

ACCESS OFFICE HOURS



Réseau de recherche sur les données de santé du Canada
Health Data Research Network Canada

Discover how HDRN Canada and CanPath can help you navigate multi-regional data access through DASH

Dedicated to reconciliation with Indigenous Peoples

We acknowledge the traditional territories of the Mississauga of the New Credit First Nation, Anishnawbe, Wendat, Huron, and Haudenosaunee Indigenous Peoples on which the CanPath National Coordinating Centre at the University of Toronto now stands. The territory was the subject of the Dish With One Spoon Wampum Belt Covenant, an agreement between the Iroquois Confederacy and Confederacy of the Ojibwe and allied nations to peaceably share and care for the resources around the Great Lakes.

With CanPath teams working across Canada from coast to coast, we also acknowledge the ancestral territories that are home to many Indigenous people from across Turtle Island, and we are grateful to have the opportunity to work on this land.

Welcome to Access Office Hours!

- HDRN Canada's Data Access Support Hub (DASH) presented by Joanna Ou, DASH Coordinator
- CanPath Access Process presented by Nouar Elkhair, CanPath Access Officer
- CanPath Biosamples presented by Treena McDonald, CanPath Biosamples Coordinator
- CanPath Data & Navigating the Portal presented by Sheraz Cheema, CanPath Data Manager



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HDRN Canada's Data Access Support Hub (DASH)

DASH

DASH is a service for researchers conducting multi-regional research

- Service provided by a coordination team of representatives from 13 data centres across Canada
- Facilitates data access in provincial/territorial & pan-Canadian data centres & helps navigate local requirements
- Data are available & accessible through the data centres



HDRN Canada Member Organizations



Manitoba Centre for Health Policy



Statistics Canada

Statistique Canada



Data Access Support Hub (DASH)

DASH simplifies the data access process by providing:

**Navigational
support &
coordination**

**Centralized
resources &
tools**

**Harmonized
services**

**Technological
solutions**



Data Access Support Hub (DASH)

A one-stop data access service portal for researchers interested in pursuing multi-regional health & health-related administrative data in Canada.

182

Inquiries Received

156

Project Feasibility Reports

28

Active Projects

574

Data Assets

185

Algorithms



Data assets

- Administrative data
- Clinical data
- Social data
- New data sources (e.g., CanPath, CLSA)
- Opportunities for linking researcher collected data to administrative data

For more information: <https://www.hdrn.ca/en/dash/inventory/>



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Linked data availability

CanPath - HDRN Canada

BC	AB	SK	MB	ON	QC	NB	NS	PE	NL	CIHI	StatCan
✓	✓	+	+	✓	Other: CARTaGENE	✓	✓	In progress	In progress	*	*

✓ Available for request, upon project review and approval

In progress: Working on a process and a data-sharing agreement

+ Recruitment in progress with CanPath

* On a per-project basis, to be determined upon review and approval


Other: At this time, linked CanPath data is not directly available from Institut de la statistique du Québec (ISQ) but may be available through another organization



How DASH Works

PHASE 1
1 COMPLETE INTAKE FORM

1. Sign up for a DASH account
2. Submit an Intake Form
3. Review DASH resources



DASH TEAM COORDINATES: Intake call between Researcher & data centre to review the project
⌚ 5 BUSINESS DAYS

+

Consultations between Researcher & data centres to confirm project feasibility

+

Data centre feasibility assessment & cost estimate* sent to Researcher
⌚ 2 - 4 WEEKS



PHASE 2
2 COMPLETE DATA ACCESS REQUEST (DAR) FORM

DASH Team: Assists Researcher in completing Data Access Request (DAR) Form

+

Guides Researcher on local instructions & documents required for DAR

+

Coordinates a project kick-off meeting between Researcher & relevant data centres



NEXT STEPS:

1. DASH Team coordinates regular meetings with Researcher to ensure project progression
2. DASH Team & relevant data centres support Researcher to obtain:
 - Project approval including Original Data Provider/Data Custodian approvals
 - Privacy, Confidentiality & Security Review
 - Data Sharing Agreements
 - Data Access



PHASE 3
3 DATA RELEASE & INVOICING

Researcher accesses data according to each data centre's policies & procedures
hdrn.ca/en/dash/data-access-process/

Data centres invoice Researcher for data access services
hdrn.ca/en/dash/about-dash/data-related-services-costs/



*IF APPLICABLE

Innovative Resources

- **Data Assets Inventory:** hdrn.ca/en/dash/inventory/
- **Algorithm Inventory:** hdrn.ca/en/dash/algorithms/
- **Pan-Canadian Privacy Legislation Tool:**
hdrn.ca/en/dash/resources/privacy/privacy-legislation/
- **Ethics & study design** considerations: hdrn.ca/en/dash/resources/
- **Web portal** for centralized forms & tools: dash.hdrn.ca/en/accounts/login/



Thank you!

