

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.

About this sheet



This sheet has information about a research project.



To **research** means to do things to try to understand something in the world better.

This is done by asking questions and looking for answers.



This research wants to make **contraceptive healthcare** more inclusive for people with intellectual disability.



Contraceptives are things you can use to not get pregnant after sex.

It is sometimes called birth control.

Some types of contraceptives include:



- The **contraceptive pill** which is taken daily



- The **intrauterine device** or **IUD** which goes in the body



- The **contraceptive injection** which is a needle given every 3 months



- The **contraceptive implant** which is a small rod that goes in the arm.



You can ask someone you trust to help you understand this sheet.



We will ask at the bottom of this sheet if you consent to being a part of this study.

Consent is when you give permission or agree something is OK.

Who is doing the project



We work at the National Centre of Excellence in Intellectual Disability Health.



UNSW
SYDNEY

We are located at the University of New South Wales Sydney.



Our team includes:

- Maryann Barrington



- Tahli Hind



The study will also be supported by other researchers:

- Julian Trollor
- Patsie Frawley
- Karen Fisher
- Janelle Weise
- Bronwen Merner
- Clare Boerma

Who can take part in this project



People who are 14 or older.

If you are younger than 18 a parent or guardian must be present.



A **guardian** is a person who helps you make decisions about parts of your life when you cannot make decisions by yourself.



People who live in Australia.



People with Intellectual Disability.



People with experience with contraceptive healthcare.



People who know what this research is about and can give **consent** to participate.

What will happen if you take part



We will ask you to call us and answer some questions.

These questions are to check if you can take part in the project.



If you want to help us with this project you can choose how we will ask you about your ideas.



To take part you can

- Have an interview

Or

- Communicate in a group



To **communicate** is how you understand and share your feelings or information.



If you choose to communicate in a group there will be about 3 other people with intellectual disability in the group.



You might want to take part in one or more of the ways below

- By yourself
- With a support person
- With other people who have intellectual disability

A support person might be a

- Family member
- Friend
- Support worker



It will take about 1 to 2 hours.



We will ask you about your experience with contraceptive healthcare.

You can choose how you take part.

You can take part in one of the ways below

- In person at UNSW Sydney
- By phone
- Online using programs like Zoom



- In a different way that works for you like drawing



We will try to communicate in a way that suits you.

What we will ask you about



We will ask you questions about your:

- Age
- Gender
- Where you live (a city or somewhere rural)



We will ask you about the information you were given about contraceptives.



For example, did you think the information you were given was helpful?



We will ask you if you think that your doctor listened to you and respected you.



We will ask if you felt like you had a choice about your contraception.



We will ask you what things can make contraceptive healthcare more inclusive.



You only have to take part if you want to.

You can say no.

It is your choice.



We will ask to record what you let us know.

To **record** is a way to save something to look at or listen to again later.



It is OK if you do not want us to record you.

If you do not want us to record you can

- Let us know
- Still be part of the study

We will write down what you tell us.



If you choose to communicate in a group we must record it.



Anything that is shared in the group must be kept **confidential**.

Confidential means that you do not share things people say in the group with other people outside the group.



If you use communication aids to help you to communicate, we will ask to take photos of these aids.



If we meet in person we will decide where we will meet beforehand.



We will meet in a room at 3DN UNSW Sydney.
We are located at UNSW Sydney in Kensington.

We will give you directions to the room.



You will get an \$80 Coles/Myer gift card to say thank you.

Do you have to take part



You only have to take part if you want to.

You can say no.

It is your choice.

No one will be angry if you say no.



If you decide to help us with the project you can

- Stop at any time
- Leave the project at any time



If you decide to take part in our study some questions might make you feel upset or stressed.

You do not have to answer a question if you do not want to.

You might not want to share information in a group.



You can choose an interview if you prefer.



If you choose to have someone support you there might be questions that you do not want to answer in front of them.

You do not have to answer a question you do not want to.

You can ask them to leave the room for the question if you want to.

You can choose the person you want to bring to support you.

What will happen to my information



We will store your information at UNSW on our computers.

We will keep your information for 5 years.



The computers have a password.

Only the researchers in this project will know the password.



A **researcher** is a person who tries to understand something in the world better.

They do this by asking and looking for answers to questions.



We will keep your information private.

To keep **private** means other people cannot see or hear things about you that you do not want them to know.



We will only share your personal information if

- You say it is OK

- You or other people are in danger
- The law says we must



We will write about what we find out from the interviews and communications in a group.

If you want we can send you a summary of what we find out.

Where to get more information about the project



If you have question or want to join the project contact Maryann Barrington.

Maryann is a researcher on the project.



To contact Maryann

- Call **02 9065 4445**
- Email maryann.barrington@unsw.edu.au



For more information go to [insert webpage]



If you are not happy with the way the project is being done you can make a complaint.

A **complaint** is when you tell someone you are not happy with something.

To make a complaint contact a Human Research Ethics Coordinator.



Human Research Ethics Coordinator is person who will

- Listen to your complaint
- Find out what happened

They are called a HREC for short.

When you make a complaint you will need to tell the HREC the ethics number for this project.



The ethics number for this project is: iRECS9229.

This number lets the HREC know which project you want to make a complaint about.

