Perinatal Services BC
An agency of the Provincial Health Services Authority

BC Perinatal Data Registry (PDR)
Data Access Requests (DAR) for Research Purposes
(non-PopData Projects)

Frequently Asked Questions (FAQ)

(V.1.5 – August 3, 2017)

Determining which application process to follow

1. PDR data are available through Population Data BC and from Perinatal Services BC. Which option should I choose?

It depends on what data you need to answer your research questions. Research projects that require data from most other external administrative databases (including but not limited to: Vital Statistics Births, Vital Statistics Deaths, Medical Services Plan, and Discharge Abstract Database), must be submitted through Population Data BC (PopData). Only those projects that involve data exclusively from the PDR, or those that involve linkage to a dataset outside of Population Data BC's holdings are submitted directly to PSBC. If you are not sure which route is appropriate for your study, please contact PSBC (psbc@phsa.ca) for further information prior to completing your Application for Access to Health Data for Research Purposes (DAR).

2. I am interested in deliveries or births at a single hospital, where do I submit my request?

If the only variables required are those in the PDR, please follow the research request processes for the Health Authority in which the hospital is located. If you require data from any of the administrative databases held by PopData, please submit your application through their processes.

About the BC Perinatal Data Registry (PDR)

3. What is the BC Perinatal Data Registry (PDR)?

The PDR is a provincial database that contains individual-level obstetrical and neonatal data for virtually all births that occur in BC. At present, the PDR contains over 300 data variables for approximately 45,000 births per year. Data from the PDR are used for surveillance and research purposes and to support health care providers, researchers, health care leaders, and policy makers in their work to improve maternal, fetal, and neonatal health outcomes as well as to enhance the delivery and quality of perinatal services in BC.

The current system maintains a client/server model, whereby client PDR software is installed locally throughout the six health authorities with data entered and stored within each hospital site or Health Authority. Data are primarily retrieved from standardized provincial perinatal forms (e.g., Antenatal Record, Newborn Record) as well as hospital-specific forms (e.g., ultrasound reports) in maternal and neonatal medical charts. To avoid duplicate data entry, key data fields where available, are imported from local Admission Discharge Transfer (ADT) systems and local abstracting systems containing International Classification of Diseases (ICD) diagnostic and Canadian Classification of Interventions (CCI) procedure codes into the PDR. Diagnostic and procedure codes are assigned per the guidance of the Canadian Institute for Health Information (CIHI).

Data entry is performed by local abstractors with the exception of some small facilities that send charts directly to PSBC.

Data are regularly submitted to PSBC via secure file transfer. At PSBC, data undergo a process of data quality checks and are then consolidated into the provincial database. PSBC works closely with local Health Information Management staff to resolve data quality errors that are detected through a variety of checks and balances.

4. What data are included in the PDR?

The PDR contains maternal, fetal, and neonatal data for an estimated 99% of all births that occur in BC. The PDR includes data for both mother (delivery episode, transfers and postpartum admissions) and baby (newborn episode, transfers and readmissions). Inclusion criteria are shown below:

Table 1. Inclusion criteria for data entered into the PDR

Patient	Criteria
Mother	Delivery episode* Delivers a newborn or stillborn in a BC hospital OR delivers a newborn or stillborn en route to a BC hospital OR delivers a newborn or stillborn at home in BC with a registered healthcare provider OR delivers a newborn or stillborn at home in BC without a registered provider and is admitted to hospital within 24 hours of delivery Transfer/Postpartum readmission† (Re)admitted as either an inpatient or Surgical Day Care patient ≤42 days post-delivery
Baby	Newborn episode* Live birth born in a BC hospital OR live birth born en route to a BC hospital OR live birth born at home in BC with a registered healthcare provider OR live birth born at home without a registered healthcare provider and admitted to acute care within 24 hours of birth OR any stillbirth* born in BC. Transfer/Readmission‡ Admitted to a BC hospital from home at ≤28 days of age OR admitted to BC hospital from home at ≤28 days of birth and then transferred to another BC hospital OR transferred from a hospital to another BC hospital at <1 year of age (has not yet been discharged home)

