



Data for Decisions

Information for General Practices

Your practice is being invited to contribute to *Data for Decisions* and the Patron program of research. Please take time to read this information and ask questions about the research program. Please ensure that you understand what is involved in participation and discuss with other practice members before consenting to take part.

What are *Data for Decisions* and Patron?

Data for Decisions is a research initiative that aims to provide primary care data for research in an ethical and secure way. Patron is a database of general practice data managed by The University of Melbourne (part of the Data for Decisions initiative). The Patron database consists of non-identifiable data extracted from general practice electronic medical records. This data includes de-identified information about immunisations, medicines prescribed, illnesses, pathology and radiology results, measurements such as height, weight and blood pressure and lifestyle factors, such as alcohol intake and smoking habit. The data will be used for research investigating medication safety, disease patterns, prescribing patterns, health economics and public health. These studies will provide useful information to health professionals and the wider community on diseases, the use of medications and the outcomes of disease or treatment and will also help to guide training of medical students. Studies may be undertaken by academic researchers, government bodies or commercial companies.

What is involved in taking part?

If you agree to participate, The University of Melbourne will arrange to install the data extraction tool, GRHANITE, on a computer at your practice, or for Best Practice practices, to connect via the BP HALO interface allowing the GRHANITE data extraction solution to run. Your practice may wish to undertake additional data cleaning to improve the quality of data in the electronic medical record.

You may also be contacted by researchers at The University of Melbourne to participate in research studies related to Data for Decisions. You are under no obligation to participate in these if you do not wish to. Your decision to participate in Data for Decisions or its related activities, or not, will not affect your relationship with The University of Melbourne.

Contact us for further information



Data for Decisions Department of
General Practice and Primary Care
The University of Melbourne
Level 3, Medical Building
Parkville Victoria 3010



03 8344 3392s



vicren-enquiries@unimelb.edu.au



gp.unimelb.edu.au/datafordecisions



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code for more
information

Information for General Practices

How will practices be informed on an on-going basis?

An annual newsletter shall be distributed keeping you and your colleagues informed of projects being undertaken. The University of Melbourne's Department of General Practice and Primary Care website shall also inform general practice and consumers of activities related to *Data for Decisions* and Patron.

Does GP, practice and patient data remain confidential?

Details of participating practices and GPs will remain confidential. The data extraction tool GRHANITE encrypts data prior to transmission from the practice to Patron, or for Best Practice practices from the BP HALO interface to Patron, and will render it non-identifiable to researchers. No practitioner or patient personal details are contained in the Patron database.

Findings from projects utilising data stored in Patron may be presented at national conferences and published in peer-reviewed journals or reports. All data will be in an anonymised and aggregated format, to ensure the anonymity and confidentiality of participating practices, GPs and their patients.

Commercial entities

Commercial entities may apply to access Patron data or may provide funding to researchers to undertake research. A condition of the latter is that researchers retain the right to publish research findings regardless of the outcome of the study.

How will data be protected?

Any research data collected will be kept confidential subject to legal requirements and maintained in accordance with The University of Melbourne's Code of Conduct for Research. All Patron data is curated by The University of Melbourne and kept on secure servers. All provided program-related information is kept secure, in locked storage at the Department of General Practice and Primary Care at The University of Melbourne, or on a password-protected server at The University of Melbourne.

The de-identified research data will be kept by the research team for five years after the last publication of any data related to the Patron program of work, as stated in the NHMRC ethical guidelines, and then destroyed or deleted in keeping with Department of General Practice and Primary Care policy. Projects utilising Patron data will be required to sign a legal agreement outlining terms of data use. They retain the data, as stated in NHMRC ethical guidelines, for a minimum of five years. This may vary depending on the type of study undertaken.

What are the consent options?

If you decide to participate you will be asked to sign a consent form and legal agreement. The consent form gives you the option to agree or not to:

- de-identified data from your practice being utilised by researchers undertaking research funded by commercial entities, or to be accessed by commercial entities
- have your practice acknowledged as a partner in the program, on the *Data for Decisions* website
- to the inclusion of your practice's de-identified and anonymised clinical progress notes. The anonymisation happens before the data is sent to the Patron data repository ensuring patient anonymity. It retains the context of the notes for research purposes but ensures patient privacy is protected

What are the benefits of participating?

You will be contributing to a research program that aims to understand general practice activity, improve clinical practice and patient outcomes in the future. Through your participation, you might have opportunity to invite some of your patients to participate in clinical trials – benefits of such for patients can include improved health outcomes.

How can I find out more about the research study findings?

As researchers conclude their studies, research study findings and publications will be available from the projects webpage via the website:

gp.unimelb.edu.au/datafordecisions

Are there any risks associated with participating in Patron?

We do not anticipate any risks associated with participation in Patron. We do not expect that GRHANITE, will cause any hardware or software problems. The data extraction and reporting tool has been tested extensively with the clinical software programs that participating practices use. Trained IT staff from The University of Melbourne will guide your installation of the data extraction tool and will be available to provide support as required.

Researchers and ethics approval

Data for Decisions is being conducted by the Department of General Practice and Primary Care and the GRHANITE Health Informatics Unit at The University of Melbourne. The program researchers are:

- Prof Lena Sanci
- Prof Jane Hocking
- Prof Douglas Boyle
- A/Prof Kylie Vuong

The Patron program of research was approved by The University of Melbourne Human Research Ethics Committee on 12/12/2016 (HREC 1647396) and renewed on 20/12/21 (HREC 23358).

Further information and contacts

Thank you for taking the time to read this information. Should you have any questions about the research program at any stage, please do not hesitate to contact us:

P: (03) 8344 3392

E: vicren-enquiries@unimelb.edu.au

If you have any concerns or complaints about the conduct of the project, please contact the Research Integrity Administrator. All complaints will be treated confidentially. In any correspondence please provide the ethics ID number HREC 23358

P: (03) 8344 1376

E: research-integrity@unimelb.edu.au

*VicReN is a Victorian primary care practice-based research and education network managed from The University of Melbourne