



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

People with intellectual disability

Understanding co-teaching preferences of people with intellectual disability and their support networks

Professor Julian Trollor

1. What is the research study about?

You are invited to take part in this research study. The research study aims to find out how people with intellectual disability and people who provide support to people with intellectual disability want to be involved in teaching health students about intellectual disability. The study also aims to find out what supports people with intellectual disability and their support networks need to be involved in teaching. This research will help us to give advice to universities about how to involve people with intellectual disability and support networks in teaching about intellectual disability.

2. Who is doing this research?

The study is being done by the following researchers: Professor Julian Trollor, Dr Jenna Zhao, Claire Eagleson, Dr Janelle Weise, Tahli Hind, Michaela Kobor, Dr Seeta Durvasula and Marianne Gibney-Quinteros from the Department of Developmental Disability Neuropsychiatry, UNSW Medicine and Health and Kat Davies and 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 take part in this research study, we need to make sure that it is ok for you to take part. The research study is looking for people who meet the following criteria:

- Are 18 years of age or older
- Have an intellectual disability
- Live in Australia
- Have experience with teaching students about intellectual disability or an interest in teaching
- Can use Zoom to be part of the study.

Participants who meet the following criteria will not be able to take part in the study:

- Participants who do not meet the above criteria

4. Do I have to take part in this research study?

Participation in this research study is voluntary. Voluntary means 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 can stop taking part in the study at any time.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if you need to);
- Sign and send back the consent form if you decide to take part in the study;
- Take a copy of this form with you to keep.

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

Screening: If you agree to take part, you will be asked to complete a screening process by email or phone, depending on how you contact the research team. The screening process makes sure that you can be part of the study. Doing the screening process will take 1-2 minutes. If you are able to take part in the study, the research team will organise a time for you to take part. If you are not able to take part in the study, we will let you know and remove any information that we have received from you.

Focus group/interview: If you agree to participate you will be asked to be part of a focus group. If you are not able to join one of the focus group times or would prefer not to share your ideas in front of



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other people, you can do an interview instead. The focus group/interview will take place on Zoom. The focus group/interview will take approximately 1.5 hours.

During the focus group/interview you will be asked questions about how you would like to be involved in teaching health students about intellectual disability and what support you would need from universities to be involved. You will also be asked questions about any experiences you already have with teaching students about intellectual disability.

If you let us, the research team would like to video record the focus group/interview. If you decide to take part in a focus group, your comments along with other people in the group will be recorded during the group discussions. If you do not want your face to be recorded, you may turn off your camera during the focus group. Because of the way the focus group discussions are recorded, the research team will not be able to remove the things that you have said.

If you decide to take part in an interview and do not want us to record what you say, the research team can take notes instead.

Before the focus group/interview, you will receive an email to let you know your focus group/interview time and how to join the session. We will also send some information about what we will be discussing so that you can prepare. Two days before the focus group/interview, you will receive a reminder.

Additional Costs and Reimbursement: You do not need to pay any money to take part in this research study. We will pay you a \$150 Coles or Coles-Myer gift card to thank you for taking part.

Support people who attend the focus group/interview with you will not receive any money or gift cards from the research team.

Psychological Distress: You may feel that some of the questions we ask are stressful or upsetting. If you do not want to answer a question, you may skip it. You may also stop being part of the focus group/interview at any time by letting the research team know.

If you become upset from taking part in the research project, the research team will be able to organise counselling or other support for you. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge. We also include information about free contactable support services in Section 10.

Confidentiality: If you take part in a focus group, there is a very small chance that other members may share information from the focus group with others outside of the group. The research team will remind everyone at the beginning and end of each focus group not to repeat information from the focus group to people who were not part of the group. You can also choose not to answer a question if you are worried about your answer being repeated to people outside of the group.

6. What will happen to information about me?

By signing the consent form, you agree 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:

- At least 5 years after the publication of the research results



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The information about you will be stored in a:

- Re-identifiable format where any information about you 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 that only approved researchers can access.
- Audio or video recordings will be stored on a UNSW password protected OneDrive that only approved researchers will be able to access. The recordings will also be given to a professional transcription service. Recordings will only be given to the transcription service after they have signed a confidentiality agreement. A confidentiality agreement means they agree not to share the recording and what you have said with anyone else.

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 ask for the information to be corrected and changed, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. More information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

7. How and when will I find out what the results of the research study are?

The research team plan 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 putting 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 take part in the research study, 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 take part. Your decision not to take part or to withdraw from the study will not affect your relationship with UNSW Sydney 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 ask that any identifiable information about you be removed from the research project.

9. What if I have a complaint or any concerns about the research study?

If you have a complaint about 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
Reference Number	iRECS5819



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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 need further information about 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 Jenna Zhao
Position	Project Manager (Education)
Telephone	(02) 9065 1742
Email	jenna.zhao@unsw.edu.au

Chief Investigator

Name	Prof Julian Trollor
Position	Chair of Intellectual Disability Mental Health, Head of 3DN
Telephone	(02) 9348 2126
Email	j.trollor@unsw.edu.au

Support Services Contact Details

If at any stage during the study, you become distressed or require additional support from someone not involved in the research please call:

Name/Organisation	Dr Rachael Cvejic
Position	Senior Research Fellow
Telephone	(02) 9065 1625
Email	r.cvejic@unsw.edu.au

You can also contact the Beyond Blue support line at any time on any day.

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



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Consent Form – Participant providing own consent

Declaration by the participant

- I understand I am being asked to provide consent to take part 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 audio/video 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 take part 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: _____

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.



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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to take part in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales and 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 any information collected about me during my participation in a focus group cannot be withdrawn given the nature of the focus group.

Participant Name

Name of Participant (please print)	
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:	Rm 241, Level 2 Biolink Building (E25), UNSW Sydney, 2052