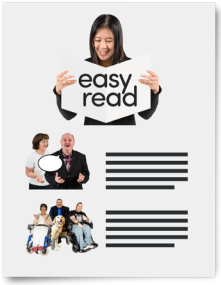
My Health Choices My Way

PARTICIPANT CONSENT FORM



The full name of this document is Participant information statement and consent form for families, carers and supporters of people with intellectual disability (Step 1)



It has information about a **research** study called

- My Health Choices My Way



Research means finding out

- what people think about things
- using the information to help other people.



You can ask someone you know and trust

- to support you to understand this information.

Who is doing the research



Iva Strnadová

- I am a researcher at the University of New South Wales.
- I am a Board member at Self Advocacy Sydney Inc.



Emma Palmer

- I am a researcher at the University of New South Wales.



Mrs Julie Loblinzk Refalo OAM

- I am a researcher at the University of New South Wales
- I am a Board member at Self Advocacy Sydney.

What we want to find out



- What you think about **moving to adult health care**
- How do you think it should be done



And, for people who care for or support someone who **moved to adult health care**

- What it was like to have **moved to adult health care**



Moving to adult care means the young person:

- stops seeing children's doctors
- starts seeing adult doctors



They make more choices. They may:

- book appointments
- ask questions

- decide about their own care.

What we will do



We will ask you questions in person or online.



You can choose to talk one-on-one.

Or you can choose to join a focus group.



You can also choose how to talk to us.



We will ask to record what you say.

- If you do not want us to, that is OK.



A trusted person might

- listen to the recording
- type the words people said.

This helps us remember what people said.



The trusted person will keep the information private.



UNSW ChatGPT-edu might

- listen to the recordings
- help us type the words people said.

UNSW SYDNEY x ChatGPT Edu

UNSW ChatGPT-edu is an **artificial intelligence** tool.

It will be used only to type the words people said.



Artificial Intelligence (AI) is how computers have learnt to

- answer questions
- do some tasks that people do.



UNSW ChatGPT-edu will not use the recording

- for training
- for any other purpose.



The University of New South Wales will keep the recording safe.

You can read more about

- how ChatGPT-edu keeps information safe here:
- https://openai.com/enterprise-privacy/



You can change your mind about being in a focus group.



If you leave the group

- we cannot remove you from the recording
- because the group conversation is recorded together
- but we will not use what you said in our study.



You can choose which questions to answer.

- It is OK to not to answer a question.

We will talk with you for 30 – 90 minutes.





Your personal information will be private.



If you want we can send you

- An Easy Read summary of what we find.



We will give you a gift card

- as a thank you for your time.

Who we want to talk to



People who have a family member with intellectual disability

This includes

- parents
- siblings



- grandparents



People who

- support a person with intellectual disability
- or are their legal guardians



People who

- are 18 years or older
- live in Australia.



You can have someone you trust,

- come to the interview

It is your choice.



For example you may choose for

- your parent or
- your friend

to join you.

If you want to take part



If you want to, you can take part in this study.

You can say no - it is your choice.



No one will be angry if you decide

- you do not want to do it.



Even if you say yes

- you can change your mind later.



Please read this information

- or have someone read it to you
- so you can understand.



Please check that you understand

- what will happen during the study
- and why it is happening.



Make sure that you

- ask questions if you want to.



Please know that you can keep a copy of this form.



Your information will be private.

No one will know it was you who took part.



If you want to take part

- please sign the consent form

We will then contact you.

If you have any questions



You can get in touch with Iva Strnadová

- Phone 02 9065 1627
- Email i.strnadova@unsw.edu.au

If you want to complain



You can get in touch with the Human

Research Ethics Coordinator

- Phone: (02) 9385 6222
- Email: humanethics@unsw.edu.au



Tell them this number 10582.

It is their job to listen to you

- and find out what happened.

If you feel upset



There is a small chance that some questions

- might make you feel upset or sad.



If that happens you can

- ask to skip the question

- leave the meeting.



If you are upset you can talk to some who supports you or call



- Beyond Blue on 1300 224 636
- People with Disability Australia on (02) 9370 3100
- Kids Helpline on 1800 55 1800
- 13Yarn (Aboriginal or Torres Strait Islander Crisis Support Line) on 139276



We will also check on you later



and we can arrange

- for you to talk to a health worker.

My Health Choices My Way

I want to take part



I am signing this form because

- I understand about this research
- I want to take part.



I agree to

- ❑ My interview or focus group being audio recorded
- ❑ Secure UNSW ChatGPT-edu being used to type up the recording.



My signature

_____



Date

_____



My phone number

_____



My address

_____



My email address

_____



I understand that you will only use my contact details

- for me to take part in the research
- to tell me about what you find out afterwards.



Witness signature

_____



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

_____



Date

_____

My Health Choices My Way

I do not want to take part



- I do not want to take part.
- I do not want you to use what I said
- I signed this form as I changed my mind.



My signature

_____



Date

_____



Witness signature

_____



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



Date

_____



You can sign the form online or download and send it to

- i.strnadova@unsw.edu.au

OR

- mail it to

Professor Iva Strnadová

School of Education, Faculty of Arts, Design and Architecture

Morven Brown G23

UNSW SYDNEY 2052

<<The participant will have the option to provide digital consent and personal information in Qualtrics or to download the form and email to Iva Strnadova>>