



## Accessing Data

November 12, 2025



**Land Acknowledgement**

# Housekeeping



Please mute your microphone



Recording in progress




Closed Captioning



Type questions in chat  
Include your name, *if you'd like to ask yourself*



An aerial photograph of the Dalhousie University campus in Halifax, Nova Scotia. The image shows a mix of historic stone buildings with multiple windows and a central clock tower, alongside more modern, multi-story academic buildings. A large green soccer field with white markings is visible in the upper right. The campus is surrounded by trees and urban infrastructure.

# Accessing Data at Health Data Nova Scotia (HDNS)

Presented by: Katelyn Frizzell



# About HDNS

- An agent of the Nova Scotia Department of Health and Wellness (DHW)
- Department of Community Health and Epidemiology, Dalhousie University
- Partnered with the Maritime SPOR SUPPORT Unit (MSSU)
- HDRN Canada member organization
- Facilitate research and innovation
  - linking data
  - performing analyses
  - secure environment
  - protecting privacy and confidentiality



# Who are we?

## HDNS Team



**Dr. Samuel Stewart, PhD**  
Director, HDNS

**Lindsay Stewart, MSc**  
Manager, HDNS

**Sandra Pauls, DipBA**  
Regulatory Compliance and Finance  
Administrator

**Katelyn Frizzell, MSc**  
Data Navigation Manager

**Yoko Ishigami-Doyle, PhD**  
Research Analyst/Documentation Specialist

**Lihui Liu, PhD**  
Senior Research Data Analyst

**Yan Wang, MCS**  
Senior Research Data Analyst

**Yves Ibeme, BAS, MTEI**  
Senior Research Database Administrator

**Xuyuan Zhang, MPH, DSc**  
Research Data Analyst/Data Navigator

### Consultants

**Jordan Farrell, MHI** -  
Systems administration

**Akash Rupareliya,**  
**MACS** -Website  
development

**Sam Tung, MPH** - Data  
analysis



## HDNS Provincial Healthcare Utilization Databases

Medical Services Insurance (MSI) Physician Billings	CIHI Discharge Abstract Database	CIHI National Ambulatory Care Reporting System	Family/Seniors' Pharmacare	Drug Information System
<ul style="list-style-type: none"><li>• Contains administrative records for each health service rendered by a physician and paid for by the provincial government</li><li>• Utilizes ICD-9 diagnostic and procedure coding</li><li>• Includes approximately 35 variables</li><li>• Note: A separate database containing records on dental services covered by MSI is also available at HDNS</li></ul>	<ul style="list-style-type: none"><li>• Contains information on each hospital admission recorded in a Nova Scotia hospital</li><li>• Includes inpatient services</li><li>• Includes diagnoses and procedures performed, types of services, and service transfers</li><li>• Utilizes ICD-9 coding prior to March 31, 2001, and utilizes ICD-10 coding from April 1, 2001 onward for diagnoses and procedures</li><li>• Includes approximately 600 variables</li></ul>	<ul style="list-style-type: none"><li>• Contains information on all types of ambulatory care including day surgery, outpatient and community-based clinics and emergency departments</li><li>• Includes diagnoses and procedures performed, types of services, service transfers and specialty of service provider</li><li>• Includes approximately 410 variables</li><li>• Note: Level of reporting varies based on the facility</li></ul>	<ul style="list-style-type: none"><li>• Contains information on prescriptions paid through provincial prescription drug programming (e.g., Seniors' Pharmacare)</li><li>• Utilizes the WHO, Anatomical Therapeutic Chemical (ATC) classification system and the Drug Identification Number to categorize drugs</li><li>• Quantity of drug dispensed (dosage)</li><li>• Includes approximately 30 variables</li></ul>	<ul style="list-style-type: none"><li>• Contains information on all prescriptions filled in a community pharmacy in Nova Scotia</li><li>• Contains prescription dates, drug codes, drug strength, drug type, quantity, length of prescription, etc.</li><li>• Utilizes the Drug Identification Number to identify specific drugs</li><li>• Note: Drug information is not available from hospital pharmacies or other institutions not serviced by community pharmacies</li></ul>





## HDNS Provincial Population-Based Databases

Insured Patient Registry	Licensed Provider Registry	Vital Statistics
<ul style="list-style-type: none"><li>• Contains longitudinal information about every individual registered as a beneficiary of MSI in Nova Scotia</li><li>• Includes approximately 20 variables</li><li>• Note: this database also contains a dataset on Long Term Care residency (EGROUP)</li></ul>	<ul style="list-style-type: none"><li>• Contains demographic information on prescribers who are registered and licensed to practice in Nova Scotia</li><li>• Includes approximately 20 variables</li></ul>	<ul style="list-style-type: none"><li>• Contains information on date and cause of death of Nova Scotia residents</li><li>• Utilizes ICD-9 to identify causes of death up to Dec. 31, 1999, and utilizes ICD-10 coding from Jan. 1, 2000 onward</li><li>• Includes approximately 40 variables</li></ul>

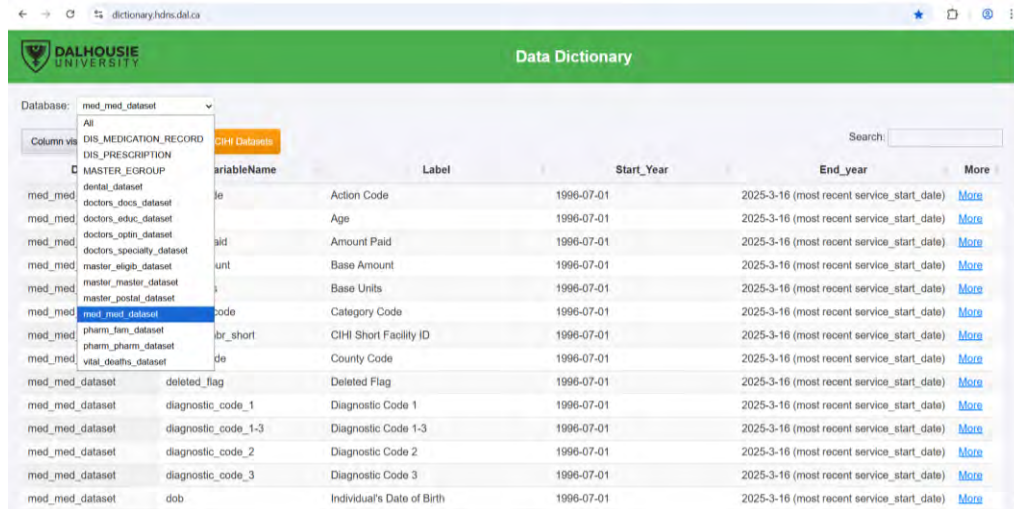
## HDNS Provincial Research Databases

Canadian Longitudinal Study on Aging (CLSA)	Atlantic Partnership for Tomorrow's Health (PATH)
<ul style="list-style-type: none"><li>• Large, national, long-term study, ~4,500 Nova Scotians involved</li><li>• Baseline recruitment: 2010-2015. Follow-up every three years until 2033</li><li>• Questionnaire data on biological, medical, psychological, social, lifestyle and economic aspects of people's lives</li></ul>	<ul style="list-style-type: none"><li>• Large, national study, ~34,000 Atlantic Canadians involved</li><li>• Baseline recruitment: 2009-2015, follow up: 2016-2018. Covid data: 2020-2023</li><li>• Questionnaire data, biological samples (blood, urine, saliva, toenails), physical measures, toenail clippings</li></ul>



# Data Access - Where to start\*

- Contact a Data Navigator
  - Consultation
  - Help with forms
- Review data availability (<https://dictionary.hdns.dal.ca/>)



The screenshot shows the Dalhousie University Data Dictionary interface. The header is green with the Dalhousie University logo and the text "Data Dictionary". Below the header, there is a search bar and a table of datasets. The table has columns for "Database", "VariableName", "Label", "Start\_Year", "End\_year", and "More". The "Database" column is currently set to "med\_med\_dataset". The "VariableName" column lists various medical variables, and the "Label" column provides descriptions for these variables. The "Start\_Year" and "End\_year" columns show the time range for each variable. The "More" column contains links to further information.

