

Participant Information and Consent Form

What does ‘accessible knowledge exchange’ involve?



This sheet has information about research you can be part of.

Research means finding out what people think about things and using the information to help other people.



The sheet is to help you decide if you want to take part.



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

What is the research about?



We want to find out about what it means to share information and knowledge about the health of people with intellectual disability in accessible ways.



We will use what we find out to make a Knowledge Exchange Hub. It will be a place to share information about the health of people with intellectual disability.



We are asking you to take part because you are part of the Knowledge Exchange Hub Advisory Group at the National Centre of Excellence in Intellectual Disability Health.

Who is doing the research?



We are a research team from UNSW.

The people in the team are:



Ariella Meltzer



Patsie Frawley



Grace Sharkey



Rory Keyes



Jen Xiang

How can I be involved in the research?



We will invite you to be part of 4 focus groups.

A focus group is a group discussion.



You do not have to be part of all 4 focus groups. You can choose how many you want to do.



You can choose which questions to answer. You can say no if you don't want to answer a question.

What will the focus groups be about?

The focus groups will be about what it means to share information and knowledge about the health of people with intellectual disability in accessible ways.



Group 1. Who uses information about health and how it is made



Group 2. How information about health is given to people and used by them



Group 3. What makes information about health trustworthy and useful for taking action



Group 4. Checking our findings with you.

What happens if the focus groups are upsetting?



We won't ask personal questions in the focus groups. Some people might still find some questions upsetting or stressful.

If you feel upset, you can:



- Stop taking part.
- Skip a question.



- Take a break and come back.



- Ask the researchers for help finding support.



- Contact a support service. Some contact details are at the end of this sheet.

What else do I need to know about the focus groups?



Each focus group will take 1 ½ hours.



The focus groups will be on Teams.



We will record what you say.
Because it is in a group, there is
no option to take notes instead.



If you want to, you can bring someone you trust to help you.



If you are not being paid by another organisation to take part, we will pay you \$75 for each focus group you do.



We can pay the money into your bank account or as a gift card.

Do I have to take part?



You only have to take part if you want to.

You can say no. It's your choice. No one will be angry if you say no.

Even if you say yes, you can change your mind later and stop taking part.

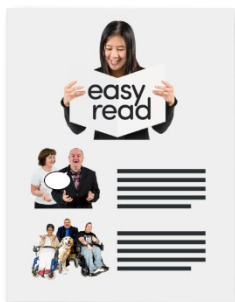
What will happen to my information?



We will store your information at UNSW for 5 years.

We will keep your information private.

No one will know it was you who took part.



We will write about what we find out.

We will send you a summary.

Who can I get in touch with about the research?

If you have any questions, get in touch with:



Grace Sharkey

(02) 9065 9761

g.sharkey@unsw.edu.au



Ariella Meltzer

(02) 8936 0910

a.meltzer@unsw.edu.au



If you want to complain about the research, get in touch with the Human Research Ethics Coordinator at UNSW. It is their job to listen to you and find out what happened.

Phone: (02) 9385 6222

Email: humanethics@unsw.edu.au

Tell them this number: iRECS####

Who can I get in touch with for support?

If you feel upset from taking part, you can talk to some who supports you. You can also call:



My Lived iD

www.mylivedid.org.au/mental-health-services/



SANE Australia

1800 187 263



Blue Knot Helpline

1300 657 380



13 YARN

13 92 76



I want to take part

What does 'accessible knowledge exchange' involve?

I am signing this form because I understand about the research and I want to take part.

My signature:

Date:

My phone number:

My email address:

I understand that you will only use my contact details for me to take part in the research and to tell me about the findings afterwards.

Witness signature:

Date:

A witness is someone who saw you sign the form.



I don't want to take part anymore

What does 'accessible knowledge exchange' involve?

I am signing this form because I changed my mind. I don't want to take part anymore and I don't want you to use what I said.

My signature: _____

Date: _____

Witness signature: _____

Date: _____

A witness is someone who saw you sign the form.

Send this form to:

Ariella Meltzer

a.meltzer@unsw.edu.au

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