Carer Wellbeing Survey

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1.0 Overview of the User Guide

This document provides information on the methods used to sample and recruit survey participants for the *Carer Wellbeing Survey* (CWS), samples achieved, weighting used and measures reported on.

In addition to this User Guide, the following documents are important references to examine when using the dataset:

- Survey questionnaire. The questionnaires administered in each year of the survey are available as separate documents. Each is available in two versions: a general document with questions provided in easy-to-read format and a second that documents how questions were presented online in Qualtrics for survey participants (including information on display and piping logic used in the online survey).
- Metadata. The metadata file provides a list of all variables in the data set for each wave of the survey, and information about measurement.
- Reports. Reports produced by the University of Canberra from this survey are available at https://www.carersaustralia.com.au/carer-wellbeing-survey/

This User Guide provides an overview of:

- Survey objectives and scope (Section 2.0)
- Questionnaire design and survey platforms (Section 3.0)
- Survey sampling and participant recruitment (Section 4.0)
- Sample weighting process (5.0)
- Timing, recruitment and sample achieved by year (Section 6.0)
- Appendices providing further information on
    - The groups reported by in the data tables and reports (Appendix 1)
    - Measured used in other surveys (Appendix 2)
    - Calculation of scales/measures reported (where relevant) (Appendix 3)

The User Guide is a living document that is updated at least once annually. The edition and date identify when this version of the User Guide was produced.

2.0 Survey background, objectives and scope

In 2021, the national Carer Wellbeing Survey (CWS) was launched in partnership between Carers Australia, the Australian Government Department of Social Services (DSS), and the University of Canberra (UC). The survey aims to develop a comprehensive picture of the wellbeing of carers, how that wellbeing is changing over time, and how wellbeing of carers can be supported. The 2021 CWS provided an initial baseline set of insights from which change over time could begin to be examined.

2.1 Survey objectives

The objectives of the Carer Wellbeing Survey are to:

- Understand different dimensions of wellbeing and quality of life of Australian carers
- Understand how wellbeing and quality of life is changing for carers
- Understand how the wellbeing differs depending on the type of carer role a person has, and wellbeing risks associated with different carer roles
- Identify which types of support are effective in supporting the wellbeing of carers and their ability to be an effective and successful carer

2.2 Survey scope

The CWS samples unpaid carers aged 14 and older residing in Australia. An unpaid carer is defined as any person who provides unpaid assistance to a person with a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal/serious illness, or old-age related frailty. The survey is conducted annually, usually during a two-month period between February and April, with the exact timing within these months varying depending on circumstances.

2.2.1 Scope criteria - Participant age

The CWS examines carers from the age of 14 and over, so that young carers can also be examined. Any survey participants who indicated they are younger than 14 are not directed to the survey.

Participants are able to complete the survey without providing their age if they choose, with age being a voluntary question. The start of the survey explains that the survey is restricted to carers aged 14 and over, and those who are eligible are asked to click ‘next’ to start the survey online. Participants are subsequently asked to identify their age. Those who opt not to provide information on their age at this point are retained in the data set. This is to enable dataset users to examine potential response bias associated with the decision to answer questions on age.

2.2.2 Scope criteria – Carers

The CWS examines unpaid carers. While the survey is focussed on carers who are caring at the time of the survey (current carers), it is also open to carers who’s caring role has ended (past carers). The start of the survey defines who is eligible as an unpaid carer, and early in the questions respondents are asked what type of caring they do. Respondents are only asked to continue with the survey if they indicate that they are a current or past unpaid carer. If the respondent is only a paid carer, or a carer through an organised volunteer organisation providing care, they are presented with an explanation that they are not eligible to complete the survey. Current carers are asked the full set of questions, while past carers are only asked some.

The carers who typically participate in the CWS are mostly those for whom caring represents a significant part of their day-to-day life. Those who provide only occasional care, or for whom caring duties represent a small part of their life (for example, 1 or 2 hours a week), are typically less likely to participate. When comparing CWS data with ABS data it is important to note this, as ABS Census collects carers related data from all carers including those whom caring is a minor part of their lives, while the CWS is predominantly made up of carers whom caring represented a significant part of their day-to-day life.

2.2.3 Proportion of survey items completed

The final criterion used to define a valid survey participant is the proportion of survey items completed. Similar to the age criteria, participants who have not completed all survey items are retained in the dataset if they have completed at least 10 items. Those who completed only a small proportion of survey items above the minimum valid completion limit of 10 items are retained in the dataset, primarily to enable identification of non-response bias between those who opted to complete all or almost all survey items, and those who did not.

2.3 Ethics

The CWS operates under the University of Canberra Human Research Ethics Committee protocol 1887.

2.4 Funders

The 2021, 2022 and 2023 CWS was funded by Carers Australia using funding sourced from Department of Social Services.

The 2024, 2025 and 2026 CWS is primarily being funded through the Australian Research Council (ARC) Industry Fellowship Grants – with Carers Australia and Department of Social Services being industry partners with University of Canberra to continue collection of data for a further three years. The Department of Social Services is also providing additional funding to Carers Australia to deliver the CWS until 2026.

3.0 Survey design and survey platforms

For copies of the CWS, email carerwellbeing@canberra.edu.au.

3.1 Questionnaire design

The CWS is designed to collect data on a range of topics, all focused on carer wellbeing, experiences, access to services and support, and carer outcomes. The initial survey items included in 2021 were selected based on a review of Australian and international literature on carer wellbeing, and on expert knowledge provided by Carers Australia and the Department of Social Services.

In subsequent years, a core set of items were repeated in all surveys, while in each year additional 'special topic' questions were included. The following process is undertaken each year:

- Previous year survey content is reviewed, and measures to be repeated annually identified, as well as any measures requiring amendment
- Carer views about important topics related to carer wellbeing, reported in previous surveys, are reviewed to identify priorities for additional 'special' topics
- Consultation with key stakeholders (Carers Australia and others) are used to revise the content of the initial survey, with at least two rounds of consultation and revisions.
- Pilot testing of the survey is undertaken in two rounds. First, a small group of 10-20 people (including both carers and representatives of care provider and carer representative organisations) test the survey and provided feedback. The revised survey is then tested by a sample of 30-50 carers selected at random from the CWS contact database.
- Final revisions are made before official launch.

The survey includes some measures that are asked in other surveys, in particular the annual Regional Wellbeing Survey. These are used to enable comparison of carers to the broader Australian adult population. Appendix 2 identifies measures used in other surveys, original sources of the questions, and whether the question was modified for purposes of use in the CWS. Questions designed specifically for the CWS and used as part of a broader scale/measure are also identified in Appendix 3.

3.2 Survey length

The CWS contains a large number of questions, and completion of the full survey can take over one hour. As many people are not able to commit this amount of time to completing a survey, a shorter version of the survey is offered as an option online, with all participants asked to choose if they wish to complete the shorter or the longer version of the survey. Those who opt to complete the longer version receive more entries into the prize draw as an incentive to complete the long version, and are also clearly informed of the length of the survey.

Subsequent sections of this user guide describing each survey year identify the proportion of survey participants who opted to complete the short versus long version of the survey in that year.

3.3 Survey platforms

Surveys can be conducted in a range of ways, and the most appropriate will depend on the type of data required to address the research question. These include those administered by a survey collector, and often done face-to-face or by phone, and those that are self-administered, usually on paper, or electronically (e.g. through a website or an app). In the case of the CWS, participants are able to complete the survey either online or on a paper form.

The online survey is hosted on the website *qualtrics.com*, which provides a platform for designing and administering online surveys. Participants are also given the option of completing a survey on paper. Online surveys work well in most areas of Australia, but the inclusion of a paper survey option recognises that, as de Leeuw and Berzelaz (2016) state, 'the single-mode paradigm, which implies that one data collection method fits all respondents equally well, no longer applies in the twenty-first century'. Not all regions across Australia have adequate internet access, or participants may have a preference for paper surveys over online surveys.

Online and paper surveys can help to minimise 'social desirability effects', where a respondent answers survey items based on what they think is the most acceptable rather than how they feel (Heerwegh 2009, Krumpal 2013), as they do not require a person to interact with another person when answering survey questions. This approach also minimises 'mode effects', where different surveys delivered in different ways produce different results (Grandcolas et al. 2003, Hennigan et al. 2002): both online and paper surveys involve self-completion without direct interaction with another person.

The majority of survey participants – over 95% - complete the survey online, while the remainder complete a paper survey.

3.3 Survey support

Survey support is provided in the form of a free-call phone number which is prominently displayed in all survey promotional material (including emails, and online and paper survey forms). In addition, an email address is provided that participants or those with questions about the survey can contact with questions or to request a copy of the paper survey.

All survey promotional materials include a clear statement explaining the survey can be completed either online (with the URL provided), or as a paper survey, and that those who wish to have a paper survey mailed to them can ring the free-call number to request it be posted to them, or request a copy via the email address. The 1800 number is displayed in large, bold text.

4.0 Participant recruitment

This section explains the methods used to recruit survey participants. Subsequent parts of the User Guide specify the exact participant recruitment methods used by year of the survey.

4.1 Overall survey sampling objectives

The CWS sample is designed to achieve the following goals:

- **A sample of unpaid carers across Australia.** The survey is open to those aged 14 and older, and participants recruited from anywhere in Australia.
- **Enable comparison of different regions (States/Territories, Remoteness)** when analysing the sample.
- **Enable comparison of key groups.** The survey seeks to achieve a sample that enables analysis of a range of groups, including some with relatively small populations.
- **Enable use of statistical weighting while reducing risk of error amplification resulting from weighting.** This requires achieving sufficient sample within different identified groups of people to support statistical weighting.

The objectives specified above enable both (i) analysis of specific subgroups and (ii) with use of appropriate statistical weighting, estimates that are representative of the carer population of Australia.

4.2 Participant recruitment

Survey participants are generally recruited using the following methods:

- Previous participants: Carers who participated in previous years of the CWS and who had given permission to be contacted about future surveys are invited to take part in the current CWS.
- Regional Wellbeing Survey database: Those who identify as being a carer in their responses to the nationwide Regional Wellbeing Survey, and who have given permission to be contacted for other surveys, are invited to take part in the CWS.
- Care provider organisations: Organisations who provide professional services to carers across Australia are asked to email their clients to request their participation in the survey.
- Carer representative organisations: A number of carer organisations around Australia send emails to their membership inviting participation, advertise the survey on their websites, and promote the survey on their social media channels.
- Social media advertising: Paid advertising on Facebook and Instagram are used to recruit carers, including some advertising in the different languages the survey had been translated into.
- A prize draw incentive is offered to encourage participants to take part in the survey. Prizes offered are gift cards, with winners able to choose their preferred gift card from a list of options that are most relevant and meaningful to them.

These recruitment methods aim to reach as wide a range of carers as possible. Having multiple recruitment methods help to ensure biases resulting from any one method of recruitment are minimised. For example, it is expected that carers recruited via care provider organisations and carer representative organisations may have more complex and challenging caring needs compared to carers recruited via the Regional Wellbeing Survey (RWS) database. Recruiting via the RWS database, social media advertising and online survey panel enables a wider sample of carers to be reached.

4.3 Tracking how survey participants are recruited

Each year, participants are asked to identify how they heard about the CWS when completing the survey. Details about how survey participants heard about the survey in each year are included in the description of data collection by survey year in Section 6.

Not all survey participants choose to answer these questions: some participants opt not to identify how they heard about the survey. These participants are retained in the dataset for the following reasons:

- If weighting uses weights against benchmark population only (rather than a two-stage weighting process of weighting by recruitment probability followed by post-hoc sample bias correction), it is possible to include these respondents as many provided sufficient information to enable weighting against benchmark target population data.
- Many of those who did not indicate how they heard about the survey did provide an email address and permission to be contacted for follow-up years, and thus can form an important part of longitudinal data sets going forward.
- Retaining these participants enables subsequent analysis of potential bias in those who opt to identify how they were recruited or not, which can be used to inform design of model-based weighting.

5.0 Weighting process

The CWS is used to generate insights into the adult carer population of Australia. When generating data for Australian carers, statistical weighting is used to address differences between the sample of people who respond to the survey, and the characteristics of the Australian carer population.

Weighting is a strategy employed to adjust data that is for some reason not representative of the population of interest – in this case Australian unpaid carers. This data is often derived from surveys which cannot achieve perfectly representative responses. To correct for differences between the sample and the population, and to generate estimates of population characteristics, statistical weights can be generated. Weights are a “multiplying factor applied to some or all of the respondents in a survey” (Sharot 1986) when data are analysed, which address bias in the sample and enable production of estimates that are – as far as possible – representative of the population being surveyed. Weights can be any positive number. Weights above one will increase the relative contribution of an individual response, and weights between 0 and 1 will reduce the contribution. Weighting of survey responses is used in many surveys, including large household surveys conducted by national statistical agencies such as the Australian Bureau of Statistics, as well as in large sampling surveys conducted by both market research and non-market research organisations (Keeter et al. 2017).

