



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

The impact of the Easy Read format on comprehension of health information by people with intellectual disability
Dr Ellen Lee

1. What is the research study about?

You are invited to take part in this research study. The research study aims to look at how the way information is presented in Easy Read documents can affect learning and understanding of the information. The research will help us to understand how to better show health information to people with intellectual disability so that they can learn more about their health.

2. Who is doing this research?

The study is being done by the following researchers: Dr Ellen Lee from the School of Education, UNSW Sydney, Dr Janelle Weise from the Department of Developmental Disability Neuropsychiatry, School of Clinical Medicine, UNSW Sydney and Dr Jenna Zhao from the School of Education and Department of Developmental Disability Neuropsychiatry, UNSW Sydney.

Research Funder: This research is being supported by the Department of Developmental Disability Neuropsychiatry. The Department of Developmental Disability Neuropsychiatry will receive not make any money from what we find out from the research.

3. Inclusion/Exclusion Criteria

Before you decide to take part in this research study, we need to make sure that it is ok for you to take part. The research study is looking for people who meet the following criteria:

- Have an intellectual disability,
- Are 18 years of age or older,
- Are able to read simple English, and
- Live in Sydney and can come to the campus of UNSW Sydney to be part of the research.

People who meet the following criteria will not be able to take part in the study:

- Have vision problems that stop them from being able to read information in simple English, or
- Need support from another person to read information in simple English.

4. Do I have to take part in this research study?

Taking part in this research study is voluntary. Voluntary means if you do not want to take part, you do not have to. If you decide to take part and later change your mind, you can stop taking part in the study at any time.

If you decide you want to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if you need to);
- Sign and give us the consent form if you decide to take part in the study;
- Take a copy of this form with you to keep.

5. What does taking part in this research require, and are there any risks involved?

If you agree to take part you will be asked to come to UNSW Sydney 2 times. Each time you will be asked to answer some questions about some health topics and read some information about the health topics. You will also be asked to answer some questions about what you did to read and learn the information we gave you about the health topics. We will also ask you to tell us your age and your gender. Each session will take about 1 hour. Across both sessions, the study will take 2 hours in total.

Once the first session is finished, you will be asked to come back exactly 1 week later to do a second session. Each time a session is organised, the research team will send you an email with the details



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

The impact of the Easy Read format on comprehension of health information by people with intellectual disability
Dr Ellen Lee

and you will receive an email reminder 1 day before the session. We can also send you a text message 1 day before to remind you.

If you let us, the research team would like to audio record your answers. If you do not want to be recorded but you would like to take part, you can let the research team know and you can write down your answers instead. If you do not wish to write down your answers, the research team can take written notes about what you say.

Additional Costs and Reimbursement: You do not need to pay any money to take part in this research project. We will pay you a \$50 Coles-Myer gift card for each session. You will get the gift card at the end of each session. If you attend both sessions, you will get \$100 in Coles-Myer gift cards in total.

Support people who come with you to the research sessions will not receive any money or gift cards from the research team.

Psychological Distress: You may feel that some of the questions we ask are stressful or upsetting, especially if you do not know the answers. If you do not know the answer, you may skip the question by telling us you don't know and want to go to the next question. You may also stop at any time by letting the research team know.

You may also feel worried about your own health after learning more about the health topics. If you become upset from taking part in the research project, the research team will be able to organise counselling or other support for you. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided for free. We also include information about free contactable support services in section 10.

6. What will happen to information about me?

By signing the consent form, you agree to the research team collecting and using information about you for the research study.

The research team will store the data collected from you for this research project for:

- At least 5 years after the publication of the research results.

The information about you will be stored in an identifiable format, where your identity will be known.

Information collected from you using paper will be stored in Room 241 Biolink Building UNSW Sydney, and only the approved researchers will have access to this information. The information will be turned into an electronic format and stored on a UNSW password protected OneDrive that only approved researchers can access. After 3 months, the paper information will be destroyed.

