



## Regional Data Linkage Supplementary Letter

Thank you for submitting your access application to the CanPath Access Office. Based on the initial review of your application, it appears that you will require data from a provincial administrative health data holder. As this data is outside the scope of the CanPath Access Process, this document is intended to provide you with additional steps that may be needed to obtain that data.

**First step:** If you request administrative data other than cancer incidence data only, please visit the [Data Access Support Hub \(DASH\)](#) of the Health Data Research Network to submit a Data Access Request form. The DASH team will help guide you through the data access process after you obtain approval from the CanPath Access Committee.

**Second step:** Based on the province(s) for which you plan to obtain administrative-linked data, there are additional access steps that need to be completed. Review the information below to help you start preparing the necessary documents.

### British Columbia

#### Data holder: PopData BC

PopData conducts the linkage for approved projects between their data and external data (e.g., CanPath-provided data). The administrative linked data is not available outside of PopData BC, and all research using this administrative data must be conducted through their Secure Research Environment (SRE).

Researchers requesting data from PopData BC will need to complete a Data Access Request form, obtained by emailing the Data Access Unit at [dataaccess@popdata.bc.ca](mailto:dataaccess@popdata.bc.ca). Information about how to start a Data Access Request (DAR) can be found here: [The PopData/HDPBC Data Access Request \(DAR\) process | Population Data BC](#)

BCGP provides the Personal Health Numbers of participants selected for a researcher approved project to PopData BC. PopData BC will then use this to pull administrative data for these participants. The PHN will never be released to the researcher. Instead, a project-specific participant identifier is generated. When BCGP provides the list of PHNs to PopData, we also send the requested harmonized CanPath/BCGP datasets. These data are released to PopData on a project-specific basis.

If a project involves the use of BCGP samples, PopData BC will also be given the corresponding sample IDs for each participant. Data generated from the analysis of samples can be provided by the researcher team to PopData BC, who will then link this biosample data to their dataset(s).

A BCGP invoice includes the cost of reviewing the application, the cost of the datasets, and the cost of biosamples (if applicable). PopData BC charges for their own review of the application, the datasets they provide, and for the service of linkage.

#### Data holder: BC Cancer Registry

Researchers must submit a British Columbia Generations Project (BCGP) Data Access Application. A BC Cancer Registry representative on the BCGP Access Committee will review the application. There will be a \$1,000 fee for the cancer registry variables. This fee is included in the invoice from BCGP and is directed to the BC Cancer Registry by BCGP.

Situation 1) If we are using the limited cancer registry data just to identify participants (e.g. Cases and controls), and no cancer registry variables will be included in the released data, we charge for the time that is required at \$190/hr and provide the derived variable that details whether a participant was a case or control.

Situation 2) If we are using the registry to identify participants, and they require the cancer variables from the cancer registry, we charge the flat \$1000\* fee for this data, even if the researcher will also be getting a case/control identifier.

Situation 3) If the researcher requests specific variables from the limited Cancer registry dataset, then the \$1000.00\* fee applies.

\*This does not include the \$500 administrative review fee applicable to all access requests involving data-only. If an application is for data and samples, there is a \$750 review fee, following the current Cost-Recovery Access Fees.

#### **Alberta**

##### Administrative health records

CanPath applications requiring administrative health data will need to contact [Data Access Support Hub \(DASH\)](#) of the Health Data Research Network to submit a Data Access Request form (as mentioned at the beginning of this document). The DASH team will connect with members of the Alberta Strategy for Patient-Oriented Research Support Unit (AbSPORU), which is responsible for facilitating Alberta's linkage process. The AbSPORU linkage process may differ case-by-case depending on the requested datasets.

In most instances, however, individual-level data may leave Alberta if:

- Alberta ethics approval has been obtained
- A Data Disclosure Agreement has been signed between the researcher and Alberta Health Services (AbSPORU operates within Alberta Health Services).

Researchers are encouraged to find an Alberta collaborator who can obtain Alberta ethics approval. However, if they are unable to do so, Alberta's Tomorrow Project (ATP) may assist with this. Note:

- When applying for ethics, the researcher must specify that Alberta Health Services resources will be utilized and must list the specific datasets that will be accessed.
- There is a cost for accessing administrative datasets.
- AbSPORU does not provide Alberta Cancer Registry data. Instead, researchers will need to request this data from Alberta's Tomorrow Project (ATP) - see below for more information.

