Australian Carer Data Sources

A Comprehensive Comparative Guide - 2026 Edition

A regularly updated overview of all major datasets, surveys and research sources containing insights about informal carers in Australia — for researchers, policy makers, practitioners and carers.

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.

This resource is regularly updated. If you notice an error, have a suggestion, or are aware of another data source that should be included, please contact the Carers NSW Research team: ✉ research@carersnsw.org.au ✆ 02 9280 4744

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About This Guide

Multiple sources of data about carers exist across Australia, but not all are publicly available or widely known. This guide aims to raise awareness of existing data sources among researchers, policy makers, practitioners and carers, to reduce duplication of effort and to reduce the need for carers to share their stories multiple times.

Purpose

This guide supports evidence-based practice and policy by making data sources accessible and comparable. We encourage researchers and policy makers to use existing data where possible, and to engage consistently with the carer evidence base.

Who is a Carer?

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness, or who is frail due to age.

How to Use This Guide

Each source is listed with its collection frequency, most recent data, access pathway, key carer-specific insights, scope and known limitations. Sources marked NEW were added in this 2026 edition. Always verify directly with each institution for the most current release.

Access Key

- **Green text** = Freely available online, no application needed
- **Orange text** = Application or ethics approval needed for microdata access
- **Purple text** = Cost or platform subscription required

Most Comprehensive Single Source

- The Survey of Disability, Ageing and Carers (SDAC) remains the gold standard — the most comprehensive population-representative survey of carers in Australia, conducted by the ABS approximately every four years.
- For in-depth, non-representative data on lived carer experience, the National Carer Survey is the richest single source.

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Key Statistics at a Glance

3 million carers
in Australia

Australian Bureau of Statistics 2022 Survey of Disability, Ageing and Carers

1 in 8
Australians is a carer

Australian Bureau of Statistics 2022 Survey of Disability, Ageing and Carers

391,300 carers
under the age of 25

Australian Bureau of Statistics 2022 Survey of Disability, Ageing and Carers

$77.9 billion
the cost to replace carers for only one year

Deloitte Access Economics 2020, The value of informal care in Australia

8 million hours
of care provided every week

Australian Bureau of Statistics 2022 Survey of Disability, Ageing and Carers

54% of carers
report high psychological distress

Carers NSW 2024 National Carer Survey

Quick Reference: Which Source for Which Question?

- How many carers are there? → SDAC (national) or Census (local).
- Carer Payment recipients? → DSS Benefit & Payment Demographics.
- Carers' life experiences? → National Carer Survey.
- Impact of NDIS on families? → NDIS Family & Carer Outcomes Reports.
- Carer wellbeing? → Carer Wellbeing Survey and National Carer Survey.
- Carers' employment & income over time? → HILDA.

National Carer Strategy 2024 – 2034
Priority Outcome Area 6: Build the evidence base about carers to better understand who carers are, including their diversity, what their experiences are, what works for them and why.

How This Guide Contributes to National Carer Strategy Priority Outcome Area 6

The National Carer Strategy 2024–2034 was released by the Australian Government on 10 December 2024. It sets out a decade-long national agenda to support Australia's unpaid carers, co-designed with carers themselves. Priority Outcome Area 6 directly addresses the need to build a stronger, more comprehensive evidence base — one that reflects the true diversity of carers and generates knowledge that can drive effective policy and practice.

This guide is a direct contribution to that priority. It maps the full landscape of existing data — identifying what we know, how reliably we know it, and where the gaps are. It is designed to:

- Support researchers and policy makers to use existing data efficiently, rather than designing new studies that duplicate what already exists.
- Ensure that data-driven decisions about carer policy are grounded in the best available evidence, including its limitations.
- Promote data sharing and integration across sectors — encouraging linkage of administrative, longitudinal and survey datasets to generate richer insights.
- Identify and advocate for investment in the specific evidence gaps that remain, particularly around diverse carer populations and what actually works to support carers.

The Three Questions Priority Outcome Area 6 Asks — and What Each Requires

1. Who carers are, including their diversity

This requires population-level, identity-disaggregated data. The SDAC (ABS) provides the best national estimate of carer numbers and demographics, but its definition of carer is narrower than the *Carer Recognition Act 2010*, and it does not provide reliable estimates for Aboriginal and Torres Strait Islander carers, CALD carers, or LGBTQIA+ carers. The ABS Census provides local-area estimates but with very limited detail. Convenience-based surveys like the National Carer Survey and Carer Wellbeing Survey capture richer diversity data but are not population-representative.

