Extended Aged Care at Home Census 2002

The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is *Better health and wellbeing for Australians through better health and welfare statistics and information*.

AGED CARE STATISTICS SERIES
Number 15

Extended Aged Care at Home Census 2002

A report of the May 2002 census prepared for the
Australian Government Department of Health and Ageing

February 2004

Australian Institute of Health and Welfare
Canberra

AIHW cat. no. AGE 33

This publication is part of the Australian Institute of Health and Welfare's Aged Care Statistics Series. A complete list of the Institute's publications is available from the Publications Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601, or via the Institute's web site (http://www.aihw.gov.au).

ISSN 1329-5705

ISBN 1 74024 362 5

Suggested citation

Australian Institute of Health and Welfare (AIHW) 2004. Extended Aged Care at Home (EACH) Census: A report on the results of the census conducted in May 2002. AIHW cat. No. AGE 33. (Aged Care Statistics Series No. 15). Canberra: AIHW.

Any enquiries about or comments on this publication should be directed to:

Ageing and Aged Care Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601

Phone: (02) 6244 1219

Email: ageingandagedcare@aihw.gov.au

Published by the Australian Institute of Health and Welfare

Printed by Pirion

Contents

List of tables

List of figures

Acknowledgments

The Extended Aged Care at Home census was conducted at the request of and with funding from the Commonwealth Department of Health and Ageing. Jeff McKenzie and Carolyn Dunn compiled this report. We thank our colleagues at the Australian Institute of Health and Welfare, Dr Anne Jenkins, Paula Angus, Evon Bowler, Kim Farrell, Rod Hall and Ben Nelson. We also acknowledge the assistance of Anne McNeill, Michael Lidman and Kate McCauley from the Department of Health and Ageing.

This report would not have been possible without the assistance of the Extended Aged Care at Home service providers. We wish to express our thanks to these service providers who set aside time to provide information for this valuable collection.

Introduction

This report summarises the data collected in the census of the Extended Aged Care at Home (EACH) program, conducted by the Australian Institute of Health and Welfare during the week commencing 6 May 2002. The census followed an initial evaluation of the pilot program conducted by consultants to the Commonwealth Department of Health and Ageing (Siggins Miller 2001). The AIHW conducted the census at the request of the Department in order provide access to EACH program data that are consistent with previous Community Aged Care Packages (CACP) data collections and the CACP census.

The EACH program is designed to deliver to home-based recipients a standard of nursing and personal care that is equivalent to high-level residential care. The pilot program was conducted through 10 providers, located in five jurisdictions three in NSW—three in Victoria, two in Western Australia, one in South Australia and one in the ACT (Siggins Miller 2001). At the time of the census, 290 EACH packages were available.

The EACH data are reported in four categories: the care recipient profile, the service episode, the service provider profile, and a comparison of the EACH program with other community care programs on selected variables.

The care recipient profile provides the following information:

- demographic information about the care recipient—sex, date of birth, country of birth, Indigenous status and first spoken language;
- dementia status;
- accommodation setting and living arrangements;
- carer status and carer co-residency status; and
- activity limitations.

The service episode category provides the following information:

- date when EACH-related funding was first claimed for the care recipient;
- care recipients' access to Department of Veterans' Affairs (DVA) entitlements and funding arrangements from other programs;
- types and patterns of service provision;
- equipment provision;
- leave and residential respite care during the census period; and
- date of exit from the EACH program and reason for exit.

The service provider profile provides the following information:

- organisation type;
- brokerage of services that are funded through the EACH program; and
- number of EACH packages provided.

There are similarities between the EACH program, the CACP program and the Home and Community Care (HACC) program. CACP provides or organises assistance to older people at a level approximately equivalent to low-level residential care. HACC is designed for frail older people and younger people with disabilities and helps clients across a broad range of dependency levels to live at home. Where appropriate, comparisons are made in this report between the EACH program, the CACP and HACC programs. For further information on

these programs readers may refer to publications such as *Australia's Welfare* 2001 (AIHW 2001*), Community Aged Care Packages in Australia 2001–2002: a statistical overview* (AIHW 2002b) and *Home and Community Care (HACC) National Minimum Data Set 2001–2002: annual bulletin* (Commonwealth Department of Health and Ageing 2002).

Data sources and limitations

Data sources

Census form

The census form for the EACH census collection, undertaken in the week beginning 6 May 2002, is shown at Appendix A. It consists of:

- a service provider form (Form A), asking questions about the provider's auspice, size and extent of brokerage; and
- care recipient data forms (Form B), asking questions about client demographic details, living arrangements, dependency level, carer characteristics, and use of services and equipment.

The data elements collected in the census were developed through a process of consultation with service providers and government stakeholders. The development process incorporated data development work done by AIHW in 2001 and 2002 relating to the Community Aged Care Package program. This work used concepts consistent with elements contained in the National Community Services Data Dictionary (AIHW 2000), the Aged Care Assessment Program Data Dictionary (AIHW 2002a) and the Home and Community Care Program Data Dictionary (AIHW 1998). The project steering committee and representatives of peak organisations provided comment on the census form that was developed to measure these data elements.

Collection method

Service providers were advised of the census one month before the census week. Two weeks before the census was to commence, census forms were sent to all providers, along with advice (see Appendix A) about the importance of their complying with privacy legislation, how to return the completed census forms, and how to complete the question about the types of assistance provided.

A telephone help line was open for providers during the census period and until the end of the period for the return of the forms.

Service providers were asked to return census forms to the Commonwealth Department of Health and Ageing two weeks after the census week. After a short follow-up period for late returns, in which providers were contacted by telephone, a 100% response rate was achieved. Before the census forms were supplied to AIHW, department officers deleted the full names of care recipients from all forms and substituted letters of names, in a format consistent with the HACC linkage key (AIHW 1998).

Limitations of the data

Summary analyses of the EACH census data are presented in this report. At the time of the census there were 288 clients in the EACH program. Given this small client base, it has not

been possible to present very detailed analyses: a number of census response categories applied to very few care recipients. In order to safeguard the privacy of care recipients and to avoid presenting data that identify individuals, there is no reference to the location of any care recipients or the particular service provider.

While detailed data development work was done to identify data elements to be included in the EACH census, including consultation with providers and government stakeholders, the external constraints on the timing of the census did not allow for pilot testing of the census form. Consequently, analysis of the collected data has revealed a number of data quality issues that require further refinement of the census form to improve the reliability and validity of the collection.

All percentages relating to the EACH census data have been rounded to whole numbers.

Some specific qualifications regarding the consistency of responses in four areas and their possible interpretation are presented in Appendix B.

Main features

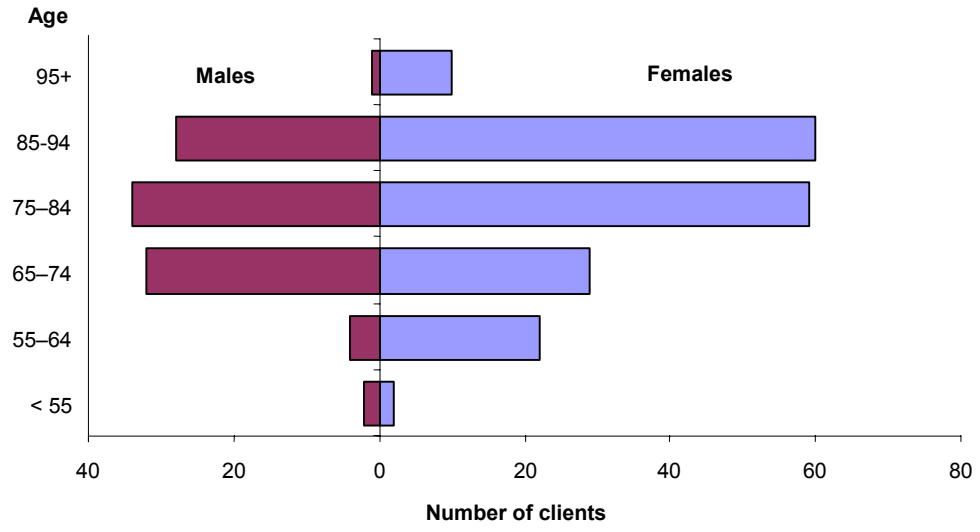
The EACH care recipient profile

The EACH census collected data on a variety of characteristics of care recipients who were receiving EACH-funded assistance or were enrolled but on leave during the week beginning 6 May 2002.

Age and sex

Almost two-thirds (64%) of the EACH recipients were female. Females were represented highly in all age groups, with the exception of care recipients aged between 65 and 75 years, where men slightly outnumbered women (Figure 1.1, Table 1.1). There was only one male aged over 95 years, compared with 10 females. The EACH program had a similar proportion of female care recipients as HACC (66%) but a slightly lower proportion than CACP (70%) (Table 4.1).

Eighty-nine percent of EACH recipients were aged 65 years and over. Both the EACH and CACP programs had just over one-third of care recipients aged 85 years and over (34% and 36% respectively), compared with HACC, where 21% of care recipients were in this group. Like CACP recipients, very few EACH recipients were aged under 50 years (1%), whereas HACC had 12% of care recipients in this age group. HACC can be expected to have a greater number of younger care recipients than EACH and CACP, given that it is intended to help younger people with disabilities, as well as frail older people, stay in the community and avoid institutional care.



Source: Table 1.1.

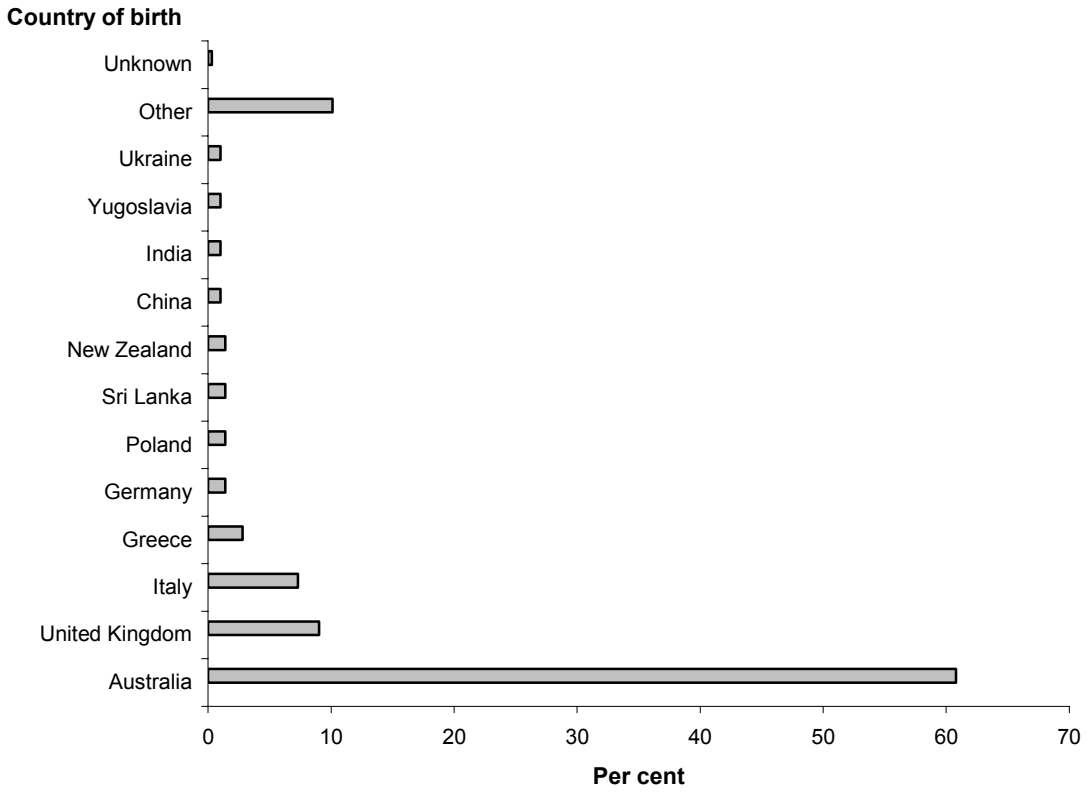
Figure 1.1: EACH recipients, by age and sex, census week May 2002

Indigenous status

No EACH recipients were identified as being of Aboriginal or Torres Strait Islander origin.

Country of birth

The *Aged Care Act 1997* defines particular groups of older Australians as being more likely to be disadvantaged in terms of access to aged care services compared with older Australians in general. Among these groups are people from culturally and linguistically diverse backgrounds. One of the government's objectives is for aged care services to specifically target the needs of these people to provide for their equitable access to programs. Country of birth is shown in Figure 1.2 and Table 1.2. EACH recipients came from 35 different countries of birth, with 61% having been born in Australia. The United Kingdom was the second most common country of birth (9% of care recipients), followed by Italy (7%) (Figure 1.2). The proportion of care recipients who were born overseas was higher in the EACH (39%) and CACP (40%) programs than in the HACC program (24%) (Table 4.2).



Note: 'Other' countries were Croatia, Egypt, Hungary, Ireland, Malta, the Netherlands, the United States, Vietnam, Austria, Belgium, Cyprus, France, Laos, Lebanon, Lithuania, Latvia, the Russian Federation, Spain, Thailand, Turkey and Uruguay.

Source: Table 1.3.

Figure 1.2: EACH recipients, by country of birth, census week May 2002

Language used at home and English proficiency

Almost 75% of care recipients spoke only English at home (Table 1.3). Of those who did not speak English at home, over half spoke English poorly or not at all (Table 1.4). EACH (95%) and CACP (76%) recipients were less likely than HACC recipients (91%) to speak English at home (Table 4.3).

