

Application Date: _____ Internal Reference Number: _____

Use this Application to request data administered by Population Data BC or other data sources.

This Application is also used for linkages involving “External Data.” External Data refers to data not administered by Population Data BC and for which a checklist has not been provided. Examples of External Data include survey data, a clinical data set, or some other outside source. Applicants applying to use External Data are required to complete any necessary protocols for requesting those data as well as their linkage, and include the request as part of this complete application.

The cohort(s) or control group(s) for the study can be defined either by data from Population Data BC or by External Data.

Population Data BC administers data and coordinates applications for research data linkages; however, the Data Steward of the public body (e.g., the Ministry of Health Services, WorkSafeBC) that have custody or control over the data holds the legal authority for carrying out full review and approving the disclosure of the data for a specific research purpose. If this, or a revised, Data Access Request is approved by the applicable Data Steward(s), the Application becomes a Schedule to a legally enforceable Research Agreement. The Applicant must sign the Research Agreement before data are released, as required by the BC Freedom of Information and Protection of Privacy Act (FIPPA), section 35(d).

Information collected on these forms is governed by FIPPA.

The collection of personal information on this form by the public body holding the data requested is authorized under section 26(c) of FIPPA. The personal information that is collected, such as name, address, phone number and any other personal information is required to process and adjudicate the application and to contact you to discuss any issues relevant to the application. Do not include the personal information of others unless you have their authorization (i.e., consent) to do so. Questions regarding the collection of personal information may be directed to the public body in question or, to assist in contacting the public body, to:

Privacy Officer, Population Data BC
440 - 2206 East Mall
Vancouver, BC V6T 1Z3

Phone: 604.822.8544
Fax: 604.822.0640
privacy@popdata.bc.ca

Please note that Population Data BC would like the opportunity to publish details about successful applicants, including on the Population Data BC website. Please indicate below your consent for use of all or part of the described personal information collected on this Application:

- Yes, I give Population Data BC permission to publish project information that includes my name, institution, project title, funding agency, approved data sets and related publication information as needed, including on the Population Data BC website.
- I give Population Data BC permission to publish the following project information as needed, including on the Population Data BC website:
- | | |
|--|--|
| <input type="checkbox"/> Name | <input type="checkbox"/> Funding agency |
| <input type="checkbox"/> Institution | <input type="checkbox"/> Approved datasets |
| <input type="checkbox"/> Project title | <input type="checkbox"/> Publication information |
- No, I do not give Population Data BC permission to publish project information which includes my name, institution, project title, funding agency, approved datasets and publication information.

APPLICATION SUBMISSION PROCESS

The application process requires that researchers:

1. Become familiar with all material outlining access requirements, data holdings, cohort definitions, and privacy considerations on Population Data BC's website. Questions about the application process or any part of your application are to be directed to the Researcher and Data Steward Liaison Unit at Population Data BC: rlu@popdata.bc.ca.
2. Ensure that the ethics and peer review requirements of the Data Steward(s) have been met through review with researcher liaison staff, and/or further consultation with relevant Data Steward(s) as appropriate. Please see Population Data BC's website for more information.
3. Submit a completed DAR to Population Data BC, including all required attachments.

Please note

1. Population Data BC submits applications to the relevant Data Stewards on behalf of the researcher. The completeness of the application will be assessed by the Researcher and Data Steward Liaison Unit at Population Data BC; only complete applications will be submitted for Data Steward review.
2. If approved by the applicable Data Stewards, the Research Agreement will be sent to the applicant for signature.
3. The Principal Investigator must sign the application below.
4. The Principal Investigator must be the same individual listed in the ethics board approval as well as in External Data linkage approvals. If this is not feasible, it should be addressed with the Researcher and Data Steward Liaison Unit.

Applications and attachments must be submitted electronically to the Researcher Liaison Unit at Population Data BC: rlu@popdata.bc.ca

SIGNATURE

I declare that all information provided in this application is complete and correct.

