

ONLINE PARTICIPANT INFORMATION STATEMENT

*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 design a generative AI reasoning tool that will help people with intellectual disability and their family, carers and disability support workers notice signs of deteriorating physical or mental health and seek medical help sooner. This component of the project includes reviewing the literature, conducting in-depth interviews and online surveys. All of the information collected will be considered at the co-design workshops. You have been invited because you have been identified as a supporter, advocate, disability service provider or health service provider of people with intellectual disability, and your contact details were obtained from research team members.

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 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
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		

Lead by 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 to recruit people who meet the following criteria:

- family and carers of people with intellectual disability
- advocates for people with intellectual disability
- service provider of people with intellectual disability
- health service providers of people with intellectual disability

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

- Not meet the inclusion criteria
- Not able to complete the Online survey in English and/or are aged under 18 years

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

Participation in any research study is voluntary. If you do not want to take part, you do not have to.

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);
- Complete the online questionnaire.

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

If you decide to take part in the research study, we will ask you to complete an online questionnaire. The questionnaire will ask you questions about your current situation, ability to recognise deterioration, escalation experience, communication with service providers, information needs, use of care plans, use of technology and acceptance of using of AI. It should take approximately 15 minutes to complete.

If you experience discomfort or feelings of distress while participating in the research and you require support, you can stop participating at any time. You can also tell a member of the research team and they will provide you with assistance or alternatively a support service and their contact details are provided below.

6. What are the possible benefits to participation?

We hope to use information we get from this research study to inform the co-design workshops being undertaken to develop a prototype for the AI reasoning tool that will help people with intellectual disability and their supporters notice signs of deteriorating physical or mental health and seek medical help sooner.

7. What will happen to information about me?

Submission of the online questionnaire is an indication of your consent. By clicking the 'I agree to participate' button you are providing your permission for the research team to collect and use 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 a:

- Non-identifiable format where your identify will be unknown.

You will be asked to provide your consent for the research team the 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

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

8. 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.

9. 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 this by closing the questionnaire. If you withdraw from the research, we will destroy any information that has already been collected. Once you have submitted the questionnaire however, we will not be able to withdraw your responses as the questionnaire is anonymous.

International Centre for Future Health Systems, Faculty of Medicine
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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**.

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

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

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

Contact for feelings of distress

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

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	Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference Number	iRECS10700

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Consent Form – Participant providing own consent

Declaration by the participant

By starting the questionnaire below:

- I understand I am being asked to provide consent to participate in this research study;
- I have read the Participant Information Sheet, or it has been provided to me in a language that I understand;
- 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; I provide my consent for the information collected about me to be used for the purpose of this research study only;
- I understand that if necessary, I can ask questions and the research team will respond to my questions;
- 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 give approval for the research team to share or use the information collected from you in future research which is an extension of, or closely related to, the original project; or is in the same general area of research.

I agree, start questionnaire