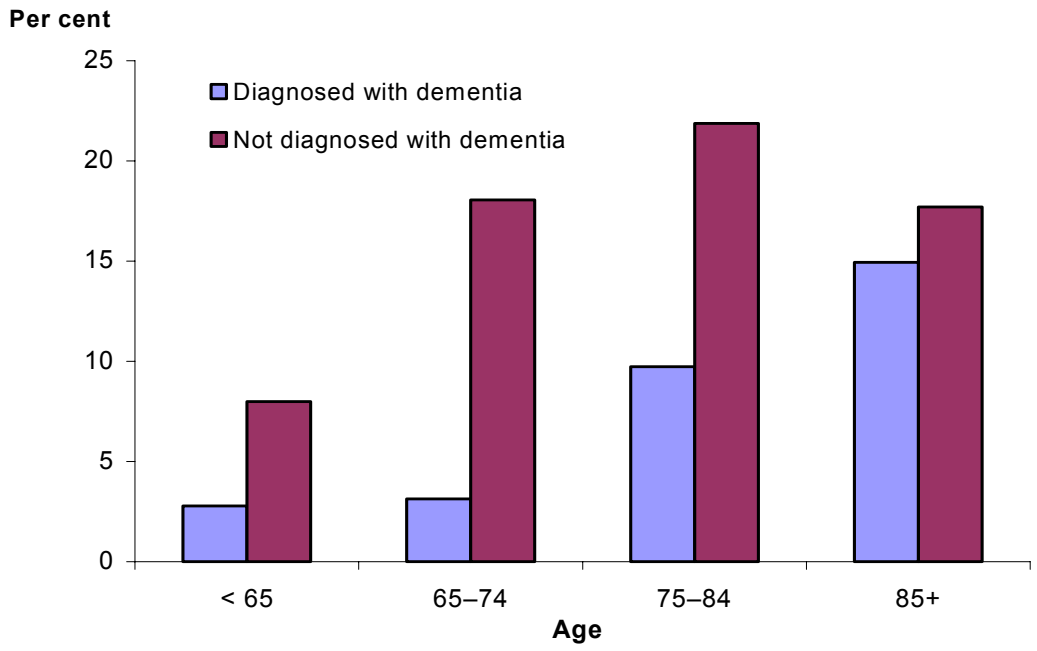
The detailed analysis by provider showed that for one provider only 27% of its care recipients spoke English at home, for two other providers less than 60% of their care recipients spoke English at home.

Dementia

Dementia describes a syndrome associated with a range of diseases that are more prevalent in people of advanced age than in the general population, it is characterised by the progressive impairment of brain functions, including language, memory, perception, personality and cognitive skills. In 2000 there were an estimated 146,800 Australians aged 65 years or over with dementia. These people made up 6% of the 2,360,200 Australians aged 65 years or over (AIHW 2001). Almost one in three of EACH recipients had been diagnosed with dementia (31%). Figure 1.3 shows the age-based distribution of the dementia affected care recipients. The percentage of dementia-affected care recipients (15%) aged over 85 was only slightly below that for those not affected by dementia (18%) (Figure 1.3, Table 1.5). Care recipients aged 65–74 were much more likely not to have been diagnosed (18%) than to have been diagnosed (3%) with dementia.

The EACH recipients who had been diagnosed with dementia were reported to need assistance with more core activities than recipients without dementia: 43% of dementia-affected recipients required assistance in all 11 listed areas, compared with 18% of those without dementia (Tables 3.6 and 3.12). However, when care recipients had carers, the average hours of assistance provided to those with dementia was similar to that for those without dementia (17.3 hours per care recipient with dementia and 17.7 hours per care recipient without dementia). For care recipients without carers, those with dementia had a higher average number of hours of assistance provided compared with those without dementia (26.0 hours for those with dementia and 18.6 hours for those without dementia) (Table 1.7). The small number (three) of care recipients with dementia but without a carer received an average of 32% more service hours than care recipients without dementia.

The detailed analysis by provider showed that for two providers 47% of their EACH recipients had been diagnosed with dementia. The lowest proportion of dementia-diagnosed care recipients dealt with by a provider was 20%.



Source: Table 1.5.

Figure 1.3: EACH recipients, by dementia status and age, census week May 2002

Type of accommodation

During the census week, 81% of EACH recipients lived in residences that were privately owned or being purchased (Table 1.8). Public and private rentals accounted for 14% of recipients. EACH recipients were much more likely to be living in privately owned residences than CACP recipients (52%). For HACC recipients, the corresponding proportion was 74% (Table 4.4).

The detailed analysis by provider showed that the proportion of recipients in a privately owned residence differed widely—from 55% to 93%.

Living arrangements

EACH recipients (22%) were much less likely to live alone than CACP care recipients (48%) (Table 4.5). The detailed analysis by provider showed that there was a large variation between providers in the proportions of care recipients living alone—from 7% to 42%.

Recipients living with family accounted for about 76% of all EACH recipients; about 80% of recipients living in privately owned residences were living with family (Table 1.9). Care recipients in public rental properties, community housing or retirement accommodation were evenly divided between living alone and living with family.

Carer status and relationship

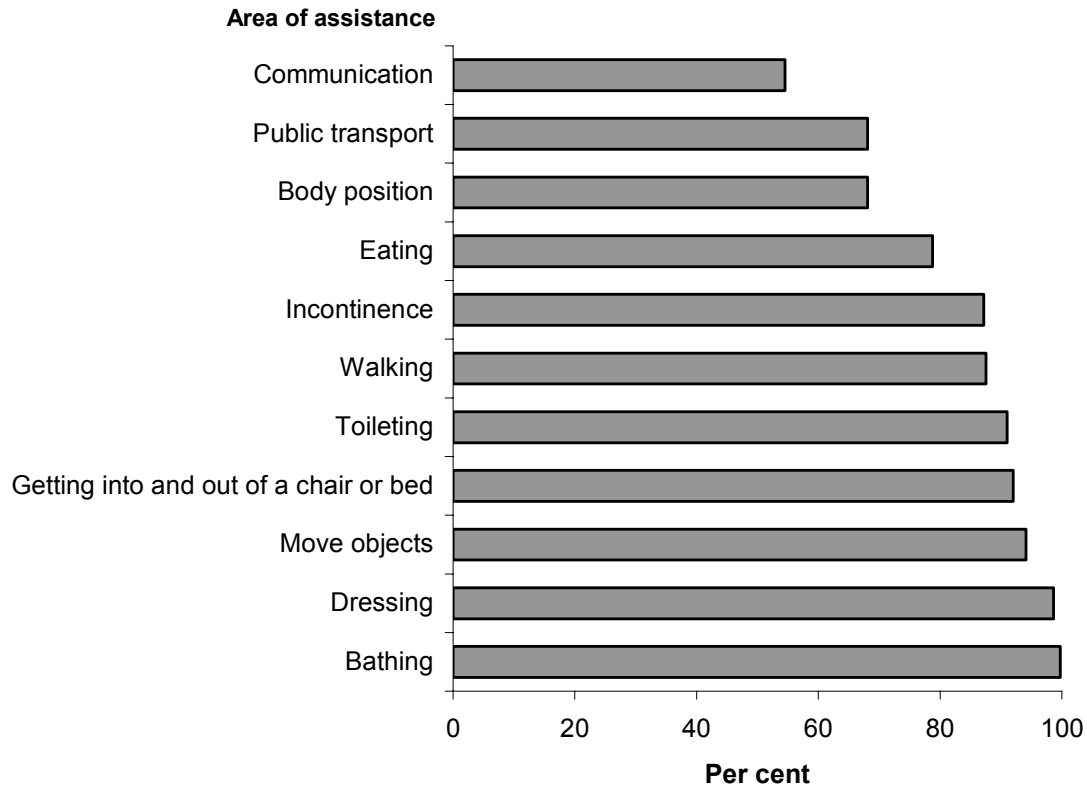
Many EACH recipients are able to remain at home only because a carer provides regular assistance with physical tasks. Seventy-five per cent of EACH recipients had co-resident carers and 15% had non-resident carers (Table 1.10). Of the 9% of EACH recipients who had no carer, almost all were women (Table 1.11).

Fifty-one per cent of all EACH recipients had a carer who was a spouse or partner. Wives or female partners formed the highest proportion of (27%), followed by daughters (25%) and husbands or male partners (24%). However, the proportions of men and women in the total recipient population surveyed need to be considered; women outnumbered men by 185 to 101. Thus, men receiving EACH assistance were almost twice as likely to have their co-resident spouse as carer than women receiving EACH assistance. Non-resident carers were mostly daughters (63%); sons comprised 19% of non-resident carers (Table 1.10).

EACH recipients were much more likely (90%) to have a carer than HACC recipients (52%) (Table 4.6). The detailed analysis by provider showed that the highest proportion of providers' care recipients with co-resident carers was 88% and the lowest was 58%.

Core activity limitations

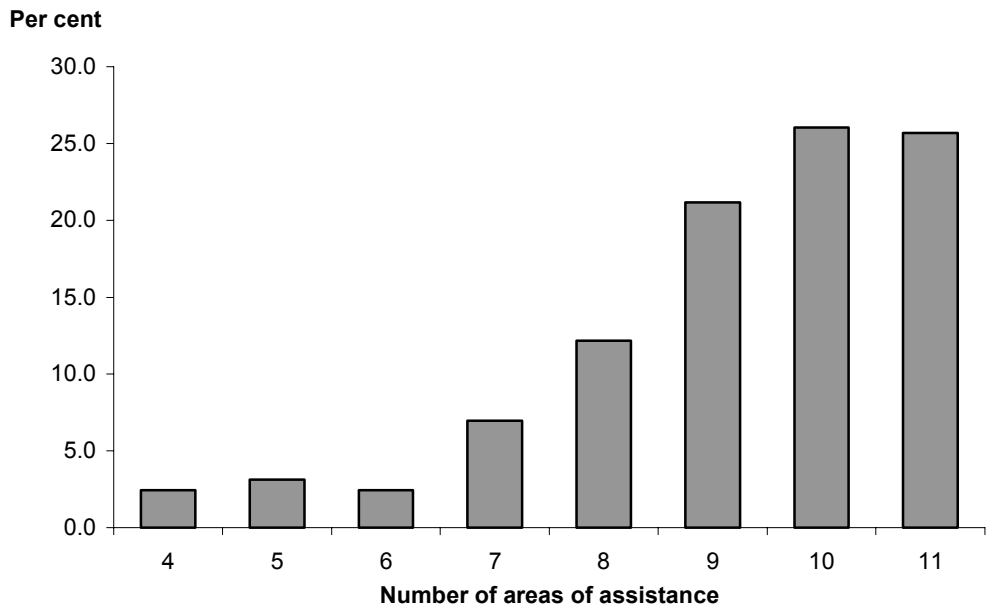
The census measured EACH care recipients' needs for assistance in the 11 areas of core activity limitation. The nominated activities fall within the three broad categories of self-care, mobility and communication limitations and help determine the extent to which care recipients can be regarded as severely or profoundly disabled. Figure 1.4 shows the proportion of care recipients needing assistance in each of the 11 areas. Over 98% of care recipients needed assistance with bathing and dressing (Figure 1.4 and Table 1.12). Communication was the area in which the lowest proportion of care recipients were reported to need assistance, although over half (55%) required assistance in this area.



Source: Table 1.12.

Figure 1.4: EACH recipients, by area in which assistance was needed, census week May 2002

Many care recipients needed assistance in more than one of the specified core activity limitation areas. Figure 1.5 and Table 1.13 show the percentages of care recipients by the number of areas in which assistance was required. Almost 73% of EACH recipients were reported to need assistance in nine, 10 or 11 areas.



Source: Table 1.13.

Figure 1.5: EACH recipients, by numbers of areas in which assistance was needed, census week May 2002

Entitlement to Department of Veterans' Affairs benefits

Nine per cent of all EACH recipients were reported to be entitled to Department of Veterans' Affairs benefits and 86% were reported to have no DVA entitlement (Table 1.14). The data could, however, have been distorted by the relatively high 'unknown' response rate of 5%. Seven per cent of CACP care recipients and 11% of HACC recipients were entitled to a DVA benefit (Table 4.7).

Service episodes

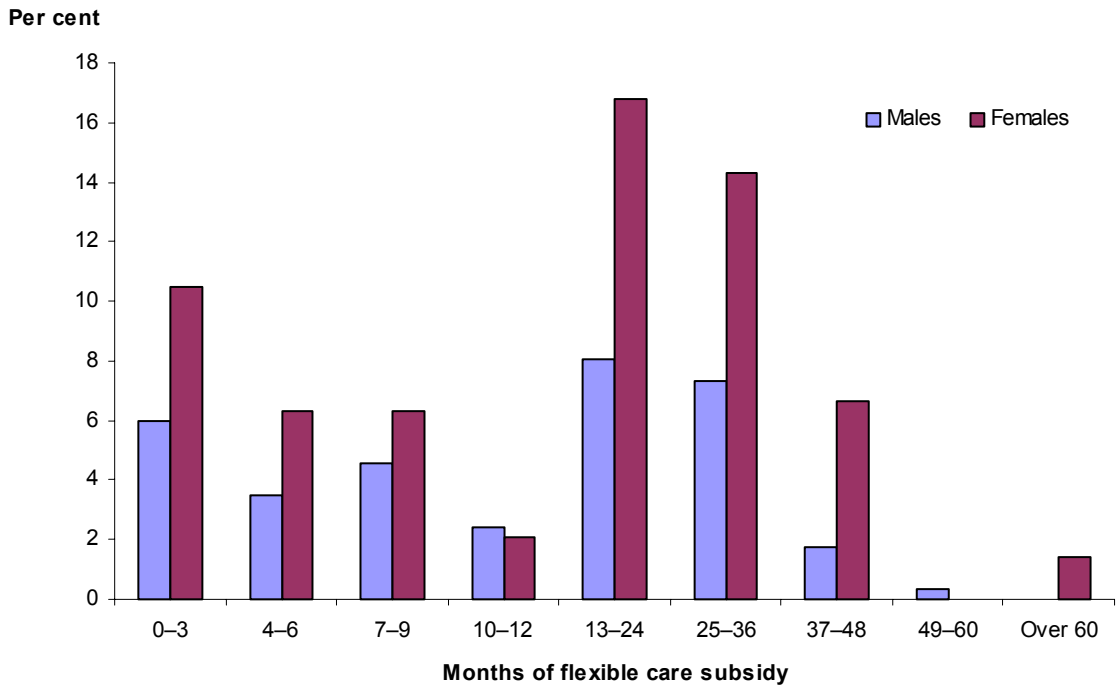
The EACH census collected data on the characteristics of the episodes of service provision during the census week beginning 6 May 2002.

Length of service provision

The length of service provision for an EACH recipient is influenced by the length of time the service provider has been part of the EACH program. As the program becomes more

established, it can be expected that the number of people receiving EACH services for longer periods will increase.

The recurrent (Flexible Care) subsidy for EACH recipients was claimed by approved service providers for between 13 and 48 months for 55% of care recipients (Table 2.1). The proportion of care recipients receiving services for in excess of 48 months is about 2% (Figure 2.1, Table 2.1). Although the EACH program was formally established in 1998, two services in South Australia and Western Australia, were established in 1993 and 1997 respectively.



