



Health Data Platform (HDP)

Frequently Asked Questions



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General

1. What is the Health Data Platform (HDP)?

The HDP supports research and analysis both within the health sector and in academia, by allowing access to health data from multiple sources to be brought together as required (on-demand), linked, de-identified and analyzed on a single secure platform.

The goal of the HDP is three-fold:

- *Provide more timely, secure and consistent access to integrated 'big' health data*
- *Establish a standard and enhanced privacy and security landscape*
- *Increase process transparency and efficiency for data providers and data consumers*

Using consistent and streamlined processes, users can expect a faster and more transparent experience when requesting and obtaining approval to data access. Users will now have a consistent and single source to request and access data, rather than multiple.

This work is being developed and led by the Ministry of Health with matched funding from the Canadian Institutes of Health Research (CIHR) through their national Strategy for Patient-Oriented Research (SPOR), the BC SUPPORT Unit (an operating unit of BC AHSN that implements SPOR in BC), and the Province of BC.

Note: Please see question #4 (How and who will govern the HDP?) for further detail on the governance of the HDP.

2. Why do we need the HDP?

Currently, researchers and health authority analysts experience a time-consuming and non-transparent request, approval and data access process. Each data source researchers and analysts may wish to access is individually governed and supported by its own set of request, approval and data access business processes. Managing multiple applications, varying timelines and the needs of each process can be a cumbersome and time-consuming experience.

Working in this siloed environment has resulted in difficulties in achieving dependable timely access to data, effecting our ability to unlock the value of our growing data resource.

Population Data BC and the Ministry of Health have been working together for two decades to improve access to health data for researchers. Building upon this, the HDP, using standardized and streamlined process for requests, approval and data access, will greatly improve timeliness and transparency to safely access data.





3. How is the data in the HDP being kept safe and individual privacy being protected?

The HDP Initiative was developed in partnership with privacy experts and has been reviewed by the Office of the Information and Privacy Commissioner. The program complies with B.C.'s strict laws and embodies world-leading best practices for data privacy and security.

The HDP has developed a Data Access Framework that complies with existing legislation and based on the International Five SAFEs Privacy and Security Framework (Five SAFEs) and three approval paths. The HDP uses only de-identified data, or data stripped of any information that could reasonably be used to re-identify. Even still, data is treated as confidential, sensitive, and subject to the Freedom of Information and Protection of Privacy Act.

All Analysts or Researchers must submit an application for data access, which is then rigorously reviewed and screened using the 5 SAFEs privacy model. If the application is approved, the data can be accessed only in a secure setting and analysts will not have access to personally identifiable information. Currently, two have been identified: HDP Secure Environment operated by, and under the oversight of, the Ministry of Health and the Secure Research Environment operated by Population Data BC (PopData).

Note: Please see question #4 (How and who will govern the HDP?) for further detail on the governance of the HDP and question #10 (How are the 5 safes used to determine if a request is pre-approved or not?) on the application of the 5 Safes.

4. How and who will govern the HDP?

The interim governance structure of the HDP is shown below. It is important to note that the Health Data Council will be responsible for reviewing cross-organizational data access requests, rather than the current environment which requires individual review by each organization. In addition, the Data Stewardship Committee will continue to review requests for access to data for a research purpose, as required by legislation, for PharmaNet data and data from a designated Health Information Bank.

The interim structure will focus on representation from the Ministry and Health Authorities who bring perspectives into privacy, research operations, and sector analytics needs. Work will continue to refine this structure and transition to an ongoing operations structure where we will see more inclusive membership representative of the broader community, including citizens.



