



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Developing a mental health service website for people with 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 look at what supports people with intellectual disability and their support networks need at each stage of a person with intellectual disability's mental health journey. This will assist us to develop a mental health service pathway web-tool. This Tool will link people with intellectual disability and mental health professionals to the resources that they need to support a journey through mental health services and to promote good mental health.

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, and Dr Jenna Zhao from the Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Medicine.

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 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.
- Be 18 years or over.
- Live in NSW.
- Have experience supporting a person with intellectual disability who has accessed health services for a physical or mental health problem.

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?

Screening: If you would like to participate, you will be asked to take part in a short telephone 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 1-2 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



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Developing a mental health service website for people with intellectual disability

Professor Julian Trollor

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 questions about your experiences helping the person you support to find health services and supports, and what supports you think people with intellectual disability need at each stage of a mental health journey. You will also be asked to complete a short Demographics questionnaire. Face to face interviews/focus groups will take place either at 3DN, UNSW Sydney, conference rooms close to Central Station, or at another agreed upon location. Video conferences will take place over Zoom or Skype. Interviews will take approximately 2 hours, while focus groups will take approximately 2 ½ 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 Visa prepaid gift card voucher to reimburse you for any travel/parking and other 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 number of free contactable support services are 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;

The information about you will be stored in an/a:

- Re-identifiable format where any identifiers such as your name, address, date of birth will be replaced with a unique code.

You will be asked to provide your consent for the research team to share or use the information collected from you in future research that:

- Will be specific to the aims of this research;



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Developing a mental health service website for people with intellectual disability

Professor Julian Trollor

- Will be an extension of, or closely related to, the original project; or is in the same general area of research;

Your information will only be shared in a format that will not identify you.

- Information collected from you in an electronic format 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, 34 Botany Street 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:



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Developing a mental health service website for people with intellectual disability

Professor Julian Trollor

Complaints Contact

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	HC200964

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

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

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:

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



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Developing a mental health service website for people with intellectual disability

Professor Julian Trollor

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 reuse of data and future research:

- I provide my consent for the information collected about me to made available to other researchers as described at section 6 of this document.
- 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.



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Developing a mental health service website for people with intellectual disability

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 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 34 Botany Street UNSW Sydney NSW 2052