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Information Statement for the Research Project

Caring for those who care: A global survey of the health behaviours and health-related needs of informal caregivers

Version 3

You are invited to participate in the research project identified above, which is being conducted by a team of researchers led by Prof. Billie Bonevski from the School of Medicine and Public Health at the University of Newcastle.

Why is the research being done?

Informal caregivers of someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness, such as spouses and family members, may experience a change in lifestyle after they take on the caregiving role. These may be changes including smoking, risky alcohol drinking, poor diet, and lack of exercise. We also wish to investigate the needs of caregivers after taking on a caregiving role for someone who requires informal support.

Our research aims to explore health behaviours and needs of informal caregivers. With this information, we will be able to develop helpful tools and resources to support informal carers in achieving healthier lifestyles.

Who can participate in the research?

Participating in this research is suitable for you if:

- Aged 18 years and over
- Comfortable participating in English
- Are an informal carer of a person with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. This includes unpaid spouses, family members and friends and more

Participating in this research is **not** suitable for you if:

- Are a formal/paid carer of someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. This includes nurses, doctors and other paid professionals

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you in any way, or be disclosed to anyone outside of the research team. If you do decide to participate, you may withdraw from the project at any time prior to submitting your completed survey. Please note, due to the anonymous nature of the survey, you will not be able to withdraw your response after it has been submitted.

What would you be asked to do?

Participants will be asked to complete a brief online survey of health behaviour and needs, and some demographics.

How much time will it take?

The survey will take about 15 minutes to complete.

What are the risks and benefits of participating?

We cannot promise you any specific benefit from participating in this research. However, we hope that by obtaining a better understanding of the health behaviours and needs of informal caregivers of someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness we will be able to develop effective programs and services to assist carers in achieving healthier lifestyles.

If at any point you feel distressed during or after participating in our survey, please consider contacting the following sources of support:

For support in Australia, click here:

<http://www.mentalhealthcommission.gov.au/get-help.aspx>

For support in New Zealand, click here:

<https://www.mentalhealth.org.nz/get-help/in-crisis/helplines/>

For support in Canada, click here:

<http://www.mentalhealthhelpline.ca/>

For support in the United Kingdom, click here:

<https://www.getselfhelp.co.uk/helplines.htm>

For support in the United States, click here:

<https://www.healthyplace.com/other-info/resources/mental-health-hotline-numbers-and-referral-resources/>

How will your privacy be protected?

All the information collected from you for the study will be treated confidentially, and only authorised members of the research team will have access to it. The survey will be conducted on an online program called QuON, a user-friendly survey system. Only the research team will have access to the data collected on the program. All electronic information will be stored in password protected files on a secure, University-hosted online platform, with access available only to authorised research team members. At the end of the study, all information will be stored securely for at 7 years at the University of Newcastle, after which time all paper documents will be shredded and all electronic information permanently deleted.

How will the information collected be used?

The research is part of Alexandra Denham's studies at the University of Newcastle, supervised by Professor Billie Bonevski from the Faculty of Health and Medicine at the University of Newcastle.

The information collected may be published in scientific journals and be presented at relevant scientific conferences. Individual participants will not be identified in any reports arising from the project. A summary of the results of the study will be available at the study's conclusion. If you wish to receive a summary of the results, please do not hesitate to let the research team on our project e-mail HealthOfCarers@newcastle.edu.au. We expect that results will be available over the next two years.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact the research team.

If you would like to participate, please access the online survey, and begin the online survey by clicking "next". This will be taken as your informed consent to participate.

Further information

If you would like further information please contact the research team on 02 4033 5712, or e-mail the research team at HealthOfCarers@newcastle.edu.au

Thank you for considering this invitation.



Professor Billie Bonevski



Alexandra Denham

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2017-0312.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.