

Perinatal Services BC Research Review Committee Terms of Reference

Preamble

The Perinatal Data Registry (PDR) is a repository of secondary administrative data that is collected on hospital and home births across British Columbia. Since 2000, the PDR has been a comprehensive source of information for surveillance, quality improvement, policy development, and research on maternal and newborn health. Many of these functions can be fulfilled by the sharing of aggregated, de-identified data. However, research often requires that investigators are able to access and work with row-level about specific individuals within the dataset. This release of this information requires a rigorous review to ensure that the data being released is being used for appropriate and bona fide research projects by authorized individuals. It also requires that the minimum amount of data required to complete the research is released and that any access occurs in a secure setting. Any products of research from requested data are required to be reviewed by Perinatal Services BC (PSBC) prior to release.

Authority over *Level 3 - Identifiable Data* held at PSBC is delegated to the Provincial Executive Director and PSBC's Research Review Committee by Memorandum of Agreements and Partnership Accords with each Health Authority in BC and with the Ministry of Health. These agreements set out the criteria for releasing identifiable data:

- The request must be from a bona fide researcher accredited by an Institute of Technology/University or an individual affiliated institution or hospital.
- The request must pertain to an identified research project that has received prior ethics and peer review approvals from an academic institution, or other publicly funded body (e.g. hospital Perinatal Committee).
- The request must be formally submitted to the Perinatal Research Review Committee of the BCPDR for review and final approval.
- In the event linked health data is required, the Access Policy for Research Uses of Linked Health Data used by the Centre for Health Services and Policy Research at the University of British Columbia (1998) will be applied.
- Terms, conditions and the procedure(s) for the release of personal information (patient name or PHN) for research purposes will be formally documented by the BCPDR and must be in conformance with the Freedom of Information and Protection of Privacy Act (FIPPA) legislation.

Purpose

The purpose of the Research Review Committee (RRC) is to review all Researcher requests of Level 3 – Identifiable data as well as aggregate data requests for research purposes in accordance with FIPPA and other applicable legislation, ethical considerations, and best practices. The RRC members will provide expert advice and make recommendations to PSBC on the release of data that protect the privacy and security of personal information, and enable the appropriate use of this information in support of research.

Eligible Researchers

A researcher is:

- Either a student, teacher, or other individual enrolled, appointed or employed by any of the following:
 - A university, where the university status is defined under the *BC University Act*.
 - A college, university college or provincial institute as defined under the *Colleges and Institute Act* R.S.B.C. 1996, c. 52.
 - The Open Learning Agency as continued under the *Open Learning Agency Act* R.S.B.C. 1996, c. 34.
 - Royal Roads University continued under the *Royal Roads University Act* R.S.B.C. 1996, c. 409.
 - Another equivalent educational institution in another jurisdiction outside B.C. but within Canada.
- Any other individual agreed to by PSBC

Authority

The Committee is accountable to the Provincial Executive Director, PSBC.

If a Data Access Request (DAR) includes data that is stewarded by BC Women's or Children's Hospital, the request must be sent to the PHSA Data Analytics, Reporting & Evaluation team (DARE). They are responsible for seeking approval from the Data Steward prior to a research DAR being approved by the RRC.

Responsibilities

The responsibilities of Committee members are as follows:

- Review all data requests requiring personally identifiable information and other sensitive data elements
- Assess data requests against study questions in the research proposal
- Provide expertise in current privacy laws and practice
- Recommend acceptance or amendment of requests
- Abstain from participating in discussions/decisions where conflict of interests exist
- Review the minutes and distributed materials and notify PSBC of any errors or omissions

Membership

The committee will consist of seven voting members including the chair, who will be the Director, Quality and Research. Membership should include, but is not limited to, members with the following backgrounds:

- Researchers, academics, and individuals with specialized expertise related to women's health, maternal, and newborn health
- Health professionals including those with research, practical, or clinical experience
- Members with knowledge of data governance and/or government policy related to the release of data and information

At least one member will have a primary appointment from an academic department, and one member from the Ministry of Health.

The chair may adjust the number of members as necessary, to ensure the appropriate scope of knowledge, expertise and experience. Members will serve for a period of three years; the term of membership may be renewed for two consecutive terms. Membership will be reviewed every two years.

The chair also assigns ex-officio members from PSBC's Quality and Research team to attend RRC meetings as required. Ex-officio members are non-voting members of the committee. The role of the ex-officio member is to communicate knowledge, content, and context of the DAR and PDR.

Format of meeting

Meetings will be held in-person, by teleconference, or both as the context requires.

Meetings

- The Committee will meet on a monthly basis, when there is a need to review research data requests
- Meetings can be held at the call of the chair if there is a reason to do so
- Quorum will be met when 50% or more of the voting members are in attendance, either in-person or virtually
- Decisions will be made by consensus. Where consensus cannot be reached, decisions will be made through voting with a simple majority of those present

New voting procedure (since January 25, 2024)

- RRC Members are to enter their vote into the chat box – Y or YES if approved; N or NO if not approved (if on the phone without the Teams app, they will need to verbalize their vote).
- This voting system will enable the committee members to track better whether a DAR is approved and what committee members are voting for.

Review of Requests Outside of Meetings

DARs may be reviewed by email for time-sensitive DARs or related matters of the committee. The chair will determine if a request warrants a decision outside of a regularly scheduled meeting.

Documentation Protocol

- The minutes, agenda and other documentation related to the Committee will be the responsibility of the chair and may be delegated as they see fit
- For non-data specific issues, PSBC's Provincial Executive Director and/or chair have full authority on decision-making regarding administrative changes to DARs
- Minutes of each meeting, and decisions made, shall be recorded and distributed to all members and other attendees, via e-mail within a reasonable time following a meeting
- Action items will be brought forward at subsequent meetings and the status will be reported up as required

Amendment to the Terms of Reference

- The Committee may amend the terms of reference at any time, and should formally review the terms of reference every two (2) years

Confidentiality

- Each committee member must sign a Conflict of Interest and Confidentiality Agreement at the time of their appointment indicating their agreement to maintain their impartiality and the confidentiality, security, and integrity of all materials during and after their term on the Committee.

Perinatal Services BC Research DAR Review Process

