

8 Expenditure on dementia

Traditionally, expenditure on dementia has been estimated by examining the total health and care costs incurred for people with dementia as their main health condition, regardless of the cost impact of any other health conditions experienced by the individual (e.g. the total hospital costs for a person hospitalised because of dementia or the residential aged care subsidy for a person whose main condition is dementia).

This report presents updated estimates for 2003 using this method (see Table 8.2). However, the report also presents the results of a different approach to estimating expenditure that takes account of the presence of other health conditions. This approach results in estimates of expenditure that can be attributed to the dementia condition and its impact on the cost of care rather than the total care cost of people with dementia as their main condition.

According to the ABS SDAC, older people with dementia have an average of 5.26 health conditions per person (see Chapter 5, Table 5.22), while people with dementia living in permanent residential aged care have an average of 5.1 health conditions per person (Table 8.5). The expenditure estimates presented in this chapter assume that all of a person's health conditions contribute to the cost of their care.

This approach results in only a portion of the expenditure for people whose main health condition is dementia being allocated against dementia. Part of their expenditure is allocated to other comorbid conditions. However, it takes account of expenditure on people who have dementia, but whose main condition is a different health condition. For example, this method measures the cost impact of having dementia for admitted hospital patients who are admitted for another reason. This recognises that, for this patient, dementia is likely to result in higher care needs while in hospital.

In this report, we have referred to the traditional method of calculating expenditure as the 'Main condition cost allocation method'; the alternative approach is referred to as the 'Multiple conditions cost allocation method'. The Multiple conditions cost allocation method has been used to estimate expenditure that can be attributed to dementia for:

- residential aged care, using data from the ABS SDAC which extensively sampled people in residential aged care and collected comprehensive information about residents' comorbid conditions
- hospital services, using data about principal and additional diagnoses recorded for admitted patients.

Expenditure on medical services is only for GP consultations which occurred for the management of dementia. Medical services received by people with dementia which related to the management of other health conditions were excluded. Similarly, expenditure on pharmaceuticals is limited to those prescribed for the treatment and management of dementia.

This chapter also provides an estimate of expenditure on people with dementia using the ACAP and other community care programs. These expenditure estimates have been based on the proportion of program expenditure incurred for program clients with dementia using the Main condition cost allocation method.

8.1 Health and aged care system expenditure on dementia for 2003

Total health and aged care system expenditure for dementia in 2003 is estimated at \$1.4 billion (Table 8.1). The majority is in the residential aged care sector where \$993 million was attributed to dementia. Admitted patient expenditure of \$149.3 million, pharmaceutical expenditure of \$72.8 million and out-of-hospital medical service expenditure of nearly \$20 million are also attributed to people with dementia. Expenditure for program support from HACC, EACH, Veterans' Home Care, CACP and ACAP is estimated to be \$135 million.

Table 8.1: Health and aged care system expenditure for dementia and Alzheimer's disease, 2003

Health and aged care sector	\$ million
Admitted patient services	149.3
Hospital services for non-admitted patients	unknown
Unreferred (GP) services ^(a)	10.0
Pathology & imaging services ^(a)	4.1
Specialist services ^(a)	5.4
Pharmaceuticals requiring a prescription ^(b)	72.8
Residential aged care	992.8
<i>Community care—2003–04^(c)</i>	<i>134.6</i>
Veterans' Home Care	4.6
HACC	45.9
CACP	67.7
ACAP	11.5
EACH	5.0
Total	1,369.2

(a) Expenditure for the out-of-hospital medical services is for the year ending March 2004.

(b) Includes expenditure for all drugs prescribed by GPs for the management of dementia, and antimentia drugs prescribed by specialists. Does not include expenditure for other drugs prescribed by specialists for dementia management. Includes patient contribution to the cost of drugs. Private and under co-payment pharmaceuticals included as well as PBS/RPBS drugs.

(c) Community care includes ACAP, Veterans' Home Care, HACC, CACP and EACH. Expenditure listed here is for 2003–04 financial year.

Comparison of methods used for these estimates and for previous estimates

The Multiple conditions cost allocation method is different from the traditional methodology used to calculate previous expenditure methods:

1. The inclusion of estimates of costs for people with an additional diagnosis of dementia in hospitals, not just the principal diagnosis, has increased the estimate by \$68 million to \$149 million in 2003.
2. The main change in method occurred for the residential aged care sector where the new method estimates the costs imposed by the dementia itself, rather than the total costs of caring for residents whose designated main condition was dementia. This results in a large reallocation of residential aged care costs between conditions (Table 8.3). Hearing loss and mental health are allocated a greater proportion and dementia, mobility and

stroke a lower proportion. The cost imposed by dementia itself is \$1.0 billion compared to the costs of caring for residents whose main problem is dementia of \$1.6 billion.

These new methods mean that the estimates for 2003 cannot be compared with estimates published in AIHW (2004f) and AIHW (2005d).

Table 8.2: Comparison of the Multiple conditions cost allocation method with the Main condition allocation method (\$ million)

Health and aged care sector	Main condition allocation (old) method	Multiple conditions cost allocation (new) method
Admitted patient—principal diagnosis	81	81
Admitted patient—additional diagnosis	Not estimated	68
<i>Total cost of care for people with dementia as the main condition in residential aged care (old method)</i>	1,598	. .
<i>Residential aged care—costs of care due to dementia for all residents with dementia (new method)</i>	. .	993
Other sectors ^(a)	227	227
Total	1,906	1,369

(a) Other sectors includes: unreferral services, pathology, imaging, specialist, pharmaceuticals and community care services. Methods used to estimate expenditure in these sectors have not changed.

Under the Multiple conditions cost allocation method, the \$1,598 million in expenditure for people with a main condition of dementia is attributed to each disease group: \$726 million is allocated to dementia and \$872 million is allocated to the seven other disease groups.

This new method of estimating costs in residential aged care results in different allocation between the different conditions (Table 8.3). The share of total expenditure decreases for dementia and Alzheimer's disease (\$605 million), cardiovascular disease (stroke and other diseases) (\$134 million), diseases causing problems with mobility (\$100 million) and Parkinson's disease (\$70 million), and increases for hearing loss (\$274 million), mental conditions (\$80 million) and other conditions (\$554 million).

Table 8.3: Comparison of residential aged care expenditure allocation using the multiple conditions and main condition methods

Condition groups	Expenditure (\$m)			Proportions of total residential aged care expenditure	
	Main condition method (old)	Multiple conditions method (new)	Difference between Main condition method & Multiple conditions method	Main condition method (old)	Multiple conditions method (new)
Dementia & Alzheimer's disease	1,598	993	605	38%	24%
Stroke	445	335	110	11%	8%
Mobility	752	652	100	18%	16%
Mental	380	460	-80	9%	11%
Other cardiovascular disease	200	176	24	5%	4%
Hearing loss	28	303	-274	1%	7%
Parkinson's disease	156	87	70	4%	2%
Other conditions	612	1,166	-554	15%	28%
Total	4,171	4,171	0	100%	100%

8.2 Residential aged care services

Government funding in the form of the residential care subsidy is paid to approved providers for providing residential care for residential aged care services. It comprises a basic subsidy plus supplements for special needs and less any reduction specific to the resident's circumstances (DoHA 2005c:Chapter 6). The residential care subsidy is paid according to the level of care needed and in 2003 ranged from \$41,038 (RCS 1) to \$8,773 (RCS 7). There is no funding for RCS 8 residents.