A process of survey weighting is used to produce findings from the CWS that are representative of carers nationally. The weight was developed by first comparing characteristics of the sample to known characteristics of Australian carers from existing data sources. This comparison is shown in Table 1. From this, weights were developed to correct for those types of carers found to be over- or under-represented in the survey responses. For example, the 2016 and 2021 ABS Census and the ABS Survey of Disability, Ageing and Carers (SDAC) all suggest that around 40% of carers are male and around 60% female, although estimates vary by 2-3% across these different sources of benchmark data. In contrast, 17.2% of CWS participants in 2023 were male and 81.2% female in 2023. Weights were assigned to address this bias: each female respondent was assigned a weight less than 1 so in analysis their response would count as a smaller proportion of the total, and male respondents a weight above 1 so their responses counted as a higher proportion. The weights assigned mean that the weighted sample findings are representative of a carer population that is 39.8% male and 60.2% female, the distribution identified in the 2021 Census of Population and Housing. The specific benchmarks used can be found under each year of the survey in Section 6.

This weighting process was used to correct for both intentional over-sampling of states and territories with smaller populations, and Aboriginal and Torres Strait Islander population. It was also used to correct oversampling of carers aged 45 and older and under-representation of those carers under the aged of 45 and to address over-representation of carers with 40 or more hours of caring obligations a week in the sample.

Weights were assigned using the ‘Rake Weights’ command in IBM SPSS Statistics. This uses a raking process to iteratively assign weights. Several sets of benchmark categories were trialled, until a set of weights with suitable statistical properties was achieved.

Table 1 Comparing survey respondent characteristics to benchmark characteristics of Australian carers

Characteristics of carers		ABS Census, 2016	ABS Census, 2021[a]	Survey of Disability, Ageing and Carers, 2018-19	Survey of Disability, Ageing and Carers 2022	2021 Carer Wellbeing Survey respondents	2022 Carer Wellbeing Survey respondents	2023 Carer Wellbeing Survey respondents	2024 Carer Wellbeing Survey respondents	2025 Carer Wellbeing Survey respondents
Gender	Male	39.6%	39.8%	42.7%	39.9%	19.3%	16.9%	17.2%	18.4%	16.5%
	Female	60.4%	60.2%	57.3%	60.1%	80.7%	83.1%	81.2%	81.6%	83.5%
Age group	15-24	7.1%	6.4%	1.8%	9.8%	3.7%	4.4%	2.4%	3.9%	2.3%
	25-34	11.7%	10.5%	7.2%	10.6%	5.4%	3.6%	6.7%	6.2%	2.9%
	35-44	16.8%	16.6%	10.2%	16.5%	11.9%	12.2%	13.1%	13.6%	12.7%
	45-54	22.0%	21.7%	13.9%	19.2%	19.5%	24.2%	19.9%	19.0%	19.5%
	55-64	22.6%	22.7%	21.2%	18.1%	26.0%	21.4%	25.5%	24.0%	24.6%
	65-74	13.2%	14.3%	21.2%	15.7%	22.1%	20.3%	19.9%	20.2%	22.5%
	75+	6.7%	7.7%	15.7%	10.1%	11.4%	13.9%	12.4%	13.1%	15.4%
Gender by age group	Male, 15-24	3.2%	2.9%	0.8%	1.7%	1.6%	1.3%	1.2%	0.9%	0.5%
	Male, 25-34	4.5%	4.1%	3.6%	2.7%	1.3%	0.5%	1.4%	1.5%	0.3%
	Male, 35-44	6.4%	6.3%	4.4%	3.2%	2.0%	1.0%	1.0%	1.5%	0.8%
	Male, 45-54	8.3%	8.2%	5.0%	4.4%	2.0%	1.8%	1.6%	1.9%	1.5%
	Male, 55-64	8.5%	8.7%	8.3%	7.1%	3.3%	2.6%	2.9%	3.3%	3.4%
	Male, 65-74	5.4%	5.8%	8.6%	12.3%	5.1%	4.2%	4.0%	3.9%	4.6%
	Male, 75+	3.2%	3.8%	7.0%	8.7%	3.9%	5.4%	5.4%	5.4%	5.4%
	Female, 15-24	3.9%	3.5%	1.0%	2.4%	1.8%	3.4%	1.3%	2.5%	1.5%
	Female, 25-34	7.2%	6.4%	3.6%	4.1%	3.9%	2.9%	3.6%	4.0%	2.3%
	Female, 35-44	10.4%	10.3%	5.8%	9.5%	10.1%	11.0%	10.8%	11.0%	11.6%
	Female, 45-54	13.7%	13.5%	8.9%	12.2%	17.6%	22.3%	18.5%	17.2%	17.5%
	Female, 55-64	14.1%	14.1%	12.9%	11.8%	22.6%	18.9%	22.1%	21.3%	21.9%
	Female, 65-74	7.8%	8.5%	12.6%	13.0%	17.0%	16.2%	17.9%	17.1%	18.6%
	Female, 75+	3.4%	4.0%	8.7%	7.0%	7.7%	8.4%	8.6%	8.6%	10.1%
State/ Territory	NSW	33.1%	30.7%	32.3%	31.7%	20.1%	18.9%	20.3%	16.4%	16.0%
	Vic	26.2%	27.8%	26.6%	25.1%	18.2%	22.5%	24.2%	27.7%	28.3%
	Qld	19.0%	19.4%	20.2%	21.7%	17.9%	19.8%	13.6%	18.3%	15.6%
	SA	7.9%	7.8%	6.9%	7.8%	11.7%	13.5%	17.4%	12.1%	17.4%
	WA	9.2%	9.3%	8.8%	8.6%	16.0%	12.4%	12.7%	14.1%	12.5%
	Tas	2.3%	2.4%	3.0%	2.9%	10.6%	7.7%	5.9%	6.4%	6.0%

	NT	0.7%	0.7%	0.4%	0.4%	1.9%	1.8%	1.6%	1.9%	1.4%
	ACT	1.7%	1.8%	1.9%	1.9%	3.6%	3.4%	4.3%	3.0%	2.8%
Aboriginal & Torres Strait Islanders	Aboriginal and/or Torres Strait Islander	2.8%	3.1%[a]	No data	No data	4.2%	4.5%	7.3%	3.8%	3.4%
	Other	97.2%	96.9%			95.8%	95.5%	92.7%	96.2%	96.6%
Language	English usually spoken at home	77.6%	No data	No data	89.1%	78.6%	82.0%	84.1%	80.6%	78.6%
	Language other than English spoken at home	22.4%			10.9%	21.4%	18.0%	15.9%	19.4%	21.4%
Labour force status	Employed	54.6%	No data	Primary carers: 55.7%	Primary carers: 47.3%	43.0%	37.0%	39.4%	41.8%	37.5%
	Unemployed	4.9%		Primary carers 4.7%	Primary carers: 1.9%	4.2%	4.4%	3.5%	2.8%	3.6%
	Not in the labour force	40.5%		Primary carers 39.6%	Primary carers: 50.8%	52.7%	58.6%	57.2%	55.4%	58.9%
Weekly caring hours	<20	No data	No data	45.8%	56.5%	39.8%	39.1%	25.1%	39.1%[b]	38.0% [b]
	20-39			19.3%	17.8%	13.9%	14.1%	17.4%	13.9%	14.1%
	40+			34.9%	25.7%	46.3%	46.8%	57.5%	47.0%	47.9%

[a] Estimates of the proportion of carers from the 2021 ABS Census are based on data published in June 2022 on (i) Unpaid work and care data (ABS 2022a), (ii) Aboriginal and/or Torres Strait Islander data summary tables which included information on the number of Aboriginal and Torres Strait Islanders who reported being carers in the 2021 Census (ABS 2022b), and (ii) Census datapacks that provided data by state and territory on number of carers (ABS 2022c).

[b] includes response option ‘varied or hard to say’.

6.0 Description of data collection by survey year

This section describes the specific survey timing, participant recruitment, sample achieved, and weighting benchmarks for each year of the survey. It is updated as each wave is conducted. On occasion, information for an earlier wave may be updated if an issue is identified or a method changes. For example, if new weights are generated for a wave of the survey, information about the generation of statistical weights will be updated.

6.1 CWS 2021

Survey timing

The 2021 CWS was open between 24 March and 13 May 2021.

Survey platforms

The survey could be completed either online or as a paper survey. The paper form was sent directly to some carers who did not have an email address. Carers who received an email or text inviting them to do the survey, or saw a social media post about it, could also request a paper survey form by calling a free call number displayed prominently on survey promotional material. In total, 1% of survey participants (51 respondents) completed the survey using a paper form; the large majority opted to complete the survey online.

Survey focus

The 2021 CWS asked carers about:

- Caring responsibilities, including number of people cared for, length of time the person had been a carer, needs of care recipients, and typical hours spent on caring responsibilities each week
- Health and wellbeing of the carer, using several existing validated measures including the Personal Wellbeing Index, general health measure, Kessler 10 psychological distress scale, and loneliness scale (see Schirmer and Miranti 2021 for documentation of scales used).
- Challenging life events experienced in last 12 months, including experiencing loss or change of employment, illness, moving house, financial stress, crime, and changes in caring responsibilities
- Quality of time use, assessing extent to which carers had the ability to achieve desired and healthy levels of sleep, caring, work, exercise, and recreation
- Positive and negative experiences associated with being a carer, using both some existing scales (including a modified version of the Caregiver Burden Scale) and a small number of new questions designed specifically for the CWS
- Ability to identify and access both formal and informal support for the person’s role as a carer
- Types of formal support accessed, organisations via which these supports were accessed, and level of satisfaction with these supports
- Socio-demographic characteristics of the carer such as age, gender, employment, type of home lived in, and household structure
- Open-ended questions asking about overall challenges experienced in accessing support as a carer, and about other topics carers wanted to have recognised and examined in the CWS in future.

Survey languages

The 2021 CWS was translated into simplified Chinese, Arabic, Italian and Vietnamese, selected as the highest prevalence languages other than English spoken by carers based on data from the 2016 ABS *Census of Population and Housing*.

Participant recruitment

Survey participants were recruited using the following methods:

- Existing database: An existing database of carers held by the University of Canberra was used to recruit participants. This was the Regional Wellbeing Survey database: the Regional Wellbeing Survey is an annual survey, in which all participants are asked to identify whether they are a carer. Of the 21,000 people surveyed in 2020, all those who identified they were carers and gave permission to be contacted for a subsequent survey were invited to take part in the survey.
- Care provider organisations: Organisations who provide professional services to carers across Australia were asked to email their clients to request their participation in the survey.
- Carer representative organisations: A number of carer organisations around Australia sent emails to their membership inviting participation, advertised the survey on their websites, and promoted the survey on their social media channels.
- Social media advertising: Paid advertising on Facebook and Instagram was used to further recruit carers.
- Online survey panel: The Qualtrics online panel service was used to recruit a sample of carers.
- Gift incentives: A prize draw incentive was offered to encourage participants to take part in the survey. A prize draw of $5,000 was offered, with winners having a choice of a Flight centre, Coles-Myer, WISH, Bunnings, iTunes or Google Play Store gift cards. Prizes had the following values: $1500; second prize: $1000; third prize: $500; 10 runner-up prizes of $200.

A key goal of participant recruitment was to ensure sufficient sample to enable reporting for every Australian State and Territory. This required deliberate over-sampling in States and Territories with smaller populations, specifically in the Northern Territory, Australian Capital Territory, and Tasmania. Similarly, carers identifying as Aboriginal and/or Torres Strait Islander, and from other culturally and linguistically diverse backgrounds, were deliberately over-sampled to ensure it would be possible to specifically analyse the experiences of carers in these groups. The sampling done via the online panel, social media advertising, and carer organisations was designed to result in a sample that achieved sufficient representation of these regions and groups to enable analysis of their experiences.

These recruitment methods aimed to reach as wide a range of carers as possible. Having multiple recruitment methods help to ensure biases resulting from any one method of recruitment were minimised. For example, it was expected that carers recruited via care provider organisations and carer representative organisations may have more complex and challenging caring needs compared to carers recruited via the Regional Wellbeing Survey (RWS) database. Recruiting via the RWS database, social media advertising and online survey panel enabled a wider sample of carers to be reached.

Sample

There were a total of 5,808 valid responses to the survey. Of these respondents, 1,010 heard about the survey via the RWS database, 1,170 from a care provider organisation, 1,530 from a carer representative organisation, 1,005 from social media advertising, 530 via the Qualtrics online panel and 250 from other methods such as a person hearing about the survey via friends or family. Some participants did not specify how they heard about the survey.

Many carers have very limited time, and may be unable to complete a long questionnaire. Given this, the questionnaire was designed to give carers choice regarding the length of survey they wished to complete. Those completing the survey online (the majority of participants) were asked if they wished to complete a shorter or longer version of the survey. The short version of the survey was designed to take 5-10 minutes to complete, while the longer version took 15 to 30 minutes depending on how many questions were applicable to the person completing the survey. In total, 69% of respondents opted to complete the long version of the survey, while 31% opted to complete the short version of the survey.

Weighting benchmarks

Table 2 specifies the benchmark categories used to develop statistical weights for the 2021 CWS, and the source of benchmark data used. Note that in some cases a weight is specified for those who did not provide information. The benchmark data source has been adjusted to enable inclusion of those who did not report some characteristics in the weighting; in all cases, the proportion of these unspecified categories does not exceed the non-response reported in the Census.

Table 2 Benchmark data specifications used to develop statistical weights: 2021

	Benchmark data source	Benchmark specifications	Variable name in data set and coding
Gender	ABS Census, 2016, adjusted to provide ‘other’ gender option	Male – 37.3% Female – 56.9% Other/not specified – 5.8%	cGenderWT 2 = Male 1 = Female 3 = Other/not specified
Age groups	ABS Census 2016, adjusted to enable inclusion of those who opted not to respond (included at less than the reported non-response rate in the Census)	13-34 18.0% 35-44 16.1% 45-64 42.7% 65+ 19.1% Age not specified 4.1%	cAgeWT 1 = 13-34 2 = 35-44 3 = 45-64 4 = 65+ 5 = unspecified
State/Territory	ABS Census 2021, adjusted to enable inclusion of respondents who did not report state of residence	NSW 31.4% Vic 24.9% Qld 18.1% SA 7.5% WA 8.7% Tas 2.2% NT 0.6% ACT 1.6% Not specified 5%	cGEOGSTEwt 1 = NSW 2 = Vic 3 =QLD 4 =SA 5 = WA 6 = Tas 7 = NT 8 = ACT 9 = Unspecified
Language other than English	2016 Census of Population and Housing	Not used to weight as responses close to benchmark	
Aboriginal and Torres Strait Islander	2016 Census of Population and Housing	Not used to weight*	
Labour force status	2016 Census of Population and Housing	Employed 52.1% Unemployed 4.9% Not in labour force 38.0%	cLFSwt 1 = employed 2 = unemployed

		Not specified 5%	3 = not in labour force 4 = unspecified
Weekly caring hours	Survey of Disability, Ageing and Carers, 2018-19	<20 hours weekly or varied/ hard to say hours 44.3% 20-39 hours weekly 18.3% 40+ care hours weekly 33.4% Unspecified = 4%	cCareHoursWT 1 = < 20 hours 2 = 20-39 hours 3 = 40+ hours 4 = Unspecified

*While there were more ATSI participants than are in the population, we explored weighting to correct for this but found no meaningful change. In the interests of reducing risk of small cells in weighting structures, we decided not to weight for this characteristic as there was no evidence it would change findings if weighting was applied.

Past carers were not weighted.

6.2 CWS 2022

Survey timing

The 2022 CWS was open between 27 January and 17 April 2022.

Survey platforms

The survey could be completed either online or as a paper survey. The paper form was sent directly to some carers who did not have an email address. Carers who received an email or text inviting them to do the survey, or saw a social media post about it, could also request a paper survey form by calling a free call number displayed prominently on survey promotional material. In total, 1.6% of survey participants (84 respondents) completed the survey using a paper form; the large majority opted to complete the survey online.

Survey focus

The 2022 CWS asked carers about:

- The type of caring responsibilities they had, length of time spent caring, and key needs of the person or people they cared for
- Their health, wellbeing and psychological distress symptoms
- Positive and negative outcomes they experienced related to their caring duties
- Carer choice and wellbeing: How many carers take on their caring role as an active choice versus feeling obligated to do so, and is the level of choice involved associated with differences in wellbeing?
- Navigating formal support systems: How easy or difficult do carers find it to access and navigate the formal systems that provide support for carers and for the people they care for, and what are the most common barriers experienced to accessing support?
- Health professionals and health records: To what extent are carers recognised and included in care discussions by health professionals, and how many have access to the My Health Record of care recipients?
- Awareness and use of Carer Gateway and, amongst those who used it, satisfaction with Carer Gateway (including with Carer Gateway service providers)
- Peer support groups: What types of peer support groups are being accessed by carers, and how useful do they find these groups?
- COVID-19 impacts: How have the effects of the COVID-19 pandemic impacted carers, including their access to support in their caring role, level of social interaction, employment, and access to health services?

- Transport access: How many carers have adequate access to transport needed for caregiving purposes?

Survey languages

The 2022 CWS was translated into simplified Chinese, Arabic, Italian and Vietnamese, selected as the highest prevalence languages other than English spoken by carers based on data from the 2016 ABS *Census of Population and Housing*.

Participant recruitment

Survey participants were recruited using the following methods:

- Previous participants: Carers who participated in the 2021 CWS and who had given permission to be contacted about future surveys were invited to take part in the 2022 CWS.
- Regional Wellbeing Survey database: All those who identified being a carer in their responses to the nationwide Regional Wellbeing Survey, and who had given permission to be contacted for other surveys, were invited to take part in the 2022 CWS.
- Care provider organisations: Organisations who provide professional services to carers across Australia were asked to email their clients to request their participation in the survey.
- Carer representative organisations: A number of carer organisations around Australia sent emails to their membership inviting participation, advertised the survey on their websites, and promoted the survey on their social media channels.
- Gift incentives: A prize draw incentive was offered to encourage participants to take part in the survey. Prizes offered were gift cards, with winners able to choose their preferred gift card from a list of options that enabled the winner to choose what was most relevant and meaningful to them. A prize draw of $5,000 was offered, with winners having a choice of a Flight centre, Coles-Myer, WISH, Bunnings, iTunes or Google Play Store gift cards. Prizes had the following values: $1500; second prize: $1000; third prize: $500; 10 runner-up prizes of $200.

Sample

There were a total of 5,992 valid responses to the survey. Of these, 5,948 completed the English language version of the survey, while 35 completed the Chinese, 7 the Arabic, and 2 the Vietnamese version of the survey. None completed the Italian language version. It is important to note that the survey did include a significant proportion of respondents whose primary language spoken at home was not English: 921 reported that the primary language spoken in their home was not English and, of these, 32 who opted to complete the survey using the English language version reported that Mandarin/Chinese was their primary language spoken at home, 42 spoke Italian at home, 20 spoke Arabic at home, and 13 spoke Vietnamese at home. This suggests that most of those who spoke Italian at home opted to complete the English language version of the survey, as did the majority of Arabic and Vietnamese speakers. Only Chinese speakers were as likely to opt to complete the survey in simplified Chinese as they were to complete it in English.

Carers were given the option of completing a shorter or longer version of the survey if they completed it online. The short version of the survey was designed to take 20-30 minutes to complete, while the longer version took 30 to 60 minutes depending on how many questions were applicable to the person completing the survey. Of the online respondents, 64.9% opted to complete the long survey (compared to 69% in 2021), and 35.1% opted to do the short survey (compared to 31% in 2021).

Of the respondents, 1,063 heard about the survey via direct contact from the University of Canberra (being a previous participant in either the CWS and/or the RWS), 1,499 from a care provider organisation, 2,051 from a carer representative organisation, 1013 from social media advertising, 530 via the Qualtrics online panel and 684 through other means including seeing information about the survey on a website, friends or family. Some participants did not specify how they heard about the survey. As noted earlier, 144 completed the survey using a paper form, while the large majority (97.6%) completed the survey online.

Weighting benchmarks

Table 3 specifies the benchmark categories used to develop statistical weights for the 2022 CWS, and the source of benchmark data used. Note that in some cases a weight is specified for those who did not provide information. The benchmark data source has been adjusted to enable inclusion of those who did not report some characteristics in the weighting; in all cases, the proportion of these unspecified categories does not exceed the non-response reported in the Census.

Table 3 Benchmark data specifications used to develop statistical weights: 2022

	Benchmark data source	**Benchmark specifications**	**Variable name in data set and coding**
Gender	ABS Census, 2021, adjusted to provide 'other' gender option	Male – 36.4% Female – 57.8% Other/not specified – 5.8%	bGenderWT 2 = Male 1 = Female 3 = Other/not specified
Age groups	ABS Census 2021, adjusted to enable inclusion of those who opted not to respond (included at less than the reported non-response rate in the Census)	13-34 15.9% 35-44 15.6% 45-64 43.4% 65+ 21.0% Age not specified 4.1%	bAgeWT 1 = 13-34 2 = 35-44 3 = 45-64 4 = 65+ 5 = unspecified
State/Territory	ABS Census 2021, adjusted to enable inclusion of respondents who did not report state of residence	NSW 29.2% Vic 26.3% Qld 18.4% SA 7.3% WA 8.8% Tas 2.4% NT 0.8% ACT 1.8% Not specified 5%	bGEOGSTEwt 1 = NSW 2 = Vic 3 = SA 4 = WA 5 = Tas 6 = NT 7 = ACT 8 = Unspecified
Language other than English	2016 Census of Population and Housing	Not used to weight as responses close to benchmark Main language at home not English 20.4% Main language at home English 71.6% Unspecified 8%	bLOTEwt 1 = LOTE 2 = Main language English 3 = unspecified
Aboriginal and Torres Strait Islander	2016 Census of Population and Housing	Not used to weight as responses close to benchmark Aboriginal and/or Torres Strait Islander 3.1% Other/unspecified 96.9%	bATSIwt 1 = ATSI 2 = other/unspecified
Labour force status	2016 Census of Population and Housing	Employed 52.1% Unemployed 4.9% Not in labour force 38.0%	bLFSwt 1 = employed 2 = unemployed

		Not specified 5%	3 = not in labour force 4 = unspecified
Weekly caring hours	Survey of Disability, Ageing and Carers, 2018-19	<20 hours weekly or varied/ hard to say hours 44.3% 20-39 hours weekly 18.3% 40+ care hours weekly 33.4% Unspecified = 4%	bCareHoursWT 1 = < 20 hours 2 = 20-39 hours 3 = 40+ hours 4 = Unspecified

The resulting weight (variable name WTsample) had a small number of extreme weights, with 4.3% of the sample having a weight of 3.01 or higher, with the highest weight being 17.06. The weight was trimmed to reduce risk of outlier responses creating bias in findings, with weights of 3.01 and above trimmed to a weight of 3.00. This resulted in a trimmed weight, WTsampleTRIMMEDmaxwt3.

Past carers were not weighted.

6.3 CWS 2023

Survey platforms

The survey could be completed either online or as a paper survey. The paper form was sent directly to some carers who did not have an email address. Carers who received an email or text inviting them to do the survey, or saw a social media post about it, could also request a paper survey form by calling a free call number displayed prominently on survey promotional material. In total, 1% of survey participants (31 respondents) completed the survey using a paper form; the large majority opted to complete the survey online.

Survey timing

The 2023 CWS was open between 13 February and 17 April 2023.

Survey focus

The 2023 questionnaire asked about the following annual topics, which are examined each year:

- Caring responsibilities, including number of people cared for, length of time the person had been a carer, needs of care recipients and types of support provided to them, typical hours spent on caring responsibilities each week, and whether caring was provided continuously or episodically
- Health and wellbeing of the carer, using several existing validated measures including the Personal Wellbeing Index, general health measure, Kessler 10 psychological distress scale, and loneliness scale
- Challenging life events experienced in last 12 months, including experiencing loss or change of employment, illness, moving house, financial stress, crime, and changes in caring responsibilities
- Quality of time use, assessing extent to which carers had the ability to achieve desired and healthy levels of sleep, caring, work, exercise, and recreation
- Positive and negative experiences associated with being a carer, using both some existing scales (including a modified version of the Caregiver Burden Scale) and a small number of new questions designed specifically for the CWS
- Ability to identify and access both formal and informal support for the person's role as a carer
- Types of formal support accessed, organisations via which these supports were accessed, and level of satisfaction with these supports
- Socio-demographic characteristics of the carer such as age, gender, employment, type of home lived in, and household structure
- Access to mobile phone reception, internet and transport; some waves of the survey may ask about other services as well
- Open-ended questions asking for other comments about role as a carer.

In addition, as noted in the introduction to this report, the 2023 questionnaire included questions about the following topics:

- Navigating formal support systems
- Health professionals and health records
- Peer support groups
- COVID-19 impacts
- Transport access
- Rising costs of living.

Survey languages

The 2023 CWS was translated into simplified Chinese, Arabic, Italian and Vietnamese, selected as the highest prevalence languages other than English spoken by carers based on data from the 2021 ABS *Census of Population and Housing*.