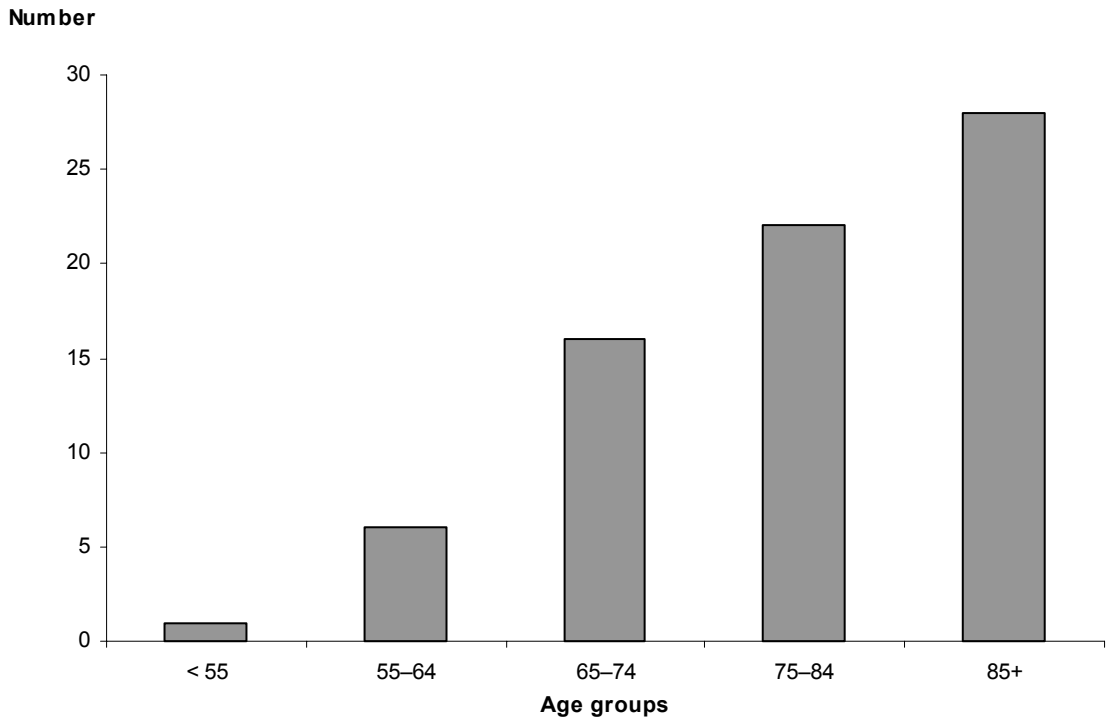
Source: Table 2.1.

Figure 2.1: EACH recipients, by length of subsidy period and sex, census week May 2002

Use of other government programs

EACH recipients have access to assistance from other government programs and specialised services. Some of these programs and services provide more than one type of assistance. The census measured two aspects of the provision of extra assistance. The first aspect was the type of assistance and the second asked providers to nominate the government-funded program that assisted EACH recipients, if the program was known. Eighty-eight care recipients (31%) were reported to have used additional non–EACH funded services (Table 2.2). A single area of other assistance was provided to 16% of care recipients, while 12% of care recipients used between two and five additional areas of assistance. Only 61 of the 88 care recipients who were reported to use other services nominated which other programs provided assistance. These 61 recipients were reported to have had 73 contacts with other government programs. The HACC program was reported to have been used by 29 EACH recipients. Fourteen other assistance providers were also reported to have provided service to EACH recipients (Table 2.3). The use of other programs increased as EACH recipients became older (Figure 2.2). It is possible that the use of other programs has been over-

reported. Some agencies may have reported use of these programs even when the services were paid for as part of the EACH program.



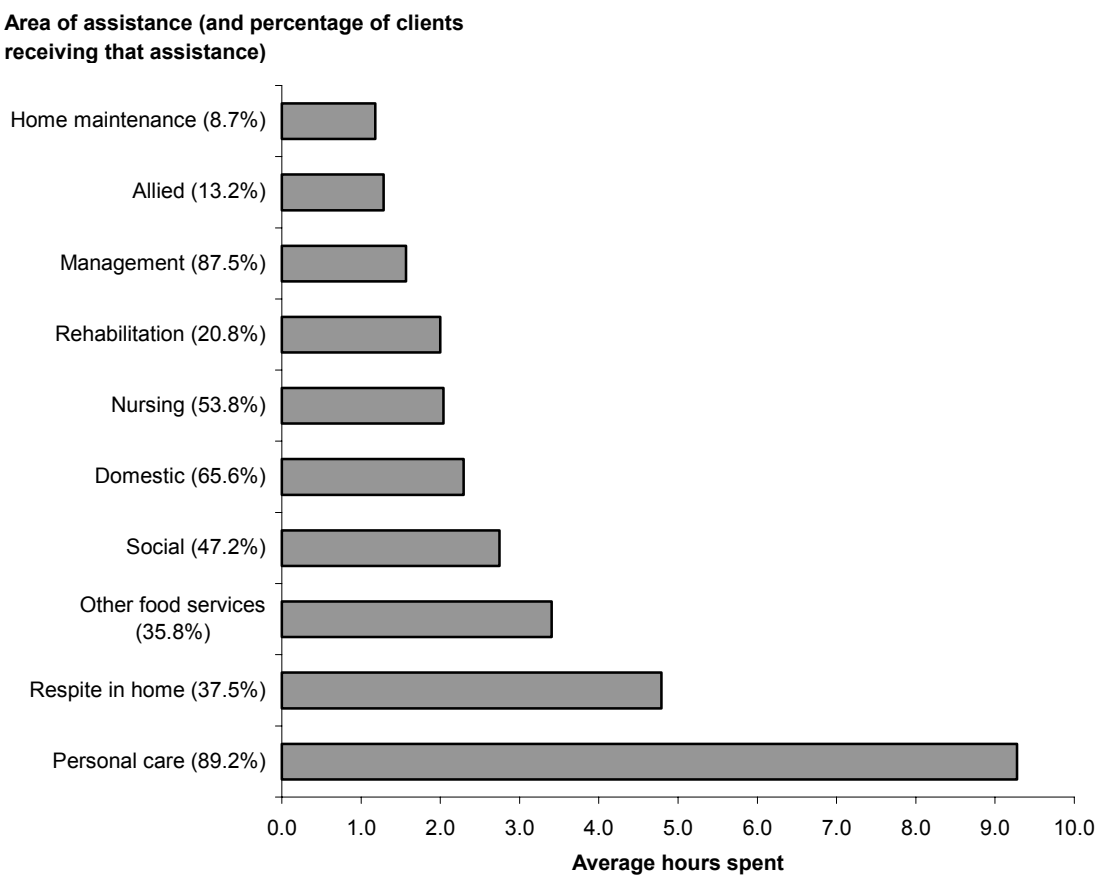
Source: Table 2.3.

Figure 2.2: EACH recipients, by use of non–EACH funded government programs and age, census week May 2002

Assistance provided

The amount of EACH-funded assistance provided was measured in 13 areas. In 10 areas the assistance was measured by time spent (Figure 2.3, Table 2.4). Figure 2.3 shows the EACH-funded assistance areas that were measured in total hours over the census week, averaged over care recipients who received the assistance. Personal care was provided to a higher proportion of recipients (89%) than any other type of assistance and was provided for the longest average time (9.3 hours). The average time spent providing respite care in the home was next longest (4.8 hours) and was provided to 38% of care recipients. Overall, total assistance provided to care recipients during the census week averaged 17.6 hours (median 18 hours), while the maximum time spent assisting a care recipient was 45.8 hours and the minimum time was half an hour.

Three other services—delivered meals, linen services and transport—were measured by the number of service episodes (Table 2.5). Of these service categories, delivered meals was provided to the largest percentage of care recipients (11%) and with the highest frequency (5.4 service episodes per recipient).



Source: Table 2.4.

Figure 2.3: Average hours of EACH-funded assistance, by area of assistance and percentage of clients receiving that assistance, census week May 2002

Registered nursing services

The services of registered nurses are available to EACH recipients. The categories of nursing care assistance measured were review of nursing care, wound care, medication management, continence management, stoma management, enema management, and other activities. During the census week 215 (75%) care recipients received services from registered nurses (Table 2.6). The most commonly received types of service were a review of nursing care (57%), continence management (29%), and wound care and medication management (both 21%). Wound care occupied the largest amount of treatment time, with the 61 care recipients who were treated receiving an average of 1.6 hours of treatment in the census week.

Equipment available at care recipients' residences

Table 2.7 deals with the types of care-related equipment present in care recipients' residences during the census week. Of the 288 EACH recipients, 275 (95%) had at least one piece of equipment at their place of residence. Wheelchairs and shower chairs were present in over 70% of residences and 41% of care recipients had access to a hoist or lifter to aid mobility. Sixty-two per cent of the equipment was owned or leased by the EACH providers. Over 90 different equipment items were reported in the 'other' category.

Residential respite care

In the 12 months preceding the census 78 EACH recipients were reported as receiving an average of 2.2 booked or emergency episodes of residential respite care, with the highest average being recorded for the 55–64 age group. The average number of booked or emergency days per recipient was 31, with the 55–64, 85–94 and 95+ age groups being higher than average users of respite care (Table 2.8).

Funding of home modifications

The EACH program enables providers to help care recipients cope with disabling conditions by making modifications to their homes, such as installing grab rails, hand rails, ramps, appropriate tap sets and emergency alarms. Since starting with the EACH program, 41 care recipients had been provided with home modifications ranging in cost from $25 to $8,510 (Table 2.9). The median amount spent on home modifications was $210, with three-quarters of all modifications costing $500 or less.

Leave arrangements

EACH providers are entitled to receive a Flexible Care subsidy when a care recipient is hospitalised. At the time of the census there was no limitation on the amount of hospital leave for which subsidy was payable. EACH providers are also entitled to receive continued subsidy for a maximum of 56 days in a financial year for social and respite leave, although only 28 of the 56 days can be social leave. Twenty-eight care recipients were on leave during the census week, but only 12 care recipients were on leave for the whole week. The reasons for care recipients going on leave during the census week were hospital leave (14 recipients), respite leave (12 recipients) and social leave (two recipients) (Table 2.10).

Care plan reviews

The EACH guidelines recommend that a formal review of care recipients' care plans take place every six months. Ninety-six per cent of the care recipients whose EACH subsidy period was greater than six months were reported to have had their care plans reviewed at some time. Eighty-one per cent were reported to have received a care plan review in the preceding six months (Table 2.11).

The detailed analysis of providers showed that the proportion of plans reviewed during the 12 months preceding the census varied between providers, from 82% to 100%; six EACH providers had completed care plan reviews for 100% of their clients.

Cessation of EACH packages

Only two EACH recipients stopped receiving an EACH package during the census week. Both moved to a high care residential aged care service.

Funding for associated services

EACH providers are able to claim a supplement for oxygen and enteral feeding when these services are provided to eligible care recipients in accordance with the Residential Care Subsidy Principles (under the *Aged Care Act 1997*). Table 2.12 shows that providers claimed a

financial supplement for oxygen treatment or enteral feeding, or both, for 7% of EACH recipients. Of the 13 EACH recipients receiving specialised registered nursing services, eight were fully funded by EACH funding (Table 2.13). Allied health practitioner services were fully funded for 39 of the 64 EACH recipients who received services such as podiatry and physiotherapy during the census week (Table 2.14).

EACH service providers

The census collected data on the characteristics of EACH service providers as at 6 May 2002. The following key results were obtained.

Provider organisation type and care recipient numbers

All of the 10 EACH providers were not-for-profit organisations: six were religious organisations, two were government organisations, and two were classified as 'other'. Three providers had 15–20 care recipients, six had 21–36 care recipients and one had 50 care recipients.

Brokerage of services

All EACH providers subcontracted to other agencies at least part of the assistance provided to EACH recipients. Case management and nursing care were the services least likely to be subcontracted (Table 3.1). Four of the services that directly provided nursing care also provided personal care and domestic assistance directly. Allied health care was the service most likely to be subcontracted, with only two EACH providers directly offering this service.

Care recipient numbers

The number of EACH recipient forms (288) did not tally with the number of EACH recipients recorded by the EACH providers (286). In the case of one provider, one EACH recipient ceased receiving services and another started during the census week, leading to care recipient numbers exceeding packages and recipient numbers by one. Another provider had a new EACH recipient start during the week. Two other providers delivered services to one fewer care recipient than their approved package numbers during the census period.

Care recipients with agreements

Ninety-six per cent of care recipients were reported to have signed agreements with EACH providers (Table 3.2).

Section 1

EACH recipient profile

Table 1.1: EACH recipients, by age and sex, census week May 2002

Sex	Aged under 55	55–64	65–74	75–84	85–94	95+	Age not stated	Total
				Number				
Male	2	4	32	34	28	1	0	101
Female	2	22	29	59	60	10	3	185
Sex not stated	0	0	1	0	1	0	0	2
Total	**4**	**26**	**62**	**93**	**89**	**11**	**3**	**288**
				Per cent				
Male	0.7	1.4	11.1	11.8	9.7	0.3	0.0	35.1
Female	0.7	7.6	10.1	20.5	20.8	3.5	1.0	64.2
Sex not stated	0.0	0.0	0.3	0.0	0.3	0.0	0.0	0.7
Total	**1.4**	**9.0**	**21.5**	**32.3**	**30.9**	**3.8**	**1.0**	**100.0**

Table 1.2: EACH recipients, by country of birth, census week May 2002

Country of birth	Number	Per cent
Australia	175	60.8
United Kingdom	26	9.0
Italy	21	7.3
Greece	8	2.8
Germany	4	1.4
Poland	4	1.4
Sri Lanka	4	1.4
New Zealand	4	1.4
China	3	1.0
India	3	1.0
Yugoslavia, Federal Republic of	3	1.0
Ukraine	3	1.0
Other	29	10.1
Unknown	1	0.3
Total	**288**	**100.0**

Note: The 'other' category represented 21 countries: Croatia, Egypt, Hungary, Ireland, Malta, the Netherlands, the United States, Vietnam, Austria, Belgium, Cyprus, France, Laos, Lebanon, Lithuania, Latvia, the Russian Federation, Spain, Thailand, Turkey, and Uruguay.

Table 1.3: EACH recipients, by language spoken regularly at home, census week May 2002

Language spoken regularly at home							
Only English	Italian	Greek	German	Non-verbal	Other	Not stated	Total
Number							
215	20	8	5	5	32	3	288
Per cent							
74.7	6.9	2.8	1.7	1.7	11.1	1.0	100

Note: 'Non-verbal' designates care recipients for whom the responses 'cannot speak' or 'will not speak' were recorded. They were coded on the advice of the Australian Bureau of Statistics and consistent with the CACP census classifications.

