



**Participant Information Sheet for Online Survey  
Support Networks**

Evaluation of the Intellectual Disability Mental Health Connect webtool

Professor Julian Trollor and Dr Janelle Weise

**Health/Social Science Research - Adult providing own consent**

*South Eastern Sydney Local Health District*

<b>Title</b>	Evaluation of the Intellectual Disability Mental Health Connect webtool
<b>Short Title</b>	Evaluation of the IDMH Connect webtool
<b>Protocol Number</b>	v1.1
<b>Project Sponsor</b>	Department of Social Services
<b>Coordinating Principal Investigator/ Principal Investigator</b>	Professor Julian Trollor
<b>Location</b>	South Eastern Sydney Local Health District

**Part 1 What does my participation involve?**

**1 Introduction**

You are invited to take part in this research project, which is called *Evaluation of the Intellectual Disability Mental Health Connect webtool*. You have been invited because we would like your opinion on the webtool as you support a person with intellectual disability.

This Participant Information Sheet tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether to take part, you might want to talk about it with a relative, friend or colleague.

Participation in this research is voluntary. If you do not wish to take part, you do not have to.

If you decide you want to take part in the research project, by submitting this online survey you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to be involved in the research described
- Consent to the use of your personal information as described.

You will be given a copy of this Participant Information Sheet to keep.

## **2 What is the purpose of this research?**

The purpose of this research is to test out the new *Intellectual Disability Mental Health Connect* webtool before launching it statewide in NSW. People with intellectual disability tell us that they sometimes have difficulty finding the right mental health support. This webtool 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 online survey aims to seek feedback from support networks of people with intellectual disability who have used the webtool around whether it is helpful and easy to use.

Your feedback will be used to help us refine the content and design of the final webtool, which we hope to launch in early 2023.

This research has been initiated by a team led by Professor Julian Trollor from the Department of Developmental Disability Neuropsychiatry, UNSW Sydney with funding from the Information, Linkages and Capacity Building program, Department of Social Services.

## **3 What does participation in this research involve?**

If you decide to participate in this study, you will be asked to complete an online survey after using the IDMH Connect webtool at least once at [www.idmhconnect.health](http://www.idmhconnect.health). You can complete this survey by clicking on the link provided via the IDMH Connect webtool. You do not necessarily need to complete the survey after your first use of the webtool. You may want to complete it after using the webtool several times. You will have until September 2022 to complete the survey.

The first part of this survey will determine if you are eligible to take part. Completing the screening questionnaire will take approximately one minute. If the screening questionnaire shows that you meet the requirements, then you will be able to start the research project. If the screening questionnaire shows that you cannot be in the research project, the research coordinator can discuss other options with you.

The survey will take no longer than 10 minutes and will ask you i) brief details about yourself, ii) whether you found the webtool useful, iii) if you were able to find information you were looking for, and iv) general feedback about the webtool.

Any information obtained in connection with this research project will remain confidential. You will not be asked for your name or contact details (unless you provide your email address in a separate survey form to enter the prize draw).

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way.

There are no costs associated with participating in this research project. At the end of the survey, you can elect to put your name in a draw to win a \$100 gift voucher.

#### **4 Other relevant information about the research project**

We will also be seeking feedback from people with intellectual disability and professionals.

#### **5 Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish to take part, you do not have to. If you decide to leave the research project, the researchers will not collect additional information from you. Please note that once you submit the survey, we will not be able to delete your responses as the survey is completely anonymous.

If you do decide to take part, you will be given a copy of this Participant Information Sheet to keep.

Your decision whether to take part or not, or to take part and then withdraw, will not affect your relationship with UNSW Sydney, the Council for Intellectual Disability, or the Department of Social Services.

#### **6 What are the possible benefits of taking part?**

We cannot guarantee or promise that you will receive any benefits from this research. The findings of this survey will help us to refine the webtool which may benefit people with intellectual disability and their support networks in future when looking for information to help support their mental health. It may also assist professionals to improve their mental health care for people with intellectual disability in future. However, there will be no clear benefit to you personally from your participation in this research.

#### **7 What are the possible risks and disadvantages of taking part?**

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 tell us you wish to skip it and go to the next question, or you may stop immediately.

