



THE UNIVERSITY OF
SYDNEY

Brain and Mind
Centre

Brain and Mind Centre
Faculty of Medicine and Health

Participant Information Sheet/Consent Form

Non-Health Professional

Study title	Co-designing digital decision-support tools to personalise care pathways within youth mental health services
Protocol Number	2021/HE000680
Project Sponsor	The University of Sydney
Principal Investigator	Professor Ian Hickie
Coordinating Principal Investigator	Dr Frank Iorfino
Associate Investigator(s)	Dr Haley LaMonica Dr Jo-An Occhipinti Dr Ante Prodan Ms Sarah Piper Mr William Capon Dr Rafael Dos Santos De Oliveira Dr Roman Marchant Matus Dr Mathew Varidel Ms Min Kyung Chong Dr Sarah McKenna Dr Ashlee Turner Dr Adam Poulsen Ms Josephine Brogden Ms Zsofi de Haan Ms Jingxuan Li Li Ms Jenni De Luca Bamber Ms Sam Huntley
Location	Brain and Mind Centre, The University of Sydney

1 What is this study about?

We are running a research study to determine how digital decision-support tools can be designed to improve triage processes, clinical assessment, formulation, and treatment planning within youth mental health services, and support services to deliver better and more appropriate care to young people presenting with mental health concerns.

We are inviting you to take part in this study because we are interested in hearing ideas and opinions from the potential users of these digital tools, including young adults (18 to 30 years), their support people (i.e. partners, family, friends), as well as mental health clinicians, service administrators, and service managers.

This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to take part in the research. Please read this sheet carefully and ask questions about anything that you would like to understand further.

Participation in this research study is voluntary.

By giving your consent to take part in this study you are telling us that you:

- Understand what you have read
- Consent to take part in the research project as outlined below
- Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information Sheet to keep.

2 Who is running this study?

This research study is being conducted by researchers from The University of Sydney's Brain and Mind Centre. The names of the researchers are listed on page one of this information sheet. The research is funded by a Commonwealth Government Medical Research Future Fund National Critical Research Infrastructure grant over a five-year period, from 30th June 2023 to 29th June 2028.

3 Who is eligible to participate in the study?

You are eligible to participate in this study if you are a:

- Young person (aged 18 to 30 years); or
- Support person of a young person (e.g. family member, close friend, partner, etc).

4 What does participation in this research study involve?

This study involves two potential activities. Participating in these activities do not require any prior knowledge or experience with digital mental health technologies or artificial intelligence. You can tell us which activity you would like to participate in on the consent form.

Activity 1. Online surveys

The online survey consists of three parts: demographics, perceptions about digital technologies and chatbots in mental health care, and Australian youth language.

Part A: Demographics – This will include general demographic information (e.g., age). All participants will be required to complete this section.

Part B: Perceptions about digital technologies and chatbots in mental health care – The purpose of this section is to understand your perceptions about the use and design of digital technologies and chatbots in mental health care.

Part C: Australian youth language – The purpose of this section is to collect Australian youth language relating to mental health to support the co-design of digital decision support tools for young people.

You may choose to complete Part B (Perceptions about digital technologies and chatbots in mental health care), Part C (Australian youth language), or both. All participants will be required to complete Part A (demographics).

Time commitment	Up to 20 minutes total (15 minutes for Part B and 5 minutes for Part C)
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Who is eligible?	Young adults (18 to 30 years old)
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Activity 2. Co-design workshops

You will be asked to participate in a workshop (either face-to-face or online) to create and test digital decision-support tools for use in mental health services. Workshops will involve:

- The conceptual development and design of digital decision-support tools for youth mental health services. That is, the development of the look, feel, and function of the tool.
- Gathering feedback on the usability of an early prototype/mock design of the tool, to further refine its development
- Discussion around the potential use of the tool within services (e.g. barriers and enablers, effect on engagement, and integration of the tool into service).

The workshop will be coordinated by two to three facilitators (clinicians and/or researchers). This will include a scribe to take handwritten notes during the workshop (please note, no identifying information will be included in notes). Additionally, with your permission, group photographs will be taken for the purposes of study advertising, promotion, and recruitment.