Get in touch: dash@hdrn.ca



Réseau de recherche sur les données de santé du Canada
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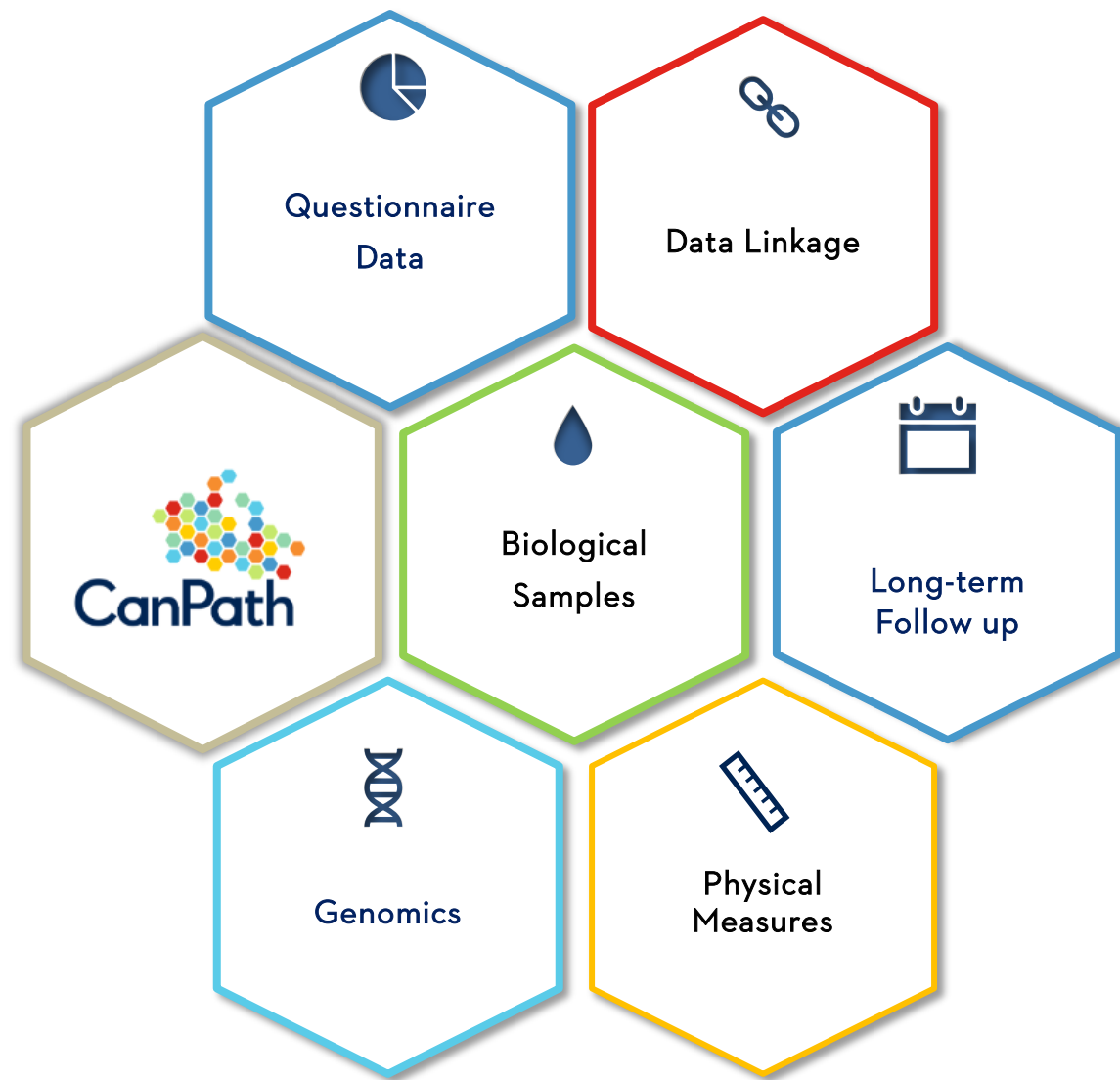
DASH Data Access
Support Hub



CanPath Access Process Overview

Nouar Elkhair | CanPath Access Officer

CanPath is a population-health research platform for assessing the effect of genetics, behaviour, health history and environment on chronic diseases. CanPath follows the health of 330,000 adult Canadians.



