



THE UNIVERSITY OF
MELBOURNE

—
Department of General Practice
Faculty of Medicine, Dentistry and Health Sciences

Patron Data Governance Committee

Terms of Reference

15 March 2019



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Glossary

Term	Description
Approved project	Project status once a request for access to Patron data has been approved by the Patron Data Governance Committee.
Data Custodian	The Data Custodian is the Head, Department of General Practice and is ultimately responsible for the data contained in the Patron database.
Data Governance Framework	A document that details data governance arrangements for the Patron database and the Patron program more broadly, including details on procedures related to the operation of the Data Governance Committee.
Data for Decisions	A research initiative within The University of Melbourne Department of General Practice that incorporates the Patron database and program of work.
Data Steward	The Data Steward has the delegated responsibility to manage the physical security and other data curation activities of the Patron data collection.
HaBIC R²	Health and Biomedical Informatics Centre – Research Information Technology Unit, Department of General Practice, The University of Melbourne
Patron database / data repository	The Patron database is a secure repository of de-identified primary care data housed within The University of Melbourne, it is part of the Data for Decisions research initiative.
Patron program	The Patron program of work encompasses approved use of de-identified general practice patient data from the Patron database. The Patron program is incorporated within the Data for Decisions research initiative.
Principal Investigator	The Principal Investigator is named on the Patron program ethics application (HREC ID 1647396).
Program Management Group	Provides advice and support to the Patron Data Governance Committee, including feasibility review of Data Request Applications, communicating with researchers seeking access to Patron data, and day to day operation of the Patron program.
Standard Operating Procedures	A document detailing the management of data held within the Patron database, including data compliance, quality, retention, security, warehousing, conditions and scope of use, incident reporting, and ethics review process.

Background

The University of Melbourne ('the University') and its Department of General Practice recognise the value and potential of primary care data for research, policy development and teaching, and our ability to utilize the GRHANITE™ technical platform to obtain such data for these purposes in an ethical manner. *Data for Decisions* (incorporating the Patron primary care data repository and program of work) is a research initiative based within the Department of General Practice (Faculty of Medicine, Dentistry and Health Sciences) that seeks to make better use of existing primary care data to improve knowledge and ultimately improve health systems, services and practices to benefit Australian. The Patron program of work collects, curates and makes available de-identified primary care data for research, policy development and teaching purposes. The Patron program commenced with its successful approval by The University of Melbourne's Human Research Ethics Committee (HREC) on the 12th December 2016 (ethics ID number 1647396). The Patron data repository operates within a robust technological, legal and ethical landscape which is detailed in the Patron Data Governance Framework. An establishment committee played a governance role at the commencement of the Patron program (2016) to provide oversight from start-up to the establishment of the independent Data Governance Committee. See also www.gp.unimelb.edu.au/datafordecisions

The Patron Data Governance Framework outlines the program's governance procedures, the legal and ethical environment within which the program operates, and provides a framework for the identification and management of privacy risks. The Data Governance Framework is dynamic and subject to change.

Guiding principles: Patron program of research

- Ethical and transparent collection, monitoring and use of data in partnership with primary care practice and consumers.
- That international good practice data security standards and proactive risk mitigation strategies are employed when collecting or handling data to protect privacy (as per Australian legal and regulatory requirements).
- The generation of meaningful knowledge to answer consumers', clinicians', policymakers' and researchers' questions to advance primary care and improve health services and health outcomes.
- Connecting disciplines and de-identified datasets to build understanding of health systems and the patient journey.

This document describes the purpose, functions, membership, operation and reporting structure of the Patron Data Governance Committee ('the Committee') and should be read in conjunction with the *Patron Data Governance Committee Operational Instructions and Guidelines* which provide greater detail on Committee procedures. The Committee is supported by a Program Management Group which includes the Committee Secretariat, and HaBIC R² technical and implementation staff. The management group provides independent advice to the Patron Data Governance Committee on the suitability of the projects, the researchers and their institutions to access Patron data. The composition and relationship of the Committee with the Head of Department (Data Custodian), named researchers, the Program Management Group, and researchers seeking access to data, is shown at [Appendix A](#).

Purpose

With advice from the Data Steward and the Patron program researchers, the Committee provides independent advice and decision-making to ensure ethical and transparent use of Patron data within the *Data for Decisions* research initiative.

Functions of the Committee

1. To oversee the Patron Data Governance Framework and Standard Operating Procedures in accordance with University of Melbourne research ethics and legal requirements.
2. To review applications for access to Patron data and be responsible for approval of projects using Patron data.
3. To provide advice to the Patron Data Custodian, the Program Principal Investigator and the Data Steward on the application process in accordance with the Patron Data Governance Framework.
4. To provide advice to program technical support staff on incident management, and to refer incidents to The University of Melbourne Human Ethics Committee (HREC), where appropriate, and in line with the Patron Data Governance Framework and Standard Operating Procedures.
5. To contribute to the development and execution of transparent and efficient processes for the approval of data access for research, teaching and policy development.

