Health
South Eastern Sydney
Local Health District

UNSW SYDNEY

DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

Participant Information Sheet for Interview/Focus Group
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*
SESLHD Mental Health Services

Title	Evaluation of the Intellectual Disability Mental Health Connect webtool
Short Title	Evaluation of the IDMH Connect webtool
Protocol Number	v1.1
Project Sponsor	Department of Social Services
Coordinating Principal Investigator/ Principal Investigator	Professor Julian Trollor
Location	SESLHD Mental Health Services

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 and Consent Form 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 local health worker.

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 this project, you will need to read and sign the Consent Form below. 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.

The interviews/focus groups aim to seek more in-depth feedback from support networks of people with intellectual disability around how they have used the webtool, its utility and ease of use, and capacity to assist people with intellectual disability get access to mental health care.

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 attend an interview or focus group. Please contact our Project Officer Claire Eagleson on 02 9065 9516 or idmhconnect@unsw.edu.au if you would like to take part.

The first part of this process will determine if you are eligible to take part. Completing the screening questionnaire will take approximately five minutes over the phone with us. 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 will discuss other options with you.

Interviews take approximately 1 hour and focus groups take approximately 2 hours and will ask you i) demographic questions (e.g., about your age and gender), ii) how you used the webtool, iii) if you were able to find information about different topics, iv) if the webtool helped you and the person you support in practical ways, and v) your feedback on the webtool.

Any information obtained in connection with this research project will remain confidential
This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way.

After you take part, you can request access to your transcript and provide clarifying information. However, it is only possible for participants who took part in individual interviews to ask that certain information is not included in the analysis. It would not be possible for your contribution to a focus group to be removed later given your individual responses are part of the general discussion.

There are no costs associated with this research project.

4 Other relevant information about the research project

We are also 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 take part and later change your mind, you are free to withdraw from the project at any stage by signing and returning the Withdrawal of Participation Form provided below.

If you do decide to take part, you will be given a Participant Consent Form to sign and 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 research 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, who can help to arrange this support.

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

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

Name/Organisation	Lifeline Australia
Telephone	13 11 14
Address	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. If you no longer wish to have your data stored or do not wish to be contacted for research purposes you can withdraw your information by completing the withdrawal of consent form below or by phoning our Project Officer, Claire Eagleson on 02 9065 9516 or idmhconnect@unsw.edu.au and letting them know. Please note, your data would not be able to be removed from any data analysis or publications already developed.

Please note, if you decide to withdraw part way through an interview or 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.

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. 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 signing the Consent Form below, you consent to the research team collecting and using personal information about you for the research project. 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.

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 Street, UNSW Sydney, Sydney 2052. Access to this data is restricted to research team members.

Audio or video recordings of you 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.

Data will be retained for 5 years post publication of resulting manuscripts. After this time, electronic data will be permanently deleted from all storage devices and paper-based data will be shredded.

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 Compensation

You will receive a $50 gift voucher for your time.

13 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).

14 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 HREC of NSW Health.

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.

15 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

Ms Claire Eagleson
Project Officer
c.eagleson@unsw.edu.au

Ms Dominique Abagi
Project Officer
d.abagi@unsw.edu.au

16 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 SESLHD Mental Health Services: 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 and quote the reference number (2021/STE05206).

Thank you for taking the time to consider this study.

If you wish to take part in it, please sign the attached consent form.

This information sheet is for you to keep.

Declaration by the participant

- I have read the Participant Information Sheet or someone has read it to me in a language I understand;
- I understand the purposes, study tasks and risks of the research as described in the Participant Information Sheet;
- I have had the opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project and withdrawal will not affect my relationship with any of the named organisations and/or the names research members;
- I understand that I will be given a copy of the Participant Information Sheet to keep
- I understand that the research team will audio/video record the interviews/focus groups; I agree for myself to be recorded for this purpose.

Participant Signature

Name of Participant (please print):	
Signature of Research Participant:	
Date:	
Postal address: (If gift card will be sent out)	

Declaration by researcher*

I have given a verbal a verbal explanation of the research project, the project activities and the risks and I believe that the participant has understood the explanation.

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 project.

Note: all parties signing the consent section must date their own signature.

Withdrawal of Participation Form

I wish to **WITHDRAW** my consent to participate in the research project described in the Participant information Sheet and understand that such withdrawal **WILL NOT** affect my relationship with any of the named organisations and/or the names research members.

Participant Signature

Name of Participant (please print):	
Signature of Research Participant:	
Date:	

The Withdrawal of Participation Form should be forwarded to:

Chief Investigator Name:	Professor Julian Trollor
Email:	j.trollor@unsw.edu.au
Postal Address:	34 Botany St, Randwick, NSW, 2031