

## Participant Information Statement

### **Research study: Survey for developing a consumer handbook about Dual Sensory Impairment (DSI)**

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#### **1. What is this study about?**

We are conducting a research study about the type of information needed by people living with the combination of hearing loss and vision loss from any cause and of any duration. This combination has many names including dual sensory impairment, dual sensory loss and deafblindness. Often it has no name, people may think their hearing and sight loss is just 'old age'. Here we will use the term dual sensory impairment to describe everyone who lives with sight and hearing loss together. We are asking people who live with dual sensory impairment, their carers and professionals working with them, what information they think is most needed to understand what is happening and to get through daily life as well as possible. The survey is to gather knowledge, expertise and tips from people who have experience living with or working in relation to dual sensory impairment. This will help tell us what needs to be included in a consumer and carers handbook. Taking part in this study is voluntary.

**Please read this sheet carefully and ask questions about anything you don't understand or want to know more about.**

#### **2. Who is running this study?**

The study is being carried out by the following researchers:

- CI: Dr Annmaree Watharow, Lived Experience Researcher, Centre for Disability Research and Policy, University of Sydney [annmaree.watharow@sydney.edu.au](mailto:annmaree.watharow@sydney.edu.au)
- PI: Dr Moira Dunsmore, Senior Lecturer, Sydney Nursing School, University of Sydney [moira.dunsmore@sydney.edu.au](mailto:moira.dunsmore@sydney.edu.au) Ph: 9351 0784
- PI: Dr Julie Schneider, Research Affiliate, Centre for Disability Research and Policy/ Research consultant to Dr Annmaree Watharow, University of Sydney [julie.schneider@sydney.edu.au](mailto:julie.schneider@sydney.edu.au)

- PI: Dr Emily Kecman, Postdoctoral Research Fellow, University of Faculty of Medicine and Health (Communication sciences and disorders), University of Sydney [emily.kecman@sydney.edu.au](mailto:emily.kecman@sydney.edu.au)

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### **3. Who can take part in the study?**

We are seeking survey respondents with knowledge and experience of dual sensory impairment (combined sight and hearing loss of any type or cause), including people living with dual sensory impairment themselves, people living with or caring for someone with dual sensory impairment, or professionals and support workers working with clients who have dual sensory impairment.

### **4. What will the study involve for me?**

If you decide to take part in this study, you will be asked to complete a brief survey of around 30 questions (30 minutes or less) about a range of topics related to living with dual sensory impairment. The questions are a combination of closed-ended and open-ended questions. An online version of the survey is available, or for those who prefer to complete a hard/paper copy of the survey this is also available. If you have any other accessibility requests for the format of the survey we are happy to accommodate. Your responses to the survey will inform the develop of consumer and carers handbook to improve the quality of information about dual sensory impairment available to the public.

### **5. Can I withdraw once I have started?**

Being in this study is completely voluntary and you do not have to take part. Your responses to the survey will remain anonymous. By completing and submitting your survey, you consent to take part in the study. You can withdraw any time before you submit without penalty. However, once your responses are submitted, they cannot be withdrawn because all responses are anonymous, and we will not be able to tell which one yours is.

If you choose not to participate or if you withdraw from the study before submitting the survey there will be no negative consequences.

### **6. Are there any risks or costs?**

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

## 7. Are there any benefits?

You will not receive any direct benefits from being in the study, though your participation will contribute to improving the state of information about dual sensory impairment on offer to the wider community in the future.

## 8. What will happen to information that is collected?

By completing the survey you are providing your consent, you are agreeing to us collecting information from or about you for the purposes of this study. The survey does not seek any sensitive or personal information from participants.

Any identifiable information you provide us will be stored securely and will only be disclosed with your permission unless we are required by law to release information.

We plan to publish the study findings, potentially in journal articles and as part of the consumer and carers handbook.

We will store this information and dispose of it securely following the University's Recordkeeping Policy. For more details about how your information will be handled please see the University's [privacy webpage](#).

## 9. Will I be told the results of the study?

You have the right to receive feedback about the overall results of this study. Participants who wish to receive feedback should indicate this at the end of the survey in the comment section. This feedback will be in the form of a brief summary of the survey responses. The consumer and carers handbook will be widely available in the community.

## 10. What if I would like more information?

When you have read this information, the following researcher(s) will be available to discuss it with you further and answer any questions you may have:

- Dr Annmaree Watharow, Dr Moira Dunsmore Dr Julie Schneider

## 11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [ethics reference: **2024/HE000556**] according to the National Statement on Ethical Conduct in Human Research.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager

[human.ethics@sydney.edu.au](mailto:human.ethics@sydney.edu.au)

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*This information sheet is for you to keep*