

International Centre for Future Health Systems, Faculty of Medicine
and Health



ADMINISTERED QUESTIONNAIRE PARTICIPANT INFORMATION STATEMENT

PEOPLE WITH INTELLECTUAL DISABILITY

Know Me, Support Me: AI reasoning tool for identifying and managing health issues of people with intellectual disability - Consultation and Co-design

CI-Associate Professor Margo Barr

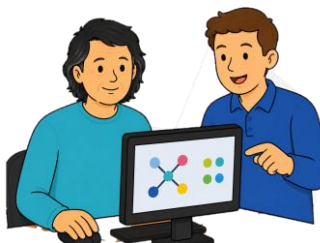
EASY READ VERSION

1. What is this study about?



We are doing a research study.

We want to make a new computer tool (AI)



This tool will help:

- People like you with intellectual disability
- Your carers and family



The tool will help people:

- Notice when your health is getting worse
- Help you get help sooner

Sample



We want to ask you some questions

We are asking you because:

- You are a person with intellectual disability
- You have lived experience
- Your ideas are important



We are also talking to people who:

- Support people with intellectual disability
- Work in health or disability services

Sample

2. Who is doing the study?



Study is led by Margo Barr at the University of New South Wales (UNSW) with researchers and health and disability service providers across Australia.



The study is paid for by the government

3. Who can take part?



You can take part if you are a person with Intellectual disability

4. Do I have to take part?



No

It is your choice. You can say no

If you say No, nothing bad will happen



5. What will I do if I take part?



If you say yes you will:

- Read this page
- Ask questions
- Do a survey

You will:

- Answer questions in a survey
- It takes about 15 minutes

We will ask about:

- Your experiences
- Your ideas

Some questions might make you feel upset.

Sample

What are the benefits?



This study may help people with intellectual disability:

- Get better care
- Get hep sooner

7. What happens to my information?



If you do the survey:

You are saying YES to take part



Your information will be anonymous (no name).

This means no one knows it is you.



Your information will:

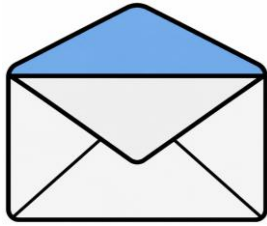
- Be kept safe
- Kept for 7 years
- May be used in future research

8. How will I get the results?



We will:

- Write reports
- Publish results



No one will know it is you

If you want us to send you the results

Give your email address

9. Can I stop?



Yes, you can stop anytime

Just ask for the person to stop asking you questions

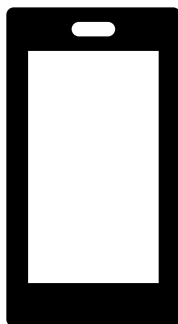
If you stop early:

- your answers are deleted

If you finish and submit:

- We cannot remove answers
- Because we do not know which one is yours

10. Who can I talk to?



Contact:

Margo Barr

02 9065 6041

margo.barr@unsw.edu.au

Contact a support service

Disability Gateway

1800 643 787

disabilitygateway@benevolent.org.au



Complaints

You can complain if needed:

+61 2 9385 6222

humanethics@unsw.edu.au



If you say yes to the questions:

And we start the survey”

It means:

I understand the study

I agree to take part

I can stop anytime

My answers are anonymous

I won't be asked to say yes again for this part

I can choose to say yes to other parts later

Optional (your choice)

☐ Send me results

☐ Use my data in future research



Your details (optional)

Name: _____

Address: _____

Email: _____