



ONLINE PARTICIPANT INFORMATION STATEMENT

Support networks
Evaluation of the Intellectual Disability Mental Health Connect webtool
Prof 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* (IDMH Connect) website that has recently launched in NSW. 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.

You have been invited because you support someone who has 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, Ms Claire Eagleson, Dr Jenna Zhao, Ms Dominique Abagi, and Ms Tahli Hind from the Department of Developmental Disability Neuropsychiatry, Discipline of Psychiatry and 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 ok for you to take part. The research study is looking recruit people who meet the following criteria:

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

There are no specific exclusion criteria for this study.

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.

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);
- Complete the online survey.

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

If you decide to take part in the research study, we will ask you to complete an online survey after using IDMH Connect at least once. The survey will ask for your feedback on the website including i) whether you found it useful, ii) if it has helped you to navigate the mental health system for the person you support, and iii) the utility of specific features of the website. It should take approximately 15 minutes to complete.

Reimbursement and Incentives - At the end of the survey, you can elect to put your name in a draw to win a \$100 Coles Myer gift card. There is 1 gift card available for each participant group (1x support networks, 1x people with intellectual disability, 1x professionals). The competition will be drawn on 16 October 2023.

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 team and



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they will provide you with assistance or alternatively a support service's 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 better understand how we can provide people with intellectual disability and their support networks with information online that can help to support their mental health. It may also assist professionals to improve their mental health care for people with intellectual disability in future.

7. What will happen to information about me?

Submission of the online survey is an indication of your consent. By clicking the 'I agree to participate' button you are providing your permission for the research team to collect and use information about you for the research study.

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

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

The information about you will be stored in a non-identifiable format where your identity will be unknown.

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. 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 contacting Claire Eagleson at c.eagleson@unsw.edu.au or 02 9065 9516. We will only use these details to send you the results of the research. The summary will also be on our website <https://www.3dn.unsw.edu.au/projects/intellectual-disability-mental-health-service-pathway-tool>.

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 this by closing the survey. If you withdraw from the research, we will destroy any information that has already been collected. Once you have submitted the survey however, we will not be able to withdraw your responses as the survey is anonymous.

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](#).



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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

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

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

Contact for feelings of distress

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

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



UNSW
Department of Developmental
Disability Neuropsychiatry



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Consent Form – Participant providing own consent

Declaration by the participant

By checking the I agree/start survey option below:

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet, or it has been provided to me in a language that I understand;
- I provide my consent for the information collected about me to be used for the purpose of this research study only.
- I understand that if necessary, I can ask questions and the research team will respond to my questions.
- 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 can download a copy of this consent form from <https://www.3dn.unsw.edu.au/projects/intellectual-disability-mental-health-service-pathway-tool>

[I agree, start survey](#)