

PARTICIPANT INFORMATION STATEMENT**An evaluation of the intellectual disability health web tool****Professor Julian Trollor****1. What is the research study about?**

You are invited to take part in this research study which aims to evaluate the intellectual disability health web tool. This tool will assist local health districts and specialty health networks to understand and respond to the mental and physical health needs of people with an intellectual disability in their district.

You have been invited as a possible participant in this project because you have registered to use the intellectual disability health web tool.

2. Who is conducting this research?

The study is being carried out by the following researchers: Professor Julian Trollor, Dr Janelle Weise, and Dr Preeyaporn Srasuebkul from the Department of Developmental Disability Neuropsychiatry (3DN), UNSW Sydney.

Research Funder: This research is being funded by Mental Health and Drug & Alcohol Office, New South Wales Ministry of Health, Australia.

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 New South Wales.
- Have registered and plan to use the intellectual disability health web tool developed by 3DN.

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);
- Take a copy of this form with you to keep;
- Respond to the on-line survey and complete the consent question.

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

If you decide to take part in the research study, you will be asked to participate in an on-line survey at four points in time. A hard copy of the survey can be made available to you if you prefer.

When you initially register to use the intellectual disability health web tool you will be asked to complete a registration/minimum user data survey. You will be asked if you consent to this information being used for research purposes. At this time, you will also be invited to participate in the evaluation of the tool.

If you consent, you will be asked to complete a base-line data survey prior to accessing the web tool for the first time. You will then be asked to complete two follow up on-line surveys. The first will be after your initial use of the tool and the second will be 3 months after you first used the tool.

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The surveys will collect the following types of information: i) demographics, ii) your reasons for using tool, iii) the usability of the web tool, iv) your knowledge of physical and mental health needs of people with an intellectual disability, v) your understanding of health service use and associate costs by people with an intellectual disability, vi) the capacity of your health service to meet the health needs of people with an intellectual disability, and vii) what capacity building activities have been undertaken in the area of intellectual disability health.

We will ask you to provide the research team with an email address. The team will use this to remind you to participate in the follow up surveys.

6. What are the possible benefits to participation?

We aim to use information we get from this research study to evaluate i) the utility of intellectual disability health web tool, ii) if the tool supports local health districts and specialty health networks to understand and respond to the mental and physical health needs of people with an intellectual disability in their district, and iii) is a web tool useful for making research findings accessible.

This knowledge can in turn be used to make recommendations for adaptations to the intellectual disability health web-tool

7. What will happen to information about me?

By consenting to participate in this project you are agreeing to the research team collecting and using information about you for this research study. Your data will be kept for 7 years after the project's completion.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. De-identified data will be use when publishing the findings from this study.

All data will be stored in adherence to UNSW IT Security Standards & Guidelines policy. This will include the storage of paper-based information in a dedicated, lockable cabinet at UNSW Sydney, 34 Botany Street. Electronic data will stored on a UNSW Sydney server which requires authorisation and a password to gain access

We plan to present and publish the results at relevant conferences, in peer reviewed journals, and in documents to be distributed to other key stakeholders, such as NSW Health. Information collected for this research project may be made available to other research projects in de-identified form only.

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.

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Further information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

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 study in a variety of ways. All information published will be done 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.

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 so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document. Alternatively, 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 or the Mental Health and Drug & Alcohol Office, New South Wales Ministry of Health.

If you decide to leave the research study, the researchers will not collect additional information from you. Any identifiable information about you will be withdrawn from the research project.

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	Dr Janelle Weise
Position	Project Officer
Telephone	(02) 9931 9160
Email	j.weise@unsw.edu.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 NSW Population & Health Services Research Ethics Committee

Complaints Contact

Position	Executive Officer, Manager Research Ethics
Telephone	02 8374 5662
HC Reference Number	CINSW 2013/02/446 sub study: 2019UMB0906



DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY



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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 or the Mental Health and Drug & Alcohol Office, New South Wales Ministry of Health. In withdrawing my consent I would like any information which I have provided for the purpose of this research study withdrawn.

Participant Signature

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

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Professor Julian Trollor
Email:	j.trollor@unsw.edu.au
Phone:	(02) 9931 9160
Postal Address:	The Department of Developmental Disability Neuropsychiatry, 34 Botany Street, UNSW Sydney, 2052