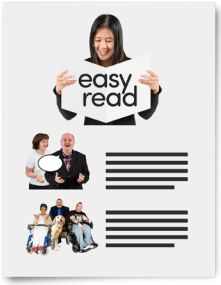
My Health Choices My Way

PARTICIPANT CONSENT FORM



The full name of this document is Participant information statement and consent form for people with intellectual disability (Step 1 Part 2: Interviews and focus groups)



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 have **moved to adult health care**

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



Moving to adult care means:

- you stop seeing children's doctors
- you start seeing adult doctors



You make more choices. You may:

- book appointments
- ask questions
- decide about your 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.



You can also take part by

- **Body mapping**
- **Photovoice**



Body mapping is when we draw an outline of your body

- you can draw on and around the outline
- about your experiences
- we will then talk to you about
- what you have drawn.



Photovoice is when you can

- choose photos that show your feelings and experiences.



We will ask to record what you say.

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



A trusted person will

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

This helps us remember what people said.



The trusted person will keep the information private.



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 – 120 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 with intellectual disability who are

- aged 12-28 years
- 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

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



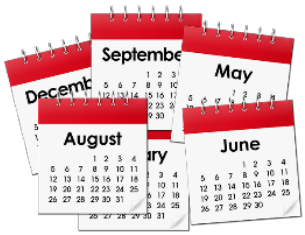
I am signing this form because

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



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

_____



Send this form 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