

# **Introduction to Pathways in Aged Care 2014**



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# Introduction to Pathways in Aged Care 2014

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#### Australian Institute of Health and Welfare

Board Chair Director

Dr Mukesh C Haikerwal AO Mr Barry Sandison

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

Digital and Media Communications Unit

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601 Tel: (02) 6244 1000 Email: info@aihw.gov.au

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### **Abbreviations**

ACAP Aged Care Assessment Program

ACAT Aged Care Assessment Teams

AIHW Australian Institute of Health and Welfare

CACP Community Aged Care Packages

EACH Extended Aged Care At Home

EACHD Extended Aged Care At Home Dementia

HACC Home and Community Care

KBL Key-based linkage

MDS Minimum Data Set

NACDC National Aged Care Data Clearinghouse

NDI National Death Index

PIAC Pathways in Aged Care

RAC Residential Aged Care

SLK Statistical Linkage Key

TCP Transition Care Program

VHC Veterans Home Care

### 1 Introduction

Over the last 30 years, policy direction, and consequently program development, has been influenced by a small number of underlying principles. These include that many older Australians: prefer to live in the community rather than in residential care; prefer to 'age in place' rather than change residence when care needs change; and want aged care services to be flexible and accessible. Since the early 1980s the Australian Government has implemented a range of reforms that have increasingly moved the focus of care provision from residential aged care (RAC) to include a wide range of community-based aged care services. Exploring how Australians access these programs and move between them is an important part of understanding the complex needs of older Australians and how the aged care system is meeting them.

While national unit record level data have been available for most of the aged care programs since July 2006, the data collections for the different programs do not use a common client identifier, and so are not fully integrated. Consequently, most analyses are program-specific. To overcome the limitations arising from this lack of integration, key community care, residential care, assessment program and deaths data have been brought together using statistical data linkage processes. Data from aged care service programs, ACAT assessments and the National Death Index were linked to create the Pathways in Aged Care (PIAC) link map. This database is suitable for person-based analysis of aged care pathways and patterns of program use over time.

PIAC originally covered aged care assessments and use of 7 aged care service programs, as well as deaths from 1 July 2002 to 30 June 2011. The programs included:

- Aged Care Assessment Program (ACAP)
- Residential aged care (RAC)
- Aged care package programs (CACP/EACH/EACHD)—in August 2013, these programs were replaced by the Home Care Packages Programme, Home Care data are not included in PIAC 2014
- Transition Care Program (TCP)
- Home and Community Care (HACC)
- Veterans' Home Care (VHC) not included in PIAC 2014
- National Death Index (NDI).

PIAC 2014 is an expansion of the linkage available to include all program use reported in linkable data sets and deaths between 1 July 1997 and 30 June 2014, however, PIAC 2014 does not include expanded VHC or any Home Care Packages data. A new linkage phase is currently underway to include Home Care Packages data, this document will be updated once that process is complete.

This document is designed to support users of PIAC and provides an introduction to the linkage processes and a description of the various aged care programs and data sources. Notes on data quality affecting use and exclusions for the aged care data and deaths data are also included.

### 2 Developing the PIAC

In order to facilitate investigations into how people access and move between aged care programs, as well as people's aged care pathways from first use until death, data on the use of key aged care service programs, Aged Care Assessment Teams (ACAT) assessments and deaths have been linked using statistical linkage processes to allow data from different programs to be combined for statistical analysis—the resulting database is termed the PIAC link map.

The current link map (PIAC 2014) has built on, and benefited from, two earlier linkage projects:

- The PIAC cohort study: An initial link map which included program use between July 2003 and June 2006 for a cohort of 2003–04 ACAP clients undertaken by a consortium of researchers at the Australian Institute of Health and Welfare (AIHW), University of Queensland and La Trobe University (see AIHW 2009, 2010, 2011a, 2011b; Karmel et al. 2010, 2012).
- PIAC 2011: A second linkage project extended the link map derived for the PIAC cohort study to cover all program use and deaths during the period 1 July 2002 to 30 June 2011 (see AIHW 2014, 2015b).

PIAC 2014—has further extended the linkage to include all program use reported in linkable data sets and deaths between 1 July 1997 and 30 June 2014. Box 1 provides a description of the aged care programs included in PIAC 2014.

