

## PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT

- Family or friends: 1:1 interview -

# Recommendations for an early warning system of acute deterioration in residential aged care: DETECT (Do Enact on Residents in Acute Deterioration)

## **QUT Ethics Approval Number 2021000167**

#### Research team

Principal Researcher: Dr Margaret MacAndrew Associate Researchers: Dr Shirley Chambers

Associate Professor Christina Parker

Dr Linda Schnitker Dr Amy Spooner Dr Leanne Jack

Professor Elizabeth Beattie

**Distinguished Professor Patsy Yates** 

Ms Katy Wyles

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**Queensland University of Technology (QUT)** 

# Why is the study being conducted?

The purpose of this project is to examine the views of family members or friends of people living in residential aged care facilities (RACF) about your role in identifying early signs of acute deterioration in residents and the action you and care staff take when acute deterioration is detected. Findings from this project will inform the development of an intervention that promotes the detection of the early warning signs of acute deterioration in RACFs.

You are invited to participate in this research project because you are a family member or friend who has resided at [name of participating facility] for at least three months and you visit your relative or friend at least once a month.

## What does participation involve?

Your participation will involve a 1:1 online interview with a member of the research team. The 1:1 interview will take place at a time convenient to you and will take approximately 60 minutes of your time. Zoom video conferencing will be used to conduct and record the interview and a member of the research team can provide support for using Zoom if needed.

Questions that will be asked during the interview include:

- What changes in the person's health would cause you to think that they have become unwell and need medical intervention?
- Which care staff in the RACF would you discuss your concerns with if you noticed deterioration in the person's health?
- What are the barriers to, and facilitators of, early detection of acute deterioration?

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. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT or [name of the facility].

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

It is expected that this research project will not benefit you directly. You will have an opportunity to share your ideas and learn more about the importance of early detection of acute deterioration in people living in RACFs. In addition, your input may help to improve outcomes for RACF residents in the future.

To recognise your contribution should you choose to participate in an interview, the research team is offering you a \$50 voucher.

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

Certain risks have been identified as associated with your participation. You may become fatigued during the interview so you will be offered a break mid-way to avoid this. There is also the possibility that you may feel uncomfortable when responding to some of the guiding questions that may bring up memories related to your relative or friend becoming unwell. As it is not the intention to cause discomfort if you do not wish to answer a question you do not have to.

QUT provides for limited free psychology, family therapy or counselling services (in person or by telehealth) 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 please call the Clinic Receptionist on **07 3138 0999** (Monday–Friday only 9am–5pm), QUT Psychology and Counselling Clinic, 44 Musk Avenue, Kelvin Grove, and 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. If you are aged up to 25, you can also call the Kids Helpline on **1800 551 800**.

## What about privacy and confidentiality?

All comments and responses are coded i.e., it will be possible to re-identify you. A re-identifying code stored separately to personal information (e.g., name, address) will only be accessible to the research team, and the code plus identifying information will be destroyed after we have completed publishing our findings.

Any personal information that could potentially identify you will be removed or changed before files are shared with other researchers or results are made public. The information that will be removed includes your name and names of care staff and residents, the name of the facility and your location.

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.

As the research project involves an audio recording:

 You will have the opportunity to verify your comments and responses at the end of the interview.

- The audio recording will be retained for the minimum retention period of 5 years after the last research activity. The video component will be destroyed after the interview.
- The recording will not be used for any other purpose.
- 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, or names will be changed, and/or details such as dates and specific circumstances will be excluded. Nevertheless, while unlikely, it is possible that due to the small number of people associated with <a href="[name of facility]">[name of facility]</a> invited to take part in the research project if you are quoted directly your identity may become known to others in the organisation as a participant in this research.

The research project is funded by the Nursing and Midwifery Research Fellowship and they will not have access to the data obtained during the project.

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

If you are interested in participating and have access to an internet connected computer with a camera and microphone, please click on this link XXX to provide your consent and to register your interest.

#### 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:

Margaret MacAndrewmargaret.macandrew@qut.edu.au07 3138 5956Katy Wylescatherine.wyles@qut.edu.au07 3138 3852

## 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 <a href="mailto:humanethics@qut.edu.au">humanethics@qut.edu.au</a>.

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