



**DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY**



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

Can people with an intellectual disability find information about their health and health care that they can understand?

Professor Julian Trollor

1. What is the study about?

This study aims to determine if people with an intellectual disability can find information about their health and health care that they can understand.

It also aims to determine what types of information people with an intellectual disability would like about their health and health

You have been invited to provide support for a research participant.

2. Who is conducting this research?

The study is being carried out by the following researchers: Professor Julian Trollor, Dr Janelle Weise, Ms Bronwyn Newman from the Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Medicine.

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

3. What does it involve?

3DN are conducting interviews and focus groups with people with intellectual disability.

You may be able to be a support person if you are:

- Over 18 years of age
- Not experiencing an acute mental illness

As a support person, your role is to sit in on the interview with the person with intellectual disability and help them to communicate in the best way possible with the researcher. Your role as a support person in this research is to:

- Facilitate and interpret the person's speech or communication
- Rephrase questions in words or ways that the person will understand
- Give an example that might help the person understand better
- Alert the researcher to subtle signs of the person being upset or distressed
- Provide moral support and motivation

Your role as a support person is not to answer the questions for the person with intellectual disability but, instead to help that person answer themselves.

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.

5. What are my responsibilities as a supporter?

Your responsibilities as a supporter are:

- To help the person with intellectual disability communicate in the best way possible
- To assist in ways that are reflective of the person's opinion
- To be discrete about the information you hear from the person during the interview and to respect the person's confidentiality.



**DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY**



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

Can people with an intellectual disability find information about their health and health care that they can understand?

Professor Julian Trollor

6. Are there any risks involved?

We don't expect the interview/focus group to cause any harm; however, you or the person you are supporting may become upset because of reflecting on their health and experiences in a health service (or your experience of supporting someone to access a health service).

7. What are the potential benefits?

This research study will provide people with intellectual disability an opportunity to offer insights into their experiences and facilitate change to improve services. Your support will allow the person you are supporting to contribute to this important area of need.

We aim to use the information from this research study to provide evidence around the accessibility of health-related information for people with an intellectual disability and they types of health-related information that needs to be developed.

8. What will happen to information about me and the person I am supporting?

The information provided by you and the person you are supporting will be kept for a period of 7 years after the project is completed. We will store information about you in a non-identifiable format.

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 the Department of Developmental Disability Neuropsychiatry. Electronic data will be stored on a server which requires authorisation and a password to gain access.



**DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY**



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

Can people with an intellectual disability find information about their health and health care that they can understand?

Professor Julian Trollor

9. What am I consenting for?

We would like to take notes during the interview and seek your permission to record what you say to make our notes better.

Please note that if the person being interviewed consents to the audio recording but you don't, the interview will still be recorded. However, we will not transcribe what you say or use your input in the data analysis.

10. How and when will I find out the results of the study?

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 or the person you are supporting.

If you would like to receive a copy of the results you can let the research team know by ticking the box below that says, "I would like to know the results of the research" and providing your address or email address.

11. What if I change my mind?

You may withdraw from the study 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 Mental Health and Drug & Alcohol Office, New South Wales Ministry of Health, Australia.

If you decide to withdraw part way through a 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.

12. What if I have more questions?

If you have any questions about the research project or if you have any problems related to your involvement in the project, you can contact the following member of the research team:

Research Team Contact

Name	Janelle Weise
Position	Project Officer
Telephone	(02) 9931 9160
Email	j.weise@unsw.edu.au



**DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY**



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

Can people with an intellectual disability find information about their health and health care that they can understand?

Professor Julian Trollor

Support services contact details

If at any stage during the project you or the person you are supporting becomes distressed or requires additional support from someone not in the research, please call:

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	HC180917



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

Can people with an intellectual disability find information about their health and health care that they can understand?

Professor Julian Trollor

Consent Form – Support person

Declaration by participant

- I understand I am being asked to provide consent to participate as a support person in this research project.
- I have read the participant information and consent form.
- I understand the aim of the research and I understand what I am being asked to do.
- I agree not to disclose any information discussed during the focus groups and to maintain group confidentiality.
- I understand that the research team will audio record the interview/focus group; and I provide consent for this to happen.
- I have had an opportunity to ask questions and am satisfied with the answers I have received.
- I freely agree to participate in this research project and understand that I am free to withdraw at any time during the project and withdrawal will not affect my relationship with UNSW Sydney or research team members.
- I would like to know the results of the research. I have provided my details below and ask that they are used for this purpose only.

Name:
Address:
Email address:

- I understand I will be given a signed copy of this document to keep.

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 Signature¹

Name of Researcher (please print)	
Signature of Researcher	
Date	

¹ 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.



**DEPARTMENT OF
DEVELOPMENTAL
DISABILITY
NEUROPSYCHIATRY**



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

For someone supporting a person with an intellectual disability

Can people with an intellectual disability find information about their health and health care that they can understand?

Professor Julian Trollor

Form for Withdrawal of Participation

I wish to **withdraw** my consent to participate in this research study and understand that such withdrawal will not affect my relationship with UNSW Sydney. I would like any information collected about me that has been provided for this research project to be withdrawn. I understand that the information collected during participation in the focus group cannot be withdrawn given the nature of the focus group.

Signature

Name of support person (print):

Signature of support person:

Date: