



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Students' experiences and preferences regarding intellectual disability health education
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 understand in more detail students' experiences (if any) receiving education around the health of people with intellectual disability, their preferences for learning about intellectual disability, and what resources they require. This will help us to develop resources to support health education in this area.

2. Who is conducting this research?

The study is being carried out by the following researchers: Prof Julian Trollor, Ms Claire Eagleson, Dr Jenna Zhao, Dr Janelle Weise, Dr Seeta Durvasula, Ms Tahli Hind, Ms Michaela Kobor, and Ms Marianne Gibney-Quinteros from the Department of Developmental Disability Neuropsychiatry (3DN), UNSW Medicine and Health, and Ms Kat Davies and Ms Zoe Hannah-Whitehouse from the Health and Disability Interface Section, Department of Health and Aged Care.

Research Funder: This research is being funded by the Department of Health and Aged Care.

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:

- Current enrolment in a pre-registration health education degree or program (e.g. medicine, dentistry, nursing, allied health, and other health-related disciplines)
- At mid to advanced stage of degree or program (preferably with some clinical/placement/work integrated learning experience)
- Live in Australia

Participants who meet the following criteria will be excluded from the study:

- Participants that do not meet the above criteria.

You do not have to have received education around intellectual disability.

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);
- Sign and return the consent form if you decide to participate in the study;
- Take a copy of this form with you to keep.

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

If you agree to participate you will be asked to complete the following research procedures.

You will have a choice of taking part in an interview or focus group (focus groups are subject to availability).

Interview: At an online video interview, and you will be asked questions about your experiences receiving education around intellectual disability (if any) including teaching methods and whether



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Students' experiences and preferences regarding intellectual disability health education
Prof Julian Trollor

people with intellectual disability were involved in teaching; teaching methods you prefer to learn about intellectual disability health; and what resources are required in this area and how they could best be developed. The interview will take place on Zoom or similar software (e.g. Teams) and will take approximately 1 hour. With your permission the research team would like to video/audio record the interview. If you do not wish to be recorded but you would like to participate you can advise the research team and written notes will be taken. You can also choose to turn your camera off.

Focus Group: All focus group sessions will take place online via Zoom or similar software (e.g. Teams) and will take approximately 1.5 hours. During the focus group you will be asked questions about your experiences receiving education around intellectual disability (if any) including teaching methods and whether people with intellectual disability were involved in teaching; teaching methods you prefer to learn about intellectual disability health; and what resources are required in this area and how they could best be developed. With your permission the research team would like to video/audio record the interview. If you decide to participate in the focus group, your comments along with other participants' will be recorded during the group discussions. Because of the way in which the focus group discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses. You can choose to turn your camera off if you would like.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project, nor will you be paid. However, you will receive a \$50 gift card to reimburse you for your time.

6. What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using 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:

- Re-identifiable format where any identifiers such as your name, address, date of birth will be replaced with a unique code.
- Information collected from you in an electronic format will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators.
- Video/audio recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators. They may be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed.

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](#).



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Students' experiences and preferences regarding intellectual disability health education
Prof Julian Trollor

7. 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 inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

8. 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 or 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 or the Department of Health and Aged Care. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project. Please note that data cannot be withdrawn from a focus group once it has been completed.

9. 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	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
Project ID	5827

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

Chief Investigator

Name	Prof Julian Trollor
Position	Head of Department, 3DN UNSW Sydney
Telephone	02 9348 2126
Email	j.trollor@unsw.edu.au



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Students' experiences and preferences regarding intellectual disability health education
Prof Julian Trollor

Consent Form – Participant providing own consent

Declaration by the participant

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research described in the study;
- Recordings: I understand that the research team will video/audio record the interviews/focus groups; I agree to be recorded for this purpose.
- I provide my consent for the information collected about me to be used for the purpose of this research study only.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- 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 would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: _____

Address: _____

Email Address: _____

The results of the research will also be made available on the <https://www.3dn.unsw.edu.au/projects/resources-support-intellectual-disability-health-capability-framework> website.

- I would like to receive a physical gift card by post (rather than electronic version by email). N.B. Gift cards **cannot** be sent to PO Boxes. Please send to:

Address: _____

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 Signature*

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 study.**

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



UNSW
 Department of Developmental
 Disability Neuropsychiatry



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Students' experiences and preferences regarding intellectual disability health education
 Prof Julian Trollor

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 Department of Health and Aged Care.

- I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.
- I understand that the information collected during participation in the focus groups cannot be withdrawn given the nature of the focus group. However, information I provide will not be analysed.

Participant Name

Name of Participant (please type)	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Prof Julian Trollor
Email:	j.trollor@unsw.edu.au
Phone:	02 9348 2126
Postal Address:	Department of Developmental Disability Neuropsychiatry Room 241 Biolink Building E25 UNSW Sydney NSW 2052