Participant recruitment

Survey participants were recruited using the following methods:

- Previous participants: 6283 carers who participated in the 2021 and/or 2022 CWS and who had given permission to be contacted about future surveys were invited to take part in the 2023 CWS.
- Care provider organisations: Organisations who provide professional services to carers across Australia were asked to email their clients to request their participation in the survey.
- Carer representative organisations: A number of carer organisations around Australia sent emails to their membership inviting participation, advertised the survey on their websites, and promoted the survey on their social media channels.
- Social media advertising: Advertising on Facebook and Instagram was used to recruit carers, including some advertising in the different languages the survey had been translated into.
- Gift incentives: A prize draw incentive was offered to encourage participants to take part in the survey. Prizes offered were gift cards, with winners able to choose their preferred gift card from a list of options that enabled the winner to choose what was most relevant and meaningful to them, from Coles-Myer cards enabling purchase of groceries through to fashion, to Bunnings gift cards. A prize draw of $5,000 was offered, with winners having a choice of a Flight Centre, Coles-Myer, WISH, Bunnings, iTunes or Google Play Store gift card. Prizes had the following values: $1500; second prize: $1000; third prize: $500; 10 runner-up prizes of $200.
    -

These recruitment methods aimed to reach as wide a range of carers as possible. Having multiple recruitment methods help to ensure biases resulting from any one method of recruitment were minimised. For example, it was expected that carers recruited via care provider organisations and carer representative organisations may have more complex and challenging caring needs compared to carers recruited via social media. Recruiting via social media advertising enabled a wider sample of carers to be reached.

Sample

There were a total of 5,881 valid responses to the survey. Of these, 5,039 completed the English language version of the survey, while 270 completed the Chinese (a significant increase from 2022 with 35 completed in Chinese), 8 the Arabic, 1 the Vietnamese and 1 the Italian version of the survey.

Carers were given the option of completing a shorter or regular length version of the survey if they completed it online. This was done to ensure carers who had limited time could still participate in the survey. Online participants were asked if they wished to complete the short or regular version, and told how long each was expected to take to complete. The short version of the survey was designed to take 20-30 minutes to complete, while the regular version took 30 to 60 minutes depending on how many questions were applicable to the person completing the survey. Of the online respondents, 69.8% opted to complete the regular survey (compared to 64.9% in 2022 and 69% in 2021), and 30.2% opted to do the short survey (compared to 35.1% in 2022 and 31% in 2021).

Of the respondents, 1,681 heard about the survey via direct contact from the University of Canberra (being a previous participant in the CWS), increasing from 1063 in 2022. This increase is expected as the database of previous participants grows over the years. A total of 1,033 heard about the survey from a care provider organisation and 1,609 from a carer representative organisation – a slight decrease from 2022. A further 1,262 heard about the survey from social media advertising and 777 through other means including seeing information about the survey on a website, friends or family. Some participants did not specify how they heard about the survey, and participants were able to select more than one option.

Weighting benchmarks

Table 4 specifies the benchmark categories used to develop statistical weights for the 2023 CWS, and the source of benchmark data used. Note that in some cases a weight is specified for those who did not provide information. The benchmark data source has been adjusted to enable inclusion of those who did not report some characteristics in the weighting; in all cases, the proportion of these unspecified categories does not exceed the non-response reported in the Census.

Table 4 Benchmark data specifications used to develop statistical weights: 2023

	Benchmark data source	Benchmark specifications	Variable name in data set and coding
Gender	ABS Census, 2021, adjusted to provide 'other' gender option	Male – 36.4% Female – 57.8% Other/not specified – 5.8%	cGenderWT 2 = Male 1 = Female 3 = Other/not specified
Age groups	ABS Census 2021, adjusted to enable inclusion of those who opted not to respond (included at less than the reported non-response rate in the Census)	13-34 15.9% 35-44 15.6% 45-64 43.4% 65+ 21.0% Age not specified 4.1%	cAgeWT 1 = 13-34 2 = 35-44 3 = 45-64 4 = 65+ 5 = unspecified
State/Territory	ABS Census 2021, adjusted to enable inclusion of respondents who did not report state of residence	NSW 29.2% Vic 26.3% Qld 18.4% SA 7.3% WA 8.8% Tas 2.4% NT 0.8% ACT 1.8% Not specified 5%	cGEOGSTEwt 1 = NSW 2 = Vic 3 =QLD 4 =SA 5 = WA 6 = Tas 7 = NT 8 = ACT 9 = Unspecified
Language other than English	2016 Census of Population and Housing	Not used to weight as responses close to benchmark Main language at home not English 20.4% Main language at home English 71.6% Unspecified 8%	cLOTEwt 1 = LOTE 2 = Main language English 3 = unspecified
Aboriginal and Torres Strait Islander	2016 Census of Population and Housing	Not used to weight* Aboriginal and/or Torres Strait Islander 3.1% Other/unspecified 96.9%	cATSIwt 1 = ATSI 2 = other/unspecified

Labour force status	2016 Census of Population and Housing	Employed 52.1% Unemployed 4.9% Not in labour force 38.0% Not specified 5%	cLFSwt 1 = employed 2 = unemployed 3 = not in labour force 4 = unspecified
Weekly caring hours	Survey of Disability, Ageing and Carers, 2018-19	<20 hours weekly or varied/ hard to say hours 44.3% 20-39 hours weekly 18.3% 40+ care hours weekly 33.4% Unspecified = 4%	cCareHoursWT 1 = < 20 hours 2 = 20-39 hours 3 = 40+ hours 5 = Unspecified

*While there were more ATSI participants than are in the population, we explored weighting to correct for this but found no meaningful change. In the interests of reducing risk of small cells in weighting structures, we decided not to weight for this characteristic as there was no evidence it would change findings if weighting was applied.

The resulting weight (variable name WTsample) had 13% with a weight of 3.01 or higher, with the highest weight being 60.31 but the majority being between 3.01 and 8.00. The weight was trimmed to reduce risk of outlier responses creating bias in findings, with weights of 3.01 and above trimmed to a weight of 3.00. This resulted in a trimmed weight (WTsampleTRIMMEDmaxwt3). Where a weight was not possible due to one or more weighting variables having missing data, the weight was set to 1.00 (no weight) - WTsampleTRIMMEDmaxwt3Noblank.

Past carers were not weighted.

SPSS syntax:

```
SPSSINC RAKE DIM1 =  cGenderWT 1 0.578 2 0.364 3 0.058

DIM2= cAGEWT 1 0.159 2 0.156 3 0.434 4 0.210 5 0.041

DIM3= cGEOGSTEwt 1 0.292 2 0.263 3 0.184 4 0.073 5 0.088 6 0.024 7 0.008 8 0.018 9 0.050

DIM4= cLFSwt 1 0.521 2 0.049 3 0.380 4 0.050

DIM5= cCareHoursWT 1 0.443 2 0.183 3 0.334 4 0.040

FINALWEIGHT= WTsample

/OPTIONS ITERATIONS=20 CONVERGENCE=.0001 DELTA=.5 SHOW=NO

/PLOT HISTOGRAM=YES.
```

6.4 CWS 2024

Survey platforms

The survey could be completed either online or as a paper survey. The paper form was sent directly to some carers who did not have an email address. Carers who received an email or text inviting them to do the survey, or saw a social media post about it, could also request a paper survey form by calling a free call number displayed prominently on survey promotional material. In total, 1% of survey participants (79 respondents) completed the survey using a paper form; the large majority opted to complete the survey online.

Survey timing

The 2024 CWS was open between 12 February and 15 April 2024, with some late responses received until 9 May.

Survey focus

The 2024 questionnaire asked about the following annual topics, which are examined each year:

- Caring responsibilities, including number of people cared for, length of time the person had been a carer, needs of care recipients and types of support provided to them, typical hours spent on caring responsibilities each week, and whether caring was provided continuously or episodically
- Health and wellbeing of the carer, using several existing validated measures including the Personal Wellbeing Index, general health measure, Kessler 10 psychological distress scale, and loneliness scale
- Challenging life events experienced in last 12 months, including experiencing loss or change of employment, illness, moving house, financial stress, crime, and changes in caring responsibilities
- Quality of time use, assessing extent to which carers had the ability to achieve desired and healthy levels of sleep, caring, work, exercise, and recreation
- Positive and negative experiences associated with being a carer, using both some existing scales (including a modified version of the Caregiver Burden Scale) and a small number of new questions designed specifically for the CWS
- Ability to identify and access both formal and informal support for the person's role as a carer
- Types of formal support accessed, organisations via which these supports were accessed, and level of satisfaction with these supports
- Socio-demographic characteristics of the carer such as age, gender, employment, type of home lived in, and household structure
- Access to mobile phone reception, internet and transport; some waves of the survey may ask about other services as well
- Transport access
- Open-ended questions asking for other comments about role as a carer.

In addition, as noted in the introduction to this report, the 2024 questionnaire included questions about the following topics:

- Navigating formal support systems
- Health professionals and health records
- Access to and experiences of respite care
- Access to and knowledge about support services for carers of people with dementia
- Rising costs of living.

Survey languages

The 2024 CWS was translated into simplified Chinese, Arabic, Italian and Vietnamese, selected as the highest prevalence languages other than English spoken by carers based on data from the 2021 ABS *Census of Population and Housing*.

Survey testing

In 2024, the CWS was initially tested by 5 people working within Carers Australia and Department of Social Services, and 7 people within University of Canberra. The survey was then sent to 100 past CWS participants, of which 27 pilot tested the 2024 CWS.

Participant recruitment

Survey participants were recruited using the following methods:

- Previous participants: 8505 carers who participated in the 2021, 2022 and/or 2023 CWS and who had given permission to be contacted about future surveys were invited to take part in the 2024 CWS (8380 emails and 125 paper surveys).
- Care provider organisations: Organisations who provide professional services to carers across Australia were asked to email their clients to request their participation in the survey.
- Carer representative organisations: A number of carer organisations around Australia sent emails to their membership inviting participation, advertised the survey on their websites, and promoted the survey on their social media channels.
- Social media advertising: Advertising on Facebook and Instagram was used to recruit carers.
- Gift incentives: A prize draw incentive was offered to encourage participants to take part in the survey. Prizes offered were gift cards, with winners able to choose their preferred gift card from a list of options that enabled the winner to choose what was most relevant and meaningful to them, from Coles-Myer cards enabling purchase of groceries through to fashion, to Bunnings gift cards. A prize draw of $5,000 was offered, with winners having a choice of a Flight Centre, Coles-Myer, WISH, Bunnings, iTunes or Google Play Store gift card. Prizes had the following values: $1500; second prize: $1000; third prize: $500; 10 runner-up prizes of $200.

These recruitment methods aimed to reach as wide a range of carers as possible. Having multiple recruitment methods help to ensure biases resulting from any one method of recruitment were minimised. For example, it was expected that carers recruited via care provider organisations and carer representative organisations may have more complex and challenging caring needs compared to carers recruited via social media. Recruiting via social media advertising enabled a wider sample of carers to be reached.

Sample

There were a total of 9,166 valid responses to the 2024 survey. Of these, 9,121 completed the English language version of the survey, while 31 completed the Chinese, 12 the Arabic, one the Vietnamese and one the Italian version of the survey.

Carers were given the option of completing a shorter or regular length version of the survey if they completed it online. This was done to ensure carers who had limited time could still participate in the survey. Online participants were asked if they wished to complete the short or regular version, and told how long each was expected to take to complete. The short version of the survey was designed to take 20-30 minutes to complete, while the regular version took 30 to 60 minutes depending on how many questions were applicable to the person completing the survey. Of the online respondents, 71.1% opted to complete the regular survey (compared to 69.8% in 2023, 64.9% in 2022 and 69% in 2021), and 28.9% opted to do the short survey.

Of the respondents, 4,513 heard about the survey via direct contact from the University of Canberra (being a previous participant in the CWS), increasing from 1,681 in 2023. This increase is expected as the database of previous participants grows over the years. A total of 1,062 heard about the survey from a care provider organisation (similar to the 1,033 in 2023) and 2,384 from a carer representative organisation (an increase from the 1,609 in 2023). A further 418 heard about the survey from social media advertising and 546 through other means including seeing information about the survey on a website, friends or family. Some participants did not specify how they heard about the survey, and participants were able to select more than one option.

Weighting benchmarks

Table 5 specifies the benchmark categories used to develop statistical weights for the 2024 CWS, and the source of benchmark data used. Note that in some cases a weight is specified for those who did not provide information. The benchmark data source has been adjusted to enable inclusion of those who did not report some characteristics in the weighting; in all cases, the proportion of these unspecified categories does not exceed the non-response reported in the Census.

