

Participant Information Statement

Ethics approval number: 16447

Title: Perspectives on social wellbeing programs: adults with dual sensory impairment and their communication partners

Principal Investigator (PI): Professor Bamini Gopinath

1. Introduction

You are invited to participate in this study called ‘Perspectives on social wellbeing programs: adults with dual sensory impairment and their communication partners’. Dual sensory impairment (DSI) is the term we use when a person has both hearing loss and vision loss. You are invited to take part in this study because you:

- a) Have self-reported dual sensory impairment (DSI) and are: 1) an adult aged ≥ 18 years, 2) score >2 on the De Jong Loneliness Scale, and 3) have English fluency to provide informed consent, OR
- b) Have identified as a communication partner to the participating individual with DSI and are: 1) an adult aged ≥ 18 years, 2) have English fluency to provide informed consent.

This Participant Information Statement (PIS) tells you about the research study. It explains what taking part in this study will involve. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about. Our research team are happy to go through this information with you and answer any questions you may have.

Participation in this study is voluntary. If you don’t wish to take part, you don’t have to.

If you decide you want to take part in the study, you will be asked to provide verbal consent acknowledging your agreement to participate. This consent will be audio-recorded for our records. By providing this consent you are telling us that you:

- Understand what you have read,
- Consent to take part in the research this study,
- Consent to the use of your interview data as captured by the interview transcript. You will be given an opportunity to review this transcript and suggest changes within a two-week period.

You will be given a copy of this Participant Information Statement to keep.

2. What is the purpose of this research?

The purpose of the study is to understand:

- the impacts of DSI on social participation from your perspective as a person with DSI or a communication partner.
- your perspective towards participating in a health and wellbeing program.

3. What does participation in this research involve?

If you have expressed an interest in participating in the study, your eligibility will be screened by a research team member via a telephone, email or text message. If you meet the criteria listed above, you will be sent this Participant Information Statement to review. A research team member will then follow up with you in at least one week to confirm your interests in the study and answer any questions you may have.

If you agree to participate, the research team member will schedule your interview. We will interview the individual with DSI and the communication partner individually but you also have the option of completing the interview together. It will take approximately 40 minutes per interview.

You can choose to complete the interview remotely via phone call or video call using Zoom or Teams or in-person at Macquarie University. For

individuals living within 30 minutes from the University, a home visit to complete the interview can be arranged.

With your permission, the interview will be audio recorded, and there will be an opportunity for you to review the interview transcript to edit your responses within a two-week period.

There are no costs associated with participating in this research study. On completion of the interview, each participant will be reimbursed a \$40 gift voucher for a remote interview or home visit. Participants completing the interview at Macquarie University will be reimbursed a \$100 gift voucher to account for travel time and costs.

4. Do I have to take part in this research study?

Participation in any research study 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 withdraw from the study at any time. Please note that since you are participating as a pair, if one of you wish to withdraw, then both of you will be withdrawn from the study.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with Macquarie University.

5. What are the possible benefits of taking part?

You will receive a \$40-\$100 voucher for your participation in the study. No other direct benefits are expected with participating in this study, however, your participation will help to better understand impacts of DSI on social participation and the factors that impact participation in a social health and wellbeing program.

6. What are the possible risks and disadvantages of taking part?

We don't anticipate any risks of taking part in this study. However, if there are any questions or topics that you are not comfortable discussing for any reason, please let the researcher know and this question will be skipped. If any questions such as those from the De Jong Loneliness Scale cause distress, please inform the researcher you will guide you towards

further support. In addition, a list of free help services have been listed at the end of this document.

7. What if I withdraw from this research study?

If you consent to participate and change your mind, you can withdraw at any time and without giving a reason. If you decide to withdraw from the study, please inform the research team as soon as possible, and they will facilitate your withdrawal.

If you decide to withdraw from the study, we will not collect any further information from you. Any non-identifiable information we have already collected will be retained to ensure that the results of the study can be analysed properly. You should be aware that data collected up to the time you withdraw will form part of the research study results.

8. What will happen to the information collected about me?

By providing verbal consent to participate in the research study, you agree to the research team collecting and using the interview data you provide.

Any information or personal details gathered in the course of the study are confidential, except as required by law. It is anticipated that the results of this research study will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

The research team has put a number of procedures in place to protect the confidentiality of participants. Your name or other personal details will not be associated with your data and the audio recording of your verbal consent will be kept separate from your interview data. All electronic data will be stored on a password protected server.

Data collected may be shared in an anonymised form to allow reuse by the research team for an extension of this study or a very similar study. These anonymised data will not allow any individuals to be identified or identifiable. Appropriate ethics approvals will be sought if the data is to be used as extension of this project or a very similar project.

9. Who is organising and funding the research?

This study is being led by the following researchers: Professor Bamini Gopinath, Dr Diana Tang, Assistant Professor Carly Johnco, Professor Kerry Sherman, and Associate Professor Jessamine Chen.

This research is being funded by a Lifespan Health and Wellbeing Research Centre Innovation Grants Scheme.

10. Who has reviewed this study?

The ethical aspects of this research study have been approved by an Ethics Committee at Macquarie University.

11. Further information and who to contact

If you require further information, have any questions or would like to withdraw from the study or withdraw your data then please contact:

Research contact person

Name	Mimansa Thakore
Position	Research Assistant
Telephone	(02) 9850 8753
Email	sensoryloss.research@mq.edu.au

Chief Investigator

Name	Professor Bamini Gopinath
Department	Health Sciences
Faculty	Medicine Health and Human Sciences
Telephone	(02) 9850 8962
Email	bamini.gopinath@mq.edu.au

Complaints contact details

If you have any complaints about any aspect of the study, the way it is being conducted or any questions about being a research participant in general, then you may contact The HREC that approved this study:

Name	Macquarie University Human Research Ethics Committee
Telephone	(02) 9850 7854
Email	ethics@mq.edu.au

Support Services Contact Details

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

Lifeline	13 11 14 https://www.lifeline.org.au/
Beyond Blue	1300 22 46 36 https://www.beyondblue.org.au/

Thank you for taking part in this study. You should keep this participant information sheet as it contains important information and the research teams.