & cross-cultural portability<br>Not under copyright; however, author requests information about research projects that use the tool | There is mixed evidence about the usefulness of informant-based assessment tools<br>May be influenced by age & gender of the patient<br>Informant reports are subjective & may be influenced by the patient's or informant's emotional states<br>Requires responses from someone close to the person with suspected dementia—some patients have no suitable informant available<br>Some functions associated with dementia are not assessed |

*(continued)*

**Table 2.3 (continued): Summary of selected cognitive assessment and screening tools**

| Screening test/ assessment tool | Authors | Purpose & use | Benefits | Limitations |
|---|---|---|---|---|
| Psychogeriatric Assessment Scales (PAS) | Jorm et al. (1995) | Designed to assess two major psychogeriatric disorders: dementia & depression | Consists of 6 scales: the patient interview covers cognitive impairment, depression & stroke; the informant interview covers cognitive decline, behaviour change & stroke<br>The patient & informant interviews give independent perspectives on the subject's behaviour, provided the subject & informant are interviewed separately—discrepancies between the two sources can be informative<br>Can be used by non-medical staff after brief training<br>The 6 scales can be treated as independent modules | Only suitable for use with people who are fluent in English<br>The cognitive impairment scale may be influenced by education & premorbid intelligence rather than be symptomatic of cognitive decline (though the cognitive decline scale is not influenced by education or intelligence earlier in life)<br>Informant reports can be influenced by the informant's emotional state, particularly if the informant is depressed |
| General Practitioner Assessment of Cognition (GPCOG) | Brodaty et al. (2002) | Designed for use as a brief screening tool in general practice in Australia<br>Recommended in the NSW Health *Care of patients with dementia in general practice* guidelines | Assesses cognitive impairment & allows a brief assessment of functional status<br>Can be administered within a standard GP consultation (approximately 7 minutes to administer)<br>Includes a cognitive test & informant questionnaire—either can be used alone with only a slight loss in psychometric properties<br>The informant section can be used alone if language problems preclude cognitive testing | Results of the test may be influenced by: impaired performance due to dysphasia, sight impairment, deafness, poor educational level, cultural factors & awareness of being tested or fear of testing; or factors that may overcome decreased cognition such higher pre-morbid intelligence & education<br>Floor effect so that poor discrimination of low & very low functioning patients<br>May have insufficient range as measure of change; designed as a screening instrument |
| Kimberley Indigenous Cognitive Assessment (KICA) | LoGiudice et al. (2006) | Designed for use in the Kimberley region of Western Australia, an area with a diverse & widely spread Indigenous population comprising approximately 30 language groups<br>Currently being trialled in the Northern Territory | Comprises a medical history, smoking & alcohol history, cognitive assessment & assessment of emotional well-being (through assessment of the client & family reports), as well as assessment of behaviour & activities of daily living (through family reports)<br>Valid for use within various Indigenous communities & language groups in the Kimberley region, for whom mainstream assessment tools may not be suitable<br>Developed in conjunction with communities, Indigenous health & aged care organisations, language centres & older people in the region—has higher community acceptance & support than other dementia screening & assessment protocols<br>Presented in simple English, enabling it to be translated directly by an interpreter when required | Currently being validated<br>Versions are specific to particular Indigenous communities &/or language groups<br>Labour-intensive to administer—requires specific language skills & cultural knowledge |

*(continued)*

**Table 2.3 (continued): Summary of selected cognitive assessment and screening tools**

| Screening test/ assessment tool | Authors | Purpose & use | Benefits | Limitations |
|---|---|---|---|---|
| Rowland Universal Dementia Assessment Scale (RUDAS) | Storey et al. (2004) | Developed as a valid cognitive assessment tool for use with people across cultural & language groups<br>Used clinically in New South Wales, South Australia, Victoria & New Zealand<br>Follow-up studies are currently being conducted in New South Wales, South Australia & Victoria | Tests multiple cognitive domains<br>Portable & easily administered by primary health care clinicians<br>Appears not to be affected by gender, years of education, differential performance factors, or preferred language (Rowland et al. 2006)<br>Easily administered in languages other than English & appears to be culturally fair, provided suitable interpreter services are available | |
| Clock drawing tests | Various authors, 1986 onwards (see McDowell & Newell 1996:297–300) | Tests cognitive function, proposed as a screening test for dementia<br>Initially introduced as an indicator of constructional apraxia<br>Used as a subscale in some other tests, such as the 7 Minute Screen & Mini-Cog | Provides a rapid screening method that respondents may find more interesting (& less insulting) than 'childish' items included in other tools<br>May be more suitable for use with people from culturally and linguistically diverse backgrounds than verbally-based items in other tools<br>May be useful as an adjunct to other assessment tools &/or as part of the diagnosis & care planning process | Easily differentiates 'grossly abnormal' performance from 'normal' performance but gradations of abnormal performance are difficult & subjective to establish<br>Creation of a reliable numerical scoring system for distortions in clock drawing is complex & many scoring systems have been proposed<br>Unsuitable for people with visual impairments or non-cognitive motor impairments<br>May be affected by education & pre-morbid intelligence level<br>Is unlikely to suffice as a screen for dementia in isolation |
| Dementia Rating Scale (DRS) | Mattis (1973), cited in McDowell & Newell 1996) | Intended for use with severely affected institutionalised patients for whom standard neurological tests would be too demanding | Covers attention, preservation, construction, conceptualisation & verbal & non-verbal memory<br>Can be used to differentiate severity of dementia<br>Appropriate where a clinical rating scale is needed for use for severely ill patients in institutional settings | Must be administered by a clinician<br>Principally useful as a research instrument—not suitable as a screening instrument |
| 7 Minute Screen | Solomon | Brief cognitive assessment for use in primary care settings | Incorporates the Clock Drawing Test, Temporal Orientation Test, Enhanced Cued Recall Test & Verbal Fluency Test<br>Can be administered in less than 10 minutes by anyone with an hour of basic training<br>A useful screening tool for discriminating patients with dementia from cognitively intact patients | |