There were 139,051 permanent residents of residential aged care facilities at 30 June 2003. Basic funding for permanent residents in the calendar year 2003 was \$4.2 billion. Additionally, supplements totalling \$600 million¹² were paid in 2003. Reductions for income-tested fees for 2003 totalled \$210 million. The supplements include concessional supplements, charge exempt supplement, oxygen and enteral supplement, pensioner supplement and conditional adjustments.

This analysis uses questions related to need for assistance from the SDAC to rank SDAC respondents according to their need for assistance in areas similar to those used in assessing a residential aged care residents classification (see also Chapter 7, Box 7.5). This ranked list is divided proportionally according to the actual RCS distribution to model the RCS categories. These modelled RCS categories are used throughout the analysis.

According to the SDAC, those 139,000 permanent residents had 753,081 long-term conditions. The number of conditions per person ranged from 8.4 in Residential Classification Scale 1 (RCS 1) to 3 conditions per permanent resident in RCS 7 (Table 8.4).

Table 8.4: Number of conditions in residential aged care, by modelled RCS level, RCS 1–RCS 8, 2003

Modelled RCS classification	Permanent residents	Number of conditions			Conditions per person
		Residents with dementia	Number of other conditions	All conditions	
RCS 1	28,470	20,535	217,447	237,982	8.4
RCS 2	34,213	20,603	176,760	197,363	5.8
RCS 3	20,255	12,051	86,468	98,519	4.9
RCS 4	6,558	3,049	28,914	31,963	4.9
RCS 5	15,474	5,872	63,953	69,825	4.5
RCS 6	14,969	3,718	54,042	57,760	3.9
RCS 7	17,698	1,646	51,582	53,228	3.0
RCS 8	1,414	177	6,263	6,440	4.6
Total RCS 1–8	139,051	67,650	685,430	753,081	5.4

It is estimated from the SDAC that there were 67,650 people with dementia living in residential aged care and, of these, 45,425 had dementia recorded as the main problem. These 67,650 residents with dementia made up 45% of people in residential aged care, and for 30% out of this 45% (two-thirds) dementia was the main problem for which assistance was needed. Although the SDAC may somewhat underestimate the number with dementia,

¹² Calculated assuming that subsidy paid in June 2003 for the permanent resident population at 30 June 2003 was the average for the whole year (i.e. \$50 million in subsidies paid in June 2003 extrapolated across 12 months).

particularly those with mild dementia, this will not markedly affect the cost estimates, as the costs of care for those with milder dementia are unlikely to be significant.

Table 8.5: Number of conditions for permanent residents for whom the main condition is dementia or Alzheimer’s disease, by modelled RCS level, 2003

Modelled RCS classification	Permanent residents with dementia as main condition	Number of additional conditions	Total number of conditions when main condition is dementia	Conditions per person
RCS 1	12,948	82,866	95,839	7.4
RCS 2	13,693	58,679	72,372	5.3
RCS 3	8,212	21,967	30,180	3.7
RCS 4	2,209	5,339	7,548	3.4
RCS 5	4,415	10,879	15,294	3.5
RCS 6	2,603	5,365	7,968	3.1
RCS 7	1,166	1,645	2,812	2.4
RCS 8	177	190	368	2.1
Total RCS 1–8	45,425	186,929	232,379	5.1

Previous methods have estimated the cost of dementia as the total costs of care for residents with dementia as the main problem. This would only be a correct estimation method if dementia was the only condition that caused a need for assistance. Table 8.5 shows, that, for a person with dementia as the main condition for which assistance is required, the average number of conditions for which assistance is needed is 5.1. So a person with dementia will typically need assistance in a wide range of areas, and only some of that need for assistance will be due to dementia-induced problems. They may need assistance with mobility due to a stroke they have experienced. They may need assistance in communication both because of hearing loss and dementia. In the method developed for this project, only the assistance for problems due to the dementia is counted.

While dementia is often considered to be a so-called ‘tipping condition’ – that is, the condition that causes the movement from home care to residential care – data identifying the ‘tipping condition’ for residents are not available. Similarly, data are unavailable about the relative severity of a resident’s comorbid conditions. In this analysis there is no assumption made about the reason a person is in residential aged care, and the problem recorded as the main problem is treated no differently than any of the other conditions listed.

Health conditions¹³ recorded in the SDAC were allocated across eight categories grouped according to similarities in the likely need for assistance for the condition. For example, arthritis is grouped with hip damage from injury in the group ‘Conditions affecting mobility’. The eight groups are listed in Table 8.6 (and Table A8.1 for a list of conditions). Each group was only counted once which means that someone who had two conditions that are allocated to the same group only had one of them counted (i.e. the disease group is an on/off variable and does not count more than once the multiple conditions within each group).

A regression model was established using all possible combinations of the eight condition groups. The dependent variable was the RCS score with more than 200 independent

13 High cholesterol and hypertension have been left out of this analysis since they do not add significantly to the need for care.

variables being the combinations of conditions. The model has 207 degrees of freedom, an F value of 13.36 (Pr > F = 0.0001) and an adjusted R² of 0.39.

From this model a predicted RCS score is generated for each combination of the condition-groups which provides an average RCS score and hence level of funding for each set of conditions within the model.

Comparisons could then be made between sets of conditions with dementia and the same set of conditions without dementia and the impact of the dementia on that set of conditions in terms of change in RCS score and associated level of funding ascertained. For example, the result for a resident with dementia, stroke and mobility problems is compared with the result for a resident with just stroke and mobility. The level of funding needed to care for the problems brought about by dementia is the difference between the level of funding for the group of conditions without dementia and the level of funding for the group of conditions plus dementia. Using this method, a cost of dementia is allocated to each person in the SDAC according to the conditions listed for that person.

Table 8.6: Condition groups for medical conditions from the SDAC

Condition group	ABS codes
CG1. Dementia & Alzheimer's disease	511, 605
CG2. Stroke	923
CG3. Conditions affecting mobility	1301, 1303, 1306, 1307, 1399, 1802, 1804, 707, 612, 607, 1904
CG4. Mental health	500, 512, 513, 521, 522, 599
CG5. Other cardiovascular disease	910, 913, 914, 919, 929, 508
CG6. Hearing loss	803, 804, 810, 811, 899
CG7. Parkinson's disease	604
CG8. Other conditions ^(a)	All codes not mentioned above excluding 404 & 922

(a) High cholesterol (404) and hypertension (922) have been excluded from this analysis because they do not add significantly to the need for care.

