



Participant Information Sheet and Consent Form

Support Person

Sexual and reproductive rights for people with intellectual disability: Exploring stigma and attitudes toward contraceptive decision-making

Dr Maryann Barrington et al.

1. What is the research study about?

The person with intellectual disability that you support is invited to take part in this research study. The research study aims to better understand and improve contraceptive healthcare for people with intellectual disability. This part of the project will communicate with people with intellectual disability. We will ask the person you support questions about their experiences getting contraceptive healthcare.

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: Maryann Barrington, Julian Trollor, Patsie Frawley, and Tahli Hind from the National Centre of Excellence in Intellectual Disability Health (NCEIDH). The study will also be supported by external investigators: Clare Boerma (Family Planning Australia), Bronwen Merner (University of Melbourne), Janelle Weise (University of Sydney), and Karen Fisher (UNSW Sydney).

Research Funder: This research is being funded by a joint Australian Human Rights Institute and Disability Innovation Institute seed grant.

3. Inclusion Criteria

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

- 18 years of age or older

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

Participation as a support person 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?

NCEIDH are conducting interviews and focus groups with people with intellectual disability about their experiences with contraceptive healthcare. These interviews will also include demographic questions such as age and gender.

As a support person, your role is to sit in on the interview or focus group with the person with intellectual disability and help them to communicate in the best way possible with the researcher.

If you are supporting someone to participate in a focus group it is important to remember that information shared by people participating in focus groups must be kept confidential.

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.

Following the initial interview/focus group we will go through the interview recording and make note of the key points we believe were communicated by the person you support.

Additional Costs and Reimbursement: There are no costs associated with participating in this research study, nor will you receive any payment in your role as a support person.

Risks to Participants

Emotional Distress: The person you support may feel that some of the questions we ask are stressful or upsetting. If they do not wish to answer a question, they may skip it and go to the next question, or you may stop immediately. If the person you support/you become upset or distressed because of participation in the research study, the research team will be able to arrange for counselling or other appropriate support. Alternatively, a number of free contactable support services are included in section 11. 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.

Reputational Harm: The person you support may not want to answer some questions in front of their support person or in a focus group. Support them to identify if they would prefer to participate in an interview or focus group. Talk to them about what they can say if they do not want to answer a question in front of you (e.g., they can ask you to leave the room, they can ask to skip the question).

Risks to Guardians and Support Persons

Emotional Distress: You may feel upset or distressed by some of the questions asked, and some of the responses from the participant. If you are feeling distressed and want a break you can let the interviewer know. If you need to discontinue support in the interview, you can let the interviewer know.

Alternatively, a number of free contactable support services are included in section 11. 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.

6. 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.

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

By signing the consent form, you consent to the research team collecting and using information about you.

The research team will store the data collected from the person you support/you for this research study for:

- A minimum of 5 years after the publication of the research results;

The information about the person you support/you will be stored in a:

- Re-identifiable format where any identifiers such as their/your name, address, and date of birth will be replaced with a unique code.

Your information will only be shared for the purposes of this research in a format that will not identify you or the person you support.

- Information collected from you in an electronic format will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators.
- Information collected from you using paper-based measures will be stored in the NCEIDH, Biolink Building E25 UNSW, NSW 2052 and only the approved research investigators will have access to this information.
- Audio or video recordings 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.

The information the person you support/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](#).

8. 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.

Face to face interviews/focus groups will take place at UNSW Sydney.

Video conferences will take place over Microsoft Teams or Zoom. Interviews will take approximately 1 hour, while focus groups will take approximately 2 hours.

With your permission, the research team would like to audio record the interview/focus group. For interviews, if you do not want to be recorded but you would like to participate you can advise the research team and written notes will be taken (this is not possible for focus groups). The person you support/ you will also have the option to turn off the video during a video conference (interview or focus group). If video is recorded, this will be promptly deleted and only the audio file will be kept. 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. We will not transcribe or include your data in the analysis if you withdraw from the study.

Please note that if the person being interviewed consents to the 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.

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

10. What if I want to withdraw from the research study?

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 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 Sydney or the project team. You can request that any identifiable information about you be withdrawn from the research study.

If you decide to withdraw part way through a focus group, information already collected about you cannot be withdrawn given the nature of the focus group. However, we will not transcribe what you say or use your input in the data analysis.

11. 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
HC Reference Number	9229

12. 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 the person you support's involvement in the study, you can contact the following member/s of the research team:

Chief Investigator Details

Name	Maryann Barrington
Position	Senior Research Fellow
Telephone	02 9065 4445
Email	Maryann.barrington@unsw.edu.au

13. Support Services Contact Details

If at any stage during the study, the person you support/you becomes distressed or requires additional support from someone not involved in the research please call:

Name/Organisation	1800RESPECT
Telephone	1800 737 732
Website	https://www.1800respect.org.au/

Name/Organisation	Relationships Australia
Telephone	1300 364 277
Website	https://www.relationships.org.au/

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

Name/Organisation	Lifeline Australia
Telephone	13 11 14
Email	https://www.lifeline.org.au/

Consent Form

Declaration by the Support Person

- ☐ I understand I am being asked to provide consent to participate as a support person in this research study;
- ☐ I have read the Participant Information Statement, 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;
- ☐ I understand that the research team will audio/video record the interviews/focus groups; I agree to be recorded for this purpose.
- ☐ I agree not to disclose any information discussed during the interview/ focus groups and to maintain group confidentiality
- ☐ 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 understand that I will be given a signed copy of this document to keep.
- ☐ 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.

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 and the people and organisations involved in this project.

☐ 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. I understand the research team will not transcribe or include my data in the analysis if I withdraw from the study.

Participant Name

Name of Participant (please type)	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Dr Maryann Barrington
Email:	maryann.barrington@unsw.edu.au
Phone:	02 9065 4445
Postal Address:	National Centre of Excellence in Intellectual Disability Health Biolink Building E25 UNSW NSW 2052