THE UNIVERSITY OF QUEENSLAND
AUSTRALIA
CREATE CHANGE

Participant Information Sheet

People receiving Home Care Services

Research Title: Evaluating the impact of hearing and vision support in home care settings – Part 2

Project Leads

- **Prof Piers Dawes**, Professor of Audiology, The University of Queensland.
- **Dr Melinda Toomey**, Research Fellow, The University of Queensland.

Research Team

- **Prof Nancy A Pachana,** Healthy Ageing Initiative, The University of Queensland
- **A/Prof Iracema Leroi**, Global Brain Health Institute, Trinity College, Dublin.
- **Prof Lisa Keay**, School of Optometry and Vision Science, University of New South Wales.
- **Prof Hamid Sohrabi**, Centre for Healthy Ageing, Murdoch University.
- **Dr Yuanyuan Gu,** Centre for the Health Economy, Macquarie University
- **Dr Marianne Coleman,** Department of Optometry and Vision Sciences, The University of Melbourne
- **Dr Carly Meyer,** The Centre for Hearing Research, The University of Queensland
- **Prof Chyrisse Heine**, Institute of Health and Wellbeing, Federation University Australia.
- **Dr Sheela Kumaran,** School of Optometry and Vision Science, University of New South Wales
- **Dr John Newell**, Department of Linguistics, Macquarie University.
- **Dr Sabrina Lenzen,** Centre for the Business and Economics of Health, The University of Queensland
- **Prof Judy Lowthian,** Bolton Clarke Research Institute
- **Ms Emma Scanlan**, Hearing Australia, Macquarie University.
- **Dr Leander Mitchell,** School of Psychology, The University of Queensland
- **Ms Tiffany Militano,** Wesley Mission Queensland
- **Dr Rebecca Bennett,** School of Health and Rehabilitation Sciences, The University of Queensland
- **A/Prof Melanie Ferguson**, Brain & Hearing, Curtin University
- **Dr Smriti Raichand,** Centre for the Health Economy, Macquarie University
- **Dr Helen Gurteen,** Research Fellow, The University of Queensland
- **Ms Bronwyn Franco**, Research Allied Health Clinician, The University of Queensland
- **Ms Lana Wilson**, PhD Candidate, The University of Queensland
- **Dr Dayna Cenin,** Brightwater Research Centre
- **Ms Carrie Lidscombe.** Ballycara

Thank you for your interest in participating in this research project. Please read the following information about the project so that you can decide whether you would like to take part in this research. Please feel free to ask any questions you might have about our involvement in the project.

If you decide to participate in this research, please keep in mind that your participation is voluntary. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, you are free to stop at any time, and you would not need to give any explanation for your decision to stop participating.

You will be given the Participant Information and Consent Form to sign, and you will be given a copy to keep. Your decision whether you take part, or not to take part, or to take part and then withdraw, will not affect your relationship with the University of Queensland.

What is this research about?

Our study is about helping older Australians stay in their own homes and communities as they age. We know that staying at home can be better for your health and costs less than moving into a care home. We want to evaluate the impact of a hearing and vision support intervention that is aimed at improving the quality of life and overall well-being of home care recipients and their informal caregivers.

We are recruiting older people (65 years or older) receiving home care services with hearing or vision impairment and family members of people receiving home care services.

What will I need to do?

If you agree to participate, you will be asked to:

1. **Attend 4 to 6 sessions with a Sensory Support Worker over a 3-month period** at your home (approx. 2 hours per session). The Sensory Support Worker will ask you about your hearing and vision needs and preferences, organise transport to and from hearing/vision appointments, provide training in the correct use of the sensory device (hearing aids/spectacles),

support your progress towards individualised goals, support effective communication between you and your family member, provide information, and after discussing it with you, referral onto relevant support services (e.g., psychological services, falls clinic, low vision services etc.,) and foster social inclusion through hobbies, interest and groups.

