

**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM****Making health information accessible for people with an intellectual disability****Professor Julian Trollor****1. What is the research study about?**

You are invited to take part in this research study. The research study aims to learn about the accessibility of health-related information for people with an intellectual disability. It also aims to learn about the type of information that people with an intellectual disability want to access when they experience a health problem, and what makes health-related information accessible to them.

You have been invited as a possible participant in this project because you are a family member or support person (paid or non-paid) of a person with an intellectual disability. Your lived experience of supporting a person when they access health services will provide valuable insights into accessible health-related information for people with an intellectual disability.

**2. Who is conducting this research?**

The study is being carried out by the following researchers: Professor Julian Trollor, Dr Janelle Weise, and Ms Bronwyn Newman from the Department of Developmental Disability Neuropsychiatry, UNSW Sydney.

**Research Funder:** This research is being funded by Mental Health and Drug & Alcohol Office, New South Wales Ministry of Health, Australia.

**3. Inclusion/Exclusion Criteria**

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:

- Are a family member or support person (paid or non-paid) of a person with an intellectual disability and co-occurring mental ill health.
- Be 18 years or over.
- Live in New South Wales.
- Have experience support a person with intellectual disability and co-occurring mental ill health to access mental health services in New South Wales.

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

Participation in this research study is voluntary. If you do not want 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 stage.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

**5. What does participation in this research require, and are there any risks involved?**

If you decide to take part in the research study, you will be asked to participate in a telephone screening interview to assess whether you meet the inclusion criteria for this study. The research team can either call you or you can call the research team to undertake this telephone screening.

If you are not eligible to participate we will destroy any information that has been collected.

**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM****Making health information accessible for people with an intellectual disability****Professor Julian Trollor**

If you are eligible to participate, the research team will ask for contact details to organise a convenient time to participate in the research

You will be asked to participate in a forum or an interview, depending on your individual preferences. The forums will be held at UNSW Sydney or a suitable venue within metro New South Wales, and interviews can take place at UNSW Sydney or via email, telephone or video conferencing.

During the forum or interview you will be asked questions about the accessibility of health-related information for people with an intellectual disability. You will also be asked about the types of information that people with an intellectual disability want to access when they experience a health problem, and what makes health-related information accessible to them. The forum should take approximately 2.5 hours to complete and an interview should take approximately 1.5 hours to complete.

To ensure we collect the responses accurately, we seek your permission to digitally record the interview using an audio tape. If you would like to participate but do not wish to be recorded, you will need to discuss the options for your participation with the research team.

If you decide to take part in the research study, the research team we will ask you to contact the research team to organise a convenient time to participate in the study, complete the consent form, and complete a personal details form. It should approximately 15 minutes to complete the task.

If you participate you will be provided with a \$50 gift voucher.

If you experience discomfort or feelings of distress while participating in the research and you require support, you can stop participating at any time. You can also tell a member of the research and they will provide you with assistance or alternatively a list of support services and their contact details are provided below.

**6. What are the possible benefits to participation?**

We hope to use information we get from this research study to contribute to the generation of knowledge on the accessibility of health-related information for people with an intellectual disability across their health journey. This knowledge can in turn be used to make recommendations about the types and content of health-related material that need to be developed. These recommendations may also lead to the development of their resources which in turn may lead to more accessible health care for people with an intellectual disability which in turn may lessen the burden of supporting a person across their health journey.

**7. What will happen to information about me?**

By signing the consent form you consent to the research team collecting and using information about you for the research study. Your data will be kept for 7 years after the project's completion.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. De-identified data will be use when publishing the findings from this study.

**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM****Making health information accessible for people with an intellectual disability****Professor Julian Trollor**

All data will be stored in adherence to UNSW IT Security Standards & Guidelines policy. This will include the storage of paper-based information in a dedicated, lockable cabinet at UNSW Sydney, 34 Botany Street. Electronic data will be stored on a UNSW Sydney server which requires authorisation and a password to gain access.

Your de-identified information will be used to learn about the accessibility of health-related information for people with an intellectual disability. We plan to present and publish the results at relevant conferences, in peer reviewed journals, and in documents to be distributed to other key stakeholders, such as NSW Health. Information collected for this research project may be made available to other research projects in de-identified form only.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

**8. How and when will I find out what the results of the research study are?**

The research team intend to publish and report the results of the research study in a variety of ways. All information published will be done in a way that will not identify you. If you would like to receive a copy of the results you can let the research team know by including your details in the space provided in the consent form.

**9. What if I want to withdraw from the research study?**

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or the Mental Health and Drug & Alcohol Office, New South Wales Ministry of Health.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

If you decide to participate in the focus group, your comments along with other participants will be recorded during the group discussions. Because of the way in which the focus group discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses.

**10. What should I do if I have further questions about my involvement in the research study?**

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

**Research Team Contact Details**



DEPARTMENT OF  
DEVELOPMENTAL  
DISABILITY  
NEUROPSYCHIATRY



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Professor Julian Trollor

<b>Name</b>	Dr Janelle Weise
<b>Position</b>	Project Officer
<b>Telephone</b>	(02) 9931 9160
<b>Email</b>	DDD@unsw.edu.au

### What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

### Complaints Contact

<b>Position</b>	UNSW Human Research Ethics Coordinator
<b>Telephone</b>	+ 61 2 9385 6222
<b>Email</b>	<a href="mailto:humanethics@unsw.edu.au">humanethics@unsw.edu.au</a>
<b>HC Reference Number</b>	HC180917

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## Consent Form – Participant providing own consent

### Declaration by the participant

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet or someone has read it to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research described in the study;
- I agree not to disclose any information discussed during the focus groups and to maintain group confidentiality.
- I understand that the research team will audio record the interviews; I agree to be recorded for this purpose.
- I provide my consent for the information collected about me to be used for the purpose of this research study.
- I understand that information collected for this research project may be made available to other research projects in de-identified form only.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to participate in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only;

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

- I understand that I will be given a signed copy of this document to keep;

### Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

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**Declaration by Researcher\***

- I have given a verbal explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

**Researcher Signature\***

Name of Researcher (please print)	
Signature of Researcher	
Date	

\*An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.

**Note: All parties signing the consent section must date their own signature.**

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## Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales or the Mental Health and Drug & Alcohol Office, New South Wales Ministry of Health. In withdrawing my consent I would like any information which I have provided for the purpose of this research study withdrawn. I understand that the information collected about me during my participation in the focus group cannot be withdrawn given the nature of the focus group.

### Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

### The section for Withdrawal of Participation should be forwarded to:

CI Name:	<a href="#">Professor Julian Trollor</a>
Email:	<a href="mailto:j.trollor@unsw.edu.au">j.trollor@unsw.edu.au</a>
Phone:	<a href="tel:(02)99319160">(02) 9931 9160</a>
Postal Address:	<a href="#">The Department of Developmental Disability Neuropsychiatry, 34 Botany Street, UNSW Sydney, 2052</a>