HEALTH DATA NOVA SCOTIA (HDNS)
A Guide to Using our Services

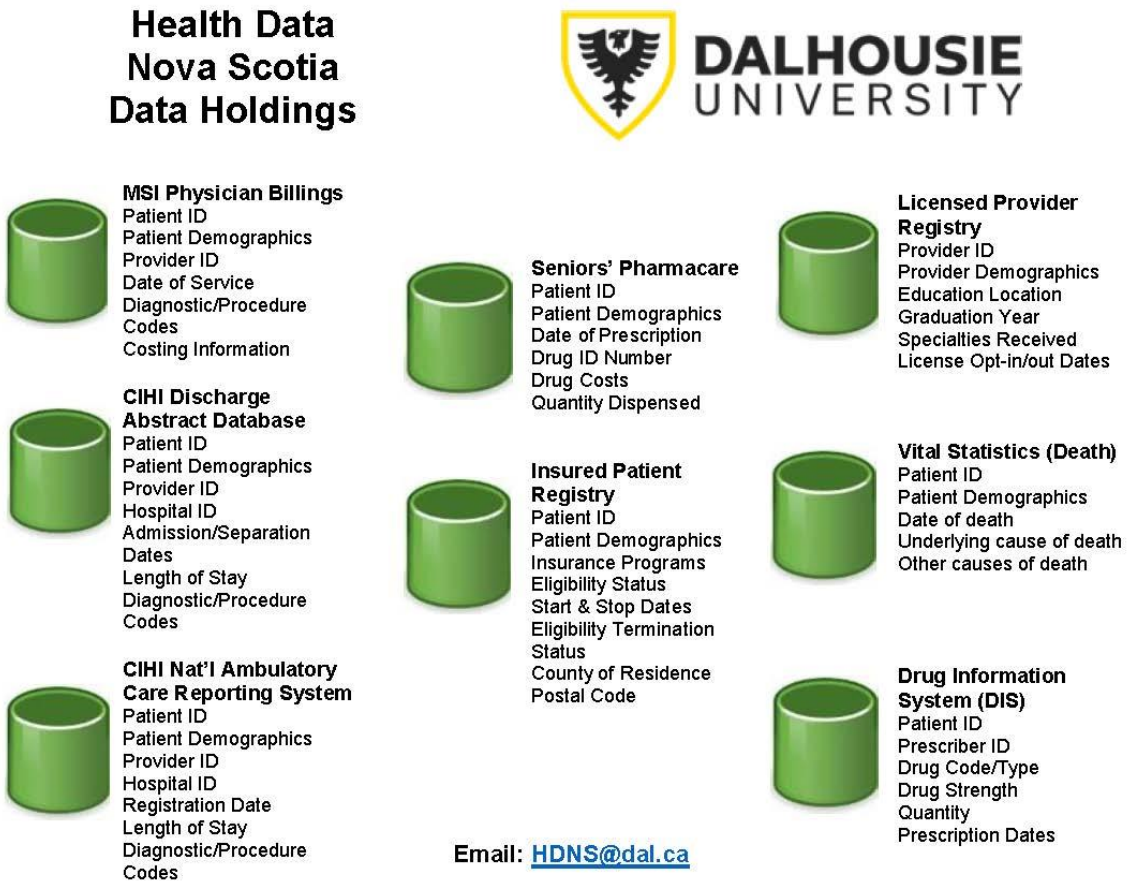
Health Data Nova Scotia
FACULTY OF MEDICINE
Department of Community Health and Epidemiology
Dalhousie University
Email: hdns@dal.ca
Website: medicine.dal.ca/hdns

1.0 Purpose

Health Data Nova Scotia (HDNS) is committed to facilitating research and innovation in Nova Scotia by providing access to linkable administrative health data and analysis for research and health service assessment purposes in a secure, controlled environment, while respecting the privacy and confidentiality of Nova Scotians. We work with:

- researchers
- government bodies
- other research institutions
- granting agencies
- community health boards
- the private sector

In accordance with its policies and procedures, HDNS manages data access, for research purposes, to Nova Scotia health datasets including:



HDNS extends coverage of the policies to any other datasets that HDNS manages on behalf of other researchers or clients.

2.0 Applicable Legislation and Policies

PERSONAL HEALTH INFORMATION ACT

The *Personal Health Information Act* (*PHIA*) governs the collection, use, disclosure, retention, disposal and destruction of personal health information (PHI) in Nova Scotia. *PHIA* recognizes both the right of individuals to protect their PHI and the need of custodians to collect, use and disclose PHI to provide, support and manage health care.

HDNS acts as an agent for the Nova Scotia Department of Health and Wellness (DHW), for its administrative health datasets. HDNS is obligated to comply with data sharing agreements with DHW and with the associated obligations under *PHIA.* The legislation can be reviewed at the following website:
http://novascotia.ca/dhw/phia/documents/PHIA-complete-toolkit.pdf

To comply with those requirements, HDNS has established policies and procedures to protect the privacy, confidentiality and security of PHI during the information lifecycle. HDNS policies can be viewed on the HDNS website: medicine.dal.ca/hdns.