*(continued)*

**Table 2.3 (continued): Summary of selected cognitive assessment and screening tools**

| Screening test/ assessment tool | Authors | Purpose & use | Benefits | Limitations |
|---|---|---|---|---|
| CogHealth Memory Monitoring System (CogHealth) | CogState Ltd. | A commercially developed assessment tool designed to detect mild cognitive impairment prior to the patient developing significant symptoms or morbidity<br><br>Designed to be used directly by individuals under the supervision of a medical practitioner<br><br>Promoted as a means for anyone who is worried about or may be at risk of developing dementia to establish a baseline for their own cognitive performance & monitor any changes over time<br><br>Used in some drug trials to test efficacy of pharmacotherapy<br><br>Currently available for use around Australia | A computerised test designed for baseline & follow-up testing to measure change in performance over time<br><br>Includes reaction time, choice decision time, working memory & monitoring & learning tasks<br><br>Takes approximately 15 minutes to complete & can be supervised by non-medical staff—results are returned by email within minutes<br><br>Uses ordinary playing cards as stimuli, limiting reliance on verbal items—this may improve application across cultural & language groups<br><br>May be useful for testing for mild cognitive impairment based on improved performance (i.e. learning) over multiple tests administered on the same day<br><br>May encourage people to be more active in monitoring their own cognitive function<br><br>Available to anyone who has a credit card and access to the internet—however, CogHealth recommend that testing occur under medical supervision<br><br>Can be administered in English, German, Spanish, French, Italian, Russian, Norwegian, Danish, Finnish, Greek, Hungarian, Japanese or Chinese Mandarin | Sensitive to cognitive change from any cause, not just dementia. There is a risk that individuals may misinterpret results, especially if medical supervision is absent<br><br>Requires a computer for administration, & an internet connection & means to pay in order to access scoring services<br><br>Costs to have the test scored are $70 + GST per test for individuals & between $25 + GST & $45 + GST per test submitted by a medical practitioner<br><br>Designed to identify intra-individual changes in performance over time, rather than classification/diagnosis of cognitive function based on a single score<br><br>Performance may be impaired by non-cognitive factors such as fatigue, visual impairment or physical limitations<br><br>People wishing to download & use the test are encouraged to practise before submitting the test for scoring—practice effects may not be adequately controlled in the absence of medical supervision |
| Clinician's Interview-Based Impression of Change (CIBIC)<br><br>&<br><br>Clinician's Interview-Based Impression of Change with Caregiver Input (CIBIC-plus) | | The CIBIC is a global rating scale intended to provide an index of the clinical importance of change that cannot be obtained from quantitative assessment measures such as mental status examinations<br><br>The CIBIC-plus is the CIBIC with inclusion of input from caregivers or other family informants<br><br>Most often used to assess efficacy of treatments<br><br>Widely used in antidementia drug trials | A semi-structured, subjective instrument intended to examine 4 major areas of patient function: general, cognitive, behavioural & activities of daily living<br><br>Includes clinicians' notes about patients' behaviour, function & cognition, & a 7-point clinical global impression of change scale that summarises patients' changes during treatment<br><br>May help to identify 'meaningful' cognitive improvements, as clinicians may be sceptical of (& less likely to rate) cognitive changes not supported by like changes in function or behaviour<br><br>Can be used as evidence to establish eligibility for ongoing access to subsidised anticholinesterases through the PBS, under certain circumstances (see Box 2.2) | Must be performed by a clinician with appropriate expertise—repeat measures should be conducted by the same clinician<br><br>Global ratings may be more subjective than quantitative assessments<br><br>Not suitable as a screening instrument, or to establish severity of cognitive impairment |

*(continued)*

**Table 2.3 (continued): Summary of selected cognitive assessment and screening tools**

| Screening test/ assessment tool | Authors | Purpose & use | Benefits | Limitations |
|---|---|---|---|---|
| Mini-Cog | Borson et al. (2000) | Brief screening tool designed for use in primary care settings<br><br>Used as a screening test or to test executive functioning where there is a clinical suspicion of cognitive impairment | Incorporates a 3 item word learning & recall task & a clock drawing task (as a distracter before the word recall)<br><br>Requires less time (approximately 3 minutes) to administer than the MMSE with similar effectiveness<br><br>Not as susceptible as the MMSE to bias from cultural background, language & education<br><br>Can detect mild cognitive impairment & a range of types of dementia | Only tests executive functioning<br><br>May not be useful in patients with visual impairment or difficulty holding a writing implement |
| Cambridge Mental Disorders of the Elderly Examination (CAMDEX) | Roth et al. (1988) | Provides a formal diagnosis in a number of categories one of which is dementia<br><br>One of the eight sections is the CAMCOG, designed to assess cognitive function | Covers a wider range of cognitive functions & is able to detect mild levels of impairment<br><br>Semi-structured diagnostic interviews may be used as a more comprehensive alternative to the MMSE | Provides systematic procedures for the diagnosis of dementia—not suitable as a screening tool<br><br>Lengthy & time-consuming to administer—may be used on a more routine basis in specialist settings (e.g. memory clinics) |
| Consortium to Establish a Registry for Alzheimer's Disease (CERAD) | CERAD | Developed as a suite of standardised & reliable procedures for the evaluation & diagnosis of patients with Alzheimer's disease & other dementias<br><br>Can be used to gather data on normal persons as well as on cognitively impaired or behaviourally disturbed individuals to identify dementia based on clinical, neuropsychological, behavioural &/or neuropathological criteria | Includes clinical history, informant report, systemic disorders, cerebrovascular disease, parkinsonism, depression, the Blessed Dementia Rating Scale, Short Blessed Test, calculation, clock & language tests, physical examination, laboratory studies, the Clinical Dementia Rating scale & finally, a diagnostic impression of either Alzheimer's disease alone, Alzheimer's disease associated with other disorders, or non-Alzheimer's disease dementia<br><br>The neuropsychological assessment includes measures of verbal fluency, confrontational naming (15-item Boston Naming Test), the MMSE, measures of verbal learning, recall & recognition & constructional praxis performance & recall<br><br>Covers a wider range of cognitive functions & can detect mild levels of cognitive impairment<br><br>Semi-structured diagnostic interviews may be used as a more comprehensive alternative to the MMSE<br><br>Can be administered in languages other than English, including Bulgarian, Chinese, Dutch, Finnish, French, German, Italian, Japanese, Korean, Portuguese & Spanish<br><br>Can be used for research purposes as well as for patient care | Provides systematic procedures for the diagnosis of dementia—not suitable as a screening tool<br><br>Lengthy & time-consuming to administer—may be used on a more routine basis in specialist settings (e.g. memory clinics) |

## Comprehensive assessment

### Diagnostic protocols

Diagnostic protocols are standardised forms of major clinical assessments that can be used in diagnosing dementia. They generally include clinical interview (e.g. covering patient history and current situation), standardised testing of cognitive performance, and a series of diagnostic algorithms to guide differential diagnosis. They tend to be time-consuming and are required to be administered by a specialist who is qualified to make a formal diagnosis of dementia. Examples include (McDowell & Newell 1996:332–3):

- Structured Interview for the Diagnosis of Dementia
- British Present State Examination
- American Diagnostic Interview Schedule
- Geriatric Mental State Examination
- Canberra Interview for the Elderly
- Comprehensive Assessment and Referral Evaluation.

### Neuropsychological, behavioural and functional assessments

Generally, a clinical diagnosis of dementia is made following a combination of neuropsychological, behavioural and functional assessments. Neuropsychological assessments are usually questionnaires, and are distinguished from screening tests by focusing on specific domains of cognition, rather than performing a broader assessment of cognitive functioning.

Functional and behavioural assessments may be particularly useful in the moderate or more severe stages of dementia. Behavioural assessment considers the non-cognitive aspects of dementia which include personality, mood, psychotic symptoms and behaviours of concern, as well as sleep, eating and sexual disorders. These non-cognitive characteristics can be used to improve diagnostic accuracy and to distinguish different causes of dementia (Mirea & Cummings 2000, cited in Black et al. 2001). Behaviours may be assessed by direct observation, interviews, questionnaires or case notes.

A functional assessment aims to determine a person's ability to complete activities of daily living and instrumental activities of daily living, and the type and amount of assistance needed to complete these tasks. A functional assessment can be a self-report, a report by a carer or an observation of performance (Black et al. 2001), although the latter methods are preferred as people with dementia tend to exaggerate their ability to complete activities of daily living and instrumental activities of daily living (Carswell & Spiegel 1999, cited in Black et al. 2001).