Database	VariableName	Label	Start_Year	End_year	More
med_med_dataset	action_code	Action Code	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	age	Age	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	amount_paid	Amount Paid	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	base_amount	Base Amount	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	base_units	Base Units	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	category_code	Category Code	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	cihi_short_facility_id	CIHI Short Facility ID	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	county_code	County Code	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	deleted_flag	Deleted Flag	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	diagnostic_code_1	Diagnostic Code 1	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	diagnostic_code_1-3	Diagnostic Code 1-3	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	diagnostic_code_2	Diagnostic Code 2	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	diagnostic_code_3	Diagnostic Code 3	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>
med_med_dataset	dob	Individual's Date of Birth	1996-07-01	2025-3-16 (most recent service_start_date)	<a href="#">More</a>

\*Process is different  
for multi-regional  
projects

# What next?

- Feasibility and Cost Estimate form
  - Submitted with a project proposal or summary
  - Senior Analyst reviews
- Apply for funding  
or
- Move on to the next step

## Data Access Feasibility and Cost Estimate Request Form

(Please note there is a separate application form for the HDNS Data Access Committee approval process)

Date: \_\_\_\_\_

### Full Project Title:

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### Contact Information:

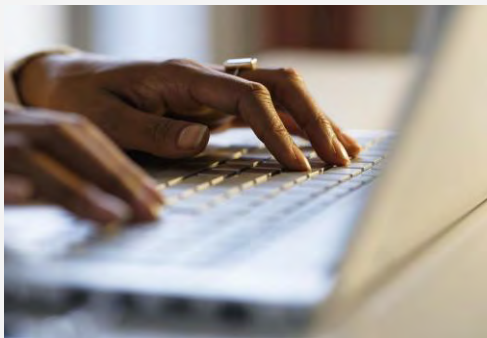
Principal Investigator Name(s)	Position (please state if student)	Name of organization

Co-Investigator(s)	Position (please state if student)	Name of organization

Mailing Address

# The Full Submission

- Data Access Committee (DAC) Submission
  - Data Access Request (DAR)
  - Full submission to DAC
    - DAR form and appendices
    - REB full submission
    - Proposal



## List of Variables by Project Objective

Please complete this table as per the examples provided below. Depending on the nature of the study methods and the data being requested, it may facilitate the work of the Data Access Committee to create separate tables for specific study objectives or research questions. Alternatively, the table(s) may be completed in a separate file and attached as Appendix 4.

For information on HDNS datasets and variables, refer to the HDNS Data Dictionary

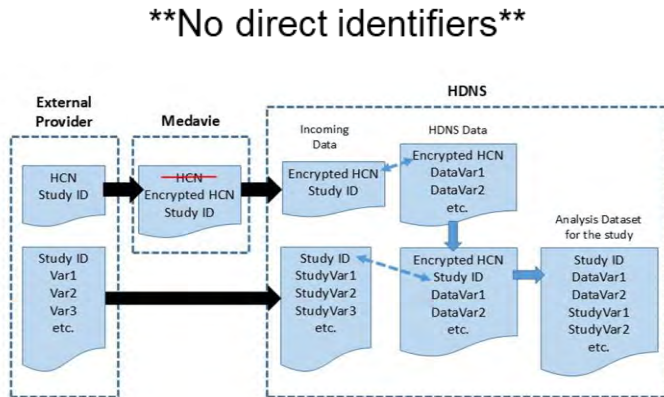
### Objective X:

Source Dataset	Variable (Identify whether HDNS or derived variable)	Level of Identification	Time Span (full date)	Why is this element required in the analysis?	Why is this level of identification required?
MASTER	e.g. Age (derived)	Age of each person >65	Apr. 1, 2003 – March 31, 2023	To calculate age- adjusted incidence rates	Categorized age variable cannot be used for calculating age adjusted incidence rates
CIHI DAD	e.g. Postal code	Urban/rural flag based on second digit of postal code	Apr. 1, 2003 – March 31, 2023	To adjust for rural residence	A flag is sufficient for adjusting for rural residency



# Tips for a Successful Submission

- Become familiar with datasets and variables
- Detailed objectives/methodology
- Common mistakes
  - Saying there are no risks involved
  - Justification for not obtaining consent
  - Variable lists
  - Describing how data will be accessed
  - Describing linkage



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# The HDNS Data Access Committee (DAC)



- Purpose: to review requests to conduct secondary data analysis for research or quality assessment purposes using the administrative databases held by HDNS for privacy, security, and confidentiality concerns
- Membership: reflects expertise in data management, secondary use of data, health services research methods, privacy and Patient/Public Partnership
- DAC Meeting
  - Monthly
  - Research team member attendance required
    - Project overview
    - Answer questions
  - Clarification request

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## What happens after the DAC meeting?



- Address DAC comments and re-submit for approval
- Sign approved DAR
- REB approval letter
- Sign
  - Confidentiality Agreements (CA)
  - Contractual Agreement for Data Access and Management (CADAM)
- HDNS Privacy Training
- CVs
- Project charter



# Data Storage and Access



- Privacy training first!
- The secure data platform, Citadel, provides a data storage and analytical processing environment
- Windows front-end accessed through remote desktop connection
  - using Dalhousie NetID
  - Dalhousie VPN connection
- SAS, Stata, R Studio and Python



For more information:

Contact: [kfrizzell@dal.ca](mailto:kfrizzell@dal.ca)

Visit: <http://medicine.dal.ca/hdns>



# MSSU Presents:

## Accessing Data

2025-11-12



*Meaghan Pike & Afton Lavigne*





# DataNB Presentation Outline

- Rebrand
- Data Access Request (DAR)
  - DAR Type
  - Getting Started
  - Feasibility Submissions
  - DAR Overview
  - DAR Approval Steps
- Data Transfer
  - Transfer Process
  - Agreement Types & Data Types
  - Data Holdings
- Questions & Comments
  - Socials
  - Contact Us

# Rebrand: Becoming DataNB



# Data Access Request (DAR) Types



# DAR Types | Retrospective

- Retrospective: leverages existing data sets to look into the past
  - E.g. Years of interest 1995-2025
- Prospective: extends into the future; amendments will be needed as new years of data are added to our platform.
  - E.g. Years of interest 2020-2035
- Successive: a series of connected projects changing one element
  - E.g. The project may ask the same research questions and use the same methodology to examine the same disease within a different county of the province



