

## Working with data providers to advance data driven research and innovation

At PopData we recognise that balancing the benefits of research in the public interest, with the privacy rights of the individual, is critical for any public or private body which collects data and makes those data available for research.

We have a **COMPREHENSIVE** and **FLEXIBLE package of SERVICES** to help data providers to achieve that balance.

### We offer:

**Secure data handling and storage**



**Data linkage**



**Data access request management**



**Online tracking and reporting**



Making data available for research can be a daunting prospect for organizations and individual researchers alike. There are legal and ethical considerations, data management and data access issues, and safety and security risks.

### So why make your data available for research?

- Because linking your data has the potential to positively affect public policy and the health and well-being of your community
- To raise your profile as an organization or researcher
- So the value of your data is recognised through citation in publications
- Because data sharing connects you and your organization with researchers and policy makers
- Partnerships between researchers and data providers can shape the direction of future data collection



Linkage of data across different sectors, such as health, education, childhood development, workplace and the environment, enables the pursuit of innovative research that would not otherwise be possible.

Population Data BC has been providing privacy-sensitive, person-specific data and related services to data users across Canada for over 25 years.

The use of complex linked data generates evidence about the production of well-being in individuals, communities and societies. This evidence has a crucial role in informing programs, policies, and investments for healthier communities.

## Secure data handling and storage



We operate one of the most secure data centres in Canada, exceeding all relevant legal, ethical, recommended best practice and legislative guidelines for data protection and privacy.

### What are the data storage options?

Partnering with PopData does not require that you store your data with us. Options include:

- The data provider maintains data and pulls extracts to fulfill approved projects - we coordinate and manage data requests
- The data provider has technical systems allowing PopData to pull data to fulfill approved projects - we coordinate and manage data requests
- Data are housed and managed by PopData, and are extracted to fulfill approved projects - we coordinate and manage data requests

### How are data protected?

#### Technical measures

Our information security measures are fully compliant with recognized ISO/IEC 27002 requirements. Network controls include:

- Firewall protection
- Access to Red Zone network, which holds the data, requires dual-factor authentication and is restricted to named personnel
- All access is logged and audited
- Content data and identifier data are stored separately in encrypted logical areas
- Red Zone networks are logically moated and have no direct connection to outside networks
- All stored data, including Personal Information, is encrypted

#### Procedural measures



Only named researchers have access to data



Everyone on the research team signs a confidentiality pledge



Data can only be used for the requested purpose



Privacy training for researchers is mandatory



Pre-publication transcripts are reviewed by data providers



Data is destroyed upon project closure

## Data linkage



PopData uses personal identifiers and mathematical linkage techniques to link records belonging to the same individual across files and over time.

We are a **trusted third party** for linkage as:

- We are not a data provider and we do not approve data access requests
- We do not conduct research or have our own research agenda
- We are university-based and publicly funded

### The Secure Research Environment (SRE)

Our SRE provides researchers with a central location for access and processing of data, secure storage and back up of their data extract and free software for data analysis.

With PopData providing researchers with a secure alternative to storing the data themselves, data providers can rest assured that their own requirements for security standards are being met and that the risk of unauthorized access to data is minimised.

## Data access request management

PopData saves time and resources for data providers by providing:

- A central intake point for applications
- A streamlined and transparent application process
- Coordination of the entire process through our Data Access Unit (DAU)

The DAU is the hub of all communication with researchers. Specialist staff oversee the stages of the data access process from initial inquiries and application planning and submission, through to data delivery and project closure.

DAU activities include:

- Providing information and advice to support applicants preparing Data Access Requests (DARs)
- Reviewing applications to ensure that all required documentation and information is included
- Forwarding DARs to the relevant data provider(s) for full review and approval
- Confirming research team composition and ensuring all have completed confidentiality undertakings, including privacy training

### The Data Access Process



### Data Sharing Agreements

All usage of data is regulated by a Data Sharing Agreement between Population Data BC and you as the data provider. The Agreement forms the essential governance foundation for data access for approved research in the public interest, in compliance with The Freedom of Information and Protection of Privacy Act (FIPPA) and other pertinent legislation.

**As a data provider you maintain control (or stewardship) of the data and approve all Data Access Requests from researchers on a case-by-case basis. PopData has no authority whatsoever in terms of authorizing access to the data.**

A Data Sharing Agreement can be for multiple projects or just for a specific project (data can become part of PopData's data holdings or only available for a specific project and be time-limited).

Security requirements and compliance monitoring are standard in our Data Sharing Agreements, and include logging, reporting and auditing.

## Online tracking and reporting



Comprehensive tracking and reporting throughout the data access process is available to data providers via our custom-made online management tools.

### DARonline

Data providers can now view all their DARs using DARonline. Features include user-friendly navigation, the ability for data providers to generate application summaries, and one place to see all pending requests.

### AppTracker

We developed AppTracker to help us efficiently track our research projects. Data providers can also use AppTracker to view project information such as expiry dates, team members, data releases, data storage location, and more.