Blood screening, computed tomography or MRI may be used to confirm or eliminate other (and potentially reversible) causes of cognitive impairment. MRI may also be used to differentiate between mild cognitive impairment and Alzheimer's disease, and single photon emission computed tomography (SPECT) may be used in early differentiation of frontal dementias from Alzheimer's disease. However, SPECT, as well as functional magnetic resonance imaging (fMRI), positron emission tomography (PET), electroencephalography (EEG), biomarkers and genetic testing are predominantly used in the research setting rather than as diagnostic tools.

## Differential diagnosis

There are many conditions other than dementia that may have cognitive impairment as part of their presentation. It is therefore imperative that comprehensive assessment culminates in a differential diagnosis of dementia. By way of illustration, Table 2.4 provides a summary of how dementia can be differentiated from a range of other conditions using the DSM-IV, as described by First et al. (1995).

**Table 2.4: Differential diagnosis for dementia**

| Dementia (memory and other cognitive impairments) must be differentiated from… | In contrast to dementia, the other condition… |
|---|---|
| Delirium | Is characterised by a disturbance in consciousness and a fluctuating course. Dementia is not diagnosed if the cognitive deficits occur exclusively during delirium. However, periods of delirium can occur in the context of a dementia and should be diagnosed if present. |
| Amnestic disorder | Is characterised by memory impairment occurring in the absence of other cognitive deficits (i.e. aphasia, agnosia, apraxia, executive functioning). Amnestic disorder is not diagnosed if the memory disturbance occurs exclusively during dementia. |
| Cognitive impairment in substance intoxication or substance withdrawal | Remits when the acute effects of intoxication or withdrawal subside. In contrast, substance-induced persisting dementia may be diagnosed if the dementia persists long beyond the period of intoxication or withdrawal. |
| Mental retardation | Must have an onset before age 18 years. |
| Cognitive impairment and deterioration in functioning in Schizophrenia | Has a generally earlier age at onset, less severe cognitive impairment, a characteristic symptom pattern (e.g. delusions and hallucinations), and is not due to the direct effects of a general medical condition or substance use. |
| Memory deficits and difficulty concentrating in Major depressive disorder | Improves when the depression remits, is associated with other characteristic depressive symptoms, is often associated with prior history (or family history) of depression, and is not due to the direct effects of a general medical condition or substance use. |
| Age-related cognitive decline | Is characterised by cognitive impairment that is in keeping with what would be expected for the individual's age and is not due to the direct effects of a general medical condition or substance use. |
| Mild neurocognitive disorder (i.e. cognitive disorder not otherwise specified) | Does not meet the severity threshold for dementia. |

*Source:* First et al. 1995.

# 2.3 Defining and classifying dementia and its outcomes

## International classifications of dementia

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

Most existing Australian data sources define, diagnose, classify and/or measure dementia using one or more of these classifications.

### International Statistical Classification of Diseases and Related Health Problems

The purpose of the ICD is to permit the systematic recording, analysis, interpretation and comparison of mortality and morbidity data collected in different countries or areas and at different times. However, in practice the ICD has become the international standard diagnostic classification for all general epidemiological and many health management purposes. These include the analysis of the general health situation of population groups and monitoring of the incidence and prevalence of diseases and other health problems in relation to other variables such as the characteristics and circumstances of the individuals affected.

It is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and hospital records. In addition to enabling the storage and retrieval of diagnostic information for clinical and epidemiological purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics.

The ICD-10 (WHO 1992a:312) and ICD-10-AM (NCCH 2002b:99) define dementia (F00–F03) as:

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

Diagnostic guidelines for dementia are included the clinical descriptions and diagnostic guidelines accompanying the ICD-10 in (WHO 1992b:46) and in the mental health manual accompanying the ICD-10-AM (NCCH 2002a:38), which state:

> *the primary requirement for diagnosis is evidence of a decline in both memory and thinking which is sufficient to impair personal activities of daily living. The impairment of memory typically affects the registration, storage, and retrieval of new information, but previously learned and familiar material may also be lost, particularly in the later stages. Dementia is more than dysmnesia: there is also impairment of thinking and of reasoning capacity, and a reduction in the flow of ideas. The processing of incoming information is impaired, in that the individual finds it increasingly difficult to attend to more than one stimulus at one time, such as taking part in a conversation with several persons, and to shift the focus of*

*attention from one topic to another. If dementia is the sole diagnosis, evidence of clear consciousness is required. However, a double diagnosis of delirium superimposed upon dementia is common (F05.1). The above symptoms and impairments should have been evident for at least 6 months for a confident clinical diagnosis of dementia to be made.*

ICD-10 codes are used in the classification of mortality and morbidity in hospitals in Australia. The ICD-10 and ICD-10-AM also form the basis of health condition codes used in the Aged Care Assessment Program (ACAP), and the Australian Bureau of Statistics (ABS) National Health Survey (NHS) and Survey of Disability, Ageing and Carers (SDAC).

### Diagnostic and Statistical Manual of Mental Disorders

The DSM, published by the American Psychiatric Association, contains a listing of mental disorders and corresponding diagnostic codes, as well as diagnostic criteria and information about each disorder, including associated features, complications, course and differential diagnosis. It is utilised by mental health professionals from a variety of disciplines for a range of clinical, research, administrative and educational purposes. The DSM allows for a multiaxial assessment:

- Axis I—clinical disorders and other conditions that may be a focus of clinical attention
- Axis II—personality disorders and mental retardation
- Axis III—general medical conditions
- Axis IV—psychosocial and environmental problems
- Axis V—global assessment of functioning.

The use of a multiaxial system in the DSM facilitates comprehensive and systematic evaluation with attention to the various mental disorders and general medical conditions, psychosocial and environmental problems, and level of functioning that might be overlooked if the focus were on assessing a single presenting problem (American Psychiatric Association 2000). The DSM describes diagnoses in terms of patterns of symptoms that tend to cluster together—the symptoms can be observed by the clinician or reported by the patient or family members. This also avoids incorporating unproven theories into diagnostic definitions, where the cause of most mental disorders is currently unknown and subject to speculation. However, this is also an important limitation, as patients sharing the same diagnostic label do not necessarily have disturbances that share the same aetiology and do not necessarily respond to the same treatment.

Although particular types of dementia are defined, the DSM-IV-TR[2] does not provide a concise definition of dementia itself, simply stating that the disorders in the *Dementia* section are characterised by the development of multiple cognitive deficits (including memory impairment) that are due to the direct physiological effects of a general medical condition, to the persisting effects of a substance, or to multiple aetiologies (e.g. the combined effects of cerebrovascular disease and Alzheimer's disease). The disorders in this section share a common symptom presentation but are differentiated based on aetiology (American Psychiatric Association 2000).

However, the essential feature of a dementia is described as the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning

2 There is no difference between the diagnostic criteria for dementia in the DSM-IV and DSM-IV-TR (Pioggiosi et al. 2003).

(American Psychiatric Association 2000). Memory impairment and intellectual impairment must be sufficiently severe to cause significant social and occupational impairments and must represent a decline from a previously higher level of functioning.

The DSM-IV is the international classification used by most clinicians. However, it is evident from the literature that the DSM-III-R is still in use and this edition of the classification will also be discussed, where appropriate.

