



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

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

1. What is the study about?

This 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.

You have been invited to provide support for a research participant.

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

You may be able to be a support person if you:

- Are over 18 years of age
- Live in New South Wales

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

Participation in any research study is voluntary. If you do not want to take part, you do not have to.

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

3DN are conducting interviews and focus groups with people with intellectual disability.

As a support person, your role is to sit in on the interview with the person with intellectual disability and help them to communicate in the best way possible with the researcher. Your role as a support person in this research is to:

- Facilitate and interpret the person's speech or communication
- Rephrase questions in words or ways that the person will understand
- Give an example that might help the person understand better
- Alert the researcher to subtle signs of the person being upset or distressed
- Provide moral support and motivation

Your role as a support person is not to answer the questions for the person with intellectual disability but, instead to help that person answer themselves.

Psychological Distress: We don't expect the interview/focus group to cause any harm; however, you or the person you are supporting may become upset because of reflecting on their mental health



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

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

and experiences in a mental health service (or your experience of supporting someone to access a mental health service).

Additional Costs and Reimbursement: There are no costs associated with participating in this research study, nor will you receive any payment in your role as a support person.

6. What are my responsibilities as a supporter?

Your responsibilities as a supporter are:

- To help the person with intellectual disability communicate in the best way possible
- To assist in ways that are reflective of the person's opinion
- To be discrete about the information you hear from the person during the interview and to respect the person's confidentiality.
- To keep information heard about other people during a focus group confidential.

7. What will happen to information about me and the person I am supporting?

By signing the consent form, you consent to the research team collecting and using information about you and the person you are supporting.

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/the person you are supporting 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 are supporting/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



UNSW
Department of Developmental
Disability Neuropsychiatry



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

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

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. What am I consenting for?

We would like to take notes during the interview and seek your permission to record what you say to make our notes better.

Please note that if the person being interviewed consents to the audio recording but you don't, the interview will still be recorded. However, we will not transcribe what you say or use your input in the data analysis.

9. 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 or the person you are supporting.

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.

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

You may withdraw from the study 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. You can request that any identifiable information about you be withdrawn from the research study.

If you decide to withdraw part way through a focus group, we will not be able to remove your comments from the recording. However, we will not transcribe what you say or use your input in the data analysis.



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

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

11. 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

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC220792

12. 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 have any questions about the research study or if you have any problems related to your involvement in the study, you can contact the following member of the research team:

Research Team Contact Details

Name	Claire Eagleson
Position	Project Officer
Telephone	02 9065 9516
Email	c.eagleson@unsw.edu.au

Chief Investigator

Name	Prof Julian Trollor
Position	Head, 3DN UNSW Sydney, Chair IDMH
Telephone	02 9065 8076
Email	j.trollor@unsw.edu.au

13. Support Services contact Details

If at any stage during the study you or the person you are supporting becomes distressed or requires additional support from someone not in the research, please call:

Name/Organisation	Beyond Blue
Telephone	1300 224 636
Website	www.beyondblue.org.au



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

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

Consent Form – Support person

Declaration by participant

- I understand I am being asked to provide consent to participate as a support person 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 for the person I support/myself to be recorded for this purpose.
- I agree not to disclose any information discussed during the focus groups and to maintain group confidentiality.
- 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 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: _____

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.



UNSW
 Department of Developmental
 Disability Neuropsychiatry



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

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

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 from the study 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 about me during their 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