CanPath brings together seven cohorts across ten provinces



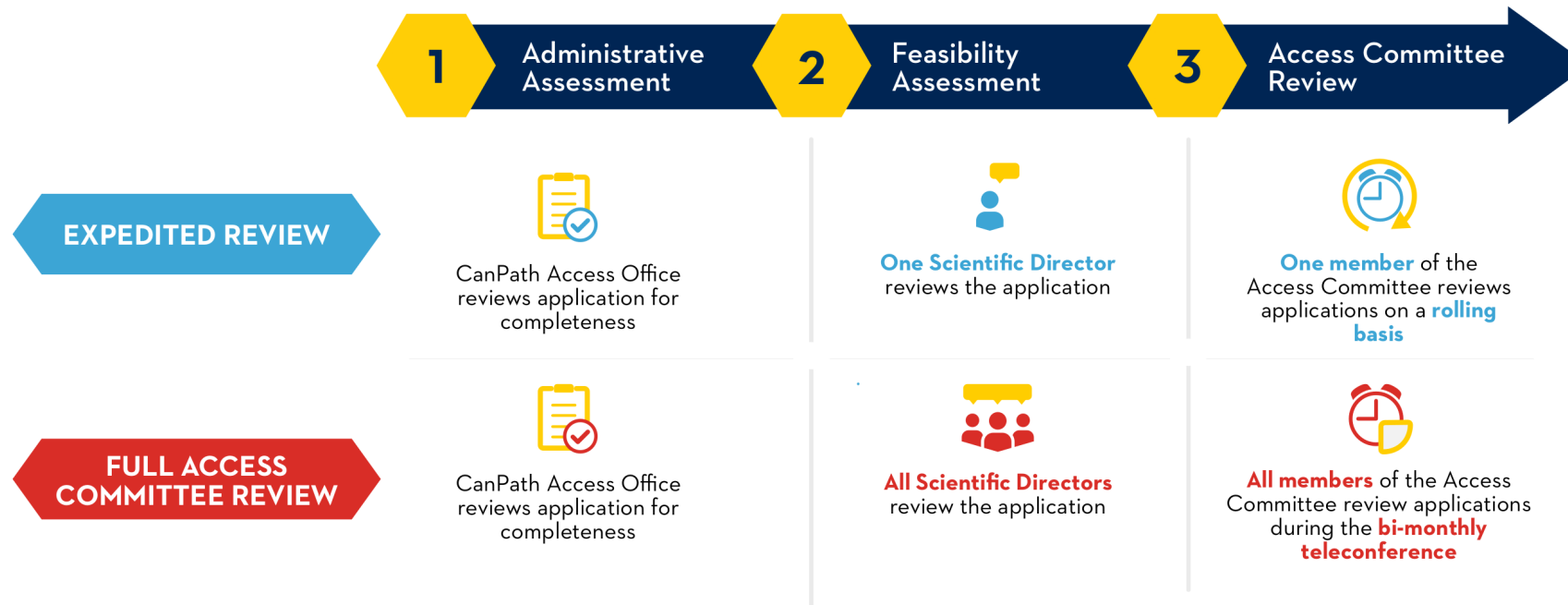


What documents are required to access CanPath Data and Biosamples?

- **Access Application Form** (register on the [access portal](#))
- **Research protocol** (having received ethics approval)
- **Research Ethics Board approval letter**
- **2-page CV** of the principal applicant
- **Proof of scientific review or peer review**, if available
- **Evidence of funding**, if applicable
- **Contact information of your legal institutional representative**

How quickly can I access Data or Biosamples?

Expedited vs. Full Access Review



Which access applications are Expedited?

- Applications for Harmonized datasets are eligible for an Expedited Review.
- CanPath's Harmonized datasets include:
 - Baseline Health and Risk Factor Questionnaire (Qx) & Additional Diseases
 - Baseline Mental Health
 - Baseline Physical Measures
 - Follow-Up 1 Health and Risk Factor Questionnaire
 - COVID-19 2020 Qx
 - COVID-19 Antibody Qx | Results | Follow-up 1
 - Environmental Health Data (CANUE)
 - Genotype Data * (*Added genotype data is available at regional cohorts*)

Which applications require a **Full Review**?

- **Full Access Review**
- **Biosample requests**
- **Linkage:** Projects that will link CanPath data to
 - Administrative health data (ICES, AbSPOR, PopDataBC)
 - Cancer registries
- **Regional data:** Projects that request access to regional datasets held by provincial cohorts
 - Genotype data held by OHS & CaG

How much will it cost to access data?