## International Classification of Primary Care

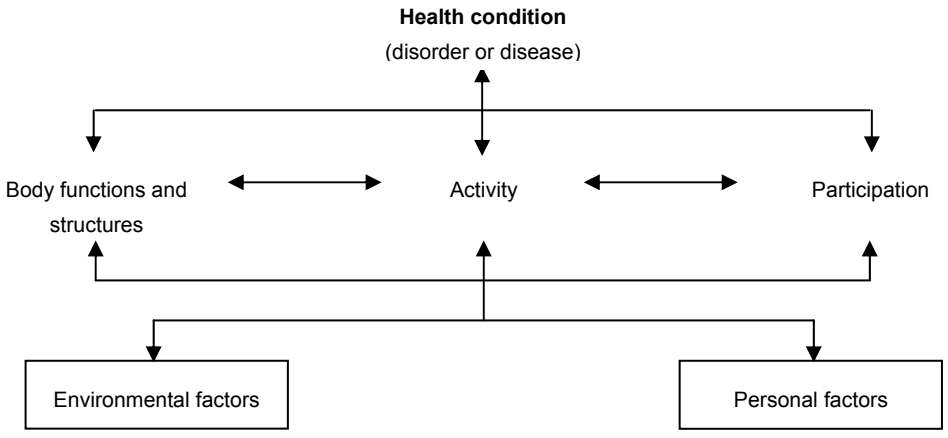
The second edition of the International Classification of Primary Care (ICPC-2) classifies patient data and clinical activity in the domains of general/family practice and primary care, taking into account the frequency distribution of problems seen in these domains. It allows classification of the patient's reason for encounter, the problems/diagnosis managed, interventions, and the ordering of these data in an episode of care structure.

It has a biaxial structure and consists of 17 chapters, each divided into seven components which deal with: symptoms and complaints; diagnostic, screening and preventive procedures; medication, treatment and procedures; test results; administrative; referrals and other reasons for encounter; and diseases. The chapter titled *Psychological* contains codes for dementia and other organic psychosis.

Data about patients seen, reasons people seek medical care, problems managed and treatments provided in general practice in Australia collected by the Bettering the Evaluation and Care of Health (BEACH) survey are coded using ICPC-2 Plus codes.

## International Classification of Functioning, Disability and Health

Key to diagnosing dementia according to the ICD and the DSM is that cognitive impairment is 'sufficient to impair personal activities of daily living', or causes significant social and occupational impairments. The ICF provides a framework for the conceptualisation, classification and measurement of functioning (AIHW 2003c). The ICF does not define dementia, but provides a framework for understanding and measuring the functional outcomes of dementia in terms of three components: body functions and structures; activities and participation; and environmental factors (Figure 2.1).




*Source:* WHO 2001:18.

**Figure 2.1: Interactions between components of the ICF**

Within each component, a classification structure is provided, which can be used to organise information on various domains of the disability experience. The framework provides a means of describing human functioning on a continuum, with *functioning* used to describe the neutral or positive health states of body functions and structures and activities and participation, and *disability* used to describe impairments, activity limitations or participation restrictions.

**Box 2.3: Definitions used in the International Classification of Functioning, Disability and Health**

***Body functions*** *are the physiological functions of body systems (including psychological functions)*

***Body structures*** *are anatomical parts of the body such as organs, limbs and their components*

***Impairments*** *are problems in body function and structure as a significant deviation or loss*

***Activity*** *is the execution of a task or action by an individual*

***Participation*** *is involvement in a life situation*

***Activity limitations*** *are difficulties an individual may have in executing activities*

***Participation restrictions*** *are problems an individual may experience in involvement in life situations*

***Environmental factors*** *make up the physical, social and attitudinal environment in which people live and conduct their lives.*

*Source:* WHO 2001.

Under the ICF framework, different diseases and injuries may cause cognitive impairment which impact on functioning and disability as illustrated with examples in the diagram below (Figure 2.2)—the dementia syndrome can be considered to be a particular type of cognitive impairment. The suggested ICF minimum data requirements for cognition come from the *Body functions* chapter, and include: b140 *attention functions*; b144 *memory functions*; and b164 *higher-level cognitive functions* (WHO 2001:253). The code b117 *intellectual functions* also lists dementia as an inclusion. Additionally, the *Body structures* chapter includes 10 codes for different parts of the brain structure; the *Activities and participation* chapter includes a number of codes that describe activities of daily living and instrumental activities of daily living; and the *Environmental factors* chapter includes codes describing facilitators and barriers.

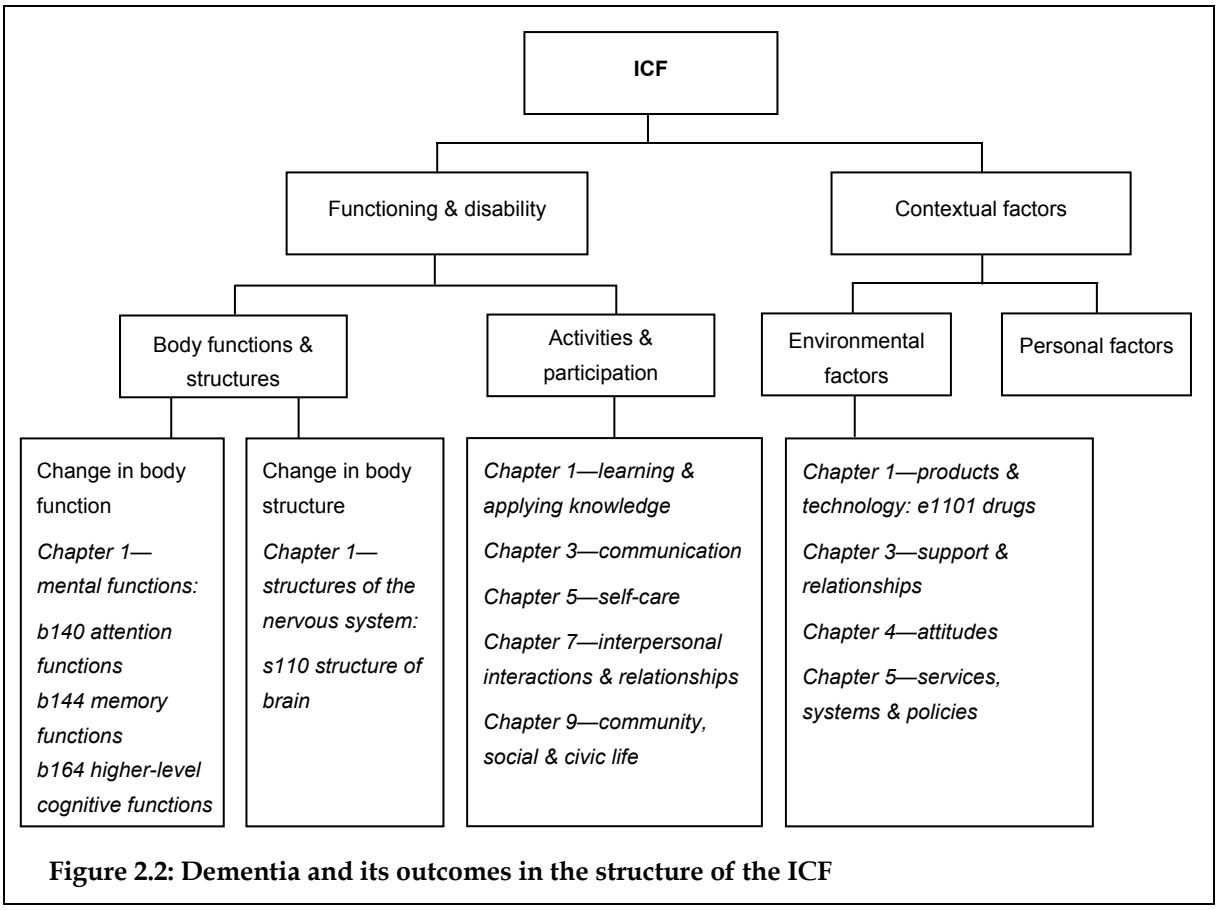



**Figure 2.2: Dementia and its outcomes in the structure of the ICF**

Muo et al. (2005) recently reported that the ICF is a useful tool to describe health status in patients with Alzheimer's disease in that it underlies important aspects of daily living generally not considered by activity of daily living scales, such as communication, social relationships and recreation and leisure. Its inclusion of environmental factors also encourages consideration of these important factors in the care of people with dementia.

