

Australian carer data sources: A comparative guide

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Australian carer data sources: A comparative guide is a regularly updated overview of datasets and major reports available in the Australian context that contain results relating to individuals who provide care and support to a family member or friend who lives with a disability, mental illness, alcohol or drug dependency, chronic condition, terminal illness or who is frail due to age. Multiple sources of data about carers exist across Australia, however not all are publicly available or widely known. This resource aims to raise awareness of existing data sources among researchers, policy makers, practitioners and carers in order to:

- Ensure that carer-related research, policy and practice is informed by reliable evidence
- Reduce duplication in effort and resourcing directed to generating evidence about carers
- Reduce the impost of data collection on carers, who often share their stories multiple times and may not always have time to participate in research
- Encourage integration and consistency between carer-related datasets

Data source	Access	Institution	Description	Limitations
<i>Australian Government datasets</i>				
Survey of Disability, Ageing and Carers (SDAC) (2022 latest data)	Published reports and data cubes, Tablebuilder, access to CURFS requires approval	Australian Bureau of Statistics (ABS)	Most comprehensive population-representative survey of carers and people receiving care	Estimates not reliable for smaller geographies, no estimates for Aboriginal and Torres Strait Islander population, focus on primary carers
Census (2021 latest data)	Published reports and data cubes, interactive data tools Tablebuilder, access to CURFS requires approval	Australian Bureau of Statistics (ABS)	General information on the Australian population, including whether someone provided care, reliable for smaller populations	No information about person receiving care or details of caring role

National Study of Mental Health and Wellbeing (2020-22 latest data)	Published reports and data cubes, own analysis requires authorisation and approval of undertaking	Australian Bureau of Statistics (ABS)	In depth mental health data	Cross-sectional only, carer identification only in microdata, results for carers not published
Time Use Survey (2020-21 latest data)	Published reports and data cubes	Australian Bureau of Statistics (ABS)	Population-representative time use study	Care defined as physical care only, underestimation of time spent on care activities when compared to care-focused surveys
Person Level Integrated Data Asset (PLIDA, formerly MADIP)	Own analysis requires authorisation and approval of undertaking, published reports	Australian Bureau of Statistics (ABS)	Provides whole-of-life insights through combination of Census and government datasets (ATO, Medicare, PBS, DSS/Centrelink, Education) for 2011 to 2019	Limited information on specifics of caring role
Gen Aged Care	Public, published reports	Australian Institute of Health and Welfare (AIHW)	Provides data on aged care service users and providers, e.g. usage, costs, care needs	Does not capture informal carers as providers of care, carer identification only available for Commonwealth Home Support Program (CHSP) participants (not for Home Care Package recipients or users of residential care), provides data on respite as reason for use of aged care services

Data On Multiple Individual Occurrences (DOMINO)	Analysis requires authorisation and approval of undertaking	Department of Social Services (DSS) and Australian Institute of Health and Welfare (AIHW)	Longitudinal dataset on DSS payment recipients' demographics, benefits history, concessions, education (where available) and housing.	Limited to carers who receive care-related Centrelink payments, no identification by care activity, no information about caring role
Dementia in Australia	Public articles and downloadable tables	Australian Institute of Health and Welfare (AIHW)	In-depth, cohort-specific analysis of carer data from the SDAC	Draws on other existing datasets
Australia's Welfare	Public reports and articles	Australian Institute of Health and Welfare (AIHW)	Biennial statistical summaries and long-form articles exploring topical welfare issues	Draws on other existing datasets
DSS Benefit and Payment Recipient Demographics (released quarterly)	Public data tables	Department of Social Services (DSS)	Quarterly data on demographics of DSS payment recipients	Limited to carers who receive care-related Centrelink payments, no identification by care activity, no information about caring role. Some issues with data extraction over the years has resulted in some inaccuracies in Carer Payment data, especially in relation to duration of payment. Cross-sectional, limited in comparability and cross-referencing of variables.

