

Appendix 4: Privacy information

Community Aged Care Package Census 2002

**Collection, use and disclosure of information
Protected information under the *Aged Care Act 1997*
Personal information and the *Privacy Act 1988***

The Department of Health and Ageing (the Department) has engaged the Australian Institute of Health and Welfare (AIHW) to assist with their census of the Community Aged Care Package (CACP) Programme.

The aim of the census is to provide an up to date national profile of CACP providers, CACP care recipients and the assistance they receive.

Information collected through this census will provide a level of detail which is required for more complex analyses of the CACP programme such as equity of access and effectiveness of service provision along with basic information such as number of care recipients. This will help the Department administer CACPs and will support performance measurement, policy development and future planning of the programme.

A full report of the CACP 2002 census will be produced by AIHW by mid 2003. In addition, AIHW will produce a summary of the CACP 2002 census report in mid 2003.

Census information relating to care recipients is to be collected and remain in de-identified form, through the use of a statistical linkage key and strict Department and AIHW protocols. This will protect the privacy of care recipients, and comply with the protected information provisions applying to the Department and approved providers in the *Aged Care Act 1997*, and the Information Privacy Principles and National Privacy Principles in the *Privacy Act 1988*.

Census information relating to care recipients will be collected through the use of a statistical linkage key. The sealed census envelopes will be received by the Department at a dedicated-Mail Drop Point and sent unopened to AIHW. The Department will not thereafter seek to access the census data held by AIHW. AIHW will analyse the census data under strict protocols, including protocols to protect the de-identification process. In addition, all CACP 2002 census forms will be destroyed 4 months after analysis is completed. The AIHW report and summary will not contain any personal information relating to care recipients. This process will ensure that the identity of care recipients will not be apparent, or reasonably able to be ascertained, from the census information, and the census information will not therefore constitute personal information under the *Aged Care Act 1997* or the *Privacy Act 1988*.

The Department's responsibility to care recipients and approved providers

It is the Department's responsibility to meet the requirements of the protected information provisions in the *Aged Care Act 1997* (Division 86) and the Information Privacy Principles under the *Privacy Act 1988*, in relation to requesting, protecting, using and disclosing census data relating to approved providers and care recipients.

The Department has decided to protect the interests of approved providers and care recipients by:

- seeking, through use of a statistical linkage key and Departmental/AIHW protocols, only de-identified census data in relation to care recipients (Form B, care recipient data); and
- seeking the written consent of approved providers to the collection of census data in relation to approved providers (Form A, service outlet data). A request for written consent appears at the end of this form.

The responsibility of the Australian Institute of Health and Welfare to care recipients and approved providers

It is the responsibility of AIHW to meet the requirements of the Information Privacy Principles in the *Privacy Act 1988* and section 29 of the *Australian Institute of Health and Welfare Act 1987* (confidentiality provision).

AIHW (like the Department), through the use of the statistical linkage key and strict protocols, will receive and process only de-identified data in relation to care recipients. In relation to approved providers, the data will not be de-identified, and each approved provider will be asked to provide written consent to the collection of census data in relation to that approved provider.

The responsibility of approved providers to care recipients

It is the responsibility of each approved provider to protect the privacy of care recipients, under section 62-1 of the *Aged Care Act 1997* (responsibilities relating to protection of personal information), and, under paragraph 23.95(h) of the *User Rights Principles 1997* (community care agreement with care recipients).

Approved providers may also be subject to the National Privacy Principles in the *Privacy Act 1988*. It is the responsibility of each approved provider to determine whether it is subject to the National Privacy Principles, and, if so, to comply with the National Privacy Principles. In addition, approved providers may be subject to state privacy legislation. Again, it is the responsibility of each approved provider to comply with state privacy legislation.

In the Department's view, given the use of a statistical linkage key and strict Department/AIHW protocols, census information relating to care recipients is provided and will remain in de-identified form, so that the identity of care recipients will not be apparent, or reasonably able to be ascertained, from the census information, and provision of completed census forms to the Department will not constitute disclosure of personal information under the *Aged Care Act 1997* or the *Privacy Act 1988*.

In addition, it is the Department's view that the use of care recipient personal information to complete the census forms is 'for a purpose connected with the provision of aged care to the person by the approved provider' [paragraphs 62-1(a)(i), *Aged Care Act 1997*] as the de-identified information will be used to enhance provision of community care to all care recipients.

Written consent of approved provider

I agree to the use and disclosure of information regarding the following approved provider

Print name of approved provider

in relation to the following service outlet/s- *Print name/s of Service outlet/s*

For data collected in census forms in the CACP 2002 census, for the following purposes:

- provision to AIHW for analysis and preparation of reports; and
- AIHW produced CACP 2002 census report and CACP 2002 summary of census report.

Signature

Print name

being authorised to provide written consent on behalf of the approved provider in relation to the above service outlet/s

Dated

The approved provider's original written consent is retained by the Department, and should be sent, in a separate envelope to the completed census forms, to:

Assessment and Community Care
MDP 32
Attention: Sue Thomas
PO BOX 9848
Canberra ACT 2601

Unlike the census forms the written consents do not go to AIHW and are not destroyed 4 months after analysis is complete – they will be kept on a Departmental file.

Please retain a copy of this written consent for your records.

Appendix 5: Definitions of activities of daily living

The following definitions of the types of activities listed in this question are based on definitions in the International Classification of Functioning, Disability and Health (World Health Organization, 2001) .

If a person sometimes or always needs supervision or assistance for any part of the tasks included in a particular definition of an activity then that activity should be ticked.