However, use of the ICF as a practical tool to measure behavioural outcomes associated with the syndrome of dementia may have limitations. These would be largely associated with the need to make choices on which ICF domains to focus assessment; the multi-dimensional nature of the ICF may increase user burden in assessment of impairments associated with dementia. At the same time, the multi-dimensional nature of the ICF may improve the extent to which the complexity of dementia and its outcomes is described. This may help with the diagnosis of different types of dementia, describing exactly what is happening for the person with dementia, and examining possible environmental determinants.

On the face of it, the ICF appears not to describe or classify behavioural symptoms of dementia in a way which is helpful for diagnosis, treatment or management. However, it may be useful to differentiate impairments or other functional limitations (e.g. mobility) from signs and symptoms that arise from impairments or other functional limitations (e.g. wandering). For example, wandering and getting lost may be an indication that someone has an impairment of orientation, or possibly a new environment with which they are not familiar. While the behaviour is visible and measurable, it is not actually a function. Similarly, a person may have communication difficulties because of problems with speech, but problems may also be environmentally determined. By separating communication from

speech, one can examine the aetiology of the limitations and possible interventions can be better aligned.

The ICF is used to support consistency of data relating to support needs for people with disability between the ABS SDAC, the Commonwealth-State/Territory Disability Agreement National Minimum Data Set (CSTDA NMDS), the National Community Services Data Dictionary and the 2006 Census of Population and Housing.

Both the ICD and ICF belong to the family of international classifications developed by the World Health Organization (WHO) for application to various aspects of health, and are complementary. In a recent presentation, Madden (2006) mapped the components of the ICD definition of dementia (i.e. higher cortical function, emotional control, social behaviour and motivation) to domains within the mental functions chapter of the ICF. Table 2.5 provides an example of this mapping. Madden (2006) noted that ICF domains including temperament and personality (b126), energy and drive functions (b130), attention (b140), psychomotor (b147), perceptual (b156) and higher level cognitive functions (b164) were not included in the ICD definition.

AIHW (2004c) also identify a number of codes in the learning and applying knowledge chapter that are relevant to cognitive functioning, for example focusing attention (d160), thinking (d163), reading (d166), writing (d170), calculating (d172), solving problems (d175) and making decisions (d177), but note that registration is not coded in the ICF. Additionally, they note that although behaviour is not separately included in the ICF classification, several codes describe components of behaviour and mental functions relevant to behaviour, for example temperament and personal functions (b126), emotional functions (b152) and complex interpersonal interaction (d720).

**Table 2.5: Mapping the ICD definition of dementia to the ICF**

| Components of ICD definition | Mapped ICF domains | ICF codes |
|---|---|---|
| Memory | Memory | b144 |
| Thinking | Thought | b160 |
| Orientation | Orientation | b114 |
| Comprehension | Mental functions of language | b167 |
| | Reading | d166 |
| Calculation | Calculation | b172 |
| Learning capacity | Learning and applying knowledge | d110–d199 |
| Language | Mental functions of language | b167 |
| Judgement | Higher level cognitive functions: Judgement | b164: b1645 |
| Emotional control | Emotional | b152 |
| Social behaviour | Interpersonal interactions and relationships | d710–d799 |
| Motivation | Energy and drive functions: Motivation | b130: b1301 |

*Source:* Based on Madden 2006 and advice from AIHW Functioning and Disability Unit.

## Comparison of the ICD and DSM classifications of dementia

Each of these classifications has certain limitations in relation to measuring and diagnosing dementia. For example, the ICD-10 and DSM-IV tend to focus on Alzheimer's disease, with memory loss (along with impairment in other cognitive domains) a requirement for a diagnosis of dementia. Chui (2005) argues that benchmarking other forms of dementia

against Alzheimer's disease leads to a marginalisation of non-Alzheimer's disorders and a restriction of the clinical use of both the ICD-10 and DSM-IV. Although the ICD-10 and DSM-IV definitions aim to distinguish dementia from delirium and restricted cognitive impairments such as aphasia or amnestic syndrome, Sachdev (2000) argues that the emphasis on memory loss is restrictive and may delay diagnosis of dementias such as vascular dementia and frontotemporal dementia, where impairment of other cognitive domains may be more prominent in the early stages of the disease. Additionally, memory loss may be present for some time in someone with Alzheimer's disease before other cognitive deficits become apparent, warranting a diagnosis of amnestic syndrome rather than dementia at the early stages of the disease.

Furthermore, the diagnostic guidelines accompanying the ICD-10 do not specify criteria for dementia in Lewy body disease, or frontotemporal dementia, which are no longer rare conditions—DSM-IV mentions them as requiring further research (Chui 2005). Dementia is also difficult to verify using the ICD without the presence of an informant.

The preparation of the DSM-IV was closely coordinated with the preparation of Chapter V (Mental and behavioural disorders) of the ICD-10—consultations between the American Psychiatric Association and the World Health Organization attempted to develop DSM-IV codes and terms that are fully compatible with those of the ICD-10 (American Psychiatric Association 2000). However, the full compatibility of the two systems is fairly limited due to inconsistency of the diagnostic criteria/guidelines between them. Table 2.6 provides a comparison of the classification of dementia in recent versions of the ICD and DSM.

**Table 2.6: Comparison of classification of dementia in the ICD and DSM**

| ICD-10: Organic, including symptomatic mental disorders | DSM-III-R: Organic mental disorders | DSM-IV: Delirium, dementia & amnestic & other cognitive disorders | DSM-IV-TR: Delirium, dementia & amnestic & other cognitive disorders |
|---|---|---|---|
| **F00 Dementia in Alzheimer's disease** | **290.1x Primary degenerative dementia of the Alzheimer type, presenile onset *(also code 331.0 Alzheimer's disease on Axis III)*** | **290.1x Dementia of the Alzheimer's type, with early onset *(also code 331.0 Alzheimer's disease on Axis III)*** | **294.1x Dementia of the Alzheimer's type, with early onset *(also code 331.0 Alzheimer's disease on Axis III)*** |
| F00.0 Dementia in Alzheimer's disease with early onset | 290.10 Uncomplicated | 290.10 Uncomplicated | 294.10 Without behavioural disturbance |
| F00.1 Dementia in Alzheimer's disease with late onset | 290.11 With delirium | 290.11 With delirium | 294.11 With behavioural disturbance |
| F00.2 Dementia in Alzheimer's disease, atypical or mixed type | 290.12 With early onset, with delusions | 290.12 With early onset, with delusions | **294.1x Dementia of the Alzheimer's type, with late onset *(also code 331.0 Alzheimer's disease on Axis III)*** |
| F00.9 Dementia in Alzheimer's disease, unspecified | 290.13 With depressed mood | 290.13 With depressed mood | 294.10 Without behavioural disturbance |
| *Specify if (optional):* | **290.xx Primary degenerative dementia of the Alzheimer type, senile onset *(also code 331.0 Alzheimer's disease on Axis III)*** | **290.xx Dementia of the Alzheimer's type, with late onset *(also code 331.0 Alzheimer's disease on Axis III)*** | 294.11 With behavioural disturbance |
| *.x0 without additional symptoms* | 290.00 Uncomplicated | 290.00 Uncomplicated | |
| *.x1 with other symptoms, predominantly delusional* | 290.20 With delusions | 290.20 Delusions | |
| *.x2 with other symptoms, predominantly hallucinatory* | 290.21 With depression | 290.21 With depressed mood | |
| *.x3 with other symptoms, predominantly depressive* | 290.30 With delirium | 290.3 With delirium | |
| *.x4 with other mixed symptoms* | | | |

