



Understanding the recall period for a new questionnaire

PARTICIPANT INFORMATION SHEET

Research Team

This research is being conducted by University of Tasmania researchers Dr Jessica Roydhouse, Dr Kathleen Doherty and Dr Karen Wills, University of Technology of Sydney (NSW) researchers Dr Tim Luckett, Dr Brendan Mulhern and Dr Carrie-Anne Ng, Curtin University (WA) researcher Dr Richard Norman and University of Sheffield (UK) researcher Dr Jill Carlton.

Contact information (Principal Investigator): Jessica Roydhouse, Menzies Institute for Medical Research, University of Tasmania, +61 3 6226 4794, SM-Questionnaire.Study@utas.edu.au

1. Invitation

You are invited to participate in a study that will tell researchers and clinicians how best to interpret and use reports from carers about the health and well-being of a person living with dementia who is unable to provide this information themselves ('proxy reports').

2. What is the purpose of this study?

This study aims to understand how carers answer questions about the health and well-being of persons living with dementia when they are asked to do so as part of healthcare or a research project.

A new questionnaire called the EQ HW-B has been developed that will be widely used in research to understand people's health and well-being and inform healthcare. The questionnaire has been developed so that people with mild dementia can answer it. A version has also been developed for carers to answer the same questions about the person if their dementia is too severe for them to complete the questionnaire themselves.

3. How is the study being funded?

The study has been funded by the EuroQol Foundation.

4. Why have I been invited to participate?

You are eligible to take part in this study because you are:

- an adult (aged 18+ years)
- live in Australia
- care for someone living with dementia
- have had to provide a report about the health of the person living with dementia on their behalf.



You do not have to take part in this study. There are no consequences if you decide not to participate. Choosing to take part or not take part will not affect your current or future participation in the Understanding Dementia Massive Open Online Course (UDMOOC), other studies, employment, health care or any relationship with the University of Tasmania.

5. What will I be asked to do?

We will ask you to participate in an individual interview about how you would answer questions about the health and well-being of the person you care for. The questions are about how the person with dementia's life has been over a specific time period. You will also be asked some questions about yourself and the person you are caring for.

To find a time for this interview, we will ask you for your contact information. A member of the research team will contact you and work with you to find a time for the interview.

Your interview will be online. If you need it, we will send you a webcam so you can see us and we can see you during the interview.

We will send you a paper copy of the questionnaire. This questionnaire is only for you to look at during the interview and should not be used for anything else.

The interviews will be recorded, with your consent. The recorded interviews will be sent to a third party company for transcription. All file transfer will be done securely. You will be offered the opportunity to review the transcript of your interview.

The interview is likely to take up to 1 hour of your time.

6. Are there any possible benefits from participation in this study?

We do not expect the study to directly help the people who take part in this study. The study will provide insight into how carers answer questions about persons living with dementia. This information is useful for researchers, clinicians and decision makers as well as support organisations for helping them to interpret and use the information provided.

7. Are there any possible risks from participation in this study?

The two main risks from this study are needing to give up some time and possibly experiencing some discomfort when talking about how you answer questions. You will not have to answer any questions you do not want to, and you can choose to end your participation at any time.

8. What if I change my mind during or after the study?

You do not have to take part in this study, and you can stop at any time.

9. What will happen to the data when this study is over?

All data will be kept for five years following publication in a password-protected secure electronic database behind institutional firewalls at the University of Tasmania. Only researchers involved in this study will have access to the data.



Information that can be used to identify you (e.g., name, postal address, telephone numbers, email) will not be used for any purpose other than to conduct this project.

We are only asking for your contact information to schedule the interviews and to send you a copy of the study results or your interview transcript, if you would like.

10. How will the results of the study be shared?

The results of this study might also be published as a report or article or presented at a scientific conference. You will not be identifiable in any written publications or presentations. We may include quotes of what you or other participants have said. These quotes will never include your name or other identifying information.

You will be asked if you wish to be notified of the results of this study.

11. What if I have questions about this study?

If you have any queries, concerns or issues with this study, please feel free to contact the principal investigator, Dr Jessica Roydhouse on +61 3 6226 4794 or via email at SM-Questionnaire.Study@utas.edu.au.

This study has been approved by the University of Tasmania Human Research Ethics Committee (HREC). If you have concerns or complaints about the conduct of this study, you can contact the Executive Officer of the HREC on (03) 6226 6254 or email human.ethics@utas.edu.au. The Executive Officer is the person nominated to receive complaints from research participants. You will need to quote Project ID H0030051.

12. How can I agree to be involved?

If you would like to participate in the study, please proceed to this page [here](#). You will be taken to a secure project database to enter your contact information to schedule the interviews.

If you do not wish to participate, please click [here](#) to return to the previous page.

Thank you for your time



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By clicking the box below, I confirm:

- I am an adult over the age of 18 years
- I live in Australia
- I care for someone living with dementia
- I have had to provide a report about the health of the person living with dementia on their behalf.

By clicking the box below, I confirm that I have read and understood the information sheet and in particular:

- I understand that my involvement in this research will include:
 - Being contacted by a member of the research team to schedule an individual online interview that should take approximately 60 minutes
 - If I request it, receiving a webcam via post for this interview, which I will return after the interview via a prepaid reply envelope provided by the research team
 - Receiving a copy of the questionnaire via post for the interview
 - Participating in an online interview where I will be asked about how I answer questions about the health and well-being of the person with dementia I am caring for
 - Providing my views on how I answer questions about the health and well-being of the person with dementia I am caring for
- I understand that the research will include audio recording
- I understand that the research will involve audio transcription
- I understand that participation involves the risk that I might feel some discomfort when talking about how I answer questions



- Any questions that I have asked have been answered to my satisfaction
- I understand that the researcher(s) will maintain confidentiality and that any information I supply to the researcher(s) will be used only for the purposes of the research.
- I understand that all study data will be securely stored at the University of Tasmania for five years following publication of study results and will then be destroyed
- I understand that study results may use quotes of things I have said but my name or other identifying information will not be attached to these
- I understand that the results of the study will be published so that I cannot be identified as a participant
- I understand that my participation in this research is voluntary
- I understand that I am free to withdraw at any time, without explanation or penalty
- I agree to participate in the study

Please enter the study [here](#).