

Survey for developing a consumer and carer handbook for older people living with dual sensory impairment.

Question 1- Introduction

Thank you for taking part in this survey. The purpose of this survey is to gain insights that will inform the design of a consumer and carers handbook for people with combined vision and hearing loss – also known as deafblindness or dual sensory impairment.

We are seeking the expertise and first-hand knowledge of people with lived experience in this area. We want to know the issues and topics that are most important to you, and we want to know about the areas where either more, different or better information is needed: The type of information you have ever wished you could have accessed for yourself.

We are seeking input directly from people with combined hearing and vision loss (or dual sensory impairment as it is known) as well as carers, families, professionals, support workers and others who live or work with people with dual sensory impairments. We want to hear your thoughts about the type of information that should be included in the consumer handbook to make it useful, comprehensive, relevant and user-friendly.

Your participation in this study is completely voluntary. You can choose whether to participate or not to participate.

Your completion of the survey is taken as your consent to participate. You have the right to withdraw from the study without penalty. For example, if you start the survey but do not complete it you will have withdrawn your participation.

However, once your responses are submitted, they cannot be withdrawn from the study because all responses are anonymous and we will have no way of identifying which ones are yours to remove them.

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

Please refer to the Participant Information Statement PIS found here:

[Participant Information Statement HE000556](#)

to inform your decision. Please tick this box to indicate you have read and understood the PIS and are ready to commence.

Question 2

We would like to understand a bit more about you and your experience with combined hearing and sight loss, known as dual sensory impairment.

Please select all that apply.

- I am a person living with combined hearing and sight loss of any type, also known as dual sensory impairment
- I am a family member or carer of a person with dual sensory impairment
- I am a professional or practitioner working with clients with dual sensory impairment
- I am a support worker working with clients working with dual sensory impairment
- I work at an organisation for people with disabilities
- Other (a space for further details is provided in question 4)

Question 3

Which of the following best describes the length of time of your experience living, working or caring for someone with dual sensory impairment? For people with combined sight and hearing loss, we mean how long have you lived with both.

- Less than 1 year
- 1-2 years
- 2-5 years

- 5-10 years
- 10-15 years
- Longer than 15 years

Question 4

How did you first find out about dual sensory impairment or deafblindness? Are there any further details you would be able to provide to help us understand your experience with dual sensory impairment?

Question 5

If you experience dual sensory impairment, or care for someone who does, were you able to get good information

about hearing and sight loss, complications, treatments or kinds of supports available?

- Yes
- No
- Not applicable

Question 6

If you are a health or social care professional, do you feel you have the knowledge, training and skills you need to provide care and support to people with dual sensory impairment?

- Yes
- No
- Not applicable

Question 7

We would like to understand your views on existing information sources about dual sensory impairment, particularly, how helpful you found them for meeting your information needs or answering your questions.

Listed in the next 6 questions are common sources of information. For each item please tick whether you used this source of information. If so, please note how helpful you found it (very helpful, somewhat helpful or not at all helpful). If you did not access this type of information, please choose not applicable NA.

Question 8

Information brochure or booklet from health care providers

- Very helpful
- Somewhat helpful
- Not at all helpful
- Not applicable as I did not receive this type of information

Question 9

Appointments with health care professionals

- Very helpful
- Somewhat helpful
- Not at all helpful
- Not applicable as I did not receive this type of information

Question 10

Internet

- Very helpful
- Somewhat helpful
- Not at all helpful
- Not applicable as I did not receive this type of information

Question 11

Community/ peer support group

- Very helpful
- Somewhat helpful
- Not at all helpful
- Not applicable as I did not receive this type of information

Question 12

Social media groups (e.g., Facebook, WhatsApp)

- Very helpful
- Somewhat helpful
- Not at all helpful
- Not applicable as I did not receive this type of information

Question 13

Webinars

- Very helpful
- Somewhat helpful
- Not at all helpful
- Not applicable as I did not receive this type of information

Question 14

Information sessions/seminars (in person)

- Very helpful
- Somewhat helpful
- Not at all helpful
- Not applicable as I did not receive this type of information

Question 15

Are there additional sources of information not mentioned above that you would like to comment on?