Table 1.4: EACH recipients regularly using a language other than English at home, by level of spoken English, census week May 2002

How well care recipient speaks English	Number	Per cent
Very well	9	13.2
Well	14	20.6
Not well	19	27.9
Not at all	19	27.9
Not known/ not able to assess	7	10.3
Total	**68**	**100**

Table 1.5: EACH recipients diagnosed with dementia, by age and sex, census week May 2002

Sex	Under 55	55–64	65–74	75–84	85–94	95+	Age not stated	Total
				Number				
Males	0	3	4	9	11	0	0	27
Females	0	5	5	19	26	5	2	62
Sex not stated	0	0	0	0	1	0	0	1
Total	0	8	9	28	38	5	2	90
				Per cent				
Males	0.0	3.3	4.5	10.0	12.2	0.0	0.0	30.0
Females	0.0	5.6	5.6	21.1	28.9	5.6	2.2	68.9
Sex not stated	0.0	0.0	0.0	0.0	1.1	0.0	0.0	1.1
Total	**0.0**	**8.9**	**10.1**	**31.1**	**42.2**	**5.6**	**2.2**	**100.0**

Table 1.6: Number of personal activities in which EACH recipients sometimes or always need the assistance or supervision of another person, by dementia status, census week May 2002

	Number of personal activities requiring assistance								
Dementia status	4	5	6	7	8	9	10	11	Total
					Number of EACH recipients				
Care recipients with dementia	1	1	0	2	7	16	24	39	90
Care recipients without dementia	5	7	7	16	27	45	49	34	190
Not stated	1	1	0	2	1	0	2	1	8
					Per cent				
Care recipients with dementia	1.1	1.1	0.0	2.2	7.8	17.8	26.7	43.3	100.0
Care recipients without dementia	2.6	3.7	3.7	8.4	14.2	23.7	25.8	17.9	100.0
Not stated	12.5	12.5	0.0	25.0	12.5	0.0	25.0	12.5	100.0

Table 1.7: Average EACH-funded service hours provided to care recipients, by area of assistance, dementia status and carer status, census week May 2002

	With dementia		Without dementia	
Area of assistance	With carer (N=87)	Without carer (N =3)	With carer (N=167)	Without carer (N =23)
Management	1.8	–	1.5	1.8
Domestic	2.2	–	2.3	2.7
Social	2.5	–	3.0	1.3
Nursing	1.9	–	2.2	1.4
Allied health	1.0	–	1.3	1.5
Personal care	8.5	–	9.4	10.0
Other food services	2.5	–	3.4	4.8
Respite in home	5.0	–	4.6	–
Home maintenance	1.3	–	1.2	–
Rehabilitation	1.8	–	2.1	1.3
Average hours per care recipient who received service	**17.3**	**26.0**	**17.7**	**18.6**

– Three or fewer care recipients receiving a type of assistance.

Table 1.8: EACH recipients, by accommodation type, census week May 2002

Type of accommodation	Number	Per cent
Private residence—owned	234	81.3
Private residence—private rental	19	6.6
Private residence—public rental or community housing	20	6.9
Independent—retirement village	12	4.2
Other (including supported community accommodation)	3	1.0
Total	**288**	**100**

Table 1.9: EACH recipients, by accommodation type and living arrangements, census week May 2002

	Accommodation type					
Living arrangements	Private residence: owned/ purchasing	Private rental	Public rental or community housing	Independent living within a retirement village	Other(including supported community accommodation)	Total
			Number			
Lives alone	43	4	9	6	1	63
Lives with family	188	15	9	6	2	220
Lives with others	3	0	2	0	0	5
Total	**234**	**19**	**20**	**12**	**3**	**288**
			Per cent			
Lives alone	18.4	21.1	45.0	50.0	33.3	21.9
Lives with family	80.3	78.9	45.0	50.0	66.7	76.4
Lives with others	1.3	0.0	10.0	0.0	0.0	1.7
Total	**100**	**100**	**100**	**100**	**100**	**100**

Table 1.10: EACH recipients, by relationship to carer and carer co-residency, census week May 2002

	Co-resident carer		Non-resident carer			
Relationship to carer	Number	Per cent	Number	Per cent	Total number with carers	Percentage (N=288)
Wife/female partner	78	36.1	0	0.0	78	27.1
Husband/male partner	68	31.5	0	0.0	68	23.6
Mother	1	0.5	0	0.0	1	–
Father	0	0.0	0	0.0	0	0.0
Daughter	44	20.4	27	62.8	71	24.7
Son	14	6.5	8	18.6	22	7.6
Daughter-in-law	6	2.8	0	0.0	6	2.1
Son-in-law	0	0.0	1	2.3	1	–
Other female relative	1	0.5	2	4.7	3	1.0
Other male relative	1	0.5	2	4.7	3	1.0
Friend/neighbour—female	3	1.4	2	4.7	5	1.7
Friend/neighbour—male	0	0.0	1	2.3	1	–
Total	**216**	**100**	**43**	**100**	**259**	**89.9**

Note: There were two care recipients for whom the carer was wife/partner, but the carer residence was not stated.

– rounded to zero.

Table 1.11: EACH recipients, by sex, living arrangement and carer status, census week May 2002

	Carer available				Carer not available		
Sex	Lives alone	Lives with family	Lives with others	Total	Lives alone	Lives with family	Total
				Number of EACH recipients			
Male	5	90	2	97	4	0	4
Female	32	127	3	162	22	1	23
Not stated	0	2	0	2	0	0	0
Total	**37**	**219**	**5**	**261**	**26**	**1**	**27**
				Per cent			
Male	5.2	92.8	2.1	100.0	100.0	0.0	100.0
Female	19.8	78.4	1.9	100.0	95.7	4.3	100.0
Not stated	0.0	100.0	0.0	100.0	0.0	0.0	0.0
Total	**14.2**	**83.9**	**1.9**	**100.0**	**96.3**	**3.7**	**100.0**

Table 1.12: EACH recipients needing assistance with core activities, by activity, census week May 2002

Core activity	Number	Percentage of all care recipients (N=288)
Eating	227	78.8
Bathing	287	99.7
Dressing	284	98.6
Toileting	262	91.0
Incontinence	251	87.2
Body position	196	68.1
Move objects	271	94.1
Getting into and out of a chair or bed	265	92.0
Walking	252	87.5
Public transport	196	68.1
Communication	157	54.5

Table 1.13: EACH recipients, by number of core activity areas in which assistance was needed, census week May 2002

Number of areas of need for assistance	Number	Percentage of all care recipients (N=288)
4	7	2.4
5	9	3.1
6	7	2.4
7	20	6.9
8	35	12.2
9	61	21.2
10	75	26.0
11	74	25.7
Total	**288**	**100.0**

Table 1.14: EACH recipients with Department of Veterans' Affairs entitlements, by entitlement type, census week May 2002

Type of entitlement	Number	Percentage of all care recipients (N=288)
Gold card	14	4.9
Orange card	0	0.0
White card	1	0.3
No card	11	3.8
No entitlement	248	86.1
Unknown	14	4.9
Total	**288**	**100.0**

Section 2

EACH service episodes

Table 2.1: EACH recipients, by duration of Flexible Care subsidy period and sex, as at 6 May 2002

Period of EACH subsidy	Male	Female	Sex not stated	Total
		Number		
0–3 months	17	30	0	47
4–6 months	10	18	0	28
7–9 months	13	18	0	31
10–12 months	7	6	0	13
13–24 months	23	48	0	71
25–36 months	21	41	1	63
37–48 months	5	19	1	25
49–60 months	1	0	0	1
Over 60 months	0	4	0	4
Not stated	4	1	0	5
Total	**101**	**185**	**2**	**288**
		Percentage of all care recipients (N=288)		
0–3 months	5.9	10.4	0.0	16.3
4–6 months	3.5	6.3	0.0	9.7
7–9 months	4.5	6.3	0.0	10.8
10–12 months	2.4	2.1	0.0	4.5
13–24 months	8.0	16.7	0.0	24.7
25–36 months	7.3	14.2	0.3	21.9
37–48 months	1.7	6.6	0.3	8.7
49–60 months	0.3	0.0	0.0	0.3
Over 60 months	0.0	1.4	0.0	1.4
Not stated	1.4	0.3	0.0	1.7
Total	**35.1**	**64.2**	**0.7**	**100.0**

Table 2.2: EACH recipients, by number of non-EACH funded government services used, census week May 2002

Number of extra services used	Number of recipients	Percentage of all care recipients (N=288)
10	1	0.3
9	0	0.0
8	1	0.3
7	2	0.7
6	2	0.7
5	9	3.1
4	3	1.0
3	8	2.8
2	15	5.2
1	47	16.3
0	167	58.0
Unknown	33	11.5
Total	**288**	**100.0**

Table 2.3: EACH recipients, by nominated non–EACH funded government programs that provided assistance, census week May 2002

Other government program	Number reporting program as assistance provider
HACC	29
Day therapy centre	4
Continence Aids Assistance Scheme	3
CSDA-funded disability support services	2
National Respite for Carers Program	4
Department of Veterans' Affairs	6
Other	25
Total	**73**

Note: 'Other' services nominated and numbers of care recipients accessing them were hospitals, 4; Department of Transport, 10; Community Aids and Equipment Program (CAEP), 2; MS Society Outreach Group, 3; Provision of Aids for Disabled People (**PADP**) program, 1; Nursing Homes, 3; Marianne's Kitchen, 1; Access Cabs, 1.

Table 2.4: EACH recipients, by area and average hours of EACH-funded assistance received, census week May 2002

Area of assistance	Number of recipients	Percentage of all care recipients (N=288)	Average number of hours	Percentage of total assistance time
Management	252	87.5	1.6	8.0
Domestic	189	65.6	2.3	8.7
Social	136	47.2	2.7	7.5
Nursing	155	53.8	2.0	6.4
Allied health care	38	13.2	1.3	1.0
Personal care	257	89.2	9.3	48.0
Other food services	103	35.8	3.4	7.1
Respite in home	108	37.5	4.8	10.4
Home maintenance	25	8.7	1.2	0.6
Rehabilitation	60	20.8	2.0	2.4

Table 2.5: EACH recipients, by other service episodes, census week May 2002

Other services	Number of service episodes	Number of care recipients	Average number of service episodes per care recipient during census week
Delivered Meals	172	32	5.4
Linen deliveries	51	20	2.6
Transport trips	77	26	3.0
Total	**300**	**78**	**3.8**

Table 2.6: EACH recipients, by type and average hours of registered nursing services, census week May 2002

Registered nursing service	Average number of hours per care recipient	Number receiving service	Percentage of all care recipients (N=288)
Registered nurse review	1.4	163	56.6
Wound care	1.6	61	21.2
Medication management	0.9	60	20.9
Continence management	1.0	84	29.1
Stoma management	0.9	12	4.2
Enema administration	0.6	14	4.9
Other activities	1.0	66	22.9
No registered nursing service		73	25.3
All registered nursing services	**2.6**	**215**	

Table 2.7: EACH recipients, by equipment type and ownership, census week May 2002

Equipment item	Owner or lessor: EACH provider	Care recipient	Other	Ownership unknown	Total
			Number		
Hoist/lifter	87	9	22	0	118
Syringe driver	0	0	0	0	0
Wheelchair	90	64	55	11	220
Hospital bed	76	10	13	4	103
Pressure relieving mattress	85	8	3	2	98
Commode	115	25	29	10	179
Shower chair	119	25	45	13	202
Other	280	68	81	25	454
Total	**852**	**209**	**248**	**65**	**1374**
			Per cent		
Hoist/lifter	73.7	7.6	18.6	0.0	100.0
Syringe driver	0.0	0.0	0.0	0.0	0.0
Wheelchair	40.9	29.1	25.0	5.0	100.0
Hospital bed	73.8	9.7	12.6	3.9	100.0
Pressure relieving mattress	86.7	8.2	3.1	2.0	100.0
Commode	64.2	14.0	16.2	5.6	100.0
Shower chair	58.9	12.4	22.3	6.4	100.0
Other	61.7	15.0	17.8	5.5	100.0
Total	**62.1**	**15.2**	**18.0**	**4.7**	**100.0**

Note: More than 90 'other' equipment items were reported—for example, slide sheets, 17, walking frames, 21, bed rails, 22.

Table 2.8: EACH recipients, by age and respite care received during the 12 months preceding census week May 2002

	Age							
Episodes/days	**< 55**	**55–64**	**65–74**	**75–84**	**85-94**	**95+**	**Unknown**	**Total**
Number of booked or emergency episodes	3	35	38	42	46	4	1	**168**
Number of care recipients accessing booked or emergency episodes	3	13	17	24	19	2	1	**78**
Average number of booked or emergency episodes per care recipient	*1.0*	*2.7*	*2.2*	*1.8*	*2.4*	*2.0*	*1.0*	***2.2***
Number of booked or emergency days	21	387	484	625	493	14	49	**2,073**
Number of care recipients accessing booked or emergency days	3	11	17	21	15	1	1	**68**
Average number of booked or emergency days per care recipient	*7.0*	*35.2*	*28.5*	*29.8*	*32.9*	*31.7*	*49*	***30.5***

Table 2.9: EACH recipients, by amount spent by provider on home modifications since the commencement of care recipient's package, census week May 2002

Cost of modifications ($)	Number of recipients	Total cost of modifications ($)
4,000 to 8,510	3	19,293
500 to 1,500	10	7,400
201 to 499	10	2,995
25 to 200	18	2,255
Total	**41**	**31,943**

Table 2.10: EACH recipients taking leave at any time during the May 2002 census period, by leave category

Leave category	Number	Per cent
Hospital	14	4.9
Respite	12	4.2
Social	2	0.7
No leave taken	260	90.3
Total	**288**	**100.0**

Table 2.11: EACH recipients, by time elapsed since care plan review, as at 6 May 2002

Months since care plan review	Number of recipients	Percentage of all recipients (N=288)
0–3 months	139	66.2
4–6 months	31	14.8
7–9 months	13	6.2
10–12 months	13	6.2
13–36 months	5	2.4
Not stated	9	4.3
Total	**210**	**100.0**

Table 2.12: EACH recipients for whom a supplement was claimed for part or all of census week, by supplement type, census week May 2002

Supplement type	Number of recipients	Percentage of all recipients (N=288)
Oxygen	3	1.0
Bolus enteral feeding	6	2.1
Non-bolus enteral feeding	10	3.5
No supplement claimed	265	92.1
Not stated	4	1.4
Total	**288**	**100.0**

Table 2.13: EACH recipients receiving specialised registered nurse services, by funding source, census week May 2002

Funding source	Number of recipients	Percentage of all recipients (N=288)
Fully funded	8	2.8
Part funded	1	0.3
No funding	4	1.4
No specialised nurse service provided	275	95.5
Total	**288**	**100.0**

Table 2.14: EACH recipients receiving allied health services, census week May 2002

Funding source	Number of recipients	Percentage of all recipients (N=288)
Fully funded	39	13.5
Not funded	25	8.7
No allied health practitioner service	224	77.8
Total	**288**	**100.0**

Section 3

EACH service providers

Table 3.1: EACH providers, brokerage and subcontracting, by service type, census week May 2002

Assistance type	Provides all assistance	Brokers/subcontracts some assistance	Brokers/subcontracts all assistance
Case management	10	0	0
Nursing care	6	1	3
Allied health	2	2	6
Personal care	4	3	3
Domestic assistance	5	2	3

Note: Number of providers = 10

Table 3.2: EACH recipients with a signed care recipient agreement, census week May 2002

Agreement status	Number of care recipients	Percentage of all recipients (N=288)
Signed agreement	276	96
No signed agreement	9	3
Not stated	3	1
Total	**288**	**100**

Section 4

The EACH, CACP and HACC programs: a comparison

Table 4.1: Care recipients by age, sex and program, 2001–02 (per cent)

	Sex		Age group	
Program	Male	Female	Under 50	85 and over
EACH [(a)]	36	64	1	34
CACP [(b)]	30	70	2	36
HACC [(c)]	34	66	12	21

(a) EACH census data, Table 1.1.