From this analysis, dementia is the most expensive condition group (\$993 million), followed by mobility (\$652 million) and mental health conditions (\$460 million) (Table 8.7).

Table 8.7: The amount of basic funding, by condition groups and modelled RCS classification (\$ million)

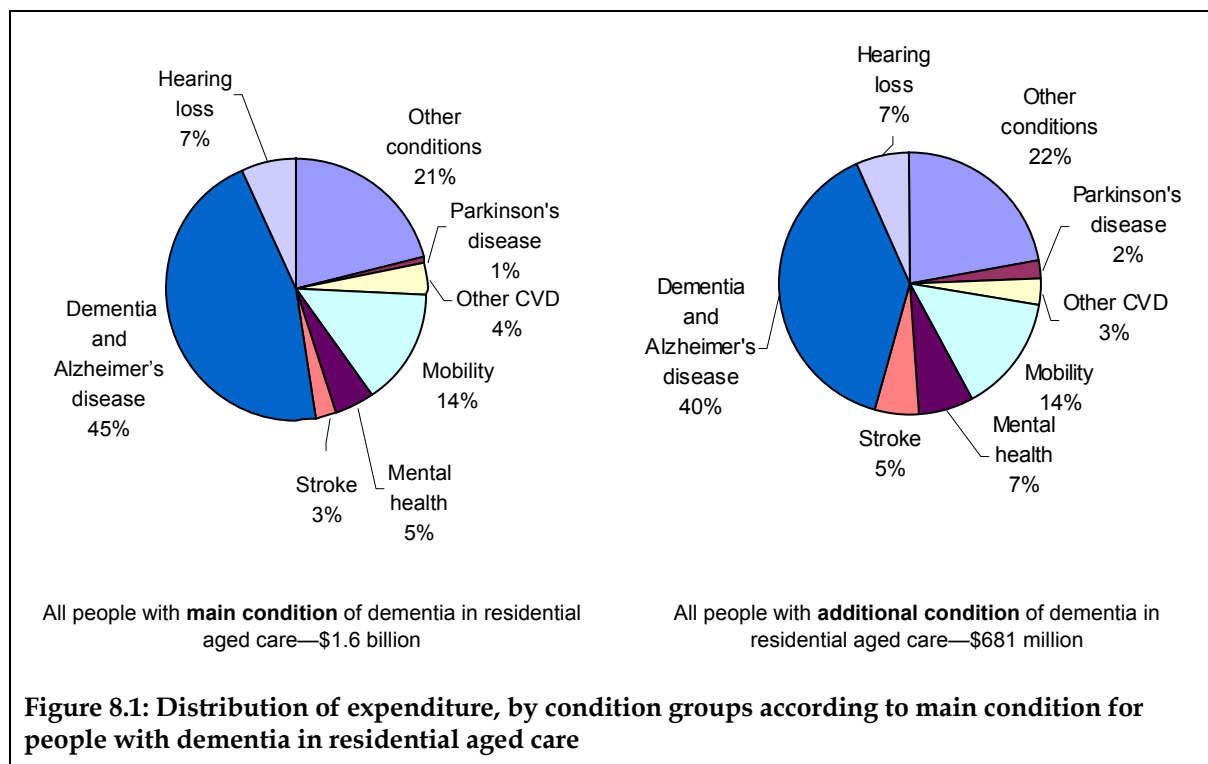
Condition group	Modelled residential classification scale classification							Total
	RCS 1	RCS 2	RCS 3	RCS 4	RCS 5	RCS 6	RCS 7	
CG1. Dementia	329	331	190	43	65	29	8	993
CG3. Mobility	215	193	107	31	51	35	19	652
CG4. Mental	164	147	65	21	32	20	11	460
CG2. Stroke	112	115	53	16	19	12	6	335
CG6. Hearing	106	98	52	9	20	10	7	303
CG5. Other cardiovascular disease	64	56	28	7	14	5	2	176
CG7. Parkinson's disease	26	32	18	3	3	3	1	87
CG8. Other conditions	377	366	178	54	94	64	34	1,166
Total	1,393	1,339	691	183	299	178	88	4,171

Funding for care of the 45,425 people in aged care facilities with dementia where dementia is recorded as the main problem is \$1.6 billion (Table 8.8). This is more than twice the \$681 million in funding for people whose dementia is **not** their main condition. The proportion of this \$1.6 billion in funding that is estimated to be due to dementia is nearly 45% (\$726 million) with the remaining \$872 million allocated to the other 187,000 conditions (Table 8.5). The distribution across all conditions is shown in Figure 8.1. The number of conditions recorded for people whose main condition is dementia, 5.1 conditions per person, is lower than for all permanent residents (5.4). The number of conditions per person with the main condition being dementia ranges from 7.4 in RCS 1 to 2.1 in RCS 8 (Table 8.5).

Table 8.8: Expenditure for dementia in residential aged care where dementia is recorded as the main problem

Modelled RCS classification	Residents with dementia as their main condition	Proportion of residents where main condition is dementia	Funding for people with dementia as main condition (\$ million)	Expenditure for dementia when dementia is the main condition (\$ million)	Expenditure for other conditions when dementia is the main condition (\$ million)
RCS 1	12,948	0.45	601	234	367
RCS 2	13,693	0.40	556	236	320
RCS 3	8,212	0.41	247	141	105
RCS 4	2,209	0.34	58	34	24
<i>Total high care</i>	<i>37,063</i>	<i>0.41</i>	<i>1,461</i>	<i>645</i>	<i>816</i>
RCS 5	4,415	0.29	95	54	40
RCS 6	2,603	0.17	34	21	13
RCS 7	1,166	0.07	8	6	2
RCS 8	177	0.13	0	0	0
Total RCS 1–8	45,425	0.33	1,598	726	872

Figure 8.1 shows that whether dementia is the main or an additional condition does not impact greatly on the distribution, across condition groups, of expenditure for people with dementia in residential aged care. For residents with dementia, dementia has the greatest allocation of expenditure – 45% if dementia is the main condition and 40% if dementia is **not** the main condition. Stroke, Parkinson’s disease and ‘other conditions’ show a small increase in the proportion of expenditure allocated when dementia is **not** the main condition.



If all residents with dementia are considered, not just those whose main problem is dementia, the funding for care due to dementia is just under \$1 billion, with \$3.2 billion being for care due to other conditions (Table 8.9).