# DAR Types | Multi-Phase

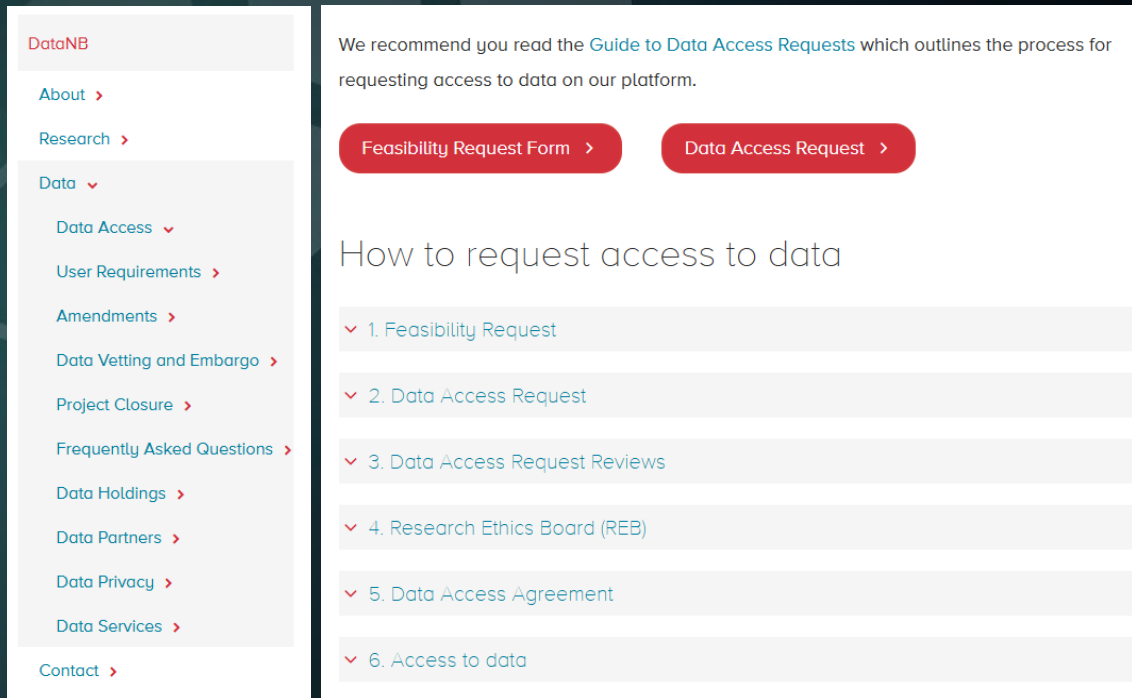
- Multi-Phase:
  - Phase 1 - Data Collection (qualitative)
  - Phase 2 - Data Linkage (quantitative)
- Reminder: Engage with DataNB as you are ready to begin each phase. The UNB REB office must receive a letter of recommendation from DataNB before they will approve the project.





# Getting Started

# <https://www.unb.ca/datanb/data/access/>



The screenshot shows the DataNB website interface. On the left is a navigation menu with the following items: DataNB, About, Research, Data (expanded), Data Access, User Requirements, Amendments, Data Vetting and Embargo, Project Closure, Frequently Asked Questions, Data Holdings, Data Partners, Data Privacy, Data Services, and Contact. The main content area is titled 'How to request access to data' and includes a recommendation to read the 'Guide to Data Access Requests'. Below this are two red buttons: 'Feasibility Request Form' and 'Data Access Request'. A list of six steps is shown, each with a dropdown arrow: 1. Feasibility Request, 2. Data Access Request, 3. Data Access Request Reviews, 4. Research Ethics Board (REB), 5. Data Access Agreement, and 6. Access to data.

DataNB

About >

Research >

Data ▾

- Data Access ▾
- User Requirements >
- Amendments >
- Data Vetting and Embargo >
- Project Closure >
- Frequently Asked Questions >
- Data Holdings >
- Data Partners >
- Data Privacy >
- Data Services >

Contact >

We recommend you read the [Guide to Data Access Requests](#) which outlines the process for requesting access to data on our platform.

Feasibility Request Form > Data Access Request >

## How to request access to data

- 1. Feasibility Request
- 2. Data Access Request
- 3. Data Access Request Reviews
- 4. Research Ethics Board (REB)
- 5. Data Access Agreement
- 6. Access to data

- Before a DAR is submitted, a Feasibility request must be approved.
- All project questions or correspondence should be directed to: [DAR.DataNB@unb.ca](mailto:DAR.DataNB@unb.ca)



# **Feasibility Submissions**

# Feasibility Requests

Navigation

Search document

HeadingsPagesResults

Instructions

Multi-Regional Study Request\*

Project Title & Resource Management

Funding\*

Analytical Services\*

Patient/Public Engagement\*

Section 1: Safe Data\*

Qualitative Data

Platform Data

Data Importation

Indigenous Data\*

- Section 2: Safe People
  - Principal Investigator (PI) Information\*
- Section 3: Safe Project
  - Project Type\*
  - Project Topic\*
  - Preliminary Project Summary\*
  - Preliminary Cohort Description\*
- Section 4: Safe Output
  - Timelines\*
  - Other

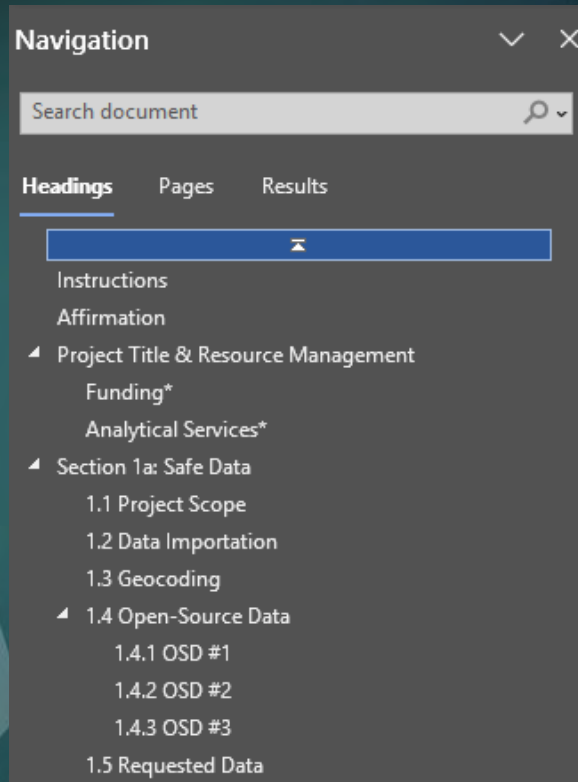
- The Five Safe Frameworks:
  - Safe Data
  - Safe People
  - Safe Projects
  - Safe Output
  - Safe Settings



# **DAR Overview**



# Data Access Requests (DAR)



- Section 1b: Safe Data (Variables)
  - 1.6 Requested Variables
    - 1.6.1 Data Set #1
    - 1.6.2 Data Set #2
    - 1.6.3 Data Set #3
- Section 2: Safe People
  - 2.1 Principal Investigator (PI)
  - 2.2 Research Team Members
    - 2.2.1 Research Team Member #1 Details:
    - 2.2.2 Research Team Member #2 Details:
    - 2.2.3 Research Team Member #3 Details:
- Section 3: Safe Project
  - 3.1 Consent | Linkage
  - 3.2 Project Summary\*
  - 3.3 Research Question(s)\*
  - 3.4 Methodology\*
- Section 4: Safe Output
  - 4.1 Research Consultation\*
  - 4.2 Research Output\*
  - 4.3 Special Terms and Conditions

- The Five Safe Frameworks:
  - Safe Data
  - Safe People
  - Safe Projects
  - Safe Output
  - Safe Settings



# **DAR Approval Steps**

# DAR Approval | Step 1: IR

## **Institute Review**

Upon receipt of the DAR, an Institute Review will be scheduled by the Data Access Coordinator. Following the Institute Review, the PI is given the opportunity to edit to the DAR and/or request a meeting to discuss the results.

# DAR Approval | Step 2: DRC

## **Data and Research Committee (DRC) Review**

Scheduled by Data Access Coordinator, the PI and research team will be invited to participate in a DRC review with the Data Business Owners (DBOs). Following the DRC review, minutes are provided, and the PI is given the opportunity to make edits to the DAR.

# DAR Approval | Step 3: PERC

## **Preliminary Ethics Review Committee (PERC)**

Initiated by the Data Access Coordinator, a PERC is scheduled to ensure everything is in place for the REB review. This includes a final privacy review. The PI submits their finalized DAR and REB Application to:

[DataNBdar@unb.ca](mailto:DataNBdar@unb.ca)

When the review concludes, the results are provided to the PI and a REB recommendation letter is prepared.