*(continued)*

## Table 2.6 (continued): Comparison of classification of dementia in the ICD and DSM

| ICD-10: Organic, including symptomatic mental disorders | DSM-III-R: Organic mental disorders | DSM-IV: Delirium, dementia & amnestic & other cognitive disorders | DSM-IV-TR: Delirium, dementia & amnestic & other cognitive disorders |
|---|---|---|---|
| **F01 Vascular dementia** | **290.4x Multi-infarct dementia** | **290.4x Vascular dementia** | **290.4x Vascular dementia** |
| F01.0 Vascular dementia of acute onset | 290.40 Uncomplicated | 290.40 Uncomplicated | 290.40 Uncomplicated |
| F01.1 Multi-infarct dementia | 290.41 With delirium | 290.41 With delirium | 290.41 With delirium |
| F01.2 Subcortical vascular dementia | 290.42 With delusions | 290.42 With delusions | 290.42 With delusions |
| F01.3 Mixed cortical & subcortical vascular dementia | 290.43 With depression | 290.43 With depressed mood | 290.43 With depressed mood |
| F01.8 Other vascular dementia | | | Specify if: with behavioural disturbance |
| F01.9 Vascular dementia, unspecified | | | |
| *Specify if (optional):* | | | |
| *.x0 without additional symptoms* | | | |
| *.x1 with other symptoms, predominantly delusional* | | | |
| *.x2 with other symptoms, predominantly hallucinatory* | | | |
| *.x3 with other symptoms, predominantly depressive* | | | |
| *.x4 with other mixed symptoms* | | | |
| *.xx0 mild* | | | |
| *.xx1 moderate* | | | |
| *.xx2 severe* | | | |
| **F02 Dementia in other diseases classified elsewhere** | **Organic mental disorders associated with Axis III physical disorders or conditions or whose aetiology is unknown** | **294.xx Dementia due to other general medical conditions** | **294.1x Dementia due to other general medical conditions** |
| F02.0 Dementia in Pick's disease | 294.10 Dementia | 294.9 Dementia due to HIV disease *(also code 042 HIV on Axis III)* | 294.1x Dementia due to HIV disease *(also code 042 HIV on Axis III)* |
| F02.1 Dementia in Creutzfeldt-Jakob disease | | 294.1 Dementia due to head trauma *(also code 854.00 Head injury on Axis III)* | 294.1x Dementia due to head trauma *(also code 854.00 Head injury on Axis III)* |
| F02.2 Dementia in Huntington's disease | | 294.1 Dementia due to Parkinson's disease *(also code 331.82 Dementia with Lewy bodies on Axis III)* | 294.1x Dementia due to Parkinson's disease *(also code 331.82 Dementia with Lewy bodies on Axis III)* |
| F02.3 Dementia in Parkinson's disease | | 294.1 Dementia due to Huntington's disease *(also code 333.4 Huntington's disease on Axis III)* | 294.1x Dementia due to Huntington's disease *(also code 333.4 Huntington's disease on Axis III)* |
| F02.4 Dementia in HIV disease | | 290.10 Dementia due to Pick's disease *(also code 331.11 Pick's disease on Axis III)* | 294.1x Dementia due to Pick's disease *(also code 331.11 Pick's disease on Axis III)* |
| F02.8 Dementia in other specified diseases classified elsewhere | | 290.10 Dementia due to Creutzfeldt-Jakob disease *(also code 046.1 Creutzfeldt-Jakob disease on Axis III)* | 294.1x Dementia due to Creutzfeldt-Jakob disease *(also code 046.1 Creutzfeldt-Jakob disease on Axis III)* |
| *Dementia in: cerebral lipidosis; epilepsy; hepatolenticular degeneration; hypercalcaemia; hypothyroidism; acquired, intoxications; multiple sclerosis; neurosyphilis; niacin deficiency (pellagra); polyarteritis nodosa; systemic lupus erythematosus; trypanosomiasis; vitamin $B_{12}$ deficiency* | | 294.1x Dementia due to [indicate the general medical condition not listed above] *(also code the general medical condition on Axis III)* | 294.1x Dementia due to… [indicate the general medical condition not listed above] *(also code the general medical condition on Axis III)* |
| *Specify if (optional):* | | | *Code presence or absence of a behavioural disturbance in the fifth digit for dementia due to a general medical condition* |
| *.x0 without additional symptoms* | | | *0=without behavioural disturbance* |
| *.x1 with other symptoms, predominantly delusional* | | | *1=with behavioural disturbance* |
| *.x2 with other symptoms, predominantly hallucinatory* | | | |
| *.x3 with other symptoms, predominantly depressive* | | | |
| *.x4 with other mixed symptoms* | | | |
| *.xx0 mild* | | | |
| *.xx1 moderate* | | | |
| *.xx2 severe* | | | |

*(continued)*

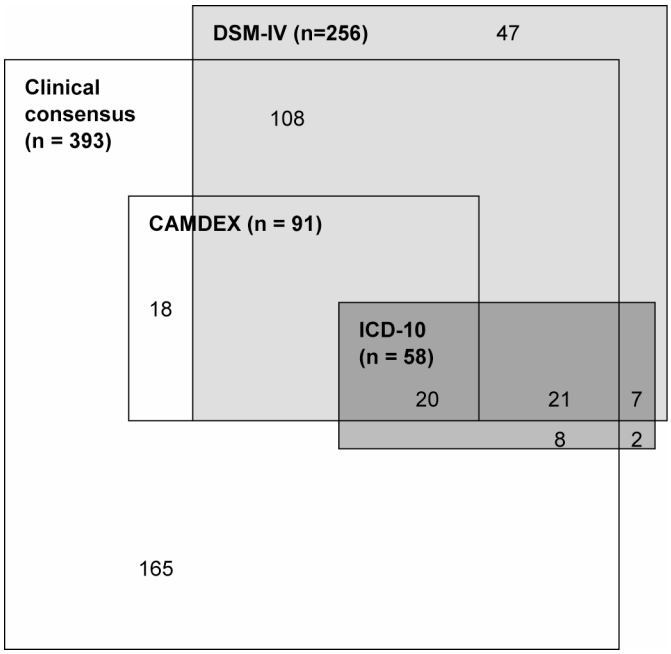
## Table 2.6 (continued): Comparison of classification of dementia in the ICD and DSM

