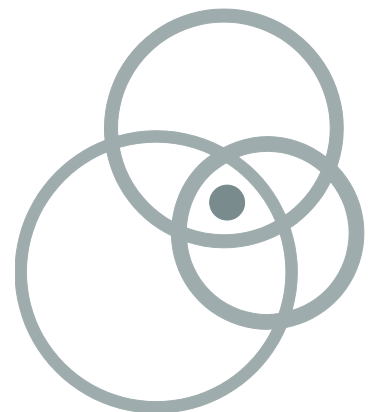


# Data Access Request Student's Manual

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**The Data Access Request application form (“DAR”) has been developed and approved by the Data Stewards participating in Population Data BC. It is intended to be used to request data administered by Population Data BC even when they involve linkage to External Data. (Definitions of this and other terms in bold typeface can be found at the end of this document.) Only one Data Access Request application form needs to be completed for a project involving data housed at PopData, no matter how many data sources are involved. For projects involving External Data (for example, PharmaNet), additional forms and separate reviews may be required. Please contact the RLU to learn which data sets will require additional forms and any appropriate contacts for applications.**

All requests for data are adjudicated by **Data Stewards** who in turn are bound by BC’s *Freedom of Information and Protection of Privacy Act* and other relevant laws and regulations of the Province, and ethical guidelines. Population Data BC works on behalf of Data Stewards and Researchers to help with the process, but has no role in the actual adjudication of requests. A **Research Data Access Framework** presents principles and responsibilities in the Data Access Request process. Researchers are encouraged to familiarize themselves with the **Research Data Access Framework** before submitting applications for data. See <http://www.popdata.bc.ca/dataaccess/rdaf> for complete document.

### **Types of student data requests**

There are two main avenues for student access to data: as an independent applicant, and as an additional user of a supervisor’s existing data extract. In the first case, the student must complete a full application as the primary applicant and becomes primarily responsible for use and security of the data. In the second case, the student must be working on a question already approved as part of the supervisor’s access, with minimal/no changes to the data or research questions. The supervisor shares responsibility with the student for use and security of the data for the duration of the student’s project. Data stewards will confirm that the student requests falls within the parameters of the original approvals for use of the data.

### **Note on student use of existing research project data**

Students may request access to and use of an existing research extract if their research question falls within the approved scope of use for that data and they are being supervised by the researcher who is responsible for the data. For example, their supervisor may have an approved DAR and RA, and the student may have been working on the data as a listed research assistant.

If the student requires data for a thesis or dissertation topic that is not one of the approved research questions, or if additional linkages or new variables or years of data are required, they must complete a separate, new DAR and receive an independent approval of their proposed use. A new extract will be provided.

If the thesis question is an approved research question under their Supervisor's Project and can be addressed with existing data (i.e., no new linkages or additional variables or years of data), the student may only need to complete a partial DAR. Please contact the RLU for assistance on all student applications requesting access to an existing Research Extract. Note that the stewards of external data may have different requirements or policies regarding student data use, which should be confirmed with them. The RLU may be able to assist with confirming these requirements.

## PLANNING AND COMPLETING A DATA ACCESS REQUEST FOR USE OF A SUPERVISOR'S EXISTING DATA EXTRACT

### Why is a DAR form needed?

Data Stewards require specific information about your project in order to adjudicate it. Population Data BC staff also need specific information in order to prepare data, once a DAR is approved. The DAR is designed to collect and present this information in the most efficient manner possible.

### A summary of the DAR Process

You may already have funding for your project and an ethics certificate. The data access request process requires, but is separate from, those processes. Data access approval is not automatic and must be taken as seriously as those other steps. Completing a DAR takes time, planning, and attention to detail, as they are reviewed thoroughly. Students using the DAR for data that has been approved for another research project will not complete the entire DAR and must contact the RLU before completing an application. The application process requires that researchers:

- Become familiar with all material outlining access requirements, data holdings, study population definitions, and privacy considerations, as presented on the Population Data BC website and as identified by data stewards
- Ensure that the ethics and peer review requirements of the **Data Steward(s)** have been met
- If **external data** is to be used, ensure that the appropriate applications and approvals are sought, including linkage requirements
- Submit your DAR to Population Data BC, including all required attachments
- Work with Population Data BC to confirm that the technical definition section is reflective of the researcher's planned study population.

Please visit Population Data BC's website [FAQs](#) sections for more information. Questions about the application process or any part of your application are to be directed to your PopData Researcher Liaison staff: [rlu@popdata.bc.ca](mailto:rlu@popdata.bc.ca).