Chair and membership

Membership

Committee members should represent key stakeholder groups, as follows:

- 2 consumer representatives (if possible include a patient from a practice contributing data);
- 1 member from a general practice contributing data to the program (non-University of Melbourne: e.g. CEO, practice manager, practice owner);
- 1 legal representative or legal academic (to provide international perspective, not from The University of Melbourne Legal Services);
- 1 to 2 end users of data (e.g. researchers. Ideally both should not represent The University of Melbourne);
- 1 to 2 GP representatives: from VicReN (Victorian primary care practice-based Research Network) and/or contributing data to the program;
- 1 to 2 representatives from general practice professional associations or other bodies (e.g. Royal Australian College of General Practitioners, Primary Health Networks).

One consumer representative should be a member of the Department of General Practice Health Users Advisory Group. One general practice representative should be a member of the General Practice Advisory Group. See Appendix A.

Procedure for becoming a member

A potential member can be identified via nomination by an existing Committee member, expression of interest / advertisements based on identified knowledge gaps, and unsolicited expressions of interest received directly from interested individuals.

Appointment

The Data Custodian (*Head of Department of General Practice*) shall appoint members of the Patron Data Governance Committee by direct letter of invitation.

Selection of Chair

The Chair and Deputy Chair of the Data Governance Committee may not be an employee of The University of Melbourne. The Chair and Deputy Chair will be selected by the Head of Department of General Practice, in consultation with the Head of the Melbourne Medical School and the Associate Dean of Research, Faculty of Medicine, Dentistry and Health Sciences, The University of Melbourne.

Tenure

The tenure of members of the Patron Data Governance Committee will be 2 years. The *Head of Department of General Practice* may remove or replace any member at any time. Members may have two consecutive 2 year periods on the Committee.

Member numbers

The Patron Data Governance Committee will consist of no fewer than 8 members and a maximum of 10 members, excluding the secretariat and the Data Steward who shall provide advice to the Committee.

Remuneration

Committee members receive remuneration for their time (excluding staff of the University of Melbourne). Member contributions will also be recognised in any reports resulting from the Patron Committee meetings. A list of Committee members will be published on the *Data for Decisions* website including an indication of each member's area of expertise.

Responsibilities of members

Patron Data Governance Committee members are expected to be active participants and contribute to the work of the Committee. Committee members have the following responsibilities:

1. To provide impartial and independent advice to support the work of the Patron program of work;
2. To contribute appropriate up to date advice that is relevant to their agreed area(s) of expertise;
3. Declare any real or perceived conflict of interest;
4. Accept that all deliberations of the Committee are confidential, including discussions, correspondence and advice provided. Members will sign a confidentiality agreement (non-disclosure agreement).

Operating procedures

Secretariat

The Secretariat of the Committee will be provided by the Department of General Practice. All records, including the agenda, minutes and any reports or recommendations will be prepared and managed by the Secretariat.

Notice for Committee meetings

Members of the Committee should be provided with adequate notice before a meeting is to be convened. The Secretariat will provide administrative support to set up an annual planner or other document providing notice of upcoming meetings.

Agenda, minutes and reports

The secretariat will draft and prepare the agenda for the committee meeting in consultation with the Committee Chair. All meetings will be minuted by the Secretariat and will be promptly finalised and distributed. The minutes of the previous meeting will be tabled at the next committee meeting for approval. Reports to researchers applying to access data will be prepared by the secretariat in consultation with the Committee Chair and the Data Steward.

Quorum

A minimum of fifty percent of current members.

Frequency of meetings

The Committee will meet as frequently as is necessary to undertake its role effectively and, in any event, at least 3 times per year and to a maximum of 6 meetings per year.

Location of Committee meetings

Generally, the location for meetings will be at the Department of General Practice Boardroom, Faculty of Medicine, Dentistry and Health Sciences, Melbourne Medical School, The University of Melbourne, 200 Berkeley Street, Carlton, Victoria 3053. Video conferencing facilities are available.

Transparency

The Committee will operate transparently. Meeting agendas and minutes will be made publicly available on request. Detailed researcher data access requests and the Committee's decision reports to researchers remain confidential.

Reporting

The Committee operates independently and provides advice to the Data Custodian (Head of the Department of General Practice) and Principal Investigator.

The composition and relationship of the Committee with named researchers and researchers seeking access to data is shown in Appendix A.

The Committee secretariat will provide a written report to the Data Custodian and Principal Investigator immediately following a Committee meeting via briefing notes, draft minutes or other means as required. In consultation with the Chair and the Data Steward, the secretariat will report back to researchers seeking access to data following the relevant Committee meeting.