Table 5 Benchmark data specifications used to develop statistical weights: 2024

	Benchmark data source	Benchmark specifications	Variable name in data set and coding
Gender	ABS Census, 2021, adjusted to provide 'other' gender option	Male – 38.9% Female – 59.3% Other/not specified – 1.8%	dGenderWT 2 = Male 1 = Female 3 = Other/not specified
Age groups	ABS Census 2021, adjusted to enable inclusion of those who opted not to respond (included at less than the reported non-response rate in the Census)	13-34 18.7% 35-44 16.7% 45-64 44.5% 65+ 19.8% Age not specified 0.3%	dAgeWT 1 = 13-34 2 = 35-44 3 = 45-64 4 = 65+ 5 = unspecified
State/Territory	ABS Census 2021, adjusted to enable inclusion of respondents who did not report state of residence	NSW 33.0% Vic 26.1% Qld 18.8% SA 7.9% WA 9.2% Tas 2.3% NT 0.7% ACT 1.7% Not specified 0.3%	dGEOGSTEwt 1 = NSW 2 = Vic 3 =QLD 4 =SA 5 = WA 6 = Tas 7 = NT 8 = ACT 9 = Unspecified
Language other than English	2016 Census of Population and Housing	Not used to weight as responses between 2016 Census and 2022 SDAC benchmarks are inconsistent	dLOTEwt 1 = LOTE 2 = Main language English 3 = unspecified
Aboriginal and Torres Strait Islander	2021 Census of Population and Housing	Not used to weight as responses close to benchmark	dATSIwt 1 = ATSI 2 = other/unspecified

Labour force status	Survey of Disability, Ageing and Carers, 2022	Employed 46.9% Unemployed 1.9% Not in labour force 50.4% Not specified 0.8%	dLFSwt 1 = employed 2 = unemployed 3 = not in labour force 4 = unspecified
Weekly caring hours	Survey of Disability, Ageing and Carers, 2022	<20 hours weekly or varied/ hard to say hours 56.4% 20-39 hours weekly 17.8% 40+ care hours weekly 25.7% Unspecified 0.1%	dCareHoursWT 1 = < 20 hours 2 = 20-39 hours 3 = 40+ hours

The resulting weight (variable name WTsample) had 5.3% with a weight of 3.01 or higher, with the highest weight being 16.99 but the majority being between 3.01 and 7.00. The weight was trimmed to reduce risk of outlier responses creating bias in findings, with weights of 3.01 and above trimmed to a weight of 3.00. This resulted in a trimmed weight (WTsampleTRIMMEDmaxwt3). Where a weight was not possible due to one or more weighting variables having missing data, the weight was set to 1.00 (no weight) - WTsampleTRIMMEDmaxwt3Noblank.

Past carers were not weighted.

SPSS syntax:

```
SPSSINC RAKE DIM1 =   dGenderWT 1 0.593 2 0.389 3 0.018

DIM2=  dAGEWT 1 0.187 2 0.167 3 0.445 4 0.198 5 0.003

DIM3=  dGEOGSTEwt 1 0.330 2 0.261 3 0.188 4 0.079 5 0.092 6 0.023 7 0.007 8 0.017 9 0.003

DIM4=  LFSwt 1 0.469 2 0.019 3 0.504 4 0.008

DIM5=  dCareHoursWT 1 0.564 2 0.178 3 0.257 4 0.010

FINALWEIGHT= dWTsample

/OPTIONS ITERATIONS=20 CONVERGENCE=.0001 DELTA=.5 SHOW=NO

/PLOT HISTOGRAM=YES.
```

6.5 CWS 2025

Survey platforms

The survey could be completed either online or as a paper survey. The paper form was sent directly to some carers who did not have an email address. Carers who received an email or text inviting them to do the survey, or saw a social media post about it, could also request a paper survey form by calling a free call number displayed prominently on survey promotional material. In total, 1% of survey participants (96 respondents) completed the survey using a paper form; the large majority opted to complete the survey online.

Survey timing

The 2025 CWS was open between 19 February and 30 April 2025, with some late responses received until 22 May.

Survey focus

The 2025 questionnaire asked about the following annual topics, which are examined each year:

- Caring responsibilities, including number of people cared for, length of time the person had been a carer, needs of care recipients and types of support provided to them, typical hours spent on caring responsibilities each week, and whether caring was provided continuously or episodically
- Health and wellbeing of the carer, using several existing validated measures including the Personal Wellbeing Index, general health measure, Kessler 10 psychological distress scale, and loneliness scale
- Challenging life events experienced in last 12 months, including experiencing loss or change of employment, illness, moving house, financial stress, crime, and changes in caring responsibilities
- Quality of time use, assessing extent to which carers had the ability to achieve desired and healthy levels of sleep, caring, work, exercise, and recreation
- Positive and negative experiences associated with being a carer, using both some existing scales (including a modified version of the Caregiver Burden Scale) and a small number of new questions designed specifically for the CWS
- Ability to identify and access both formal and informal support for the person's role as a carer
- Types of formal support accessed, organisations via which these supports were accessed, and level of satisfaction with these supports
- Socio-demographic characteristics of the carer such as age, gender, employment, type of home lived in, and household structure
- Access to mobile phone reception, internet and transport; some waves of the survey may ask about other services as well
- Transport access
- Open-ended questions asking for other comments about role as a carer.
- Navigating formal support systems

In addition, as noted in the introduction to this report, the 2025 questionnaire included questions about the following topics:

- Young carer experiences
- Defence force family experiences (caring for a veteran, or currently in a defence force family)
- Past carer experiences

- Identifying as a carer
- Access to and experiences of respite care

Survey languages

The 2025 CWS was translated into simplified Mandarin, Cantonese, Arabic and Hindi, selected as the highest prevalence languages other than English spoken by carers based on data from the 2021 ABS *Census of Population and Housing*. Previous years of the CWS included Italian and Vietnamese, however very few (if any) participants chose to do the survey in these languages.

Survey testing

In 2025, the CWS was initially tested by 5 people working within Carers Australia and Department of Social Services, and 6 people within University of Canberra. The survey was then sent to 100 past CWS participants, of which 28 pilot tested the 2025 CWS.

Participant recruitment

Survey participants were recruited using the following methods:

- Previous participants: 10,715 carers who participated in the 2021, 2022, 2023 and/or 2024 CWS and who had given permission to be contacted about future surveys were invited to take part in the 2025 CWS.
- Care provider organisations: Organisations who provide professional services to carers across Australia were asked to email their clients to request their participation in the survey.
- Carer representative organisations: A number of carer organisations around Australia sent emails to their membership inviting participation, advertised the survey on their websites, and promoted the survey on their social media channels.
- Social media advertising: Advertising on Facebook and Instagram was used to recruit carers.
- Gift incentives: A prize draw incentive was offered to encourage participants to take part in the survey. Prizes offered were gift cards, with winners able to choose their preferred gift card from GiftPay, enabling the winner to choose what was most relevant and meaningful to them. A prize draw of $5,000 was offered, with the following values: First prize $1500; second prize: $1000; third prize: $500; 10 runner-up prizes of $200.

These recruitment methods aimed to reach as wide a range of carers as possible. Having multiple recruitment methods help to ensure biases resulting from any one method of recruitment were minimised. For example, it was expected that carers recruited via care provider organisations and carer representative organisations may have more complex and challenging caring needs compared to carers recruited via social media. Recruiting via social media advertising enabled a wider sample of carers to be reached.

Sample

There were a total of 10,918 valid responses to the 2025 survey. Of these, 10,871 completed the English language version of the survey, while 24 completed the survey in Mandarin, 4 in Cantonese, 15 in Arabic, and 2 in Hindi.

Carers were given the option of completing a shorter or regular length version of the survey if they completed it online. This was done to ensure carers who had limited time could still participate in the survey. Online participants were asked if they wished to complete the short or regular version, and told how long each was expected to take to complete. The short version of the survey was designed to take 20-30 minutes to complete, while the regular version took 30 to 60 minutes depending on how many questions were applicable to the person completing the survey. Of the online respondents, 66.2% opted to complete the regular length survey (compared to 71.1% in 2024, 69.8% in 2023, 64.9% in 2022 and 69% in 2021), and 33.8% opted to do the short survey.

Of the respondents, 5,546 heard about the survey via direct contact from the University of Canberra (being a previous participant in the CWS), increasing from 4,513 in 2024. This increase is expected as the database of previous participants grows over the years. A total of 1,134 heard about the survey from a care provider organisation (an increase from 1,062 in 2024) and 2,702 from a carer representative organisation (an increase from the 2,384 in 2024). A further 458 heard about the survey from social media advertising and 685 through other means including seeing information about the survey on a website, friends or family. Some participants did not specify how they heard about the survey, and participants were able to select more than one option.

Weighting benchmarks

Table 6 specifies the benchmark categories used to develop statistical weights for the 2025 CWS, and the source of benchmark data used. Note that in some cases a weight is specified for those who did not provide information. The benchmark data source has been adjusted to enable inclusion of those who did not report some characteristics in the weighting; in all cases, the proportion of these unspecified categories does not exceed the non-response reported in the Census.

Table 6 Benchmark data specifications used to develop statistical weights: 2025

	Benchmark data source	Benchmark specifications	Variable name in data set and coding
Gender	ABS Census, 2021, adjusted to provide 'other' gender option	Male – 38.9% Female – 59.3% Other/not specified – 1.8%	eGenderWT 2 = Male 1 = Female 3 = Other/not specified
Age groups	ABS Census 2021, adjusted to enable inclusion of those who opted not to respond (included at less than the reported non-response rate in the Census)	13-34 18.7% 35-44 16.7% 45-64 44.5% 65+ 19.8% Age not specified 0.3%	eAgeWT 1 = 13-34 2 = 35-44 3 = 45-64 4 = 65+ 5 = unspecified
State/Territory	ABS Census 2021, adjusted to enable inclusion of respondents who did not report state of residence	NSW 33.0% Vic 26.1% Qld 18.8% SA 7.9% WA 9.2% Tas 2.3% NT 0.7% ACT 1.7% Not specified 0.3%	eGEOGSTEwt 1 = NSW 2 = Vic 3 =QLD 4 =SA 5 = WA 6 = Tas 7 = NT 8 = ACT 9 = Unspecified
Language other than English	2016 Census of Population and Housing	Not used to weight as responses between 2016 Census and 2022 SDAC benchmarks are inconsistent	eLOTEwt 1 = LOTE 2 = Main language English 3 = unspecified
Aboriginal and Torres Strait Islander	2021 Census of Population and Housing	Not used to weight as responses close to benchmark	eATSIwt 1 = ATSI 2 = other/unspecified

Labour force status	Survey of Disability, Ageing and Carers, 2022	Employed 46.9% Unemployed 1.9% Not in labour force 50.4% Not specified 0.8%	eLFSwt 1 = employed 2 = unemployed 3 = not in labour force 4 = unspecified
Weekly caring hours	Survey of Disability, Ageing and Carers, 2022	<20 hours weekly or varied/ hard to say hours 56.4% 20-39 hours weekly 17.8% 40+ care hours weekly 25.7% Unspecified 0.1%	eCareHoursWT 1 = < 20 hours 2 = 20-39 hours 3 = 40+ hours 4 = unspecified

The resulting weight (variable name WTsample) had 14% with a weight of 7.01 or higher, with the highest weight being 30.44 but the majority being between 7.01 and 10.00. The weight was trimmed to reduce risk of outlier responses creating bias in findings, with weights of 7.01 and above trimmed to a weight of 7.00. This resulted in a trimmed weight (WTsampleTRIMMEDmaxwt7). Where a weight was not possible due to one or more weighting variables having missing data, the weight was set to 1.00 (no weight) – WTsampleTRIMMEDmaxwt7Noblank.

Past carers were not weighted.

SPSS syntax:

```
SPSSINC RAKE DIM1 =   dGenderWT 1 0.593 2 0.389 3 0.018

DIM2=  dAGEWT 1 0.187 2 0.167 3 0.445 4 0.198 5 0.003

DIM3=  dGEOGSTEwt 1 0.330 2 0.261 3 0.188 4 0.079 5 0.092 6 0.023 7 0.007 8 0.017 9 0.003

DIM4=  LFSwt 1 0.469 2 0.019 3 0.504 4 0.008

DIM5=  dCareHoursWT 1 0.564 2 0.178 3 0.257 4 0.010

FINALWEIGHT= dWTsample

/OPTIONS ITERATIONS=20 CONVERGENCE=.0001 DELTA=.5 SHOW=NO

/PLOT HISTOGRAM=YES.
```

7.0 Data cleaning and preparation

Raw survey data are cleaned and prepared for analysis using standard techniques. Data from paper surveys are entered into a specially prepared Qualtrics survey, and the data entry is then checked for errors. By using an online entry form which constrains answers to the options provided on the survey, errors in data entry are minimised, as it is not possible to enter a value outside the range permitted by the question. Once data entry is completed for a survey year, a specific error check is conducted on the data entered from a subset of the paper surveys (usually 10% of surveys). This involves checking all data entered using the original paper survey form. Further error checking occurs through the initial analysis of the data, with every variable analysed and inspected for patterns of response that may indicate data entry error, and errors corrected if any are found.

Following entry of data from the paper surveys, the complete data set is:

- Checked for invalid survey responses, with these responses removed. It is possible a small number of invalid survey responses remain in the dataset, and researchers using the dataset are encouraged to report suspected invalid responses to the survey managers, for consideration for removal
- Checked to ensure no ‘out of range’ values have been reported on close-ended questions
- Checked to ensure consistent coding of question answers across the panels of the survey
- Recoded to include missing data, and to follow the data coding conventions described in this Guide
- Geocoding is performed to categorise participants into a geographic region, including state, LGA and remoteness.

