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PARTICIPANT INFORMATION STATEMENT

Building public confidence in the secondary use of general practice data for research: Modified Delphi Survey with General Practitioners

(1) What is this study about?

You are invited to take part in a research study investigating General Practitioner (GP) views on 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 GPs on these issues are critically important. 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	alberto_nettel-aguirre@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

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 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, you will take part in a modified Delphi survey. The Delphi method is a form of survey where panels of experts answer questionnaires in two or more rounds. After each round, the experts are provided with an anonymised summary of the previous round of responses. Then experts are encouraged to revise their earlier answers in light of the replies from other members of their panel. In this study, we will anonymise and summarise the results from three rounds of survey, inviting participants to comment further with the aim of reaching a consensus by round three.

The modified Delphi survey is expected to take approximately 20 minutes to complete (per round). Each time you will be asked a series of questions relating to sharing general practice data for research, including questions about recommendations recently proposed by two community juries* conducted earlier in 2023. You will be asked about the extent to which you support these recommendations and how easy or difficult it would be to implement these recommendations in general practice.

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

Each modified Delphi survey will take approximately 20 minutes to complete. The modified Delphi survey rounds will be open for 3-4 weeks per round and expected that the surveys will take 60 minutes in total over the three rounds. The surveys will be administered using the Qualtrics software.

(5) Who can take part in the study?

We will be selecting 50-75 participants who have interest and expertise in general practice research. Our goal will be to constitute broadly inclusive group, with a range of years in general practice, genders, cultural backgrounds, from a range of geographic areas (urban, regional and rural), sizes of general practice, and role in practice (owner, employee) in order to recruit as diverse a sample as possible.

(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 researchers or anyone else at the University of Wollongong.

If you decide to take part in the study and then change your mind later, you are free to withdraw up until you have submitted the last Delphi survey round three without having to give a reason. 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).

** Community juries bring a group of people together to discuss, deliberate and develop solutions to policy issues. The jury members are provided with information and encouraged to work together to come up with recommendations that focus on the collective needs of the whole community. Our research team held two community juries with members of the community in Sydney (July 2023) and Melbourne (August 2023). Each jury considered the charge 'Under what circumstances, if any, should we share general practice data for research purposes?'. The jury members were provided with information by expert witnesses with the opportunity to question experts, interspersed with structured deliberation supported by guiding questions.*

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. Aside from giving up your time, we do not expect that there will be any risks or 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 GPs' views on using information from general practice records for research, 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 tools to guide future policy and practice. The wider community will benefit through the integration of our findings into development and implementation of policies surrounding sharing general practice data for research. Participants will be provided with a \$125 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 modified Delphi will only be accessible to members of the research team. They will be kept on a password protected server. The study results will be presented at conferences 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).

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

When analysis of the modified Delphi data is complete, researchers will provide participants with a summary of the findings. This will likely occur in mid-2024.

(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: 2023/348). 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.