Question 16

What was the most useful source of information you received? Can you explain what made it most helpful? How could it have been more helpful? If no good information was provided to you, explain what type of information you would have liked access to.

Question 17

Do you agree there is a need for a consumer and carer handbook for people living with dual sensory impairment and their carers?

- Yes
- No
- No opinion

Question 18

Medical and scientific information.

Please consider the list of topics below that relate to medical and scientific information about dual sensory impairment. Tick which of these topics you think are important to include in an information handbook on dual sensory impairment:

- Common causes of sensory losses
- Diagnosis
- Visual hallucinations
- Delirium
- Sensory loss and cognitive decline or dementia
- Tinnitus
- Recent research articles
- Tips and support for caring for someone with dual sensory impairment
- Tips and stories from people living with dual sensory impairment

Question 19

What else would you like to see included in a section about medical and scientific information about dual sensory impairment?

Question 20

Information about communication strategies and approaches.

Please consider the list of topics below related to communication strategies. Tick which of these topics you think are important to include in an information handbook on dual sensory impairment:

- Strategies for good communication
- How families, carers, professionals and supports can help communication
- Tactile signs
- Social-haptic communication
- Guiding and mobilising
- Documenting and sharing touch messages

- Glossary / dictionary of important touch messages
- Illustrated manual to explain important touch messages
- Using assistive technologies to help communication
- Tips and stories from people living with dual sensory impairment

Question 21

Do you have comments or suggestions about improving information about communication strategies and approaches?

Question 22

Information about navigating health systems and appointments.

Please consider the list of topics below which relate to navigating health systems and appointments. Tick which of these topics you think are important to include in an information handbook on dual sensory impairment:

- Preparing for appointments
- Keeping records
- Medicare and financial matters
- Role of a support worker at appointments
- Legal and life matters (such as Power of Attorney, wishes for treatment and decision making)
- Tips and stories from people living with dual sensory impairment

Question 23

Do you have any tips or resources to share about navigating health systems and appointments from your experience that you wish to provide to enhance the consumer booklet?

Question 24

Information about looking after mental health and well-being.

Please consider the list of topics below which relate to mental health and well-being. Tick which of these topics you think are important to include in an information handbook on dual sensory impairment:

- Depression and anxiety
- Seeking support
- Exercise
- Healthy eating
- Support from others also experiencing vision and hearing loss
- Supporting carers and families
- Social interaction and support groups
- Wellness strategies from experts
- Tips and stories from people with lived experience

Question 25

Do you have any tips or know of any resources about supporting health and well-being which you can suggest to other people living with dual sensory impairment or their families and carers?

Question 26

Emergency preparedness.

Please consider the list of topics below which relate to being prepared for emergencies. Tick which of these topics you think are important to include in an information handbook on dual sensory impairment:

- Falls prevention
- Hospital preparedness
- Disaster preparedness
- Managing emergencies at home
- Documenting important information
- Stories and tips from people with lived experience

Question 27

Do you have any additional information for a section about emergency preparedness you would like to share with us?

Question 28

Information about assistive technology and devices.

Please consider the list of topics below which relate to information about technology and devices. Tick which of these topics you think are important to include in an information handbook on dual sensory impairment:

- Hearing aids
- Cochlear implants
- Personal amplifiers
- Headphones
- Low vision aids e.g., Magnifiers
- High tech vision aids
- Simple aids for daily living
- Training sessions
- Accessibility features of smart phones and tablets
- Useful apps
- Accessibility software
- Text to audio
- Speech to text
- Braille devices
- Screen readers
- Video magnifiers
- Recent developments
- Tips and stories from people with lived experience

Question 29

Information about assistive technology

Please provide details about any assistive technology, apps etc that you have found particularly useful (or difficult), and why.

Question 30

Practical tips and advice

We would like to compile a list of practical tips for daily tasks such as how to make a cup of tea, or tips for specific situations such as when going out shopping.

Share any advice from your experiences of living with dual sensory impairment or supporting someone who does.

Consider, are there things you know now that you wished you knew earlier? Please share your top practical tips about living with or working with dual sensory impairment below.

Conclusion

Thank you so much for your time and input. If you have any insights, questions or comments please feel free to contact annmaree.watharow@sydney.edu.au