

## Australian carer data sources: A comparative guide

Last updated November 2024

*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>				
<a href="#">Survey of Disability, Ageing and Carers (SDAC)</a> (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
<a href="#">Census</a> (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

<a href="#">National Study of Mental Health and Wellbeing (2020-21 latest data)</a>	Published reports and data cubes, own analysis requires authorisation and approval of undertaking	Australian Bureau of Statistics (ABS)	Summary statistics on key mental health issues including national and state and territory estimates of prevalence of mental disorders	Cross-sectional only, carer identification only in microdata, results for carers not published
<a href="#">Barriers and Incentives to Labour Force Participation (released quarterly)</a>	Data cubes, own analysis requires authorisation and approval of undertaking	Australian Bureau of Statistics (ABS)	Annual and quarterly data on people not working, or working less than they prefer, including whether they want to work, are looking for work, and factors for them to start working	Caring responsibilities and inflexible arrangements included as barriers, flexible working arrangements as incentives
<a href="#">Time Use Survey (2020-21 latest data)</a>	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
<a href="#">Person Level Integrated Data Asset (PLIDA, formerly MADIP)</a>	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
<a href="#">National Aboriginal and Torres Strait Islander Health Survey (2022-23 latest data)</a>	Data cubes, own analysis requires authorisation and approval of undertaking	Australian Bureau of Statistics (ABS)	Information on health, use of health services, health risk factors and social and emotional wellbeing of Aboriginal and Torres Strait Islander peoples	Data on whether or not participants provide unpaid care

<a href="#">Gen Aged Care</a>	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
<a href="#">Data On Multiple Individual Occurrences (DOMINO)</a>	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
<a href="#">Dementia in Australia</a>	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
<a href="#">Australia's Welfare</a>	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
<a href="#">DSS Benefit and Payment Recipient Demographics</a> (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. Crossectional, limited in comparability and cross-referencing of variables.
<a href="#"><u>Growing up in Australia: The Longitudinal Study of Australian Children (LSAC)</u></a>	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
<a href="#"><u>Footprints in Time: The Longitudinal Study of Indigenous Children (LSIC)</u></a>	Published reports, own analysis requires authorisation and approval of undertaking	Department of Social Services	Longitudinal study following the development of around 1,700 Aboriginal and Torres Strait Islander children and their families across urban, regional and remote Australia.	Child's caring responsibilities added in Wave 9
<a href="#"><u>HILDA (Household Income and Labour Dynamics in Australia)</u></a>	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
<a href="#"><u>Ten to Men: The Australian Longitudinal Study on Male Health</u></a>	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.

<a href="#">Australian Longitudinal Women's Health Survey</a>	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 data, administrative health data, educational outcomes of children	Limited carer respondents, no information about specifics of caring role
<a href="#">Longitudinal Surveys of Australian Youth (LSAY)</a>	Published reports and data tables, own analysis requires authorisation and approval of undertaking	National Centre for Vocational Education Research (NCVER), Department of Education and Wallis Social Research	Longitudinal study of youth transitions into adulthood, links to administrative educational datasets	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
<a href="#">National Disability Insurance Scheme (NDIS) Families and Carer Outcomes Reports</a>	Published reports	National Disability Insurance Agency (NDIA)	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.	Opt-in participation with high drop off for successive years, not inclusive of all families and carers of NDIS participants.
<a href="#">WGEA Data Explorer</a>	Dashboard	Workplace Gender Equality Agency (WGEA)	Annual collection of workplace data from Australian employers, captures prevalence of flexible working arrangements policies for	While greater emphasis has been placed on separating out parental leave information, data relating to carer-focused workplace policies does not



			carers and flexible working options across industries and employers	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
<a href="#">Report on Government Services (ROGS) (14 Aged care services)</a>	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.
<a href="#">GENERATION Survey</a>	Published reports and data tables, own analysis requires authorisation and approval of undertaking	Centre for Social Research Methods, Australian National University, funded by the Australian Department of Education and all state and territory governments	A study of students from about 300 schools across the country that aims to reflect the collective experience of young Australians – inside and outside school, while providing both participants and educators valuable insights into career interests and post-school plans.	In Wave 2, young people were asked whether they were a young carer in the last 6 months. Year 10 and Year 11 students only to date.
<i>Non-government data sets</i>				

<a href="#">National Carer Survey</a>	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
<a href="#">Carer Wellbeing Survey</a>	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
<a href="#">Relationship Indicators: National Survey of the State of Relationships in Australia</a>	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
<a href="#">Australian Unity Wellbeing Index</a>	Annual published reports and interactive dashboard	Australian Unity and Deakin University	General population survey running for over 20 years monitoring Personal Wellbeing Index scores	Carer variable included, with some carer-specific outputs
<a href="#">45 and Up Study</a>	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,	NSW sample only

			hospital, cancer registry and other datasets	
<a href="#">Cost of Living in NSW Survey</a>	Annual published reports	NSW Council of Social 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](mailto: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. For more information about the Carer Knowledge Exchange, please visit [www.carerknowledgeexchange.com.au](http://www.carerknowledgeexchange.com.au).