2. What carers' experiences are

Experience data — wellbeing, financial hardship, employment, social isolation, service access — is captured most richly by the National Carer Survey, the Carer Wellbeing Survey, and HILDA (for longitudinal tracking). NDIS Family and Carer Outcomes Reports provide strong experience data for the subset of carers connected to the NDIS. However, no single survey regularly captures the experiences of carers who do not identify themselves as carers or are not connected to any formal service or payment system — the so-called 'hidden carers'.

3. What works for carers, and why

This is the weakest part of the current evidence base. As the AIFS Rapid Scoping Review (2024), commissioned to support the National Carer Strategy, concluded that evidence on what works to support carers is critical for informing policy, but very scant. No dataset in this guide systematically evaluates the effectiveness of carer supports or interventions. The National Carer Survey and Carer Wellbeing Survey track service use alongside wellbeing but do not constitute rigorous program evaluations. Addressing this gap will require dedicated investment in program evaluation frameworks embedded in future policy design.

National Carer Strategy context

The Strategy's companion Action Plan 2024–2027 commits the Australian Government to a monitoring and evaluation framework to track progress against Strategy outcomes. This guide can inform that framework by identifying existing measures for each priority area and flagging where new data collection is needed. Priority Outcome Area 6 does not stand alone — building the evidence base is an enabler for all other priority areas, from recognition and identification of carers (Area 1) through to improving carer wellbeing (Area 5).

References:

- *Department of Social Services (2024). National Carer Strategy 2024–2034. Australian Government. health.gov.au/our-work/national-carer-strategy*
- *Sibly, C. & Andersson, C. (2024). Building the evidence base for the National Carer Strategy: Rapid review of the evidence. AIFS for DSS.*

Section 1 – Government Datasets

Population-representative and administrative data collections managed by Australian Government agencies

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
Survey of Disability, Ageing and Carers (SDAC) *Australian Bureau of Statistics (ABS)*	**Every ~4 years**	2022 data (released July 2024)	• **Public reports** • **Application required for microdata**	– 3.0 million carers = 11.9% of Australians (up from 10.8% in 2018) – 1.2 million primary carers; 43.8% have disability themselves – 391,300 young carers (under 25) — up from 235,300 in 2018 – 12.8% of females are carers vs 11.1% of males – 95.9% of older Australians live in households; 39.8% need assistance at home	**National** **Population-representative** *⚠ No Aboriginal or Torres Strait Islander estimates; focus on primary carers; not reliable at smaller geographies*	abs.gov.au
ABS Census of Population and Housing *Australian Bureau of Statistics (ABS)*	**Every 5 years**	2021 (next: 2026)	• **Freely available online** • **Application required for microdata**	– Identifies those providing unpaid care in the reference week – Reliable estimates at small geographies (LGA and suburb level) – Useful baseline for local carer population planning and service distribution	**National to suburb level** *⚠ No detail on person receiving care or nature of caring role*	abs.gov.au/census
National Study of Mental Health and Wellbeing *Australian Bureau of Statistics (ABS)*	**Irregular**	2020–21	• **Authorisation required**	– In-depth mental health data linkable to carer status in microdata – Can examine intersections of mental ill-health and caring roles	**National** *⚠ Cross-sectional only; carer results not published separately; carer identification only available in restricted microdata*	abs.gov.au
Time Use Survey *Australian Bureau of Statistics (ABS)*	**Irregular (~10 years)**	2020–21	• **Freely available online**	– Quantifies hours Australians spend on unpaid care activities – Reveals gendered distribution of care time across the population	**National** *⚠ Care is defined as physical care only — underestimates total time and effort involved in caring*	abs.gov.au

