



Participant Information and Consent Form

This sheet has information about research called
The impact of the Easy Read format on comprehension of health information by people with intellectual disability

The research is about finding out how information can be shown to people with intellectual disability so that they can learn and understand the information better.

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

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

Who is doing the research? What is it about?



My name is Ellen Lee.

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



The University of New South Wales is also called **UNSW**.



I am working with Jenna Zhao.



I am also working with Janelle Weise.



We want to find out how we can show information to people with intellectual disability to help them learn and understand the information better.

Who can take part in the research?



You can take part in the research if you

- Have an intellectual disability



- Are 18 years old or over



- Are able to read simple English

Simple English means short sentences with words that are not hard.



- Live in Sydney and can come to UNSW to be part of the research



You cannot take part in the research if you

- Have vision problems that stop you from being able to read information in simple English



- Need support from another person to read information in simple English

What does taking part involve?

Taking part involves answering some questions in person at UNSW.



We will ask you about your age and your gender.

We will also ask you what you know about some health topics.

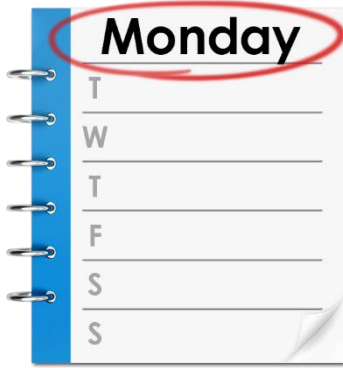


We will also ask you to read and learn some information in simple English.



We will ask you to come to UNSW to answer questions and read information 2 times.

There will be 1 week in between each time.



For example if you visit us on Monday at 9am the first time, you will visit us a second time on Monday at 9am the next week.



We will ask you about

- What you know about some health topics



- What you did to learn the information we asked you to read



You can choose which questions to answer.

You can say no if you do not want to answer a question.



We will ask to record what you say.



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

You can write down your answers instead.



If you do not want to write down your answers, we can take notes instead.



The research will take about 1 hour each time.



If you come to do the research 2 times, it will take 2 hours in total.



We will meet you at UNSW.



The research will happen in a private room.



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

But they cannot help you with the research study.



Each time you will get a \$50 Coles-Myer gift card to say thank you.

You will get a total of \$100 if you do the research both times.

Do I 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.



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 and recordings on our computers.



The computers have a password.

Only we will know the password.



We will put any information you write down on paper on to our computers.

We will keep the papers for 3 months in a locked cabinet.



We will destroy the papers after 3 months so that nobody can see them.



We will store your information and records for 5 years after we write reports about it.



Private

We will keep your information private.

We will not tell anybody your name or where you live.

No one will know it was you who took part.



We will write about what we find out.

If you want we will send you a summary.

Who can I get in touch with about the research?



If you have any questions about the research you can contact Ellen Lee by

- Phone at **(02) 9348 1286**

Or

- Email at **heemin.lee@unsw.edu.au**



If you want to complain about the research you can contact the Human Research Ethics Coordinator.

The **Human Research Ethics Coordinator** is someone who will listen to you and find out what happened.



You can contact the Human Research Ethics Coordinator by

- Phone at **(02) 9385 6222**

Or

- Email at **humanethics@unsw.edu.au**



You will need to tell the Human Research Ethics Coordinator that the research study number is **HC####**.



If you feel upset after taking part in the research you can talk to someone who supports you.



You can also call Beyond Blue at **1300 224 636**.

Anyone can call this number any time of the day.



Beyond Blue has a website too.

It is **www.beyondblue.org.au**

I want to take part

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I am signing this form because I understand about the research and 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 and to tell me about the findings afterwards.

I understand that you would like to record what I say in the study.

- I would like you to record what I say

OR

- I do not want you to record what I say. I would like you to take notes about what I say instead

Witness signature: _____

Date: _____

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

I don't want to take part anymore

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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:

Ellen Lee

Email: heemin.lee@unsw.edu.au

Post: Room G20 Morven Brown Building
UNSW Sydney, 2052, NSW