Audio or video recordings will be stored on a UNSW password protected OneDrive that only the approved researchers will be able to access.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right to access the personal information held about you by the University, the right to ask for the information to be corrected and changed, and the right to make a complaint about a breach of the Information Protection Principles as contained in the



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

The impact of the Easy Read format on comprehension of health information by people with intellectual disability
Dr Ellen Lee

PPIP Act. More information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

7. How and when will I find out what the results of the research study are?

The research team plan to publish and/ report the results of the research. All information will be published in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by writing your email or mailing address in the consent form. We will only use these details to send you the results of the research.

8. What if I want to withdraw from the research study?

If you do consent to take part in the research study, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document or you can ring the research team and tell them you no longer want to take part. Your decision not to take part or to withdraw from the study will not affect your relationship with UNSW Sydney. If you decide to leave the research study, the researchers will not collect additional information from you. You can ask that any identifiable information about you be removed from the research project.

9. What if I have a complaint or any concerns about the research study?

If you have a complaint about any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

| | |
|----------------------------|--|
| Position | UNSW Human Research Ethics Coordinator |
| Telephone | + 61 2 9385 6222 |
| Email | humanethics@unsw.edu.au |
| HC Reference Number | [INSERT HC reference number] |

10. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact Details

| | |
|------------------|--|
| Name | Jenna Zhao |
| Position | Research co-ordinator |
| Telephone | (02) 9065 1742 |
| Email | jenna.zhao@unsw.edu.au |

Chief Investigator

| | |
|------------------|--|
| Name | Ellen Lee |
| Position | Lecturer |
| Telephone | (02) 9348 1286 |
| Email | heemin.lee@unsw.edu.au |



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

*The impact of the Easy Read format on comprehension of health information by people with intellectual disability
Dr Ellen Lee*

Support Services Contact Details

If at any stage during the study, you become distressed or need additional support from someone not involved in the research please call:

| | |
|--------------------------|--|
| Name/Organisation | Julian Trollor |
| Position | Chair of Intellectual Disability Mental Health, UNSW Sydney |
| Telephone | (02) 9065 8076 |
| Email | j.trollor@unsw.edu.au |

You can also contact the Beyond Blue support line at any time on any day.

| | |
|--------------------------|--|
| Name/Organisation | Beyond Blue |
| Telephone | 1300 224 636 |
| Website | www.beyondblue.org.au |



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

The impact of the Easy Read format on comprehension of health information by people with intellectual disability
Dr Ellen Lee

Consent Form – Participant providing own consent

Declaration by the participant

- I understand I am being asked to provide consent to take part in this research study;
- I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research described in the study;
- I provide my consent for the information collected about me to be used for the purpose of this research study only.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to take part in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I understand that I will be given a signed copy of this document to keep.
- Recordings: I understand that the research team would like to audio record the research sessions
 - I agree to be recorded for this purpose.
 - I prefer to have written notes taken instead of being recorded.
- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: _____

Address: _____

Email Address: _____

Participant Signature

| | |
|------------------------------------|--|
| Name of Participant (please print) | |
| Signature of Research Participant | |
| Date | |

Declaration by Researcher*

- I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

| | |
|-----------------------------------|--|
| Name of Researcher (please print) | |
| Signature of Researcher | |
| Date | |

***An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

Note: All parties signing the consent section must date their own signature.



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

*The impact of the Easy Read format on comprehension of health information by people with intellectual disability
Dr Ellen Lee*

Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to take part in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales.

- I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.
- I am withdrawing my consent to take part in further components of this research and provide my permission for the research team to retain and/or use information collected about me which I have provided for the purpose of this research.
- I am withdrawing my consent and I understand that any information already published and/or not linked to my identity cannot be withdrawn from the research.

Participant Name

| | |
|--------------------------------------|--|
| Name of Participant (please type) | |
| Date | |

The section for Withdrawal of Participation should be forwarded to:

| | |
|-----------------|--|
| CI Name: | Ellen Lee |
| Email: | heemin.lee@unsw.edu.au |
| Phone: | (02) 9348 1286 |
| Postal Address: | Room G20, Morven Brown Building, UNSW Sydney, 2052, NSW |