7.1 Invalid survey responses

Survey responses are assessed for validity using some standard procedures, as well as some qualitative assessment of the data for completeness and accuracy. Survey responses are recorded as INVALID with the reason for this assessment in a copy of the dataset, then removed from the master dataset. Responses are considered invalid if they are:

- Test surveys (checked for reference to ‘test’, completed before formal pilot testing, or any other evidence of it being a test survey)
- Those who declined to participate in the survey
- Those who agreed to participate but did not answer any further questions beyond this point
- People living outside of Australia
- People who are not currently, or never were, unpaid carers
- Duplicate entries (duplicate emails, IP addresses, surnames, addresses): First the entry is assessed to ensure it is not different people from the same household completing the survey.
- Participants who completed less than 10 survey items past the point of determining carer status
- Participants under the age of 14
- BOT/scam responses (see below).

The number of BOT and scam responses received in the Carer Wellbeing Survey has risen dramatically since 2023. This is not dissimilar to other surveys reported in the literature, with fraudulent responses being reported as high as 94% in other surveys (Comachio et al. 2025), and is increasingly becoming a problem in research due to concerns around data quality and validity, particularly in online survey data collection in the last 5 years (Ménard et al. 2025).

Survey responses are assessed for scam/BOT responses using the following as a guide (using a combination of at least two or more):

- Qualtrics ReCaptcha score below 0.5 indicate possible BOTs
- Qualtrics RelevantIDDuplicateScore above 1 (or ID duplicate 'TRUE' or Duplicate Score over 75) indicates likely duplicates
- Qualtrics RelevantIDfraudscore of 30 or more are inspected for possible fraudulent responses
- Duration is checked for concerningly short times to complete the survey
- Check for odd emails (e.g. long strings of random letters and numbers)
- Check for patterns in the way the names are written – e.g. no spaces and exactly the same as email, or with a capital initial in the middle of a first and last name
- Check those who do not provide a postal address or name
- Check for patterns in job description (e.g. In 2023, most BOTs used the same job descriptions - teacher, retail, nurse, staff and workers, peasant. In 2024 many BOTs used job descriptions like sale, sell, tutor, Taxi/Uber/Lyft Driver, Server/Waitstaff, Pet Sitter/Dog).
- Sort open-ended questions and inspect for meaning and duplicates – many BOTs will use identical open ended responses. Assessing open ended responses is one of the most effective ways to identify fraudulent responses when at least one other flag is evident. Legitimate responses are usually more persona, mentioning the relationship to the person they care for (e.g. "my husband" or "my mum") whereas fraudulent responses are often impersonal and vague and often refer to the person they care for as "the patient" or "the client".
- Matching state/postcode/locality – mismatches are a flag for potential invalidity. Some BOTs will use the same locality, for example in 2024 many invalid responses used CARWELL or abbotsbury as the locality.
- Clusters of survey responses (at least 5 responses) that have the same survey end time and/or start time.
- Identification as Aboriginal or Torres Strait Islander. A large proportion of fraudulent responses indicate being Aboriginal or Torres Strait Islander. We know that the proportion of valid participants identifying as Aboriginal or Torres Strait Islander is unlikely to be high (unless specific recruitment is undertaken in Aboriginal or Torres Strait Islander communities), so this offers another good flag to investigate further.

7.2 Geocoding

The CWS collects information about survey participants' residential location, including:

- State/territory they live in
- Name of rural locality, town or suburb they live in
- Postcode they live in

The information on location collected using the questions above is used to match participants to specific geographic boundaries at different scales (referred to as geographies). These procedures are referred to as geocoding. Geocoding enables research to be conducted at a wide range of geographies which are specifically relevant to the stakeholders involved at the national, regional and local scale.

The locality information provided above is cleaned and used to geocode the response first to Local Government Area (LGA). This information is then used to geocode to remoteness area, and Public Health Network area. Where only postcode and state information is given, this can still be geocoded to an LGA where (i) that postcode sits within only one LGA, or (ii) the majority of the postcode area is within one LGA. In some circumstances, respondents will name the locality as a major city, such as Sydney or Melbourne, but the postcode is specific to a suburb within the broader area. In these circumstances the postcode is used to geocode to LGA.

CWS data tables report by State/Territory and by Remoteness.

There are five groups of remoteness that people are categorized into, however reporting typically requires grouping some of the more remote regions due to low response numbers from these regions. The remoteness categories are based on the Australian Statistical Geography Standard (ASCS) Remoteness Structure. These include:

- Major cities of Australia
- Inner regional Australia
- Outer regional Australia
- Remote Australia
- Very remote Australia

These classes of remoteness are classified on the bases of relative access to services, measured using the Accessibility and Remoteness Index of Australia (ARIA+) and published by the ABS. For more information see: https://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/D964E42C5DF5B6D4CA257B03000D7ECB?opendocument.

7.3 Variable naming

In the data set, variable names are limited in most cases to 32 characters, enabling them to be used in SPSS, R, STATA and SAS. Note that in some cases coding conventions vary slightly between years, but in general:

- The first character indicates the year of the survey the data were collected in. 2021 data has ‘a’, 2022 data has ‘b’, 2023 data has ‘c’ and so on.
- Characters in capital letters immediately following the first character indicate the general topic area of the variable.
- Remaining characters, in a mix of upper and lower case, indicate the specific nature of the variable. When naming variables, the naming has incorporated key elements of the wording and meaning of questions used to collect data for the variable. This can assist the subsequent analysis of these variables by providing a subject reference that is reasonably easy to interpret and find when undertaking analysis.

7.4 Data coding

The questions asked in the CWS have multiple response formats. Table 7 provides examples of the numeric coding conventions used for common question formats used in the survey, while Table 8 identifies numeric codes used throughout the data set, irrespective of the variable, to indicate different types of missing data or other characteristics.

The CWS metadata file specified coding for each individual survey item. This can be requested separately via carerwellbeing@canberra.edu.au.

Table 7 Examples of numeric coding conventions used for common response formats used in CWS questions

Question response format	**Numeric coding convention used**
Present/absent (i.e., the question asked the respondent to tick characteristics they do or do not have, with only a present or absent option possible)	1 = present, 0 = absent
Yes/No	1 = 'yes', 0 = 'no'
Open-ended variables	Text as written by respondent is reproduced
7-point scale: 1 'strongly disagree' to 7 'strongly' agree	Responses coded from 1 to 7, with 1 representing 'strongly disagree', and 7 representing 'strongly agree'.
7-point scale: 1 (very poor) to 7 (very good)	Responses coded from 1 to 7, with 1 representing 'very poor, and 7 representing 'very good'
7-point scale: How often do you do the following things: never or almost never; rarely, occasionally, sometimes, quite often, very often, always or almost always	1 = Never, or almost never; 2 = Rarely; 3 = Occasionally; 4 = Sometimes; 5 = Quite often; 6 = Very often; 7 = Always or almost always
7-point scale from 1 = Very unlikely to 7 = Very likely	Responses coded from 1 to 7, with 1 representing 'very unlikely, and 7 representing 'very likely'
8-point impact/affect scales	0 = No impact; 1-7 are a seven-point scale from 1 = Very negative impact to 7 = very positive impact.
5-point general health scale	1 = Excellent, 2 = Very good, 3 = Good, 4 = Fair, 5 = Poor. -999 = did not answer question
11-point life satisfaction scale	11 point scale in which 0 = Completely dissatisfied, 10 = Completely satisfied. -999 = did not answer question.
5-point K10	1 = None of the time; 2 = A little of the time; 3 = Some of the time; 4 = Most of the time; 5 = All of the time
3-point physical activity scale	1 = Yes, limited a lot; 2 = Yes, limited a little; 3 = No, not limited at all

Table 8 Coding of missing variables and other variables occurring across the CWS data set

Numeric code	**Description**
-88	Respondent selection 'Not applicable' in response to the question
-22	Respondent selected 'Don't know' or 'Unsure' in response to the question
-999	Respondent was asked to complete the item but did not complete it (i.e., it was left blank on the survey form).
-777	The item was in the survey the respondent completed, but was not seen because the question was deliberately not displayed (due to piping/display logic)
-333	The item was in the survey the respondent completed, but was not seen because the respondent 'dropped out' of the survey before the item was displayed.
-666	The item was not in the survey that the respondent completed. E.g. the respondent completed a paper form, which did not include all items in the online version of the survey). This occurs because not all items are included in all versions of the survey due to space constraints.
-555	Missing from variables that are constructed from other variables, but not collected directly from the participants

8.0 Data tables

Detailed data tables are provided as an excel spreadsheet in an appendix to the annual reports (Schirmer et al. 2022, Mylek and Schirmer 2023, Mylek and Schirmer 2024). These can be requested through the CWS email (carerwellbeing@canberra.edu.au).

UC sends the data tables directly and keeps a record of those requesting the data tables in a spreadsheet. This spreadsheet is provided to Carers Australia at the end of each month. Details in the spreadsheet include the year of CWS being requested, date requested, name of person, email, organisation, role and date sent.

9.0 Accessing survey data

To access unit record data from the CWS, users first need to apply for permission to use the dataset. This applies to all users seeking to access unit record level data. Data can only be made available for projects that fit within the objectives of the CWS and requires permission from Carers Australia. The data owners also reserve the right to request evidence of Ethics committee approval for your research project, if your research is likely to present moderate or high risk.

To request a copy of the CWS Data Access Protocols, email carerwellbeing@canberra.edu.au.

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Appendix 1: Socio-demographic and carer groups reported

This Appendix details how the different socio-demographic and carer groups are defined for purposes of reporting, particularly in data tables.

Survey participants are asked up front whether they are a previous survey participant. Those that indicate they have participated in the survey in the past are asked whether they would like us to link some of their socio-demographic and caring responses from previous surveys in order to avoid answering these questions again. Where participants agree to have their responses linked from previous years, some questions are not asked. Every 3-4 years, all questions are asked of all participants to provide a 'check point' in responses and links.

Carers: Current and past

A carer is defined as a person who provides unpaid care to a person who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal or serious illness, or age-related frailty. The Australian government Carers payment and Carers allowance are not considered to represent payment for care, with recipients of these government benefits included in the definition of unpaid carers. Everyday care for children is not included in the definition of carer, however if a person is caring for a child with a specific disability, illness, condition or frailty, they are considered a carer.

Current and past carers are identified in a number of ways:

Past participants who agree to link responses across years are first asked whether any of a number of things have changed since they last completed the survey, including whether they have stopped caring altogether. If this is selected, they are no longer considered current carers, and are now past carers (below).

The remaining participants are first asked the following:

Have you ever done any of the following types of caring?	**Yes, currently doing this**	**Not currently, but I have in the past**	**I've never done this**
Looking after someone (or helping look after someone) who has a **disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who is frail or needs care due to ageing?** *Note: Doing this type of role for a short period counts as looking after someone.*	○	○	○
Everyday care for your own or other people's children *Note: If any of the children you care for/have cared for has a disability, illness or other special caring needs, please select the option above **as well as** this one.*	○	○	○

Participants are potentially considered current carers if they select 'yes, currently doing this' for looking after someone with a disability, mental illness, drug or alcohol dependency, chronic condition, dementia, terminal or serious illness, or who is frail or needs care due to ageing. If they select 'not currently, but I have in the past' they are considered past carers.

If participants select 'I've never done this' they are not considered carers and not eligible to continue with the rest of the survey.

Participants who selected yes currently, or not currently but in the past for caring above are then asked:

You indicated that you either currently or in the past have looked after someone with a disability, illness, dependency or frailty. Have you done this:	**Yes, currently doing this**	**Not currently, but I have in the past**	**I've never done this**
As part of paid work? *Note that for the purpose of this question, do not include a carer's payment or allowance as 'paid work' – we're wanting to know if you are paid a salary or wage for your caring, not a government payment.*	○	○	○
As part of volunteering for an organisation that does caring work?	○	○	○
As a family member, friend or neighbour?	○	○	○

A participant is not considered a current carer and taken to the remainder of the survey if they select 'yes currently doing this' for the first option. If they do not select this, but select 'not currently but I have in the past', they are considered a past carer. If they do not select these options at all, they are not considered carers and not eligible to complete the survey.

Some further inspection of the survey responses is required past this point to identify past and current carers. Sometimes participants who indicate they currently care for someone subsequently indicate they have stopped caring for someone – these participants are then considered 'past carers'. Conversely, some participants who indicate that they don't currently care for someone subsequently indicate that they currently care for one or more people, and go on to answer questions about the people they currently care for. These participants are then considered current carers.