Table 8.9: Funding for care due to dementia and other conditions in residential aged care where dementia is recorded as a problem, 2003

Modelled RCS classification	Permanent residents	Permanent residents with dementia	Proportion of residents who have dementia	Funding for care due to dementia (\$ million)	Funding for care due to other conditions (\$ million)
RCS 1	28,470	20,535	0.72	329	1,064
RCS 2	34,213	20,603	0.60	331	1,008
RCS 3	20,255	12,051	0.59	190	502
RCS 4	6,558	3,049	0.46	43	140
<i>Total high care</i>	<i>89,496</i>	<i>56,237</i>	<i>0.63</i>	<i>892</i>	<i>2,715</i>
RCS 5	15,474	5,872	0.38	65	234
RCS 6	14,969	3,718	0.25	29	149
RCS 7	17,698	1,646	0.09	8	80
RCS 8	1,414	177	0.13	0	0
Total RCS 1–8	139,051	67,650	0.49	993	3,178

Residents' contributions to residential aged care

The costs of residential aged care services are mostly funded by governments, with some funding from residents' contributions.

Government funds are allocated to aged care homes to cover the full costs of care that residents require in 20 areas of need – areas of toileting, personal hygiene, mobility,

assistance with eating and drinking, nursing procedures, and so on. The residents' contributions cover the remaining costs which are the normal costs of living – such as food, board and cleaning. It is assumed that the normal costs of living are not due to any health conditions or problem. Therefore these costs are not allocated by health condition.

Thus the only costs allocated by health condition are those costs funded by government subsidy.

In 2003–04 residential aged care subsidies were \$5,336.0 billion, basic daily care resident contributions were \$1,411.8 million and income-tested resident contributions were \$119.2 million (AIHW 2005b:188). Supplements for people in residential aged care in 2003 were approximately \$50 million per month or \$600 million per year.

Funding for dementia and Alzheimer's disease in residential aged care in 2003 was \$993 million (Table 8.10): 78% of this funding was for females and 59% was for people aged 85 and over. Over 90% of funding for dementia and Alzheimer's disease was in high level residential aged care, with RCS 2 (33.3%) and RCS 1 (33.1%) allocated the greatest proportion of the overall funding.

Table 8.10: Funding allocated to dementia and Alzheimer's disease in residential aged care facilities, by age and sex, 2003 (\$ million)

Sex/age	High level residential aged care (\$ million)				Total high level residential aged care	Total residential aged care
	RCS 1	RCS 2	RCS 3	RCS 4	RCS 1-4	RCS 1-7
Males						
45-49	0.3	0.0	0.0	0.0	0.3	0.3
50-54	0.0	0.0	0.0	0.0	0.0	0.0
55-59	0.3	0.7	0.6	0.0	1.6	1.6
60-64	1.9	0.3	0.5	0.0	2.8	2.9
65-69	1.3	1.2	0.8	0.7	4.0	5.1
70-74	6.8	4.4	2.6	0.0	13.8	16.8
75-79	9.5	8.1	7.0	1.9	26.6	30.3
80-84	21.5	14.9	12.5	2.5	51.3	55.9
85+	43.8	27.3	16.6	3.9	91.6	100.8
<i>Total</i>	<i>85.3</i>	<i>57.1</i>	<i>40.6</i>	<i>9.0</i>	<i>192.0</i>	<i>213.7</i>
Females						
45-49	0.0	0.0	0.0	0.0	0.0	0.1
50-54	1.2	0.0	0.6	0.0	1.8	2.1
55-59	0.3	0.8	1.4	0.0	2.5	3.1
60-64	1.1	0.6	0.1	0.0	1.8	2.2
65-69	1.9	2.8	2.2	0.0	6.8	9.4
70-74	5.7	9.8	5.0	0.0	20.6	25.4
75-79	19.5	23.3	15.3	4.9	63.0	72.2
80-84	50.4	62.2	37.8	12.0	162.5	182.8
85+	163.2	174.1	86.8	16.7	440.9	481.9
<i>Total</i>	<i>243.3</i>	<i>273.6</i>	<i>149.2</i>	<i>33.6</i>	<i>699.8</i>	<i>779.1</i>
Persons						
45-49	0.3	0.0	0.0	0.0	0.3	0.5
50-54	1.2	0.0	0.6	0.0	1.8	2.1
55-59	0.6	1.5	2.0	0.0	4.1	4.8
60-64	3.0	0.9	0.6	0.0	4.6	5.1
65-69	3.2	4.0	3.0	0.7	10.9	14.5
70-74	12.5	14.3	7.5	0.0	34.3	42.2
75-79	28.9	31.5	22.4	6.8	89.5	102.4
80-84	71.9	77.1	50.3	14.4	213.8	238.6
85+	207.0	201.4	103.4	20.7	532.5	582.7
Total	328.6	330.7	189.8	42.6	891.8	992.8

8.3 Hospital services

There were nearly 83,000 separations from hospital for people with dementia in 2003–04: 11,000 were admitted with a principal diagnosis of dementia at a cost to the health system of \$81.6 million. There were 72,000 admissions with an additional diagnosis of dementia where it is estimated that dementia was responsible for \$69 million of hospital costs. Therefore the total admitted patient expenditure due to dementia or Alzheimer's disease was \$150.5 million.

People with dementia may be admitted to hospitals for their dementia or for another condition. When the main reason for admission to hospital is dementia (principal diagnosis of dementia or Alzheimer's disease), a Diagnosis Related Group code will be allocated to that separation. In this analysis, the public hospital weighted cost per Diagnosis Related Group is applied to any separation where the principal diagnosis is dementia or Alzheimer's disease.

When a patient is admitted and an additional diagnosis of dementia is recorded (principal diagnosis is a condition other than dementia but a diagnosis of dementia is recorded on the record), then it is assumed that the care needed by the patient is affected by the patient having dementia. The analysis of expenditure for care due to dementia in residential aged care has shown that the average amount of funding attributed to people with dementia or Alzheimer's disease in residential aged care is \$40.20 per day (\$992.8 million divided by 24.7 million bed-days). Since care is more expensive in hospitals, the cost of caring for dementia in aged care has been increased by 50% – that is, a cost of \$60.30 has been applied per bed-day in hospital for dementia when dementia is not the principal diagnosis.

Using this method, admitted patient expenditure for people with a principal diagnosis of dementia or Alzheimer's disease was \$81.6 million in 2003–04 (Table 8.11). There was a steady increase from \$62.9 million in 1999–00. In 2003–04, admitted patient expenditure for females was \$44.7 million (55%) and for males \$36.9 million (45%); \$23.2 million (28%) was for patients aged between 80 and 84 years and \$27.5 million (34%) for patients 85 years and over.

The admitted patient expenditure due to dementia or Alzheimer's disease (regardless of principal diagnosis) was \$150.5 million in 2003–04 (Table 8.12). This was a steady increase from \$130.8 million in 1999–00. In 2003–04, admitted patient expenditure for females was \$87.1 million (58%) and \$40.6 million (27%) was for patients aged between 80 and 84 years old.