** The PDR classifies live births and stillbirths using the same definition as the BC Vital Statistics Agency (i.e., ≥20 weeks gestation and/or ≥500 grams birth weight)*

† *Available from April 1, 2008 discharges onwards*

‡ *Includes companion well babies*

Table 1. Inclusion criteria for PDR data

Patient	Criteria
Woman	Delivery episodes* • Delivers a newborn or stillbirth in a BC acute care hospital; • Delivers a newborn or stillbirth in a BC acute care hospital's emergency room, en route to a BC acute care hospital, or in a clinic and is admitted to the hospital ≤24 hours of delivery; • Delivers a newborn or stillbirth at home in BC under the care of a registered healthcare provider; • Delivers a newborn or stillbirth at home in BC without the attendance of a registered healthcare provider and is admitted to a BC acute care hospital ≤24 hours of delivery. Postpartum episodes† • Surgical day care or inpatient admissions to a BC acute care hospital ≤42 days post-delivery; • Woman who delivered a live birth or stillbirth in a BC hospital's emergency room, en route to a BC acute care hospital, or in a clinic and is admitted to a BC acute care hospital >24 hours and ≤42 days post-delivery; • Woman who delivered a live birth or stillbirth at home under the care of a registered healthcare provider and is admitted to a BC acute care hospital >24 hours and ≤42 days post-delivery (until March 31, 2014); • Woman who delivered a live birth or stillbirth at home under the care of a registered healthcare provider and is admitted to a BC acute care hospital ≤42 days post-delivery (effective April 1, 2014); • Woman who delivered a live birth or stillbirth at home but not under the care of a registered healthcare provider and is admitted to a BC acute care hospital >24 hours and ≤42 days post-delivery; • Companion well mothers ≤42 days post-delivery.
Baby	Newborn episodes* • Live birth or stillbirth born in a BC acute care hospital; • Live birth or stillbirth born in a BC acute care hospital's emergency room, en route to a BC acute care hospital, or in a clinic and is admitted to the hospital ≤24 hours of birth; • Live birth or stillbirth born at home in BC under the care of a registered healthcare provider; • Live birth or stillbirth born at home in BC without the attendance of a registered healthcare provider and is admitted to a BC acute care hospital ≤24 hours of birth; Transfer/readmission episodes • Baby ≤28 days old admitted to a BC acute care hospital from home; • Baby transferred to a BC acute care hospital from another acute care hospital where baby has not yet been discharged to home; • Baby born in a BC acute care hospital's emergency room, en route to a BC acute care hospital, or in a clinic and is admitted to the hospital >24 hours and ≤28 days post-birth; • Baby born at home under the care of a registered healthcare provider and is admitted to a BC acute care hospital >24 hours and ≤28 days post-birth (until March 31, 2014); • Baby born at home under the care of a registered healthcare provider and is admitted to a BC acute care hospital ≤28 days post-birth (effective April 1, 2014). • Babies born at home in BC without the attendance of a registered healthcare provider and is admitted to a BC acute care hospital >24 hours after birth; • Companion well babies ≤28 days old.

* The PDR classifies live births and stillbirths using the same definition as the BC Vital Statistics Agency (i.e., ≥20 weeks gestation and/or ≥500 grams birth weight)

† Available from April 1, 2008 discharges onwards

5. What data are not included in the PDR?

The following are some of the most common misunderstandings about data in the PDR.

The PDR does not include data on all pregnancies in British Columbia; it contains data on pregnancies that result in delivery of a live born infant, and pregnancies that result in a stillbirth at ≥20 weeks or ≥500 grams birthweight. The PDR does not include data for deliveries that are therapeutically or spontaneously delivered at <20 weeks gestation and are <500 grams fetal birth weight. The PDR does not include data for unattended deliveries or deliveries at home attended by an unregistered healthcare provider.

Not all information recorded on the provincial perinatal forms produced by PSBC is included in the PDR. The data variables available in the PDR are those included in Appendix A of the Application for Access to Health Data for Research Form (DAR) form.

The PDR is a delivery-based registry, not a person-based registry. For example, if Jane Doe delivers three times in British Columbia, she will have three separate records in the PDR, each of them with a unique event identifier.