Time commitment	Up to four (4) hours
Who is eligible?	Young adults (18 to 30 years old), their support people (e.g. family members, friends, partners)

5 How much of my time will the study take?

The total time commitments for each activity are summarised above. It is important to know that you can choose to take part in just one or all of the activities, depending on your eligibility.

6 Where will the study take place?

The surveys will be conducted online. The co-design workshops will be held either on site at Moore College (Newtown, NSW) or via Zoom, depending on the participant's preference. Further details of the location will be provided closer to the date of the scheduled session. All participants will be advised well whether the workshops will be run in-person or online.

7 Do I have to take part in this research project? Can I withdraw from the study once I have started?

Participation in any research project is voluntary. If you do not wish 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 project at any stage. You can do this by informing research staff. Withdrawing from this study will not affect your relationship with The University of Sydney or the Brain and Mind Centre.

If you do withdraw your consent during the research project, the relevant study staff will not collect additional information from you. You should be aware that data collected up to the time at which you withdraw will continue to form part of the research project results. If you do not want them to do this, you must tell them before you join the research project. Importantly, as no identifying information is collected in this study, the researchers will not be able to determine which responses were from you. Given that only aggregate data will be collected, you will not have the opportunity to review or edit your responses after you have contributed. However, as stated, any contributions that you make will not be able to be linked to you in any way.

8 What are the possible risks and disadvantages of taking part?

Aside from giving up some of your time, we do not expect that there will be any risks or costs associated with taking part in this study.

In the unlikely event that you become upset or distressed as a result of your participation in a co-design workshop, there will be a mental health professional available before and after the workshop (regardless of whether the workshop is run online or in-person). It is not anticipated that the surveys will cause distress; however, we recommend that you contact your general practitioner or other trusted clinician should you become upset. Crisis support is available via Lifeline (call: 13 11 14; text: 0477 13 11 14) or, in the case of an emergency, call: 000.

9 What are the possible benefits of taking part?

By participating in this study you may learn more about new and emerging digital technologies that can assist people to monitor and improve their mental health and wellbeing. Your participation will help us develop a digital decision-support tool to support triage processes, clinical assessment, case formulation, and treatment planning for mental health care, which in turn may lead to better care for people accessing health and wellbeing services.

For Activity 1 (online survey), you will be eligible to receive an online voucher of your choice (e.g., Woolworths, Big W, Caltex, Coles, Target, Kmart or JB HiFi or Prepaid Mobile Recharge) as reimbursement for your time. You will be eligible to receive \$15 for completion of Part B and \$5 for completion of Part C (up to \$20 total for completion of all sections of the survey). Participants recruited for the online survey via Prolific will be reimbursed for completing each survey component at the same rates via the Prolific platform.

For Activity 2 (co-design workshop), you will be offered remuneration in line with what is currently recommended by the NHMRC. This is calculated as 1.5x (the applicable minimum wage in Australia [\$24.10 as of September 2024] + 25% casual loading) = \$45 per hour. Reimbursement will be provided in the form of an online gift voucher of choice (e.g., Woolworths, Big W, Caltex, Coles, Target, Kmart, JB Hi Fi or Prepaid Mobile Recharge).

10 What happens when the research project ends?

It is anticipated that the results of this study will be published in academic journals and policy documents and be presented at local and international scientific conferences. Results will also be communicated to the wider community through public talks and media. In any publication and/or presentation, information will be provided in such a way that you cannot be identified as we will not collect or use any personal information as part of this study. A summary of the findings will also be provided to you via post or email at your request when the study has been completed.

11 What will happen to information about me?

All information that you give us will be kept in a locked office at Moore College, or for electronic data, on a secure server, which only selected researchers will have access to. We will write a report about the study and show it to other people but we won't say your name in the report and no one will know that you were in the study. The data collected in this study are non-identifiable, meaning that it cannot be linked to you.

Workshops will be video- (for online workshops) and audio-recorded. The audio recordings will be transcribed using external transcription services from Otter.ai. All data uploaded to Otter.ai for transcription will be processed in accordance with Otter.ai's privacy and security policies. Otter.ai employs industry-standard encryption to protect data both in transit and at rest. Transcripts and recordings stored on Otter.ai will be deleted from the platform immediately after the transcription process is complete. The original audio recordings will be stored on a secure server hosted by the

University of Sydney and deleted once the transcription is complete and verified. Transcripts will be stored on the same secure server and will only be accessible to authorised members of the research team. By participating in a workshop, you consent to your data being processed by Otter.ai for the purposes of transcription.

