

PARTICIPANT INFORMATION SHEET

Building public confidence in the secondary use of general practice data for research: Semi-Structured Interviews with Practice Managers and/or Practice Owners

Chief Investigator:

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1. What is this study about?

You are invited to take part in a research study investigating practice managers' and/or practice owners' views of the use of information from general practice records for research in Australia. 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 Practice Managers and /or Practice Owners on these issues are critically important. This <u>Participant Information Sheet</u> 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 and funded by the Digital Health Cooperative Research Centre (DHCRC), research project (DHCRC-0217).

The Investigators are:

Name	Affiliation	Email
Senior Professor Annette Braunack-Mayer	University of Wollongong	abmayer@uow.edu.au
Honorary Professor 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 Carolyn Adams	Macquarie University	Carolyn.adams@mq.edu.au
Dr Anthony Brown	Health Consumers NSW	abrown@hcnsw.org.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

3. What will the study involve for me?

If you agree to participate, you will take part in a semi-structured interview, conducted by Dr Heidi Green via Zoom. During the interview, you will be presented with a case study related to sharing general practice data for research. Following, you will be asked questions to reflect on or highlight key issues that you see as relevant to your role and general practice.

4. How much of my time will the study take?

The semi-structured interviews will run for approximately 45 – 60 minutes on the Zoom video conference platform.

5. Who can take part in the study?

We will be selecting 20 practice managers and/or practice owners nationally from a range of practice types and general practice locations to participate in the interviews.

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

Participation in this research project is voluntary. If you do not wish to take part, you do not have to participate. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage before your information is analysed by researchers and integrated with information from other participants. This will be up until 2 months after your interview date. After that time, we will have analysed the data and begun the publication submission process.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your relationship with any of the Project Partners. If you do decide to take part, you should keep a copy of this Participant Information Sheet.

Withdrawal from the study can be organised by contacting the lead Chief Investigator Senior Professor Annette Braunack-Mayer (Ph 02 4298 1228 or 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 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?

There are some possible risks involved in participating in this research project and we have developed certain strategies to mitigate those risks.

There is a potential <u>risk of re-identification</u>. To mitigate this risk:

- All interview audio recordings will be destroyed once they are transcribed and checked.
- Once the interview data has been analysed, all identifiers will be removed from the interview transcripts and replaced with a code, which will be stored separately to the interview transcripts.
- Only three researchers will have access to this identifiable information, Senior Professor Annette Braunack-Mayer, Dr Heidi Green and Ms Lucy Carolan.

It is possible that, in the course of the interview, you may be asked to discuss an <u>issue that is confidential</u> or that otherwise makes you uncomfortable. To mitigate this risk:

- If you do not wish to answer any question or discuss any issue, you are free to say so and we will simply move to the next question.
- There will be no pressure to answer any question or discuss any issue that makes you uncomfortable.
- If you wish to stop the interview, or take time out to consider your response, please indicate this to the interviewer.

There may be <u>time inconveniences</u>, which we have tried to minimise by scheduling the interviews at a time that works best for you.

8. Are there any benefits associated with being in the study?

We cannot guarantee that you will receive any benefits from this research; however, possible community benefits may include improved regulatory arrangements for the use of general practice data for research, leading to greater confidence in and use of the data. Our aim is to develop a best practice model that will enhance the social, ethical and legal acceptability of the use of general practice data for research to better realise the potential of these data for research in Australia. You will be provided with a \$250 e-Visa Gift Card as a thank-you for your time.

9. What will happen to information about me that is collected during the study?

By consenting to participate in this research, you consent to the research team collecting and using personal information about you for the research project. All information collected from you will be stored on secure University of Wollongong servers. Only members of the research team who require access for analysis will have access to this identifiable information – Senior Professor Annette Braunack – Mayer, Dr Heidi Green and Ms Lucy Carolan. Once the identifiable information has been analysed, personal details and organisational details will be removed and replaced with a code. The codes will be stored separately from the interview information. All data will be stored securely and disposed of five years after the completion of the project.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that neither you, nor your organisation, can be identified. The research results will either be aggregated or will be presented using pseudonyms or codes. Any quotes used will be assessed to ensure that they do not inadvertently identify you or your organisation.

Any information obtained for this research project that can identify you will be treated as confidential and securely stored.

10. What if I would like further information about the study?

When you have read this information, Senior Professor 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 Senior Professor Braunack-Mayer (Ph 02 4298 1228 or 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 at the end of 2025. If you would like to be contacted with results, please let Dr Heidi Green 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: 2025/060). 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).

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 to register your interest.