

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
KEY STAKEHOLDER IN-DEPTH INTERVIEWS

Know Me, Support Me: AI reasoning tool for identifying and managing health issues of people with intellectual disability - Consultation and Co-design

CI-Associate Professor Margo Barr

1. What is the research study about?

You are invited to take part in this research study. The research study aims to develop an AI tool to help carers notice changes in people with intellectual disability and seek medical help when needed. The tool will also help them talk about the signs with health professionals, so they can make health plans. We will work with people with intellectual disability and their family, carers and disability support workers to co-design the AI tool and test it.

This is the first part of the research project which includes the co-design of the requirements for an AI reasoning tool with stakeholders. This stage includes stakeholder consultations, a scoping review, phone questionnaires with people with intellectual disability, online supporters survey and co-design workshops.

This recruitment is specifically for the Key Stakeholder In-depth interviews.

2. Who is conducting this research?

The study is being carried out by the following researchers:

Margo Barr	- University of NSW	Julian Ward	- 7DX
Lisa Hutchinson	- Aruma Disability Services	Eb Eyeson-Annan	- UNCAPT
Rachel Anne Skoss	- The Kids Institute	Kathleen Woolford	- Livit Disability Support
Frank Iorfino	- University of Sydney	Michael Kidd	- University of NSW
Peri O'Shea	- University of NSW	Julian Trollor	- University of NSW
Janelle Weise	- University of Sydney	Donna Gilles	- NDIS Commission
Karen Fisher	- University of NSW	Nishant Valecha	- University of NSW
Nathan Wilson	- Western Sydney University	Shona Bates	- University of NSW
Stuart Wark	- University of New England	Brendan Goodger	- Central and Eastern PHN
Rhonda Faragher	- University of Queensland	Peter Brown	- University of NSW
Erin Forrester	- University of NSW	Cat Lancaster	- Life Without Barriers
Natalie Taylor	- University of NSW	Yang Li	- University of NSW
Dinesh Palipana	- Gold Coast University	Kathryn Thorburn	- University of NSW
Vivienne Riches	- University of Sydney	Nina El-Haddad	- University of NSW
Cathy O'Callaghan	- University of NSW		

Led by the International Centre for Future Health Systems, University of NSW.

Research Funder: This research is being funded by MRFF RG245412.

3. Inclusion/Exclusion Criteria

Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:
key informants including families, support workers, advocates, academics and health professionals.

Participants who meet the following criteria will be excluded from the study:

Not meet the inclusion criteria

Not able to complete the interview in English and/or are aged under 18 years.

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

Participation in this research study is voluntary. 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 are free to withdraw from the study at any stage.

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

- Read the information carefully (ask questions if necessary);
- Provide verbal consent form if you decide 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 to participate you will be asked to complete the following research procedures.

Interview: An online video or telephone interview, and you will be asked questions about Health outcomes for people with intellectual disability, specifically the current system, gaps and challenges, what future systems should look like and the role of AI in improving care. The interview will take place using Teams or via the phone and will take approximately 40 minutes. With your permission the research team would like to audio/video record the interview. If you do not wish to be recorded but you would like to participate you advise the research team and written notes will be taken. If requested, we can conduct the interview with groups of participants from the same organisation.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project, nor will you be paid. However, you will receive a \$50 gift card to reimburse you for any reasonable expenses while completing the in-depth interview.

Psychological Distress: You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your 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 9. 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 me?

By signing the consent form, you consent 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:

- A minimum of 7 years after the completion of the research;

The information about you will be stored in an/a:

- Re-identifiable format where any identifiers such as your name, address, date of birth will be replaced with a unique code.

You will be asked to provide your consent for the research team to share or use the information collected from you in future research that:

- Will be an extension of, or closely related to, the original project; or is in the same general area of research

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Your information will only be shared in a format that will not identify you.

- Information collected from you in an electronic format stored on a UNSW password protected OneDrive only accessible to the approved research investigators.
- Audio or video recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you 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 you.

If you 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 from the research study?

If you do consent to participate, 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 participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or any of the organisations involved in this research. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you 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	iRECS10700



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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	Dr Cathy O'Callaghan
Position	Research Fellow
Telephone	+61 2 9065 6735
Email	c.ocallaghan@unsw.edu.au

Chief Investigator

Name	Margo Barr
Position	Associate Professor
Telephone	+61 2 9065 6041
Email	margo.barr@unsw.edu.au

Support Services Contact Details

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

Name/Organisation	Mental Health Line
Position	24-hour telephone service operating seven days a week across NSW. It provides connections to crisis support and counselling.
Telephone	1800 011 511
Email	https://www.health.nsw.gov.au/mentalhealth/Pages/Mental-Health-Line.aspx

OR

Name/Organisation	Medicare Mental Health
Position	a free national phone service operating weekdays 8:30am-5:00pm, excl. public holidays.
Telephone	1800 595 212
Email	https://www.health.nsw.gov.au/mentalhealth/Pages/Mental-Health-Line.aspx

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Consent Form – Participant providing own consent verbally

Declaration by the participant

- ☐ I understand I am being asked to provide consent 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 understand that I will only be asked to provide consent once for this data collection activity;
- ☐ I understand that the consent I provide here does not cover any other data collection activity;
- ☐ Recordings: I understand that the research team will audio/video record the interviews; I agree to be recorded for this purpose.
- ☐ 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 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.
- ☐ I understand that the results of the research will be made available on the International Centre for Future Health Systems, Faculty of Medicine and Health, UNSW website.
- ☐ 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: _____

Optional Consent for reuse of data and future research:

- ☐ I provide my consent for the information collected about me to be made available to other researchers as described at section 6 of this document.
- ☐ I provide my consent for my name and contact details to be retained in a register so I can be contacted about other research projects in the future.

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Verbal Consent Script that will be used to gain your consent on the day of the interview

Now that I have explained what your involvement in the research study requires, do you provide your permission for me to audio record your agreement for consent?

If yes, start audio recording before asking:

1. Please confirm that I have provided you with a verbal description of what the research involves and you understand what your involvement in the research requires.
2. Please confirm that I have answered any questions you have raised in relation to the research.
3. Do you agree to provide your consent to take part in this research project?
4. Please state your name, the time, and the date for the recording.
5. End this recording of consent process.

If no, enter the responses to the below questions into an excel spreadsheet or a word document:

1. Please confirm that I have provided you with a verbal description of what the research involves and you understand what your involvement in the research requires.
2. Please confirm that I have answered any questions you have raised in relation to the research.
3. Do you agree to provide your consent to take part in this research project?
4. Please state your name, the time, and the date for the recording.
5. End this recording of consent process.

→ Commence with data collection.

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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales, other participating organisations and/or professionals.

- ☐ 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 participate 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:	Margo Barr
Email:	Associate Professor
Phone:	+61 2 9065 6041
Postal Address:	margo.barr@unsw.edu.au