

# Introduction

## Data for Decisions & the Patron program of research

### Project Aim

To make better use of existing primary care data, grow research capacity and data quality, and improve knowledge, medical education, health care policy and the way medical care is delivered.

### History

*Data for Decisions* and the Patron repository adhere to national and international best practice guidelines. The first general practices consented in 2018 and the first researchers accessed data in early 2019.

### Due Process

Researchers using data from Patron must gain approval from an NHMRC approved ethics committee, the independent Data Governance Committee, and commit to a legal agreement stipulating terms of data use.

### Researchers

Prof Jon Emery

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Prof Jane Hocking

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Dr Jo-Anne Manski-Nankervis

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The Patron program of work is part of the Data for Decisions research initiative. The program was established by the Department of General Practice, The University of Melbourne, in partnership with general practice.

### Our Commitment

*The University of Melbourne is committed to the ethical advancement of health-related research to improve population health by enabling controlled 'secondary' use of data that has previously been collected for other purposes.*

We are committed to project transparency, data security and protecting privacy. We de-identify both **patient AND practitioner**-related information. Data re-identification is only possible within the practice by the practice using their unique re-identification key.

The Patron program is not-for-profit and adheres to the ethical principles in the *National Statement on Ethical Conduct in Human Research*. We are committed to making research outcomes accessible and to publishing research findings. We work with a GP network to design research studies and to facilitate practice improvements and innovation. Curated data is held only within University controlled, on-shore, secure data storage facilities.



### Data for Decision's Patron Program in a nutshell

1. A University of Melbourne developed and controlled software program (GRHANITE™) is used to securely de-identify and collect information from general practice patient records from partnering practices.
2. Because the patient (and practitioner) information is de-identified, patient consent is not required, but patients can 'withdraw' if they choose. Participating practices need to ensure that practice staff agree to the data collection.
3. The de-identified data stored within the Patron repository – an enduring dataset that facilitates research and knowledge generation.
4. An independent data governance committee oversees the appropriate storage and use of the data, assessing all applications for use of data.
5. Researchers apply to access the data to undertake clearly defined studies. They must meet strict **legal and ethical standards** and agree to make available plain language summaries of their research findings.
6. GPs can choose, at their discretion, whether to be involved in additional research or clinical trials that might arise relating to *Data for Decisions* and the Patron program of work.
7. Feedback is provided to GPs and opportunities for quality improvement.

## Frequently Asked Questions

### What is Data for Decisions and the Patron program of work?

*Data for Decisions* is a University of Melbourne research initiative in partnership with general practices. It is an exciting undertaking that makes possible primary care research projects to increase knowledge and improve healthcare practices and policy. The Patron program invites general practices to contribute de-identified patient data, and researchers are invited to apply to access curated data held in the Patron primary care data repository.

### What is de-identified data?

De-identified patient and practitioner data has information that links it to an individual removed from it (e.g. NO name, address, full date of birth). In this program, the patient and practitioner data are de-identified before it leaves the general practice so researchers do not know people's identity.

### Why is Data for Decisions needed?

Most Australians receive most of their healthcare from GPs, yet only a fraction of research occurs in the primary care space. Usually, when data are collected from GPs for a research study, it can only be used for that one study. A lot of time and money is spent recruiting general practices to participate in research, and this is duplicated over and over at great cost. This program enables data reuse for projects deemed worthy by an independent committee.

### How does the program work?

When general practices consent, a data extraction software tool, GRHANITE™, is installed on a practice computer. This tool interfaces with the general practice clinical software program (e.g. Medical Director, Best Practice, Zedmed) to de-identify data before it securely transmits it (using encrypted transmission) to a University of Melbourne controlled secure data storage facility.

### How ready is GP clinical data for research?

Some GPs think their data is not complete enough to share. As part of the program we can use statistical methods to manage missing data.

### What is the impact to practice work-flow?

Participation in *Data for Decisions* can be a way for general practices to be involved in research without having to commit much time. The data extraction software (GRHANITE™) is designed to work seamlessly with general practice software. When a general practice agrees to take part, our trained IT staff remotely install the data extraction tool onto a designated computer at the practice. Practice staff should not notice any difference to their day-to-day use of their computer system as a result of installing GRHANITE™.

### Can GPs share data with other institutions if they are participating in Data for Decisions?

YES! For example, many general practices share data with multiple organisations using a variety of tools such as GRHANITE™, Pen CS and POLAR. Using one tool does NOT prevent other tools from also being used.

### Is there any risk associated with the research program?

There is little risk associated with participation in *Data for Decisions*. The data extraction tool (GRHANITE™), developed at the University of Melbourne, has been extensively used for over 10 years. This project builds on this experience and testing and many proactive risk mitigation strategies and quality assurance mechanisms in place – including regular checks by the University's Cyber Security team.

### What is data linkage?

GRHANITE™ enables privacy-protected record linkage so research can link, for example, primary care data with hospital and registry data, so that more can be learned about onset and progression of disease, care pathways and patient outcomes.

## Our core principals

- ✓ Not for profit
- ✓ In partnership with general practice and healthcare consumers
- ✓ Maintain transparency in project aims, data management and use
- ✓ Protect patient and practitioner privacy
- ✓ Employ proactive data security and risk management strategies to ensure safe and privacy protected use of data
- ✓ Engage with general practice to ensure that research undertaken is clinically relevant and appropriately interpreted
- ✓ Provide useful and wanted feedback to general practices
- ✓ Connect data and disciplines to maximise new knowledge

Information videos are available at:  
[gp.unimelb.edu.au/datafordecisions](http://gp.unimelb.edu.au/datafordecisions)

## Get in touch

[www.gp.unimelb.edu.au/datafordecisions](http://www.gp.unimelb.edu.au/datafordecisions)

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