Once all necessary approvals are in place, a **Research Agreement** must be signed by the Applicant. This is a legal agreement between the public bodies that the **Data Steward(s)** represent and the **Applicant**. The DAR forms part of the **Research Agreement**.

### **How to complete the form**

The DAR form has been set up as a PDF 'form-fill' application. Using the tab or arrow keys, the cursor will advance to the next input field, with the document text being protected from inadvertent changes. The DAR is divided into sections and the insertion point can be moved to the beginning of the next section by double clicking on the page/section area of the status bar (usually the lower left hand corner of the screen) and then selecting go to 'section' followed by either entering a specific section number or using the 'next' button. Checkboxes can be checked by clicking with a mouse, using the space bar, or entering an 'x'.

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## **CONSENT TO USE OF PROJECT INFORMATION BY POPULATION DATA BC**

Population Data BC would like to publish information about approved research projects whose data Population Data BC administers, including on the Population Data BC website. The purpose of this documentation (such as researcher's name, project title) is to provide information to the public and prospective researchers about the types of research projects Population Data BC facilitates. Please indicate on the form your consent for use of none, all or part of the described personal information collected on the application.

Please note that your participation is voluntary and you may withdraw your consent at any time for any reason by contacting Population Data BC.

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## **SIGNATURE**

Signature by Applicant must appear to acknowledge that application is complete and correct.

## **REQUIRED DOCUMENTATION CHECKLIST**

The purpose of this section is twofold -- one, to assist Population Data BC and the Data Steward(s) to assess the content of the DAR package; and, two, to assist the applicant in organizing the different parts of the application.

- Peer Review (funding reviews and confirmation letters, supervisor or committee letter)
- Ethics Certificate

- Cohort and comparison group definition forms (e.g., to identify a sub-group of the overall cohort that will be used for thesis purposes)
- Plain language description of all data fields to be retained for analysis
- Description of all measures taken to **minimize** risks to privacy and confidentiality of data, if not the same as for existing extract (e.g., stored at a different location)

If the applicant requires assistance or clarification regarding this checklist or completeness of the DAR, questions should be forwarded to the [Researcher Liaison Unit](#) (RLU) at Population Data BC.

Applications that are not complete will not be forwarded to Data Stewards for review.

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## SECTION I: APPLICANT INFORMATION

### Applicant information

If the student is using a supervisor's extract, the supervisor retains overall legal responsibility for the data. The student is legally responsible for their own use of data for their approved analyses, and must sign an RA with data stewards on their own behalf.

The Applicant on a student DAR:

- Must be the student
- Should be the same individual who has obtained Ethics Approval (or official waiver) from an accredited Ethics Review Board (REB)
- Is the person who will be held personally and professionally accountable in the case of breaches to the **Research Agreement** (of which the DAR is a part)
- 
- Is the person with whom Population Data BC will communicate during the application and approval process

### Principal Investigator

This is the student, for the purposes of the student's thesis or dissertation.

### Co-Investigators

This section is not required for student DARs unless the supervisor will be listed as a Co-Investigator. The name, position, and institutional affiliation of each Investigator on the research project must be provided. This is expected to mirror the Investigator list on the grant, if grant funding is in place.

### **Persons who will have access to the data**

ALL INDIVIDUALS, including faculty, students, research staff, and supervisors who will have access to the study data must be specified. The name, position, and institutional affiliation of each is requested.

In cases where access via the Secure Research Environment (SRE) is requested, this list will indicate those who will receive SecurIDs.

Each person on this list will be required to 1) sign a confidentiality undertaking, and 2) complete Population Data BC privacy training prior to release of data.

This list should be kept up to date with Population Data BC. Adding or deleting individuals from this list is permitted. New individuals must meet the aforementioned requirements. Data Stewards are kept informed about all changes.

Please note that not using the SRE imposes additional requirements as outlined on the DAR. These requirements are in place because not using the SRE means that Population Data BC can exercise less administrative control over data security and access on behalf of the Data Stewards. We recommend that researchers take advantage of the SRE.

### **Thesis / dissertation supervisors**

As a graduate student is applying for access to data, the student, NOT the academic supervisor, is identified as the Applicant. Use this section to identify the graduate student's academic supervisor. Please ensure that if this individual will have access to data, that they are also listed under "persons who will have access to the data".

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## **SECTION II: RESEARCH PROJECT DESCRIPTION**

### **Question 1: Project title**

The Applicant must indicate the complete title of the research project in the field provided. This should be the same title used on ALL other supporting documents attached to the DAR, e.g. the ethics review or the funding application / peer review.