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DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
Person Level Integrated Data Asset (PLIDA / formerly MADIP) *Australian Bureau of Statistics (ABS)*	**Ongoing / longitudinal**	Updating (data to 2019+)	**• Approval required**	– Links Census, ATO, Medicare, PBS, DSS and Education data – Enables whole-of-life insights — carer payment history, health service use, education – Powerful for longitudinal policy analysis of carer outcomes over time	**National** *⚠ Limited specifics on caring role; complex approval process via ABS DataLab*	abs.gov.au
DSS Benefit & Payment Recipient Demographics *Department of Social Services (DSS)*	**Quarterly**	March 2026	**• Public data tables**	– Numbers receiving Carer Payment and Carer Allowance each quarter – Demographics: age, gender, state/territory, payment duration – Tracks trends in formal carer support uptake over time	**National** *⚠ Centrelink recipients only; no information on caring role, the person receiving care, or carer wellbeing*	data.gov.au
Data On Multiple Individual Occurrences (DOMINO) *DSS & AIHW*	**Ongoing / longitudinal**	Ongoing	**• Approval required**	– Longitudinal dataset on DSS payment recipients – Links demographics, benefit history, concessions, education and housing – Enables tracking of carer payment trajectories across years	**National** *⚠ Centrelink payment recipients only; no care activity identification or carer wellbeing data*	aihw.gov.au
WGEA Data Explorer Dashboard *Workplace Gender Equality Agency (WGEA)*	**Annual**	2024–25	**• Public dashboard**	– Captures carer-related flexible working policies reported by employers – Covers industries and sectors; identifies gaps in carer-friendly workplaces	**National** **Employer-level** *⚠ Does not separate carer vs parent flexible working; not all employers required to report*	wgea.gov.au
NDIS Family and Carer Outcomes Reports *National Disability Insurance Agency (NDIA)*	**Annual (since 2018)**	To 30 June 2024 (released Dec 2024)	**• Published reports + interactive dashboard**	– 75% of families/carers feel more confident about the future of their family member – 81% agree the NDIS helped them better care – 55% of families/carers in paid employment – Longitudinal data from 2016 covering health, wellbeing and community participation	**National** **NDIS participants only** *⚠ Opt-in sampling with high drop-off rates; not all NDIS-supported families included*	dataresearch.ndis.gov.au

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
Report on Government Services (ROGS) — Community Services *Productivity Commission*	**Annual**	2026 (2024–25 data)	• **Public reports & data cubes**	– Annual report on provision of government aged care services nationally – Includes carer satisfaction with aged care and respite use (service use data)	**National** *⚠ Relies on existing SDAC data; does not collect new primary carer satisfaction data independently*	pc.gov.au
Barriers and Incentives to Labour Force Participation *Australian Bureau of Statistics (ABS)*	**Annual (quarterly outputs)**	December 2025 (quarterly); 2024–25 financial year (annual)	• **Freely available online** • **Application required for microdata**	– Captures reasons people are not working or not fully employed — including caring for children or family members – 'Caring for children' is consistently the leading reason women aged 25–39 do not want a paid job; caring for family members is a key barrier across all age groups – Reveals gendered and age-based patterns of care-related labour force withdrawal; quarterly and annual outputs available; microdata accessible via TableBuilder and DataLab	**National** *⚠ Not a dedicated carer survey; care is captured indirectly as a reason for non-participation; does not distinguish type of caring role. Survey currently transitioning to a new format from 2025–26 onward*	abs.gov.au
National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) *Australian Bureau of Statistics (ABS)*	**Irregular (~4–5 years)**	2022–23 (released 2024)	• **Application required for microdata**	– Largest health survey of Aboriginal and Torres Strait Islander peoples; collects data on health conditions, disability, use of health services, and social and emotional wellbeing – 31% of people aged 18+ in non-remote areas experienced high or very high psychological distress; 41% of households experienced food insecurity — both key indicators of carer burden in First Nations communities – Best available source for understanding the health context of caring in Aboriginal and Torres Strait Islander communities; linkable to biomedical data from the companion NATSIHMS	**National** *⚠ Aboriginal and Torres Strait Islander peoples only; does not identify carers explicitly — carer status must be inferred from disability and health condition data; irregular collection cycle*	abs.gov.au
ABS Labour Account — Unpaid Care Experimental Estimates *Australian Bureau of Statistics (ABS)*	**Annual (experimental)**	June 2025 (time series Jun 2006–Sep 2024)	• **Freely available online**	– First national experimental estimates of the total hours and monetary value of unpaid adult care in Australia; adult care valued at $136.7 billion in the September quarter 2024	**National** *⚠ Experimental estimates only; methodology still maturing; does not identify individual carers or carer demographics beyond sex*	abs.gov.au

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
				— Covers unpaid adult care (excluding childcare) using a replacement cost methodology drawn from ABS Time Use Survey data — Breaks down estimates by sex and age; planned for annual release as part of the Labour Account from mid-2026 onwards – Provides the most comprehensive economic valuation of unpaid care work available in Australia; directly relevant to carer recognition and workforce participation policy	*and age; no carer health or wellbeing data*	