- Cost recovery fees for **data-only applications** for **academic** researchers are available on the CanPath website.
- For **biosamples and industry-based research requests**, contact access@canpath.ca

	Cost for the first dataset	Cost for each subsequent dataset
Researcher	\$3,000	\$1,000
Early-Career Researcher [†] <i>Canadian Institution</i>	\$750	\$250
Early-Career Researcher [†] <i>Non-Canadian Institution</i>	\$1,800	\$600
Graduate Student or Postdoctoral Fellow [‡]	\$250	\$190



FAQ

- Before applying, can I get sample size estimates for my project?
 - Yes, CanPath provides preliminary aggregate data for Data and Biosamples meeting your selection criteria.
- Can I get a Cost Estimate and/or Letter of Support before submitting an application?
 - Yes, complete the form (available on the CanPath Portal)
 - Send it to apply@canpath.ca (~10 business days)
 - Requests for regional data & biosamples may require more time
- What are the estimated timelines for accessing CanPath data & biosamples?
 - Expedited reviews: can be completed in 12 weeks
 - Full Access review: timelines vary



CanPath Biosamples Overview

Treena McDonald | CanPath Biosamples
Coordinator

Biosamples | What's available?

- **Blood derivatives:** serum, plasma, DNA, red blood cells, whole blood in DMSO
(>145K participants donated one or more blood derivative)
- **Urine** (>100K participants)
- **Toenails** (Atlantic PATH only, >30K participants)
- **Saliva:** DNA

Access to Biosamples

- *Biosample Access Guidelines* and *Biosample Feasibility Review* are available from the CanPath portal (<https://portal.partnershipfortomorrow.ca/page/samples>)
- Asks of >500 uL for non-DNA samples and >2 ug for DNA samples are considered a large ask and will require extraordinary scientific justification to be considered.
- Full Access Committee review is required for submissions seeking biosamples.
- Approved biosamples may be conditionally released in a staggered format.

Application Tips



Alignment

- Ensure that the requested biosamples are the same in the protocol and application.



Measurement Units

- Clearly detail units of measurements for serum (volume)/ DNA (mass).



Service Provider

- If a service provider is being used, please provide details regarding samples requested by the provider.



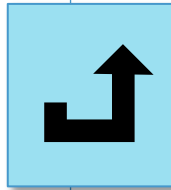
of Participants

- If count is different than sample size, provide explanation and justification.



Tests vs. Biomarkers

- Test: are number of assays
- Biomarkers: number of markers measured
- e.g. 1 Test can measure 96 biomarkers.



Return of Data

- Raw and analyzed data **must** be returned
- Add details on the format of the returned data

CanPath Data Overview

Sheraz Cheema | CanPath Data Manager



Datasets | What's available?

CORE DATA

The objective of the CanPath Harmonization Initiative is to understand the relationship between the environmental, lifestyle, and genetic factors for the development and progression of cancer and chronic diseases in the Canadian population.



GENOTYPE DATA

Genotype data on more than 4,800 CanPath participants are available. The genotype data provide information on over 820,000 SNPs (Affymetrix UK Biobank Axiom® 2.0 gene chip). Marker categories include disease markers, pharmacogenomics, Human Leukocyte Antigen (HLA), inflammation and Expression ...



ENVIRONMENTAL EXPOSURE DATA

The CIHR-funded Canadian Urban Environmental Health Research Consortium (**CANUE**) collates and generates standardized area-level environmental data on air and noise pollution, land use, green/natural spaces, climate change/extreme weather, and ...



CAHHM DATA

The Canadian Alliance for Healthy Hearts and Minds (CAHHM) aims to understand the association of socio-environmental and contextual factors with cardiovascular risk factors, subclinical vascular disease, and cardiovascular and other chronic disease outcomes. CAHHM brings together participants ...



CanPath Datasets | Core

- Baseline Health and Risk Factor Questionnaire
- Baseline Health and Risk Factor Questionnaire – Additional Diseases
- Baseline Mental Health
- Baseline Physical Measures
- Follow-Up 1 Health and Risk Factor Questionnaire
- COVID-19 (2020) Questionnaire
- Baseline COVID-19 Antibody Questionnaire & Results
- Follow-up 1 COVID-19 Antibody Questionnaire & Results
- Genotyping Data available through CanPath and Regional cohorts (~50K participants)

Application Tips



Participants

- Case definition: participant self-report or registry data.



Number of Participants

- Avoid "all" or 'as many as possible'. (beyond scope)



Selection Criteria

- Clear inclusion/exclusion criteria
- Clarify required vs optional criteria



Case - Control Studies

- Clarify case-control matching criteria, for example, age or history of cancer



Variables

- Choose to receive a full dataset or select variables (a list of variables can be generated on the CanPath Portal).



Data Linkage

- How will the data be linked?
- Specify data holders and regions

Q & A



CanPath.ca



CanPath

Canadian Partnership
for Tomorrow's Health