| ICD-10: Organic, including symptomatic mental disorders | DSM-III-R: Organic mental disorders | DSM-IV: Delirium, dementia & amnestic & other cognitive disorders | DSM-IV-TR: Delirium, dementia & amnestic & other cognitive disorders |
|---|---|---|---|
| **F1x.7 Residual and late-onset psychotic disorder**<br>F1x.70 Flashbacks<br>F1x.71 Personality or behaviour disorder<br>F1x.72 Residual affective disorder<br>F1x.73 Dementia<br>F1x.74 Other persisting cognitive impairment<br>F1x.73 Late-onset psychotic disorder<br>For use with mental and behavioural disorders due to…<br>F10 use of alcohol<br>F11 use of opioids<br>F12 use of cannabinoids<br>F13 use of sedatives or hypnotics<br>F14 use of cocaine<br>F15 use of other stimulants, including caffeine<br>F16 use of hallucinogens<br>F17 use of tobacco<br>F18 use of volatile solvents<br>F19 due to multiple drug use & use of other psychoactive substances | **291.20 Dementia associated with alcoholism**<br>**292.82 Other or unspecified psychoactive substance dementia** | **—.— Substance-induced persisting dementia *(refer to substance-related disorders for substance-specific codes)***<br>291.2 Alcohol-induced persisting dementia<br>292.82 Substance (Inhalant, sedative, hypnotic & anxiolytic, other (or unknown))-induced persisting dementia | **—.— Substance-induced persisting dementia *(refer to substance-related disorders for substance-specific codes)***<br>291.2 Alcohol-induced persisting dementia<br>292.82 Inhalant-induced persisting dementia<br>292.82 Sedative-, hypnotic- or anxiolytic-induced persisting dementia<br>292.82 Other (or unknown) substance-induced persisting dementia |
| **F03 Unspecified dementia**<br>Presenile: dementia nos, psychosis nos<br>Primary degenerative dementia nos<br>Senile: dementia nos; (depressed or paranoid type, nos), psychosis nos<br>*Specify if (optional):*<br>*.x0 without additional symptoms*<br>*.x1 with other symptoms, predominantly delusional*<br>*.x2 with other symptoms, predominantly hallucinatory*<br>*.x3 with other symptoms, predominantly depressive*<br>*.x4 with other mixed symptoms*<br>*.xx0 mild*<br>*.xx1 moderate*<br>*.xx2 severe* | **290.00 Senile dementia nos *(specify aetiology on Axis III if known)***<br>**290.10 Presenile dementia nos *(specify aetiology on axis III if known e.g. Pick's disease, Jakob-Creutzfeldt disease)*** | **—.— Dementia due to multiple aetiologies *(code each of the specific aetiologies)***<br>**294.8 Dementia nos** | **—.— Dementia due to multiple aetiologies *(code each of the specific aetiologies)***<br>**294.8 Dementia nos** |
| **F05.1 Delirium superimposed on dementia**<br>**F06.7 Mild cognitive disorder**<br>*Specify if (optional):*<br>*.70 not associated with a systemic physical disorder*<br>*.71 associated with a systemic physical disorder* | | **294.9 Cognitive disorder not other specified**<br>Mild neurocognitive disorder, postconcussional disorder<br>**Other conditions that may be a focus of clinical attention**<br>780.9 Age-related cognitive decline | **294.9 Cognitive disorder not other specified**<br>Mild neurocognitive disorder, postconcussional disorder<br>**Other conditions that may be a focus of clinical attention**<br>780.93 Age-related cognitive decline |

*Sources:* American Psychiatric Association 1986, 1994, 2000; WHO 1992a.

Differences between the various classification systems may yield different prevalence estimates when used in the same population (Henderson 1994b). In a survey of 1,045 persons aged 70 years and over, Henderson et al. (1994) found that the ICD-10 identified many fewer cases of dementia (3.2% of the sample), compared with the DSM-III-R (7.3% of the sample). In a study of only 34 nonagenarians and centenarians, Pioggiosi et al. (2003) found that the DSM-III-R and DSM-IV identified 47.1% and 41.2% people as having dementia, whereas the ICD-10 only identified 29.4% as having dementia.

Erkinjuntti et al. (1997) also investigated the effect of different diagnostic criteria on the estimates of dementia prevalence in a sample of 1,879 people. Figure 2.2 shows that the DSM-IV identified 256 people (13.7% of the sample) as having dementia; although not shown in Figure 2.2, the DSM-III-R identified 326 people (17.3% of the sample). In comparison, the ICD-10 only identified 58 people (3.1% of the sample) as having dementia. Despite substantial overlap between the two classifications only 48 people were diagnosed under both criteria.




*Source:* Reproduced from Erkinjuntti et al. 1997.

**Figure 2.3: Subjects identified as having dementia according to various diagnostic classification systems**

Although the DSM-III-R and DSM-IV identified many more cases of dementia in the study sample[3] (e.g. the DSM classification systems included more cases with mild dementia[4] and there was a trend toward detecting a shorter mean duration of symptoms), the difference is not simply due to the ICD-10 being more restrictive than the DSM-III-R and DSM-IV. The systems identify different individual subjects as having dementia. Erkinjuntti et al. (1997) identified the factors that best predicted disagreement between the DSM-IV and ICD-10 as:

3 The DSM is generally broader than the ICD, and tends to be more inclusive of some types of dementias.

4 The ICD classification systems are more likely to identify advanced cases of dementia in which the diagnosis is quite apparent (Erkinjuntti et al. 1997).

- impairment of long-term memory (as well as short-term memory) in the DSM-IV (and DSM-III-R)
- executive function—the ICD is stricter in requiring there to be impairment of all three executive functions of abstract thinking, judgement and problem-solving, whereas the DSM only requires there to be impairment of abstract thinking or judgement (or other higher cortical function or behavioural and emotional function)
- the presence or absence of aphasia
- impairment of work or social activities in the DSM-IV (and DSM-III-R) versus impairment of activities of daily living in the ICD-10[5]
- duration of symptoms—although the DSM-IV (and DSM-III-R) requires a decline in functioning before dementia is diagnosed, a six-month history (like that used by the ICD-10) is not imposed.[6]

The factors that best predicted disagreement between the classification systems in the study by Pioggiosi et al. (2003) differed from those reported by Erkinjuntti et al. (1997), although this may be due to the higher cognitive and functional impairment in nonagenarians and centenarians (also, the diagnostic difficulty for dementia increases with age). For example, Pioggiosi et al. (2003) did not find significant differences related to long-term memory impairment, impairment of activities of daily living (versus social function) or to the duration of symptoms. Additionally, all the subjects identified as having dementia by the other classification systems were also identified as having dementia by the DSM-III-R criteria, indicating that the differences were due to the more restrictive nature of the other classifications rather than identifying different individuals. Concordance and agreement between the DSM-III-R and ICD-10 was weaker than that between the other classification systems. As indicated by the study by Erkinjuntti et al. (1997), the DSM-III-R and ICD-10 were differentiated by the weight given to cognitive impairment—all three executive functions have to be impaired according to the ICD-10.

In general, Pioggiosi et al. (2003) reported that there was good concordance and agreement between the DSM-III-R and the DSM-IV. Both Erkinjuntti et al. (1997) and Pioggiosi et al. (2003) reported a similar proportion of cases using the DSM-III-R as compared with using the DSM-IV. Pioggiosi et al. (2003) noted that the factors that best predicted disagreement between DSM-III-R and DSM-IV were calculation impairment and the absence of personality changes. In a study of ageing in Sydney, Waite et al. (2001) (cited in Chui 2005) reported that the DSM-III criteria were more inclusive that the DSM-IV criteria.