The video recordings for online workshops are used to support the transcription process and includes the video of you during the workshop (i.e., your face and presence on camera if you have your video turned on). The research team will use the video recordings to identify who is speaking so that consistent pseudonyms (e.g., “Young person 1”, “Young person 2”) can be assigned in the transcripts. This ensures that your responses are non-identifiable in the transcripts. The video also provides context for interpreting your responses, for example, if a participant refers to something shown on the research team’s shared screen during the workshop, the video helps to clarify what was being discussed. Only the research team’s screen is shared and recorded. Your screen is not visible or recorded. Video recordings will be stored securely and deleted once the transcription is complete and verified.

All data will be stored securely for a period of five years and then destroyed. All paper documents then will be shredded and disposed of to maintain participant confidentiality. Similarly, electronic data will be deleted permanently from the online server.

12 Other relevant information about the research project

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by The University of Sydney’s Human Research Ethics Committee.

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

This research project involves the development of digital decision-support tools, incorporating feedback from study participants. These tools may be built/manufactured by InnoWell Pty Ltd, a joint venture by The University of Sydney and Price Waterhouse Coopers (Australia). Professor Ian Hickie (this study’s Principal Investigator) is the Scientific Advisor to, and 5% equity shareholder in, InnoWell. No other researchers involved in this project expect to obtain any direct or indirect financial or other benefits from conducting this research.

13 Further Information

When you have read this information, a Research Officer will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Ads Poulsen via email adam.poulsen@sydney.edu.au.

14 Ethics Approval and Complaints

This study has been approved by The University of Sydney’s Human Research Ethics Committee. Any person with concerns or complaints about the conduct of this study should contact the Ethics Office at The University of Sydney on 02 9036 9161 and quote Protocol number 2021/HE000680.

This participant information sheet is for you to keep.



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Location	Brain and Mind Centre, The University of Sydney

Declaration by Participant

- ✓ I have read the Participant Information Sheet or someone has read it to me in a language that I understand.
- ✓ I understand the purposes, procedures and risks of the research described in the project.
- ✓ 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 project as described and understand that I am free to withdraw at any time during the project without affecting my future health care.
- ✓ I understand that I will be given a signed copy of this document to keep.

I consent to participating in (please tick Yes or No for each activity):

Activity 1 (online surveys) – young adults ☐ Yes

Part B: Complete an online survey (approximately 15 minutes) exploring your perceptions about digital technologies and chatbots in mental health care. ☐ No

Part C: Complete a short online survey (approximately 5 minutes) collecting Australian youth language relating to mental health. ☐ Yes
☐ No

Activity 2 (co-design workshop) – young adults and support people ☐ Yes

Attend 1 x online or face-to-face group workshop (up to 4 hours) to help design and develop a digital decision-support tool. ☐ No

Still images (photographs)

Group still shots (photographs) may be used for reports and presentations, therefore if these images are used you may be identifiable. However, for all still shots, every effort will be made to exclude faces. ***Please tick one box only.***

☐ **I give permission** for the researchers to use still shots which may identify me

☐ **I give permission** for the researchers to use still shots only where my face is not shown (thus making my non-identifiable)

☐ **I give permission** for the researchers to use still shots only where my face is pixelated (thus making me non-identifiable)

☐ **I do not give my permission** for the researchers to use still shots (whether identifiable or non-identifiable)

Future research (please tick Yes or No) I consent to being contacted to discuss other potential research activities for which I may be eligible, including relevant future co-design workshops as part of this study	<input type="checkbox"/> Yes <input type="checkbox"/> No
I consent for other research collaborators to use my data for future research purposes. I understand that before they can use my data, they must seek additional ethics approval.	<input type="checkbox"/> Yes <input type="checkbox"/> No

Name of participant (please print): _____

Signature: _____

Date: _____

Declaration by Senior Researcher

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of senior researcher (please print): _____

Signature: _____

Date: _____

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