# DAR Approval | Step 4: REB

## **UNB Research & Ethics Board (REB) Review**

Upon the conclusion of the PERC, the Data Access Coordinator will send the whole REB package to the Research & Ethics Board for review on behalf of the PI.

The Chair of the REB will review and e-mail the PI with the approval decision and, if approved, will set the REB expiry date and assign a REB#.

# DAR Approval | Step 5: DAA

## Data Access Agreement (DAA) Review & Signing

Upon receipt of the REB approval from the REB Chair, the Data Access Coordinator confirms all Administrative Safeguards have been completed and a signed Budget letter is on file.

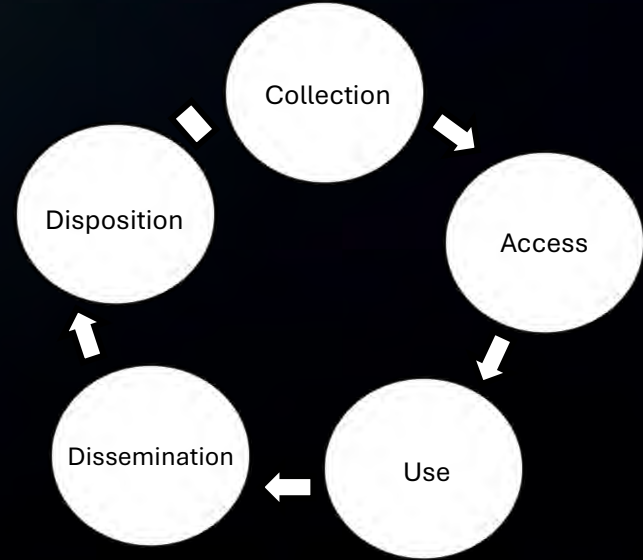
The draft Data Access Agreement is then prepared and sent to the Vice President (Research) for signature; followed by signature from the PI.

Once signed the project is active. The Data Access Coordinator will send a Welcome letter to the PI and will also make an internal request to prepare the project folder and approved user accounts.

# Data Transfer



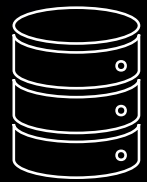
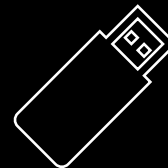
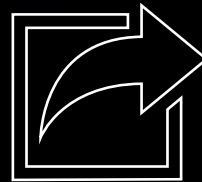
# Transfer Process



**We offer support throughout the data lifecycle.**

# Transfer Process | Data Importation

- Secure transfer and storage of all data, including project specific data
- Facilitate creation of Crosswalk file
- Over 130 data sets available to link





# Transfer Agreement Types & Data

## Agreement Types:

- Master Data Sharing Agreement
  - + Individual Disclosure Schedule
- Data Sharing Agreement
- Information Manager Agreement

## Data Types:

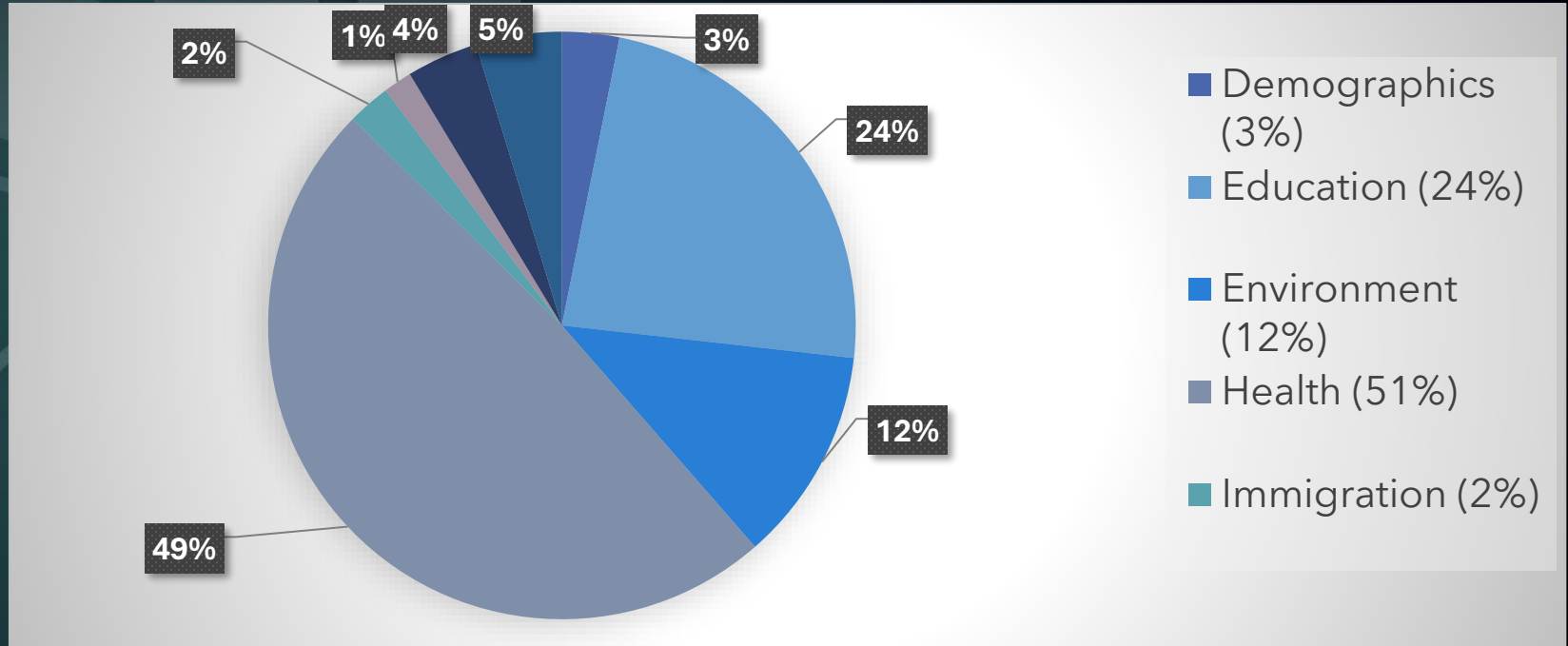
- Platform Data
- Project Specific Data
- Information Management Data



**Data Holdings**

<https://www.unb.ca/datanb/data/holdings/>

# Data Holdings | Platform Data



# Questions & Comments



# Socials

## Follow / Subscribe / Like / Share!

- DataNB Blog:

<https://blogs.unb.ca/newsroom/category/datanb.php>

- DataNB Newsletter (click to sign up)

<https://ggr.sh/sYW3>

- Facebook

[https://www.facebook.com/DATANB.UNB/?utm\\_source=chatgpt.com](https://www.facebook.com/DATANB.UNB/?utm_source=chatgpt.com)

- YouTube

<https://www.youtube.com/@datanb>

- Bluesky

<http://datanb.bsky.social/>

- Instagram

[https://www.instagram.com/datanb.unb/?utm\\_source=chatgpt.com](https://www.instagram.com/datanb.unb/?utm_source=chatgpt.com)

- LinkedIn

<https://www.linkedin.com/company/datanb/%20ca.linkedin.com>



# Contact Us

<https://www.unb.ca/datanb/>

[Services.DataNB@unb.ca](mailto:Services.DataNB@unb.ca)

- Request a consultation
- For general questions (including those about Data Transfer)

[DAR.DataNB@unb.ca](mailto:DAR.DataNB@unb.ca)

- Submit Feasibility, DAR & Amendments
- Submit Dissemination Requests
- For questions about your project

[Privacy.DataNB@unb.ca](mailto:Privacy.DataNB@unb.ca)

- Request Privacy Training
- Submit Administrative Safeguards
- For questions related to Safeguards, Privacy or Ethics

**UNIVERSITY OF NEW BRUNSWICK**





# MAKING A DIFFERENCE THROUGH *data*



# Secure Island Data Repository

linkable • de-identified • health-related data

Description, data availability & data access

# Session Overview

- Nov 12, 2025
- Presented by:  
Robyn Kydd &  
Alex Ouédraogo

## Accessing Data at the Secure Island Data Repository (SIDR) – PEI

- Description
- Data availability
- Data access
  - Who can access SIDR data?
  - How does a researcher access SIDR data?