For admitted patients with a principal diagnosis of dementia or Alzheimer's disease the average length of stay was 26 days, the average cost per separation was \$7,429 and the average cost per bed-day was \$282 (Table 8.13). When a patient with dementia was admitted for a reason other than dementia, the average length of stay was 15 days. With the cost attributed to caring for the dementia estimated at \$60.30 per day, the average cost per separation was \$921.

Table 8.11: Hospital expenditure due to a principal diagnosis of dementia or Alzheimer's disease during a hospital stay, 1999-00 to 2003-04, (\$ million)

Sex/age	1999-00	2000-01	2001-02	2002-03	2003-04	2003^(a)
Males						
0-59	0.9	1.0	0.9	0.9	0.9	0.9
60-64	0.8	0.9	0.9	1.2	1.1	1.2
65-69	1.7	2.0	2.0	1.9	1.8	1.9
70-74	3.7	4.4	4.3	4.7	3.8	4.3
75-79	6.5	7.9	7.0	7.9	8.5	8.2
80-84	7.2	9.3	9.3	10.2	10.2	10.2
85-89	5.9	7.1	6.5	7.2	7.3	7.3
90-94	1.5	2.3	2.7	2.5	2.7	2.6
95+	0.3	0.4	0.5	0.4	0.7	0.6
<i>Total</i>	<i>28.5</i>	<i>35.4</i>	<i>33.9</i>	<i>37.0</i>	<i>36.9</i>	<i>37.0</i>
Females						
0-59	0.7	0.8	0.8	0.7	1.0	0.9
60-64	0.7	0.8	0.5	0.8	0.8	0.8
65-69	1.2	1.6	1.2	1.2	1.4	1.3
70-74	3.0	3.7	3.9	3.6	3.7	3.7
75-79	6.6	8.3	7.8	7.7	7.9	7.8
80-84	9.0	11.2	10.6	11.8	13.0	12.4
85-89	9.6	10.8	10.3	10.7	10.5	10.6
90-94	3.1	5.1	5.0	5.5	5.1	5.3
95+	0.6	1.1	1.2	1.3	1.2	1.3
<i>Total</i>	<i>34.4</i>	<i>43.3</i>	<i>41.2</i>	<i>43.4</i>	<i>44.7</i>	<i>44.1</i>
Persons^(b)						
0-59	1.5	1.8	1.7	1.6	1.9	1.8
60-64	1.5	1.6	1.4	2.0	2.0	2.0
65-69	2.9	3.6	3.2	3.2	3.1	3.2
70-74	6.6	8.1	8.1	8.3	7.5	7.9
75-79	13.1	16.2	14.8	15.6	16.3	16.0
80-84	16.2	20.5	19.9	22.1	23.2	22.7
85-89	15.5	17.9	16.8	17.8	17.8	17.8
90-94	4.7	7.4	7.6	8.1	7.8	8.0
95+	0.9	1.5	1.7	1.8	1.9	1.9
Total	62.9	78.6	75.2	80.4	81.6	81.0
Inflation adjusted^(c)	72.0	87.1	80.7	83.4	81.6	82.5

(a) Estimated expenditure for the 2003 calendar year.

(b) Includes expenditure for admitted patients whose gender is unknown.

(c) Total admitted patient expenditure adjusted to 2003-04 dollars using the hospital/nursing home care deflator (AIHW 2005d).

Source: AIHW analysis of the National Hospital Morbidity Database and the National Public Hospital Establishments Database.

Table 8.12: Hospital expenditure due to any diagnosis of dementia or Alzheimer's disease during a hospital stay, 1999-00 to 2003-04 (\$ million)

Sex/age	1999-00	2000-01	2001-02	2002-03	2003-04	2003^(a)
Males						
0-59	2.3	2.0	1.6	1.8	2.0	1.9
60-64	1.3	1.5	1.4	1.8	1.9	1.9
65-69	3.7	3.1	3.3	3.6	2.9	3.3
70-74	7.0	7.3	7.1	7.0	6.4	6.7
75-79	11.4	13.3	12.0	13.1	13.8	13.5
80-84	13.1	15.3	15.7	16.9	16.9	16.9
85-89	11.2	12.4	12.1	12.4	13.3	12.9
90-94	3.2	4.5	5.1	5.1	5.1	5.1
95+	0.5	0.7	0.9	0.8	1.1	1.0
<i>Total</i>	<i>53.7</i>	<i>60.1</i>	<i>59.1</i>	<i>62.5</i>	<i>63.4</i>	<i>63.0</i>
Females						
0-59	2.4	1.3	1.6	3.0	2.7	2.9
60-64	1.7	1.0	1.0	1.3	1.4	1.4
65-69	2.1	2.6	2.2	2.6	2.3	2.5
70-74	5.6	6.1	6.8	6.1	6.1	6.1
75-79	13.0	14.5	14.2	13.6	14.2	13.9
80-84	18.9	21.4	21.6	22.3	23.7	23.0
85-89	24.0	21.9	21.3	21.5	22.6	22.1
90-94	7.5	11.3	11.5	12.0	11.5	11.8
95+	1.8	3.1	2.8	3.0	2.8	2.9
<i>Total</i>	<i>77.1</i>	<i>83.2</i>	<i>82.8</i>	<i>85.5</i>	<i>87.1</i>	<i>86.3</i>
Persons^(b)						
0-59	4.7	3.3	3.1	4.8	4.6	4.7
60-64	3.1	2.6	2.3	3.0	3.3	3.2
65-69	5.8	5.6	5.5	6.2	5.2	5.7
70-74	12.6	13.4	13.9	13.1	12.5	12.8
75-79	24.5	27.8	26.1	26.7	28.0	27.4
80-84	32.0	36.7	37.3	39.3	40.6	40.0
85-89	35.2	34.3	33.4	33.9	35.9	34.9
90-94	10.6	15.8	16.6	17.1	16.6	16.9
95+	2.3	3.8	3.7	3.9	3.9	3.9
Total	130.8	143.3	141.9	148.1	150.5	149.3
Inflation adjusted^(c)	149.7	158.8	152.3	153.5	150.5	152.0

(a) Estimated expenditure for the 2003 calendar year.

(b) Includes expenditure for admitted patients whose gender is unknown.

(c) Total admitted patient expenditure adjusted to 2003-04 dollars using the hospital/nursing home care deflator (AIHW 2005d).

Source: AIHW analysis of the National Hospital Morbidity Database and the National Public Hospital Establishments Database.