### **Question 2: Explanation of title discrepancy**

If there is disparity amongst titles, the Applicant must state the reasons for this in the box provided.

### **Question 3: Public interest / benefit**

The Data Steward(s) readily support high-quality research on human health, well-being and the development of British Columbians and welcome research proposals aiming to inform policy-making that leads to healthier BC communities. As stipulated in FIPPA, the Data Steward(s) will assess projects with an eye for public interest value, and relevant legislation.

### **Question 4: Project objectives, research questions and hypotheses**

The student must identify how their proposed research questions are related to the questions already approved under the supervisor's approved project. If the questions are not identical, describe the derivation of the new question and where associated information can be found in the supervisor's project documentation.

The Data Steward(s) assess research questions in accordance with current provincial and national laws, regulations, and ethical standards. Research questions are reviewed for public interest value and compliance with legislation and policy - particularly the BC *Freedom of Information and Protection of Privacy Act* (FIPPA), and the Tri-Council Policy Statement for guidelines involving ethical research on humans.

Applicants must list ALL anticipated research objectives and questions, and should be as specific as possible. Consideration should be given to 'preliminary' research questions; re-workings of any hypotheses; and any theoretically 'predictable' outcomes of the analysis when designing the set of research questions.

Any change in direction or scope of research questions needs to be brought back for Data Steward review, and may constitute a new project or amendment (requiring a new application and new data extract.)

### **Question 5: Project description**

The Applicant must provide a brief description of the project. The Applicant must provide details for any relationship to other on-going studies; the involvement of linkages to external databases; intent to apply using the "phased approach" (e.g., may intend to link to PharmaNet once preliminary analysis is complete). A general description of an area of investigation such as "to create a database on the health of health care workers" is not permissible.

Please note that Data Steward(s) approve access to data on a "need to know" basis for specific purposes only. As such, the research objective(s) will always be measured against the specific data requested.

### **Question 6: Achieving Research Objectives; Data Justification**

If you are applying to use an existing Research Extract, describe Supervisor's data and linkages and information from their DAR for this question. This may also be found in supporting documents or communications. Data Steward(s) and, in turn, Population Data BC are permitted to release only those data that are necessary to achieve a specific research objective. It is the responsibility of the Applicant to draw this connection. Reviewers expect to see solid rationales outlining the relationship between the question(s) and the data requested. This section is expected to be fairly detailed in nature. It is recommended that this be filled out as one of the last sections.

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### **SECTION III: DATA LINKAGES**

This section is not required for student use of a supervisor's data extract.

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### **SECTION IV: FUNDING, AFFILIATIONS, AND REVIEWS**

#### **1. Who is funding**

Students applying for data must identify ALL funding, commissioning and contracting sources, including those requested but not yet confirmed. Please include the funder and the expiry date of funding.

If the project is funded by contract, students must attach a copy of the contract, removing financial information.

Please be advised that if a student is funded by a for-profit organization, the industry sponsor must not influence the study direction or analysis, or be given access to the data except in the final published results. Furthermore, no employees, contractors or agents of the sponsor may be on the researcher's project team, or work on the research project in any other way. Be aware of these rules **before** you negotiate a contract with an industry sponsor for a research project that requires access to data administered by Population Data BC. Receiving funding that is considered a conflict of interest for the Data Providers involved in your Request may mean your DAR will be denied.

#### **2. External Peer Review**

Students should check "My project is a thesis or dissertation and has been reviewed by my supervisory committee". Please attach supervisor's letter when submitting the DAR.

If you have had your thesis or dissertation reviewed externally, please check all relevant boxes.

### 3. Ethical Review

Students must indicate the status of the research project's ethical review by a Research Ethics Board, Institutional Review Board, or other institutional ethics review committee, and provide the necessary documents as indicated.

As stated on the DAR, only non-profit ethics review committees, such as those at universities, are acceptable. The Data Steward(s) reserve the right to decide the acceptability of ethics review committees. If the project has not been approved or submitted for review by an acceptable ethics review committee, the application will not be considered.

Ethical reviews are updated periodically. It is the responsibility of the Applicant to ensure that any updates to ethical review are provided to Population Data BC who will in turn share them with the Data Steward(s).

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## SECTION V: DATA SECURITY AND ACCESS

**Students using their supervisor's existing Research Extract do not need to complete Section V unless there is a change in the location of access or use of the data.**

### 1. Use of Secure Research Environment at Population Data BC

Data for approved research projects will be housed on Population Data BC's Secure Research Environment (SRE) unless otherwise authorized. The SRE is a computer server accessible via Virtual Private Network (VPN) using a SecurID token for authentication.