Signature

Print Name

Date Signed

REQUIRED DOCUMENTATION CHECKLIST

Ethics review may be pending, but all other documents must be included. Final, unconditional ethics approval certificates must be provided before data will be released. Electronic copies of all documents must be provided.

REQUIRED DOCUMENTATION: CONFIRM ATTACHMENT OF DOCUMENTS LISTED BELOW

	SECTION
<input type="checkbox"/> Peer review: copy of description of project submitted for review, reviewers' comments and final funding letter; or institutional letter of review; or supervisory letter of review; or applicant CV.	III
<input type="checkbox"/> Institutional ethical review: copy of application for review, including all supporting documents, and certificate or conditional, interim approvals.	III

REQUIRED DOCUMENTATION: SELECT DOCUMENTS YOU ARE ATTACHING

	SECTION
<input type="checkbox"/> Copy of all funding contracts, removing financial information (if project is funded).	III
<input type="checkbox"/> Cohort and comparison group definition forms for any additional cohorts or comparisons required.	VI
<input type="checkbox"/> Plain-language description of all fields to be retained for analysis.	V
<input type="checkbox"/> Authorization for use of the data that will be linked to data administered by Population Data BC: e.g., agreement with or letter from External Data source including application, consent documents (if applicable to the project).	V
<input type="checkbox"/> Informed consent form and any attachments provided to participants, as approved by a research ethics review board (if applicable to the project).	V
<input type="checkbox"/> Description of all measures taken to minimize the privacy risks of any proposed linkage, and Privacy Impact Assessment if available.	V

POPULATION DATA BC FIELD EXTRACTION CHECKLISTS

- Consolidation file.
- Medical Services Plan payment information file.
- PharmaCare file.
- Hospital separations file (Discharge Abstracts Database).
- Home and Community Care (Continuing Care) file.
- BC Cancer Agency file.
- WorkSafeBC file (Workers' Compensation Board).
- Vital Statistics births and clinical births.
- Vital Statistics stillbirths.
- Vital Statistics deaths and clinical deaths.
- Vital Statistics marriages.
- Mental Health Services file.
- Early Development Instrument.
- Other (specify): _____

All of the above documents will become part of the Research Agreement between the Applicant and the applicable Data Steward(s).

SECTION I: APPLICANT INFORMATION

APPLICANT (if the project is a thesis or dissertation, this must be the student)

LAST NAME		FIRST NAME			TITLE	
STREET ADDRESS			CITY	PROV	COUNTRY	POSTAL CODE
PHONE	FAX		EMAIL			
POSITION			INSTITUTION NAME			

INSTITUTION ADDRESS (if different from applicant address)

STREET ADDRESS			CITY	PROV	COUNTRY	POSTAL CODE
PHONE	FAX		EMAIL			

PRINCIPAL INVESTIGATOR (if different from applicant)

The Principal Investigator should be the same one listed in the ethics board approval as well as in External Data linkage approvals. If this is not feasible, it should be addressed with the RLU.

LAST NAME		FIRST NAME			TITLE	
STREET ADDRESS			CITY	PROV	COUNTRY	POSTAL CODE
PHONE	FAX		EMAIL			
POSITION			INSTITUTION NAME			

PROJECT COORDINATOR/MANAGER (primary contact person for correspondence, etc.)

LAST NAME		FIRST NAME			TITLE	
STREET ADDRESS			CITY	PROV	COUNTRY	POSTAL CODE
PHONE	FAX		EMAIL			
POSITION			INSTITUTION NAME			

CO-INVESTIGATORS

NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
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NAME	POSITION	INSTITUTION

PERSONS WHO WILL HAVE ACCESS TO THE DATA

Identify all individuals, excluding the Applicant, who will have access to the requested data AT ANY TIME. This includes any Co-Investigators listed above. Attach a separate sheet if necessary.

A signed confidentiality undertaking will be required of each identified individual before data are released.

NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION
NAME	POSITION	INSTITUTION

THESIS/DISSERTATION SUPERVISOR(S) (if data are to be used for a thesis or dissertation)

If the thesis or dissertation supervisor will have access to data, that person must also sign a confidentiality undertaking before data are released.

