

Sexuality for People with Intellectual Disability: A Two-Part Study

Meet our team!



Hello! Our names are:

- **Roxanna** Pebdani. Head researcher of the study.
Email: Roxanna.pebdani@sydney.edu.au
- **Mary Ann** O'Donovan Co-Investigator of the study.
Email: mary-ann.odonovan@sydney.edu.au
- **Margaret** McGrath. Co-Investigator of the study.
Email: Margaret.McGrath@sydney.edu.au
- **Ava** Levin. Honours student who will be asking you your interview questions.
Email: Alev9098@uni.sydney.edu.au
- Fang Qi "**Ashleigh**" Hoo. Honours student who will be going through the survey with you.
Email: fhoo5190@uni.sydney.edu.au

1. What is this about?



We are doing a study about Sexuality. This study will have three pathways for you to **choose** from:



Pathway One: A survey. This involves completion of the ISK-ID, an assessment tool about your sexual knowledge. You can choose to either:

- Complete the survey online by yourself.
- Complete the survey over the phone or virtually with the student researcher, either Ash or Ava.
- Complete the survey in person with the student researcher, either Ash or Ava.

The survey must be administered twice around two weeks apart and you must complete it the same way you did the first time.



Pathway Two: A one on one interview run by Ava, where we discuss your experiences with sexuality. You can choose to complete this interview either:

- In person with student researcher, Ava.
- Virtually with student researcher, Ava.

Pathway Three: Involvement in **both** the survey (pathway one) and the interview (pathway two).

If you are interested in either pathway, you need to be over the age of 18 and identify as having an intellectual disability. You will be asked to answer questions about dating, sex, intimacy, attraction, sexual orientation, body image, sexual practices, sexual health and homosexuality.

You can choose to take part in this study, but you don't have to.

This sheet will tell you more about what will happen so you can make up your mind.



If you have any questions, you can email us.

2. What will happen if I say yes?



- After you have entered your details into our system using the QR Code, you will be contacted by email where we will talk about the pathway options of the study that you are interested in engaging in.
- If you are still happy to take part and have confirmed which pathway you wish to take part in, we will ask you to confirm whether you wish to complete the survey online, virtually or in person and whether you wish to partake in the interview, and if so, virtually or in person. Based on your answer we will then arrange for a time and place to meet so you can perform the study you have provided interest in. Should you be interested in Pathway Three, we will confirm whether you are happy to perform the survey in the morning and engage in the interview section in the afternoon or organise a separate day.

- You will then be provided with a link or QR Code to our informed consent form and patient information statement.
- A week before you meet with Ava or Ashleigh, you will receive a reminder via email of the time and place.
- When you arrive at the place of meeting, you will be provided with another informed consent form on the researcher's iPad.

Pathway One:

- Do it yourself option: You will complete the survey online by yourself. Once completed, we will be notified and we will be in contact with you in two weeks time to remind you to complete this for the second time.
- Virtual or phone option: Ashleigh or Ava will Email you before we call you off a "no caller" number to complete the survey with you over the phone. Alternatively, we will email you a ZOOM link and complete the survey with you virtually. This option involves the student researcher to read out the questions and have you answer them verbally.
- In person options: Ash or Ava will email and call you to remind you of your meeting. One of them will then meet you at the designated time and place where they will read out the questions of the survey to you and you will respond with your answer. This will be in a private room with only yourself and the honours student, unless you prefer to have a support person present to observe. That is up to you.
- The survey will take no longer than an hour.
- Two weeks later, we will do this again.

Pathway Two:

- Ava will email and call you to remind you of your meeting. She will then meet you at the designated time and place where she will be asking you questions based on your experiences with sexuality. This interview will only involve yourself and the honours student in this private room unless you have requested for a support person to be present to observe. This is up to you.

- The interview will take no longer than 1.5 hours.

Pathway Three:

- If you are interested in taking part in **both** the survey and the in-person interviews, you will be asked if you have a preference of performing these meetings in one day or booking them over two days. Should you decide to book in your survey part of the study in the morning and the interview section in the afternoon, there will be a short break where light refreshments will be made available to you by the research student so you don't get hungry or tired.

If you decide you want to be in our study, this is what will happen:

- You will be sent a consent form.
- You will be sent a patient information statement.
- You will be contacted to organise a meeting for the survey and/or an interview.
- You will answer the questions from the survey and/or the interview.

When we ask you questions you can choose if you want to answer. If you don't want to talk about something, that's ok. You can stop talking to us at any time if you don't want to talk to us anymore.

If you say it's ok, we would like to record what you say with an audio recorder so we can remember what we talk about.

3. What are the good or bad things about the study?



The study will take up some of your time, but we don't think it will upset you or cost you anything. If you do get upset during the interview, please tell us and know that we will help you feel better.

4. What are your rights?



Whatever we see today and what you tell us is private. We will write about the things we learn from you, but we won't use your name and we won't say anything that could tell other people who you are. For the interview part of the study, you will be asked to choose a fake name of your choosing, so we use a different name for you to identify with.

If you change your mind that's ok. It won't change how we feel about you. All you have to do is tell us you don't want to be part of the study anymore and we won't use anything you tell us.

This would need to happen before we finish the report about the study.

It is important to know that, just like teachers and doctors, we might have to report things that make us believe you or others around you are at risk of being in danger or harm.

If you have any questions about the study, you can talk to:

- Roxana: Roxanna.pebdani@sydney.edu.au
- Ava: alev9098@uni.sydney.edu.au
- Ashleigh: hoo5190@uni.sydney.edu.au

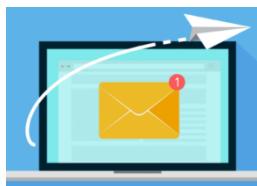
5. What if I am not happy about the study?



If you are not happy with how we are doing the study and want to contact someone else, you can:



Call the University: 02 8627 8176



Email the Manager: human.ethics@sydney.edu.au

6. What if I am upset and need further help?

If you become upset during or after the study, you can call one of these numbers for support:

13 11 14 – LifeLine

8585 0333 – FullStop Australia

This sheet is for you to keep