



Perinatal Services BC

An agency of the Provincial Health Services Authority

Policy Title: P03 Data Disclosure for External Data Requests	Web Version: 1
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Purpose:

The purpose of this document is to identify the parameters required when Perinatal Services BC (PSBC) releases and discloses data to external requestors. PSBC must comply with the *Freedom of Information and Protection of Privacy Act (FIPPA)* and the *Memorandum of Agreement* with Health Authorities and the College of Midwives.

Scope:

This policy applies to external requests for access of data/personal information under the stewardship and care of PSBC. External requestors include any person not employed within PSBC.

Agreements:

Under the *Memorandum of Agreement* with Health Authorities (HAs), PSBC can use the data contained within the British Columbia Perinatal Data Registry (PDR) for clinical review, research, planning, and evaluation purposes in accordance with the Agency's provincial role.

Statements:

1. PSBC handles all data requests in compliance with FIPPA legislation. [Sections 26 to 36 of FIPPA identify the conditions under which personal information can be collected, used and disclosed.](#)
2. Requests from the general public regarding access to their personal patient records will be transferred to the public body that originally produced or obtained the data. PSBC is normally not the originator of data within its stewardship.
3. Requests for perinatal data from a single hospital or Health Authority can be made to the Health Authority of interest. PSBC does not provide this service.
4. Aggregate data requests can be made by completing the online data request form available on the PSBC website.

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5. Research requests can be made by filling out a Data Access Request form and submitting to PSBC.
6. The Director, Provincial Registry, Surveillance, Performance and Analytics, with the Surveillance team will review the request to:
 - a. Determine the appropriateness of the request and the authority for making the request;
 - b. Assess the clarity of the request;
 - c. Classify the request as an Aggregate or Research request;
 - d. Determine if the data disclosure is in accordance with the stated purpose;
 - e. Confirm that the level of information requested is limited to the minimum amount reasonably required to meet the stated purpose; and
 - f. Determine data steward approval and signed agreement requirements.
7. Classification of external requests:
 - a. **Aggregate Data** requests are for summary provincial and sub-provincial data (e.g. total births, total cesarean sections, etc.) and do not include personal information or potential identifiers based on combination of variables and pose no potential harm to groups or individuals.

PSBC normally provides aggregate data services to health authorities and other governmental agencies for quality improvement, evaluation, or planning purposes. This service may be extended to other organizations if the request aligns with PSBC's mandate and there is resource capacity to do so.

In cases where aggregate data are requested for research purposes, such requests fall under Research Data and will be reviewed by the PSBC Research Review Committee.

All reports will have the following suppression rule applied:

Counts between one and four, rates based on numerators between one and four, and combinations of fields that may infer identification are not typically disclosed.

- b. **Research Data** requests are bona fide research requests that involve record-level or aggregate data from PSBC.

PSBC has delegated authority in research review through the PSBC Research Review Committee.

PSBC is authorized to release Research requests which meet all of the following criteria:

- The request must be from a bona fide researcher accredited by an Institute of Technology/University or an individual affiliated with an 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);

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- The request must be formally submitted to the PSBC Research Review Committee for review and final approval; and
 - Terms, conditions, and the procedure(s) for the release of personal information (e.g. postal codes or complete data of birth) for research purposes will be formally documented by PSBC and must conform with the FIPPA legislation.
8. When the data are ready for release, the Director, Provincial Registry, Surveillance, Performance and Analytics or delegate is notified. The director or delegate has the responsibility for reviewing all aggregate reports prior to disclosure to ensure that the information cannot reasonably be used in ways, whether alone or in combination with other data sources, to identify an individual.
 9. Once review is completed, the assigned staff will send the report/data to the requestor according to the Data Transfer Policy.
 10. All outputs must cite Perinatal Services BC - Perinatal Data Registry as the source of the data (i.e. written documents, PowerPoint slides, Excel spreadsheet, etc.) using the following format:

Perinatal Services BC. British Columbia Perinatal Data Registry. Years Provided: (YYYY to YYYY). Resource Type: (*Extract or tabulated data*). Data Provided on (YYYY).

Appendix A: Terminology Definition

Term	Acronym	Description
Contact Information		FIPPA defines “contact information” as information to enable an individual at a place of business to be contacted and includes the name, position name or title, business telephone number, business address, business email, or business fax number of the individual.
Freedom of Information and Protection of Privacy Act	FOIPPA or FIPPA	<p>The Freedom of Information and Protection of Privacy Act sets out the access and privacy rights of individuals as they relate to the public sector.</p> <p>FIPPA establishes an individual's right to access records - this includes access to a person's own "personal information" as well as records in the custody or control of a "public body" – see Schedule 2 and Schedule 3 for a list of public bodies that are covered by FIPPA.</p> <p>There are certain exceptions to accessing records- for example, a public body cannot disclose information that is deemed to be harmful to law enforcement, personal privacy or public safety. Policy advice and legal advice are also excluded. These exceptions are spelled out in sections 12 to 22.</p> <p>In addition to establishing an individual's right to access records, FIPPA also sets out the terms under which a public body can collect, use and disclose the "personal information" of individuals. Public bodies are held accountable for their information practices -- FIPPA requires that they take reasonable steps to protect the privacy of personal information they hold. (https://www.oipc.bc.ca/about/legislation)</p> <p>FIPPA outlines the authority and conditions for collecting, using and disclosing personal information under Part 3.</p>
Personal Information	PI	FIPPA defines "personal information" to mean recorded information about an identifiable individual other than contact information.
Personal Identity Information	PII	FIPPA defines "personal identity information" to mean any personal information of a type that is commonly used, alone or in combination with other information, to identify or purport to identify an individual.