The SRE provides researchers with secure storage and back up of data, and access to various software programs for analyzing the data. See the SRE Guide for further details.

Upon application, researchers may be granted permission to store and/or access their data at another location. To request such permission, researchers need to provide a written rationale in the space provided on the DAR, and complete questions 2, 3, 4, 5 and 6 in this section. Please work with and External Data Providers to decide on the use of the SRE before completing your DAR.

### 2. Physical location and security of personal computer

*[To be completed by non-SRE users only]*

Please 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.

### **3. Network security and backups**

*[To be completed by non-SRE users only]*

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), please indicate, and if appropriate describe, the network security measures in place.

### **4. Personal computer security and backups**

*[To be completed by non-SRE users only]*

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.

NOTE: Access and storage of record level data on laptop, notebook, handheld devices and other portable devices (e.g. external memory) is NOT ACCEPTABLE without PRIOR WRITTEN AUTHORIZATION from the Data Steward(s). Please contact the RLU at Population Data BC for more information on requesting authorization.

### **5. Data transfer security**

*[To be completed by non-SRE users only]*

Data and derived information, other than aggregated information such as statistical output, must be transferred by one of: courier; in person by someone named above as having access to the data; or secure file transfer as approved by the Data Steward(s). E-mail, regular mail and fax are not acceptable transfer methods at any time.

### **6. Data destruction and destruction security**

*[To be completed by non-SRE users only]*

All data and related materials containing data from Population Data BC holdings or linked records generated with data from Population Data BC, such as derived data, duplicated data, analysis table, working files, backups files, data on server, temporary files, etc., need to be destroyed at the end of the approved retention period.

Please note that paper records should be destroyed in a manner that leaves no possibility for reconstruction of information. The accepted method for destroying paper records is cross-cut shredding.

For more detailed information, please refer to Population Data BC's Project Closure Manual. Written notice of data destruction is to be provided, as outlined in the Research Agreement and Project Closure Manual.

## SECTION VI: DEFINING YOUR STUDY POPULATION

**Students using their supervisor's Research Extract do not need to complete Section VI if the student's study population is identical to the supervisor's original request.**

If the proposed study population is different to the original request OTHER THAN a subset of the original cohorts, a full new application is required.

If the student's study population is a subset of the original study cohorts, please describe both the original definition and the subset definitions in detail, as indicated below.

Applicants are advised that any changes to the study population post approval will incur a fee in addition to any previous estimates or costs paid. Changes will also require a new Data Steward review.

To reiterate from the DAR, 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). The cohort(s) or comparison group(s) for the study can be defined by data from Population Data BC and/or by External Data (from an External Data Provider or Researcher-Collected Data). Please indicate the specifics of this in the checkboxes provided. This provides the Data Stewards with a quick context for their review of the Study Population section.

In order to clarify what is meant by Study Population, the table below provides a few examples of study populations, and how these relate to cohort(s), comparison group(s) and the data extract that you might request for your analyses.

Study Population	Cohort	Comparison Group(s)	Data Extract
All women who gave birth in a BC hospital between 1993 and 2000, and their babies	Women who gave birth between 1993 and 2000 who are residents of Greater Vancouver	Women who gave birth between 1993 and 2000 who are residents of other parts of BC	<i>All MSP Services, hospital separations and deaths data for mothers, from one year before to two years after birth. Births data for the babies, plus all MSP Services, hospital separations and deaths data for two years after</i>

Study Population	Cohort	Comparison Group(s)	Data Extract
All children for whom there are <i>Early Development Instrument</i> scores in 1999-2002 and 2007-2008	Kids with <i>EDI</i> scores above the median	Kids with <i>EDI</i> scores below the median	<i>Foundation Skills Assessment</i> scores, other <i>Education</i> information, and <i>hospitalizations</i> for 1999 to 2008.
All individuals aged 65 and over who spent at least one night in a residential care facility between 1 April 1998 and 31 March 2008, plus a 10% random sample of other individuals aged 65+	Individuals 65 and over who spent at least one night in a residential care facility between 1 April 1998 and 31 March 2008.	A 10% random sample of individuals who did not spend a night in a residential care facility but who were 65+ and resident in BC at some point between 1 April 1998 and 31 March 2008.	<i>Home and Community Care, MSP Services, and Hospital Separations</i> data for 1998/99 to 2007/08.