(b) Aged and Community Care Information Systems data, as at 30 June 2001; AIHW (2002).

(c) Home and Community Care (HACC) National Minimum Data Set 2001-2002; Commonwealth Department of Health and Ageing (2002).

Table 4.2: Australian-born care recipients, by program, 2001–2002 (per cent)

Program	Australian-born
EACH [(a)]	61
CACP [(b)]	60
HACC [(c)]	76

(a) EACH census data 2002, Table 1.2.

(b) Aged and Community Care Information Systems (ACCMIS) data, as at 30 June 2001, AIHW 2002.

(c) Home and Community Care (HACC) National Minimum Data Set 2001-2002, DoHA 2002.

Table 4.3: Care recipients regularly using English at home, by program, 2001–02 (per cent)

Program	Regularly uses English at home
EACH [(a)]	75
CACP [(b)]	76
HACC [(c)]	91

(a) EACH census data 2002, Table 1.3.

(b) Aged and Community Care Information Systems (ACCMIS) data, as at 30 June 2001, AIHW 2002.

(c) Home and Community Care (HACC) National Minimum Data Set 2001-2002, DoHA 2002.

Table 4.4: Care recipients living in private homes, by program, 2001–02 (per cent)

Program	Owns or is purchasing own home
EACH [(a)]	81
CACP [(b)]	52
HACC [(c)]	74

(a) EACH census data 2002, Table 1.9.

(b) Aged and Community Care Information Systems (ACCMIS) data, as at 30 June 2001, AIHW 2002.

(c) Home and Community Care (HACC) National Minimum Data Set 2001-2002, DoHA 2002.

Table 4.5: Care recipients living alone, by program, 2001–02 (per cent)

Program	Per cent
EACH [(a)]	22
CACP [(b)]	48

(a) EACH census data 2002, Table 1.10.

(b) Aged and Community Care Information Systems (ACCMIS) data, as at 30 June 2001, AIHW 2002.

Table 4.6: Care recipients with a carer, by program, 2001–02 (per cent)

Program	Per cent
EACH [(a)]	90
HACC [(b)]	52

(a) EACH census data 2002, Table 1.11.

(b) Home and Community Care (HACC) National Minimum Data Set 2001-2002, DoHA 2002.

Table 4.7: Care recipients with entitlement to Department of Veterans' Affairs benefits, by program, 2001–02 (per cent)

Program	Per cent
EACH [(a)]	9
CACP [(b)]	7
HACC [(c)]	11

(a) EACH census data 2002, Table 2.1.

(b) Aged and Community Care Information Systems (ACCMIS) data, as at 30 June 2001, AIHW 2002.

(c) Home and Community Care (HACC) National Minimum Data Set 2001-2002, DoHA 2002.

Appendix A

The census forms and information

A.1 The Service provider form

Extended Aged Care at Home (EACH) Programme:
Service provider data form - MAY 2002

This form should be completed by each agency delivering Extended Aged Care at Home (EACH) Program funded care. Information provided should be for the 7-day week beginning on the 6th of May 2002.

1. Service provider name

2. Approved provider number

3. Street address of service provider

State/Territory *Postcode*

4. Postal address of service provider

State/Territory *Postcode*

5. Details for a person we can contact if we have any queries about this form

Name

Position

Phone *Fax*

e-mail

6. Is the service provider a 'not for profit' or 'for profit' organisation?

Not for profit ☐ 1 For profit ☐ 2

7. Which code best describes the organisation? *(please tick one code)*

Religious/Charitable	☐ 1	Ex-services/veterans' service	☐ 3
Local, State or Commonwealth government	☐ 2	Other	☐ 4

8. How many EACH packages is your service approved to provide?
This may not be the same as the number of EACH care recipients you currently have.

☐ packages

---

9. How many care recipients are currently receiving EACH-funded assistance from your service?
Please report the number of care recipients who were enrolled with your service to receive EACH assistance on the last day of the previous provider claim period. This includes all care recipients who were on leave on that date.

☐ care recipients

---

10. At present, to what extent does your service broker (or sub-contract) other agencies or individuals to provide the following types of EACH assistance on your behalf?

	*Our service **provides all** of this type of assistance directly*	*Our service **brokers/sub-contracts some** of this type of assistance to other agencies or individuals*	*Our service **brokers/sub-contracts all** of this type of assistance to other agencies or individuals*
a. Case management/care co-ordination	☐ 1	☐ 2	☐ 3
b. Nursing care	☐ 1	☐ 2	☐ 3
c. Allied health care	☐ 1	☐ 2	☐ 3
d. Personal care	☐ 1	☐ 2	☐ 3
e. Domestic assistance	☐ 1	☐ 2	☐ 3
Other EACH assistance *(please specify)*			
f. ----------	☐ 1	☐ 2	☐ 3
g. ----------	☐ 1	☐ 2	☐ 3
h. ----------	☐ 1	☐ 2	☐ 3

Thank you for your time and help completing this form.

A.2 The care recipient form

Extended Aged Care at Home (EACH)
Care recipient data form - MAY 2002

For Provider Number

Information provided should be for the 7-day week beginning on the 6th of May 2002

This form should be completed for each care recipient that you currently provide EACH-funded assistance to. The form should also be completed for care recipients who are currently on leave, but are still enrolled with your agency.

1. What is the name of the care recipient?

Family name/Surname *First given name*

Often people use a variety of names, including legal names, married/maiden names, nicknames, assumed names, traditional names, etc. In order to enable statistical record linkage with other data collections, EACH staff should record the person's full (formal) first given name and family name/surname. These may be different from the name that the person may prefer the service to use in personal dealings. For example, a care recipient's first given name should be recorded as 'Thomas' although he may prefer to be known as 'Tom'.

---

2. What is the care recipient's sex? Male ☐ 1 Female ☐ 2

---

3. What is the care recipient's date of birth? d d m m y y y y

If the actual date of birth of the person is not known, an estimated date of birth for that person should be calculated in the following way. If the age of the person is known, their age should be used to derive their year of birth. If the person's age is not known, an estimate of their age should be used to calculate an estimated year of birth. An actual or estimated year of birth should then be converted to an estimated date of birth according to the following convention: *01/01/actual or estimated year of birth* .

---

4. In which country was the care recipient born?

Please select from the following list. If the country in which the person was born does not appear in this list, please write the name of the country under 'Other (please specify)'.

Australia ☐ 1101	Croatia ☐ 3204	Poland ☐ 3307
England ☐ 2102	Germany ☐ 2304	Malta ☐ 3105
Ireland ☐ 2201	Netherlands ☐ 2308	India ☐ 7103
Italy ☐ 3104	New Zealand ☐ 1201	Not known ☐ 0000
Greece ☐ 3207	China (excl. Taiwan) ☐ 6101	Other *(please specify)* ☐

5. Is the care recipient of Aboriginal or Torres Strait Islander origin?

Information about Indigenous status should be collected in sufficient detail to distinguish between people of Aboriginal and Torres Strait Islander origin. If a care recipient is of both Aboriginal and Torres Strait Islander origin, please tick both 'Yes' boxes.

- Yes, Aboriginal ☐ 1
- Yes, Torres Strait Islander ☐ 2

→ If both boxes ticked, code is 3

- No ☐ 4
- Not known ☐ 9

6a. Does the care recipient speak a language other than English at home on a regular basis to communicate with other household members or regular visitors?

No, English only *(please tick, and go to Question 7)* ☐ 02

Yes *(please specify language below)* ☐

If the person speaks more than one language other than English at home, indicate the language that is spoken most often. For persons living in non-private dwellings (such as group houses, boarding houses, hostels, etc.), this data element should be used to record the person's language of greatest competence (i.e. preferred language). If the language spoken by the person does not appear in this list, please write the name of the language in 'Other (please specify)'.

Italian ☐ 13	Dutch ☐ 05	Hungarian ☐ 26
Greek ☐ 12	Cantonese ☐ 67	Russian ☐ 32
German ☐ 03	Arabic (incl. Lebanese) ☐ 38	Croatian ☐ 22
Polish ☐ 30	Maltese ☐ 14	Vietnamese ☐ 65
Not known ☐ 96	Other *(please specify)*	

6b. How well does the care recipient speak English?

This question should only be answered for people who use a language other than English in their home.

Very well ☐ 1 Well ☐ 2 Not well ☐ 3 Not at all ☐ 4 Not known/not able to assess ☐ 5

---

7. In which suburb, town or locality does the care recipient live?

---

8. What is the postcode for the address at which the person lives?

This should relate to the suburb/town/locality identified above.

9. Has the care recipient been diagnosed with dementia?

This information should be available on the recipient's Aged Care Application & Approval (2624) form. If the person has been diagnosed with dementia since commencing on an EACH package, the recipient should only be recorded as having dementia if the EACH provider is aware that a medical practitioner has expressed a clinical opinion that the care recipient has dementia.

Yes ☐ 1 No ☐ 2

---

10. What type of accommodation does the person live in while receiving assistance from your service?

Private residence—owned/purchasing	☐ 1	Short-term crisis, emergency or transitional accommodation	☐ 6
Private residence—private rental	☐ 2		
Private residence—public rental or community housing	☐ 3	Supported community accommodation	☐ 7
Independent living within a retirement village	☐ 4	Public place/temporary shelter	☐ 8
Boarding house/rooming house/private hotel	☐ 5	Other	☐ 9

The '**private residence**' codes include private residences of a wide range of dwelling types, such as houses, flats, units, caravans, mobile homes, boats, marinas, etc. These codes distinguish between different types of tenure associated with private residences. Where the person's tenure over the residence is not clear (e.g. living rent free with friends or family), the code used should reflect the type of tenure primarily associated with the dwelling.

Private residence—owned/purchasing includes private residences which are owned or being purchased either by the person or another member of their household or family (including a non-resident relative).

Independent living unit within a retirement village includes persons living in self-care or independent-living units within a retirement village, irrespective of the type of tenure the person holds over the residence.

Short-term, crisis, emergency or transitional accommodation includes temporary or short-term accommodation provided in response to crisis or emergency situations (e.g. night shelters, hostels for the homeless), or to facilitate a transition between institutional-type settings and independent community living (e.g. halfway houses).

Supported community accommodation includes community living settings or accommodation facilities in which care recipients are provided with support in some way by staff or volunteers. This category includes domestic-scale living facilities (such as group homes for people with disabilities, cluster apartments where a support worker lives on site, community residential apartments, congregate care arrangements, etc.) which may or may not have 24-hour supervision and care. It also includes larger-scale supported accommodation facilities providing 24-hour supervision and support services by rostered care workers (such as hostels for people with disabilities and government-regulated Supported Residential Services/Facilities (Victoria and South Australia only).

Other includes multi-purpose centres.

---

11. Does the care recipient live with other related or unrelated person(s)?

Lives alone ☐ 1

Lives with family ☐ 2

Lives with others ☐ 3

This data element should be used to record the living arrangements of the person while receiving assistance from the provider. If the care recipient's household includes both family and non-family members, record '***Lives with family***'. This code should be considered to include de facto and same sex relationships.

On occasion, difficulties can arise in deciding the living arrangements of a care recipient due to their accommodation setting (for example, boarding houses, group homes, retirement villages, etc.). In these circumstances the care recipient should be regarded as living alone, except in those instances in which they are sharing their own private space/room within the premises with a significant other (e.g. partner, sibling, close friend, etc.).

If the care recipient lives in a granny flat, they should be coded as living alone if the granny flat is a separate dwelling (even if part of the same residential property) and they do not share their flat with another person. If the granny flat is part of the same dwelling occupied by another person(s), they should be coded as ***Lives with family*** or ***Lives with others*** depending on their relationship to the other person(s).

12a. Does the care recipient have a carer, i.e. someone such as a family member, friend or neighbour, who provides regular and sustained care and assistance to the care recipient without payment other than a pension or benefit?

If there is doubt about whether the level and type of assistance provided by another person is sufficient to identify them as a carer, if the removal of that assistance would significantly compromise the care available to the person to their detriment, record the person as having a carer. The presence of a carer is often a key indicator of a person's ability to remain at home, especially if the person requires assistance.

Other family members or friends may also provide support and assistance to the person, such as emotional support through regular telephone contact. This type of assistance is also very important in contributing to the health and wellbeing of the person. However, the definition of carer given here emphasises their role in providing more 'practical' or 'hands on' regular and sustained assistance that allows the person to remain in their own home. In some cases, this will mean that someone who provides emotional support or has occasional telephone contact with the person should not be coded as a carer.

Has a carer ☐ 1 Has no carer *(go to question 13)* ☐ 2

12b. Does the carer live with the care recipient?

If a recipient has both a co-resident (e.g. a spouse) and a non-resident carer (e.g. a daughter or son), the coding response to this question should be related to the carer who provides the most significant care and assistance related to the care recipient's capacity to remain living in their home.

Co-resident carer ☐ 1 Non-resident carer ☐ 2

A ***Co-resident carer*** is a person who provides care and assistance on a regular and sustained basis to a person who lives in the same household. A ***Non-resident carer*** (or visiting carer) is a person who provides care and assistance on a regular and sustained basis to a person who lives in a different household.

12c. What is the relationship of the carer to the care recipient?

Please record the relationship of the carer to the person for whom they care. If the care recipient has more than one carer (e.g. a spouse and a son), the coding response should relate to the carer who provides the most significant care and assistance related to the person's capacity to remain at home.