Eating: Eating food and drink that has been served, in culturally acceptable ways. Bringing it to the mouth, cutting and breaking food into pieces, using eating implements.

Showering/bathing: Washing and drying one's body using water and appropriate cleaning materials.

Dressing: Choosing, putting on and taking off clothes and footwear in sequence and in keeping with climatic and social conditions.

Toileting: Co-ordinating and managing urination and defecation, such as prompting, getting into proper position, getting to the toilet, undoing/redoing buttons and cleaning up afterwards.

Managing incontinence: Assistance with continence aids, e.g. pads, catheters, colostomy bags.

Maintaining or changing body position: Includes bending, turning over in bed, kneeling, sitting up unsupported and standing for a period of time such as in a queue. Excludes getting in and out of a bed, chair or vehicle, record these under 'Getting in or out of a bed or chair'.

Carrying, moving or manipulating objects related to the tasks of daily living: Such as lifting and carrying a cup, or parcel, picking up a pencil, turning a door nob, handle coins/money.

Getting in and out of a bed or chair: Moving from or to any sitting or lying position. This includes getting into a bed from a chair and getting out of a vehicle, bath or wheelchair.

Walking and related activities: Includes moving around the home or away from home, but excludes needing transport assistance.

Using public transport: Such as buses and trains. Excludes disability specific transport.

Note: If the care recipient lives in an area where there is no public transport then you need to judge whether, if available, the care recipient would be able to use public transport.

Understanding others or making oneself understood by others: Includes written, verbal and non-verbal communications. Excludes the independent use of aids and equipment, e.g. hearing aids, speech aids and assistance from interpreters.

Appendix 6: Recommendations for future census

Should the CACP census be conducted again in a similar manner, the following recommendations are put forward to inform this activity.

Recommendation 1:

It is apparent from responses to the census and from questions asked of the census helpline, that outlets have detailed knowledge of client based information and individual outlet operations. However, individual service outlets whose business is the immediate delivery of services were less aware of administrative details such as aged care planning regions and the types of package approvals. A number of outlet staff reported that they had not seen the service agreements and did not have access to them. It is recommended that administrative details not directly affecting immediate service delivery be collected in a separate module completed by the appropriate level of the organisation (e.g. the provider rather than the outlet where this is applicable).

Recommendation 2:

It is recommended the ACCMIS outlet number (C number) not be used to identify outlets. The C number does not reflect practice regarding the delivery of CACPs. Groups of packages (under one C number) may be spread across more than one service outlet as defined for the census, and outlets may provide packages allocated under more than one C number.

Inclusion of both an accurately identified service outlet number and the C number for each client's package number on the care recipient form (Form B) would however help in assessing response rates to the census and the analysis of differences between practices of service outlets.

Recommendation 3:

It is recommended that any future CACP census be conducted in two stages. The initial stage would obtain accurate and complete information about the service outlets from the approved providers, such as:

- a full and accurate list of service outlets including street addresses
- the numbers and types of individual packages that are managed by each of those outlets and the aged care planning regions for which these packages are approved
- agency characteristics that are common across the organisation.

The second stage of the census would use the information provided in the initial stage to define outlet numbers, and to distribute census kits to outlets. This stage of the census would seek operational details that were specific to each service outlet, such as information on advice provided to care recipients (privacy issues, complaints procedures), brokerage or subcontracting of service provision, and details of demographic and service provision information for individual clients.

Recommendation 4:

A substantial proportion of approved providers and/or their services outlets have the capacity to download much of the information requested in the census from existing computerised management information systems. The development of an electronic file format and the capacity to transmit data electronically would assist these organisations and reduce the burden of participation in the census for these organisations. Sufficient lead time for the development and consistent implementation of this is necessary.

Recommendation 5:

Feedback from service organisations and state offices of DoHA suggests that for future data collections a longer lead time with regular reminders would help prepare agencies and lift the response rate, particularly in the Indigenous sector.

Recommendation 6:

Minor amendments to the care recipient form are proposed.

- **Need for assistance in activities of daily living (Question 17):** In the form used in the 2002 CACP census there is no capacity for identifying uncertainty about the care recipients' need for assistance in an individual activity of daily living. If none of the boxes were ticked (including the box used to indicate that no assistance is needed in any of these activities) this was recorded as a not stated response for all core activity limitations. However, if any of the boxes were ticked all other blank responses were taken to mean no assistance was needed for those activities. However, it is possible that a care worker who did not know the care recipients need for assistance in a particular area may have left the box blank for that reason. Therefore, not stated responses may have been underestimated, and the number of care recipients with no severe or profound core activity limitations overestimated.

It is recommended that the inclusion boxes for both yes and no responses be considered.

- **Assistance from other government funded programs (Question 28a and 28b):** In the current format, these questions do not allow any analysis of the source of individual types of assistance. If this type of analysis is required the source(s) of assistance needs to be shown for each type of assistance received, as shown below.

<u>Receives additional assistance:</u>			<u>Source of assistance:</u>						
<u>Assistance type</u>	YES	NO	HACC	DVA	NRCF	DTC	CSDA	CAAS	Other programme(s) (please specify):_
Personal care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Domestic assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>
Social support etc	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text"/>

Recommendation 7:

The forms used in the census were modified versions of those field tested and included further work on formatting and layout. These changes were based on the field testing and on experience with similar census forms. Detailed field testing of the impact of these and other proposed changes, to ensure consistent interpretation of the forms, is recommended.

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