



UNSW
Department of Developmental
Disability Neuropsychiatry



Participant Information Sheet and Consent Form

Developing a model of preventive health care for people with intellectual disability



This sheet has information about a research project.

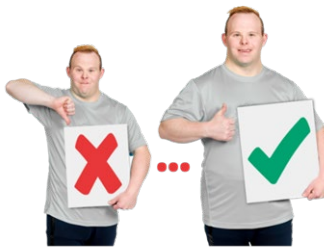


To **research** means to do things to try to understand something in the world better.

This is done by asking questions and looking for answers.



This research wants to make it easier for people with intellectual disability to get and use information about staying healthy.



Information about staying healthy can include things that tell you about:

- How to keep feeling healthy.
- How to get better when you are sick.



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



We will ask at the bottom of this sheet if you consent to being a part of this study.

Consent is when you give permission or agree something is OK.

Who is doing the project



We are a group called the Department of Developmental Disability Neuropsychiatry (or **3DN**).



We are a group who wants to improve the health of people with intellectual disability.

The University of New South Wales is part of this group.

My name is Janelle Weise.



I work at the University of New South Wales.

I am working with other people at the University of New South Wales.

These people are



Maryann Barrington



Tahli Hind



Susan Adrian

The study will also be supported by other investigators: Julian Trollor, Ben Harris- Roxas, Catherine Spooner and Karen Fisher.

Who can take part in this project



People who are 14 or older.

If you are younger than 18 a parent or guardian must be present.



A **guardian** is a person who helps you make decisions about parts of your life when you cannot make decisions by yourself.



People who live in Australia.



People with Intellectual Disability.

What will happen if you take part



We will ask you to call us and answer some questions.

These questions are to check if you can take part in the project.



If you want to help us with this project you can choose how we will ask you about your ideas.



To take part you can

- Have an interview

Or

- Communicate in a group



To **communicate** is how you understand and share your feelings or information.



If you choose to communicate in a group there will be about 3 other people with intellectual disability in the group.



You might want to take part in one or more of the ways below

- By yourself
- With a support person
- With other people who have intellectual disability

A support person might be a

- Family member
- Friend
- Support worker



It will take about 1 to 2 hours.



We will ask you about your experience finding and using information to stay healthy.

You can choose how you take part.

You can take part in one or more of the ways below

- In person at UNSW Sydney
- By phone
- Online using programs like Zoom



- In a different way that works for you like drawing



We will try to communicate in a way that suits you.

What we will ask you about



We will ask you to tell us about times when you have looked for information about staying healthy.



We will ask you about how you look for and find information about staying healthy.



We will ask you about the things that help you understand information about how to stay healthy.



We will ask you about how having information about staying healthy helps you.



We will ask you about how we can make information about staying healthy better for people with intellectual disability.



You only have to take part if you want to.

You can say no.

It is your choice.



We will ask to record what you let us know.

To **record** is a way to save something to look at or listen to again later.



It is OK if you do not want us to record you.

If you do not want us to record you can

- Let us know
- Still be part of the study

We will write down what you tell us.



If you choose to communicate in a group we must record it.



If you use communication aids to help you to communicate, we will ask to take photos of these aids.



If we meet in person we will decide where we will meet beforehand.



We will meet in a room at 3DN UNSW Sydney.
3DN is located at UNSW Sydney in Kensington.

We will give you directions to the room.



You will get a \$50 gift card to say thank you.

Making sure we understand your ideas



After this meeting, we will think about what you told us.



Then we will ask you to meet with us again.



In this second meeting we will ask you to give us feedback about how we talk about your ideas.

This second meeting might be a few months after the first meeting.



You can let us know if we understood your ideas.



You can let us know if we did not understand your ideas.

Do you have to take part

You only have to take part if you want to.



You can say no.

It is your choice.

No one will be angry if you say no.



If you decide to help us with the project you can

- Stop at any time
- Leave the project at any time

What will happen to my information



We will store your information at 3DN UNSW on our computers.

We will keep your information for 5 years.



The computers have a password.

Only the researchers in this project will know the password.



A **researcher** is a person who tries to understand something in the world better.

They do this by asking and looking for answers to questions.



We will keep your information private.

To keep **private** means other people cannot see or hear things about you that you do not want them to know.



We will only share your personal information if

- You say it is OK
- You or other people are in danger
- The law says they must



We will write about what we find out from the interviews and communications in a group.

If you want we can send you a summary of what we find out.

Where to get more information about the project



If you have question or want to join the project contact Maryann Barrington.