Wife/female partner	☐ 1	Daughter-in-law	☐ 7
Husband/male partner	☐ 2	Son-in-law	☐ 8
Mother	☐ 3	Other female relative	☐ 9
Father	☐ 4	Other male relative	☐ 10
Daughter	☐ 5	Friend/neighbour—female	☐ 11
Son	☐ 6	Friend/neighbour—male	☐ 12

Wife/female partner, ***Husband/male partner*** includes defacto and same sex partnerships.
Other female relative should be used if the carer is the grandmother, sister, niece, female cousin, etc. of the care recipient.
Other male relative should be used if the carer is the grandfather, brother, nephew, male cousin etc. of the care recipient.

13. Does the care recipient sometimes or always need the assistance or supervision of another person in any of the following areas? *(please tick all relevant areas)*

Eating ◯ a

Showering/bathing ◯ b

Dressing ◯ c

Toileting ◯ d

Managing incontinence ◯ e

Maintaining or changing body position ◯ f

Carrying, moving and manipulating objects related to tasks of daily living ◯ g

Getting in or out of a bed or a chair ◯ h

Walking and related activities *(either around the home or away from home, excludes needing transport assistance)* ◯ i

Using public transport ◯ j

Understanding others or making oneself understood by others *(excludes independent use of aids and equipment, e.g. hearing aids, speech aids and assistance from interpreters)* ◯ k

No assistance needed from another person in any of these areas ◯ l

---

14. What was the date on which your service first claimed the recurrent (Flexible Care) subsidy in respect of this person (if applicable)?

d	d	m	m	y	y	y	y

---

15. Does the care recipient receive any Department of Veterans' Affairs entitlements?

Yes—Gold card ☐ 1

Yes—White card ☐ 2

Yes—Orange card ☐ 3

Yes—no card ☐ 4

No—care recipient does not receive any DVA entitlements ☐ 5

Not known ☐ 6

---

16. What was the date on which the care recipient first received EACH assistance (as specified within the care recipient's care agreement) from your service, as part of their EACH Package?

The date recorded should reflect the date on which the care recipient was first provided with assistance according to the care recipient agreement. This assistance includes: domestic assistance, nursing care, allied health care, social support, personal care, meals, other food services, respite care in the home, home maintenance, home modification, formal linen service, transport, and rehabilitation support.

Prior to the establishment of the care recipient agreement, EACH staff will have met with the care recipient in order to assess the person against the Resident Classification Scale and assess specific needs for assistance, provide information about the EACH Program and the service that would deliver this assistance, and/or provide some short-tem assistance to the care recipient (such as social or emotional support). The date recorded here should, however, reflect the date on which the care recipient is first provided with assistance according to the care recipient agreement.

d	d	m	m	y	y	y	y

17. Is the Care Recipient Agreement between your agency and the care recipient agreed to and signed by the care recipient or their representative?

'Signed' agreements include agreements that are signed by the care recipient directly and agreements that are signed on behalf of the care recipient by a family member or other representative of the person. 'Signed' agreements also include agreements that are marked by the person (such as an 'X') and are witnessed by another person.

Yes ☐ 1 No ☐ 2

---

18. What was the date on which the care recipient last had a formal review of their care plan?

A care plan review refers to a formal review of the assistance provided to an individual under an EACH package. This would normally occur as a face-to-face meeting between the case manager (or their representative), the care recipient (and/or their representative), and may also involve other EACH care workers or other service providers (such as GPs or allied health professionals). The care plan review should include a detailed review of services provided under the existing care plan against current needs and may involve negotiation of changes to the care plan. This does not include the initial assessment and development of a care plan.

☐☐ d d ☐☐ m m ☐☐☐☐ y y y y

or Not applicable—care recipient has not had a formal review of their care plan to date ☐

---

19. In the last 12 months, or since commencing (for those who have not been on an EACH package for 12 months), has the care recipient accessed residential respite care?

Yes *(complete further information below)* ☐ ▼ No *(go to question 20)* ☐

If yes, please report how many 'episodes' of residential respite care the care recipient has received in this period, and the total number of days of residential respite care received. Report 'booked' respite care separately from 'emergency' respite care.

Episodes of respite care

a. Booked episodes of respite care	a ☐☐☐	episodes
b. Emergency episodes of respite care	b ☐☐☐	episodes
c. Total episodes of respite care	c ☐☐☐	episodes

Days of respite care

d. Booked days of respite care	d ☐☐☐	days
e. Emergency days of respite care	e ☐☐☐	days
f. Total days of respite care	f ☐☐☐	days

---

20. Has your agency funded home modifications to the care recipient's home since they commenced on the EACH program?

Home modifications includes all modifications or renovations to the person's home to help them cope with a disabling condition. Home modification includes modifications such as installing grab rails, hand rails, ramps, shower rails, appropriate tap sets, installation of emergency alarms and other minor renovations.

No *(go to question 21)* ☐ Yes *(please provide an estimate of the total cost to your agency of home modifications)* ☐ → $ ☐☐☐☐☐☐ .~~00~~

Questions 21 to 28a relate to the census week

21. If known, did the care recipient currently receive any of the following types of assistance from another government program during the census week (excluding services that you purchase for the person using EACH funds)? Refer to attachment 4 of the cover letter for definitions of these types of assistance. *Please tick all relevant types of assistance.*

If a care recipient purchases assistance from a program at full cost (i.e. without any government funded contribution), then do not record that type of assistance.

- Domestic assistance ◯ a
- Social support ◯ b
- Nursing care ◯ c
- Allied health care ◯ d
- Personal care ◯ e
- Delivered meals ◯ f
- Meal preparation/other food services ◯ g
- Respite care ◯ h
- Home maintenance ◯ i
- Formal linen service ◯ j
- Transport ◯ k
- Centre-based day care ◯ l
- Home modification ◯ m
- Provision of goods & equipment ◯ n
- Counselling/support ◯ o
- Financial assistance to buy continence aids ◯ p
- Disability services ◯ q
- No—care recipient does not receive any of these types of assistance from another program *(go to question 22)* ◯ r
- Don't know *(go to question 22)* ◯ s

21t. If the care recipient received any of the types of assistance listed above during the census week, from another government program (i.e. not purchased for the person using EACH funds), which program(s) provided that assistance (if known)?

If a care recipient purchases assistance from a program at full cost (i.e. without any government funded contribution), then do not record that type of assistance under these questions).

- Home and Community Care (HACC) ☐ 1
- Day Therapy Centre ☐ 2
- Continence Aids Assistance Scheme ☐ 3
- CSDA funded disability support services ☐ 4
- National Respite for Carers Program ☐ 5
- Department of Veterans' Affairs (excluding service pensions and income support supplements & allowances) ☐ 6
- Other programs *(please specify)* ☐

The ***Continence Aids Assistance Scheme (CAAS)*** is a Commonwealth-funded program that provides financial assistance to buy continence aids. It is targeted at people aged up to 65 years who have permanent incontinence. People aged 65 years and over may access the scheme if they continue to work 8 hours a week. The scheme does not provide continence aids and equipment directly.

The ***Day Therapy Centre Program*** provides a wide range of services (such as physiotherapy, occupational therapy, speech therapy and podiatry) to frail older people who live in the community or in Commonwealth funded residential aged care homes and some younger people with a disability. Therapy services are offered to individuals or groups to assist care recipients to either maintain or recover a level of independence which will allow them to remain living in the community or in low level residential care. Day Therapy Centres do not include Day Care Centres.

CSDA (Commonwealth-State Disability Agreement) funded disability services include a range of disability services provided by the Commonwealth Government and the State and Territory Governments under the CSDA Agreement. Services include accommodation support, community support services, services to improve community access, respite, employment services, advocacy, print disability and information services.

Other programs includes all other programs funded by Commonwealth, State or local government, or by private organisations (including for-profit and not-for-profit organisations).

22. Did your service claim a financial supplement for providing oxygen treatment and/or enteral feeding to the care recipient for all, or part of, the census week?

The oxygen supplement and enteral feeding supplement is able to be claimed when these types of care are provided to eligible care recipients in accordance with conditions outlined in the Residential Care Subsidy Principles (made under the Aged Care Act 1997).

Yes—oxygen supplement claimed ☐ 1

Yes—bolus enteral feeding supplement claimed ☐ 2

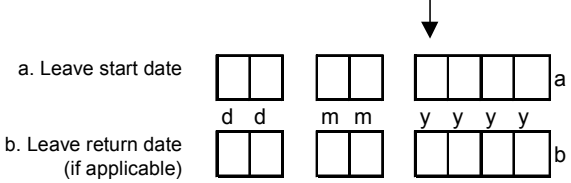
Yes—non-bolus enteral feeding supplement claimed ☐ 3

No—neither supplement claimed for this care recipient ☐ 4

---

23. Was the care recipient on leave at any time during the census week?

Yes *(please specify dates below)* ☐ No *(go to question 24)* ☐



23c. What was the main reason the care recipient went on leave?

Hospital leave ☐ 1 Respite leave ☐ 2 Social leave ☐ 3

24. What was the total amount of EACH funded assistance provided to the care recipient in the census week? Refer to attachment 4 of the cover letter for definitions of these types of assistance.

The total amount of assistance should be reported in hours and minutes, to the nearest fifteen minute period.
If a care recipient did not receive any of one type of assistance you may wish to record 'zero (0)' hours/meals delivered/deliveries/one-way trips to indicate that none of that type of assistance was provided in the census week.

a. EACH case management/care coordination	hours minutes	a
b. Domestic assistance	hours minutes	b
c. Social support	hours minutes	c
d. Nursing care	hours minutes	d
e. Allied health care	hours minutes	e
f. Personal care	hours minutes	f
g. Delivered meals	meals delivered	g
h. Meal preparation/Other food services	hours minutes	h
i. Respite care in the home (excl. residential respite care)	hours minutes	i
j. Home maintenance	hours minutes	j
k. Formal linen service	deliveries	k
l. Transport	one-way trips	l
m. Rehabilitation support	hours minutes	m

25. Were the services of an allied health practitioner provided to the care recipient during the census week?

Includes the provision of professional care by a podiatrist, occupational therapist, physiotherapist, speech pathologist, dietitian, nutritionist and social worker.

No *(go to question 26)* ☐ Yes *(complete further question below)* ☐

If yes, were the associated costs met by EACH funding? Yes ☐ 1 No ☐ 2

26. Were the services of a registered nurse provided to the care recipient during the census week?
Includes instances where the specific skills of a registered nurse were required, e.g. to undertake technical nursing treatments or procedures for which nurses receive specific training and which require nursing knowledge of expected therapeutic effect, possible side effects, complications and appropriate actions related to each.

Yes *(please specify types and amounts of assistance provided below)* ☐ No *(go to question 27)* ☐

a. Registered nurse/care recipient clinical review	hours minutes	a
b. Wound care	hours minutes	b
c. Medication management	hours minutes	c
d. Continence management	hours minutes	d
e. Stoma maintenance	hours minutes	e
f. Enema and suppository administration	hours minutes	f
g. Other activities	hours minutes	g

RN/care recipient clinical review includes assessment of skin integrity, (in)continence management, nutrition, hydration, behaviour, mobility, assessment and recording of blood pressure/blood sugar levels, and other activities requiring the skills of a registered nurse.
Wound care includes all wound care that requires intervention beyond application of single occlusive dressing.
Medication management includes establishment and supervision of complex pain management or palliative care program, insulin, assessment and liaison with medical practitioner(s), pharmacist and palliative care consultant.
Continence management includes maintenance of continence of urine and the reduction of incontinence. e.g. prompting, maintaining adequate fluid intake, bladder retraining, habit training or scheduled toiletting.
Stoma maintenance includes replacement of stoma bags and wafer systems.
Other activities includes all other activities that require the assessment and intervention of a qualified registered nurse.

Were the services of a specialised registered nurse provided to the care recipient during the census week?
Includes the provision of care by palliative care clinical support staff, a wound care consultant and continence consultants.

No *(go to question 27)* ☐ Yes *(complete further question below)* ☐

26h. If yes, were the associated costs met by EACH funding?

Yes - fully funded ☐ 1
Yes - partially funded ☐ 2
No ☐ 3

27. Which of the following pieces of equipment were available at the care recipient's residence during all, or part of, the census week?

Please report all pieces of equipment that were available in the person's house, even if they were not used in the census week. For each piece of equipment that was available in the person's house, please report:

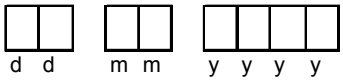
- who owns the equipment? and
- for equipment that is leased/hired from a third party, who pays for the lease/hire of the equipment?

	Equipment was present in the person's house	*Who owns this equipment?*				*Who pays for the lease/hire of this equipment?*		
		EACH provider	Care recipient	Other	Leased/ hired	EACH provider	Care recipient	Other
a. Hoist/lifter	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
b. Syringe driver	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
c. Wheelchair	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
d. Hospital bed	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
e. Pressure relieving mattress	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
f. Commode	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
g. Shower Chair	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
Other *(please specify)*								
h.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
i.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8
j.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5 →	☐ 6	☐ 7	☐ 8

28a. Did the care recipient cease receiving an EACH package from your service in the census week?

The date of cessation reported is the date on which the EACH service provider last claimed the EACH subsidy in the name of the care recipient.

Yes *(please specify date of cessation below)* ☐ No ☐



28b. What was the main reason that the person ceased receipt of an EACH package from your service?

Care recipient no longer needs assistance from our service—problem resolved or recipient is managing on their own and/or with other forms of assistance ☐ 1

Care recipient has moved to residential aged care (high care) ☐ 2

Care recipient has moved to residential aged care (low care) ☐ 3

Care recipient has moved to residential aged care (level of care not known) ☐ 4

Care recipient has moved to institutional setting with 24-hour care (e.g. hospital) ☐ 5

Care recipient referred to other community care program (including other EACH provider) ☐ 6

Care recipient moved out of area ☐ 7

Care recipient died ☐ 8

Care recipient terminated service ☐ 9

Other ☐ 10

Care recipient no longer needs assistance from our service includes instances where the person is managing on their own and/or with other forms of informal assistance, including care by family members or other informal carers.

Care recipient referred to other community care program includes cases where your EACH agency is no longer the most appropriate service provider and the person has been referred to another community care provider/program, or to another EACH provider.

Thank you for your time and help completing this form.

A.3 Census information for EACH providers

To Extended Aged Care at Home (EACH) service provider

National Census of Extended Aged Care at Home (EACH)

As you know, the AIHW has been contracted by the Commonwealth Department of Health and Ageing to conduct a National Census for the EACH program. Thank you for your comments and suggestions at the recent EACH National Workshop in Melbourne. In consultation with the Department we have incorporated as many of these suggestions as possible into the Census forms.