An annual report for the Data Custodian, Data Steward and Principal Investigator, produced by the secretariat in consultation with the Committee Chair, will summarise Committee decisions and their outcomes.

Conflict of interest

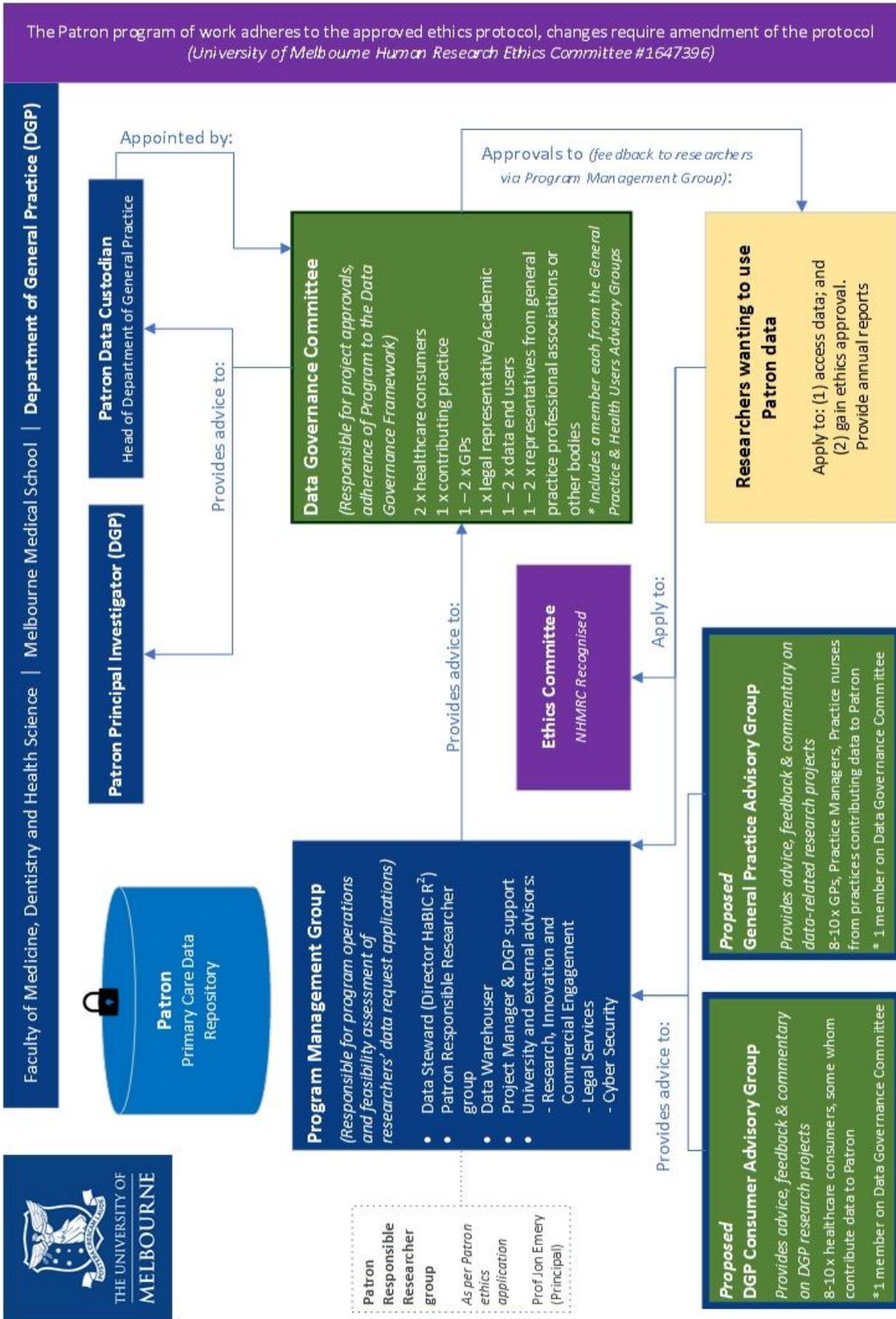
Prior to specific issues being considered by the Committee, members should declare any perceived, actual or potential conflicts of interest and vested interests that may, or may be perceived to, hinder their contribution to providing objective advice about that issue. These interests should be documented by the Secretariat. A member with a declared interest and the Chair should take and document appropriate actions to ensure that the interest does not affect the discussion of the issue or the advice developed from those discussion.

Evaluation

The Committee will review its performance against the Terms of Reference and the Patron Data Governance Framework at least every two years and make recommendations to the Data Custodian and Data Steward via its reports.

Committee membership will be subject to regular review to ensure appropriate stakeholder representation.

Appendix A: Patron Data Governance and Advisory Groups



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