### Cancer Registry Data

Cancer Registry data for Alberta residents can be obtained through Alberta's Tomorrow Project (ATP) (see Data Dictionary [here](#)). Researchers will need to:

- Submit an Alberta's Tomorrow Project (ATP) Data Access Application
- Sign a Data Disclosure Notice (between researcher and ATP)

A crosswalk file will be provided to allow the researcher to link the cancer registry data and CanPath datasets. Please contact ATP at [ATP.Research@ahs.ca](mailto:ATP.Research@ahs.ca) and reference the CanPath application ID.

Note: There is a fee for accessing Alberta Cancer Registry data.

## **Ontario**

### Data Holder: ICES

Researchers requesting access to administrative health data from ICES will need to reach out to ICES [Data Analytics Services \(DAS\)](#) ([das@ices.on.ca](mailto:das@ices.on.ca)). The OHS-linked data is not available outside of ICES. However, ICES provides researchers with access to the OHS-linked data through DAS. Once feasibility is cleared by ICES, CanPath will inform ICES that the project has received the CanPath approval to use the OHS data. No other OHS approvals are needed to proceed with the project. Separate data access fees apply to data held at ICES.

### Data Holder: Ontario Health (Cancer Care Ontario) (OH(CCO))

Researchers requesting variables from the Ontario Cancer Registry may apply directly to Ontario Health (<https://ontariohealth.ca/system/data/request> ([OH-CCO\\_Datarequest@ontariohealth.ca](mailto:OH-CCO_Datarequest@ontariohealth.ca))).

Separate application and data access fees apply. Once approval is received from CanPath and the DDSC, a data file of the requested cancer registry variables will be provided by OH(CCO); CanPath data are provided separately from the cancer registry variables. A crosswalk file will be provided to allow the researcher to link the OH(CCO) and CanPath datasets.

## **Quebec**

Final Approval: Data holders (Régie de l'assurance maladie du Québec ([RAMQ](#)), Ministère de la Santé et des Services sociaux ([MSSS](#)), Institut national de santé publique du Québec ([INSPQ](#)))

Researchers may go to the ISQ directly and fill out an online access request through the

“Guichet Unique” (<https://statistique.quebec.ca/zone-chercheur/#/login>). The ISQ team will review the application and then send it to the data holders for the final approval.

Principal Investigators from the private sector and/or from outside of Canada would need to partner with a Canadian academic (and preferably from Québec) to request access to the administrative health data.

The CARTaGENE (CaG) team offers to submit this application for the researcher and to eventually send the linked administrative data that is stored on our servers once the CAI gives the approval. CaG is the primary contact for all exchanges with ISQ and ensures an easier application process for the researcher. Separate application and data access fees apply.

Applying through CARTaGENE has the advantage of being less expensive for the researcher and faster.

### **Atlantic provinces (NB, NS, PEI, NL)**

#### Administrative Health Data

The HDRN Atlantic Canada Working Group has established workflow procedures for data access that begin with researchers approaching

- i) Atlantic PATH; ii) Regional Administrative Data Holder;\* or iii) HDRN.

A joint data access application form has been created and approved by all members of the Working Group, which includes all relevant information required by each member.

If a data access request only requires data from a regional administrative data holder and Atlantic PATH (e.g., one province only), the joint application will be processed through Atlantic PATH and members of the administrative data holder will be invited to participate in the review process.

If a data access request requires more than one Atlantic province and/or more than one cohort (e.g., Atlantic PATH and the Ontario Health Study), the joint application will be processed through HDRN's Data Access Support Hub (DASH). Please note that there is a revised access application for projects requesting administrative-linked data.

#### Cancer Registry Data

Cancer registry data can be accessed directly through Atlantic PATH's Data Access application for Newfoundland and Labrador and Nova Scotia participants. Linkage efforts for NB and PEI still in progress.

\**Health Data Nova Scotia (HDNS) at Dalhousie University; New Brunswick Institute for Research, Data and Training (NB-IRDT) at the University of New Brunswick, Secure Island Data Repository (SIDR) at the University of Prince Edward Island, and the Newfoundland and Labrador Centre for Health Information (NLCHI) at Newfoundland and Labrador Health Services*

**Saskatchewan**

Regional data linkage is not yet available in Saskatchewan, as CanPath does not yet have participant data available to researchers.

**Manitoba**

Regional data linkage is not yet available in Manitoba. Once the Manitoba Tomorrow Project concludes recruitment, they will work on procedures for accessing data.

Regards,

CanPath Access Office