<u>Growing up in Australia: The Longitudinal Study of Australian Children (LSAC)</u>	Published reports, own analysis requires authorisation and approval of undertaking	Australian Institute of Family Studies (AIFS) and Department of Social Services (DSS)	Longitudinal study following the development of 10,000 young people and their families from birth into adulthood since 2003, linkages to health and educational data	Caring variables only included in three out of nine waves, limited information about caring role
<u>HILDA (Household Income and Labour Dynamics in Australia)</u>	Published reports, own analysis requires authorisation and approval of undertaking	Department of Social Services and The Melbourne Institute	Extensive longitudinal household survey, population-representative, can link carer and person receiving care	Limited specifics about caring role
<u>Ten to Men: The Australian Longitudinal Study on Male Health</u>	Published reports, own analysis requires authorisation and approval of undertaking	Australian Institute of Family Studies (AIFS) and Department of Health and Aged Care (DOHAC)	The 6 key research areas for the <i>Ten to Men</i> study are wellbeing and mental health, use of health services, health-related behaviours, health status, health knowledge, and social determinants	Carer identification does not explicitly reference caring for someone with a long term health condition or disability, or for someone with a problem related to old age. No information about caring role.
<u>Australian Longitudinal Women's Health Survey</u>	Published reports, own analysis requires authorisation and approval of undertaking	The University of Newcastle, The University of Queensland and the Department of Health and Aged Care (DOHAC)	Extensive longitudinal health survey since 1989, linkage available to administrative health data, educational outcomes of children	Limited carer respondents, no information about specifics of caring role

Longitudinal Surveys of Australian Youth (LSAY)	<p>Published reports and data tables, own analysis requires authorisation and approval of undertaking</p>	<p>National Centre for Vocational Education Research (NCVER), Department of Education and Wallis Social Research</p>	<p>Longitudinal study of youth transitions into adulthood, links to administrative educational datasets</p>	<p>Carer identification does not differentiate between caring for with a long term health condition or disability, or for someone with a problem related to old age, and child care</p>
National Disability Insurance Scheme (NDIS) Families and Carer Outcomes Reports	<p>Published reports</p>	<p>National Disability Insurance Agency (NDIA)</p>	<p>Provides annual and longitudinal short and long form data on the experiences and outcomes of family and carers of NDIS participants up to 2022, this includes the impact of NDIS on carer social and community participation, as well as health and wellbeing.</p>	<p>Opt-in participation with high drop off for successive years, not inclusive of all families and carers of NDIS participants.</p>
WGEA Data Explorer	<p>Dashboard</p>	<p>Workplace Gender Equality Agency (WGEA)</p>	<p>Annual collection of workplace data from Australian employers, captures prevalence of flexible working arrangements policies for carers and flexible working options across industries and employers</p>	<p>While greater emphasis has been placed on separating out parental leave information, data relating to carer-focused workplace policies does not differentiate policies or uptake of arrangements by parents and carers. Additionally, not all employers are required to report to WGEA annually, reporting has previously been optional for public service agencies and small-businesses</p>

Report on Government Services (ROGS) (14 Aged care services)	Published reports and data cubes	Productivity Commission	Annual report on the provision of government aged care services. Includes carer satisfaction with aged care services and respite use data (service use data).	Relies on SDAC data, does not collect or provide new data in relation to carer satisfaction of aged care services.
<i>Peak body and not-for-profit sector datasets</i>				
National Carer Survey	Biennial published reports and fact sheets, publicly available analysis on request	Carers NSW and the State and Territory Carer Organisations	National survey of carers, focusing on caring roles, interactions with aged care, disability, mental health and health services, carer wellbeing and recognition. Limited longitudinal dataset.	Convenience sampling limits representativity
Carer Wellbeing Survey	Annual published reports	Carers Australia, University of Canberra and Department of Social Services (DSS)	Survey on the wellbeing of carers in Australia, including service use.	Convenience sampling limits representativity, service use data not publicly accessible
Relationship Indicators: National Survey of the State of Relationships in Australia	Full report and interactive dashboard	Relationships Australia and The Social Research Centre	Survey to understand Australians' most meaningful relationships, including carers	Limited detail regarding the nature of care-based relationships specifically

45 and Up Study	Fee based access for use of SURE analysis platform	The Sax Institute, Cancer Council NSW, Heart Foundation and NSW Ministry of Health	Over 15 years of longitudinal data from surveys covering broad health and social topics, along with linked data from Medicare, Pharmaceutical Benefits Scheme, hospital, cancer registry and other datasets	NSW sample only
Cost of Living in NSW Survey	Annual published reports	NSW Council of Spsocial Service (NCOSS) and Institute for Public Policy and Governance (IPPG) at the University of Technology Sydney	Annual survey on the cost of living in NSW, identifies carers' experiences of financial hardship and employment	NSW sample only

Additional data sources

This resource is regularly updated. If you notice an error, have a suggestion to improve this information, or are aware of another data source that relates to carers which should be included, please advise the Carers NSW Research team by emailing research@carersnsw.org.au or phoning 02 9280 4744.

More information

This resource was compiled by the Carers NSW Policy and Research team as part of the Carer Knowledge Exchange, a research translation project funded by the NSW Government and delivered by Carers NSW in partnership with the Institute for Public Policy and Governance at the University of Technology Sydney. For more information about the Carer Knowledge Exchange, please visit www.carerknowledgeexchange.com.au.