Table 8.13: Hospital costs allocated to dementia, by number of separations and bed-days where dementia or Alzheimer's disease is recorded as a diagnosis during a hospital stay, 2003-04

Sex/age	Principal diagnosis—Dementia and Alzheimer's disease						Additional diagnosis was dementia or Alzheimer's disease but principal diagnosis was not					
	Separations	Bed-days	Expenditure (\$ million)	Bed-days per separation	Cost per separation	Cost per bed-day (\$)	Separations	Bed-days	Expenditure (\$ million)	Bed-days per separation	Cost per separation	Cost per bed-day (\$)
Males												
0-59	119	15,916	0.9	134	7,663	57	534	16,770	1.0	31	1,894	60
60-64	148	6,067	1.1	41	7,577	185	509	12,668	0.8	25	1,501	60
65-69	232	7,856	1.8	34	7,587	224	1,012	18,004	1.1	18	1,073	60
70-74	510	14,001	3.8	27	7,421	270	2,577	42,048	2.5	16	984	60
75-79	1,135	27,983	8.5	25	7,452	302	5,792	84,740	5.1	15	882	60
80-84	1,367	34,234	10.2	25	7,449	297	7,827	107,222	6.5	14	826	60
85-89	989	24,213	7.3	24	7,373	301	6,585	95,826	5.8	15	877	60
90-94	360	7,094	2.7	20	7,386	375	2,828	38,480	2.3	14	820	60
95+	92	948	0.7	10	7,530	731	534	7,231	0.4	14	817	60
<i>Total</i>	<i>4,952</i>	<i>138,312</i>	<i>36.9</i>	<i>28</i>	<i>7,444</i>	<i>267</i>	<i>28,198</i>	<i>422,989</i>	<i>25.5</i>	<i>15</i>	<i>905</i>	<i>60</i>
Females												
0-59	135	11,056	1.0	82	7,632	93	304	26,058	1.6	86	5,169	60
60-64	108	1,855	0.8	17	7,738	450	392	8,232	0.5	21	1,266	60
65-69	174	6,019	1.4	35	7,929	229	842	14,256	0.9	17	1,021	60
70-74	501	15,368	3.7	31	7,475	244	2,425	36,954	2.2	15	919	60
75-79	1,060	23,877	7.9	23	7,429	330	6,528	100,428	6.1	15	928	60
80-84	1,752	40,680	13.0	23	7,447	321	11,656	169,496	10.2	15	877	60
85-89	1,433	35,749	10.5	25	7,345	294	12,414	191,858	11.6	15	932	60
90-94	707	13,500	5.1	19	7,261	380	7,129	101,158	6.1	14	856	60
95+	162	3,320	1.2	20	7,174	350	1,933	25,489	1.5	13	795	60
<i>Total</i>	<i>6,032</i>	<i>151,424</i>	<i>44.7</i>	<i>25</i>	<i>7,416</i>	<i>295</i>	<i>43,623</i>	<i>673,929</i>	<i>40.6</i>	<i>15</i>	<i>932</i>	<i>60</i>
Total persons	10,984	289,736	81.6	26	7,429	282	71,822	1,097,048	66.1	15	921	60

Source: AIHW analysis of the National Hospital Morbidity Database and the National Public Hospital Establishments Database.

8.4 Medical services

Data from the general practitioners' survey, Bettering the Evaluation of Care and Health (BEACH), were used to allocate private medical services by disease for both GPs and specialists. The BEACH survey collects information about the number of people who have seen their GP about dementia and who are referred to specialists because of their dementia. It is estimated, using this data, that there were 484,500 GP attendances in which dementia was managed and 43,600 out-of-hospital specialist attendances for dementia nationally in 2003–04. Expenditure for out-of-hospital medical services in 2003–04 was estimated as \$19.5 million (Table 8.14). Of this expenditure \$10 million was for GP services, \$5.4 million for specialist services, \$2.7 million for pathology and \$1.4 million for imaging. Two-thirds of this expenditure was for females and more than three-quarters was for people aged 75 or older.

People with dementia often have other conditions which are also managed by the GP. The expenditure below does not relate to these other conditions but only to attendances where dementia is managed.

Table 8.14: Out-of-hospital medical expenditure for dementia and Alzheimer's disease, 2003–04^(a) (\$ million)

Sex/age	Unreferred attendances	Imaging	Pathology	Other medical	Total out-of-hospital medical expenditure
Males					
0–64	0.2	—	—	0.3	0.5
65–74	0.5	—	—	0.8	1.3
75–84	1.3	0.4	0.3	1.0	2.9
85+	1.0	0.1	0.4	0.4	1.9
Females					
0–64	0.2	0.1	—	0.3	0.5
65–74	0.7	0.1	0.4	0.6	1.8
75–84	3.0	0.5	0.6	0.7	4.8
85+	3.1	0.3	0.9	1.4	5.7
Persons					
0–64	0.4	0.1	—	0.6	1.1
65–74	1.2	0.1	0.4	1.4	3.2
75–84	4.3	0.8	0.9	1.6	7.7
85+	4.0	0.4	1.4	1.8	7.5
Total	10.0	1.4	2.7	5.4	19.5

— Represents zero or less than \$50,000.

(a) Year ending March 2004.

Source: AIHW analysis of BEACH and the AIHW disease expenditure database.

8.5 Pharmaceuticals

There was a steep increase (38%) in the use of dementia-specific drugs between 2002–03 and 2004–05, from \$35.4 million to \$48.8 million. Donepezil had the lion's share, \$32.4 million (67%) in 2004–05, though this share dropped in the three years of analysis from 74% in 2002–03. The proportion of Galantamine increased from 14% in 2002–03 to 26% in 2004–05.

Table 8.15: Benefit paid for dementia-specific drugs on the PBS and RPBS prescribed by GPs and specialists, 2002–03 to 2004–05 (\$)

Drug name and item number	2002–03	2003–04	2004–05
Donepezil			
8495	8,253,261	8,655,315	8,807,902
8496	17,819,601	20,750,350	23,666,782
<i>Total</i>	<i>26,072,862</i>	<i>29,405,664</i>	<i>32,474,683</i>
Galantamine			
8536	1,636,474	2,468,560	2,072,519
8537	3,255,450	6,445,656	8,445,330
8756	463,332
8770	400,787
8771	978,870
8772	186,608
<i>Total</i>	<i>4,891,925</i>	<i>8,914,216</i>	<i>12,547,446</i>
Rivastigmine			
8497	1,057,656	857,891	714,121
8498	1,558,096	1,440,867	1,367,177
8499	736,892	653,861	630,152
8500	974,826	927,167	891,039
8563	93,725	82,537	129,551
<i>Total</i>	<i>4,421,195</i>	<i>3,962,322</i>	<i>3,732,040</i>
Total	35,385,982	42,282,203	48,754,169

Note: Galantamine item numbers 8756, 8770, 8771 and 8772 were not available on the PBS in 2002–03 and 2003–04.

Source: Department of Health and Ageing unpublished.

Of the \$42.3 million for prescribed antidementia drugs in 2003–04 (Table 8.15), \$27.7 million (65%) were prescribed by a GP (Table 8.16). The remaining 35% were prescribed by specialists. Other GP-prescribed prescriptions for dementia such as antipsychotics and antidepressants accounted for a government benefit paid of \$10.8 million. Antidementia drugs (\$27.7 million) and antipsychotics (\$8.6 million) contributed 95% of the total benefit paid for GP-prescribed drugs for dementia patients.

