

Pharmacogenomics in Australia's Healthcare: Perspectives of Consumers and Co-Designing Educational Resources

QUT Ethics Approval Number 9284

Research team

Principal Researcher:	Richelle Breed ^{1,2}	PhD Student
Associate Researchers:	Dr Annalese Semmler ^{1,2}	Principal Supervisor
	Dr Yasmin Antwertinger ¹	Associate Supervisor
	Assoc Prof Joanne Voisey ²	Associate Supervisor
	Adjunct Assoc Prof Esther Lau ¹	Associate Supervisor

¹ School of Clinical Sciences, Faculty of Health, Queensland University of Technology (QUT)

² Centre for Genomics and Personalised Health, Queensland University of Technology (QUT)

Why is the study being conducted?

This research project is being undertaken as part of a PhD study for Richelle Breed.

This project aims to co-design **educational resource/s** on pharmacogenomics that are relevant to the Australian public. Pharmacogenomics is the study that looks at genes (DNA) to help choose medications. We will explain what pharmacogenomics means during the workshop. We will NOT be collecting your genes (DNA).

You are invited to participate in this research project because you have experience or interest in the topic and are over 18 years old.

What does participation involve?

We will ask you some questions about your demographics and experience to make sure we include a diverse range of people in the study. Please complete a brief online expression of interest form which should take 5–10 minutes. You will be asked to provide some basic information, including your contact details and demographic information.

Selected participants will be invited to join co-design workshops. Your participation in the co-design process will involve audio-recorded workshops at the Queensland University of Technology (QUT) campuses, which will take up to 1.5 hours per workshop of your time. We will conduct multiple workshops (up to 6 workshops across the duration of 6 months) to review and refine pharmacogenomics resource/s iteratively. You will not be required to participate in every workshop; however, we will appreciate your ongoing participation. The location and time of the workshops will be based on mutual agreement among members.

If necessary, you may be provided with pre-read meeting documents beforehand and/or consulted on an ad hoc basis between meetings (for example, to provide workshop feedback and/or receive progress updates on the project). We will confirm how often you want to be updated and your preferred method for updates (e.g. email, face-to-face at the next workshop).

Workshops will be located on QUT campuses with a preference for in-person workshops; however, an online option will be made available if you cannot attend in-person on the day due to unforeseen travel issues. Please note that if you arrive late it may not be possible for you to participate.

Your participation in this research project is entirely voluntary. If you do agree to participate you can withdraw from the research project without comment or penalty. You can withdraw anytime during the workshop. However, any comments made up until that point will be included in the research due to the nature of group discussions. Your decision to participate or not participate will in no way impact upon your current or future relationship with QUT.

This is a PhD student project. QUT and the University of Queensland (UQ) will fund the research.

What are the possible benefits for me if I take part?

It is expected that this research project will not benefit you directly. The outcomes of the research, however, may benefit the general Australian public by helping to develop a pharmacogenomics resource that is applicable to the public.

To recognise your contribution should you choose to participate, the research team is offering \$100 for each workshop. This is inclusive of any pre- or post-reading, travel times and workshop participation.

What are the possible risks for me if I take part?

There are no anticipated risks beyond normal day-to-day living associated with your participation in this research project.

What about privacy and confidentiality?

This workshop is a collaborative space where participants may share personal experiences, insights, and creative ideas. We ask all participants to respect the confidentiality of others by not sharing sensitive information outside of this session.

Your comments will be attributed under a group banner name, however you have the choice to be personally identified as a member of this group.

Any data collected as part of this research project will be stored securely as per QUT's Management of research data policy. The expressions of interest from unsuccessful applicants will be deleted upon completion of the study. Data will be stored for a minimum of 5 years, and can be disclosed if it is to protect you or others from harm, if specifically required by law, or if a regulatory or monitoring body such as the ethics committee requests it. Any co-design data collected may be used for secondary use such as publications.

As the research project involves an audio recording:

- You will have the opportunity to verify notes from the workshop, and check that it captures what was discussed prior to final inclusion.
 - The recording will be retained for the minimum retention period of 5 years after the last research activity.
 - It is not possible to participate in the research project without being recorded.
 - You may withdraw your participation at any time, but due to the nature of group audio recordings it will not be possible to delete your contribution.
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How do I give my consent to participate?

Please sign a written consent form to confirm your agreement with workshop/s participation.

What if I have questions about the research project?

If you have any questions or require further information please contact one of the listed researchers:

Richelle Breed	richelle.breed@hdr.qut.edu.au	
Dr Annalese Semmler	annalese.semmler@qut.edu.au	3138 6211

What if I have a concern or complaint regarding the conduct of the research project?

QUT is committed to research integrity and the ethical conduct of research projects. If you wish to discuss the study with someone not directly involved, particularly in relation to matters concerning policies, information or complaints about the conduct of the study or your rights as a participant, you may contact the QUT Research Ethics Advisory Team on 3138 5123 or email humanethics@qut.edu.au.

**Thank you for helping with this research project.
Please keep this sheet for your information.**