LAST NAME		FIRST NAME		TITLE	
STREET ADDRESS			CITY	PROV	COUNTRY
PHONE		FAX	EMAIL		
POSITION			INSTITUTION NAME		

SECTION II: RESEARCH PROJECT DESCRIPTION

PROJECT TITLE

TITLE DIFFERENCE

If this project has a different title from the one that appears on funding approvals or ethics review documentation, indicate the reason for the discrepancy.

PUBLIC INTEREST VALUE/PUBLIC BENEFIT OF PROJECT

PROJECT OBJECTIVES: RESEARCH QUESTIONS AND HYPOTHESIS

DESCRIPTION OF PROJECT

Include methodology and its relationship to any other program of research (e.g. phased or existing studies)

[Empty box for project description]

ACHIEVING RESEARCH OBJECTIVES

Describe how data used to define cohort AND data requested from each database are necessary to achieve research objectives (e.g. Medical Services Plan, Continuing Care, etc.)

SECTION III: DATA LINKAGES

Identify all Data sources that you propose to link, including those requested from within Population Data BC and those from other sources. "External data" refer to data not administered by Population Data BC for which a checklist has not been provided. Unless otherwise stated, it is expected that linkage will occur at Population Data BC.

REMEMBER: Applicants must submit all necessary application forms (and final approvals as available) involving the use of External Data.

1. DATA SOURCES

Population Data BC's Data Holdings

- | | |
|--|--|
| <input type="checkbox"/> Consolidation file | <input type="checkbox"/> Vital Statistics births and clinical births |
| <input type="checkbox"/> PharmaCare | <input type="checkbox"/> Vital Statistics deaths and clinical deaths |
| <input type="checkbox"/> Hospital separations | <input type="checkbox"/> Vital Statistics stillbirths |
| <input type="checkbox"/> Medical Services Plan payment information | <input type="checkbox"/> Vital Statistics marriages |
| <input type="checkbox"/> WorkSafeBC | <input type="checkbox"/> Mental Health Services |
| <input type="checkbox"/> BC Cancer Agency file | <input type="checkbox"/> Early Development Instrument |
| <input type="checkbox"/> Home and Community Care (Continuing Care) | |

External Data Source

- PharmaNet
- BC Perinatal Database
- The Canadian Community Health Survey (CCHS)
- Medical charts (source): _____
- BC Cardiac Registry
- Other (provide name and source):

Researcher Collected External Data

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> Survey or questionnaire | <input type="checkbox"/> Focus Groups |
| <input type="checkbox"/> Other (describe): | <input type="checkbox"/> Interviews |

2. EXTERNAL DATA REQUEST

2(a) External Data Identifier fields to be used for linkage and removed

- Personal Health Number
- Personal Education Number
- Name
- Full Birth Date
- Full Death Date
- 6-digit Postal Code
- Full Address
- Sex
- Other (e.g. generated identifier) _____

As stipulated in the Research Agreement, a researcher can request some identifier fields to be retained for analysis. Please identify and provide a detailed rationale for such a request.

2(b) External Data Identifier fields to be used for linkage and retained for analysis

- Personal Health Number
- Personal Education Number
- Name
- Full Birth Date
- Full Death Date
- 6-digit Postal Code
- Full Address
- Sex
- Other (e.g. generated identifier) _____

Justification



ATTACHMENT

Attach a list and plain-language description of ALL External Data fields to be retained for analysis. The Data Stewards adjudicate based upon the entire linkage, and not only for the data under their authority or the use of specific identifiers.

3. REQUEST FOR LINKAGE TO OCCUR IN A LOCATION OTHER THAN POPULATION DATA BC

Yes



ATTACHMENT

If yes to the above, describe any steps that have been, or will be, taken to minimize the privacy risks of the proposed linkage at all stages. In particular, ensure you include the timeline for proposed removal and destruction of data used only for linkage.

Privacy Risk Considerations



ATTACHMENT

Attach a copy of any application(s) and approval(s) for use of the External Data that will be linked to data administered by Population Data BC.

