

RITHIM

Privacy Community of Practice

Terms of Reference

May 2020

1.0 PURPOSE

The RITHIM Privacy Community of Practice (PCoP) is a community of practice with representation from hospitals, RHAs and institutions where health research takes place in Manitoba. PCoP represents a group of professionals, informally bound to one another through exposure to common challenges and common pursuit of solutions. PCoP provides a forum for developing social capital, nurturing new knowledge, stimulating innovation, and sharing knowledge. PCoP will provide a forum to have an ongoing dialogue around issues related to the review of access to data and privacy review of research protocols in Manitoba. This group will allow members to expand their professional network, nurture new knowledge, stimulate innovation, and share knowledge around best practices, common language, and standards of review. PCoP will provide advice and expertise to collaborative efforts that aim to harmonize the ethics, impact, and privacy approval process for health research in Manitoba.

The purpose of PCoP is to contribute to bodies of knowledge around privacy review and access to data for research protocols in Manitoba and act as a forum for discussion around the development of provincial working rules and SOPs. PCoP will describe and communicate the key concerns, considerations and common challenges of access to data and privacy review as it relates to research in Manitoba. The committee will do this by:

- a. Contributing to **bodies of knowledge** around access to data and privacy review for research in Manitoba including leading practices, common understanding of legislation, guidelines, knowledge repositories, technical problem and solution discussions, working papers, and strategies.
- b. **Supporting the establishment of best practices and provincial standards** for privacy review
- c. Supporting the **planning, implementation and evaluation** of provincial research harmonization efforts through **subject matter expertise** and data to support decision making
- d. Foster **strategic partnerships** with RITHIM stakeholders and promote engagement
- e. **Provide feedback to RITHIM** project team throughout the process of implementation of RITHIM and on a continuing basis.

2.0 CHAIR AND MEMBERSHIP

Leadership

The RITHIM Privacy Community of Practice will be co-chaired by Jason Berry and Karen Meelker

RITHIM Privacy Community of Practice (PCoP) Membership:

- Brandon University
- CancerCare Manitoba
- Concordia Hospital
- Deerlodge
- First Nations Health and Social Secretariat of Manitoba
- Grace Hospital
- Health Sciences Centre
- Interlake Eastern Regional Health Authority
- Manitoba Department of Families
- Manitoba Department of Health, Seniors and Active Living
- Manitoba Department of Justice
- Misericordia Hospital
- New Directions
- Northern Regional Health Authority
- Pan Am Clinic
- Prairie Mountain Regional Health Authority

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- Red River College
- Research Manitoba
- Seven Oaks General Hospital
- Shared Health Inc.
- Southern Regional Health Authority
- St. Amant Centre
- Victoria Hospital
- University of Manitoba
- University of Winnipeg
- Winnipeg Regional Health Authority
- Researchers (2)
- Patients (2)

Additional members to be identified and suggested by initial membership and approved by the committee. It is important for this group to hear patient and researcher perspectives on privacy as it relates to research, and therefore we will try to have regular patient and researcher members attend meetings. From time to time, the group may call upon other specialists from key functional areas whose participation will be “on invitation”.

RITHIM Privacy Community of Practice - Working Groups

Working groups may be struck as needed as determined by the community of practice. Working group members do not need to be members of PCoP, and may be drawn from external leads as needed.

PCoP Administrative Support

Administrative support for PCoP will be provided by Research Manitoba. The RITHIM manager(or director) will work with the Chairs to develop agendas, organize follow-up on action items and manage communication with the group.

3.0 FUNCTIONS

The RITHIM Privacy Community of Practice is committed to improving our capacity to effectively address gaps in Research approval process due to organizational inconsistencies by:

- ⇒ Support the implementation of RITHIM recommendations by providing advice to the project team on matters related to access to data and privacy review of research, change management and overall system enhancement.
- ⇒ Review/Develop common understanding of privacy legislation to reduce inconsistencies in interpretation across the province, and to support research in Manitoba
- ⇒ Review/Develop evidence-based bodies of knowledge that will support research harmonization, identification of best practices, common challenges and education

4.0 DECISION MAKING

Decision making is by majority (50% + 1). It is noted that at times conflict may arise either within group discussion or in relating to others such as partners. At all times, consideration will be maintained, but respectful differences of opinion should be viewed as creating opportunity for dialogue, growth and change.

5.0 MEETINGS

Throughout RITHIM implementation, PCoP will meet once every eight weeks or at the call of the co-chairs.

6.0 AGENDA FORMAT

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- Welcome, introductions
- Review agenda
- Review previous minutes and approval
- Business arising from previous minutes
- New business
- Round table discussion
- Next steps
- Next meeting
- Adjournment

7.0 TERMS OF REFERENCE

The PCoP, on an annual basis or as necessary, shall review its terms of reference.

8.0 COMMITTEE MAP



CHIPER Governance Structure

(Committee for Health Impact, Privacy, and Ethics Review)