Table 8.16: PBS/RPBS benefit paid for drugs prescribed to manage dementia by GPs^(a), 2003–04

ATC ^(b) group	ATC ^(b) group name	Benefit paid ^(c) (\$)
N06D	Antidementia drugs	27,671,015
N05A	Antipsychotics	8,618,623
N05B	Anxiolytics	29,497
N06A	Antidepressants	713,503
N05C	Sedatives & hypnotics	9,205
N02B	Other analgesics & antipyretics	25,057
	Other GP-prescribed drugs	1,289,769
Total benefit paid		38,356,668

(a) Prescriptions written by specialists are not included in this analysis.

(b) Anatomical Therapeutic Chemical classification system.

(c) Benefit paid for antidementia drugs is based on PBS data (number of scripts and cost per script). The benefit paid for all other drug groups listed is derived from BEACH (number of scripts) and PBS data (cost per ATC drug group).

Source: AIHW analysis of BEACH and PBS data.

8.6 Community care services

The data on the cost of dementia for community care programs are inadequate or non-existent. However, using a number of broad assumptions an indication of the costs involved can be obtained.

Home and Community Care

In an analysis of 14,000 community care clients over 60 years of age, Silver Cross WA reported about 3% had a diagnosis of dementia, 5% showed functional pointers of cognitive loss and another 2% had 'behaviour problems/memory loss/confusion' recorded on the notes (personal communication 17 November 2005). An estimate of 5% (3% with diagnosis and half of those with cognitive loss) is applied to the total HACC funding to provide an estimate for HACC funding for people with dementia.

Of the total HACC funding for 2003–04 (\$917.1 million), the amount allocated to dementia is \$45.9 million.

Aged Care Assessment Program

Around 23.7% of ACAP clients have a primary diagnosis of dementia. Using this proportion to estimate the cost of dementia to assessment for aged care services, around \$11.5 million ($0.237 \times \48.4 million) of funding for the ACAP in 2003–04 can be attributed to dementia.

CACP and EACH programs

While the CACP and EACH 2002 censuses collected information on dementia status, they did not collect unit level costs for particular services, nor did they record the cost of providing a package to a particular client. Consequently, the cost of dementia to these

programs must also be estimated. However, data on the amount of particular services provided to clients were collected. Using these it is possible to get an indication of the cost of dementia to these programs.

From census data, it is estimated that 18% of CACP clients had dementia and that these people received 22% of the total hours of service provided under Community Aged Care Packages. For EACH, clients with dementia accounted for 32% of both clients and hours of service provided. Using the percentage of hours of service used by people with dementia to estimate the cost of dementia to the two programs, the cost of dementia to government in 2003–04 was approximately \$5.0 million for EACH and \$67.7 million for CACP. While these estimates take into account the different total hours of service provided to people with and without dementia, they do not allow for differential mix of service types by people with and without the disorder, nor are costs to users included. They also assume that dementia is the reason why services are required.

8.7 Projected expenditure

Expenditure is projected to 2030–31. Total expenditure due to dementia is projected to grow by 225% between 2003 and 2030–31. This growth is due to the ageing of the population and the total growth of the Australian population in this period. It assumes no growth in the age-specific rate of dementia, and no change in the intensity with which dementia is treated.

Table 8.17: Projected expenditure for dementia, 2003 to 2030–31 (\$ million)

	Admitted patient	All out-of-hospital medical	Pharmaceutical prescriptions	Residential aged care	Other care	Total health expenditure
2003	149	20	73	993	135	1,369
2005–06	159	21	77	1,058	143	1,458
2010–11	193	25	94	1,317	174	1,804
2015–16	238	31	116	1,625	214	2,224
2020–21	292	38	142	1,973	263	2,708
2025–26	373	48	179	2,524	337	3,461
2030–31	473	61	226	3,267	427	4,454

9 Strengths and limitations of dementia data

9.1 Introduction

All governments in Australia increasingly recognise the importance of responding to the growing prevalence and impact of dementia with coordinated and well-targeted initiatives. Effective policy and program responses to the needs of people with dementia and their carers require a solid evidence base to inform their development and evaluation. A number of initiatives funded in the 2005 Federal Budget will make important contributions to building this evidence base, including the Dementia Research Mapping project, the Dementia website, the Dementia Collaborative Research Centres and the Dementia Research Grants.

Consistent and comprehensive data about dementia are a basic building block for research, policy development and planning, program monitoring and evaluation, and developing, testing and implementing improvements in the delivery of treatment and care. When considering what kind of information and data would constitute an evidence base for policy research, three questions arise:

- What use will be made of the information and the data?
- Who will use the information and data?
- What questions are important to each end user of the data?

A fundamental requirement is that the data should help to measure the need for services, treatment and care.

This chapter summarises the limitations and strengths of the data analysed in earlier chapters in this report. Its focus is on population, service use and epidemiological data.

The remaining chapters of this report then examine dementia-relevant data elements in existing population and health and aged care service data collections for their consistency and comparability with each other. Chapter 12 recommends data elements for further development that would be designed to increase the comprehensiveness and consistency of information collected about dementia, including in terms of case identification.

9.2 Limitations of existing data

Identifying people with dementia

Chapter 3 describes existing collections and the information they include about dementia. People with dementia are not identified at all in a number of relevant collections. In particular, data from the HACC, EACH, CACP and residential aged care programs do not include any identifier for dementia. This will improve in future with the development and implementation of the ACFI in residential aged care and with the implementation of EACH

Dementia places. In addition, HACC MDSv2 will collect some information about memory problems, confusion and behavioural problems. It is important that consistency of data collected and reported about dementia is achieved as these developments occur.

In those collections where dementia is identified, it is not identified in a consistent way. This is discussed in more detail in Chapter 11 and has been apparent in data reporting in earlier chapters of this report. Dementia identification may be constrained by the data collection context – for example, as a long-term health condition lasting six months or more which restricts everyday activity (SDAC); a health condition that impacts on the client’s need for assistance (ACAP); a diagnosed health condition that is either chiefly responsible for a hospital episode, or coexistent with such a condition (hospital morbidity data).

Dementia is sometimes identified as a result of self-report or proxy-report (SDAC), sometimes on the basis of specialist diagnosis which usually includes scores on assessment tests (PBS). Some collections directly query whether a diagnosis of dementia is present (NRCP, CACP/EACH census), while others do not seek this level of confirmation (SDAC).

It is, however, important to note that there are real difficulties in collecting data on dementia. There may never be consistent and high quality data on early-stage dementia as long as problems are manageable, diagnosis delayed, treatment approaches are few and stigma remains. Further difficulties in identifying people with dementia, particularly at very old ages, arise because symptoms of co-existing health conditions mask those of dementia.