## Multi-regional data projects

- Description
- Data availability at Maritime data centers
- Data access
  - Health Data Research Network (HDRN) Canada
    - ✓ Data Access Support Hub (DASH)

# Secure Island Data Repository (SIDR)

- Our Team
- Contact:  
[sidr@upei.ca](mailto:sidr@upei.ca)



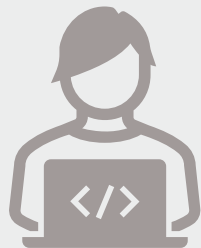
**Director**  
Mary-Ann Standing



**Manager**  
Robyn Kydd



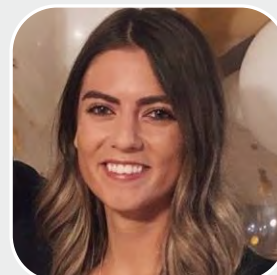
**IDEA & Engagement Lead**  
Kate Kelly



**Database Administrator**  
Vacant



**Systems Administrator (UPEI  
ITSS; In-kind support)**  
Derek Liu



**Administrative Assistant**  
Kaleigh Duffy



**Data Scientist**  
Alexandra Ouédraogo



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



Canadian Institutes of  
Health Research  
Instituts de recherche  
en santé du Canada



UNIVERSITY  
of Prince Edward  
ISLAND



Atlantic Canada  
Opportunities  
Agency

Agence de  
promotion économique  
du Canada atlantique

# Background

## Secure Island Data Repository (SIDR)

- Center for Health and Community Research, UPEI Office of the Associate Vice President of Research & Dean of Graduate Studies
- Data Custodian / Research Data Repository, as defined in PEI's Health Information Act
- First platform of its kind in PEI
- Enables secure access to data and analytical services to support research and decision making that can improve health and wellbeing

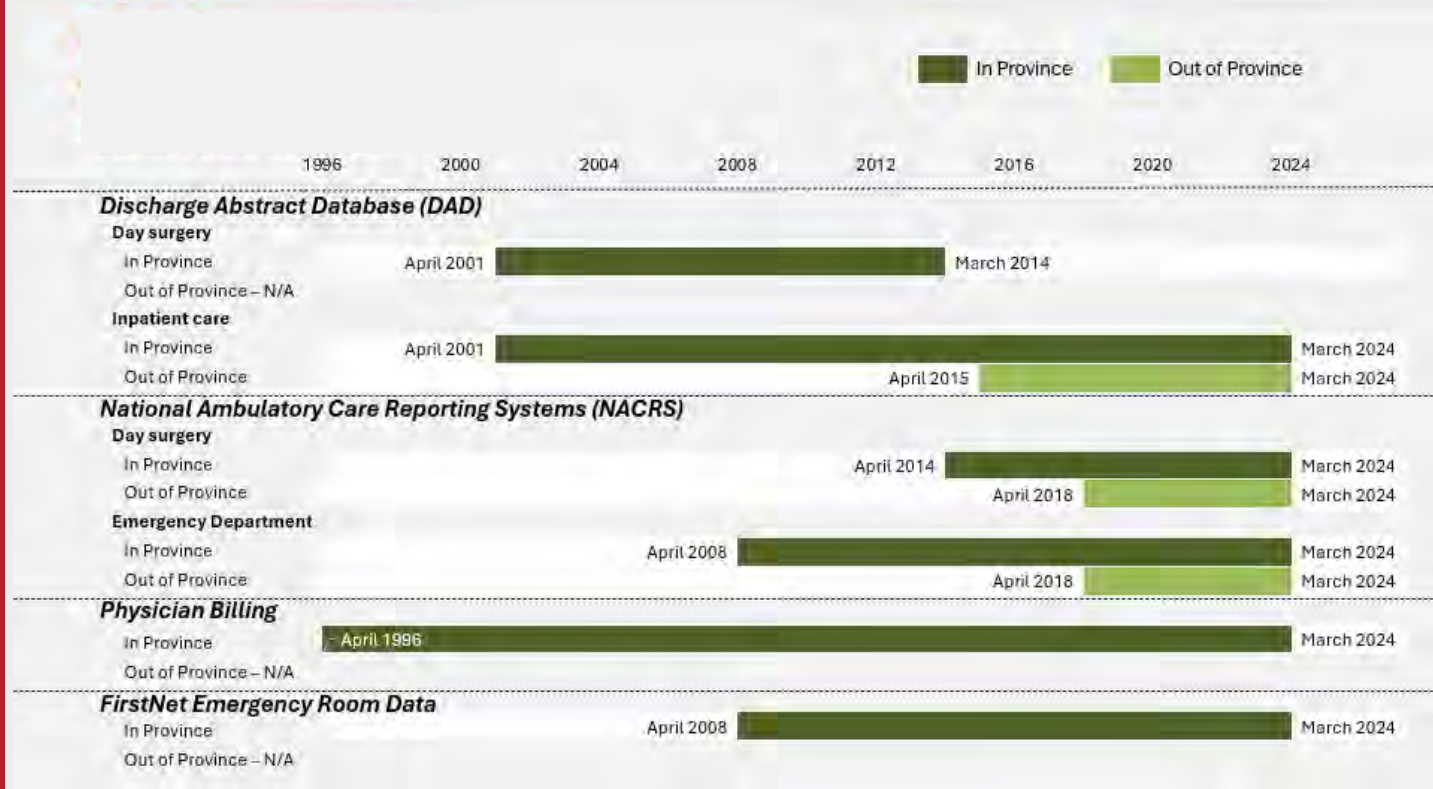


# Data availability

- Health PEI data holdings
- Annual data transfers in November

## Current data holdings

<https://sidrpei.ca/dataholdings/>



**Note:** Publicly-available area-based socio-economic measures are also available



# What data will SIDR hold in the future?

## Coming soon

### Patient (Medicare) Registry

- **Health PEI**
  - Nov 1983 to FY 2022-23

## In progress

### Canadian Longitudinal Study on Aging (CLSA)

- Agreements underway

### Atlantic Partnership for Tomorrow's Health (Atlantic PATH)

- Agreements underway

### Drug Information System (DIS)

- Department of Health & Wellness

## Future plans

### Immigration, Refugees & Citizenship Canada (IRCC)

- Assessing capacity

### Local Researcher Data

- For linkage, storage and/or future access

### Other PEI Administrative Data

- Justice, Education, Housing, Social development...
- Assessing legislation

# Who can access SDR data?

## Project data access

- **On-site data access only**
  - MSSU Privacy Training
  - SDR Security Training/Orientation
- **Research Project team members**
  - Prespecified as requiring access to SDR's secure Research Centre
- **SIDR staff** (analytical services available)

