



Te Whatu Ora | Health New Zealand
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PARTICIPANT INFORMATION SHEET

For participants

Project title

Enabling transparency in healthcare AI to promote patient trust

Research team

Lead Researcher: Associate Professor Rosie Dobson
School of Population Health, University of Auckland
Health Services Research & Evaluation, Te Whatu Ora | Health New Zealand

Study Site: Waipapa Taumata Rau | University of Auckland and Te Whatu Ora | Health New Zealand

Contact number: 09 3737599

What does the study involve?

We would like to invite you to take part in a focus group to discuss the types of information about the use of artificial intelligence (AI) in healthcare that patients want and how this should be made available to them. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign a Consent Form. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

Purpose of this study:

The purpose of this study is to improve our understanding of how patients want to be informed about the use of AI in healthcare. Your participation in the study will help contribute to the implementation of AI in healthcare and ensure it is inclusive, equitable, and responsive to the needs of all New Zealanders.

Study design:

This study involves a one-time focus group. We aim to recruit approximately 60-70 adults to participate in the focus groups, with each session including approximately 10 participants.

Who can take part in the study:

To take part in the study you must:

- Be aged 16 years or over
- Be able to read/understand English
- Be able to provide consent to participate
- Be eligible for BreastScreen Aotearoa (the national breast cancer screening service) or undergone a mammogram within the last 5 years

What will my participation in the study involve?

If after reading this information sheet you decide that you would like to take part in the study, a researcher will arrange a time with you to explain the study and answer any questions you may have. You will be asked to complete the consent form before participating in the study. Focus groups will be done in-person but accommodations are available for people who are not able to participate in-person (e.g., Zoom). The focus group will not be recorded but the researchers will take notes and ask permission to take photos of content produced during the session. During the focus group, we will first ask you to complete a short demographic survey. You will then be given some examples of how AI might be used in healthcare and asked some questions to understand your thoughts and feelings about it. We will then work with participants to understand what information they want to know about AI being used, how they want to receive this information, and why this information is important to maintain patient trust in their healthcare provider. It is estimated that each focus group will last about 4 hours and kai/refreshments will be provided. You are welcome to bring whānau/a support person to the focus group.

What will happen to my information?

The information that we will gather during the focus group will be about you and your thoughts on the use of AI in your care, and how information about it should be given to patients. We do not anticipate any of our questions to be sensitive or cause embarrassment, however you are welcome to skip any questions you do not wish to answer. Focus groups will not be recorded but notes will be taken by the facilitators. You cannot take part in this study if you do not consent to the collection of this information. If any materials from the focus groups are used in the results of this study, any potentially identifiable information (e.g., names, places) will be removed. The demographics survey will not collect information about your health and we will not be accessing your medical records.

Only the study researchers will have access to any of the identifiable information you provide. Identifiable information is any data that could identify you (e.g., your name, your phone number). To make sure your personal information is kept confidential, information that identifies you will not be included in any report generated by the researchers. Instead, you will be identified by a code. The researchers will keep a list linking your code with your name, so that you can be identified by your coded data if needed. Only the study researchers will have access to your coded information.

All future use of the information collected will be strictly controlled in accordance with the Privacy Act, 2020.

You have the right to request access to your information held by the research team. You also have the right to request that any information you disagree with is corrected. If you have any questions about the collection and use of information about you, please contact the lead researcher (Associate Professor Rosie Dobson).

Benefits and risks

What are the possible risks of this study?

We do not anticipate any risks with this study. However, taking part in this study will take some time.

What are the possible benefits of this study?

Your participation in the study will help to contribute to improving the way AI is implemented in health services, building trust and helping patients feel safe and respected when engaging with AI-supported care.

Who pays for the study?

Will any costs be reimbursed?

You will not incur any costs from participation in this study. However, in recognition of your time, you will be offered a \$160 voucher for participating.

Who is funding this study?

This research has not received any external funding.

Rights of the participant(s)

Voluntary participation and withdrawal from this study:

Your participation in this study is entirely voluntary (your choice). You do not have to take part. If you choose not to take part in this study, you will not be affected in any way. You may withdraw from the study at any time, without having to give a reason. Your withdrawal from the study will not affect your relationship with Te Whatu Ora or the University of Auckland. You are encouraged to ask questions at any time.

Right to withdraw your information:

You may withdraw your consent for the collection and use of your information at any time, by informing the researcher. If you withdraw your consent during the focus group, your study participation will end.

While focus group participants will not be able to withdraw their data once participation begins due to the nature of the method, you can withdraw at any point during the group with no impact to you. If you agree to participate, information collected up until your withdrawal from the study will continue to be used and included in the study.

Confidentiality and anonymity:

Although efforts will be made to protect your privacy, due to the nature of focus groups absolute confidentiality of your information cannot be guaranteed. We will therefore remind all participants and support person(s) of this at the start and end of each focus group. Even with coded and anonymised information, there is no guarantee that you cannot be identified.

The results of the study may be published or presented, but not in a form that would reasonably be expected to identify you.

What will happen after the study?

Your identifiable information is held at the School of Population Health, University of Auckland during the study. After the study it is transferred to a secure archiving site and stored for at least 6 years, then deleted. All storage will comply with local and/or international data security guidelines.

Can I find out the results of the study?

You will be provided with a summary of study results, if requested, within three (3) months of the end of the study. The researchers will also present the findings in a hui for participants and whānau. You will be able to add your details to the Consent Form if you are interested.

Who do I contact for more information or if I have concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Name, position: Melanie Stowell, Co-investigator
Organisation: School of Population Health, University of Auckland
Phone: 027 419 2553
Email: melanie.stowell@auckland.ac.nz

Name, position: Associate Professor Rosie Dobson, Lead Researcher
Organisation: School of Population Health, University of Auckland
Phone: 09 373 7599
Email: r.dobson@auckland.ac.nz

Name, position: Professor Judith McCool, Head of School
Organisation: School of Population Health, University of Auckland
Phone: 09 373 7599 ext. 82372
Email: j.mccool@auckland.ac.nz

If you require Māori cultural support, talk to your whānau in the first instance. You may also contact the administrator for He Kamaka Waiora (Māori Health Team)

by telephoning 09 486 8324 ext. 42324. State the title of the study and the name of the primary investigator.

For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 ext 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

Approved by the Auckland Health Research Ethics Committee on 3/11/2025 for three years. Reference number AH29745.