



## PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT

### – INTERVIEW –

#### People living with dementia

‘Knowing the Person’: A co-designed ready-to-implement approach to enhance person-centred home care for people living with dementia

**QUT Ethics Approval Number 10233**

#### Research team

|                          |                                                  |                      |
|--------------------------|--------------------------------------------------|----------------------|
| Principal Researcher:    | Ms. Olivia Liu                                   | PhD student          |
| Associate Researcher(s): | A/Prof. Margaret MacAndrew                       | Principal Supervisor |
|                          | A/Prof. Olivia Hollingdrake                      | Associate Supervisor |
|                          | Dr Linda Schnitker                               | Associate Supervisor |
|                          | <b>School of Nursing, Faculty of Health</b>      |                      |
|                          | <b>Queensland University of Technology (QUT)</b> |                      |

#### Why is the study being conducted?

This research project is being undertaken as part of a PhD study for Olivia Liu. ‘Knowing the Person’ was identified as essential for delivering high-quality in-home respite care for people living with dementia. This research seeks to understand what people living with dementia and their carers perceive as essential information, and the barriers and enablers to ‘Knowing the Person’ for people receiving in-home respite care. These insights will inform the development of an approach that supports ‘Knowing the Person’ with dementia and enhances in-home respite care.

You are invited to participate in this research project because you:

- are aged over 18 years and able to speak and understand English;
- reside in your own home in Australia (*including those receiving formal home care services and those who are not*);
- self-report a diagnosis of mild dementia or mild cognitive impairment or self-report experience of mild memory changes;
- have the capacity to give and provide informed consent to participate (see below ***How do I give my consent to participate?***); and
- have the capacity to access a computer with a camera and participate via Zoom (the researcher can provide support to set up the Zoom interview).

#### What does participation involve?

Your participation will involve:

1. Providing your consent (see below ***How do I give my consent to participate?***)
2. Attending a 1:1 online interview via *Zoom* (30 minutes) and we would like to know:
  - What ‘About me’ information would you like formal care workers to know?
  - What barriers could prevent formal care workers from getting to know you?
  - What could help address these barriers, supporting formal care workers to get to know you?

Your participation will involve an online audio and video recorded interview via Zoom. All recordings and personal information will remain confidential. If you wish, you can include your family carer during the interview to provide support.

Your participation in this research project is entirely voluntary. If you do agree to participate, you can withdraw from the research project without comment or penalty. You can withdraw anytime during the interview. If you withdraw from the study the data collected will be deleted.

### **What are the possible benefits for me if I take part?**

This research project may not benefit you directly. However, your participation will contribute to improving in-home respite care service delivery through sharing your experiences and recommendations. Your insights will help us develop an approach to supporting person-centred care for people living with dementia in home setting, while also advancing knowledge and informing future practice and policy.

To acknowledge your participation, you will receive a \$25 Woolworths Gift card by email, SMS or mail, as you prefer (If your care partner attends the interview to support you, there will not be an additional payment for them).

### **What are the possible risks for me if I take part?**

There are potential risks associated with your participation in this research project. Some questions may bring up uncomfortable feelings. You can stop or take a break anytime. The researcher will offer you support.

QUT provides for limited free psychology, family therapy or counselling services for research participants of QUT research projects who may experience discomfort or distress as a result of their participation in the research. Should you wish to access this service, appointments can be made throughout April to the end of November each year. Outside of these months, research participants may reach out to the clinic for priority allocation of the next available session from April onwards.

The QUT Psychology and Counselling Clinic is located at 44 Musk Avenue, Kelvin Grove. The clinic receptionist may be contacted on **3138 9777** (Monday–Friday 9am–4pm). Please indicate that you are a research participant. Alternatively, the National Dementia Helpline on **1800 100 500** or Lifeline provides access to online, phone or face-to-face support, call **13 11 14** for 24 hour telephone crisis support

### **What about privacy and confidentiality?**

As the research project involves an audio and video recording, please note:

- Only the audio recording will be used, confidentially, in the research.
- Due to the image identifier, the video recordings will be destroyed immediately after completing the interview.
- The recording will not be used for any other purpose.

- You will have the opportunity to verify your comments and responses prior to final inclusion.
- Only the named researchers will have access to the recording.
- It is not possible to participate in the research project without being recorded.

Every effort will be made to ensure that the data you provide cannot be traced back to you in reports, publications and other forms of presentation. For example, we will only include the relevant part of a quote, we will not use any names, and/or details such as dates and specific circumstances will be excluded. Nevertheless, while unlikely, it is possible that if you are quoted directly your identity may become known.

Any data collected as part of this research project will be stored securely as per QUT's Management of research data policy. Data will be stored for a minimum of 5 years, and can be disclosed if it is to protect you or others from harm, if specifically required by law, or if a regulatory or monitoring body such as the ethics committee requests it.

Information collected during the interview may be used as supportive data in future research related to this project. Only de-identified data will be used.

### **How do I give my consent to participate?**

If you are interested in participating in this research, please contact Olivia at [olivia.liu@hdr.qut.edu.au](mailto:olivia.liu@hdr.qut.edu.au) or 3138 7972. You will be asked a few questions to check your understanding of what your participation will involve, such as any potential risks that may arise and what to do if you wish to withdraw.

If you can demonstrate understanding of your participation, we will then ask you to give verbal consent to participate in the interview. After verbal consent has been given, you will be asked to share basic demographic information, including *age, gender, time since diagnosis, type of dementia, duration of service use*. Lastly, we will then set up a Zoom meeting to conduct the 30-minute interview with you. If you are unable to show you understand of what participation will involve, you will not be able to participate in this study.

### **What if I have questions about the research project?**

If you have any questions or require further information, please contact one of the listed researchers:

Olivia Liu [olivia.liu@hdr.qut.edu.au](mailto:olivia.liu@hdr.qut.edu.au) / 3138 7972

Margaret MacAndrew [margaret.macandrew@qut.edu.au](mailto:margaret.macandrew@qut.edu.au) / 3138 5956

### **What if I have a concern or complaint regarding the conduct of the research project?**

QUT is committed to research integrity and the ethical conduct of research projects. If you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the QUT Research Ethics Advisory Team on 3138 5123 or email [humanethics@qut.edu.au](mailto:humanethics@qut.edu.au).

**Thank you for helping with this research project. Please keep this sheet for your information.**