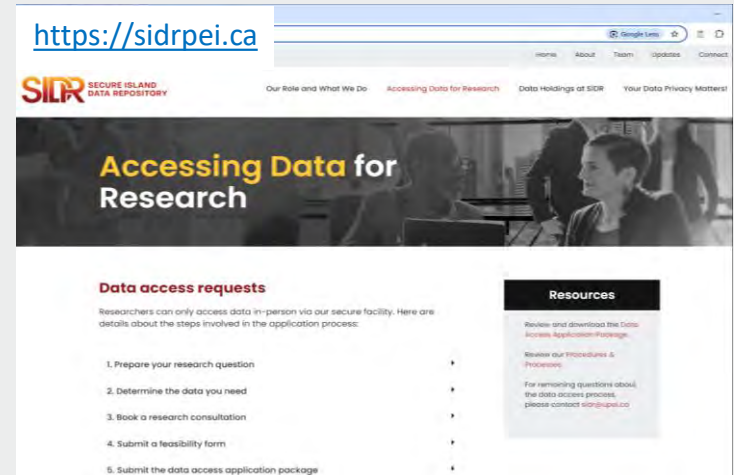
## Data uses

- Currently → Research projects
- Future → Non-research organizations

# How does a researcher access SIDR data?

## Data Access Application Workflow

- A. Initial SIDR Research Consultation
- B. Research Application Review & Approval
- C. Project Initiation, Privacy Training & Orientation
- D. Data extraction, Preparation & Account Creation
- E. Data Analysis & Disclosure Requests



# How does a researcher access SIDR data?

- Initial SIDR Research Consultation



## Initial SIDR Research Consultation

- Research questions, methods, analyses
- SIDR data access & linkage processes
  - feasibility form, data access application package etc.
  - researcher responsibilities, agreements etc.
- SIDR data availability & limitations
- SIDR fees for data access/analytical services

### Data access requests

Researchers can only access data in-person via our secure facility. Here are details about the steps involved in the application process:

1. Prepare your research question
2. Determine the data you need
3. Book a research consultation

Once you are ready to begin the data application process, email us at [sidr@upel.ca](mailto:sidr@upel.ca) to book a free initial consultation meeting.

During this meeting, we will help:

- Refine your research question
- Determine data and staff support needed
- Provide guidance about the data access process
- Assess funding needs

Stay in  
Touch!

➤ Contact us by email: [SIDR@upei.ca](mailto:SIDR@upei.ca)



<https://sidrpei.ca>

## Follow us on social media



Secure Island  
Data Repository



Centre for Health and  
Community Research



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

# Applying to Access Data from Multiple Regions

Description, data availability & data access



# Data Access Processes at Maritime Data Centres



Health Data Nova Scotia

## Health Data Nova Scotia

Department of Community Health and Epidemiology

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[Dal.ca Home](#) [Faculty of Medicine](#) [Departments](#) [Department of Community Health and Epidemiology](#) [Research](#)

### Data Access

- + STEP 1: CONTACT US
- + STEP 2: SUBMIT YOUR HDNS DATA ACCESS FEASIBILITY AND COST ESTIMATE REQUEST
- + STEP 3: SUBMIT YOUR DATA ACCESS REQUEST and APPLY TO THE RESEARCH ETHICS BOARD
- + STEP 4: SIGN THE CONTRACTUAL & CONFIDENTIALITY AGREEMENTS
- + STEP 5: SIGN PROJECT CHARTER



<https://medicine.dal.ca/departments/departments/sites/community-health/research/hdns/data-access-guidelines.html>



### DataNB

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[Feasibility Request Form](#)

[Data Access Request](#)

### How to request access to data

1. Feasibility Request

2. Data Access Request

3. Data Access Request Reviews

4. Research Ethics Board (REB)

5. Data Access Agreement



<https://www.unb.ca/datanb/data/access/>



SIDR SECURE ISLAND DATA REPOSITORY

SIDR SECURE ISLAND DATA REPOSITORY

[Our Role and What We Do](#) [Accessing Data for Research](#) [Data Holdings of SI](#)

## Accessing Data for Research

### Data access requests

Researchers can only access data in-person via our secure facility. Here are details about the steps involved in the application process.

1. Prepare your research question
2. Determine the data you need
3. Book a research consultation
4. Submit a feasibility form
5. Submit the data access application package
6. Obtain project approvals
7. Review final quote and sign a data access agreement
8. Project team members complete mandatory administrative safeguards

### Resources

Review and download the [Data Access Application Package](#).  
Review our [Privacy Policy](#).  
For more information about the data access process, please contact our [Data Access Officer](#).



<https://sidrpei.ca/accessing-data-for-health-research/>

# Selected Data Holdings at Maritime Data Centres

Datasets	NS	NB	PEI
Patient Registry	✓	✓	⌚
Inpatient Hospitalizations	✓	✓	✓
Physician Billing Claims	✓	✓	✓
ED Visits	✓	✓	✓
Day Surgeries	✓	✓	✓
Socioeconomic Status (area-based)	🔗	✓	✓
Prescription Drugs	✓	✓	💡
Provider Registry	✓	✓	
Vital Statistics	✓	✓	
Cancer Registry	🔗	✓	
Long Term Care	✓	✓	
Home Care	🔗	⌚	✓
Laboratory Tests	🔗	✓	⌚
Canadian Longitudinal Study on Aging	✓	✓	⌚
Atlantic Partnership for Tomorrow's Health	✓	✓	⌚
Immigration (IRCC)	⌚	✓	💡
Education		✓	
Social Services		✓	

Legend = dataset status	
✓	Available
🔗	Linkable dataset (held externally)
⌚	In progress
💡	Upcoming
	Not available



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

## Mission

Bring together people & organizations across Canada for transformative & world-leading health data use.

## Vision

Data across Canada drive improvements in health & health equity.

## Values

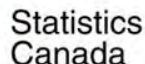
Collaboration, trust, creativity, excellence & respect.



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



# HDRN Canada Member Organizations



# HDRN Canada

## At a Glance

### Data Access Support Hub:

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



21  
Active  
Projects

107  
Project  
Feasibility  
Reports

142  
Inquiries  
Received

584  
Data  
Assets

198  
Algorithms

### HDRN Canada Initiatives:



#### Common Data Models

A project to rapidly harmonize data & better enable multi-regional research across Canada



#### Indigenous Data Sovereignty

Supporting Indigenous-led uses of Indigenous data to advance reconciliation



#### Pragmatic Trials Training Program

Equips researchers with skills to conduct efficient & high quality pragmatic trials using real world data



#### Public Engagement

Collaborations, publications & events to support public & patient engagement in health data



#### Data Privacy Tools

Resources available for conducting privacy-sensitive research on administrative data



#### Inclusion, Diversity, Equity & Accessibility

Guide purposeful action toward barriers within the data systems & research structures