Of note, for data access requests, HDNS:

- does not accept datasets that contain direct identifiers such as names or street addresses.
- only accepts encrypted health card numbers (HCNs) and health care provider numbers.
- has a Data Access Committee (DAC) which reviews requests for data access.
- provides only the data that has been approved by the DAC and only allows those individuals identified in the application to access that data.
- determines ways to make the data less identifiable. For example, providing age or year of birth instead of full date of birth; providing the first 3 digits of a postal code rather than the full postal code; or creating a yes/no flag for a given condition rather than providing all the diagnostic codes.
- is unable to facilitate re-identification of individuals in HDNS data for any purpose without express permission from the DHW. If you have this requirement, contact HDNS to discuss your project.
- does not permit researchers to report data with cells that contain less than 5 (i.e., less than 5 persons, occurrences or events).

3.0 Data Access Process Steps

STEP 1 CONTACT US

Contact HDNS for a consultation regarding the data sets and methodologies that are appropriate for your research project and objectives.

STEP 2 SUBMIT YOUR HDNS DATA ACCESS FEASIBILITY AND COST ESTIMATE REQUEST

Start by completing the **Data Access Feasibility and Cost Estimate Request Form** online at http://apply.hdns.dal.ca/signup.php. Try to be as specific as you can because

the quality of your application will directly impact the accuracy and timeliness of our assessment.

Attach a copy of your research proposal and/or summary and submit the form.

Once we've processed your request, we'll send you confirmation of feasibility and a cost estimate or request a further consultation within one week. Confirmation of feasibility is not a guarantee of data access; final decisions on data access are made by the **HDNS Data Access Committee (DAC)**.

STEP 3 GET FUNDING

Make sure you submit your proposal to a funding agency. This is entirely your responsibility.

STEP 4 SUBMIT YOUR DATA ACCESS REQUEST

To obtain data access approval, complete our **Data Access Request (DAR) Form** and supporting documentation (i.e., research proposal, complete research ethics board (REB) submission, CVs, etc.). Contact hdns@dal.ca for the most recent DAR form. Once completed, email the form and accompanying documents to hdns@dal.ca. The DAC will review the request at its monthly meeting. The PI is expected to attend the DAC meeting to provide an overview of their project and to answer questions about their data access request. After review, the DAC will notify you of their decision.

If your application is approved, please submit the original signed copy of the HDNS data access request form.

If your application is not approved, you'll be provided feedback to make the necessary modifications and re-submit.

STEP 5 APPLY TO THE RESEARCH ETHICS BOARD

Once you've secured funding, you'll need to contact the appropriate research ethics board (if applicable). It's your responsibility to both identify and contact the correct board.

Application to an REB can occur prior to, at the same time or after applying to the HDNS DAC. However, if there are modifications to your research proposal as a result of REB feedback, HDNS requires a copy of the revised proposal. If the changes are significant, HDNS may need to reassess the data access request and cost estimate.

Once you have received ethics approval, send your REB letter of approval to HDNS along with the revised proposal (if applicable).

STEP 6 SIGN THE CONTRACTUAL & CONFIDENTIALITY AGREEMENTS

Once the HDNS DAC and REB approvals have been received, HDNS will administer the **Contractual Agreement for Data Access and Management (CADAM)** with the principal investigator (PI). The CADAM specifies the terms and conditions under which HDNS grants data access to the PI and the applicable members of the research team.

The PI and any research team members accessing HDNS data must sign a **Confidentiality Agreement (CA**) and complete HDNS privacy training.

HDNS will contact the applicable members of your research team to arrange the privacy training.

STEP 7 SIGN PROJECT CHARTER

Once HDNS receives all letters and signed agreements we'll work with your research team to create a project charter that will identify the details around the project dataset creation, analysis, packaging, delivery of your data, and the quote associated with project execution. If the project scope has changed since the initial consultation, the original cost estimate may require modification.

The charter must be signed by you and HDNS. We complete all projects on a first-come, first-served basis.

STEP 8 IF APPLICABLE, PREPARE YOUR EXTERNAL DATA SETS AND SEND TO HDNS

Linkage of external data sets with HDNS data must be approved by the HDNS DAC. External datasets are data that are not currently part of the HDNS holdings such as: (i) data from a researcher's own clinical trial or other research study; (ii) data from registries including disease or population–based; or (iii) data from other organizations or departments.

When preparing a dataset to send to HDNS:

- Ensure all applicable agreements and approvals have been completed and obtained (e.g., data access approvals, data transfer agreements).
- Ensure that all direct identifiers such as names and street addresses are removed. Double check 'free comments' fields or other fields to ensure there is no potential identifying information included.
- Follow the process for encryption of HCNs and provider numbers provided by HDNS.
- Confirm that you are only sending the variables for importing that have been previously approved by HDNS.
- Only use a secure file transfer method approved by HDNS (e.g., MOVEit).

