



**UNSW**  
Department of Developmental  
Disability Neuropsychiatry



## **PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM**

Evaluation of the Intellectual Disability Mental Health Connect webtool

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 evaluate the new *Intellectual Disability Mental Health Connect* website. This website aims to help people with intellectual disability and their support networks to navigate the mental health system in NSW. It also aims to support professionals to provide quality mental health care to people with intellectual disability. This study will assist us to make the website better and develop more useful websites in future.

You have been invited because we would like your opinion on the website as you support a person with intellectual disability.

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

The study is being carried out by the following researchers: Professor Julian Trollor, Dr Janelle Weise, Ms Claire Eagleson, Dr Jenna Zhao, Ms Dominique Abagi, and Ms Tahli Hind from the Department of Developmental Disability Neuropsychiatry, Discipline of Psychiatry & Mental Health, UNSW Medicine & Health.

**Research Funder:** This research is being funded by the Department of Social Services.

### **3. Inclusion/Exclusion Criteria**

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

- Are a carer, family member, friend, support person (paid or non-paid), or advocate of a person with an intellectual disability
- Are 18 years or over.
- Live in NSW.
- Have used, or supported a person with intellectual disability to use, the Intellectual Disability Mental Health Connect website at least once

### **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.



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

**Screening:** If you would like to participate, you will be asked to take part in a short screening interview. If you provide your consent to participate in the screening process you will be asked to provide your contact details to allow the research team to contact you and organise a time to complete the telephone interview (or you can call the research team). We will ask you screening questions that will determine if you are eligible to take part. Completing the screening questions will take five minutes. If you meet the criteria for inclusion, then you will be able to participate in the research study and the research team will organise a convenient time for you to participate in the research. If the screening questions show that you cannot be in the research study, we will destroy any information that has been collected about you.

**Interview/focus group:** During a face to face, telephone or video conferencing interview or focus group, you will be asked i) demographic questions, ii) how you used the website, iii) how useful the information was, iv) if the website helped you and the person you support, and v) your feedback on the website. Face to face interviews/focus groups will take place either at 3DN, or at another agreed upon private location. Video conferences will take place over Zoom or Teams. Interviews will take approximately 1 hour, while focus groups will take approximately 2 hours. With your permission the research team would like to audio record (or video record the interview if certain video conferencing platforms are used) the interview/focus group. For interviews, if you do not want to be recorded but you would like to participate you can advise the research team and written notes will be taken (this is not possible for focus groups).

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.

**Additional Costs and Reimbursement:** There are no costs associated with participating in this research study, nor will you be paid. However, you will receive a \$50 Coles card voucher to reimburse you for your time/ any expenses while completing the interview/focus group.

**Psychological Distress:** You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research study, the research team will be able to arrange for counselling or other appropriate support. Alternatively, a free contactable support service is included at section 11. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

**6. 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.

The research team will store the data collected from you for this research study for:

- A minimum of 5 years after the publication of the research results;



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The information about you will be stored in a re-identifiable format where any identifiers such as your name, address, date of birth will be replaced with a unique code.

Information collected from you in an electronic format will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators.

Information collected from you using paper-based measures will be stored in the Department of Developmental Disability Neuropsychiatry, Room 241 Biolink Building E25, UNSW Sydney, 2052 and only the approved research investigators will have access to this information.

Audio or video recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators. It will be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed.

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](#).

### **7. 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. All Information will be published 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 inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

### **8. 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 or 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, the Council for Intellectual Disability, or the Department of Social Services. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research study.

### **9. 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:



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**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>	HC220792

**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**

<b>Name</b>	Claire Eagleson
<b>Position</b>	Project Officer
<b>Telephone</b>	02 9065 9516
<b>Email</b>	<a href="mailto:c.eagleson@unsw.edu.au">c.eagleson@unsw.edu.au</a>

**Chief Investigator**

<b>Name</b>	Prof Julian Trollor
<b>Position</b>	Head, 3DN UNSW Sydney, Chair IDMH
<b>Telephone</b>	02 9065 8076
<b>Email</b>	<a href="mailto:j.trollor@unsw.edu.au">j.trollor@unsw.edu.au</a>

**11. 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:

<b>Name/Organisation</b>	Beyond Blue
<b>Telephone</b>	1300 224 636
<b>Website</b>	<a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a>



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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 understand that the research team will audio/video record the interviews/focus groups; I agree to be recorded for this purpose.
- I understand that I will need to maintain group confidentiality and not talk about what was said in the focus group.
- I provide my consent for the information collected about me to be used for the purpose of this research study 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 understand that I will be given a signed copy of this document to keep.
- 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:** \_\_\_\_\_

**Optional Consent for future research:**

- I provide my consent for my name and contact details to be retained in a register so I can be contacted about other research projects in the future.

**Participant Signature**

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

**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, the Council for Intellectual Disability, or the Department of Social Services.

- I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.
- I understand that the information collected during participation in the focus groups cannot be withdrawn given the nature of the focus group.

### Participant Name

Name of Participant (please type)	
Date	

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

CI Name:	Professor Julian Trollor
Email:	j.trollor@unsw.edu.au
Phone:	(02) 9065 8076
Postal Address:	Department of Developmental Disability Neuropsychiatry Room 241 Biolink Building E25 UNSW Sydney NSW 2052