Total length of stay for Neonatal Intensive Care Use (level 2 and 3) is available in the PDR effective April 1, 2004 discharges. Information on Neonatal Intensive Care Use (NICU) prior to April 1, 2004 is available from the Discharge Abstract Database (DAD). To obtain DAD data, you must submit your application through Population Data BC.

Information on maternal post-delivery hospitalizations prior to April 1, 2008 is available from the Discharge Abstract Database (DAD). Postpartum hospitalizations are included in the PDR scope effective April 1, 2008. If postpartum or post-birth hospital use is a key measure in your study, use of DAD data is strongly encouraged to ensure complete case ascertainment. To obtain DAD data, you must submit your application through Population Data BC.

Complete data on maternal and infant death is available from Vital Statistics. To obtain Vital Statistics data, you must submit your application through Population Data BC.

6. What is the definition of a 'home birth' in the PDR?

A 'home birth' in the PDR includes any birth that occurred in BC outside of a hospital (usually at home) that was attended by a registered healthcare provider. The terms 'home birth' and 'delivery at home' are often used interchangeably, though the former refer to newborn records and the latter to maternal records.

Please note that data collection for deliveries at home changed effective April 1, 2014 discharges:

- Until March 31, 2014, a woman who delivered at home with a registered midwife and was admitted to a BC acute care hospital within 24 hours of delivery will have the acute care admission as her Delivery record (i.e. total record count=1).
- Effective April 1, 2014, a woman who delivered at home with a registered midwife and who was admitted to a BC acute care hospital within 24 hours of delivery will have a home Delivery record and a subsequent Postpartum acute care record (i.e. total record count=2).
- For all time periods, the PDR captures whether the delivery occurred at home or in a BC acute care hospital.

Parallel changes occurred for home birth data collection (i.e. newborn records).

It should also be noted that effective 4/1/2016 all registered-provider attended deliveries at home may be captured in the PDR.

7. How long has the PDR been collecting data?

The PDR has had provincial coverage of delivery episodes, newborn episodes, and newborn transfer/readmission episodes since April 1, 2000. Maternal postpartum transfer/readmission episodes have been collected since April 1, 2008.

The PDR underwent major revisions effective April 1, 2004 and April 1, 2008 that resulted in some new variables and some discontinued variables. The collection start and end dates, as well as details of major classification changes, can be found in Appendix A of the Application for Access to Health Data for Research Form (DAR) form.

8. Does the PDR use fiscal or calendar years?

The PDR data collection cycle is based on fiscal year from April 1 to March 31 the following year. Variable availability is based on the fiscal year in which the patient was *discharged*. Changes to diagnostic and intervention coding classifications (ICD 9, ICD-10-CA, CCP, and CCI) are also based on fiscal years.

By default, the date parameters for PDR data requests are based on the date in which the patient was discharged. The data can be prepared using different date parameters (e.g., calendar year, year of birth) by request.

9. Has the quality of data in the PDR been evaluated?

Several variable-specific validation projects have been completed, and are available from the Special Reports section of the PSBC website. A comprehensive validation project was undertaken using data from 2010/11 to 2011/12, and can be accessed from the Published Articles section of the PSBC website, or directly here.

Accessing PDR Data

10. Who can access PDR data?

Under the Freedom of Information and Protection of Privacy Act (FIPPA) Section 35, individual- level data from the PDR are available for research purposes. A Researcher is a student, teacher, or other individual enrolled, appointed or employed by a university, college, Open Learning Agency, Royal Roads University or other equivalent educational institution outside of BC, but within Canada. Any other individual can access the data if agreed to by the relevant Data Steward.

11. I am a student. Can I request PDR data?

Yes. Students enrolled in a degree program are subject to the same conditions and responsibilities as all other Researchers. All student Applications for Access to Health Data for Research Purposes (DARs) and Agreements with PSBC must be co-signed by the university Researcher who is acting as the thesis or project supervisor. Students are expected to analyze the received data. No other parties are permitted to use the data under a student application unless authorized by PSBC to do so.