2. **Complete a study logbook** after each sensory support session where you document the outcome of the session and complete short surveys on the feasibility, appropriateness, and acceptability of the session (approx 10 minutes per session).
3. **Complete questionnaires (or structured interview)** on 2 occasions: after completing the sensory support sessions and 3- months after that (approx. 1-hour). The questionnaires will ask you about your well-being, hearing, vision and cognitive function, and your behaviour.
4. Possibly take part in an **interview** with a member of the research team (approx. 1 hour).

Logbooks can be completed online or in paper form by yourself or with the help of your family member / informal caregiver.

The questionnaires can be completed online or in paper form. If an interview is easier, this can be done in-person or via Zoom. Or a family member may complete the questionnaires on your behalf.

Interviews will be audio-recorded and sent to a professional transcription service for transcription.

What are the possible benefits of taking part?

Possible benefits of participating may include improved access to hearing and vision care, hearing and vision functionality, communication, and social inclusion. Your involvement may contribute to developing improved hearing and vision care services for older people receiving home care services. Participants found to have hearing loss correctable by hearing aids will receive hearing aids provided by Starkey Hearing. Participants found to have a vision loss correctable by spectacles or low vision devices will be reimbursed up to $250 for spectacles or $300 for low vision devices. Reimbursement will be made to the participant's nominated bank account on presentation of receipts.

What are the possible risks and disadvantages of taking part?

There is a chance that you will find some of the questions upsetting or that you tire~~d~~ during sessions or data collection. You can take a break whenever needed and we can reschedule if that is a suitable option for you. You may stop taking part at any time as well. If you feel distressed by any aspect of the study, we will refer you to appropriate mental health services.

What will happen to the information about me?

All information collected about you will remain confidential. Only the research team will have access to the information gathered and all data files will be labelled with a code to preserve your anonymity. All data files will be stored securely on password protected networks. Any hard copy files for the project will be stored in locked filing cabinets in swipe-protected rooms, and accessible only to project personnel. As per Section 2.1 of the Australian Code for the Responsible Conduct of Research, all non-identifiable data will be retained for a period of at least five years and then destroyed. With your consent, as per the NHMRC Open Access policy, your non-identifiable research data will not be destroyed and will be archived on a publicly accessible repository for use by other researchers.

Your information will only be used for the purpose of this research project, unless you provide permission for your anonymous, de-identified data to be used for educational and associated research purposes by the research team. Your information will only be disclosed with your permission, except as required by law. Any information obtained during the research study may be inspected by relevant authorities to ensure that the study is being carried out properly. This is to protect you by ensuring that we are doing the research in a safe and ethical way. By consenting to participate, you authorise release of, or access to, this confidential information to the relevant research personnel and regulatory authorities, or as required by law.

In accordance with relevant Australian and/or Queensland privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please

inform the research team member named at the end of this document if you would like to access your information.

It is anticipated that the results of this research project will be published and/or presented in a variety of forms. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except with your express permission.

What will happen if I decide to withdraw?

Your participation in this research is voluntary and you are free to withdraw from the research anytime without needing to provide any explanation, and you would not receive any penalty or bias as a result of your withdrawal. You can withdraw by calling or emailing the research team and telling them you no longer want to participate. If you choose to stop participating, a member of the research team will discuss if data already collected can be used in the research and the appropriate action will be taken.

Can I hear about the results of this research?

At the end of the study, we would be happy to send you a summary of the research findings. If you would like this information or would like more information about future projects, please leave us your name and address (which we will keep confidential).