### Box 1: Aged care programs included in PIAC 2014

#### Residential aged care (respite and permanent care)

Residential Aged Care (Commonwealth-funded from 1963) provides both respite and permanent care in residential care facilities. An ACAT approval is required to access funded places.

People who live in the community can receive short-term **respite care** in aged care facilities. Respite care is available on either a planned or emergency basis to older people who intend to return to their own home, but require temporary residential aged care. It supports older people in transition stages of health, as well as providing carers with a break from their caring duties. Respite care is offered as either low or high care.

When people can no longer be supported to live independently in the community, they may move into a **permanent residential aged care**. After a person enters permanent care, the Aged Care Funding Instrument (ACFI) confirms the level of care required, calculating an overall score which is then used to determine a government subsidy amount. From 1 July 2014, the distinction between low care and high care was removed in permanent RAC as part of the 2012 aged care reforms. Individuals no longer need approval for a particular level of care, and they no longer have to move between facilities as their care needs change.

#### Home and Community Care

The largest of government-funded aged care programs is the Commonwealth HACC program, which provides a range of basic maintenance and support services for frail older people living in the community.

HACC has been operational since 1985 and brought together a number of separate programs operating from the mid-1950s under Commonwealth-state agreements. Previously funded jointly by the Commonwealth (Australian) and state and territory governments, on 1 July 2012 the Australian Government assumed full policy, funding, and day-to-day responsibility for HACC services for people aged 65 and over, and for Aboriginal and Torres Strait Islander people aged 50 and over in all states and territories except Victoria and Western Australia (termed 'Commonwealth HACC'). From July 2015, HACC became the main part of the Commonwealth Home Support Programme. An ACAT approval is not required for access.

#### **Aged Care Assessment Program (ACAP)**

Aged Care Assessment Program has been operational since 1985. Under ACAP, multi-disciplinary ACATs determine people's care needs and make recommendations on preferred long-term living arrangements for clients. Relevant approvals are required from an ACAT in order to access funded places within many of the aged care programs and packages.

## Community Aged Care Packages (CACP), Extended Aged Care at Home (EACH) & Extended Aged Care at Home Dementia (EACHD)

Community Aged Care Packages program (operational from 1992, replaced by Home Care Packages Programme in 2013) provided support services for older people with complex needs living at home who were otherwise eligible for admission to 'low-level' residential care. The packages provided a range of home-based services, but not home nursing assistance and allied health services, with care being coordinated by the package provider. Access required an ACAT approval.

Extended Aged Care at Home program (operational from 2002, replaced by Home Care Packages Programme in 2013) provided care at home equivalent to 'high-level' residential care. Access required an ACAT approval.

Extended Aged Care at Home Dementia program (operational from 2006, replaced by Home Care Packages Programme in 2013) provided a community care option specifically aimed at high-care clients with dementia and behavioural and psychological symptoms. Access required an ACAT approval.

#### Transition Care Program (TCP)

Transition Care Program (operational from 2005) provides short-term care to older people who are leaving hospital who are assessed as otherwise being eligible for at least low-level RAC. It aims to improve recipients' independence and functioning and delay entry into RAC. Access requires an ACAT approval. TCP care can be provided at home or in 'live-in' facilities, including RAC and hospital.

Source: AIHW 2014.

### 2.1 Data sources for PIAC 2014

The data sources for the various aged care programs and deaths are described below. Issues related to scope, limitations and data quality are also discussed.