Although you may have identified more than one cohort and/or comparison group in order to answer your research question, your Data Extract may contain the data covering the entire Study Population you defined earlier, depending on how you filled out the “apply to sub-population” checklists. This will ensure that you have all the data necessary to look at your cohort and comparison groups.

### Text description

Students must define their Study Population in text and use as much detail as possible. These details should include any information to assist Population Data BC in creating the study population. At this point, descriptions of cohort(s) and comparison group(s) are helpful.

### Rationale

As in Section I, a rationale or justification for the data requested must be provided. In this section, the focus is ONLY on the Study Population. In particular, justification of the size and composition of the groups required to complete the research questions and objectives is necessary

It is acceptable if some of this is repeated from the last question of Section I.

### Technical definition

Once the DAR has been completed in draft form, it needs to be passed to Population Data BC to complete this section. Based on the information provided, Population Data BC will identify the technical details for the study population required for your research. This section needs to be confirmed by the Applicant prior to DAR submission.

IMPORTANT TO 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.

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## SECTION VII: DATA FIELD EXTRACT CHECKLISTS

Students using their supervisor's full Research Extract do not need to complete Section VII. **IF USING A SUBSET OF SUPERVISOR'S DATA, students must download and complete the appropriate data file checklist(s) and select the fields to be used for analysis.**

Students need to request the data for their **extract** and not the data required to construct a **study population** when filling out the data file checklists.

The Data Steward(s) will assess each and every field to determine how each field pertains to the project objective. Justification for the fields should be provided by the Applicant in Section I of the DAR.

Students are encouraged to use all available resources such as information provided on the Population Data BC web site, discussions with RLU staff, and consultations with other successful Applicants.

Neither the Data Steward(s) nor Population Data BC will be held responsible for data selection oversights. The onus is on the student to research data holdings prior to submitting an application for data.

### How much data to request

Researchers should only request as much data as is required to complete a research project. Only those data necessary to complete the research questions can be released. Applications requesting more data than needed could be delayed due to modifications and revision of the data requested.

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## **IN CLOSING**

### **Project communications**

Once the DAR has been received by the Population Data BC, the project will be issued a project number for tracking purposes. The assignment of the tracking number does not necessarily mean the review process has been activated. While every DAR will receive a tracking number, not every DAR will be approved.

Please use the title that appears on the DAR and the Population Data BC-assigned project number on all future correspondence with Population Data BC and Data Stewards.

As Population Data BC facilitates communications and additional requirements, it needs to be copied on all direct communications/consultation with relevant Data Steward(s). Applicants should also expect to be contacted directly by Data Stewards if necessary.

Communications regarding PharmaNet applications should be sent directly to the Data Stewardship Secretariat at the Ministry of Health Services. Please copy Population Data BC on these communications to inform for their coordination efforts.

### **Questions and help**

Population Data BC's Researcher Liaison staff are available to help researchers with the DAR process. That said, staff time is a finite resource. Population Data BC is working to move many of the support related functions to the web in order to maintain high levels of support for applications. Prior to contact with the RLU, please do check to see if there are answers to your questions on the web. If you cannot find them do not hesitate to write or call.

## DEFINITIONS

**Applicant** – For the purposes of this document, the student who is legally and ethically responsible for their own use of data previously released to their supervisor, and the person with whom the Data Steward(s) will enter into a Research Agreement (RA) for that use.

**DAR** - refers to the formal Data Access Request application document for data through Population Data BC. Components of this application form include information on the researchers, the research questions, the proposed methodology, and details of the proposed cohort and data requested.

**External data** - refers to data not administered by Population Data BC and for which a checklist has not been provided.

**FIPPA** - refers to British Columbia's *Freedom of Information and Protection of Privacy Act* [RSBC 1996].

**RA** - refers to a Research Agreement between a Researcher and Data Steward(s) for the use of specific fields of data for specific research projects and outlining obligations associated with that access.

**SRE** - refers to a study-specific space on a central server (Secure Research Environment) at Population Data BC, where Research Extracts are stored and analyses can be done remotely using Virtual Private Networking.

**Student** –For the purposes of this document, a student means a person who is presently enrolled at a university in a credit course or who is designated by resolution of the senate as a student, and is under the direct supervision of an individual who is the principal investigator of a study with approved access to data holdings at Population Data BC.

**Study population** - refers to the group of subjects that a researcher wants to include in their analyses. The study population normally includes a cohort of individuals of particular interest, and may also include one or more comparison group(s).

**Supervisor** – the individual responsible for oversight and direction of the thesis or dissertation for which data have been requested by the student. This person must have current approval in place for the data to which the student has requested access.