STEP 9 ACCESS TO AND ANALYSIS OF DATA

Prior to accessing the data, researchers will be set up with secure access to their project specific data file. Orientation to the HDNS Data Platform will be provided to analysts in accordance with their level of experience.

The data must only be used for the approved research project and may not be distributed, sold or otherwise transferred to other parties without advance approval in writing from HDNS. Any additional uses or transfer of data must be approved in advance, in writing by HDNS.

If a researcher determines that they require access to additional data, the PI must submit a written amendment request which will be reviewed by the HDNS DAC.

STEP 10 DISSEMINATION OF FINDINGS

Prior to submitting a manuscript or report for a proposed publication or presentation based on HDNS data, the Applicant is required to submit an advance copy of the publication or slides to HDNS. HDNS will review the publication to ensure there is no potential identification of individuals, that cell sizes less than five (5) have been suppressed and the HDNS disclaimer as stated in the CADAM is included.

4.0 HDNS Data Access Committee

The purpose of the HDNS Data Access Committee (DAC) is to review requests to conduct secondary data analysis for research or quality assessment purposes using the administrative datasets held by HDNS of Dalhousie University for privacy, security, and confidentiality concerns. The responsibilities of the HDNS DAC are to:

- Protect the confidentiality of personal health information in the custody of HDNS and the privacy of the individual who is the subject of that information.
- Ensure that conditions pursuant to the HDNS agreement with the Nova Scotia Department of Health and Wellness (DHW) for access to DHW data have been met. Requests for data access that exceed the scope of the agreement will be forwarded by the DHW DAC representative to Senior Advisor – Privacy, Policy and Corporate Services Nova Scotia Department of Health and Wellness for the Senior Advisor – Privacy to review.
- Uphold standards of data access consistent with the highest levels of security, confidentiality and privacy in Canadian legislation, namely:
    - To maximize the protection of individual privacy;
    - To approve access to linked data files only to nominated researchers involved in specific, approved research projects;
    - To approve access by researchers to minimum datasets required for their specific project;
    - To provide data to support approved quality review initiatives; and
    - To assure data custodians that those data which are their responsibility will be used appropriately and confidentiality and security obligations will be met.
- Ensure that any proposed record linkage is not harmful to individuals or providers and the benefits derived from the record linkage are clearly in the public interest.
- Review requests for privacy, security, and confidentiality concerns based on the standards noted above.
- Apply principles of proportionate review:
    - New requests or amendments to previously approved requests deemed to be of moderate to high risk in terms of privacy, security and confidentiality concerns will undergo full committee review.
    - New requests or amendments to previously approved requests deemed to be of minimal risk in terms of privacy, security, and confidentiality concerns may undergo expedited review by the chair (or co-chair) and one (1) committee member.
    - Factors that affect risk may include the likelihood of inadvertent re-identification of individuals (patients or providers), characterization of vulnerable patient populations or communities, or inclusion of sensitive disorders or procedures.
- Communicate in writing the DAC's decision to applicants.
- Review analyses and abstracts as well as posters and reports resulting from access to data held by HDNS to ensure they include only summary data and statistical analyses which preclude the identification of individuals or clinicians.

5.0 Confidentiality and Security of Data

5.1 Confidentiality

HDNS places the highest importance on the protection of confidentiality and security of the data housed at HDNS.

It is the responsibility of the Applicant to ensure their project is PHIA compliant.

Applicants who violate conditions for release of data or any provision of this policy, or who misrepresent the nature of data supplied to them by HDNS, will be subject to sanctions, which may include refusal of future access to data, seizure of the data released and legal action. In cases where the Applicant has access to person-level data the following conditions will apply:

5.1.1 Only the minimum data required to fulfill the purpose outlined by the Applicant in the Data Access Request form will be considered for data access.

5.1.2 Data must be used only for the purposes for which it was requested and may not be distributed, sold or otherwise transferred to other parties without advance approval in writing from HDNS. Any additional uses or transfer of data must be approved in advance, in writing by HDNS.

5.1.3 HDNS must be notified when data files are no longer required for the purpose for which they were made available, and any copies of the data shall be destroyed.

5.1.4 Applicants will be responsible to ensure that anyone who will have access to HDNS data is aware of the importance of maintaining the confidentiality of personal information. The Applicant must provide HDNS with the identities of all individuals who will have access to the data. Anyone who will have access to HDNS data will also be required to sign a Confidentiality Agreement.

5.1.5 In cases where it is deemed appropriate, the knowledge and consent of the individuals in the data may be required prior to the release of the information.

5.2 Security

The data platform in which HDNS datasets are housed is secure and appropriate technology is utilized to protect data holdings from unauthorized access or tampering. Security measures shall include restricted physical access, security clearance (appropriate authorization for remote access), passwords, encryption and storing “unlinked” datasets. Access to HDNS data will be restricted to personnel authorized by HDNS.

Authorized personnel include:

- HDNS management and staff
- Associates of HDNS
- Researchers collaborating with member(s), employees or associates of HDNS in analyzing the HDNS datasets, and staff employed in their research projects, or
- An external investigator utilizing HDNS data for an approved project.