Item	Description	Data source	PIAC 2014 scope	Detailed notes—limitations/exclusion and data quality
Clients of RAC, EACH, EACHD, TCP and CACP	Use of residential aged care, pre-August 2013 high-care home package programs and the Transition Care Program is recorded on the National Aged care Data Clearinghouse (NACDC)—and on the Aged and Community Care Management Information System (ACCMIS)	National Aged Care Data Clearinghouse 2014 (NACDC14).	Clients of SPARC programs or CACP between 1 July 1997 and 30 June 2014	There are 62 cases where there was a SPARC id on the existing PIAC master list but not on NACDC14, and 15 cases where there was a CACP id on the master list but not on NACDC14. These represent a small discrepancy between data provided via ACCMIS, as used for the original PIAC database, and data provided for NACDC14.
	(replaced by the NACDC in 2013)—using integrated client identifiers. As the identifiers for these people all begin with the letters 'SPARC' they care collectively referred to as 'SPARC clients'.			Because people can use multiple programs, an individual may have both a SPARC and a CACP id. There are 1.26 million people in PIAC 2014 who were either SPARC and/or CACP clients between 1 July 1997 and 30 June 2014.
	Use of pre-August 2013 low care packages (that is, program use by CACP clients) is recorded on the NACDC—and on the earlier ACCMIS—using client identifiers which are not integrated with those for SPARC clients, even for people who have used both programs. These clients are referred as 'CACP clients'.			
ACAP assessments	Data on the provision of assessments carried out under ACAP are recorded in the annual ACAP Minimum Data Set collections (from 2003–04). Clients are not assigned a unique administrative identifier, but a statistical linkage key (SLK) is	National Aged Care Data Clearinghouse— 2014 & 2015 (NACDC14 & NACDC15). NACDC14 included ACAP MDS data only up to 2012–13.	Assessments that ended between 1 July 2003 and 30 June 2014 and that were reported on the MDS version 2, except for cases listed under exclusions given in the adjacent notes. Overall, 2,280,580 ACAP MDS distinct assessments are linked to 1.16 million people in the PIAC 2014.	Assessments with insufficient data for internal linkage were excluded from the linkage process, and consequently PIAC 2014. A record was considered to have insufficient data for internal linkage if it had more than 1 missing component of SLK-581 or any missing date of birth data.
	recorded at each assessment to allow client-level statistical analysis of program use. ACAP MDS data are provided to the NACDC annually, but 12 months behind the other program data.			Date of births recorded as 1 January 1900 and 1901 were treated as dummy values and were excluded from the linkage process. This mainly affects data from the earlier years.

Item	Description	Data source PIAC 2014 scope	Detailed notes—limitations/exclusion and data quality
		However, data for ACAP 2013–14 was included in NACDC15, and	A small number (8,058 which were included in PIAC 2011) of records on the original MDS data provisions for 2003–04 to 2010–11 could not be mapped to the data from the NACDC. These records are therefore not included in PIAC 2014.
		so NACDC15 was used as the source for ACAP data. NACDC15 was released after the name-based	Assessment level data for ACAP were collected under the ACAP MDS version 2 from 1 July 2003 and 30 June 2014. However, data are incomplete in the early years. Specifically, implementation of ACAP MDS V2 data collection was completed during 2003–04 for all jurisdictions except New South Wales and Queensland. For these 2 states, implementation was completed by the end of 2005–06.
		matching to SPARC/CACP and NDI was well underway, and so was not used for those.	Records with only 1 missing component of the statistical linkage key (SLK-581) were considered to have sufficient information for client identification if the record contained postcode. Internal deterministic linkage was then used to see if these records should be combined with other records with complete data for SLK-581. Note that, if only sex were missing from the SLK-581, this internal matching process was carried out even if postcode were also missing. Records with missing or poor DOB were not considered to have sufficient information for client identification.
			An assessment can be recorded more than once on the A MDS, usually due to updated information. The researcher need to decide which version to use for analysis (commor that with the latest effective from date).
			PIAC 2014 ACAP concordance only includes assessments reported on NACDC15. There were a number of ACAP assessments included in PIAC 2011 that were within NACDC15: 97% of these people with assessments dropped from NACDC15 were from NSW (67%) or SA (30%), and 99% were for 2003–04.
			A number of ACAP MDS assessments (300,127 with 406,325 associated records) that were in NACDC15 have been excluded from the ACAP concordance for PIAC 2014. There is an additional file listing these and showing why they were not available when accessing PIAC data.