To make a complaint

- Call **9385 6222**
- Email **humanethics@unsw.edu.au**





You can ask one of our researchers for support to make a complaint.

They can help you or find someone to help you make a complaint.

You will not get in trouble if you make a complaint.



If you feel upset after taking part in the project you can communicate with someone who supports you.



You can also get help and advice from organisations who give help over the phone and online.

Below is a list of some of these organisations.

1800RESPECT
NATIONAL SEXUAL ASSAULT, DOMESTIC
FAMILY VIOLENCE COUNSELLING SERVICE

1800 Respect

Call on **1800 737 732** any time of the day.

Text **0458 737 732** any time of the day.

Chat online any time of the day:

<https://www.1800respect.org.au/>



Relationships Australia

Call on 1300 364 277 any time of the day



Lifeline Australia

Call on **13 11 14** any time of the day.

Text **0477 13 11 14** 12 noon to 6am.

Chat online on <https://www.lifeline.org.au/crisis-chat/>
12 noon to 6 am.



Beyond Blue Support Service

📞 1300 22 4636

✉ Email or 💬 chat online

beyondblue.org.au/getsupport

Beyond Blue

Call on **1300 22 4636** at any time of the day.

Chat online on

<https://www.beyondblue.org.au/support-service/chat>

1 pm to 12 midnight.



NSW Mental Health Line

If you need to speak with a mental health worker you can ring the NSW Mental Health Line on **1800 011 511** any time on any day.



If you are in a crisis

- Call **000** for an ambulance or the police

Or

- Go to an emergency department at a hospital



A **crisis** is when you are in danger or are very upset.

You are in **danger** if you could be hurt or injured.



If you have a hearing impairment you can contact these organisations through the National Relay service.



To use the the National Relay service call **133 677**.

For Speak and Listen phone call **1300 555 727**.

Consent form



Below is a consent form.

If you want to take part in this project please fill in the form.

You can put a ☐ or a ☒ in each box if you agree with what the sentence says.

I want to take part

Developing a model of preventive care for people with intellectual disability



I am signing this form because I

- Understand what this research is about
- Want to take part

I have read the information above about this project or someone has explained this project to me.

☐ Yes ☐ No

I understand that I can change my mind later and not be in the project anymore.

☐ Yes ☐ No

I want a support person to be in the interview or group with me.

☐ Yes ☐ No

I want the researchers of this project to let me know what they find out from this project.

☐ Yes ☐ No

I have been able to ask questions and I am OK with the answers I got.

☐ Yes ☐ No

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

☐ Yes ☐ No

You can select ☒ **Yes** to both email and phone for these choices.

I want to be contacted by email.

☐ Yes ☐ No

Or

I want to be contacted by phone.

☐ Yes ☐ No

Please select ☒ **Yes** for only 1 of these choices

I want to be in an interview.

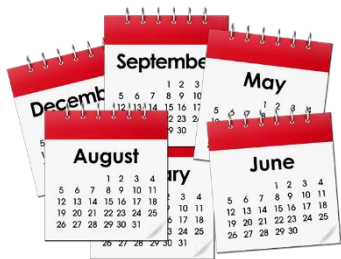
☐ Yes ☐ No

I want to communicate in a group.

☐ Yes ☐ No



My signature is



The date today is



My phone number is

I can use the phone on my own.

☐ Yes ☐ No



The address I like things to be posted to me is



My email address is

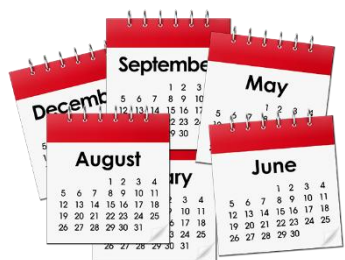
I understand that the researchers will only use my contact details

- For me to take part in the research
- To let me know what they find out afterwards

☐ Yes ☐ No



A **witness** is someone who saw you sign the form.



Witness signature

The date today is

I do not want to take part anymore

Sexual and reproductive rights for people with intellectual disability



I am signing this form because I do not want

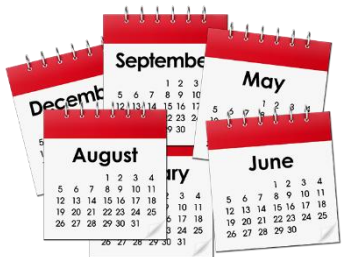
- To take part in this project anymore
- The researchers to use what I said

If I communicated in a group I understand that the audio I gave cannot be destroyed.

☐ Yes ☐ No



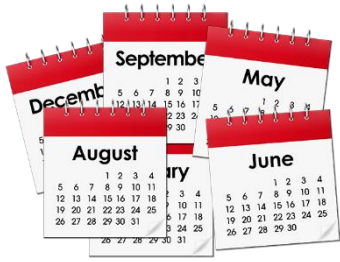
My signature is



The date today is



Witness signature



The date today is

Where to send this form



Send this form to

Dr Maryann Barrington
NCEIDH, UNSW
Rm 241 Biolink Building E25
UNSW, NSW, 2052



Or email this form to maryann.barrington@unsw.edu.au



You can also call us to tell us you do not want to take part anymore.

Call us on 02 9065 4445

