

# Participant Information Form

## Caring for others and yourself: the 2024 Carer Wellbeing Survey

This document provides information for carers who have been asked to participate in the Carer Wellbeing Survey. Please keep the information sheet for your files. If you have further questions about the survey, you can call the survey researchers on **1800 981 499**.

### Project Aim

The Carer Wellbeing Survey was started in 2021 to better understand the wellbeing and quality of life of unpaid carers across Australia, and their access to and use of support services.

### General Outline of the Project

Supporting the wellbeing of carers is critical to ensuring both that they are able to continue providing high quality care, and to ensure that carers themselves maintain a high quality of life. Unpaid carers include those receiving a carers payment or allowance, and those receiving no government payment to assist them in their caring obligations. They provide care for people who are experiencing physical or mental illness, disability or old-age related frailty, as well as those experiencing drug or alcohol addiction. The person/people they care for may live with them, or in a different home.

Previous reports from the Carer Wellbeing Survey (2021, 2022 and 2023) are available at:

<https://www.carersaustralia.com.au/carer-wellbeing-survey/>

### Who is undertaking the study, and who is funding it?

This study is lead by the University of Canberra in partnership with Carers Australia and Department of Social Services. The study is funded by the Australian Research Council. In addition, carers organisations around Australia and some service providers assist through inviting their members and clients to participate in the survey. The survey is being undertaken by the following researchers from the University of Canberra: Dr Melinda Mylek, Dr Jacki Schirmer and Ms Celia Maddox.

### Participant Involvement

Both current carers and those who have cared for someone in the past but are not currently a carer can participate in the survey. You can participate even if the caring responsibilities you have or had lasted a relatively short period of time, or you were not the main carer for the person.

You can complete the survey online at:

<https://www.carersaustralia.com.au/support-for-carers/carer-wellbeing-survey/>

[www.regionalwellbeing.org.au](http://www.regionalwellbeing.org.au)

If you need a paper survey form, call 1800 981 499, Monday to Friday, 9am-5pm, and we'll send a paper survey to you with a prepaid return envelope. The survey will take 20 to 60 minutes for most people to complete, depending on how many questions apply to you. If your internet drops out or you need to take a break, just go back to the place you first accessed the survey and click on the same survey link. The survey form should automatically remember what question you reached, however this will only work if you have cookies enabled on your device and you use the same device.

### **Voluntary participation**

Participation in this survey is entirely voluntary. You do not need to participate if you don't wish to. If you do decide to participate, you can still withdraw from the research project at any time prior to analysis of the data, including withdrawal of consent to use of any of the data you have provided, or withdrawal of consent to use some part of the data.

### **How was I identified?**

If you were sent an email about the survey, that email will explain who contacted you and how. Several carers organisations and service providers are contacting their members and clients to invite participation in the survey. These organisations have not provided your contact details to the researchers; if you do not wish to hear anything further about the survey, please let the organisation that emailed you know.

If you received an email directly from University of Canberra researchers, this is because you have participated previously in the Carer Wellbeing Survey or other studies, and given permission to be contacted by the researchers in future. The email provides details on how you can unsubscribe from future contact if you wish to.

### **What is being offered to participants?**

Survey participants can enter our prize draw to win one of 13 prizes worth a total of \$5,000, including a first prize of a \$1,500 gift card, second prize of a \$1,000 gift card, third prize of a \$500 gift card, or one of 10 runners up prizes of a \$200 gift card. You can have one or more entries into the prize draw, depending on whether you do a shorter or longer version of the survey. Winners will have their choice of a Flight Centre, Coles-Myer, WISH, Bunnings, iTunes, or Google Play Store gift card. Prize draw terms and conditions can be found at the end of this information sheet.

### **Risks of Participation**

We understand that the survey takes up valuable time, particularly when you are busy with caring responsibilities. By participating in this research, you may be providing information that could be sensitive or distressing for you. If at any time during your participation you feel distressed, need to pause participation, or need assistance, you can contact the research team (details below), or these services for assistance: Beyond Blue - 1300 22 4636 Lifeline - 13 11 14.

### **Privacy and confidentiality issues**

Information you provide as part of the survey will be kept confidential as far as the law allows. Neither your name, nor information that enables people to identify you, will be identified in any publication of our study results.