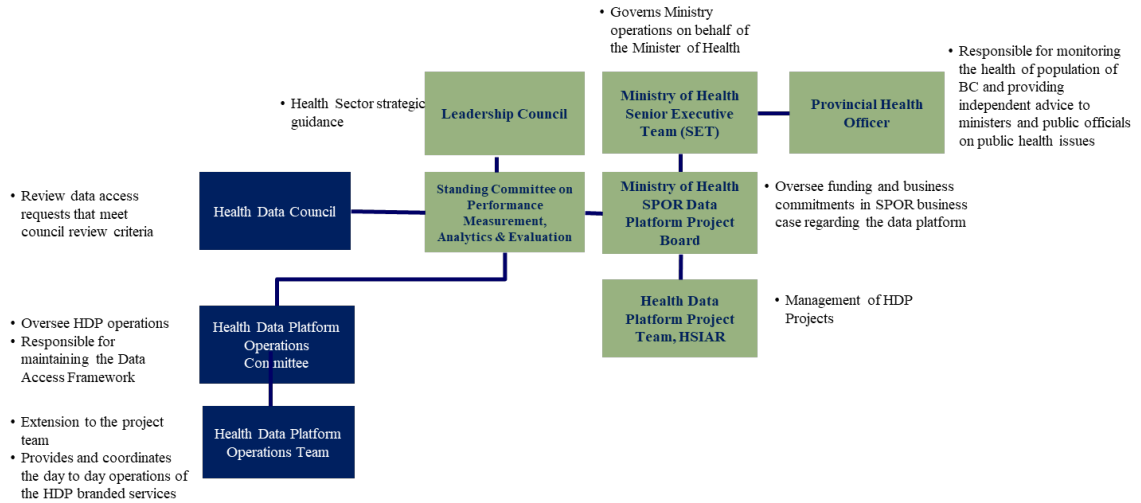


Figure 1. HDP interim governance structure

Health Data Council Membership from the following organizations:

- Vancouver Island Health Authority
- Vancouver Coastal Health Authority
- Fraser Health Authority
- Interior Health Authority
- Northern Health Authority
- Providence Health Care
- Provincial Health Services Authority
- BC Ministry of Health
- First Nations Health Authority

Health Data Platform Operations Committee Membership from the following organizations:

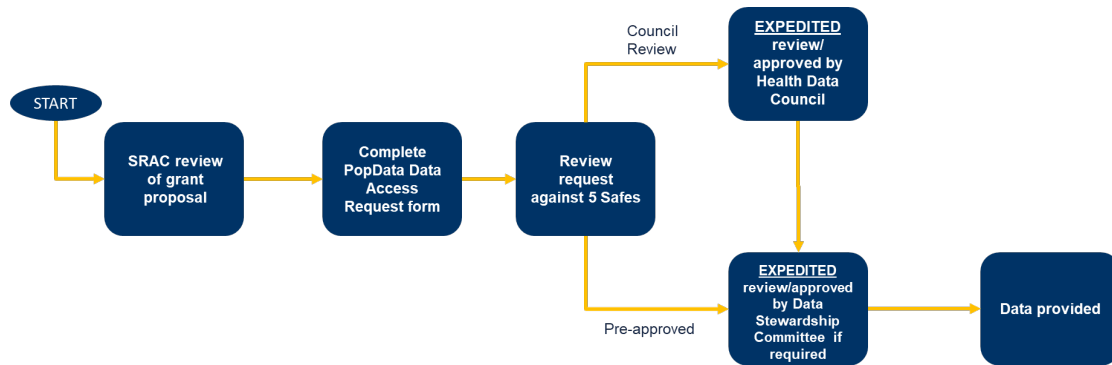
- Vancouver Island Health Authority
- Vancouver Coastal Health Authority
- Fraser Health Authority
- Interior Health Authority
- Northern Health Authority
- Providence Health Care
- First Nations Health Authority
- BC SUPPORT Unit
- Provincial Health Services Authority
- BC Ministry of Health

Note: Please see question #5 (How do I request access to COVID-19 data sets in the HDP?) for further detail on how to make a request to the HDP for access to the COVID-19 data sets.





5. How do I request access to COVID-19 data sets in the HDP?



Step 1 – SRAC Review: COVID-19 Strategic Research Advisory Committee (SRAC) reviews winners of grants to determine if the project meets the prioritization criteria. *Note: If the grant is awarded from Genome, MSFHR or CIHR, SRAC review is not required and you can proceed with Step 2 and complete your PopData Access Request form for COVID-19 data.

Step 2 - Application for Data: If your COVID-19 project has been approved by SRAC, please contact dataaccess@popdata.bc.ca for support on completing your Data Access Request (DAR) form and submitting your request.

Step 3 – 5 Safes & Expedited Reviews: Once your request is submitted, it is assessed against the 5 Safes. If the request meets all 5 Safes, it is pre-approved and proceeds for expedited review by the Data Stewardship Council, if required. If it is not pre-approved, the request proceeds to expedited review by the Health Data Council and then the Data Stewardship Council, if required.

Step 4 – Approvals: Once final approval has been received, your request will be expedited for data retrieval and access.