Section 2 – Government Synthesis Reports

Reports synthesising data from multiple collections into accessible policy intelligence

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
Australia's Welfare — Informal Carers *Australian Institute of Health and Welfare (AIHW)*	**Biennial**	2025 edition (Oct 2025)	**• Freely available online**	– Synthesises SDAC, NDIS, carer surveys and administrative data into one accessible report – Covers carer wellbeing, demographics, service use and care recipient characteristics – Key policy reference — tracks trends across editions since 1993	**National synthesis** *⚠ Draws on other datasets; no primary data collection*	aihw.gov.au
Dementia in Australia *Australian Institute of Health and Welfare (AIHW)*	**Updated periodically**	2024	**• Public articles & data tables**	– In-depth, cohort-specific analysis of carer data drawn from the SDAC – Focuses on carers of people living with dementia — a large and growing cohort – Covers carer burden, weekly care hours and support service use	**National** *⚠ Draws on SDAC and existing datasets; not a new primary data collection*	aihw.gov.au
GEN Aged Care Data *Australian Institute of Health and Welfare (AIHW)*	**Annual**	2024-25 (released Oct 2025)	**• Freely available online**	– Data on aged care service users, providers, costs and assessed care needs – Identifies carer support via Commonwealth Home Support Programme (CHSP) – Tracks respite use as a measure of carer support need	**National** *⚠ Does not capture informal carers as providers; carer identity not available in Home Care Packages or residential care*	gen-agedcaredata.gov.au
Australia's Disability Strategy Outcomes Framework — Annual Report NEW *AIHW*	**Annual**	3rd Annual Report (2025)	**• Freely available online**	– Dedicated section on informal and carer supports – Tracks whether carers of people living with disability are receiving adequate support – Links carer outcomes to Australia's Disability Strategy 2021–2031 goals	**National** *⚠ Measures primary carers only; draws on existing datasets*	aihw.gov.au

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
Consumer and Carer Perspectives of Mental Health Care (AIHW Mental Health Online Report) NEW *Australian Institute of Health and Welfare (AIHW)*	**Annual (updated multiple times per year)**	Data to 2022–23; updated September 2025	**● Freely available online**	– National synthesis of Carer Experience Survey (CES) data from NSW, Queensland and Victoria; presents carer-rated experience scores by service setting, age, and Indigenous status – NSW has publicly reported CES data since 2015–16; Victoria from 2016–17 (via the Victorian Mental Health Services Annual Report); Queensland for 2015–2017 and 2019 only – Scores reflect carer experience across domains including respect, involvement in care, and making a difference; calculated from the nationally standardised CES instrument – Only national synthesis of CES data across jurisdictions; key source for cross-state comparison of mental health carer experience	**National (NSW, Qld, Vic only); SA, WA, Tas, ACT, NT not currently reporting** *⚠ Data coverage is 2015–16 to 2022–23; Queensland data limited to early years only; carers of people in private mental health services not captured; significant jurisdictional gaps*	aihw.gov.au
Income Support Payments for the Working Age Population NEW *Australian Institute of Health and Welfare (AIHW)*	**Updated annually (with quarterly DSS source data)**	Data to March 2025	**● Freely available online**	– Tracks Carer Payment and Carer Allowance recipients over time, with demographic breakdowns by age, sex, state/territory, and duration on payment – As at March 2025, 256,000 working-age people (aged 16–64) were receiving Carer Payment — 1.5% of the population in that age group – Draws on DSS Benefit and Payment Recipient Demographics (quarterly); links to companion reports on income support for older Australians and First Nations people – Key source for tracking trends in formal carer recognition through the income support system; useful for policy advocacy on adequacy of Carer Payment	**National** *⚠ Administrative data only; counts payment recipients, not all carers; excludes carers who do not meet eligibility criteria or who have not applied; no data on carer wellbeing or caring intensity*	aihw.gov.au
National Drug Strategy Household Survey (NDSHS) 2022–23 NEW *Australian Institute of Health and Welfare (AIHW)*	**Every 3 years**	2022–23 (released 2024; updated May 2025)	**● Freely available online; microdata via DataLab**	– National household survey of 21,663 people aged 14+; covers use of alcohol, tobacco, e-cigarettes, and illicit drugs, and harms experienced by family members from others' drug use	**National** *⚠ Does not identify respondents as carers; family member harm data does not distinguish caring relationships from other*	aihw.gov.au

