



THE UNIVERSITY OF
MELBOURNE

Faculty of Medicine,
Dentistry & Health
Sciences

Data for Decisions

Information Statement for General Practices

Your practice is being invited to contribute to the Patron database and program of research, part of the *Data for Decisions* initiative. Please take the 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 deciding whether 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). Patron consists of non-identifiable data extracted from general practice electronic medical records. This data includes 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 University of Melbourne does not have access to practitioner or patient personal details, only to de-identified medical records. The data will be used for research into topics such as 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. These studies may be performed by academic researchers, government bodies or commercial companies amongst others.

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. Your practice may wish to undertake additional data cleaning to improve the quality of data in the electronic medical record. This may be undertaken by practice staff other than GPs (e.g., removing inactive patients) and by GPs (e.g. applying diagnosis codes to relevant patients where free text was used for diagnoses). Some practices may be asked to participate in a validation study where data extracted by GRHANITE and stored in Patron is compared to data in the practice.

For further information please contact

Patron
Department of General Practice,
The University of Melbourne
200 Berkeley Street
Carlton Victoria 3053

03 8344 3392

vicren-enquiries@unimelb.edu.au

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

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

An annual newsletter shall be distributed keeping you and your colleagues aware of projects being undertaken. The newsletter shall contain contact details for the *Data for Decisions* and Patron programme should you wish to discuss any aspects, including your continued practice participation. Web-pages within the University of Melbourne's Department of General Practice 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 and will render it non-identifiable to researchers. In the case of electronic data, all will be stored on secure servers curated by University of Melbourne technical experts. Any paper-based records or data will be stored in locked cabinets in a secure area of the Department of General Practice at the University of Melbourne.

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 information provided will be kept secure, in locked storage at the Department of General Practice 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 5 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 policy. Projects utilising Patron data will be required to retain data as stated in NHMRC ethical guidelines which may vary depending on the type of study undertaken; this will be for a minimum of five years.

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. Also, if you wish, you may have opportunity to join a Community of Practice that can contribute to the shape of research that is related to the Patron dataset.

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, the data extraction tool used in the project, 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

The Patron program of research is being conducted by the Department of General Practice and the GRHANITE Health Informatics Unit at the University of Melbourne. The researchers on this program of work are Prof Jane Gunn, Prof Jon Emery, Prof Jane Hocking, Assoc Prof Douglas Boyle, Assoc Prof Lena Sanci and Dr Jo-Anne Manski-Nankervis. The Patron program of research was approved by the University of Melbourne Health Research Ethics Committee on 12/12/2016 (HREC 1647396).

Further information and contacts

Thank you for taking the time to read this information. Should you have any questions about the research program, either prior to agreeing to participate or once your participation has been established, please do not hesitate to contact the VicReN* Manager on (03) 8344 3392, or email vicren-enquiries@unimelb.edu.au.

The Patron program of research has been approved by the Human Research Ethics Department, University of Melbourne.

If you have any concerns or complaints about the conduct of the project, please contact: Ms. Kate Murphy, Manager, Human Research Ethics, Office for Research Ethics & Integrity, the University of Melbourne, 3010.
P: (03) 8344 2073
E: HumanEthics-complaints@unimelb.edu.au

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