Notes:

Require assistance from PopData with your COVID-19 data request? Please see: www.popdata.bc.ca/COVID-19_research_support

6. How do I request access to data sets that are not COVID-19 related?

To access non-COVID-19 data, follow the established process for data access through PopData. A range of non-COVID-19 data sets relating to health and health care services are available to eligible researchers through PopData. Please visit: <https://www.popdata.bc.ca/data> for





information on data available and <https://www.popdata.bc.ca/dataaccess> for information on the data access process.

7. How are PopData, the BC SUPPORT Unit and the HDP working together to support data access?

The HDP is an additional service to the sector. It does not replace current data sources in the Ministry or Health Authorities.

PopData BC, the BC SUPPORT Unit and HDP are working collaboratively on this project. PopData will continue to be the front counter service for health data requests from researchers, which currently includes cross-organizational requests. The HDP will offer a separate front counter for organization-based health (health authority or Ministry of Health) data requests, operated on an interim basis from the Ministry of Health, with options for a permanent arrangement to be explored in the coming months.

The mission of the BC SUPPORT (Support for People and Patient-Oriented Research and Trials) Unit, which implements the national Strategy for Patient-Oriented Research (SPOR) and is an operational unit of the BC Academic Health Science Network (BC AHSN), is to support high-quality patient-oriented research in British Columbia. One of the commitments to support the goals and objectives of the Unit is to build and implement a program for a distributed health data environment, which has been recognized as critical to health system transformation.

Conceptualizing a provincial HDP to support research within the context of the BC SUPPORT Unit's goals has provided a means to re-envision this commitment. The process has enabled new partnerships aimed at accelerating the sharing of data to external parties; streamlining data requests and access processes; and developing products and services that promote greater responsible data use and accessibility.

8. When will the HDP be ready?

*The HDP will be launching on July 20th, 2020 with **COVID-19 data sets for access to priority projects**.*

Further data sets and data access for non-COVID related projects through the HDP environment will become available to researchers in Fall 2020.





July Launch

9. What changes will I see with the launch of the HDP?

Researchers:

- Starting July 20th:
 - **Making a request for COVID-19 data sets:** All Data Access Requests (DAR) will be done through PopData: https://my.popdata.bc.ca/COVID-19_research_support.
 - High priority COVID-19 requests (as deemed by the COVID-19 Strategic Research Advisory Council) will follow an expedited approval path
 - All other data access requests will continue to follow existing processes.
- Starting in the Fall of 2020:
 - More data sets will become available
 - New streamlined request and approval process for HDP available data sets will be launched.
 - Which data sets to be available in the HDP are to be determined.

Note: Please see question #5 (How do I request access to COVID-19 data sets in the HDP?) for more information regarding the data access request and approval process for COVID-19 data.

10. How are the 5 safes used to determine if a request is pre-approved or not?

When a request is submitted to the HDP, it undergoes a review against the 5 safes to make informed decisions when protecting data privacy and security and making decisions that benefit the people of BC. The criteria will evolve over time. The 5 safes for the HDP for the July launch are as follows:

1. **Safe People**
Principal investigator is from a Canadian Institution **OR**
Analyst from a BC health authority or MoH as approved by the organization’s delegate
2. **Safe Project**
Research: High priority research project as determined by Strategic Research Advisory Council (SRAC)
Organization: High Priority Organization Project as determined by the requesting organization designate
3. **Safe Data**
Core Data set provided by each organization
4. **Safe Environment**
HDP secure environment **OR**
PoPData secure research environment
5. **Safe Output**
Statistical products





11. What COVID-19 data sets will be available on July 20th?

Data Sets	Scope
COVID test lab data	Individuals tested and their result, starting Jan 2020
Case data	Lab confirmed positives, starting Jan 2020
All ICU admission	Starting Jan 2020
COVID acute admissions	Starting Jan 2020
Mortality data – Vital Statistics	Back to 2008, including current year
Fee for Service (MSP) data	All available years, including open year
Chronic Disease Registry	Latest version
Discharge Abstract Data (DAD)	All available years, including open year
National Ambulatory Care Reporting System (NACRS)	All available years, including open year
Health System Matrix	Latest version
Pharmanet	All available years, including open year
Client Roster	Latest version
811	All available years

Next Steps

12. What datasets will be available next and when?

The HDP Project Team, Project Committee and Project Board are currently planning which data sets will be available in the HDP after the COVID-19 launch on July 20th, and when. The Project team will provide updates as they become available through the HDP Newsletter, which will be released monthly.

Questions? Please contact the HDP team at: mohanalytics@gov.bc.ca