# How the Data Access Support Hub (DASH) supports multi-regional data access

**DASH simplifies the data access process by providing:**

**Navigational  
Support &  
Coordination**

**Centralized  
resources and  
tools**

**Information  
governance to  
harmonize data**

**Technological  
solutions**

<https://www.hdrn.ca/en/dash>

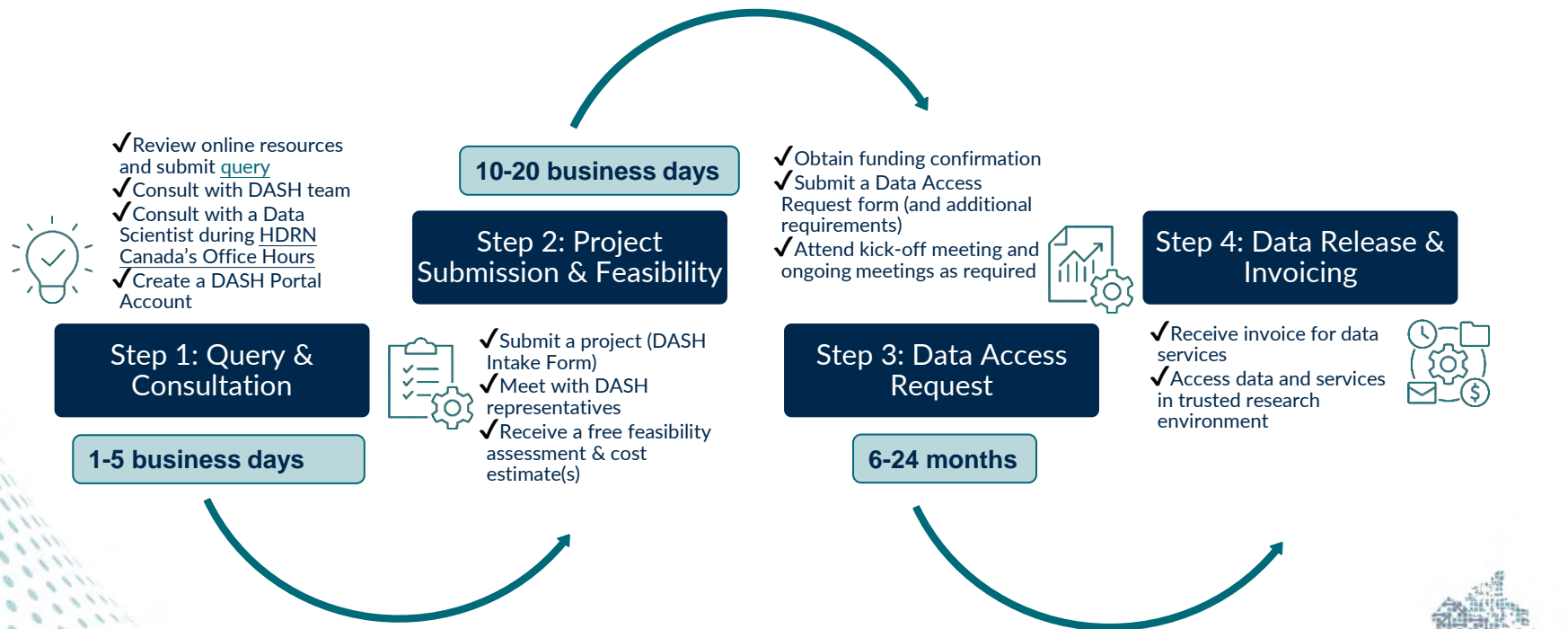


Réseau de recherche sur les données de santé du Canada  
Health Data Research Network Canada

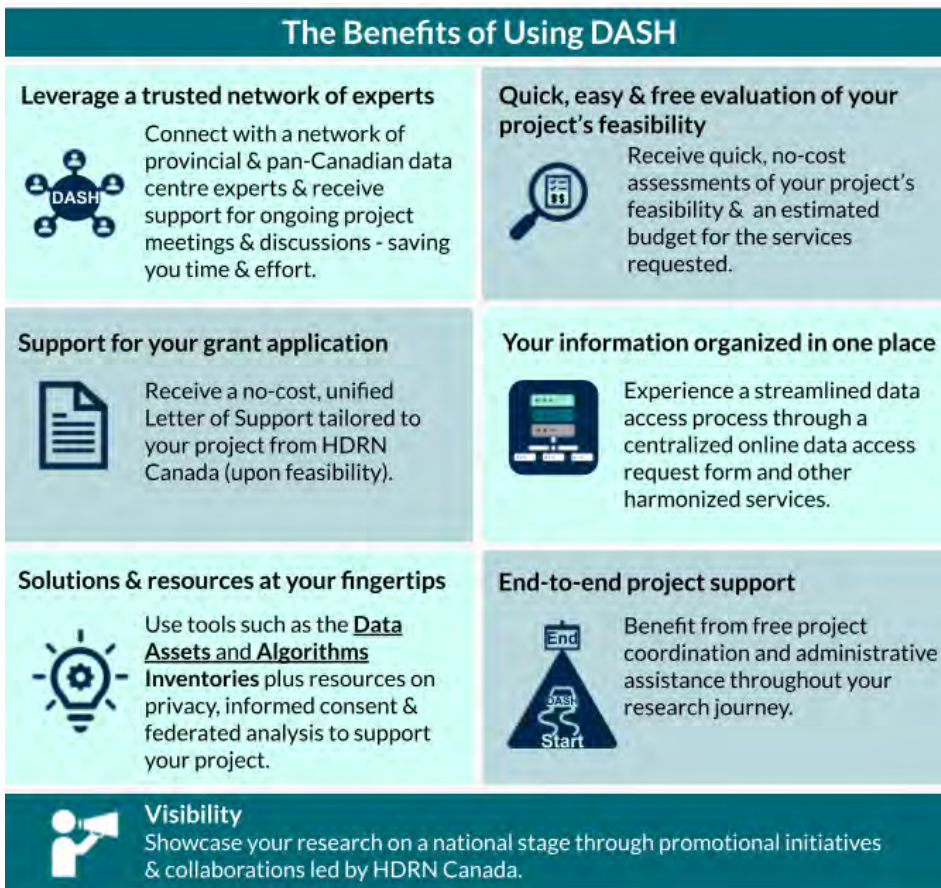


# Data Access Support Hub (DASH)

Coordination service for researchers requesting multi-regional health and health related data.



# How can DASH make multi-regional research easier?



# Innovative Resources

## DASH Resources



### Privacy

Resources for researchers on privacy compliance and privacy legislation



### Indigenous Data

Resources for researchers on Indigenous data sovereignty



### Informed Consent

Resources for researchers on informed consent



### Benefits of DASH

Top 7 benefits of using DASH for multi-regional research



### Distributed Analysis

Analyze datasets from multiple regions without physically pooling data



### IDEA

Resources for researchers on inclusion, diversity, equity and accessibility in data

## DASH Inventories



### Data Assets Inventory



### Algorithms Inventory



### COVID-19 Inventory

Request data through DASH

Questions? Get in touch with DASH

## Regional Data Information

High-level information about requirements and procedures for accessing data at each HDRN Canada Member Organization.

[Learn More](#)



<https://www.hdrn.ca/en/dash/>



# Regional Data Information

## Requirements & Services

The table below outlines key requirements as well as additional details to consider in each region, including ethics approval, remote data access, secure access environments and software capabilities.

	BC	AB	SK	MB	ON	QC	NB	NS	PE	NL	NT	CIHI	StatCan
Research Ethics Board Approval Required □	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✗
In-Province Ethics Approval Required §	✗	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✗	✗
Local or Affiliated Principal Investigator Required	✗	✓	✓	✓	✗	✓	✗	✓	✗	✗	✓	✗	✗
Centre Offers Analytical Services †	✗	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓
Centre Offers Remote Data Access ◇	✓	✗	✓	✓	✓	✓	✗	✓	✗	✓	✗	✓	✓
Centre has a Trusted Research Environment (TRE) Δ	✓	✗	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓





# DASH Data Assets Inventory

Search

Clear All

Filters Selected - 0

Region	Q	x	Aa↑	#↓
Alberta (AB)				216
British Columbia (BC)				226
Manitoba (MB)				275
New Brunswick (NB)				290
Newfoundland (NL)				217
Northwest Territories (NT)				176
Nova Scotia (NS)				206
Nunavut (NU)				175
Ontario (ON)				308
Prince Edward Island (PE)				192
Quebec (QC)				178
Saskatchewan (SK)				202

Data Categories	Q	x	Aa↑	#↓
Continuing Care				1
Day Surgery Visits				2
Demographics				335
Diagnosis				177
Drugs (Dispensed)				55
Drugs (Prescribed)				27
Education				100
Emergency Visits				2
Employment				83
Ethnicity/Race				91
Gender				38
Geographic Location				305

Site	Q	x	Aa↑	#↓
Alberta SPOR SUPPORT Unit				21
Canadian Institute for Health Information				23
DataNB				97
Health Data Nova Scotia				13
Health Research Data Platform - Saskatchewan				7
Institut de la Statistique du Québec				8
Institute for Clinical Evaluative Sciences				102
Manitoba Centre for Health Policy				77
Newfoundland and Labrador Health Services				26
Population Data BC				30
Statistics Canada - Research Data Centres				190
University of Prince Edward Island				2





# DASH Data Assets Inventory

Filters Selected - 3

Region

Q x Aa#

Prince Edward Island (PE) 1

Data Categories

Q x Aa#

Diagnosis 2

Emergency Visits 1

Geographic Location 2

Healthcare Encounter 2

Healthcare Facility 2

Inpatient Hospitalizations 1

Site

Q x Aa#

University of Prince Edward Island 1

Showing 1 to 1 of 1 datasets (filtered from 596 datasets)

Name	Region	Description
National Ambulatory Care Reporting System (NACRS)	PE	Administrative health data that consists of demographic, clinical, administrative, and service-specific data elements. For PEI, this includes hospital and ambulatory care information from day surgery and emergency department (ED) visits. The data includes information on wait time, triage level, asse ...