Item	Description	Data source	PIAC 2014 scope	Detailed notes—limitations/exclusion and data quality
HACC	Data on the provision of services provided through HACC are recorded in the HACC MDS annual data collections (from 2001–02). Up to 2009–10, the HACC MDS was collected by the state and territory governments, and then collated into a national data set by the Australian Government. Clients are not assigned a unique administrative identifier, but an SLK is reported on each service record to allow client-level statistical analysis of program use.  Data on services provided by HACC were collected via the HACC MDS v1 for 2001–02 to 2004–05 and using HACC MDS v2 from 2005–06.	For PIAC 2014, HACC MDs data for 2001–02 (v1) and for 2011–12 to 2013–14 (v2) were linked to PIAC 2011. As the NACDC only contains MDS v2 data, MDS v1 linkage data for 2001–02 came from the original provision of the annual data. MDS v1 data are contained in the annual HACC tables in the HACC reference library. Data for MDS v2 (i.e. for 2011–12 to 2013–14) come from the 2015 provision of data for the NACDC—the most recent data provision at the time of linkage.	HACC services provided between 1 July 2001 and 30 June 2014 and that were reported on the minimum data set (MDS) version 1 or 2 are included on PIAC 2014, except for cases listed under exclusions.	Records with insufficient data for internal linkage were excluded from the linkage process, and consequently PIAC 2014. A record was considered to have insufficient data for internal linkage if it had more than 1 missing component of SLK-581 or any missing date of birth data.  Data on services provided by HACC have been collected via the HACC MDS v1 for 2001–02 to 2004–05 and HACC MDS v2 from 2005–06.  For HACC MDS v1 for 2002–03 to 2004–05, the records were split into those for care recipients and those for carers (records with respite only, apart from assessment or case management services).  For HACC 2002–03 to 2010–11, linkage files for both care recipients and carers were prepared. Initially both files were linked to PIAC 2011 for each year. However, inconsistent reporting for carers in MDS v1 and the poor quality of the linkage data for carer's under MDS v2 meant that this was not completed for PIAC 2011 and was not considered for the PIAC 2014 update. Consequently, PIAC is not suitable for examining interactions between care recipient and carer.  For 2001–02, to streamline data preparation all records were assumed to be for care recipients and linked to PIAC 2014.  For MDS v2, the NACDC variable  LINKAGE_KEY_INFO_MISSING on the HACC MDS table was used to determine the quality of the SLK-581 data for linkage; that is whether recipient and/or carer SLK-581 data are not included in the concordance.  As for PIAC 2011, 1 January 1900 and 1901 DOBs were treated as dummy values. Consequently, records with these dates of birth were excluded from the linkage process, and therefore PIAC 2014, as having insufficient data for internal linkage. This mainly affects data from the earlier years.  Other records with 1 January dates of birth that did not link to a record on the link map with full name data were also assumed to be dummy dates of birth and were not added to the map file.

Item	Description	Data source	PIAC 2014 scope	Detailed notes—limitations/exclusion and data quality
				For records with only 1 missing component of SLK-581, records were considered to have sufficient information for client identification if the record contained reported postcode and complete SLK-581 data except for 1 of sex, letters of first name or letters of last name. Internal deterministic linkage was then used to see if these records should be combined with other records with complete data for SLK-581. Note that, if only sex were missing, this internal matching process was carried out even if postcode were also missing. Records with missing or poor DOB were not considered to have sufficient information for client identification.
				A small number (1,072 with good name data) of records on the original MDS v2 data provisions for 2005–06 to 2010–11 could not be mapped to NACDC. These records are not included in the HACC concordance files for PIAC 2014.
Deaths	The NDI is a database, housed at the AIHW, which contains records of all deaths occurring in Australia since 1980. The data are obtained from the Registrars of Births, Deaths and Marriages in each state and territory. The Index is designed to facilitate the conduct of epidemiological studies—see NDI (AIHW). It contains name and demographic data to facilitate matching to other data sets, as well as a registration number. The latter is used to derive a mortality id which can be used to import causes of death from National Mortality Database (NMD) for projects with an appropriate Ethics Committee approval.	NDI as at October 2015.	Apart from the exclusions listed, all deaths from 1 January 1997 on the NDI at the time of extraction late in	Exclusions include: those who were born and died on the same day according to the NDI and unreported deaths; and deaths reported after September 2015.
				2.56 million deaths are included in PIAC 2014.
			2015 are included in PIAC. Consequently, nearly all deaths for 1997-98 to 2014- 15 are included. The scope was made larger than the PIAC period to ensure that we identified, as far as	Deaths may be reported more than once on the NDI. Multiple versions are generally assigned the same mortality id. All versions have been retained to facilitate bringing in causes of death information (where approved). There are 2,559,167 distinct p_id:date of death pairs on the NDI concordance file for PIAC (1.0013 records per p_id with a death).
			possible, all deaths of PIAC clients.	Some people have more than 1 mortality id. In a small number of cases, due to processing errors different people may have been given the same mortality id. Where possible, these have been resolved. There are 2,558,201 distinct p_id:mortality id pairs on the NDI concordance file for PIAC (1.0010 mortality ids per p_id with a death).
				In a small number of cases the date of death as reported on the NDI is not valid.