In this package you will find a copy of **Form A: EACH service provider form** (plus a spare copy). This form includes the name of your organisation and your Approved Provider number (derived from the Department's records). If any of this information is incorrect please provide us with the correct information.

You will also find multiple copies of **Form B: EACH care recipient form** in this package. We hope we have included sufficient copies for all of your EACH care recipients (plus a few spare copies). If not please photocopy any extra forms that you need. To assist you with completing Form B, we have also included some additional guidelines for recording the types of assistance received by an EACH care recipient during the Census week (**see Attachment 4).** One EACH care recipient form should be completed for every person on an EACH package with your organisation at any time during the Census week. This includes EACH care recipients who are on leave during the Census week.

EACH Census week:

Monday 6th May to Sunday 12th May 2002

Please return your completed Form A: EACH service provider form and all of your completed EACH care recipient forms (Form B) to:

EACH National Census
Aged Care Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601

by the 20th May 2002

Please see over for an important message about privacy

The confidentiality of data sent to the AIHW for this EACH National Census is protected under the provisions of the *Australian Institute of Health and Welfare Act 1987* and also the *Privacy Act 1988.* On December 31st 2001, the *Privacy Amendment (Private Sector) Act 2000* came into effect. The provisions of this Act apply to all organisations in the private sector, including non-government organisations.

Three documents have been attached to assist all people participating in the EACH National Census to undertake their role in the collection in accord with relevant legislation.

Attachment 1: the Information Privacy Principles in plain English (from the *Privacy Act 1988*).

Attachment 2: overview of the Privacy Amendment (Private Sector) Act 2000.

Attachment 3: excerpts from AIHW policy and procedures on information security and privacy.

One important principle, common to both the *Privacy Amendment (Private Sector) Act 2000* and the *Privacy Act 1988*, is that the person about whom personal information is collected and reported, should be generally aware of the purpose of the data collection and any third parties to which the collecting agency discloses such information.

In the case of the EACH National Census, personal information about EACH care recipients that is collected by EACH service provider agencies will be sent to the AIHW. Since the beginning of the EACH program, personal information about EACH care recipients has been collected and reported to the Department of Health and Ageing for processing of EACH care subsidy payments and general accountability purposes. However, prior to the forthcoming National Census, this information has not been supplied to the AIHW.

In keeping with the spirit of both of the above pieces of privacy legislation, and in addition to other data security, access, and disclosure procedures required of all parties, AIHW recommends that EACH service providers ensure that EACH care recipients who will be included in the National Census be informed of the conduct of the Census. The AIHW suggests that a formal notice advising EACH care recipients about the Census and the proposed destination of data be issued. The following wording is recommended.

EACH National Census

During the week 6th to 12th May 2002, a National Census of the Extended Aged Care at Home (EACH) program will be conducted by the Australian Institute of Health and Welfare. This means that information about EACH service provider agencies and their clients will be sent to the Australian Institute of Health and Welfare for statistical analysis. This information will be kept confidential.

This information will be used for statistical purposes only and will not be used to

Note: Copies of all relevant source documents are available from the AIHW on request.

If you require further information regarding these materials and the Census please call **Karen Malam** at the AIHW on **02 6244 1227 or Evon Bowler** at the AIHW on **02 6244 1173**.

Thank you for your time in completing this Census collection.

Attachment 1

Attachment 1 provides a summary of the Information Privacy Principles contained in the *Privacy Act 1988*. The Information Privacy Principles regulate the information-handling practices of Commonwealth government agencies and their contractors, including the Commonwealth Department of Health and Ageing and the Australian Institute of Health and Welfare.

The Information Privacy Principles in plain English

(Graham Greenleaf – July 1989)

Principle 1 - Restricting collection of information to lawful purposes and by fair means

Agencies must not collect personal information unless:

(i) it is collected for a lawful purpose directly related to a function or activity of the agency; and

(ii) the means of collection are lawful and fair.

Principle 2 - Informing people why information is collected

Agencies must ensure that people from whom they solicit personal information are generally aware, before collection, or as soon as practical thereafter, of:

(i) the purpose of collection;

(ii) any legal authority for the collection, and

(iii) any third parties to which the collecting agency discloses such information as a usual practice.

Principle 3 - Ensuring personal information collected is of good quality and not too intrusive

Where an agency solicits personal information (whether from the person that the information is about or otherwise), it must take reasonable steps to ensure

(i) that the information is relevant to the purpose of collection, up-to-date and complete; and

(ii) that its collection does not unreasonably intrude upon the person's personal affairs.

Principle 4 - Ensuring proper security of personal information

An agency must protect personal information against misuse by reasonable security safeguards including doing everything within its power to ensure that authorised recipients of the information do not misuse it.

Principle 5 - Allowing people to know what personal information is collected and why

Any person has a right to know whether an agency holds any personal information (whether on him or her or not), and if so

(a) its nature;

(b) the main purposes for which it is used:

(c) the classes of persons about whom it is kept;

(d) the period for which each type of record is kept;

(e) the persons who are entitled to have access to it, and under what conditions; and

(f) how to obtain access to it.

Each agency must maintain an inspectable register of this information, and must inform the Privacy Commissioner annually of its contents.

Principle 6 - Allowing people access to their own records

A person has a right of access to personal information held by an agency, subject to exceptions provided in the *Freedom of Information Act 1982* or any other law.

Principle 7 - Ensuring that personal information stored is of good quality, including allowing people to obtain corrections where it is not

Agencies must make corrections, deletions and additions to personal information to ensure that it is:

(i) accurate; and

(ii) relevant, up-to-date, complete and not misleading (given the purpose of collection and related purposes), subject to exceptions provided in the *Freedom of Information Act 1982* or any other law.

Agencies are also required to add a reasonable statement by a person to that person's record, on request.

Principle 8 - Ensuring that personal information is of good quality before using it

Agencies must take reasonable steps to ensure that personal information is accurate, up-to-date and complete (given the purpose of collection and related purposes) before using it.

Principle 9 - Ensuring that personal information is relevant before using it

Agencies may only use personal information for purposes to which it is relevant.

Principle 10 - Limiting the use of personal information to the purposes for which it was collected

Agencies may not use personal information for purposes other than for which it was collected, except

(a) with the consent of the person;

(b) to prevent a serious and imminent threat to a person's life or health;

(c) as required or authorised by law;

(d) where reasonably necessary for the enforcement of criminal or revenue laws; or

(e) for a directly related purpose.

In the case of exception (d), but not otherwise, the use must be logged.

Principle 11 - Preventing the disclosure of personal information outside the agency

Agencies may not disclose to anyone else personal information, with the same exceptions as apply as to Principle 10 (a) - (d), plus an additional exception where the subject of the information is reasonably likely to be aware of the practice of disclosure (or reasonably likely to have been made aware under Principle 2). The recipient of information under one of these exceptions may only use it for the purpose for which it was disclosed.

Attachment 2

Attachment 2 is extracted from Information Sheet 1, developed by the Office of the Federal Privacy Commissioner (2001) about the new private sector privacy law. Further information on privacy can be obtained from the Federal Privacy Commissioner's website at www.privacy.gov.au.

An overview of the Privacy Amendment (Private Sector) Act 2000

The *Privacy Amendment (Private Sector) Act 2000* regulates the way the private sector organisations can collect, use, keep secure and disclose personal information. For the first time, it gives individuals the right to know what information an organisation holds about them and a right to correct that information if it is wrong.

What does the Act mean to care recipients?

The Act means care recipients now have the right to know why a private sector organisation is collecting their personal information, what information it holds about them, how it will use the information and who else will get the information. Except for some special circumstances, care recipients can ask to see this information and for the information to be corrected if it is wrong. Care recipients can also make a complaint if they think their information is not being handled properly. A care recipient could also apply to the Federal Court or the Federal Magistrate's court for an order to stop an organisation from engaging in conduct that breaches the National Privacy Principles (NPPs).

Who will the new private sector provisions apply to?

The Act will apply to 'organisations' in the private sector. An organisation can be an individual, a body corporate, a partnership, an unincorporated association or a trust. It will cover:

- businesses, including not-for-profit organisations such as charitable organisations, sports clubs and unions, with a turnover of more than $3 million;
- federal government contractors;
- health funded agencies that hold health information (even if their turnover is less than $3 million);
- organisations that carry on a business that collects or discloses personal information for a benefit, service or advantage (even if their turnover is less than $3 million);
- small businesses with a turn-over of less than $3 million that choose to opt-in;
- incorporated State Government business enterprises;
- any organisation that regulations say are covered.

The new provisions will not apply to:

- State or Territory Authorities, e.g. Ministers, departments, courts and local government councils;
- Political parties and acts of political representatives in relation to electoral matters;
- Most small businesses with an annual turnover of less than $3 million;
- Acts or practices in relation to employee records of an individual if the act or practice directly relates to a current or former employment relationship between the employer and the individual;

- Acts or practices of media organisations in the practice of journalism.

When does the Act come into operation?

Most organisations, including all health services holding health information, will have 12 months to get ready for the new scheme. The new provisions will start to apply 21 December 2001. Small businesses (except health services) covered by the new provisions have an additional twelve months and the new provisions will apply in December 2002.

What are the National Privacy Principles (NPPs)?

The NPPs set the base line standards for privacy protection. Organisations may have and enforce their own codes. These codes must be approved by the Privacy Commissioner as having obligations at least equivalent to the NPPs and meet other requirements. The code must have an independent code adjudicator to handle complaints. If the code does not provide for a complaints handling mechanism the Privacy Commissioner is the code adjudicator.

Organisations that do not have their own code must comply with the NPPs set out in the *Privacy Amendment (Private Sector) Act*. The Privacy Commissioner handles complaints in these circumstances.

The NPPs are ten principles or rules in the Act about how organisations should handle personal information. They cover collection (NPP1), use and disclosure (NPP 2), data quality (NPP3), data security (NPP 4) openness (NPP 5), access and correction (NPP6), identifiers (NPP7), anonymity (NPP 8), transborder flow of data (NPP 9) and sensitive information (NPP 10).

Only some of the NPPs will apply to information organisations already hold when the new provisions start to apply. The NPPs relating to data security, data quality when information is used and disclosed, identifiers and transborder flow will apply regardless of when the information was collected. The principle relating to access and correction will apply to all information collected after the new provisions apply, and any already existing information that is used. Those principles relating to collection, use and disclosure, data quality when it is collected, and sensitive information will not apply to information collected before the new provisions start to apply.

What is 'personal information'?

The Act covers personal information. It has special protection for personal information that is sensitive information. The Privacy Act only applies to information that is recorded in some form, which can include in an electronic record.

Personal information is information or an opinion that can identify a person.

Sensitive information is information about an individual's racial or ethnic origin, political opinions, membership of a political association, religious beliefs or affiliations, philosophical beliefs, membership of a professional or trade association, membership of a trade union, sexual preferences or practices, criminal record, or health information.

Source: AIHW Commonwealth/State Disability Agreement (CSDA) Minimum Data Set Data Guide 2002.

Attachment 3

AIHW policy and procedures on information security and privacy: excerpts

The AIHW has documented procedures, approved by its Board, covering these topics. These policies and procedures seek to operationalise the requirements of the Institute's legislation and other relevant legislation (i.e *The Privacy Act 1988*). The AIHW has particularly strong attributes as a data custodian as we are bound by our own legislation in addition to privacy legislation and have a strong culture of ensuring data security.

The principles relating to data custodianship complement the Information Privacy Principles in Appendix A, and are worth considering in the context of the EACH National Census. A brief excerpt follows.

Selected principles on information storage, retention and retrieval

1. Data Custodians are responsible for ensuring their data holdings are protected from unauthorised access, alteration or loss.
2. Paper-based identifiable information must be kept securely locked away when not in use. The minimum requirement is that, outside normal working hours, the information must be stored in locked drawers or cabinets.
3. Particular care must be taken regarding the printout and photocopying of paper-based information. Users must stand by printers, photocopiers and fax machines while this material is being printed, copied, sent or received.
4. Information users must follow normal practice for the use of IT systems to ensure the security and privacy of in-confidence information stored on computer systems including, but not limited to:
   - user account and password protection, use and management
   - automatic screen shutdown or automatic log-off in place on all PCs.
5. Identifiable information must not be copied or removed from Institute premises without specific approval from the relevant Data Custodian (where the release has been approved by the AIHW Ethics Committee).
6. Identifiable information must not be copied to or held on work station hard disks.
7. In published tables, the amount of information in small cells should be reduced to decrease the potential for identification.

Source: AIHW Commonwealth/State Disability Agreement (CSDA)Minimum Data Set Data Guide 2002.

Attachment 4

Recording types of assistance received

The amount of each type of EACH assistance received by a care recipient in the census week should be recorded. The total amount of assistance received by the care recipient over the census week for types of assistance measured in hours should be reported in hours and minutes, to the nearest 15 minute period. Total amounts of less than seven minutes should be rounded up to 15 minutes. The time spent providing each type of assistance at each occasion of service delivery in the census week should be recorded by the service outlet in five minute units, e.g. 5 minutes, 25 minutes, 30 minutes etc.

The types of assistance measured by quantity are 'Meal deliveries', 'Formal linen services', and 'Transport'. The service outlet should record the total amount of 'Meal deliveries' received by the care recipient during the census week as the total number of delivered meals received, regardless of the number of deliveries involved in providing those meals. The service outlet should record the total amount of assistance with 'Formal linen services' received by the care recipient during the census week as the total number of laundry deliveries. The service outlet should record the total amount of assistance with 'Transport' received by the care recipient during the census week as the total number of one-way trips.

The types of assistance

EACH case management/care coordination: Refers to all activities that are directly related to the management of the complex care needs of a care recipient by a person who has been formally designated as responsible for ensuring the coordinated and appropriate delivery of assistance to care recipients with complex care needs.

'EACH case management/care coordination' includes the development, monitoring and formal review of a care plan to meet the care recipient's needs, as well as the coordination of the range of assistance that is provided to individuals with complex care needs. This includes the coordination of assistance provided directly by the EACH service outlet, and the organisation and negotiation of assistance provided by external agencies—whether or not this assistance is funded by EACH Program funds. For example, EACH case management may involve arranging personal care directly through the EACH service outlet, arranging home modifications through an external agency (regardless of which agency funds the modifications), or arranging medical, dental or allied health services on behalf of the care recipient.