Previous

1

Next



# DASH Data Assets Inventory

## National Ambulatory Care Reporting System (NACRS)

Dataset Information	
<b>Name</b> ⓘ	National Ambulatory Care Reporting System (NACRS)
<b>UUID</b> ⓘ	95f638bc-fa20-4baa-ab87-e2a42eb7b2ec
<b>Site</b> ⓘ	University of Prince Edward Island
<b>Region</b> ⓘ	Prince Edward Island
<b>Description</b> ⓘ	Administrative health data that consists of demographic, clinical, administrative, and service-specific data elements. For PEI, this includes hospital and ambulatory time, triage level, assessment  NACRS offers 3 options for data collection: Level 1 (includes Level 1 information), Level 2 (includes Level 1 information and Level 3 (includes Level 1 information and Level 2 information) currently contains Level 1 information)  Participation in NACRS data elements evolve over time. Data type is numerical and categorical.
<b>Data Level</b> ⓘ	Individual
<b>Collection Period</b> ⓘ	Day Surgery (NACRS) (a) In-province: QEH & PCH from 2014-04-01 to 2024-03-31. (b) Out-of-province: 2018-04-01 to 2024-03-31.  Emergency Department (NACRS) (a) In-province: QEH Level 3 data from 2021-04-01 to 2024-03-31; PCH Level 1 data from 2008-04-01 to 2014-03-31 & Level 3 data from 2014-04-01 to 2024-03-31. (b) Out-of-province: 2018-04-01 to 2024-03-31.  *Note: collection period date ranges are based on patient registration dates.



# Distributed Analysis Resources

## Distributed Analysis

### Distributed Analysis for Multi-regional Research



## Distributed Analysis Resources

Distributed analysis facilitates multi-regional research, providing a solution to address the siloing of health data and other barriers to data transport outside of institutions. Distributed analysis avoids the constraints on data pooling. It allows data to remain in their home Trusted Research Environment while being analyzed as part of a single but partitioned dataset. Distributed analysis can facilitate use of sensitive health data and supports data sovereignty. Our approach to distributed analysis will protect privacy and enable innovative methods for producing robust, generalizable results to inform policy decisions and improve health systems and health outcomes. To learn more, download our [Distributed Analysis FAQ](#) and [Glossary of Terms](#) or visit our [Distributed Analysis Resources page](#).

## Conducting multi-regional research? HDRN Canada can help!

**Distributed Analysis** is a class of methods for conducting multi-regional data analysis without pooling data in a single location. How does it work? Data are first harmonized, creating a single dataset that is partitioned across Trusted Research Environments (TRE). Analyses are run in each TRE, and summary results are shared with a coordinating centre. The coordinating node integrates information from all data centres to generate the final analysis. The final results can then be accessed by the researcher.

Interested? Contact our [Data Access Support Hub/DASH](#) team: [dash@hdrn.ca](mailto:dash@hdrn.ca). Download our [Distributed Analysis Factsheet](#).

## Distributed Analysis



## Frequently Asked Questions

What is a distributed analysis?



How does a distributed analysis differ from a pooled analysis?



Why is distributed analysis important?



What type of statistical parameters are shared?



How are the statistical parameters shared between a data node and a coordinating node?



What affects the quality of a distributed analysis?



How does a distributed analysis differ from a federated analysis?



What is required for a distributed analysis?



What methods are available for undertaking a distributed analysis?



What is the process for completing a distributed analysis at HDRN Canada?



What is the cost of completing a distributed analysis?



Who can I reach out to if I have more questions?



<https://hdrn.ca/en/distributed-analysis//>

# Distributed Analysis Resources

## FACT SHEET: Distributed Analysis

### Conducting multi-regional research? HDRN Canada can help!

*Distributed Analysis can produce results that are the same as data pooling*

**Distributed Analysis** is a method for conducting a multi-regional analysis without pooling data in a single location. *How does it work?* Summary results from regional Data Centres ("Data Nodes") are shared with a Coordinating Node, which integrates information from all Data Nodes to generate the final analysis. If you're interested in conducting distributed analysis, email us: [dash@hdrn.ca](mailto:dash@hdrn.ca).

### Benefits of Distributed Analysis



#### Data stay in place

Taking "analysis to data" avoids constraints on data sharing & is consistent with data sovereignty.



#### Helps with scaling

Capability for distributed analysis makes it easier to add regions or countries to research projects.

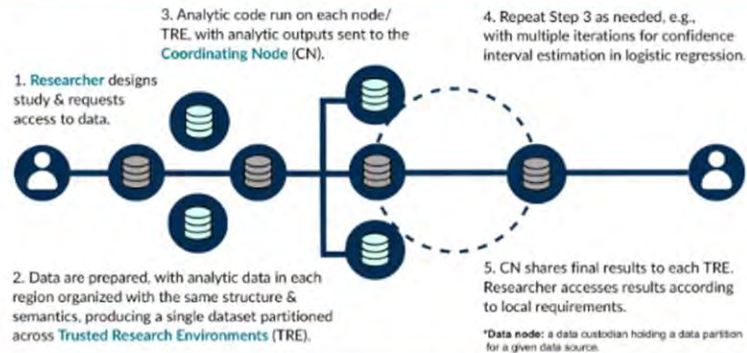


#### Supports collaboration

Enables multi-regional research while complying with local legislation.

**Currently supported analytic models:** Linear regression, logistic regression, survival analysis (Cox regression) with or without weights.

### Data Flow



**Code & documentation:**  
[github.com/OpenLHS/Distrib\\_analysis](https://github.com/OpenLHS/Distrib_analysis)



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





# Data Access Processes at Maritime Data Centres



Health Data Nova Scotia

## Health Data Nova Scotia

Department of Community Health and Epidemiology

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[Dal.ca Home](#) [Faculty of Medicine](#) [Departments](#) [Department of Community Health and Epidemiology](#) [Research](#)

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<https://medicine.dal.ca/departments/departments/sites/community-health/research/hdns/data-access-guidelines.html>



### DataNB

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<https://www.unb.ca/datanb/data/access/>



SIDR SECURE ISLAND DATA REPOSITORY

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8. Project team members complete mandatory administrative safeguards

#### Resources

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Review our [Procedures & Processes](#).  
For more information about the data access process, please contact our [Data Access Officer](#).



<https://sidrpei.ca/accessing-data-for-health-research/>

# Thank you! Any Questions?

## HDNS

Contact: [kfrizzell@dal.ca](mailto:kfrizzell@dal.ca)

Website: <https://medicine.dal.ca/hdns/>

## DataNB

Contact: [Services.DataNB@unb.ca](mailto:Services.DataNB@unb.ca) - Request a consultation

For general questions (including those about Data Transfer)

Website: <https://www.unb.ca/datanb/>

## PEI-SIDR

Contact: [SIDR@upei.ca](mailto:SIDR@upei.ca)

Website: <https://sidrpei.ca>