### 3 Overview of data linkage

Prior to undertaking the data linkage ethics approval and permission to use the required data were obtained from all relevant bodies. In addition, to protect the privacy of individuals, the linkage was carried out within the AIHW in accordance with the Institute's data linkage protocol. A detailed description of the processes used to link the contributing data sets can be found in <u>Patterns in use of aged care</u>: 2002–03 to 2010–11 (AIHW 2014).

### 3.1 Linkage strategy

Data linkage is a powerful tool for identifying multiple appearances of individuals within a data set and for integrating client information across data sets. As the information recorded for an individual may vary from data set to data set—due to either differences in reporting (for example, in first name) or errors—a robust linkage process should allow for some discrepancy in characteristics.

There are two main types of data linkage:

- Key-based record linkage (KBL), in which the linkage of records is based on exact agreement of the linkage variables. Variation in reporting can be allowed for by using a number of different keys.
- Probabilistic name-based linkage, in which the linkage of records in 2 files is based on the probabilities of agreement and disagreement between the set of linkage variables.
   Probabilistic linkage allows for variation in reporting by allowing probabilities of agreement to be less than 1 and probabilities of disagreement to be greater than 0.

Key-based linkage is commonly used when linking either using a person identifier or when full name data are not available but other data items are available which, when combined, can be used to link records. Probabilistic linkage is generally used when full name information, along with other demographic data, is available. Because only some of the data sets included in the PIAC database contain full name information, both types of linkage were used when developing the linked database.

### 3.2 Client identification

Before undertaking data linkage, data sets with appropriate client identifiers and appropriate linkage variables were derived. Two processes were used to identify distinct clients within the data sets contributing to PIAC. The process used depended on whether the data set contained an administrative program client identifier.

### 3.1.1 Data sets with administrative person identifiers

All the data sets included in PIAC which have full name data (SPARC programs, CACP, HCP and NDI) also have a unique administrative person identifier (A\_PID). However, even in these data sets it is possible for a person to have more than one identifier due to an administrative or processing error. Consequently, before linking, data sets with full name data were deduplicated using the name-based linkage process by matching a data set to itself. A small number of people with more than one A\_PID were identified in each data set. In these cases, the person was assigned a single new A\_PID to replace the original A\_PIDs.

### 3.1.2 Data sets without administrative person identifiers

There is no unique program client identifier in either the ACAP or HACC MDS, and full name is not recorded. Rather, both collections contain data items through which repeat assessments by individuals can be identified with high probability; namely, SLK-581.

Although not common, different people can have the same SLK-581, therefore, to reduce the likelihood of combining data for different people—especially in the large HACC data sets—clients were defined by SLK-581 combined with the first digit of the client's postcode of usual residence, and a collection client identifier (C\_CID) assigned accordingly. That is, essentially a client was defined by SLK-581 within a state or territory, except with New South Wales and the Australian Capital Territory being combined. Note that under this definition a person who moved during the year will be identified as two clients if, on moving, their postcode of usual residence changed in the first digit, that is, they would have two C\_CIDs. If a client's postcode was missing, the client's state of usual residence was assumed to be the same as that of the service provider.

Boxes 2 and 3 provide details of the data used in the two linkage processes.

#### Box 2: Data used in name-based linkage:

Name-based linkage was used to link when full name data are available (that is, for SPARC programs, CACP, HCP and NDI). The data used in this process included:

- first name
- last name
- middle name
- other name
- date of birth
- sex
- (possible) date of death
- last seen date
- postcode of usual residence
- suburb of usual residence (used to obtain possible postcodes if postcode had not been reported).

Note that not all variables were available on all data sets.

A person's postcode used in linkage could change depending on the data sets being matched:

- When linking SPARC to the NDI, the preferred postcode for the SPARC person was
  that of the last known residence. For people permanently living in RAC this was the
  postcode of their RAC facility; for others it was that of their home address in the
  community.
- When linking to community care programs, the preferred postcode for the people being linked was that of the last known residence in the community. For people in permanent RAC this was the postcode of their usual residence before moving into RAC.

