



UNIVERSITY  
OF WOLLONGONG  
AUSTRALIA

**Chief Investigator**

**Prof Annette Braunack-Mayer**

T +61 02 4298 1228

M +61 0410 221 514

E: [abmayer@uow.edu.au](mailto:abmayer@uow.edu.au)

ACHEEV, School of Health & Society, Level 3 Building 29

The University of Wollongong

NSW 2522 AUSTRALIA

**PARTICIPANT INFORMATION STATEMENT**

**Building public confidence in the secondary use of general practice data for research: Semi-structured interviews with experienced Australian Health Consumers**

**(1) What is this study about?**

You are invited to take part in a research study investigating Health Consumers perspectives, attitudes and beliefs about participating in data sharing or data linkage consumer groups within the Australian Health care setting. This project is part of a larger study examining how we can use general practice data for research in ways that the public, GPs and other stakeholders will find ethically justifiable and acceptable.

You have been invited to participate because the perspectives of Health Consumers on these issues are critically important and will be used to inform the development of a training intervention for other Health consumers wanting to participate in data-intensive consumer groups. This [Participant Information Statement](#) provides you with information 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 don't understand or want to know more about.

Participation in this research study is voluntary. It's up to you whether you wish to take part or not. By giving your consent to take part in this study you are telling us that you:

- ✓ Understand what you have read.
- ✓ Agree to take part in the research study as outlined below.
- ✓ Agree to the use of your personal information as described.

## (2) Who is running the study?

This project is administered through the University of Wollongong.

The Chief Investigators are:

Name	Affiliation	Email
Prof Annette Braunack-Mayer	University of Wollongong	abmayer@uow.edu.au
Prof Alberto Nettel Aguirre	University of Wollongong	alberton@uow.edu.au
Professor Justin Beilby	University of Wollongong	jbeilby@uow.edu.au
Dr Felicity Flack	Population Health Research Network	Felicity.Flack@uwa.edu.au
Dr Anthony Brown	Health Consumers NSW	abrown@hcnsw.org.au
Dr Carolyn Adams	Macquarie University	Carolyn.adams@mq.edu.au

The research staff are:

Dr Heidi Green	University of Wollongong	hgreen@uow.edu.au
Ms Belinda Fabrianesi	University of Wollongong	belindaf@uow.edu.au
Ms Lucy Carolan	University of Wollongong	lengland@uow.edu.au
Ms Roslyn Love-Myers	University of Wollongong	rlm780@uowmail.edu.au
Ms Tory Hayward	University of Wollongong	vhayward@uow.edu.au

This project is funded by the Digital Health Cooperative Research Centre (DHCRC), research project (DHCRC-0217).

## (3) What will the study involve for me?

If you agree to participate, we will contact you via phone to obtain your verbal consent to participate in the study. This will be audio-recorded. We will also collect some additional information about you to help us ensure that we are interviewing a diverse range of consumer participants.

The study will involve a semi-structured interview, conducted by Dr Heidi Green and Roslyn Love-Myers (honours student) via Zoom. The interview is expected to run for approximately 60 minutes, during which

you will be asked a series of questions relating to your experience of participating in data sharing or data linkage consumer groups within the Australian health care system.

The researchers (Dr Heidi Green and Roslyn Love-Myers) will ask you questions to reflect or highlight key issues that they see as relevant to participating in data-intensive consumer groups. If there are questions that you feel you don't want to answer you will be able to skip the question and move onto the next.

Please note that the Zoom session will be recorded, but only the audio file (not the video file) saved on a secure server.

**(4) How much of my time will the study take?**

The semi-structured interviews will run for approximately 60 minutes on the Zoom video conference platform.

**(5) Who can take part in the study?**

We will be selecting up to 12 Health Consumers nationally with a range of experience in data sharing or data linkage consumer groups to participate in the interviews. It is possible that we will not be able to interview all those who register their interest in participating in the study. This is because we are aiming to have a broad representation across health consumers. If we are not able to interview you, a member of the research team will contact you via email to let you know.

**(6) Do I have to be in the study? Can I withdraw from the study once I've started?**

Being in this study is completely voluntary and you do not have to take part. Your decision whether to participate or not will not affect your current or future relationship with the Health Consumer organisation you belong to, the researchers or anyone else at the University of Wollongong.

If you decide to change your mind about participating, you are free to withdraw (without giving a reason) at any time, up until 1 months AFTER the date of your interview. We will do our best to remove any data that was collected from you, however after that time we will have analysed the data and begun the publication submission process. After publication of a paper, it will not be possible to effectively withdraw your data from that analysis.

Whatever your decision, please be assured that it will have no consequences for you. Withdrawal from the study can be organised by contacting the lead Chief Investigator Prof. Annette Braunack-Mayer (Ph 02 4298 1228 or [abmayer@uow.edu.au](mailto:abmayer@uow.edu.au)).

If you decide to withdraw from the study, we will not collect any more information from you. Any information that we have already collected, however, will be kept in our study records and may be included in the study results.

**(7) Are there any risks or costs associated with being in the study?**

This is a low-risk project. The most significant risk is unwanted identification in reporting. To minimise this risk, we will remove any details that might reveal your identity. Digital audio files and transcripts will be kept on password protected servers at all times. There is also risk that you may describe feelings of inadequacy and insecurity in your current roles on advisory groups. If this occurs, we will offer you the opportunity to discuss this further with counselling through Lifeline 13 11 14. Aside from giving up your time, we do not expect that there will be any other costs associated with taking part in this study.

**(8) Are there any benefits associated with being in the study?**

While we intend that this research study furthers knowledge about health consumers perspectives on participating in data sharing or data linkage consumer groups, it may not be of direct or immediate benefit to you. It will provide you with opportunities to contribute your thoughts and experiences which will culminate in the development of training intervention for other health consumers. You will be provided with a \$50 Visa Gift Card as a thank you for your time.

**(9) What will happen to information about me that is collected during the study?**

All the information collected from you for the study will be treated confidentially. The transcript and digital recording of the interview will only be accessible to members of the research team, excluding Dr Anthony Brown. They will be kept on a password protected server. The study results will be presented at conferences, in an honours thesis and in scientific publications. However, any observations and quotations in the material presented will be de-identified. The data will be securely retained, then destroyed 5 years after the project ends.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement. Consent is also being sought for the use of the data in future research projects that are an extension of this original project.

**(10) What if I would like further information about the study?**

When you have read this information, Prof Annette Braunack-Mayer or another investigator on the project 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 during the study, please feel free to contact Prof Braunack-Mayer (Ph 02 4298 1228 or [abmayer@uow.edu.au](mailto:abmayer@uow.edu.au)).

**(11) Will I be told the results of the study?**

When analysis of the interview data is complete, researchers will provide participants with a summary of the findings. This will likely occur in late-2024. If you would like to be contacted with results, please let Dr Heidi Green or Roslyn Love-Myers know.

**(12) What if I have a complaint or any concerns about the study?**

This study has been reviewed by the Medical Human Research Ethics Committee at the University of Wollongong (Reference: 2024/126). In the event of any concerns/complaints regarding how the research is conducted, please contact the UOW Ethics Officer, by phone on +61 2 4239 2191 or email via [uow-humanethics@uow.edu.au](mailto:uow-humanethics@uow.edu.au)).

**(13) What do I do if I want to participate?**

If you would like to take part in this study, please email Dr Heidi Green [hgreen@uow.edu.au](mailto:hgreen@uow.edu.au) to register your interest.