PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Estimating the value of informal care provided to people with dementia in Australia

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INVITATION

Thank you for your interest in the research study entitled: '*Estimating the value of informal care provided to people with dementia in Australia*'. This information sheet explains what the research involves. Knowing what is involved will help you decide if you want to take part in the study or not. Please read this information carefully. Before deciding whether or not to take part, you might want to talk about it with a relative or friend. You can also contact Lidia to ask questions about anything that you don't understand or want to know more about. Lidia's contact details can be found at the end of this form. Once you understand the study, continuing with the online survey will imply your consent.

PURPOSE OF THE RESEARCH STUDY

The purpose of this study is to hear about YOUR experience of providing care or support on a voluntarily basis to a family member, friend or other person living with dementia. This type of support is referred to as *informal* care. Informal care can include different tasks, such as giving emotional support, keeping a close eye on someone, help with travelling, household duties, personal care, nursing care, or organizing and planning.

We know that informal carers spend a significant amount of time on caregiving. However, when policy decisions are made, such as whether or not a certain health service, drug or treatment should get reimbursed, the impact of such treatments on informal care is often not considered. The reason for that is that we often do not know what dollar value to put on the time spent providing informal care. To overcome this problem, we would like to derive a monetary value of providing informal care to a person with dementia. This will help to inform future policy decision by ensuring that the time costs of providing informal care are considered. While the overall project consists of 3 parts, you are invited to participate only in this third, final part of this study.

PROCEDURE

After you have read the study information and wish to participate, please complete the online survey. The survey will take about 15-25 minutes to complete. Once you start the survey, you need to complete it in one setting. At the end of the survey we will ask you for your mailing address so that we can send you a $10 Coles gift voucher as a thank you for completing the survey. Everyone who completes the survey can receive the voucher.

The survey will consist of two parts. In the first part, we would like to collect some information about your person and your caring experience. In the second part of the survey, you will be presented with a number of different choice scenarios that describe different caregiving situations. For each choice scenario, we would like to know which caregiving situation you prefer. There will be no right or wrong answers, as we are simply interested in your opinion.

POTENTIAL RISKS

The survey will take up some of your time and energy and may make you reflect on your life and situation. Some sections of the survey, such as questions about household income or your health, may be considered sensitive or cause some discomfort. If you do not wish to answer a question, you can select "prefer not to answer" and move onto the next question. You may withdraw from the survey at any time. While it is not expected that participating in the research will cause you to feel distress, we would like to collect your email address at the start of the survey, so we can contact you, if necessary, to lessen or prevent a serious threat to your life, health or safety or that of any other individuals. If we encounter such a threat in your responses, we will contact you to offer appropriate support and referrals to relevant services.

In addition to the risks outlined in this document, we recognise the challenging circumstances the COVID-19 pandemic has caused for many community members. As such, we would like to highlight that if you, or those close to you are experiencing distress, or are in need of additional support, you are encouraged to contact Carer Gateway on 1800 422 737, a free counselling support service for issues relating to the caring role, Beyond Blue Support Line on 1300 22 4635 or Lifeline Australia on 13 11 14. Alternatively, you can contact your GP. Your GP can refer you for broader counselling services which may or may not be related to the caring role.

POTENTIAL BENEFITS

We would like you to accept a small gift, a $10 Coles gift voucher, as a thank you for completing the survey. Whilst taking part in this research may not have any other clear, personal benefits for you, the information you give us will help us to estimate the value of informal care provided to people with dementia. This information may be used to improve policy decisions in health care and impact the availability of treatment options for individuals with dementia and their carers.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Your participation in this survey is entirely voluntary. You do not need to answer all of the questions if you do not wish to, you can select “prefer not to answer” and move onto the next question. You may also withdraw from the survey at any time without any consequences.

CONFIDENTIALITY

Your responses will be kept confidential. No information that could identify you will be used when reporting research findings. The online survey will be facilitated via the research service company Pureprofile, which provides a secure online environment to protect your information from misuse, corruption and unauthorised access. While the data will be collected via Pureprofile, it is solely owned by researchers at Deakin University. Pureprofile will send regularly new data entries to the research team at Deakin University for data analysis. However, prior to data analysis, any information that can be used to identify individual responses will be removed (e.g., email or mailing addresses). The data will be stored electronically on a password-protected computer provided by Deakin University. It is possible that future researchers working on related projects might ask to look at the survey data. Therefore, we would like your approval that we can share the anonymized survey data with other researchers, if this happens. To comply with government requirements, all data will be stored securely for a period of at least 10 years after final publication. The electronic files will then be destroyed.

STUDY RESULTS

The main study findings will be published in academic journal articles and will be presented at academic conferences. Again, in any publication, information will be provided in such a way that you cannot be identified. A summary of the results will be available for other partners, including Dementia Australia and Carers Victoria. If you would like to obtain a copy of the study results, we are happy to send it to you upon request.

CONTACT INFORMATION

If you are interested in participating in the interviews or if you have any questions or desire further information about this study, you can contact:

Dr Lidia Engel
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Telephone: +61 3 924 68573
Email: carers@deakin.edu.au

COMPLAINTS

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:
The Manager, Integrity, Ethics and Biosafety, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Telephone: 9251 7129, research-ethics@deakin.edu.au.
Please quote project number 2019-067.