#### Box 2 (continued): Data used in name-based linkage:

As people can change where they live, both in the community and in residential care, a person can have several postcodes recorded in a data set. For example, the SPARC data can contain several postcodes relating to the same client over a year: the postcode of usual residence before going into RAC and the postcodes of any RAC facility the person used. This postcode variation was used when identifying matches among the 'possible links'. For example, when linking SPARC to NDI up to 3 postcodes were used: the client's postcode in the community before entering RAC, the postcode of the last RAC facility used and the postcode of where the client died according to the NDI.

#### Box 3: Data used in key-based linkage (KBL)

Key-based linkage was used to link the ACAP and HACC annual data sets to the PIAC database. The data used in this process included:

- second and third letters of last name S23
- second and fifth letters of last name S25
- third and fifth letters of last name S35
- second, third and fifth letters of last name S235
- second and third letters of first name F23
- day of birth (d)
- month of birth (m)
- year of birth (y)
- sex (s)
- full person postcode (pc4)
- first 3 digits of person postcode (pc3)
- first 2 digits of person postcode (pc2)
- first digit of person postcode (pc1)
- suburb (used to derive pc1–pc4 if postcode was not reported, or to derive alternative postcodes)
- date of last completed ACAT assessment in a financial year (when matching ACAP MDS)
- ID of ACAT undertaking the last completed assessment in a financial year (when matching ACAP MDS).

Note that not all variables were available for linkage on all datasets. In particular, ACAT assessment data were available only for SPARC and ACAP program data. In addition, to avoid false matches due to the large number of assessments undertaken during a year, ACAT assessment date was not used without ACAT ID.

#### Box 3 (continued): Data used in key-based linkage

Since ACAP provides approvals for entry into RAC or for the use of care packages, and HACC is a service for people living in the community, the preferred postcode of usual residence used in KBL was that which related to living in the community. For people in permanent RAC this was the postcode of their usual residence before moving into RAC.

As people can move during the year, a person can have several postcodes recorded on the HACC or ACAP MDS. In such cases, all postcodes were included in the KBL process, with the priority of the postcode used in the KBL algorithm based on recency of use. In addition, for clients of permanent RAC, the postcode of their RAC facility was used as a (lower priority) alternative.

### 3.3 Quality of the data available for linkage

The presence of missing linkage data reduces the likelihood of identifying true matches. The number of missed matches is also relatively high if there are unreliable data on one of the data sets. However, if both data sets being matched have similar processes for recording poor information (for example, recording dates of birth as 1 January of the year derived from current age) then the likelihood of making false matches decreases.

The quality of the linkage data was examined in detail for PIAC 2011, and is reported in <u>Patterns in use of aged care: 2002–03 to 2010–11</u> AIHW 2014. In general, the data sets which included full name data were less likely to have missing name or date of birth information than those which contained the data for SLK-581 but not full name (ACAP and HACC MDSs). Under 0.2% of clients on data sets with full name data were missing either name or date of birth (DOB) information. From 2006–07, the ACAP MDS had similarly low numbers of records with insufficient data for linkage.

SLK data was less likely to be missing or unreliable on the ACAP MDS than on the HACC MDS. Records with missing elements of SLK-581 were less common on the ACAP MDS than on the HACC MDS from 2009–10 onwards, although in all years fewer than 0.5% of HACC quarterly records had insufficient data for linkage.

For PIAC 2014, the data are of similar quality.

# 4 Accessing PIAC 2014 data and information

Access to PIAC 2014 data and information can be facilitated in a number of ways. AIHW releases a range of reports and publications that use the linked data; these are available freely to download from the <u>AIHW Data linkage publications</u> page.

PIAC is a valuable resource and access can be facilitated through both customised data requests and through the integration of additional datasets to create an expanded linked database—the AIHW as an accredited Integrating Authority is able to facilitate both these avenues for researchers.

All data linkage projects and access to AIHW linked data can only be undertaken with the approval of the independent <u>AIHW Ethics Committee</u>. Further information on these processes is available through the <u>AIHW Data governance framework</u>.

More detailed information and supporting material for PIAC 2014 will be released in late 2017.

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