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

This study adheres to the Guidelines of the ethical review process of The University of Queensland and the National Statement on Ethical Conduct in Human Research. Whilst you are free to discuss your participation in this study with the researcher contactable on **m.toomey@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: 2023/HE002236

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Participant Information Sheet

Family Members of Home Care Recipient

Research Title: Evaluating the impact of hearing and vision support in home care settings – Study 2

Project Leads

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- **Prof Judy Lowthian,** Bolton Clarke Research Institute
- **Ms Emma Scanlan**, Hearing Australia, Macquarie University.
- **Mr Lachlan Green, Ballycara**
- **Dr Leander Mitchell,** School of Psychology, The University of Queensland
- **Ms Tiffany Militano,** Wesley Mission Queensland
- **Dr Rebecca Bennett,** School of Health and Rehabilitation Sciences, The University of Queensland
- **A/Prof Melanie Ferguson**, Brain & Hearing, Curtin University
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We are recruiting people receiving home care services with hearing or vision impairment and family members of people receiving home care services.

What will I need to do?

If you agree to participate, you will be asked to:

1. Complete a **short demographic questionnaire** about you e.g., gender, level of education, where you are living, etc.,
2. **Attend 4 – 6 sessions with a Sensory Support Worker over a 3-month period** at your family member's home (approx. 2 hours per session). The Sensory Support Worker will ask about your family member's hearing and vision needs and preferences, organise transport to and from hearing/vision appointments, provide training in the correct use of the

sensory device (hearing aids/spectacles), support your family member's progress towards individualised goals, support effective communication between you and your family member, provide your family member information on relevant support services (e.g., psychological services, falls clinic, low vision services etc.,) and foster social inclusion for your family member through hobbies, interest and groups.

3. **Complete a study logbook** after each sensory support session where you document the outcome of the session and complete short surveys on the feasibility, appropriateness, and acceptability of the session (approx. 10 minutes per session).
4. **Complete questionnaires** on 3 occasions: before seeing the sensory support worker, after completing the sensory support sessions and 3-months after that (approx. 1 hour). The questionnaires will ask you about your demographic details, cognition, well-being, quality of life, and the quality of your relationship with your family member.
5. Possibly take part in an **interview** with a member of the research team (approx. 1 hour).

Cognition	Your cognition will be assessed by a questionnaire designed to detect memory loss or decreased problem-solving ability.	10 mins

Logbooks can be completed online or in paper form by yourself or with the help of your family member / informal caregiver.

The questionnaires can be completed online or in paper form.

Interviews will be audio-recorded and sent to a professional transcription service for transcription.

What are the possible benefits of taking part?

Possible benefits of participating may include improved communication between you and your family member. Your involvement may contribute to developing improved hearing and vision care services for older people receiving home care services.

What are the possible risks and disadvantages of taking part?

There is a chance that you will find some of the questions upsetting or that you tire~~d~~ during data collection. You can take a break whenever needed, and we can reschedule if that is a suitable option for you. You may stop taking part at any time as well. If you feel distressed by any aspect of the study, we will refer you to appropriate mental health services.

What will happen to the information about me?

All information collected about you will remain confidential. Only the research team will have access to the information gathered and all data files will be labelled with a code to preserve your anonymity. All data files will be stored securely on password protected networks. Any hard copy files for the project will be stored in locked filing cabinets in swipe-protected rooms, and accessible only to project personnel. As per Section 2.1 of the Australian Code for the Responsible Conduct of Research, all non-identifiable data will be retained for a period of at least five years and then destroyed. With your consent, as per the NHMRC Open Access policy, your non-identifiable research data will not be destroyed and will be archived on a publicly accessible repository for use by other researchers.

Your information will only be used for the purpose of this research project, unless you provide permission for your anonymous, de-identified data to be used for educational and associated research purposes by the research team. Your information will only be disclosed with your permission, except as required by law. Any information obtained during the research study may be inspected by relevant authorities to ensure that the study is being carried out properly. This is to protect you by ensuring that we are doing the research in a safe and ethical way. By consenting to participate, you authorise release of, or access to, this confidential information to the relevant research personnel and regulatory authorities, or as required by law.

In accordance with relevant Australian and/or Queensland privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to

request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

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