NOTE: The External Data application must fully disclose ALL proposed linkages.

4. INFORMED CONSENT FOR EXTERNAL DATA

Typically, Informed Consent is required of Researcher Collected Data. Additionally, the Data Steward(s) **reserve the right** to request Informed Consent of research participants as a requirement under applicable law and/or government policy and procedure.

If you are requesting linkage of data from Population Data BC to Researcher Collected Data, has written, informed consent to use and link the collected data for the specified research purpose(s) been obtained, or will it be obtained, from research participants? If so, the consent documents should explicitly identify the proposed linkages and the data involved. Consult with data stewards for suggested wording.

Yes No



ATTACHMENT (IF YES)

If yes, attach a blank copy of the informed consent form and any attachments provided to participants, as approved by the research ethics review board.

IF NO, explain why not. If other methods have been used to obtain consent to access this information (e.g., oral consent), please describe:

SECTION IV: FUNDING, AFFILIATIONS, AND REVIEWS

1. WHO IS FUNDING YOUR RESEARCH PROJECT?

Identify ALL funding, commissioning and contracting sources, including those requested but not yet confirmed.

Canadian Institutes of Health Research Expiry Date: _____

Canadian Health Services Research Foundation Expiry Date: _____

Social Sciences and Humanities Research Council Expiry Date: _____

Michael Smith Foundation for Health Research Expiry Date: _____

In-kind donations (source): _____

Other (source): _____ Expiry Date: _____

No funding

Funds donated by researchers involved or their academic departments (describe): Expiry Date: _____

Funds provided by private industry (describe source(s)): Expiry Date: _____




ATTACHMENT

If the project is wholly or partly funded by contract, attach a copy of the contract, removing financial information.

If you have, and/or if your spouse, domestic partner or child has an association or connection of any kind, whether financial or non-financial, with any sponsor of the project or the manufacturer or owner of any drug, device, program, or method being evaluated in the project, provide details below. Examples of financial interests include ownership of stocks, bonds, options, patent or royalty interests, receipt of consulting, honoraria, or speaking fees, salary, subject accrual rewards or penalties, loans, lectureships, memberships on boards of directors or scientific advisory boards. Examples of non-financial relationships include previous research collaborations, student/teacher relationships, other personal or professional relationships, professional differences, or any other connection that might lead to the perception of influence on the study.


2. EXTERNAL PEER REVIEW OF YOUR RESEARCH PROJECT

My project has been reviewed by an external peer committee, such as a grant funding agency

 Attach a copy of the following documents:

- a) project description from application
- b) any reviewer comments
- c) final funding letter

My project is a thesis or dissertation and has been reviewed by my supervisory committee

 Attach a letter from the supervisory committee indicating that the proposal has been approved


My project has not been peer reviewed

 Attach a complete CV for the Applicant


3. ETHICAL REVIEW OF YOUR RESEARCH PROJECT

State the status of the research ethics board review, institutional board review, or other institutional ethics review committee approval for this specific project.

My project has been approved or waived. Submission Reference # _____

 Attach a complete copy of the application submitted to the committee and a current ethics approval certificate or formal waiver from the committee. If any documents were revised as a condition of approval, also provide the approved version.

My project has been submitted and is pending review

 Attach a complete copy of the application submitted to the review committee, and any conditional or interim approval documents, and send final certificates once received, plus any revisions required by the review committee for final approval

My project has not been submitted for review (explain why):

IF THE PROJECT HAS NOT BEEN APPROVED OR SUBMITTED FOR REVIEW BY AN ACCEPTABLE ETHICS REVIEW COMMITTEE, the Data Steward(s) may refuse to consider the application.

NOTE: Only non-profit ethics review committees, such as those at universities, are acceptable. The Data Steward reserves the right to decide the acceptability of ethics review committees in their sole and absolute discretion.