These difficulties will always affect data collected by self- or proxy-report in surveys such as the SDAC. Even in the cared accommodation component, there may be impediments to obtaining a diagnosis of dementia – is there value in doing so if it is possibly the outcome of another disease process, or if the person is too unwell to take appropriate medications? However, the introduction of the ACFI in residential aged care may lead to improved identification in that sector, with resulting improvements in the cared accommodation component of the SDAC.

The diagnosis of dementia, its definition and classification are still subject to considerable development and evolution. There is a significant amount of research being undertaken which throws new light on, or raises new questions about, previously accepted understanding in this area. Definitions and classifications are basic tools which underpin the development and collection of consistent data across collections and over time. While these tools continue to be subject to a high degree of change and/or reflect current difficulties of diagnosing dementia, data collected will be necessarily less comprehensive, consistent and/or authoritative than would be the case otherwise.

Non-reporting of collected data

In considering the comprehensiveness of information, there would appear to be potential to increase this on the basis of already collected information. In obtaining and analysing data for this report, the AIHW became aware of potentially useful information gathered in some programs which is not reported as part of the minimum data set. The most obvious instance of this were the questions about symptoms of cognitive impairment, which are included on the Aged Care Client Record completed by ACATs but not required to be reported as part of the national minimum data set (e.g. ACAP).

The NHS does not code Alzheimer’s disease or other dementias to a separate diagnostic category. Currently it is collapsed into the category of *Organic mental health problems* or *Symptoms and signs involving cognition, perceptions, emotional state and behaviour* under *Mental*

health and behavioural problems. The value of the information collected for the purposes of identifying people with dementia is therefore lost.

Non-collection of some data that are relevant

In addition, this project found that the data that are reported and available for analysis are sometimes inconsistent with what appears to be available from data dictionaries (e.g. the Dementia Education and Support Program data). This creates the impression that more or different data are available than is in fact the case.

This problem is not just one of non-reporting of collected information, but of non-collection at all. Non-collection may reflect the practicalities and relevance of some of these data items, and may signal the need to review their inclusion in data collections and dictionaries. In other cases, it may indicate a need to improve training of data collectors to ensure that relevant information is obtained.

Little national longitudinal or linked data

The analysis possible for this report has been based on a service contact perspective and on cross-sectional population data. As Chapter 3 discussed, Australia has a number of relatively small longitudinal surveys which identify people with dementia. The Australian Longitudinal Survey of Women's Health will gradually collect more national level data about older women with dementia. Longitudinal data or linked data facilitates a person-centred analysis of change over time, an important consideration with a progressive condition such as dementia.

A person-centred view with the potential to track individuals over time permits consideration of issues such as progression of the condition, effectiveness of treatment and interventions, changes in symptoms such as behaviour, changes in carer circumstances, continuity and coordination of care and service provision.

There should be serious consideration and support given to linking existing databases to facilitate such analysis. Linking ACAP, residential aged care, pharmaceutical and hospital data would enormously strengthen Australia's capacity to report on the incidence and prevalence of dementia. Linked data also have the potential to address a range of issues which are relevant to service providers and consumers as well as policy analysts. For example, by linking ACAP, residential aged care, PBS and MBS data, it would be possible to explore issues such as the use of medical services by people with dementia in residential aged care and assess whether residents are being given sufficient and appropriate medical care.

Study design issues

There are a number of characteristics of current collection methodologies which contribute to the limitations of data about dementia.

Sample size in national ABS surveys is relatively small for the purpose of identifying people with conditions with low prevalence in the general population. Oversampling of older people living in households would improve the reliability of the estimates available from this source, since dementia is much more highly prevalent at these older ages.

While the SDAC cared accommodation component represents one of the areas of strength in Australian data, it is nevertheless relatively thin in terms of data about the sociodemographic characteristics of residents.

The **reliance on self-report or proxy-reporting** is particularly problematic for any condition where the individual's cognitive functioning is impaired, where the diagnosis process can be prolonged and uncertain and where stigma may result in a reluctance to identify. It contributes to the underestimate of mild and moderate dementia in the household population through the SDAC.

Limited data about carers

As Chapter 6 noted, the majority of data about carers are from small-scale local studies based on samples of carers who have come into contact with a service. The SDAC provides adequate data about the population of carers overall, but sample sizes severely restrict the rigour and quality of the data about carers of people with dementia. In particular, there is little data about back-up or secondary carers, which results in an inadequate understanding of the complete network of care and of some of the supportive informal arrangements that contribute to an individual caregiver's capacity to cope with their caring role.

In the course of this project, there have been questions raised about the extent to which the report should focus on carers, since issues affecting them are not necessarily dementia-specific. There have been a couple of small-scale comparative studies undertaken which compare the experience of carers of people with dementia with the experience of other carers. There is an important issue to explore further, as these studies suggest there may be some areas in which carers of people with dementia have different experiences and may need different types of support. This kind of research may require a purpose-designed study which links existing administrative data and obtains additional qualitative information from carers.

9.3 Strengths of data

While a number of limitations of existing dementia data have been documented in this report, Australian data do exhibit some strengths, which provide a solid basis for further developments. There is a strong commitment to collecting good data in Australia, and well-developed infrastructure for developing and implementing data standards.

Compared with many other countries, Australia has a **considerable amount of relevant data**, as evidenced by the analysis provided in earlier chapters. In respect of health service use, data from the NHMD, the BEACH survey and the PBS together contribute to a reasonably comprehensive profile of dementia patients.

In addition, a number of Australian collections identify cases of dementia through a **formal diagnosis or assessment** which is more robust than the self-report methodology. The PBS may require MMSE scores, and the trial ACFI also collects data about assessment scores.

As mentioned above, the SDAC includes people living in **cared accommodation**. This survey component is particularly important when examining conditions which are most prevalent at older ages and which frequently result in entry to residential aged care. When used in conjunction with the administrative residential aged care data, it is possible to compare characteristics and dependency of residents with dementia with those of residents without

dementia. The development of the **ACFI** will considerably improve the data available about dementia in residential aged care.

9.4 Future directions

Four major strategies would contribute to the improvement of data about dementia in Australia on the basis of the analysis undertaken in this report:

- First, **better and earlier diagnosis** of people with dementia.
- Second, **improved consistency of identification** of people with dementia in all data collections. This issue is discussed further in later chapters of this report.
- Third, agreement about the **extent of information to be collected**, taking account of the purpose and context of data collection activity. This issue is also explored further in later chapters.
- Finally, a change in focus from services-focused data to person-focused data through **data linkage** (subject to appropriate ethical and privacy considerations), and development and analysis of **longitudinal data**. Pursuing this strategy would provide data useful to the full range of stakeholders, (consumers and service providers, as well as policy analysts and service planners). It would facilitate analysis of health and care pathways of individuals, of interactions between the health and care systems and of the impact on outcomes of health and care services. Data linkage would, over time, also provide further impetus to improve the consistency with which dementia is identified in various datasets.

