



**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM – Guardian**

For a legally recognised guardian or person responsible providing consent on behalf of a person with an intellectual disability

Evaluation of the Intellectual Disability Mental Health Connect webtool  
Professor Julian Trollor

**1. What is the research study about?**

The person with an intellectual disability that you support is invited to take part in this research study. The research study aims to evaluate a new website, *Intellectual Disability Mental Health Connect*. 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.

**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 allow the person you support to participate in this research study, we need to ensure that it is ok for them to take part. The research study is looking for people who:

- Are aged over 18 years
- Self-identify as a person with intellectual disability
- Live in New South Wales
- Have used, or been supported to use, the Intellectual Disability Mental Health Connect webtool at least once

Exclusion criteria

- Individuals currently experiencing an acute episode of mental illness

**4. Does the person I support have to take part in this research study?**

Participation in this research study is voluntary. If you do not want the person you support to take part/if they do not want to take part, they do not have to. If you agree that the person you support can take part and later change your mind, you are free to withdraw the person you support from the study at any stage.

If you decide you want the person you support 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 the person you support to participate, they/you will be asked to take part in a short screening interview. If you provide your consent for the person you support to participate in the screening process they/you will be asked to provide contact details to allow the research team to contact the person you support/you and organise a time to complete the telephone interview (or they/you can call us). We will ask screening questions that will determine if the person you support is eligible to take part. We will ask if you are their legally recognised guardian or person responsible. Completing the screening questions will take about five minutes. If they meet the criteria for inclusion, they will be able to participate in the research study and the research team will organise a convenient time for the person you support to participate in the research. If the screening questions show that they cannot be in the research study, we will destroy any information that has been collected about them/you.

**Interview/focus group:** If you agree for the person you support to take part they will be asked to participate in an interview or focus group.

Individuals can participate in an interview by themselves or with a support person present. Alternatively, they can choose to take part in a focus group with other people with intellectual disability (they can also have a support person present if they wish).

During a face to face, telephone or video conferencing interview or focus group, the person you support will be asked i) demographic questions, ii) about support they have received for their mental health, iii) if they found the information on the website useful, iv) if the website helped them, and v) further feedback on the website. Face to face interviews/focus groups will take place either at 3DN, UNSW Sydney, 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 the person you support to be recorded but you would like them 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 or the person you support be paid. However, the person you support will receive a \$50 gift card voucher to reimburse them for their time/ any expenses while completing the interview/focus group.

**Psychological Distress:** The person you support may feel that some of the questions we ask are stressful or upsetting. If they do not wish to answer a question, they may skip it and go to the next



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question, or they may stop immediately. If the person you support/you become upset or distressed because of 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 the person I support?**

By signing the consent form, you consent to the research team collecting and using information about the person you support for the research study.

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

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

The information about the person you support/you will be stored in a re-identifiable format where any identifiers such as their/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 the person you support/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 the person you support.



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If the person you support/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 for the person you support to participate, you or the person you support 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/their decision not to participate or to withdraw from the study will not affect your/their relationship with UNSW Sydney, the Council for Intellectual Disability, or the Department of Social Services. If the person you support decides to leave the research study, the researchers will not collect additional information from them. You can request that any identifiable information about the person you support be withdrawn from the research study.

If the person you support decides to withdraw part way through a focus group, information already collected about the person cannot be withdrawn given the nature of the focus group.

**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:

**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 the person you support’s 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>



**UNSW**  
Department of Developmental  
Disability Neuropsychiatry



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**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, the person you support/you becomes distressed or requires 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 – Parent/Guardian Consent

### Declaration by the participant

- I understand I am being asked to provide consent for the person I support to participate in this research study;
- I am the person's legally recognised guardian or person responsible;
- The person I am providing consent for is aware that consent is being given on their behalf
- 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 for the person I support to be recorded for this purpose.
- I understand that the person that I support 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 the person I support/myself 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 for the person I support to participate in this research study as described and understand that I/they are free to withdraw at any time during the study and withdrawal will not affect their/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.



**UNSW**  
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Disability Neuropsychiatry



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**Participant Name**

Name of Participant (please print)	
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**Parent/Guardian Signature**

Name of person providing consent (please print)	
Signature of person providing consent	
Date	

**Declaration by Researcher\***

- I have given a verbal explanation of the research study; its study activities and risks and I believe that the guardian 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 for the person I support to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my or the person I support's relationship with The University of New South Wales, the Council for Intellectual Disability, or the Department of Social Services

I am withdrawing the person I support's consent and I would like any identifiable information collected about the person I support/myself which I have provided for the purpose of this research study withdrawn.

I understand that the information collected about the person I support/myself during their participation in the focus groups cannot be withdrawn given the nature of the focus group.

**Participant Name**

Name of Participant (please print)	
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 9516
Postal Address:	Department of Developmental Disability Neuropsychiatry Room 241 Biolink Building E25 UNSW Sydney NSW 2052