Maryann is a researcher on the project.



To contact Maryann

- Call **02 9065 4445**
- Email maryann.barrington@unsw.edu.au



For more information go to

<https://www.3dn.unsw.edu.au/projects/nhmrc-partnership-project-preventive-healthcare-people-intellectual-disability>



If you are not happy with the way the project is being done you can make a complaint.

A **complaint** is when you tell someone you are not happy with something.

To make a complaint contact a Human Research Ethics Coordinator.



Human Research Ethics Coordinator is person who will

- Listen to your complaint
- Find out what happened

They are called a HREC for short.

When you make a complaint you will need to tell the HREC the ethics number for this project.



The ethics number for this project is **IRECS6158**.

This number lets the HREC know which project you want to make a complaint about.

To make a complaint



- Call **9385 6222**
- Email **humanethics@unsw.edu.au**

You can ask one of our researchers for support to make a complaint.



They can help you or find someone to help you make a complaint.

You will not get in trouble if you make a complaint.



If you feel upset after taking part in the project you can communicate with someone who supports you.



You can also get help and advice from organisations who give help over the phone and online.

Below is a list of some of these organisations.

Lifeline Australia



Call on **13 11 14** any time of the day.

Text **0477 13 11 14** 12 noon to 6am.

Chat online on <https://www.lifeline.org.au/crisis-chat/>
12 noon to 6 am.

Beyond Blue



Beyond Blue Support Service

☎ 1300 22 4636

✉ Email or 💬 chat online
[beyondblue.org.au/getsupport](https://www.beyondblue.org.au/getsupport)

Call on **1300 22 4636** at any time of the day.

Chat online on

<https://www.beyondblue.org.au/support-service/chat>

1 pm to 12 midnight.



Mens Line Australia

Call on **1300 78 99 78** at any time on any day.

Chat online on <https://mensline.org.au/phone-and-online-counselling/> at any time on any day.

NSW Mental Health Line



If you need to speak with a mental health worker you can ring the NSW Mental Health Line on **1800 011 511** any time on any day.



If you are in a crisis

- Call **000** for an ambulance or the police

Or



- Go to an emergency department at a hospital



A **crisis** is when you are in danger or are very upset.

You are in **danger** if you could be hurt or injured.



If you have a hearing impairment you can contact these organisations through the National Relay service.



To use the the National Relay service call **133 677**.

For Speak and Listen phone call **1300 555 727**.

Consent form



Below is a consent form.

If you want to take part in this project please fill in the form.

You can put a or a in each box if you agree with what the sentence says.

I want to take part

Developing a model of preventive care for people with intellectual disability



I am signing this form because I

- Understand what this research is about
- Want to take part

I have read the information above about this project or someone has explained this project to me.

Yes No

I understand that I can change my mind later and not be in the project anymore.

Yes No

I want a support person to be in the interview or group with me.

Yes No

I want the researchers of this project to let me know what they find out from this project.

Yes No

I have been able to ask questions and I am OK with the answers I got.

Yes No

I understand I will be given a signed copy of this form to keep.

Yes No

You can select **Yes** to both email and phone for these choices.

I want to be contacted by email.

Yes No

Or

I want to be contacted by phone.

Yes No

Please select **Yes** for only 1 of these choices

I want to be in an interview.

Yes No

I want to communicate in a group.

Yes No



My signature is



The date today is



My phone number is

I can use the phone
on my own.

Yes No



The address I like things to be posted to me is



My email address is

I understand that the researchers will only use my
contact details

- For me to take part in the research
- To let me know what they find out afterwards

Yes No



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



Witness signature



The date today is

I do not want to take part anymore

Developing a model of preventive health care for people with intellectual disability



I am signing this form because I do not want

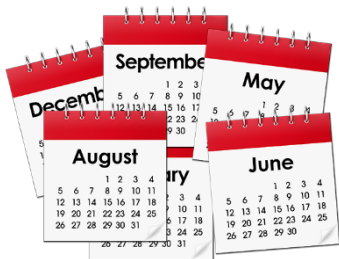
- To take part in this project anymore
- The researchers to use what I said

If I communicated in a group I understand that the audio I gave cannot be destroyed.

Yes No



My signature is



The date today is



Witness signature



The date today is

Where to send this form



Send this form to

Dr Janelle Weise
3DN, UNSW
Rm 241 Biolink Building E25
UNSW, NSW, 2052



Or email this form to j.weise@unsw.edu.au



You can also call us to tell us you do not want to take part anymore.

Call us on **02 9065 9915**