12. What do I need to know about the Freedom of Information and Protection of Privacy Act (FIPPA)?

As an agency of the Provincial Health Services Authority, PSBC is defined as a public body under Schedule 1 of the FIPPA. As such, PSBC is legislated and must comply with the FIPPA as well as other legislated Acts and rules of common law related to access and privacy of information.

PSBC is committed to collect clinical and demographic information on all births that occur in British Columbia. PSBC does not provide direct patient care as part of its mandate. The data obtained by PSBC is originally collected by the public bodies (i.e., Health Authorities) providing direct patient care and PSBC trusts that these public bodies have obtained the data by fair and lawful means in accordance to the requirements of the FIPPA. Data are submitted to PSBC on all births occurring at obstetrical facilities throughout the province as well as births occurring at home attended by registered midwives. Collection of personal information at PSBC is authorized under Section 26(c) and 27(1) of the FIPPA.

Disclosure of personal information administered by PSBC is governed by the Memorandum of Agreement and Partnership Accord established between PSBC and the Health Authorities as well as Section 34 of the FIPPA.

Disclosure of personal information under Section 34 of the FIPPA states that a public body may use and disclose personal information under various circumstances, including to other public bodies where the information is necessary for the performance of duties or operations of the receiving public body.

Section 35 of the FIPPA states that a public body may disclose personal information for research purposes as follows:

> 35 (1) A public body may disclose personal information in its custody or under its control for a research purpose, including statistical research, only if:
>
> (a) the research purpose cannot reasonably be accomplished unless that information is provided in individually identifiable form or the research purpose has been approved by the commissioner,
>
> (a.1) subject to subsection (2), the information is disclosed on condition that it not be used for the purpose of contacting a person to participate in the research,
>
> (b) any data linking is not harmful to the individuals that information is about and the benefits to be derived from the data linking are clearly in the public interest,
>
> (c) the head of the public body concerned has approved conditions relating to the following:
>
> (i) security and confidentiality;
>
> (ii) the removal or destruction of individual identifiers at the earliest reasonable time;
>
> (iii) the prohibition of any subsequent use or disclosure of that information in individually identifiable form without the express authorization of that public body, and
>
> (d) the person to whom that information is disclosed has signed an agreement to comply with the approved conditions, this Act and any of the public body's policies and procedures relating to the confidentiality of personal information.
>
> 35 (2) Subsection (1) (a.1) does not apply in respect of research in relation to health issues if the commissioner approves
>
> (a) the research purpose,
>
> (b) the use of disclosed information for the purpose of contacting a person to participate in

the research, and
(c) the manner in which contact is to be made, including the information to be made available to persons contacted.

Preparing your Application

13. What is the process of requesting and receiving PDR data for the purposes of research?

All research requests for individual-level data will be reviewed by the PSBC Research Review Committee. The Research Review Committee usually meets on the fourth Thursday of each month. To submit a research request, please complete our Application for Access to Health Data for Research Purposes (DAR), which can be found on our website. The Application for Access to Health Data for Research Purposes (DAR) and accompanying documentation (see the Required

Documentation Checklist on page 6) should be emailed to psbc@phsa.ca. If you have questions about the application process, the BCPDR, and/or documentation requirements, please email us before you submit your application at psbc@phsa.ca.

PSBC staff will follow-up with you within approximately one week to confirm whether the data request contains all required elements and to clarify any points of uncertainty. You may be asked to make revisions or provide additional information to your initial application. If so, you will receive this request in writing.

Once all requested information has been provided, the research request will be reviewed by the Research Review Committee. All materials for new research proposals must be provided at least three weeks in advance of the monthly meeting to allow for sufficient review by all members.

A PSBC representative will send you a written decision of the Research Review Committee following review of your application at the monthly meeting. If your proposal is approved, you will receive a letter outlining the conditions of the approval. Once the conditions have been met, you will also receive an Agreement to Proceed with Data Preparation as well as PSBC's Data Sharing Agreement and Pledge of Confidentiality. The Applicant (and Supervisor, for student projects) is (are) required to sign and return the Agreement to Proceed with Data Preparation before your requested data extract will be queued in our work plan.