If you become upset or distressed because of your participation in the research project, the research team will be able to recommend counselling or other appropriate support. We can assist you in contacting your GP to discuss the possibility of a Mental Health Care Plan. This will entitle you to 20 Medicare rebated mental health sessions with a Clinical or General Psychologist. Please contact our Project Officer, Claire Eagleson on 02 9065 9516 or [idmhconnect@unsw.edu.au](mailto:idmhconnect@unsw.edu.au), who can help to arrange this support.

Alternatively, you can contact several free services directly, including:

**Name/Organisation** Beyond Blue  
**Telephone** 1300 224 636  
**Website** [www.beyondblue.org.au](http://www.beyondblue.org.au)

**Name/Organisation** Lifeline Australia  
**Telephone** 13 11 14  
**Website** <https://www.lifeline.org.au/>

## **8 What if I withdraw from this research project?**

If you decide to leave the research project, the researchers will not collect additional information from you. Please note that once you submit the survey, we will not be able to delete your responses as the survey is completely anonymous.

## **9 Could this research project be stopped unexpectedly?**

There are no foreseeable reasons as to why this project will be stopped unexpectedly.

## **10 What happens when the research project ends?**

The research team intend to publish and report the results of the research project in a variety of ways. All information published will be done in a way that will not identify you.

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by emailing Claire Eagleson at [idmhconnect@unsw.edu.au](mailto:idmhconnect@unsw.edu.au). This feedback will be in the form of a one-page lay summary. You will receive this feedback after the study is finished. The summary will also be on our website <https://www.3dn.unsw.edu.au/projects/intellectual-disability-mental-health-service-pathway-tool>.

## **Part 2 How is the research project being conducted?**

### **11 What will happen to information about me?**

By submitting the survey, you consent to the research team collecting and using personal information about you for the research project. The personal information that the research team collect, and use is information from the online survey. Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

Any information obtained in connection with this research project that can identify you will remain confidential. All information in the survey is anonymous and is not identifiable. If you decide to go in the draw to win the prize your email address will be collected but will not be linked to your survey responses.

Electronic data will be stored on UNSW servers that require UNSW staff authorisation and a password to gain access. Individual logins must be used to access files. Access levels are

set by UNSW IT. Data will be stored in adherence to UNSW IT Security Standards and Guidelines Policy.

Any hard copies of data will be stored in a locked cabinet at the Department of Developmental Disability Neuropsychiatry, UNSW Sydney, 34 Botany St, UNSW Sydney, Sydney 2052. Access to this data is restricted to research team members.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

In accordance with relevant Australian and/or NSW privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

## **12 Who is organising and funding the research?**

This research project is being conducted by Prof 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, UNSW Sydney. This research is being funded by the Department of Social Services.

No member of the research team will receive a personal financial benefit from your involvement in this research project (other than their ordinary wages).

## **13 Who has reviewed the research project?**

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC).

The ethical aspects of this research project have been approved by the Greater Western HREC, NSW Health.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

## **14 Further information and who to contact**

The person you may need to contact will depend on the nature of your query. If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the following people:

### **Dr Janelle Weise**

Lecturer

[j.weise@unsw.edu.au](mailto:j.weise@unsw.edu.au)

**Ms Claire Eagleson**  
Project Officer  
[c.eagleson@unsw.edu.au](mailto:c.eagleson@unsw.edu.au)

## **15 Complaints contact person**

This study has been approved by the Greater Western Human Research Ethics Committee (2021/ETH12058). If you have any concerns or complaints about the conduct of the research study, you may contact the Executive Officer of the Ethics Committee, on (02) 6330 5948 and quote [2021/PID03324].

**Complaints about conduct of this research within South Eastern Sydney LHD:** Should you have concerns or a complaint about the manner in which the research is conducted you can direct complaints to the SESLHD Research Ethics and Governance Office: (ph) 02 9382 3587 | (e) [SESLHD-RSO@health.nsw.gov.au](mailto:SESLHD-RSO@health.nsw.gov.au) and quote the reference number (2021/STE04717).

**Thank you for taking the time to consider this study.**

**This information sheet is for you to keep.**