

Appendix B: Participant Information and Consent Form

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2020 National Carer Survey (Project ID 6233) Participant Information and Consent Form

This is an invitation to participate in a study conducted as a collaboration of the National Network of Carer Associations with researchers from Macquarie University, The University of New South Wales, the University of Sydney, the University of Technology Sydney, and the University of Queensland. The purpose of the research is to identify and highlight carers' strengths and the challenges they face in caring for a family member or friend. This research is led by Carers NSW with funding from the NSW Department of Communities and Justice.

The research team:

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What we would like you to do:

If you choose to take part, you will be asked to complete the survey questionnaire. The survey is anonymous, and you do not have to answer any questions you do not want to. It should take approximately 20 minutes to complete the survey, which you can do at any time that suits you. Please complete the online survey or return the paper survey in the reply paid envelope provided by **30 June 2020**.

You will be asked questions on the following topics:

- Yourself (e.g. your age, gender, cultural background, employment)
- The person(s) you care for (e.g. their relationship to you, the level of care required)
- Access to services and support (e.g. what services are you using?)
- Your health and wellbeing (e.g. do you feel stressed?)

By submitting a completed survey, you are indicating your consent to participate.

At the end of this survey, you will have the option to register for participation in a follow-up study in 2022 by providing Carers NSW with contact details. These details will only be used to contact you for the follow-up study, and not for any other purpose. Your contact details will be stored in a separate database and will not be part of any analysis. If you do not wish to participate in the follow-up study you still can take part in the survey.

You can also choose to enter a prize draw. One participant from each state or territory can win an Apple iPad 32 GB WiFi. The prize draw will be conducted on **30 July 2020**, the winner will be contacted via email or post.

If you have any questions or would like assistance to complete the survey, please contact Carers NSW Research Team on (02) 9280 4744.

Possible risks, inconveniences and discomforts

It is not envisaged that you will experience any discomfort as a result of participating in this survey. However, if your participation raises any issues of concern or discomfort, you are encouraged to call either of these services:

Carer Gateway
(8am – 5pm Monday to Friday)
1800 422 737

Lifeline Australia
(24 hours)
13 11 14

In an emergency, call **Triple Zero 000**

Lifeline Text
(6pm – Midnight, 7 days a week)
0477 13 11 14

If you wish to contact an Aboriginal or Torres Strait Islander Health Service, please contact the service nearest to you. A list of services is available under <https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-healthmedical-services/>.

Completing the survey is completely voluntary and you may withdraw your participation at any time. Any partially completed surveys will be excluded from the final analysis. Refusal to participate will not affect your relationship with Carers NSW or any of the collaborating universities.

Benefits of the research

This research will help to direct the advocacy and support work of the National Network of Carer Associations in Australia. Findings will be used to identify areas of greatest need amongst carers across Australia, and the particular needs of different carer groups (e.g., different geographic locations, different care recipient conditions, etc.). Survey results will be published in a report that will be made publicly available online, along with factsheets. Results will also be published in a number of peer reviewed journal articles and will also be presented at relevant conferences. Each member of the research team will have access to the information collected, however, as survey responses are anonymous, you will not be personally identified in any part of the research.

The ethical aspects of this study have been approved by the Macquarie University Human Research Ethics Committee. If you have any complaints or reservations about any ethical aspect of your participation in this research, you may contact the Committee through the Director, Research Ethics & Integrity (telephone (02) 9850 7854; email ethics@mq.edu.au). Any complaint you make will be treated in confidence and investigated, and you will be informed of the outcome.