



PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT

– INTERVIEW –

Family care partners of people living with dementia

Formal care workers

‘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

School of Nursing, Faculty of Health

Queensland University of Technology (QUT)

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 person-centred 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 in one of the following roles:

A family care partner of a person living with dementia who

- is 18 years or older and able to speak and understand English;
- has previously received or is currently receiving in-home respite care services;
- has experience supporting a person living with dementia in a home setting for at least 3 months; and
- has the capacity to access a computer with a camera and participate via *Zoom* (the researcher can provide support to set up the *Zoom* interview).

A formal care worker who

- is 18 years or older and able to speak and understand English;
- works as a home care worker, registered nurse/enrolled nurse, or home care service manager/case manager;
- has provided in-home care services for people living with dementia for at least 3 months; and
- has 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?

1. Your participation will involve: Providing your consent to participate by signing a consent form and returning it to the research team.
2. Attending a 1:1 online interview via *Zoom* (30 minutes). During the interview you will be asked about the following things:
 - Information about you including your *gender, age, duration of service use*.
 - What you perceive as essential information, and the barriers and enablers to 'Knowing the Person' in the context of people living with dementia receiving in-home respite care?

Your participation will involve an online audio and video recorded interview via *Zoom*. All recordings and personal information will remain confidential.

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 by 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.

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

There are no expected risks beyond normal day-to-day living associated with your participation in this research project. Should your participation cause you any discomfort, you may like to take a temporary break or request to leave the interview.

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, Lifeline provides access to online, phone or face-to-face support, call **13 11 14** for 24 hour telephone crisis support or National Dementia Helpline on **1800 100 500**. If you are aged up to 25, you can also call the Kids Helpline on **1800 551 800**.

What about privacy and confidentiality?

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

- Only 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?

We would like to ask you to sign a written consent form (enclosed) or reply to the email using the provided standard consent text to confirm your agreement to participate. The form also includes a question asking whether you would like to be contacted for future research opportunities.

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 / 3138 7972

Margaret MacAndrew 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.

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