SECTION V: DATA SECURITY AND ACCESS

1. USE OF SECURE RESEARCH ENVIRONMENT AT POPULATION DATA BC

Research Extracts will be housed on the Secure Research Environment at Population Data BC, unless otherwise authorized. The Secure Research Environment is a central server to which secure remote access, storage and back-ups are provided to the project-specific Research Extract, and for the provision of data analysis software.

Please see www.popdata.bc.ca for more information including a list of the software available.

Will you be requesting access on the Secure Research Environment at Population Data BC?

Yes No

IF YES, skip to item 5 in this section

IF NO, explain why not and complete items 2, 3, 4 and 5 in this section. In cases where External Data are being linked, explain measures taken to prevent re-linking of Research Extract with original data.

2. PHYSICAL LOCATION AND SECURITY OF DATA

Indicate the physical location(s) where research data will be used or accessed, including research sites and storage sites (if different). Indicate all general physical security measures in place at each location. Include measures taken to protect workstations, hard copy and source media.

LOCATION 1

ROOM NUMBER	BUILDING NAME OR NUMBER		
STREET ADDRESS			
CITY	PROV	COUNTRY	POSTAL CODE
PHYSICAL SECURITY METHODS <input type="checkbox"/> LOCKED FILE CABINET <input type="checkbox"/> DOOR KEYPAD <input type="checkbox"/> OTHER (SPECIFY):			

LOCATION 2

ROOM NUMBER	BUILDING NAME OR NUMBER		
STREET ADDRESS			
CITY	PROV	COUNTRY	POSTAL CODE
PHYSICAL SECURITY METHODS <input type="checkbox"/> LOCKED FILE CABINET <input type="checkbox"/> DOOR KEYPAD <input type="checkbox"/> OTHER (SPECIFY):			

NOTE: All physical locations housing data must be locked, except when an individual authorized to access the data is present.

3. NETWORK SECURITY AND BACKUPS

If data will be stored on a network or system to which individuals other than identified project personnel have access, or on a system connected to a public network (the Internet), indicate and describe, the network security measures in place.

Location 1

- Firewall
- Password changed every _____ days
- Password rules (minimum length, complexity)
- Drives or folders with access restricted to specific research group
- File encryption
- Other: _____
- Security audit: _____
- Access tracking: _____

Describe how, and from where, any regular maintenance and backups of your network are conducted, where backup material are stored, and backup retention schedule.

Location 2

- Firewall
- Password changed every _____ days
- Password rules (minimum length, complexity)
- Drives or folders with access restricted to specific research group
- File encryption
- Other: _____
- Security audit: _____
- Access tracking: _____

Describe how, and from where, any regular maintenance and backups of your network are conducted, where backup material are stored, and backup retention schedule.

4. PERSONAL COMPUTER SECURITY AND BACKUPS

If data will be accessed or stored on the hard drive of a personal computer, identify all security measures taken to protect data residing on the PC.

- Electronic locking system
- Logon password
- Individual file or folder passwords
- Encryption
- Removable drives
- Physical attachment to floor or object
- Software firewall (describe): _____
- Antivirus (describe): _____
- Antispyware or adware (describe): _____
- Other (describe): _____

NOTE: Storage of data on laptops, notebooks, handheld devices and other portable devices (e.g. external memory) will not be permitted. Access from portable devices is allowed only through the Secure Research Environment, and only under security conditions specified for that environment.

5. DATA TRANSFER SECURITY

NOTE: Data and derived information, other than aggregated information such as statistical output, must be transferred by courier; in person by someone named above as having access to the data; or by secure file transfer as approved by the applicable Data Steward(s).

E-mail, regular mail and fax are NOT acceptable transfer methods at any time.

- The Applicant declares the above section on data security and access requirements has been read and understood.

6. DATA DESTRUCTION SECURITY IF NOT USING Secure Research Environment

Upon project completion or cessation, the data and any copies must be destroyed using a method of destruction that is equivalent or superior to the standard established by the BC government

Written notice of such destruction is to be provided, as outlined in the Research Agreement.

SECTION VI: DEFINING YOUR STUDY POPULATION

READ THIS SECTION CAREFULLY.