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
				– Captures data on the proportion of Australians who experienced verbal or physical abuse from someone under the influence of alcohol or drugs — directly relevant to carers of people with substance use disorders – In 2022–23, around 1 in 5 people (21%) reported being harmed by someone else's alcohol use; 2.4 million women experienced harm from others' alcohol use – Next wave will be 2025–26; the most comprehensive national population-level survey of AOD harms to families and communities available in Australia	*relationships; three-yearly collection limits currency*	

Section 3 – Peak Body and Sector Surveys

Surveys conducted by carer-focused organisations providing rich lived-experience insights

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
National Carer Survey (NCS) *Carers NSW & State/Territory Carer Organisations*	**Biennial (since 2010)**	2024 (full results April 2025) – next 2026	**• Published reports & fact sheets**	– 10,096 responses across all states and territories – 54% of carers report high/very high psychological distress (up from 48% in 2020) – 59% experienced financial stress (up from 51% in 2020) – Nearly 1 in 2 carers do not feel recognised by government or community – Only 44.1% feel valued by service providers – Specific fact sheets for First Nations carers and young carers	**National** *⚠ Convenience sampling; not population-representative; respondents are connected carers*	carersnsw.org.au
Carer Wellbeing Survey (CWS) *Carers Australia, University of Canberra & DSS*	**Annual (since 2021)**	2025 (series runs to 2026)	**• Published annual reports**	– Focuses on carer wellbeing, quality of life and Carer Gateway service use – Carers consistently report among the lowest wellbeing of any Australian cohort – Unpaid carer contribution valued at $77.9 billion (Deloitte 2020 estimate) – ARC-funded longitudinal series including past carers as well as current carers	**National** *⚠ Convenience sampling; detailed service use data not publicly accessible*	carersaustralia.com.au
Relationship Indicators — National Survey *Relationships Australia & Social Research Centre*	**Annual**	2024	**• Full report + public dashboard**	– Captures Australians' most meaningful relationships including care-based relationships – Relevant to understanding social isolation and connection dimensions of caring	**National** *⚠ Limited detail on care-based relationships specifically; not designed as a carer survey*	relationships.org.au
Australian Unity Wellbeing Index (AUWI) *Australian Unity & Deakin University*	**Annual (since 2001)**	2025 (Survey 41)	**• Published annual reports + data dashboard**	– Australia's longest-running annual study of subjective wellbeing; over 78,000 Australians surveyed across 41 waves since 2001	**National** *⚠ Convenience sampling; carer data not collected in every wave; not designed primarily as a carer survey; carer results only*	australianunity.com.au

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
				– Dedicated carer module in Survey 40 (2023) found informal carers had significantly lower personal wellbeing and higher rates of mental distress than professional carers or non-carers – 2025 survey mapped wellbeing across all 148 federal electorates for the first time; measures personal and national wellbeing across seven key life domains	*available in specific themed survey years*	
Annual Young Carers Survey NEW *Little Dreamers Australia*	**Annual (first wave 2025)**	2025 (released February 2026)	**● Freely available online**	– Australia's first-ever dedicated annual young carer survey; 267 respondents aged 4–25 from across Australia; captures quantitative trends and qualitative insights into the lives of young carers – Over 1 in 3 miss school every week; 67% report affected grades; 23% missed more than 6 school days last term; 58% of families experience chronic financial stress and 47% go without essentials – 74% care for a sibling, 36% for a parent; emotional support (near-universal), cleaning, cooking, personal care, medication management and interpreting are the most common tasks; 35% care for more than one person	**National** *⚠ Small convenience sample (267); not population-representative; first wave only so no longitudinal data yet; respondents are connected young carers reached through Little Dreamers' networks*	littledreamers.org.au
At What Cost? The Experiences of Unpaid Mental Health Carers in Queensland 2023–2024 NEW *Mental Health Carers Queensland (MHCQ)*	**Irregular (first wave 2023–24)**	2023–24 (released 2024)	**● Freely available online**	– Dedicated survey of unpaid mental health carers in Queensland; covers financial impacts, employment, health and wellbeing, service access, and recognition by the mental health system – Finds that caring for someone with a mental illness has significant economic costs including lost income, reduced employment hours, and out-of-pocket care expenses – Provides Queensland-specific data on mental health carer experiences not available through the national CES or National Carer Survey – Produced by the peak body for mental health carers in Queensland; useful for state-level advocacy and system improvement	**Queensland only** *⚠ Self-selected convenience sample; not population-representative; produced by a peak body rather than independent research body; irregular collection with no confirmed future waves*	mhcq.org.au