The majority of reporting is for current carers only – except where specified that the reporting is for past carers. For example, the data tables report all groups for current carers, except for the following, which is only reported of past carers:

Past carers	Past carers - all
	Ceased caring in last 6 months
	Ceased caring 7-12 months previously
	Ceased caring more than 1 year ago

Gender

The CWS asks participants the gender they identify as, and does not ask about gender assigned at birth. Participants are able to identify as female, male, other, or to select 'prefer not to say'. We report by those identifying as Male or Female, as the response numbers for 'other' and 'prefer not to say' are typically too low. All survey participants are asked this question, even if they are a repeat participant, to assist with linking responses across years.

Age

The CWS collects data from people aged 14 and over. The survey asks participants up front how old they are, and those who indicate that they are under 14 are diverted to a message that explains the survey is for those aged 14 and older. Participants can complete the survey without answering this question. All survey participants are asked this question, even if they are a repeat participants, to assist with linking responses across years.

The following age groups are reported:

- Aged 15-24
- Aged 25-34
- Aged 45-54
- Aged 55-64
- Aged 65-74
- Aged 75+

Cultural and language diversity

Aboriginal and Torres Strait Islander peoples

The CWS asks participants whether they are of Aboriginal and/or Torres Strait Islander origin. This question is only asked of new participants and past participants who do not give permission to link responses from previous years.

CALD

Australia is home to many people from culturally and linguistically diverse (CALD) backgrounds. The CWS identifies cultural and linguistic backgrounds by asking about:

- Language spoken at home. This identifies whether the main language the person speaks at home is English or another language. If another language is the main language spoken at home, the survey participant is asked to identify the language spoken at home.
- Country of birth. This identifies whether the person was born in (i) Australia, (ii) another English speaking country, or (iii) a non-English speaking country. Those born in other countries are in most waves asked to identify their country of birth.

Additionally, the CWS is offered in four languages other than English (Chinese, Arabic, Italian and Vietnamese).

These questions are only asked of new participants and past participants who do not give permission to link responses from previous years.

LGBTIQ+

CWS survey participants are asked if they identify as LGBTIQ+, straight, or if they are unsure or prefer not to say. Sufficient sample is achieved of those who identify as LGBTIQ+ to enable reporting for this group, as well as for those who identify as straight.

Geographies

Survey participants are asked about where they live, for two reasons. One, so that subsequent questions can be suitably piped depending on what State or territory they live in, and two, so that the responses can be geocoded into geographic regions for reporting. From the responses to the below, participants can be grouped into a State/territory, and remoteness region for reporting.

Where do you live? We ask this because we will produce results for different regions of Australia to help understand if those in different locations have better or poorer access to services. To do this, we need to ask you where you live. We make sure to protect the privacy of our survey participants when we report results. *If you live in more than one place, please put in your primary residence*	**State / territory you live in:** *e.g. VIC, SA* ________________________________ **Town, suburb or rural locality you live in:** ________________________________ **Postcode you live in:** ___ ___ ___ ___

State/Territory

CWS data tables report by all state/territories: NSW, Victoria, Queensland, South Australia, Western Australia, Tasmania, Northern Territory and Australian Capital Territory.

Remoteness

There are five groups of remoteness that people are categorized into. The remoteness categories are based on the Australian Statistical Geography Standard (ASCS) Remoteness Structure, and include:

- Major cities of Australia
- Inner regional Australia
- Outer regional Australia
- Remote Australia
- Very remote Australia

These classes of remoteness are classified on the bases of relative access to services, measured using the Accessibility and Remoteness Index of Australia (ARIA+) and published by the ABS. For more information see: https://www.abs.gov.au/AUSSTATS/abs@.nsf/allprimarymainfeatures/D964E42C5DF5B6D4CA257B03000D7ECB?opendocument.

However, reporting typically requires grouping some of the more remote regions due to low response numbers from these regions:

- Major cities
- Inner regional
- Outer regional, remote and very remote.

Work and study

Labour force status

Participation in the labour force is categorised into employed carers, unemployed carers and carers not in the labour force. This is determined using the responses to the following question:

Do you currently do any of the following? *Select ALL that apply.* *Note we don't ask about your caring responsibilities here, as we have already asked about those.*	☐ Business owner/co-owner. ☐ Self-employed ☐ I have full-time paid work ☐ I have part-time paid work ☐ I have casual paid work ☐ I do unpaid work ☐ Unemployed & looking for work	☐ Retired ☐ Studying part-time or full-time ☐ I volunteer for one or more groups e.g. sports group, community group, church, school, hospital ☐ None of these

Carers who select business owner, self-employed, full-time paid work, part-time paid work or casual paid work are categorised as 'employed'. Carers who selected 'unemployed and looking for work' only, are categorised as unemployed. Carers who selected any of the remaining options, and did not also select an 'employed' option, are categorised as 'not in labour force'.

Training/study status

Carers who select 'Studying part-time or full-time' in the above question are categorised as 'Currently studying at educational institution'.

Care recipient involvement in defence force or first response (current or in the past)

In 2023, a new question was included in the CWS to identify carers of people who are currently or have been in the past involved in the defence force or first response (whether in a paid or volunteering capacity). Participants were asked:

Has the person you care for ever done any of the following types of paid or volunteer work (whether currently or in the past)? *Select ALL that apply*	☐ Defence force member (army, navy or airforce - including reservists) ☐ Paid work as a 'first responder' – this includes police officers, ambulance officers and firefighters, as well as other first responders ☐ Volunteer work as a 'first responder' e.g. volunteer fire fighter ☐ None of the above

Caring role

Carers are categorised by multiple aspects of their carers role and reported each year, including typical caring hours per week, whether they are a primary and/or sole carer, whether their role is continuous or episodic, how many people they care for, where the care recipient/s live, how long they've been a carer, their relationship to the person they care for, the care recipient disability, illness or injury type, the level of assistance needed by the care recipient and the type of support provided by carers.

Typical caring hours per week

Carers are asked:

For your current or most recent caring duties, about how many hours a week would you typically spend on your caring responsibilities? *Select one*	○ <5 hours ○ 5-9 hours ○ 10-14 hours ○ 15-19 hours	○ 20-29 hours ○ 30-39 hours ○ 40-49 hours ○ 50-59 hours	○ 60-69 hours ○ 70 or more hours ○ Hard to say ○ Varies

Cares are then reported in the following categories based on their selection:

- <20 hours per week
- 20-39 hours per week
- 40+ hours per week
- Varied/hard to say

Primary carer

Carers are asked the following about each person they care for. If they select 'yes' for any person they care for, they are categorised as a 'primary carer':

Are you the primary carer for Person 1? *Select one*	○ Yes, I provide the majority of the care for this person ○ I provide less than half the care for this person ○ I provide around half the care, and another person or other people provide the other half

Sole/assisted carer

Carers are asked the following about each person they care for. If they select 'No, I am the sole carer' for any person they care for, they are categorised as a 'sole carer':

Does anyone other than yourself provide regular care for Person 1? *Select one*	○ Yes, another family member or friend ○ Yes, one or more paid care workers ○ Yes, another person e.g. volunteer ○ No, I am the sole carer

Continuous or episodic carer

Carers are asked the following:

Are your current caring duties permanent of episodic? *If you care for more than one person, please answer for the one likely to need care for the longest time.* *Select one*	○ Permanent – I have an ongoing carer role ○ Episodic – I am sometimes required to be a carer, but there are periods when the person I care for needs little or no care

Number of people currently caring for

Carers are asked the following:

How many people have you been a carer for? *Select one*	Current number of people you are caring for (only include those you care for who have a disability, illness, drug/alcohol dependency or frailty, including children with special caring needs; but do not include children with everyday caring needs associated with standard childcare) ○ None ○ One ○ Two ○ Three ○ Four or more

Cares are then reported in the following categories based on their selection:

- Currently care for 1 person
- Currently care for 2 people
- Currently care for 3 or more people

Care recipient residence

Carers are asked the following about each person they care for. If they select 'Yes' for any person they care for, they are categorised into having a care recipient live with them:

Does Person 1 you care for live with you?	○ Yes ○ No

Length of time being a carer

Carers are asked the following:

How long were you a carer for in total? If you cared for more than one person, please answer for all the people you cared for. *Select one*	○ More than 5 years ○ 2-5 years ○ 1-2 years ○ 7-12 months ○ 3-6 months ○ 1-2 months

Cares are then reported in the following categories based on their selection:

- Carer for 5+ years
- Carer for 2-5 years
- Carer for 1-2 years
- Carer for <1 year

Care recipient disability, illness or injury type

Carers are asked the following about each person they care for. If they select any of the options for any person they care for, they are categorised as a carer of someone with that particular caring need.

Does Person 1 you care for have any of the following caring needs? *Select ALL that apply*	☐ Dementia ☐ Old-age related frailty/old-age related poor health ☐ Terminal illness other than dementia ☐ Autism spectrum disorder ☐ Other developmental disorder ☐ Mental illness and/or psychosocial disability ☐ Drug or alcohol addiction/dependency ☐ Physical disability e.g. related to sight, hearing, mobility ☐ Intellectual disability ☐ Chronic non-terminal illness (lasting 6 months or more) ☐ Shorter term illness (likely to last less than 6 months) ☐ Other, please specify ____________________

Relationships of carer to care recipient

Carers are asked the following about each person they care for. If they select any of the options for any person they care for, they are categorised as having that relationship.

Is Person 1 you care for your… *Select one*	○ Child/stepchild ○ Grandchild/step-grandchild ○ Spouse/partner ○ Ex-spouse / ex-partner	○ Parent/step-parent ○ Parent-in-law ○ Grandparent/step-grandparent/ grandparent-in-law ○ Brother/sister	○ Brother/sister-in-law ○ Other family member e.g. aunt, uncle ○ Non-family member e.g. friend

Level of assistance needed by care recipient

Carers are asked the following about each person they care for. Where survey participants care for more than one person, they are asked to answer questions for the person they care for with the highest caring needs first ("If you care for more than one person, please provide information here for the person you care for who has the highest caring needs"), followed by the next level of caring needs in the next set of questions and so on. Therefore, the caring needs of the first person they care for are used as the level of assistance needed. Some additional checking and decision making may be needed in a small number of cases where the survey participant did not follow this instruction.

How much assistance does Person 1 typically need? *Select one* *We know that caring needs often vary day to day. On a day that is 'typical' (if there is one), how much assistance would the person require (from 1 'require limited assistance' to 5 'require care for most of their day-to-day functioning)? If the person only sometimes requires care, base your answer on the times when they do need care.*	○ 1 (Not much – they require limited assistance)	○ 2	○ 3	○ 4	○ 5 (person needs care for most of their day-to-day functioning)

Level of caring needs is reported in the following categories:

- Low assistance needs (selected 1)
- Low-moderate assistance needs (selected 2)
- Moderate assistance needs (selected 3)
- High assistance needs (selected 4)
- Very high assistance needs (selected 5)

Types of support provided by carer to care recipient/s

Carers are asked the following about each person they care for. If they select any of the options for any person they care for, they are categorised as a carer providing this type of support.

Carers provide a wide range of support for the people they care for, and this support varies a lot depending on the needs of the people being cared for. **In the last 12 months, have you done any of the following for Person 1 you care for?** *Select ALL that apply*	☐ Personal care support e.g. bathing, showering, dressing, toileting ☐ Helping with transport e.g. by driving the person to appointments, organising public transport or taxi ☐ Communication support e.g. assisting person to communicate with family/friends/strangers ☐ Technology support e.g. helping person use online appointments or forms, pay bills online etc ☐ Managing/organising medications ☐ Managing/organising medical appointments

	☐ Accessing and helping to manage formal support services such as aged or disability supports. ☐ Assisting person to access and maintain employment or education/training ☐ Advocating for person's needs e.g. with school, health professionals, employer ☐ Assisting person in managing social interactions ☐ Staying with a person to ensure they remain safe from accident or self-harm ☐ Doing more housework, cooking or cleaning than you would usually do in order to help care for the person ☐ Other type of caring activity (please describe below) ☐ None of the above

Payments or allowances

Carers are asked whether they have received a carer payment or allowance, with different timeline response options below:

Do you receive, or have you tried to access, the following types of carer financial support or coordination/planning services?	**I've received this in the last 12 months**	**I've received this in the past, but not in the last year**	**I've tried to access this, but didn't receive it**	**I've never tried to access this, but would like to**	**I don't need this type of carer support**
Carer Payment (*an income support payment from the government for those giving constant care to someone who has a severe disability, illness, or who is frail and aged)*	○	○	○	○	○
Carer Allowance (*a fortnightly supplement from the government for those giving additional daily care to someone who has a disability, serious illness or who is frail and aged)*	○	○	○	○	○

Based on the responses, carers are categorised as:

- Did not receive carer payment or allowance in the last 12 months
- Received carer payment and/or allowance in the last 12 months

Appendix 2: Measures used in other surveys

The questionnaire includes some measures that are asked in other surveys, in particular the annual Regional Wellbeing Survey. These are used to enable comparison of carers to the broader Australian adult population.