Each Applicant must collaborate with Population Data BC to complete this section of the DAR.

Applicants are advised that any changes to the study population post approval may require an amendment, further review and adjudication by the Data Steward(s) and will incur a fee in addition to any previous estimates or costs paid.

A study population is the group of subjects that a researcher wants to include in their analyses. The study population may include a cohort as well as one or more comparison group(s). Based on the information provided, Population Data BC will identify the study population required for your research. Applicants must define their study groups in text and use as much detail possible. These details should include any information to assist Population Data BC in creating the study population.

NOTE: The variables described in the definition are not necessarily the variables that will be provided in the data extract. The years of data and variables required for your data extract are listed in the Checklists in Section VII below.

IMPORTANT: Data Stewards require a clear, explicit rationale for the inclusion of all proposed study population members. The rationale must be clearly related to the research question and methods.

The study population will be defined using the following data. Check all that apply:

- | | | |
|---|--------|---|
| <input type="checkbox"/> Data from Population Data BC | | |
| <input type="checkbox"/> External data | —————> | <input type="checkbox"/> Check if more than one external data set |
| <input type="checkbox"/> Researcher-collected data | —————> | <input type="checkbox"/> Check if more than one researcher collected data set |

1. TEXT DESCRIPTION

Provide a text description of your study population. This description should include as much detail as possible, such as health condition(s), age groups, date ranges or geographic areas, as well as specifications for sampling or matching, as required for your comparison group(s).

2. RATIONALE FOR STUDY POPULATION IN RELATION TO RESEARCH OBJECTIVES

Applicants must clearly illustrate how the study population is designed to meet the stated research objectives.

3. TECHNICAL DEFINITION

THIS SECTION IS TO BE COMPLETED BY POPULATION DATA BC. Technical definition for study population. This definition will be used to operationalize the study population described above.

COMPLETE IF USING EXTERNAL DATA AND / OR RESEARCHER COLLECTED DATA TO DEFINE YOUR STUDY POPULATION

Many Applicants want to use data from **outside** Population Data BC to define the project-specific study population. Population Data BC requires linkage variables to link the study population to the research data for these projects. More specifically, Population Data BC requires the Applicant to indicate whether personal health numbers (PHNs) or personal education numbers (PENs) are available for the external data to facilitate linkage. Applicants should be aware that regardless of the linking variables used, a 100% match of any study population to data at Population Data BC is not always possible.

REMEMBER: Applicants must also complete and submit any necessary protocols for requesting and linking External Data. Copies of applications and final approvals to use and link data from an external source must be submitted as part of the application package.

Data File Name: _____

Fields to be Used to Define Study Population: _____

Field Value (Range): _____

Are PHNs available for this data?

- Yes for all records
- For some records
- For no records

Are PENs available for this data?


- Yes for all records
- For some records
- For no records

If only some or no records for this data will include personal health numbers, indicate what fields will be used to facilitate linkage.

SECTION VII: COMPLETE DATA FIELD EXTRACT CHECKLISTS FOR YOUR COHORT(S) AND CONTROL GROUP(S)

IMPORTANT: Data that has not yet been collected will not be approved for use. Applicants should request data to the end of the current year only, and be aware that various databases categorize data by either fiscal year or calendar year.

NEXT STEP

 Download and complete the appropriate data field checklists (these will be hyperlinks). If your project involves more than one cohort (and comparison group), you may require a different set of data to be extracted for each cohort (and comparison group). If so, you may complete a separate data extract form(s) for each cohort (and control group) as applicable.

DATA FILES

- Consolidation File
- Medical Services Plan payment information file:
- PharmaCare file
- Hospital separations file (Discharge Abstracts Database)
- Home and Community Care (previously Continuing Care) file
- BC Cancer Agency file
- WorkSafeBC (Workers' Compensation Board) file
- Vital Statistics births and clinical births file
- Vital Statistics deaths and clinical deaths file
- Mental Health Services file
- Early Development Instrument file

These forms will become part of the legal agreement between the Applicant and the applicable Data Stewards as revised in the data steward's review process.