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
SANE Australia — National Stigma Report Card (2025 wave) NEW *SANE Australia & University of Melbourne*	**Irregular (waves in 2020 and 2024)**	2025 Report Card (based on 2024 survey; published February 2026)	**● Freely available online; data explorer on website**	— Nationally representative survey of 6,032 Australians conducted in 2024 via the Life in Australia™ probability panel; assesses experiences of stigma and discrimination among people with mental health problems — Includes a dedicated carer stigma module (reported in a companion publication); 67.7% of respondents agreed stigma and discrimination were worse than their mental health problem itself — Interactive data explorer allows filtering by mental health condition, life domain (family, work, health services), and demographic characteristics – First survey of its kind in Australia to comprehensively measure stigma and discrimination across multiple life domains; partnership between NMHC and SANE will continue with a second wave in 2028	**National** *⚠ Primary focus is people with mental health issues, not carers; carer stigma module is a sub-analysis; irregular collection cycle; 2020 wave used non-probability panel ("Our Turn to Speak" sample of ~2,000)*	nationalstigmareportcard.com.au

Section 4 – Longitudinal Studies with Carer Data

Multi-wave studies by government agencies and universities that can track carer outcomes over time

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
Household, Income and Labour Dynamics in Australia (HILDA) *DSS & Melbourne Institute, University of Melbourne*	**Annual (since 2001)**	Wave 22 (2022 data)	• **Application required**	– Tracks income, employment, health and wellbeing longitudinally across households – Can link carer status to employment, income and housing outcomes over time – Population-representative; can link carer and care recipient within a household	**National** ⚠ *Limited specifics on nature of the caring role or the condition of the person receiving care.*	melbourneinstitute.unimelb.edu.au
Longitudinal Study of Australian Children (LSAC / Growing Up in Australia) *Australian Institute of Family Studies (AIFS) & DSS*	**Biennial waves (since 2003)**	Wave 9 (2020–21)	• **Application required**	– 10,000 young Australians tracked from birth into adulthood – Contains data on parental caring roles and child development outcomes – Linkage available to health and educational administrative data	**National** ⚠ *Carer variables available in only 3 of 9 waves; limited caring role detail*	growingupinaustralia.gov.au
Australian Longitudinal Women's Health Survey (ALSWH) *University of Newcastle, University of Queensland & Dept of Health and Aged Care*	**Multiple waves (since 1989)**	Ongoing	• **Application required**	– Extensive longitudinal health survey of women across cohorts and life stages – Linkage to health administrative data and educational outcomes – Examines long-term impact of caring on women's health over decades	**National** **Women only** ⚠ *Limited carer respondents; no specifics on caring role or the person receiving care.*	alswh.org.au
Ten to Men — Australian Longitudinal Study on Male Health *AIFS & Department of Health and Aged Care*	**Multiple waves (since 2013)**	Wave 4 (2022–23)	• **Application required**	– Covers wellbeing, mental health, health behaviours and social determinants in men – Can examine male carer health outcomes longitudinally across waves	**National** **Men & boys only** ⚠ *Carer identification does not explicitly reference long-term conditions or age-related care roles*	tentomen.org.au