Once your request enters into the work queue, it may take several months before the data are ready for release (see this question for additional information). PSBC will contact you once your requested data extract is ready. The Data Sharing Agreement and Pledge of Confidentiality must be signed prior to data release. Data will be provided to you in the format agreed upon in the Application for Access to Health Data for Research Purposes (DAR) and conditions of the approval.

14. What are the minimum physical and network security measures required for me to receive PDR data?

Storage of data on laptops, notebooks, handheld devices, or other portable devices (e.g. external memory) is NOT permitted. No use of personal equipment/computer is permitted.

Locations where data reside must be secured and not physically accessible by the public. The expectation is that no data will be accessed outside the work location, in a public area, or outside Canada.

Security measures must be taken to protect workstations, hard copy, and source media. All physical

locations housing data must be locked, except when an individual authorized to access data is present.

Policies must exist and be applied with regards to account management and protection, addressing failed login attempts to a workstation, use of complex passwords, frequency of password changes, and screen locking when away from the computer.

Security Measures must be applied to secure IT infrastructure and data hosting services related to the storage and processing of data. You will be required to describe how and where regular maintenance and backups of your data are conducted, where backup materials are stored, and provide backup retention schedules.

Database security standards (industry-accepted standards such as ISO/IEC 27002) or best practices must be applied to the database product or storage mechanism that will be used to store data. We require all researchers to have the following minimal software installed on their workstations and/or networks:

(a) firewalls;
(b) antivirus;
(c) antispyware and adware;
(d) security audit capability including logs of maintenance and backup activities of network/workstation;
(e) access tracking capability; and
(f) file encryption.

15. What are the ethics review requirements to submit an Application for Access to Health Data for Research Purposes (DAR)?

Your project must have ethics approval and a current ethics certificate prior to consideration by the Research Review Committee. You will be required to provide a copy of the ethics application and approval certificate as part of your application package. Only non-profit ethics review committees, such as those at universities, are acceptable. PSBC reserves the right to decide the acceptability of ethics review committees in its sole and absolute discretion.

16. How do I request diagnoses based on ICD codes or procedures based on CCI codes?

The PDR contains diagnoses and procedure/intervention data imported from the Discharge Abstract Database (DAD). Diagnosis data are in the form of ICD 9 (April 1, 2000 through March 31, 2004 discharges) and ICD-10-CA (April 1, 2004 to present) codes, and include all diagnosis types. Diagnosis codes are generally only recorded if they affect the length of stay for the care episode. Since the majority of records contained in the PDR relate to maternal delivery or newborn episodes, unrelated or secondary diagnoses may not be documented. Procedure/intervention data are in the form of Canadian Classification of Procedures (CCP, April 1, 2000 through March 31, 2004 discharges) and Canadian Classification of Intervention (CCI, April 1, 2004 to present) codes.

If you are requesting ICD or CCI codes from the PDR, you must include a list of requested codes as an appendix to your Application for Access to Health Data for Research Purposes (DAR).

PSBC does not provide consultation or perform any checks on codes requested; request of complete and accurate diagnostic and procedure codes for all relevant Classifications (CCP, CCI, ICD 9, and ICD-10-CA) is the responsibility of the research team. Please be aware of changes to codes and coding standards across versions of ICD-10-CA and CCI. These classification systems undergo modification approximately every three years. Consultation with a health information professional with experience in

diagnostic and procedure coding may be helpful. A license to obtain the ICD-10-CA and CCP coding manuals can be obtained for a fee from CIHI. ICD-10 codes can be accessed for free from the WHO website; however, please note that there are differences between ICD-10 and ICD-10-CA (enhanced Canadian version of ICD-10) codes.

17. Is it possible that not all of the variables in my request will be approved by the PSBC Research Review Committee?

PSBC is committed to a minimum rights data model; only the minimum amount of data required to carry out an approved research project will be provided to the researcher. When completing the PSBC checklist, please select only those PSBC variables that are essential to evaluating your research question(s). Requests for variables without clear relevance to the stated hypothesis(es) may delay the Review Process.

