

PARTICIPANT INFORMATION FOR QUT RESEARCH PROJECT

Age-Related Macular Degeneration and Night Driving

QUT Ethics Approval Number 7864

Research team

Principal Researcher: Mrs. Soraya Ghaderi PhD Student

Associate Professor Sharon Bentley Principal Supervisor
Researcher(s): Professor Joanne Wood Associate Supervisor
Associate Professor Alexander Black Associate Supervisor

School of Clinical Sciences, 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 Soraya Ghaderi.

People with age-related macular degeneration (AMD) report difficulty with driving, particularly at night, even in the early stages of the disease, but little is known about AMD and night driving. This study aims to explore the night driving difficulties of licensed drivers with AMD and determine the impact of AMD on indicators of driving performance compared with individuals of similar age with normal vision. The relationship between various tests of visual function and indicators of driving performance will also be explored. *Actual* driving performance will not be measured.

The research team invites licensed drivers aged 55 years and above with either AMD or healthy eyes with normal vision to participate. In addition, you must be free of health conditions that affect driving performance (e.g., Parkinson's disease, vestibular disease, dizziness, memory problems, and use of a walking aid) and eye conditions other than AMD.

What does participation involve?

Your participation will involve attending a testing session at the School of Clinical Sciences (O Block, QUT's Kelvin Grove campus) that will require approximately 2 hours (including breaks). During this session you will be required to complete questionnaires about your general health, eye health, cognitive function, such as memory or attention and driving. In addition, you will be required to undergo a series of standard eye health tests and vision tests. Your ability to detect driving hazards using computer-based videos of day and night-time driving scenes will also be tested.

The driving questionnaires include questions about your driving experience, vision-related driving difficulties and driving habits. Example questions are, "How much difficulty do you have with seeing dark-colored cars when driving at night?", and "In the past three months, how often did you avoid driving when it was raining due to your vision?".

Standard eye health tests will be conducted to confirm you have AMD or normal vision. Vision tests will be carried out under standard indoor lighting and low lighting levels. Vision tests will include measures of your central and peripheral vision, and your ability to detect the motion of low-contrast objects, adjust to low lighting levels and adjust to glare. All eye health and vision tests are standard, non-contact, and used routinely in optometric practice. No drops are required.

You will also be asked to complete computer-based driving hazard perception tests. These are videos of driving scenes recorded under day and night driving conditions, where you will be required to identify hazards, such as pedestrians and cyclists.

If you have AMD and are currently being treated for it, you may be invited to return for a follow-up testing session six months after the first testing session. The questionnaires and tests conducted at the first testing session will be repeated to understand the effects of treatment on your vision and driving. You do not have to participate in the second testing session. You can participate in the first session without participating in the second session.

Your participation in this research project is entirely voluntary. You can withdraw from participating in answering any of the questions, any of the specific tests or the research project without comment or penalty. Any information already obtained that can be linked to you will be destroyed upon request. Your decision to participate or not participate will in no way impact your current or future relationship with QUT Optometry Clinic or other organisations involved in this research study.

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

The research will not provide any direct and immediate benefits to you other than perhaps an improved awareness of your vision-related night driving difficulties. However, information gathered in this project is expected to contribute knowledge and understanding of the effects of AMD and its treatment on night driving. This knowledge has the potential to contribute to interventions for improving road safety and quality of life. The research team will provide you a \$25 Coles Myer gift card for each session you attend to contribute toward any out-of-pocket expenses incurred during your involvement in this research (e.g., travel costs and your time). If you require parking, we will provide you with a parking voucher.

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

The research team does not believe there are any risks beyond inconvenience and minor discomfort associated with routine eye and vision testing, and answering questions about driving.

To minimise the risk of fatigue during testing, you will be provided with regular breaks between tasks, and you may request additional rest breaks at any stage.

To minimise the risk of minor levels of psychological discomfort or distress when answering questions about driving, you will receive a clear explanation of the purpose of the driving questions and the confidentiality of your responses. You will also be given the option to decline to answer some questions if you wish. In the unlikely event that a participant becomes anxious about answering the questions, they will be offered additional support through the QUT Counselling Clinic. QUT provides limited free psychology or counseling services for 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 9 am–5 pm), 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.

What about privacy and confidentiality?

All data collected during this project are coded i.e., it will be possible to re-identify you. A re-identifying code stored separately from personal information (e.g., name), will only be accessible to the research team, and the code plus identifying information will be destroyed after 15 years. 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 names, initials, and date of birth. Thus, your anonymity/confidentiality will be safeguarded in any publication of results.

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 15 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.

Please note that non-identifiable data from this research project may be used as comparative data in future research projects or stored on an open access database for secondary analysis.

How do I give my consent to participate?

We would like to ask you to sign a written consent form (enclosed) to confirm your agreement to participate.

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:

Soraya Ghaderi	soraya.ghaderi@hdr.qut.edu.au	07 3138 2478
Sharon Bentley	sharon.bentley@qut.edu.au	07 3138 5738
Joanne Wood	j.wood@qut.edu.au	07 3138 5701
Alexander Black	aa.black@qut.edu.au	07 3138 5704

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/print this sheet for your information.