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
Longitudinal Surveys of Australian Youth (LSAY) *NCVER, Department of Education & Wallis Social Research*	**Annual waves**	Ongoing	• **Application required**	– Tracks young Australians' transitions from school into employment and adulthood – Linkage to administrative educational datasets – Relevant to young carers' educational and employment outcomes	**National** **Youth only** *⚠ Carer identification does not distinguish disability/age care from general childcare*	lsay.edu.au
45 and Up Study *Sax Institute, Cancer Council NSW, Heart Foundation & NSW Ministry of Health*	**Multiple waves (since 2006)**	Ongoing (15+ years of data)	• **Fee-based (SURE platform)**	– Largest study of healthy ageing in the Southern Hemisphere (267,000+ participants) – Broad health and social topics; linkable to Medicare, PBS, hospital and cancer data – Relevant for ageing carers and the long-term health impacts of caring roles	**NSW only** *⚠ NSW sample only; requires fee-based access via the Secure Unified Research Environment (SURE)*	saxinstitute.org.au
Footprints in Time: The Longitudinal Study of Indigenous Children (LSIC) *Department of Social Services (DSS)*	**Annual waves (since 2008)**	Wave 14+ (ongoing)	• **Application required**	– Follows up to 1,759 Aboriginal and Torres Strait Islander children and their families across urban, regional and remote Australia; one of the largest longitudinal studies of Indigenous people worldwide – Primary carers (usually mothers) and significant carers (fathers) interviewed at each wave; research links carer experiences of financial strain, family stress and life events to children's social and emotional wellbeing – Designed to inform Closing the Gap initiatives; guided by a majority-Indigenous Steering Committee; data available via Australian Data Archive	**National** *⚠ Carer identification does not distinguish disability/age care from general childcare; not population-representative; non-random site selection; complex application process via Australian Data Archive*	dss.gov.au
GENERATION Survey *Australian National University (ANU), ACER & Social Research Centre; commissioned by the Department of Education*	**Annual waves (anticipated 10 years; began 2022)**	Wave 3 (2024); ongoing	• **Application required**	– National longitudinal study of young Australians tracking transitions from school to post-school; focus on how COVID-19 may affect education and career pathways; anticipated to run for 10 years – In Wave 2 16-17 year olds were asked about whether they we young carers and results were published in a dedicated report in 2024	**National** *⚠ Young people only (school-to-post-school cohort); does not always identify young carers; study commenced 2022 and is still in early waves with limited longitudinal depth*	generationsurvey.net

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
				– Collects data on disability and long-term health conditions; relevant to understanding how young carer status intersects with educational and career disruption – Linkable to NAPLAN, senior secondary results and the Australian Early Development Census; data archived at the Australian Data Archive		

Section 5 – State and Territory Datasets

Data collections that count carers within Australia's different states and territories

DATASET / SURVEY	FREQUENCY	LAST COLLECTED	ACCESS	KEY CARER INSIGHTS	SCOPE & LIMITATIONS	WEBSITE
Cost of Living in NSW Survey *NCOSS & Institute for Public Policy and Governance, UTS*	**Annual**	2024	• **Freely available online**	– Identifies carers' specific experiences of financial hardship in NSW – Covers employment impacts and cost-of-living pressures on carers in NSW – Useful for NSW-specific advocacy, budget submissions and government engagement	**NSW only** *⚠ NSW convenience sample; not population-representative.*	ncoss.org.au
NSW Health Patient Survey (carer sub-analysis) NEW *NSW Ministry of Health / Bureau of Health Information (BHI)*	**Annual**	2024	• **Freely available online (BHI)**	– Identifies carer inclusion in discharge planning and treatment decisions – Relevant for system-level advocacy on carer recognition in NSW health settings	**NSW only** *⚠ Carers identified as a subset only; not the primary focus of the survey*	bhi.nsw.gov.au

Evidence Gaps and Future Data Priorities

Despite the breadth of data sources catalogued in this guide, significant gaps remain. The 2024 AIFS Rapid Scoping Review, commissioned to support the National Carer Strategy, confirmed that while high-level population data on carers is relatively good, the evidence base on diversity and — critically — what works to support carers is still underdeveloped. The gaps below represent research and data investment priorities.

Gap 1 – Diversity: Aboriginal and Torres Strait Islander Carers

No dataset provides reliable, statistically robust data on Aboriginal and Torres Strait Islander carers at the national level. The SDAC explicitly notes it cannot produce ATSI carer estimates. Yet Indigenous communities often carry disproportionate informal caring burdens due to higher rates of disability, chronic disease, and intergenerational trauma — and caring responsibilities are deeply embedded in cultural obligation and kinship structures that may not be captured by Western definitions of 'carer'. A dedicated, culturally safe data strategy is needed.

Gap 2 — Diversity: Culturally and Linguistically Diverse (CALD) Carers

CALD carers are systematically under-identified across all major datasets. Language barriers, differing cultural conceptualisations of caring, and distrust of formal data systems mean CALD carers are less likely to respond to surveys, engage with support services, or be identified in administrative data. No dataset provides reliable disaggregated estimates by country of birth, language spoken at home, or migration status for the carer population with reference to details about their caring activities.

Gap 3 — Diversity: LGBTQIA+ Carers

LGBTQIA+ carers are not reliably identifiable in any nationally representative dataset. Neither the SDAC nor the Census currently enables analysis of carer status by sexual orientation or gender identity. This means the unique challenges faced by LGBTQIA+ carers — including potential discrimination in service settings, non-recognition of chosen family structures, and intersecting mental health vulnerabilities — are effectively invisible to policy makers.

