

Development of National policies and procedures for reporting a missing person with dementia: Deliberative Democracy

QUT Ethics Approval Number 2000000117

Research team

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Associate	Professor Elizabeth Beattie Queensland University of Technology (QUT)
Researchers:	Senior Sergeant Jim Whitehead Queensland Police Service, Water Police Unit Mr Dubhglas Taylor Dementia Advocate and carer of person with dementia
Research Assistant:	Ms Katy Wyles Queensland University of Technology (QUT)

Why is the study being conducted?

This research project has been funded by the Dementia Australia Research Foundation (DARF) and is being undertaken by Dr Margaret MacAndrew (Principal Investigator) from QUT. The purpose of this project is to use participants informed opinions to develop a set of recommendations to improve outcomes for people with dementia who get lost. The recommendations will relate to strategies that optimise safety and autonomy for the person with dementia, and policy and procedures for both reporting a missing person with dementia and emergency service response.

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

- Family carer of a person with dementia
- Professional carer experienced in caring for people with dementia (e.g. registered nurse, enrolled nurse, medical officer, allied health professional)
- Member of the emergency services (e.g. police, ambulance, fire brigade, SES); or
- Member of the general public

What does participation involve?**1. Complete education modules online**

- Complete 5 x 15 minutes online modules at your convenience at least 1 week prior to your registered session (75 minutes total)
- Content delivered by experienced police and health professionals
- Learn about the incidence of missing people with dementia in Australia, how dementia affects the brain, and how to reduce the risk of a person with dementia getting lost

2. Participate in small group online discussions

- 2 x 1.5 hours sessions on either 24 November or 1 December 2020 (3 hours total)
- Join in facilitator led discussion to help reach consensus about what is an acceptable process for reporting a missing person with dementia in Australia

3. Answer online survey

- 30 minutes (max) to complete
- Rank the discussion group recommendations in order of importance

Questions for small group discussions will be related to case studies about situations leading to a person with dementia being reported missing.

Examples of questions will include:

- What factors do you believe contributed to the person getting lost?
- What actions could have been taken to avoid the outcome experienced by the case?
- Why would this action change the outcome for the person with dementia?

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 at any time and you are not obliged to respond to questions posed during the small group discussions. If you withdraw after participating in the online forum, we are unable to withdraw your comments as we don't collect any identifying information therefore have no way of knowing which comments you made. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT or the Queensland Police Service.

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

It is expected that this research project will benefit you directly. These education modules should improve your knowledge of both reporting missing persons in Australia and the risks associated with a person with dementia going missing. The outcomes of the research may also benefit the outcomes of people with dementia who get lost in the future.

More specifically, health professionals and family carers will receive information and evidence of strategies they could implement to reduce risk of a person with dementia in their care of getting lost. Police will improve their understanding of why people with dementia can get lost. They will also gain insights into the general public's current opinions relating to reporting getting lost incidents. The general public will learn about the reporting procedure for a missing person. They will also learn why people with dementia get lost and how to recognise a lost person. They will gain an understanding about the importance of the general public's involvement in the successful search for a missing person with dementia.

To recognise your contribution should you choose to participate, the research team is offering you a \$100 Mastercard debit card which you will receive after completing the 5 online education modules and participating in the two online discussions. If you do not have access to a device with a camera and microphone you can arrange to participate using a computer located at QUT in Kelvin Grove. If you chose this option, we would pay for your parking costs.

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

There are minimal risks associated with your participation in this research project. For example, the content of the presentations and case studies may bring up personal memories related to a getting lost event. If you feel discomfort, facilitators will refer you to members of the research team who will be able to debrief you privately over the phone. These team members are registered nurses and experienced in debriefing.

If needed you will also have access to QUT counselling. QUT provides for limited free psychology, family therapy or counselling services (face-to-face only) 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, you can call the National Dementia Helpline on 1800 100 500 or Lifeline who provide 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**.

Some people may also experience fatigue from attending the two online forum sessions. To minimise this risk, each session only goes for 1.5 hours and there is a 2 hour break between sessions (total of 3-hours).

What about privacy and confidentiality?

All your comments and responses will de-identified. The Zoom meeting will be recorded (as both video and audio). However, only the audio recording will be saved. The video footage will be deleted immediately after the session. After discussion, the audio recordings will be transcribed and checked for accuracy, all identifying features in the transcripts (participants and organisation names), will be removed and digital recordings deleted. Data collected by the facilitator during discussions will also be de-identified, for example, they will record “a male member of the public stated”.

As the research project involves analysing audio recordings of the online discussions:

- You will have the opportunity to provide clarification around your comments and responses during the day, however, as your comments are not identifiable (the video footage is not being retained), we are unable to remove them.
- 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 if you are quoted directly your identity may become known. We also cannot guarantee that comments you make are not repeated outside the forum by other forum participants You should only share what you are comfortable with others knowing.

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 forum may be used as comparative data in future research related to this project. Only de-identified data will be used in the comparative analysis.

The research project is funded by Dementia Australia Research Foundation 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 in this research, please register online using EventBrite:

<https://gettinghomesafely.eventbrite.com.au>

Part of the online registration involves you giving your consent to participate.

We will also ask for your name, gender, age, contact details and your role (carer of a person with dementia, health professional, police, or member of the general public). Due to limited spaces we have quotas for each role, once each role is filled you will be unable to register for that role.

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 MacAndrew	margaret.macandrew@qut.edu.au	07 3138 5956
Katy Wyles	catherine.wyles@qut.edu.au	07 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 07 3138 5123 or email humanethics@qut.edu.au.

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