



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM – Parent Guardian

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?

The person with intellectual disability you support is 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 information to people with intellectual disability so that they can learn more about their health.

2. Who is conducting this research?

The study is being carried out 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 no direct or indirect financial benefits from the outcomes of the research.

3. Inclusion/Exclusion Criteria

Before you decide to allow the person you support to participate in this research study, we need to ensure that it is ok for the person you support 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 be excluded from 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. Does the person I support have to take part in this research study?

Participation in this research study is voluntary. If you do not want the person you support to take part, you do not have to. If you agree for the person you support to take part and later change your mind, you are free to withdraw the person you support from the study at any stage.

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

- Read the information carefully (ask questions if necessary);
- Sign and return the consent form if you decide you want the person you support to participate in the study;
- Take a copy of this form with you to keep.

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

If you agree for the person you support to participate, they will be asked to complete the following research procedures.



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The person you support will be asked to come to UNSW Sydney 2 times. Each time, they will be asked to answer some questions about some health topics and read some information about the health topics. They will also be asked to answer some questions about what they did to read and learn the information we gave them about the health topics. We will also ask them to tell us their age and their 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, the person you support 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 or the person you support an email with the details and an email reminder 1 day before the session. We can also send you or the person you support a text message 1 day before as a reminder.

With your permission the research team would like to audio record the answers of the person you support. If you do not wish for the person you support to be recorded but would like them to participate, you can advise the research team and the person you support can write down their answers instead. If they do not wish to write down their answers, the research team can take written notes about what they say.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project and the person you support will be paid a \$50 Coles-Myer gift card for each session. The person you support will receive the gift card at the end of each session. If the person you support attends both sessions, they will receive \$100 in Coles-Myer gift cards in total.

Support people who come with the person you support to the research sessions will not receive any payment from the research team.

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

The person you support may also feel worried about their own health after learning more about the health topics. If they become upset or distressed as a result of their participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Alternatively, free contactable support services are included at section 10. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

6. What will happen to information about the person I support?

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

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

- A minimum of 5 years after the publication of the research results;

The information about the person you support will be stored in an identifiable format, where their identity will be known.



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The person you support's information will only be shared in a format that will not identify them.

- Information collected from the person you support using paper-based measures will be stored in Room 241 Biolink Building UNSW Sydney and only the approved research investigators will have access to this information. The information will be converted into an electronic format and stored on a UNSW password protected OneDrive only accessible to the approved research investigators. After 3 months, the paper-based information will be destroyed.
- Audio or video recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators.

The information the person you support provides is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). The person you support has the right of access to personal information held about them by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further 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 intend to publish and/ report the results of the research. All Information will be published in a way that will not identify the person you support.

If you or the person you support would like to receive a copy of the results you can let the research team know by inserting 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 the person I support from the research study?

If you do consent for the person you support to participate, you or the person you support 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 the person you support to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney. If you or the person you support decide to leave the research study, the researchers will not collect additional information from the person you support. You or the person you support can request that any identifiable information about the person you support be withdrawn from the research project.

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

If you have a complaint regarding 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]



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10. What should I do if I have further questions about the person I support's 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 the person you support's 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

Support Services Contact Details

If at any stage during the study, you or your child becomes distressed or require 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



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Consent Form – Participant providing own consent

Declaration by the participant

- I understand I am being asked to provide consent for the person I support to participate 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 the person I support 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 for the person I support to participate 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 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;
- 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 the person I support to be recorded for this purpose.
 - I prefer to have written notes taken instead of the person I support 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: _____

Parent/Guardian Signature

Name of person providing consent (please print)	
Signature of person providing consent	
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.



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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent for the person I support to participate in this research study described above and understand that such withdrawal **WILL NOT** affect mine or the person I support's relationship with The University of New South Wales.

- I am withdrawing the person I support's consent and I would like any identifiable information collected about the person I support which they have provided for the purpose of this research study withdrawn.
- I am withdrawing the person I support's consent to participate in further components of this research and provide my permission for the research team to retain and/or use information collected about the person I support which they 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 the person who I support's 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