

Health Data Nova Scotia Data Access Committee Terms of Reference

(Revised 08 September 2022)

Purpose

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

Responsibilities

- ◆ 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 agreement with the 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.

Membership

Membership of the DAC reflects expertise in data management, secondary use of data, health services research methods, privacy and security and confidentiality issues and includes representation from HDNS and DHW.

Accordingly, the membership is structured as follows:

- ◆ Statistician
- ◆ Data analyst
- ◆ Privacy, confidentiality, security professional
- ◆ DHW representative
- ◆ HDNS representative
- ◆ Director, HDNS, Dalhousie Department of Community Health & Epidemiology (ex-officio)
- ◆ Patient/Public partner
- ◆ Other members, as appropriate

Additionally, it is desirable to have representation from a legal expert.

The general membership will be appointed by the chair (co-chair). DHW membership will be appointed by the DHW.

The full committee comprises the individuals as described above. Decisions will be made by consensus. Quorum consists of 50% of membership (excluding ex-officio). Minimal risk reviews will be conducted by the chair (co-chair) and one (1) committee member.

Minutes will include a summary record of members in attendance, questions for data requestors, and committee decisions.

Membership terms are two years. Membership will be staggered to ensure maintenance of expertise. New members will observe committee meetings prior to taking up their membership.

Meeting Frequency and Reporting Schedule

- ◆ Meetings will be held monthly, as required.
- ◆ Requests for data access requiring full DAC review are to be submitted to HDNS two weeks prior to the DAC meeting. Submissions are reviewed by the Research Data Navigator and are sent to the DAC members one week prior to the meeting.
- ◆ The DAC is accountable to the DHW Executive Director, Health Information Performance and Planning Division. Reports will be provided to the DHW Health Privacy Office annually.
- ◆ These Terms of Reference will be publicly available via the HDNS website.

Authority

The DAC operates under the authority of the Executive Director, Health Information Performance and Planning Division.