Participant Information Sheet and Consent Form

People with Intellectual Disability

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?

You are invited to take part in this research. This research wants to understand attitudes about **contraception** for people with intellectual disability. Contraception is something that stops you from getting pregnant after sex. It is sometimes called birth control. This is important because research tells us that people with intellectual disability do not have equal access to contraception, and are not always included in decisions about their contraception.

Examples of contraception include:

- Oral pills that are taken each day
- An injection that is given once every 3 months
- An implant which is a small rod placed in the arm
- An intrauterine device which is a small device placed in the uterus

To understand attitudes about contraception for people with intellectual disability we are talking to people with intellectual disability who have had contraceptive healthcare. We will ask you to tell us about times when you have received contraceptive healthcare, for example asking your doctor about contraception or talking to your pharmacist about how to use contraception. We will ask things like:

1. Did you received enough information about your contraceptive options?
2. Did you feel respected and heard by your healthcare professionals?
3. Did you feel like you had a choice about your contraception?

Your experiences will be used to help us research how we can improve contraceptive healthcare for people with intellectual disability.

This is a consent form.

A **consent form** is when you give permission or agree something is okay.

If you want to be part of this study, you can read this consent form and sign it at the bottom.

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 at the National Centre of Excellence in Intellectual Disability (NCoE). We work as part of the Faculty of Medicine & Health at UNSW**.**

The study will also be supported by external investigators: Karen Fisher (UNSW Sydney), Janelle Weise (University of Sydney), Bronwen Merner (University of Melbourne), and Clare Boerma (Family Planning Australia).

Research Funder: This research is being funded by an Australian Human Rights Institute and Disability Innovation Institute Seed Funding Grant.

3. Inclusion Criteria

Before you decide to participate in this research study, we need to make sure that it is ok for you to take part. The research study is looking to recruit people who meet the following criteria:

- 14 years of age or older
- Lives in Australia
- Has an intellectual disability
- Has experience with contraceptive healthcare
- Understands what this research involves and can give informed consent

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. It is your choice.

If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

Withdraw means to leave the study.

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

- Read the information carefully and ask any questions;
- 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.

Screening: If you would like to participate and you consent, you will be asked to take part in a short telephone screening interview.

If you provide your consent to participate in the screening process, you will be asked to provide contact details to allow the research team to contact you and organise a time to complete the telephone interview (or you can call us).

We will ask screening questions that will determine if you are eligible to take part.

Completing the screening questions will take 1-2 minutes.

If you meet the criteria for inclusion, you will be able to participate in the research study and the research team will organise a convenient time for you to participate in the research.

If the screening questions show that you cannot be in the research study, we will destroy any information that has been collected about you.

Interview/focus group: If you agree to take part you will be asked to participate in an interview or focus group. You can choose if you would prefer to do an interview or a focus group.

A **focus group** is where you communicate in a group with other people.

Anything that is spoken about in the focus group must be kept confidential. This means you do not share the things people say in the group with other people outside the group.

During a face to face, telephone or video conferencing interview or focus group, we will ask you questions about yourself. This includes your age, your gender, and where you live.

After this, we will ask you questions about your experiences with contraceptive healthcare.

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 (or video record the interview if certain video conferencing platforms are used) 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). You will also have the option to turn off your 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.

Participants in interviews can withdraw and have their information destroyed. Because of the way in which the focus group discussions are recorded, the research team will not be able to destroy individual participant responses. However, we will not transcribe or include your data in the analysis if you withdraw from the study.

Additional Costs and Reimbursement:

There are no costs associated with participating in this research study.

You will receive an $80 Coles/Myer gift card voucher to reimburse you for any costs associated with participating in the study (e.g. pre-reading, time participating, travel (if in-person)).

Emotional Distress: You may feel that some of the questions we ask are stressful or upsetting.

Reputational Harm: You may not want to answer some questions in front of your support person or in a focus group.

If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If 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.

You can choose whether to bring a support person and who that support person is. You can ask them to leave the room for a question if you would prefer to answer it alone.

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 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 study 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, 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.

- 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 responses will be stored at the National Centre of Excellence in Intellectual Disability Health, 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 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**.

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 Sydney or the project team. 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.

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.

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
HC Reference Number	9229

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 members of the research team:

Chief Investigator Contact Details

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

11. 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	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
Website	www.beyondblue.org.au

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

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 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 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