Table 2.7 shows that differences also exist when comparing results from the DSM-III, the ICD-9 and the CAMDEX. For example, Erkinjuntti et al. (1997) noted each successive revision of the DSM appeared to extend the diagnosis to fewer subjects with dementia—the inclusion of long-term memory impairment as a requirement for the diagnosis of dementia in the DSM-III-R and DSM-IV had a particularly substantial effect on the prevalence. Sachdev (2000) also noted the problematic nature of memory loss in the DSM classification systems.

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5 The ICD-10 does not include impairment of social function as a criterion for assessing dementia (Pioggiosi et al. 2003).

6 Chui (2005) notes that the six-month time limit demanded by the ICD-10 criteria indicates the statistical median but does not address outliers whose cognitive impairment may be less than the six months (e.g. Creutzfeldt-Jakob disease).

**Table 2.7: Criteria for dementia in the classification systems**

| Domain in which impairment is required | DSM-III | DSM-III-R | DSM-IV | ICD-9 | ICD-10 | CAMDEX | Clinical consensus |
|---|---|---|---|---|---|---|---|
| **Memory** | | | | | | | |
| Short-term memory (learning skills) | • | + | + | + | + | + | |
| Long-term memory | • | + | + | (•) | (•) | + | |
| **Executive function (planning, abstraction or problem-solving ability)** | | | • | | | | |
| Abstract thinking | • | • | | + | + | • | |
| Judgement | • | • | | + | + | • | |
| Problem solving | | | | + | + | | |
| **Other higher cortical function** | • | • | | | | • | |
| Aphasia (language disturbance) | | | • | | (•) | | |
| Apraxia (impairment of the ability to perform coordinated movements or manipulate objects) | | | • | | | | |
| Agnosia (inability to interpret sensory stimuli) | | | • | | | | |
| Constructional abilities | | | | | | | |
| Calculation | | | | | (•) | | |
| **Behavioural & emotional function** | • | • | | | | • | |
| Personality | | | | (•) | | • | |
| Emotional control | | | | (•) | (•) | • | |
| Motivation | | | | | (•) | | |
| Social behaviour | | | | | (•) | | |
| **Social function** | | | | | | | |
| Work | • | • | • | • | | + | |
| Social activities | • | • | • | • | | | |
| Activities of daily living | | | | | + | + | |
| Relationships with others | | • | | | | | |
| **Other features incorporated into criteria** | | | | | | | |
| Impairment | | + | | | | | |
| Progressive deterioration | | | | | (•) | + | |
| Decline from function before illness | + | + | + | + | + | + | |
| Duration of symptoms ≥ 6 months | | | | | + | + | |
| Normal consciousness | + | + | + | | + | + | |
| Assumed organic cause | + | + | | | + | | |
| Mental retardation as cause | | | | | (•) | | |
| **Prevalence of dementia (%)** | | | | | | | |
| CHSA sample (Erkinjuntti et al. 1997) | 29.1 | 17.3 | 13.7 | 5.0 | 3.1 | 4.9 | 20.9 |
| Nonagenarians & centenarians (Pioggiosi et al. 2003) | — | 47.1 | 41.2 | — | 29.4 | 38.2 | — |

*Note:* + impairment in domain is always required for diagnosis; • one or more of those bracketed is required; (•) optional, strengthens the diagnosis; CSHA Canadian Study of Health and Aging.

*Source:* Reproduced from Erkinjuntti et al. 1997 and Pioggiosi et al. 2003.

Furthermore, clinicians and researchers may differ in their use of the same classification, which may also yield different results when used in the same population. However, training or further guidance in the implementation of the classifications tends to lead to greater consistency. The clinical descriptions and diagnostic guidelines accomanying the ICD-10 (WHO 1992b) were prepared with the aim of improving diagnostic practices among health services (Henderson 1994a:6–8).

## 2.4 Conclusion

Estimates of the prevalence of dementia in a population are critical for the planning, funding and provision of appropriate treatment and care of people with dementia, whether those services are part of dementia-specific programs or where the person's dementia should be taken into account in the provision of other services. These estimates vary with the definition and diagnostic criteria used by different classifications. At the level of the individual, the use of different diagnostic criteria, and the utility and validity of the screening and assessment tools used, affect the likelihood of receiving a diagnosis, and consequently have an impact on the person's access to appropriate information, treatment and care options.

The analysis of data in Section 2 of this report is constrained by the definitions and classifications used in existing data sources. However, the major purpose of Section 3 of this report is to recommend data elements that will form the basis for further work on improving dementia data and data standards. This work needs to be supported by the use of common definitions and classifications of dementia and its outcomes. This report recommends that **both** the ICD and ICF should be used in Australia for this purpose.

Both the ICD and ICF belong to the family of international classifications developed by the WHO for application to various aspects of health. The WHO family of international classifications provides a framework to code a wide range of information about health (e.g. diagnosis, functioning and disability, reasons for contact with health services) and uses a standardised common language permitting communication about health and health care across the world in various disciplines and sciences (WHO 2001:3).

Health conditions (e.g. diseases, disorders, injuries) are generally classified using the ICD, which provides diagnosis codes for diseases, disorders or other health conditions. Functioning and disability associated with health conditions are classified using the ICF. The ICD and ICF enable consistent collection of information about diagnosis as well as human functioning. The ICD and ICF are therefore complementary, and WHO encourages the use of these classifications together to provide a more meaningful and complete picture of the health needs of people and populations (WHO 2001:4).

Although the DSM appears to be the classification used by most clinicians, the ICD is used in the classification of mortality and morbidity in hospitals in Australia and forms the basis of health condition codes used in the ACAP, the NHS and the SDAC. The ICF is used to provide consistency of data relating to support needs for people with disability between the Survey of Disability Ageing and Carers, the Commonwealth-State/Territory Disability Agreement NMDS, the National Community Services Data Dictionary and the 2006 Census of Population and Housing. Additionally, the DSM requires more training and skills to use, and is therefore difficult for non-clinicians to use.

While making this recommendation, this report is not suggesting that the ICD and ICF currently capture all aspects of dementia and its outcomes completely. The WHO constitution, which governs the activities of the Classifications, Assessment and

Terminologies team and the WHO-FIC Network, states that one of the functions of the WHO is to establish and revise as necessary international nomenclatures of diseases, of causes of death and of public health practices (WHO 1994). The ICD has well-established processes for revising its structure and definitions which allow it to respond to developments in research and medical practice. The ICF is a relatively new classification and processes to guide modifications and updates are currently being considered.

A fundamental question for the development of recommendations about standard dementia data elements also concerns whether data collection should include both diagnosed dementia and cognitive impairment more generally.

Where data are collected using dementia diagnosis as the only identifying information, it is likely that the prevalence of dementia in that program or service is underestimated. Reliance on diagnostic criteria excludes a population of people with declines in cognitive functioning who have not yet achieved the criteria for dementia diagnosis, with possible consequences that some individuals do not access services that could improve their quality of life through identifying and managing treatment and care options.

Collection of information about cognitive impairment, as well as dementia diagnosis, results in a potentially larger population being identified, some of whom may not have dementia because their cognitive impairment is attributed to some other disease process. However, it ensures the identification of people who may share some similar care needs as those with diagnosed dementia, some of whom may have early stage dementia, and/or progress to dementia.

This report recommends the collection of information about both dementia diagnosis and the presence of cognitive impairment. This is discussed further in Chapter 12, which also presents recommended data elements.