To be considered for approval by PSBC, a Data Access Request must:

(a) Be for the time-limited purpose of addressing a specific set of research questions;
(b) Not involve use of data for administrative or any other non-research purpose, or for ongoing programs of research, unless specifically approved;
(c) Be in the public interest, for example, improves the welfare of the population;
(d) Not be proprietary research such as research done for commercial marketing purposes;
(e) Have scientific merit;
(f) Have approval from a recognized Research Ethics Board, as defined by the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

Your proposal must show that you have considered how the requested data elements will fit into your proposed analyses. Data elements that do not have clear justification in your proposal will not be approved for release. If you require identifiable information, you must include a detailed written justification of why the research project cannot be completed without identifiers. Some research applicants find it helpful to justify their requested data fields in a table such as the sample shown below (Table 2). If you choose to include a table, please include and refer to it as an appendix in your Application for Access to Health Data for Research Purposes (DAR). Please note that such a table is optional to include in your initial application, but will be required if, upon initial review, the variables requested do not clearly fit into the research plan.

Table 2: Example table for justification of variable selection

Variable/Diagnosis Code/Procedure Code	**Justification**
Baby admission weight	Baby weight at birth is our main outcome of interest
Pre-pregnancy weight	Necessary to calculate gestational weight gain, which we anticipate will be one of the main predictors of baby weight at birth.
Mother admission weight	
Gestational age at delivery (by algorithm)	Necessary to adjust gestational weight gain and baby weight at birth for pregnancy length.
Body mass index (BMI) group	The gestational weight gain recommendations differ by BMI group and thus, we would like to stratify the analysis by BMI category.
Smoking during current pregnancy	Smoking has been associated with lower weight at birth and could affect gestational weight gain, thus confounding the association between gestational weight gain and baby weight at birth.
Diabetes mellitus (insulin dependent)	Pre-existing diabetes has been identified as a risk factor for large babies.
Diabetes mellitus (non-insulin dependent)	

ICD-10-CA diagnosis codes beginning with: O24.5, O24.6, O24.7	These diagnosis codes identify pre-existing diabetes. They are necessary to complement the fields "Diabetes mellitus (insulin dependent)" and "Diabetes mellitus (non-insulin dependent)". Pre-existing diabetes has been identified as a risk factor for large babies

18. Is it possible to link to other databases?

Research projects involving linkage to most external administrative databases must be submitted through PopulationData BC (PopData). The PDR can also be linked to some individual level data source(s). If you are unsure if your application should be processed through PopData BC or PSBC, please contact PSBC (psbc@phsa.ca) for further information prior to completing your Application for Access to Health Data for Research Purposes (DAR).

19. How much does it cost to use PDR data for research?

PSBC requests a cost-recovery fee at a rate of $120 per hour of PSBC analyst time related to the research project (rate subject to change at PSBC's discretion). Upon approval of your Application for Access to Health Data for Research Purposes (DAR), we will provide a cost estimate based on the estimated time anticipated to prepare your requested data extract. The actual amount charged is only available after the data extract has been completed and is ready to be sent to the researcher. Consideration to reduce or waive the fee may be given to students in a masters or doctoral degree program to conduct research in fulfillment of thesis/dissertation requirements, as well as for researchers with non-grant funded research projects. However, this decision will depend on the complexity of the request as well as the number of previous requests made by the applicant.

We understand that researchers need to budget data costs into grant applications and may need a quote ahead of time. Therefore, if you wish to inquire about costs prior to submitting a formal Application for Access to Health Data for Research Purposes (DAR) to PSBC, please contact us at psbc@phsa.ca. You will be required to provide your project proposal including details on how you intend to use data from the PDR.

If there are changes to the data extraction as a result of amendment(s), PSBC reserves the right to reassess the cost estimate originally provided to you. An administration fee of $1,000 will be charged for **all** amendments requesting additions or changes to the data, in addition to any increases associated with a revised estimate. More information on amendments is available in this section.

Review Process

20. What is the role of the PSBC Research Review Committee?

Responsibility for PDR data held at PSBC is delegated to PSBC's Provincial Executive Director and PSBC's Research Review Committee by Memorandum of Agreements & Partnership Accords with all BC Health Authorities, College of Midwives of BC, and with the Ministry of Health

The purpose of the Research Review Committee is to review all Researcher requests of individual-level data in accordance with FIPPA and other applicable legislation, ethical considerations and best practices. The Research Review Committee advises 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. More information about the Research Review Committee is available here.

