

Participant Information Sheet

COM-IC Project Stakeholder Reference Group

Research Title: Core Outcome Measures for Improving Care in Dementia (COM-IC) – Stakeholder Engagement

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Participant Information

Thank you for your interest in the COM-IC **Stakeholder Reference Group (SRG)** project. The information in this document will help you decide whether you would like to take part. If you still have questions, please feel free to ask the research team.

If you decide to join the Stakeholder Reference Group, your participation is voluntary. If you decide to take part and later change your mind, you are free to stop at any time and don't need to explain why.

Before you join the SRG, we will ask you to sign this document and the consent form. The research team will keep this signed copy. We will also give you an unsigned copy for your records. Whatever you decide, it will not affect your relationship with the University of Queensland (UQ).

What is this research about?

The COM-IC project will work with people with dementia, clinicians, researchers and providers to agree on what measures are important and relevant to people with dementia who receive care. This work will mainly be done through the SRG. Members of the SRG will be involved in making decisions at all stages of the project through a process called co-design. Co-design is about giving people a voice in decisions that directly impact them. Members of the SRG will be asked for advice on what is important when measuring dementia care, as well as whether it is practical and possible to collect that information.

All discussions and decisions of the SRG will be recorded, analysed and reported as part of a qualitative evaluation of co-design in dementia research.

What will I need to do?

Participation in the SRG is voluntary. If you decide to join, we would like you to participate for as long as possible, but no more than 2 years. You may stop your participation at any time and a new member will be recruited to replace you.

As a member of the SRG, you will be asked to perform a range of tasks, including reviewing and providing feedback on research documents, consulting with community members as required,

participating in meetings and contributing to online discussions about parts of the project. These tasks are expected to total no more than 5 hours per quarter and you will be paid for the time it takes.

What are the possible benefits of taking part?

Your participation will benefit both you and your community.

On a personal level, participating in the SRG may give you new skills for becoming involved with decisions that directly affect the care of people living with dementia, or improve your research and communication skills. You will also be paid for your participation at a rate of \$421.82 per quarter.

On a community level, your participation will make sure that this research produces outcomes that are relevant to stakeholders, including people with dementia and their care partners, service providers, government, and researchers.

What are the possible risks and disadvantages of taking part?

This research activity is considered low risk. You do not have to participate in any activity that you do not want to. If you decide to participate, we will talk to you about your experiences and preferences to identify anything that may cause discomfort. You can decline to answer any questions or provide any information without providing a reason. If you require support, it is available through the COM-IC project team. In case of severe or prolonged distress, we will connect you with Dementia Australia through their crisis support line (1800 100 500).

What will happen to the information about me?

All information collected about you will be stored securely. Due to the nature of the project, it may not be possible to be anonymous. Certain details will be visible to the wider project group. Any information that identifies you will not be included in public presentations.

Different types of information will be kept in different places. Survey data will be stored in Qualtrics (survey software). Online discussions will be stored in Loomio. Meeting audio-recordings, transcripts and any other information will be stored on UQ's secure research drive. The project team will have access to data about the SRG. You do not have to share any information that you do not want to.

Any confidential information will be securely stored on servers at UQ. Information stored by UQ includes name and contact details, confidential data, and research protocols. Any metadata is held on the project record. This record is accessible only to the named collaborators and is password protected.

It is anticipated that results will be published and presented in a variety of forms. You will not be identifiable in these publications.

What will happen if I decide to withdraw?

Your participation in this research is voluntary. You are free to withdraw at any time without providing a reason. You will not incur any penalty or unfair treatment as a result of your withdrawal. If you decide to withdraw, information already collected will remain in the dataset, but no further information will be collected.

Can I hear about the results of this research?

If you decide to participate, you will receive a copy of the final report in the format of your choice (electronic or hard copy).

Who can I contact if I have any concerns about the project?

This study complies with the guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. You are free to discuss your participation in this study with the research team on com-ic.study@uq.edu.au. If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Coordinator on +617 3365 3924 / +617 3443 1656 or email humanethics@research.uq.edu.au

This research Ethics ID number: 2021/HE001932