Table 9 summarises measures/survey items that are used in other surveys. Calculation of some of these measures are described in more detail in Appendix 3.

Table 9 Measures used in other surveys

Measure / survey items	Description	Other surveys this measure/item is used in
Subjective Wellbeing - Personal Wellbeing Index	The Personal Wellbeing Index (PWI) is a relatively commonly used measure of overall subjective personal wellbeing, both in Australia and internationally. It is calculated using the procedure described by International Wellbeing Group (2013). There have been no changes to this measure over time, or to the thresholds used to indicate low versus healthy levels of wellbeing.	Regional Wellbeing Survey HILDA
Subjective wellbeing – Global Life Satisfaction	Global Life Satisfaction (GLS) is measured using a single item, where people are asked "How satisfied are you with your life as a whole?". While this question is a good measure of subjective wellbeing, such single-item measures are less reliable than multi-item scales. It is calculated using the procedure described by International Wellbeing Group (2013). There have been no changes to this measure over time, or to the thresholds used to indicate low versus healthy levels of wellbeing.	Regional Wellbeing Survey HILDA
General health	The general health measure is one of the most widely used general health measures in available Australian datasets. This measure examines a person’s self-reported overall health using a single item that asks a person ‘overall, how would you rate your health during the last four weeks’ with response options of excellent, very good, good, fair or poor. There have been no changes in measure design, analysis or reporting since it was first included in the survey.	Regional Wellbeing Survey HILDA ACT General Health Survey ABS National Health Survey
Psychological distress (K10)	the Kessler 10 psychological distress scale (or the shortened K6 scale) is widely used both in Australia and internationally. This widely used measure asks a person how often they have experienced ten (or six) psychological distress symptoms in the last four weeks. There have been no changes in measure design, analysis or reporting since it was first included in the survey.	Regional Wellbeing Survey

Loneliness Index	The measure used is a validated three-item loneliness scale, which is used in a number of studies, some of which use slightly different variants of the response scale. There have been no changes in measure design, analysis or reporting since it was first included in the survey.	Regional Wellbeing Survey
Household prosperity	The measure used is included in a number of Australian surveys. Participants are asked 'Given your current needs and financial responsibilities, would you say that you and your family are...' and able to respond (i) Very poor, (ii) Poor, (iii) Just getting along, (iv) Reasonably comfortable, (v) Comfortable or (vi) Prosperous. There have been no changes in measure design, analysis or reporting since it was first included in the survey.	Regional Wellbeing Survey HILDA
Time use	The time-use items are a series of questions asking survey participants to indicate whether they spend less time than desired, more time than desired, or the right amount, or a range of life activities, including caring, working, cleaning, commuting etc. There have been no changes in measure design, analysis or reporting since it was first included in the survey.	Regional Wellbeing Survey
Employment and study	A question about work, study and volunteering undertaken by the survey participant is used to be able to determine whether carers are employed, unemployed or not in the labour force. There have been no changes in measure design, analysis or reporting since it was first included in the survey.	Regional Wellbeing Survey
Impacts of rising cost of living (2023)	In 2023 a special topic in the CWS was about the rising cost of living. A series of items were asked about the impacts of the rising cost of living, matching items asked in the Regional Wellbeing Survey.	Regional Wellbeing Survey

Appendix 3: Calculated scales/measures

Most of the data from the CWS is reported as responses to individual items from the survey, and the report and/or data tables describe what was asked and what is being reported. For a copy of all questions asked in the CWS email carerwellbeing@canberra.edu.au.

In some cases, the measures or scales reported are calculated using multiple individual items in the survey, using existing methods applied in other surveys, or developed by the CWS team where appropriate. This Appendix describes the methods of calculating these scales/measures.

Personal Wellbeing Index

The Personal Wellbeing Index (PWI) is a relatively commonly used measure of overall subjective personal wellbeing, both in Australia and internationally. It is calculated using the procedure described by International Wellbeing Group (2013).

The field of wellbeing research is rapidly evolving, and along with it understanding of the level of wellbeing needed to support long-term positive life outcomes. There is good evidence that those who experience low levels of wellbeing (based on the threshold above) are more likely to experience a range of negative life outcomes, such as experiencing mental health problems or life stresses. There is less evidence regarding the difference in life outcomes between those with the higher levels of wellbeing, compared to those with what is currently termed ‘typical’ levels of wellbeing. There may be justification to group those with ‘typical’ and ‘high’ levels of wellbeing into a single group described as having ‘healthy’ levels of personal wellbeing.

The survey measure is documented below.

Thinking about your own life and personal circumstances, how satisfied are you with the following at the moment?	**Completely DISSATISFIED** ⓪	①	②	③	④	⑤	⑥	⑦	⑧	⑨	**Completely SATISFIED** ⑩
Your standard of living	○	○	○	○	○	○	○	○	○	○	○
Your health	○	○	○	○	○	○	○	○	○	○	○
What you are currently achieving in life	○	○	○	○	○	○	○	○	○	○	○
Your personal relationships	○	○	○	○	○	○	○	○	○	○	○
How safe you feel	○	○	○	○	○	○	○	○	○	○	○
Feeling part of your community	○	○	○	○	○	○	○	○	○	○	○
Your future security	○	○	○	○	○	○	○	○	○	○	○

Responses to the above seven items are transformed into scales from 0 to 100 by multiplying each response value by 10. The PWI score is calculated as the mean of the responses to the seven individual items, and is calculated with up to 2 missing values (which are imputed based on the mean of the remaining 5). The following is reported:

- The mean PWI score
- The proportion of people with low wellbeing (score below 60), ‘typical’ wellbeing (score of 60 to 79), and high wellbeing (80 or higher). These thresholds are based on those emerging as meaningful in the literature (Schirmer et al. 2016).
- The mean and thresholds are also reported for the seven individual items.

Psychological distress – K10

The measure used for this indicator is the Kessler 10 psychological distress scale, which is widely used both in Australia and internationally (Andrews and Slade 2001). Psychological distress is defined as experiencing non-specific symptoms of stress, anxiety and depression. A person who is experiencing high levels of psychological distress will commonly also have poorer overall wellbeing, and vice versa. A person who has very high psychological distress is also more likely to have a diagnosable mental health disorder, although not all people with high psychological distress will have a diagnosable mental health disorder (Anderson et al. 2013).

This widely used measure asks a person how often they have experienced ten psychological distress symptoms in the last four weeks.

In the last four weeks, how often have you felt…	**None of the time**	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
Nervous?	○	○	○	○	○
Hopeless?	○	○	○	○	○
Restless or fidgety?	○	○	○	○	○
So sad that nothing could cheer you up?	○	○	○	○	○
That everything was an effort?	○	○	○	○	○
Worthless?	○	○	○	○	○

Each response is given a score, as follows:

- None of the time: 1
- A little of the time: 2
- Some of the time: 3
- Most of the time: 4
- All of the time: 5

Responses are summed to form a score from 10 (no or very low distress) to 50 (extremely high distress), with up to two items missing (the two missing values are imputed using the mean of the remaining 8 values). The following is reported:

- The mean K10 score
- % with lowest probability of serious mental illness: those with a score of 10-19
- % with low/moderate psychological distress: those with a score of 20-24.
- % with moderate/high psychological distress: those with a score of 25-29.
- % with highest probability of serious mental illness: a score of 30 or higher.

Psychological distress – K6

Sometimes a K6 measure is used in other surveys, which is made up of six out the ten items used in the above K10 measure. Where comparisons are made to other surveys that have used K6 instead of K10, then a K6 score is also calculated using the following items:

In the last four weeks, how often have you felt…	**None of the time**	**A little of the time**	**Some of the time**	**Most of the time**	**All of the time**
Nervous?	○	○	○	○	○
Hopeless?	○	○	○	○	○
Restless or fidgety?	○	○	○	○	○
So sad that nothing could cheer you up?	○	○	○	○	○
That everything was an effort?	○	○	○	○	○
Worthless?	○	○	○	○	○

Each response is given the following scores:

- None of the time: 1
- A little of the time: 2
- Some of the time: 3
- Most of the time: 4
- All of the time: 5

Responses are summed to form a score from 5 (no or very low distress) to 30 (extremely high distress), with up to two items missing (the two missing values are imputed using the mean of the remaining 8 values). The following is reported:

- % with low psychological distress: those with a score of 5-12
- % with moderate psychological distress: those with a score of 13-18
- % with high psychological distress: a score of 19 or higher.

Loneliness index

The Loneliness Index is a validated three-item loneliness scale, which is used in a number of studies, some of which use slightly different variants of the response scale, but which have all shown good characteristics for the scale (see Hughes et al. 2004, Matthews-Ewald and Zullig 2013).

Levels of loneliness are measured by asking survey respondents the following:

Thinking about your experiences in the last four weeks…	**Never**	**Hardly ever**	**Occasionally/ sometimes**	**Often**	**All of the time**
How often do you feel that you lack companionship?	○	○	○	○	○
How often do you feel left out?	○	○	○	○	○
How often do you feel isolated from others?	○	○	○	○	○

The mean scores of the three items are combined to form an index of loneliness, scored from 1 (low levels of loneliness to 5 (high levels of loneliness), with up to 1 missing item (the one missing value is imputed using the mean of the remaining 2 values).

Three groups are identified from the measure of loneliness, using the following scoring thresholds:

- Never/hardly ever lonely: Score between 1 and 2.49
- Sometimes lonely: Score between 2.50 and 3.49
- Often/always lonely: Score of 3.50 or higher.

The calculation of the index is different to that described in previous literature, but was calculated in this way to be able to report the thresholds using the existing scale options.

Carer gateway satisfaction (report not publicly available)

Satisfaction with Carer Gateway communication and interactions: Calculated based on responses to the following three items: How satisfied were you with the following aspects of Carer Gateway (i) How your needs as a carer were assessed, (ii) Professionalism of Carer Gateway staff, (iii) Helpfulness of Carer Gateway staff. The average score of these three items was calculated (scored from 0 = not at all satisfied to 10 = very satisfied). Three groups were then identified: Somewhat/very dissatisfied = score from 0 to 4.49; Neutral = score between 4.50 and 5.49; Somewhat/very satisfied = score from 5.50-10.00.

Satisfaction with Carer Gateway services received: Calculated based on average level of satisfaction with services accessed (scored from 0 = not at all satisfied to 10 = very satisfied). This average was calculated based on participant rating of satisfaction with the specific services accessed, which could include one or more of (i) carer assessment and planning service, (ii) Funding to purchase small assets to support you as a carer, (iii) Psychological counselling, (iv) Carer coaching, where a coach supported you in your role as a carer, (v) Online self-guided coaching to help you build knowledge and skills to help you as a carer, (vi) online carer skills courses, (vii) Support to enrol in education or training courses, (viii) Online forum for carers to support each other, (ix) In-person peer support meetings, (x) Cleaning services, (xi) Shopping service, (xii) Transport service, (xiii) In-home respite care, (xiv) Day-care respite care, (xv) Residential respite care, (xvi) Emergency respite care, (xvii) Other respite care. Some carers accessed only one form of support and others several; the average satisfaction score across all the services accessed via Carer Gateway was calculated. Three groups were then identified: Somewhat/very dissatisfied = score from 0 to 4.49; Neutral = score between 4.50 and 5.49; Somewhat/very satisfied = score from 5.50-10.00.

Usefulness of Carer Gateway services received: Calculated based on average rating of usefulness with services accessed (scored from 0 = not at all useful to 10 = very useful). This average was calculated based on participant rating of usefulness of the specific services accessed, which could include one or more of (i) carer assessment and planning service, (ii) Funding to purchase small assets to support you as a carer, (iii) Psychological counselling, (iv) Carer coaching, where a coach supported you in your role as a carer, (v) Online self-guided coaching to help you build knowledge and skills to help you as a carer, (vi) online carer skills courses, (vii) Support to enrol in education or training courses, (viii) Online forum for carers to support each other, (ix) In-person peer support meetings, (x) Cleaning services, (xi) Shopping service, (xii) Transport service, (xiii) In-home respite care, (xiv) Day-care respite care, (xv) Residential respite care, (xvi) Emergency respite care, (xvii) Other respite care. Some carers accessed only one form of support and others several; the average satisfaction score across all the services accessed via Carer Gateway was calculated. Three groups were then identified: Somewhat/very dissatisfied with usefulness = score from 0 to 4.49; Neutral = score between 4.50 and 5.49; Somewhat/very satisfied with usefulness = score from 5.50-10.00.

Overall satisfaction with Carer Gateway: This was calculated based on the average score of (i) Satisfaction with Carer Gateway communication and interactions (ii) Satisfaction with Carer Gateway services received and (iii) Usefulness of Carer Gateway services received. Three groups were then identified: Somewhat/very dissatisfied = score from 0 to 4.49; Neutral = score between 4.50 and 5.49; Somewhat/very satisfied = score from 5.50-10.00