Approved Applications

21. How long should I expect to wait to receive my requested data from the PDR?

Please plan for a four to six month turnaround from the date your Agreement to Proceed with Data Preparation was signed. For projects that involve linkage of PDR data to data source(s) not held by Population Data BC, please plan for a four to six month turnaround time from the date PSBC receives a complete and clean file including the identifiers to be used for linkage.

Data preparation time may be longer for complicated requests and those requiring linkage. Thank you, in advance, for your patience.

22. In what format will I receive my PDR data?

Data extracts provided directly by PSBC will be encrypted, password-protected, and saved on a CD. Researchers have the option to pick up the CD in person from the PSBC office or receive the data via bonded courier. Data are typically provided in .csv format.

Researchers who have access to the PHSA network may choose the option of having their data extract transferred through a secure File Transfer Protocol (sFTP).

Data extracts processed via PopData are transferred via secure file transfer and are subsequently available to the researcher(s) through the Secure Research Environment or other mechanisms agreed upon by PopData and the researcher.

Publication Requirements

23. Does PSBC need to review my results (e.g., abstracts, publications, or presentations) that include data from the PDR?

Yes. Section 14.00 of the Data Sharing Agreement between PSBC and researchers stipulates that any Output intended for publication must be reviewed and approved by PSBC prior to publication; researchers may not submit a manuscript for publication until PSBC has provided written approval to proceed. We request the opportunity to review materials such as manuscripts and reports at least 45 days prior to submission for publication. We understand that abstracts, oral presentations, and conference posters may require a shorter turnaround time. Therefore, we will do our best to provide feedback for these expedited materials within 5 working days. Again, please do not submit your abstract or presentation materials until feedback from PSBC is received.

The material submitted to PSBC for review must contain the content intended to be submitted or presented. PSBC recognizes that Output such as conference presentations may change slightly after submission for review. That said, PSBC also needs to know what information about the project has been made public. We request that the researcher commit to as final a draft as possible for review, notify PSBC of any subsequent material changes, and then share the document actually presented.

In all Outputs, the applicant is asked to appropriately reference Perinatal Services BC and the Perinatal Data Registry, and include the following disclaimer:

> **All inferences, opinions, and conclusions drawn in this publication are those of the authors and do not reflect the opinions or policies of Perinatal Services BC.**

"Output" includes any findings, software, data, specifications, drawing, report, document, material, scholarly work or publication of any kind, whether complete or not, that is:

(i) produced using the Data or Derived Information or using any research done using the Data or Derived Information; and
(ii) intended to be published or distributed in any form, including on any website or in any presentation, for an audience other than the applicant or research project team members.

24. What does PSBC look for when reviewing my research outputs?

PSBC reviews outputs to ensure that data from the PDR are represented accurately. We look for the following during the review process:

- Are PDR data described and cited appropriately?
- Are PDR variables described accurately?
- Have required cell suppressions been applied?
- Has disclaimer been added?
- Are the limitations of PDR data described? Common issues include (but are not limited to) describing the extent of missing data in variables, change in variable definition, variables available only for some of the study period, etc.

Once PSBC is satisfied that the data are represented accurately, approval to proceed will be given.

25. How do I cite PSBC and the PDR in publications?

In all publications using PDR data obtained directly from PSBC, please cite your data extract using the following template:

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

It may also be helpful for readers if you include information on the scope of the database.

Projects that obtain their PDR data through PopDataBC must follow the PopData citation requirements.

26. Can I publish data that includes small cell sizes?

All statistics based on counts between 1 and 4 must be suppressed. Counts and rates alike require suppression. Rates may be reported by using an appropriate proxy percentage. For example, if a characteristic was reported for four out of 200 subjects in group, the count should be reported as "<5" and the rate reported as "<2.5%" (5/200 = 2.5%). The second column of Table 1 represents the data without cell suppression. The third and fourth column of Table 1 show two options of implementing proper cell suppression for data with small cell sizes.

