

**DATA ACCESS
AND
RELEASE POLICIES**

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Standard data access policies and the Freedom of Information and Protection of Privacy Act (FOIPPA) requirements mean that no information can be released by the British Columbia Perinatal Database Registry (BCPDR) that would allow identification of patient(s), healthcare providers, or facilities (place) without the consent of said organizations. Therefore, the BCPDR will not make this information available to anyone other than the owner without the latter's permission. Nonetheless, there are opportunities to share comparative information and reports that do not identify any of these 3 categories of data (person, provider, place). There are also circumstances when a researcher may wish to obtain access to groups of individual records after they have been stripped of their identifiers.

In order to facilitate the opportunities for data sharing and devising comparative reports, and to establish a mechanism to handle data access requests, the British Columbia Reproductive Care Program (BCRCP) has drawn up a Partnership Accord/Memorandum of Agreement, signed by all the contributors to the database which details the permissions necessary for the sharing of aggregate data. An individual identified by the region acts as Data Steward for the hospital and/or all the organizations in that Health Authority. The BCPDR will keep a roster of these individuals so that permission can be sought for the release of Level 2 data, as outlined in the Partnership Accord. For all other purposes, the partnership institutions confer on the BCPDR discretion to release Level 1 and Level 3 data to a legitimate representative of a Health Authority or research institution. The 3 levels of data that are identified by the Partnership Accord are:

a) **Non-identifiable aggregate Data – level 1**

Non-identifiable aggregate data may be released to a Health Authority (or designate), or *bona fide* researchers (as described in level 3) by the Local Perinatal Database Registry (LPDR), or BCPDR. This data would be used for routine comparative evaluation and benchmarking both regionally and provincially. It may include routine reports which have been pre-approved, or ad hoc requests for non-identifiable data, i.e. *secured as to patient name, (PHN), patient's specific address and care provider*. Respect for anonymity of the patient is of cardinal importance; therefore we will not include personal identifiers such as the PHN.

b) **Partially-Identifiable Aggregate Data – level 2**

Data requests containing any of the personal identifiers, or care provider will require approval from the Regional data steward on a request-by-request basis. The BCPDR undertakes to seek such approvals from all stakeholders before releasing pertinent information. Data stewards have the right to refuse such permission if it is deemed not to be in the best interests of the client, or the provider.

c) **Identifiable Data – level 3**

The BCPDR is authorized to release specific bodies of data in which an individual patient may be identifiable by given name, or PHN under (**must include all**) the following circumstances:

- The request must be from a *bona fide* researcher accredited by an Institute of Technology/University, or an individual affiliated institution, e.g. a hospital.
- The request must pertain to an identified research project that has received prior ethics and peer review approvals from the above academic institution, or other publicly-funded body (e.g. hospital Perinatal Committee).
- The request must be formally submitted to the Perinatal Data Access Subcommittee of the BCPDR for review and 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 *FOI & PP* legislation.

Comparative reporting is one of the desirable outputs of the BCPDR and there are well-developed policies in use for other databases to permit access to the information once defined processes and approvals have been obtained.

ACCESSING DATA

We have included with this brochure an Information Request Form that can be used to submit a request to either a hospital, or the B.C. Perinatal Database Registry.

Hospital Specific Data:

Contact the hospital's Health Records/Information Analysis Department

Hospital Comparative Data:

Contact each hospital's Health Records/Information Analysis Department

Provincial Data:

Contact the B.C. Perinatal Database Registry central office (Vancouver)

BRITISH COLUMBIA PERINATAL DATABASE REGISTRY INFORMATION REQUEST FORM

Submit Request to: Hospital
BC Perinatal Database Registry

Request # _____

Requester Information

Name: _____	Title: _____
Organization: _____	
Address: _____	
Telephone #: _____	Fax: _____
Email Address: _____	Signature: _____

Data Request

Purpose: (Briefly describe the purpose for which data are being requested)

Data elements required: <i>(list of fields or queries)</i>

Date range required: _____ (or) From: _____ To: _____
Frequency of data request:
<input type="checkbox"/> One time only <input type="checkbox"/> Annually <input type="checkbox"/> Other: _____
Date required by: _____
Special Instructions: _____