Also included is assistance provided to the care recipient or their informal carer with: understanding and managing situations, behaviours and relationships associated with the person's need for care; the provision of emotional support; support to individual care recipients in accessing and using general community services/facilities (advocacy); one-to-one training or advice given to the recipient; and the provision of information (e.g. other services available in the area).

'EACH case management/care coordination' also includes activities such as supporting, communicating with, or providing information to the individual care recipient's informal carer, other family members, or their guardian.

The assignment of a 'case manager' or 'care coordinator' should be the result of a formal agreement between the care recipient, the case manager and other parties involved, or potentially involved, in the care recipient's care plan.

'EACH case management/care coordination' will often not include direct care recipient contact, but should relate to the planning and delivery of services to an individual care recipient. 'EACH case management/care coordination' does not include general administrative work related to the agency as a whole (e.g. processing accounts) or workers' completion of tasks related to their employment (e.g. completing timesheets or attendance at staff meetings or training programs). 'EACH case management/care coordination' also does not include time spent supporting or training staff members (including volunteers), even where the support or training relates to the care provided to an individual care recipient.

Domestic assistance: Refers to assistance with domestic chores, including assistance with cleaning, dishwashing, clothes washing and ironing, shopping and bill paying. In remote areas, 'Domestic assistance' may also include activities such as collection of firewood.

In deciding whether activities such as shopping or bill paying should be recorded as 'Domestic assistance' or 'Social support', the provider should use the following rule: if the person accompanies the worker during the activity this should be recorded as 'Social support'; if the worker is not accompanied by the person, the activity should be recorded as 'Domestic assistance'.

Social support: Refers to assistance provided by a EACH care worker, either within the home environment or while accessing community services or facilities, which is primarily directed towards meeting the person's need for social contact and/or accompaniment in order to participate in community life.

'Social support' includes services to assist the person to maintain their personal affairs such as letter writing, managing paperwork and making telephone-based contacts; shopping, bill paying and banking (when the person is accompanied by the care worker); keeping the person company; and, accompanying the person to social activities.

Nursing care: Refers to professional care from a registered or enrolled nurse. It includes time spent recording observations of a client, where this is considered to be part of the nurse's duty of care.

'Nursing care' should not be used for activities undertaken by registered or enrolled nurses which belong more clearly to one of the other types of assistance specified in this data element. For example, where a nurse undertakes a comprehensive review of a care recipient's care plan, the appropriate type of assistance to be recorded is EACH case management/care coordination, regardless of the fact that the review was undertaken by a registered or enrolled nurse. Similarly, if a nurse provides personal care at an occasion of service, then time spent undertaking the activity should be recorded as 'Personal care'.

Allied health care: (also known as paramedical care) refers to professional allied health care services, including podiatry, occupational therapy, physiotherapy, speech pathology and advice from a dietician or nutritionist.

'Allied health care' should not be used for activities undertaken by qualified allied health care workers which belong more clearly to one of the other types of assistance specified in this data element. For example, where an allied health care worker undertakes a comprehensive review of a care recipient 's care plan, the appropriate type of assistance to be recorded is 'EACH case management/care coordination', regardless of the fact that the review was undertaken by a qualified allied health care worker. Similarly, if an allied health

care worker provides personal care at an occasion of service, then time spent undertaking the activity should be recorded as 'Personal care'.

Personal care: Includes assistance with daily self-care tasks such as eating, bathing/showering/personal hygiene, toileting, dressing/undressing, mobility, and transfer. 'Personal care' may also include control and administration of medication prescribed by a medical practitioner, administration of treatment such as eye drops, back rubs, dressings and urine tests, and fitting of sensory communication aids, and assistance with managing incontinence.

Delivered Meals: Refers to receipt of delivered meals. It does not include meals prepared in the care recipient's home, or meals that are not paid for by the EACH service outlet. It does include meals that are prepared centrally by the EACH service outlet (or others) and then delivered to the person's home.

Meal preparation/other food services: Refers to assistance with the preparation and cooking of a meal in the recipient's home, including the storage of food.

Respite care in the home (excluding residential respite care): Includes assistance received by the care recipient from a substitute carer who provides supervision and assistance to the care recipient in their own home or in the community, in the absence of the care recipient's usual informal carer. 'Respite care' should only be applicable to care recipients who have carers, and should only be recorded if the care is funded by the EACH provider. Day Centre care, if funded by the EACH service outlet, should be recorded as 'Social support'.

Home maintenance: Refers to assistance with the maintenance and maintenance-related repair of the person's home, garden or yard to keep their home in a condition of functional safety and provide an adequate level of security.

'Home maintenance' includes minor dwelling repairs and maintenance, such as changing light bulbs, carpentry and painting, or replacing tap washers as well as some more major dwelling repairs such as installing a new roof, replacing guttering or roof retiling. 'Home maintenance' also includes garden maintenance, such as weeding, lawn mowing and removal of rubbish.

Formal linen service: Refers to the provision and laundering of linen, usually by a separate laundry facility or hospital. 'Formal linen service' should only be recorded as a type of assistance when linen is both provided and laundered. It does not include instances where the EACH service outlet takes the care recipient's linen away for laundering elsewhere. Washing of clothes and other household linen in the person's home should be recorded under 'Domestic assistance'.

Transport: Refers to assistance with transportation to help the person shop, attend appointments, or attend social activities. 'Transport' can either be provided directly by an EACH worker or contracted agency, or indirectly (e.g. taxi vouchers or subsidies).

Rehabilitation support: Includes assistance by EACH care workers where they are playing an active role in the implementation of a professionally determined rehabilitation plan. The plan will generally be for a determined length of time, and should outline assistance that is aimed at the person reaching and maintaining their optimal physical, sensory, intellectual, psychiatric and/or social functional levels. A rehabilitation plan may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or a functional limitation.

Excluded from this type of assistance is:

prompting/reminding the person to undertake an activity where the person is not directly assisted to engage in the activity;

assistance with exercises that are being carried out as a result of general advice from healthcare professionals to assist the person to complete tasks of daily living, where the assistance is not part of a formal rehabilitation plan. For example, assistance provided to a person as a result of advice given by a GP to assist the person to walk each day, where this is not part of a professionally determined rehabilitation plan, should not be recorded under 'Rehabilitation support', but should be recorded under 'Personal care' (which includes assistance with mobility) or 'Social support', depending on the needs of the person and the aim of the exercise; and

assistance with transporting or accompanying the person to a rehabilitation centre, physiotherapy appointment, etc. This type of assistance should be recorded as 'Transport' and/or 'Social support'.

Note:

Shopping: Shopping is not recorded as a separate activity. Shopping that is done by the EACH care worker on behalf of the care recipient should be recorded as 'Domestic assistance' (including all travel time associated with the shopping). Shopping activities where the care recipient is accompanied by the EACH care worker should be recorded as 'Transport' and 'Social support' (for example, 2 one-way trips (Transport) and 45 minutes Social support). If the EACH care worker transports the person to the shops but does not accompany them around the shops, this should be recorded as 'Transport' only.

Appendix B

Data qualifications

The EACH census collection instruments were the result of extensive consultation in the development of data elements and a review of the census forms by a steering committee and representatives of peak organisations. Forms were not pilot-tested prior to the census. As a consequence, some data quality deficiencies became evident after analysis. The following discussion outlines the deficiencies.

Additional services. The question about additional services from other programs (question 21t) appeared on the EACH census form before the question about services provided by the EACH program. It could have been expected that, where additional services were used, these would be services not provided or provided in lesser amounts under the EACH program. However, for this question approximately 20 census returns reported a pattern of additional service that was very similar to the service provided under the EACH program. This reporting may have arisen because care coordinators incorrectly completed the census form. Because the census was primarily about EACH service provision, care coordinators many have mistakenly ticked those services provided by the EACH program, instead of other programs. It is recommended that verification of the responses received under this question in the census form's current layout and follow-up testing of the form's layout be undertaken before the census is repeated.

Service provision by allied health care professionals. In question 24, it was expected that any assistance provided by allied health professionals would have care provided under the allied health or rehabilitation service categories. However, EACH-funded care by allied health care professionals was reported to have been provided to three care recipients who had no service reported under either of these categories. There were also inconsistencies between the number of care recipients who reported receiving services from allied health professionals and those who received allied health or rehabilitation services. This may mean that care workers who were not allied health care professionals provided these types of service. Further improvement in question wording and form layout is needed to clarify this information.

Nursing services. The census contained three questions concerned solely with or including information about nursing services. The first question, question 24, asked for the total amount of EACH-funded assistance provided to the care recipient in the census week. There were 13 assistance categories, one of which was nursing care. The second question, question 26a-g, asked for the amount of assistance provided to the care recipient in the census week by a registered nurse. There were seven assistance categories specific to the activities of a qualified registered nurse. A third question, question 26h, asked about the provision of services by a specialist registered nurse and asked how this service was funded.

While question 24 identifies the total EACH-funded nursing assistance, it is not possible to determine what types of nursing assistance are provided in total, as question 26a-g only identified the types of assistance provided by registered nurses. Other nurses such as enrolled nurses or specialist nurses may also have provided assistance.

Question 26h asked about the funding of services by a specialist registered nurse. The services of specialised registered nurses may have been included in some, none or all of the services identified in question 26a-g depending on the degree to which respondents understood overlap between registered nurses and specialised registered nurses. Very few census returns reported the funding source of specialist registered nursing services under question 26h. It is recommended that future editions of the census resolve these difficulties to facilitate consistency in reporting.

Available equipment. The level of detail in responses to this question appeared to differ between agencies. Some agencies reported only on the seven specified equipment items, while some other agencies reported as many as 12 additional pieces of equipment. It therefore seems likely that equipment use by some EACH recipients may have been under-reported. It is recommended that additional categories of equipment be included in future, in order to fully capture details of the equipment being used by EACH recipients.

Glossary

Areas of need for assistance

To establish EACH recipients' need for assistance in core activities of daily living, the census form included the following question:

> Does the care recipient sometimes or always need the assistance or supervision of another person in any of the following areas? *(please tick all relevant areas)*:
>
> Eating
>
> Showering/bathing
>
> Dressing
>
> Toileting
>
> Managing incontinence
>
> Maintaining or changing body position
>
> Carrying, moving and manipulating objects related to tasks of daily living
>
> Getting in or out of a bed or a chair
>
> Walking and related activities (either around the home or away from home, excludes needing transport assistance)
>
> Using public transport
>
> Understanding others or making oneself understood by others (excludes independent use of aids and equipment, e.g. hearing aids, speech aids and assistance from interpreters;
>
> No assistance needed from another person in any of these areas.

Brokerage of services

An arrangement under which EACH service providers subcontract other agencies or individuals to provide case management, specialised nursing care, allied health services, personal care assistance, domestic assistance or other assistance to care recipients.

Care recipient agreement

Under the terms of their agreement with the Commonwealth, approved EACH providers must offer care recipients or their representatives a formal care agreement that sets out the rights and obligations of both parties. The agreement must include details such as services provided and the level of services, costs payable by the care recipient, and termination rights.

Carer

Someone such as a family member, friend or neighbour who provides regular, ongoing assistance to the care

	recipient without payment other than a pension or benefit.
Core activity limitations	Activities of daily living in which the care recipient cannot be completely independent, as listed here under 'Areas of need for assistance'.
Country of birth	Thirteen countries of birth were listed as possible selections on the census form. 'Not known' was also listed, and a space was provided in which to write any other countries. For the purposes of this report, 'United Kingdom' comprises England, Scotland, Wales, the Channel Islands, the Isle of Man and Northern Ireland. This grouping follows the Standard Australian Classification of Countries 1998 4–digit level (Australian Bureau of Statistics, cat. No. 1269.).
Dementia	The census form stated that care recipients should be reported as having dementia only if the diagnosis was stated on the Aged Care Application and Assessment Form (2624) or if, whilst receiving an EACH package, 'a medical practitioner has expressed a clinical opinion that the care recipient has dementia'.
Day therapy centre	An organisation or organisational sub-unit that is funded by the Commonwealth, to provide its clients with individual or group therapy that has been approved by the Department of Health and Ageing.
English proficiency groups	Refers to a categorisation schema developed by the Bureau of Immigration and Population Research. English Proficiency (EP) Group 1 comprises people born in Australia, Canada, Ireland, New Zealand, South Africa, the United Kingdom and the United States. The remaining three EP groups are divided according to the English proficiency levels of recent immigrants from each country of origin. EP Group 2 comprises those countries from which 80% or more of recent arrivals speak English only or another language and good English. EP groups 3 and 4 consist of lesser proportions of immigrants with English proficiency.
EACH package	The term used to describe the nature and range of services provided to EACH recipients. The definition of EACH in section 15.6 of the Aged Care Principles states: Extended Aged Care at Home is a form of flexible care that is provided:

(a) in the care recipient's home; and

(b) in the form of services necessary to maintain the person at home, including nursing care or personal assistance (or both), in an individually tailored and managed package of care; and

(c) for the care recipient who:

(i) needs care equivalent to a high level of residential care; and

(ii) would, if he or she were not receiving extended aged care at home, have required a high level of residential care.

Flexible Care subsidy

Funding provided by the Commonwealth to an EACH approved provider for care and services provided to the EACH recipient. The rate of subsidy paid is determined under s. 44-3 of the *Aged Care Act 1997.*

Leave

Care recipients are said to be 'on leave' if they temporarily suspend services from their EACH service provider because, for example, they enter hospital, are in alternative accommodation for respite purposes, or are involved in social activity (such as a holiday) away from their primary residence.

References

AIHW (Australian Institute of Health and Welfare) 2002a. Aged Care Assessment Program Data Dictionary Version 1.0. Canberra: AIHW.

AIHW (Australian Institute of Health and Welfare) 2002b. Community Aged Care Packages in Australia 2000–01: a statistical overview. AIHW cat. no. AGE 23. Aged Care Statistics Series no. 12. Canberra: AIHW

AIHW (Australian Institute of Health and Welfare) 2001. Australia's Welfare 2001. Canberra: AIHW.

AIHW (Australian Institute of Health and Welfare) 2000. National Community Services Data Dictionary. Version 2. AIHW Cat. No. HWI 27. Canberra: AIHW.

AIHW (Australian Institute of Health and Welfare) 1998. The Home and Community Care Program Data Dictionary Version 1.0. Canberra: AIHW.

Commonwealth Department of Health and Ageing 2002. Home and Community Care (HACC) National Minimum Data Set 2001–2002 Annual Bulletin. Canberra: DoHA <http://www.health.gov.au/acc/hacc/mds/statindx.htm>.

Siggins Miller Consultants 2002. Evaluation of the Extended Aged Care at Home (EACH) Pilot Program, March 2001—No. 40. Canberra: Commonwealth Department of Health and Ageing.