#### *Who will have access to the information I provide?*

The researchers undertaking the project will have access to individual survey returns. If requested to provide de-identified data from the study to another organisation, consideration will be given to the request only if the organisation using the data agrees in writing to comply with the same confidentiality provisions we guarantee here.

#### *Data storage*

Your survey data will be stored at the University of Canberra. Completed survey forms will be stored in locked cabinets and/or offices. Electronic data will be stored in password protected computers. Records will be stored at the University of Canberra for the required five year period after which it will be destroyed according to university protocols.

#### *How will results be reported?*

Data are analysed and used to generate results for the study, which will be published in a report, and potentially also journal papers, conference papers, short reports, or articles and short pieces in newsletters and social or news media. The survey provides an option for you to tick if you want us to let you know when results of the survey are available or to receive survey updates. The survey data set is made available to organisations for research purposes, but we do not provide your name or contact details to any organisation. The survey asks whether you are willing to give permission for the information you provide to be linked across surveys or to other datasets; if you do not give permission neither the University of Canberra or any other organisation analysing the data set will be permitted to link the data you provide in one survey to any other information sources.

#### **Future Research**

If you agree, the information collected during the conduct of this research may be used in future research projects on related research areas. Any future use of your data will comply with any conditions imposed by the Human Research Ethics Committee of the University of Canberra

#### **Ethics Committee Clearance**

The project has been approved by the Human Research Ethics Committee of the University of Canberra (HREC – 13723). Queries or concerns regarding the research can be directed to the researcher and/or supervisor. Contact details are below.

If you have any complaints or reservations about the ethical conduct of this research, you may contact the University of Canberra's Research Ethics & Integrity Unit team via telephone 02 6206 3916 or email [humanethicscommittee@canberra.edu.au](mailto:humanethicscommittee@canberra.edu.au) or [researchethicsandintegrity@canberra.edu.au](mailto:researchethicsandintegrity@canberra.edu.au)

If you would like some guidance on the questions you could ask about your participation please refer to the Participants' Guide located at <http://www.canberra.edu.au/ucresearch/attachments/pdf/a-m/Agreeing-to-participate-in-research.pdf>

#### Contact the research team

**Freecall:** 1800 981 499

**Email:** [carerwellbeing@canberra.edu.au](mailto:carerwellbeing@canberra.edu.au)

**Postal address:** Att: Mel Mylek, Health Research Institute; Building 23B, University Drive South; University of Canberra; Bruce, ACT, 2617

#### Prize draw terms and conditions

Entry into the prize draw is determined by the completion of the 2024 Carer Wellbeing Survey between 8th February 2024 and 15 April 2023. Everyone aged 14 or older who completes the survey either online by going to [www.regionalwellbeing.org.au](http://www.regionalwellbeing.org.au) or returns a completed paper survey will be eligible to enter the draw to win one of 13 prizes worth a total of \$5000. Winners will have their choice of either (i) a Flight Centre, Coles-Myer, WISH, Bunnings, iTunes or Google Play Store gift card, with winner to choose which gift card they prefer, OR (ii) to donate their winnings to a registered charity of their choice: First prize: \$1500; second prize: \$1000; third prize: \$500; and 10 runner-up prizes of \$200. All prizes will be drawn at 2pm on 1 May 2024 at the Health Research Institute, Building 23, University Drive South, BRUCE ACT 2617. The winner will be notified in writing by email or post within five working days of the prize draw and listed on [www.regionalwellbeing.org.au](http://www.regionalwellbeing.org.au) within two working days of the prize draw. The minimum age of prize draw participants is 14 years. Survey promoter: University of Canberra. Contact agent: Dr. Mel Mylek, University of Canberra, Building 23, University Drive South, BRUCE ACT 2617, ABN 81 633 873 422. Phone: 1800 981 499. Any prize redraw will occur at 2pm on 1 August 2024 to give winners sufficient time to collect their prize, at the same location as the original draw. All redraw winners will be notified in writing by email or post within five working days of the redraw and listed on [www.regionalwellbeing.org.au](http://www.regionalwellbeing.org.au) within two working days of the redraw. Authorised under permit numbers: TP 24/00172 (ACT)