Gap 4 — Hidden Carers: Scale and Characteristics of the Unidentified Carer Population

Many people providing substantial informal care do not identify as carers, particularly those caring for someone with a mental health condition, those from cultural backgrounds where caring is seen as a family duty rather than a role, and those in early-stage or intermittent caring roles. The true scale of hidden carers is unknown. No dataset is designed to capture this population. Better identification methodology — including carer screening in health, housing, employment, and education settings — is a critical gap.

Gap 5 — What Works: Evaluation Evidence on Carer Supports and Interventions

This is the most significant systemic gap in the carer evidence base. No dataset currently captures rigorous evidence on whether the supports available to carers — Carer Gateway services, respite, peer support, financial payments, flexible employment supports — are actually improving outcomes. The AIFS review found that evidence on effectiveness is 'very scant', part of which is due to unclear and conflicting program objectives that make evaluation difficult. What is needed is: (1) standardised outcome measurement embedded in funded carer programs; (2) longitudinal evaluation frameworks that track outcomes over time; and (3) cost-effectiveness analysis to guide investment decisions.

Gap 6 — Secondary and 'Other' Carers

Most datasets focus primarily or exclusively on primary carers — those providing the greatest share of care to a single person. Secondary carers (who share caring with a primary carer) and 'other carers' (those providing lower-level, non-core assistance) are largely invisible. Yet these carers may number in the millions and face their own significant burdens. The SDAC partially identifies these groups but does not collect detailed data on their experiences or outcomes.

Gap 7 — Carers Not Connected to the Formal System

Administrative data (DSS payment data, NDIS outcomes data, GEN aged care data) is inherently limited to carers who are engaged with formal services or payment systems. A very large share of carers — particularly those caring for someone with mental illness, those in rural and remote areas, young carers, and those who have not sought formal support — do not appear in these datasets at all. This creates a systematic evidence bias towards the experiences of carers who are already connected to the system.

Gap 8 — Longitudinal Tracking of Carer Transitions: Into, Through, and Out of Caring

While HILDA provides the best available longitudinal tracking of carer status in Australia, it does not capture the detail needed to understand how caring roles begin, escalate, change, and end — and what happens to carers afterward. Former carers (post-bereavement, post-placement, post-recovery of care recipient) face their own distinct challenges, including grief, disrupted employment, and re-entering social and economic life. No dataset adequately tracks this carer lifecycle.

Gap 9 — Young Carers' Education and Employment Outcomes

Young carers — now estimated at 391,300 nationally (up 66% since 2018) — are a rapidly growing cohort with distinct and acute needs. While LSAY and LSAC could theoretically track young carer outcomes, neither survey contains sufficient carer-specific variables to understand the impact of caring on educational engagement, attainment, peer relationships, mental health, and early employment transitions. A dedicated young carer longitudinal study or a substantial boost to carer data in existing youth longitudinal studies is warranted.

Gap 10 – Restored Investment to Enhance Existing Data

While less representative of the broader population than the Census due to being a weighted sample survey, the SDAC provides an unparalleled level of detail about the characteristics and service engagements of carers and the older people and people living with disability for whom they care. Until recently, this allowed for in-depth analysis of carer demographics at national, state/territory and regional level that has supported policy development and service planning across Australia.

However, reductions in funding over time have significantly reduced the reliability of the 2022 SDAC data at state and territory level and within smaller geographies, especially in relation to diverse carer cohorts, with very limited reliable data now available at or below state/territory level about culturally and linguistically diverse carers, Aboriginal and Torres Strait Islander carers, young carers and rural/regional/remote carers.

It is recommended that the Australian Government work with states and territories to reinstate the availability of carer demographic data that is essential for policy development and service planning. This will also enable insights to support the monitoring of the effectiveness of the Strategy, and ensure greater inclusion and understanding of the experiences of diverse carers.

Summary: Investment Priorities for the Evidence Base

The most urgent needs, aligned to National Carer Strategy Priority Outcome Area 6, are:

1. Culturally safe, disaggregated data collection for First Nations, CALD, and LGBTQIA+ carers.
2. Standardised outcome measurement embedded in all funded carer support programs.
3. A dedicated hidden carer identification study to understand true population scale.
4. Expanded longitudinal tracking of young carers' educational and employment trajectories.
5. A cost-effectiveness evaluation framework for major carer support investments, including Carer Gateway.
6. Restored state and territory investment in the SDAC.