### MetadataCentral

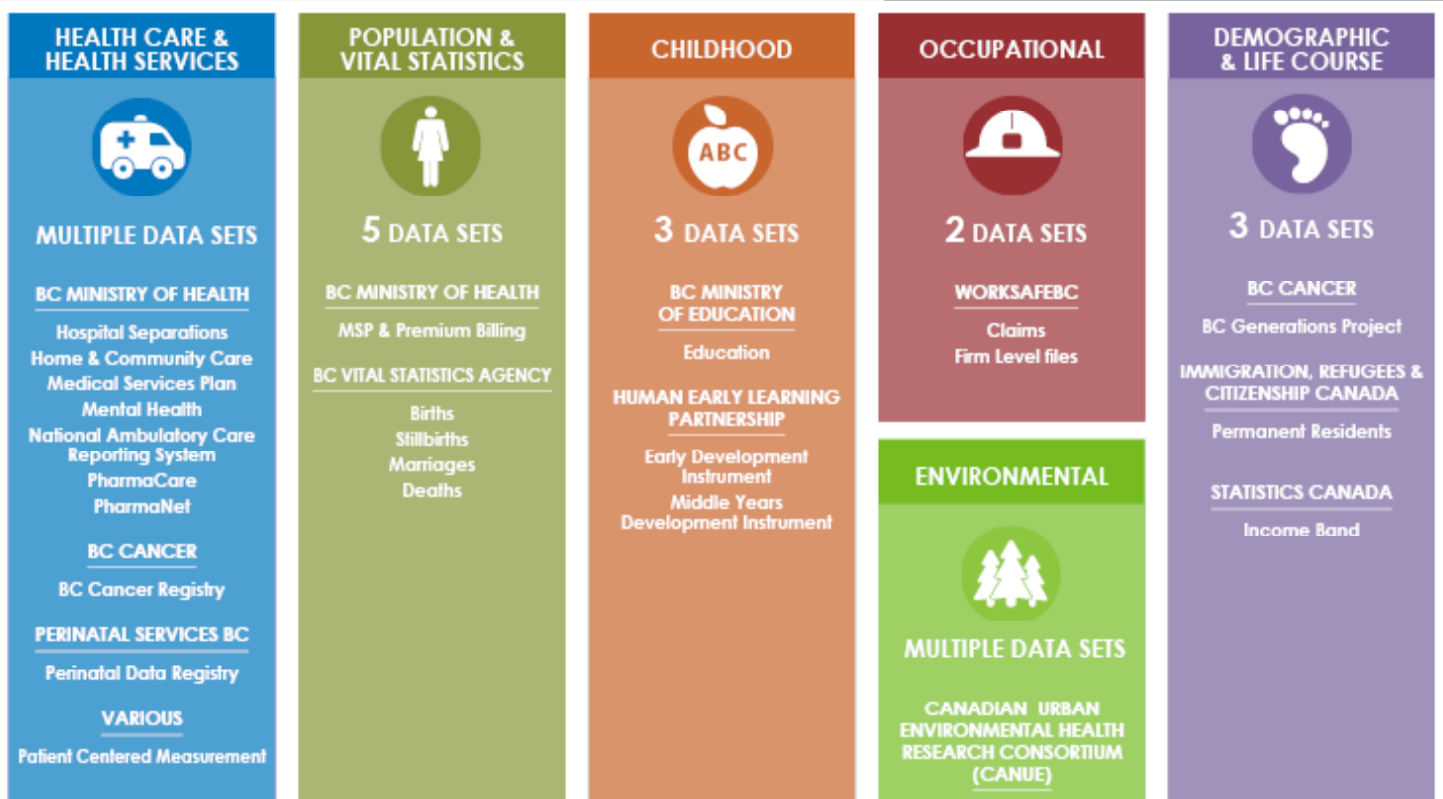
Our online data documentation system allows data providers to view summary statistics on the data we hold, such as frequency over time. Data providers can also view the current documentation we have on the data.

## Current data providers

We support research access to individual-level, de-identified, longitudinal data on British Columbia's 5 million residents. These data are linkable to each other, and to other data sets, where approved by the data provider.

We manage over 30 data sets from federal and provincial providers. We refer to these as internally-managed data holdings.

Over the years we have linked external data from over 60 different data providers to our internally-managed data holdings. We also link our internally-managed data holdings to researcher-collected data.



## Why trust us with your data?

We have been operating successfully for over 25 years and are trusted by many data providers including federal and provincial government.

A full suite of tried-and-tested security and privacy policies and procedures clearly define our operations.

The UBC Office of University Counsel, the BC Office of the Chief Information Officer and the BC Office of the Information and Privacy Commissioner have reviewed our policies and procedures.

We have successfully completed external audits from the BC Ministry of Health, Grant Thornton and Deloitte.

**NOTHING is EVER done with, or to, your data without written approval from you, as the data provider.**

To talk about how we can work together to make your data available for research, call Gitta Oldendorff on 604 822 1370