Table 2. Primary indication for labour induction in 2015/16

	Original	Option 1	Option 2
	2015/16 (N = 8,832)	2015/16	2015/16 (N = 8,832)
	N (%)	N (%)	N (%)
Prelabour rupture of membranes	2,635 (29.8)	2,635 (29.8)	2,635 (29.8)
Post dates	2,323 (26.3)	2,323 (26.3)	2,323 (26.3)
Hypertension in pregnancy	1,019 (11.5)	1,019 (11.5)	1,019 (11.5)
Other maternal condition	726 (8.2)	726 (8.2)	726 (8.2)
Fetal compromise	659 (7.5)	659 (7.5)	659 (7.5)
Diabetes	532 (6.0)	532 (6.0)	532 (6.0)
Fetal demise	71 (0.8)	71 (0.8)	71 (0.8)
Logistics	47 (0.5)	47 (0.5)	47 (0.5)
Antepartum hemorrhage	13 (0.2)	13 (0.2)	13 (0.2)
Chorioamnionitis	2 (0.02)	<5 (<0.06)	Remove this row as it is merged into Other.
Other	721 (8.2)	721 (8.2)	723 (8.2)
Unknown	84 (1.0)	84 (1.0)	88 (1.0)

Option 1: Apply the small cell size suppression by reporting statistics based on counts between 1 and 4 as <5 and <0.06%. In this example, the percentage of Chorioamnionitis is calculated as less than 5/8,832 = 0.06%. Remove the sample size (N = 8,832) to ensure readers cannot work backward to obtain any small cell size.

Option 2: Merge two or more categories to ensure no rows contain small cell sizes. In this case, Chorioamnionitis is included in the Other category, and the separate row with statistics on Chorioamnionitis should be removed from the table. A footnote, *Other includes chorioamnionitis and all not otherwise specified indications, should be added.

If you have any questions about applying suppression on small cell sizes in your results (e.g. abstracts, presentations, or publications), please consult PSBC prior to submitting your publications for review.

Amending Your Data Access Request (DAR) after approval or data delivery

27. How do I make an amendment to my request?

Researchers who receive data and realize that they need additional data fields will have to submit an amendment. Changes to the cohort definition also require an amendment.

To make an amendment to a previously submitted Application for Access to Health Data for Research (DAR), complete an Amendment to Application for Access to Health Data for Research Purposes form. Amendments to studies should be changes within the scope of the original study.

Changes such as additional variables, the addition/removal of Project Members, or a change to the requested data retention date, must be submitted as Amendments. The Amendment Application form and accompanying documentation (if applicable) should be emailed to psbc@phsa.ca. PSBC will review the request, ensure its completion, and submit it to the RRC for discussion and approval.

The Data Access and Research Coordinator will follow-up with you via email or phone within approximately one week and may request additional information or points of clarification on your request. Once all requested information has been provided, the research request will be added to an upcoming

PSBC RRC meeting. The review process for Amendments is the same as for original requests. Minor Amendments, such as changes to Project Members or project changes not directly involving PSBC data (e.g., addition of data sources), may be considered for expedited approval at the discretion of the Committee Chair without full review by the RRC.

An administration fee of $1,000 will be charged for **all** amendments requesting additions or changes to the data. If your amendment results in significant changes to the data extraction, PSBC reserves the right to reassess the cost estimate originally provided to you.

New studies that are related to (but not included in) the original studies should be submitted as a new Application for Access to Health Data for Research Purposes (DAR) Application. Also, projects that undergo changes to study objectives (research questions/hypotheses), data collection methods or study populations should be submitted in a new DAR for review and approval.

For linked projects coordinated by PopData, please submit your amendment directly to their Data Access Unit. PopData's process for amendment submission can be found on their website.

Closing Your Project

28. Project Closure and Data Destruction

PSBC must be informed when a research project is complete, and access to the data is no longer required.

PSBC will then provide the Researcher with project closure documentation which details the steps necessary to destroy and/or return all data to PSBC at the conclusion of the research project, as stipulated under the Data Sharing Agreement.

The Project Closure & Data Destruction Form can also be found in the 'Forms and Request Documentation' section of the PSBC website.

Please contact PSBC (psbc@phsa.ca) for more information.