

 DALHOUSIE UNIVERSITY Health Data Nova Scotia Dissemination of Findings Policy	Author: S.Kennedy	Review Date: 01.01.2018
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1. BACKGROUND & PURPOSE

- 1.1 The purpose of this policy is to describe the obligations of requestor(s) who access data from Health Data Nova Scotia (HDNS) regarding the dissemination of their findings.

2. APPLICATION

- 2.1 This policy applies to all researchers or health service assessment analysts - referred to as requestor(s) - who access data from HDNS.

3. DEFINITIONS

- 3.1 *Aggregate Level Data*: the result of applying statistical procedures (e.g., weighting, imputation) and analyses (e.g., means, regression) to micro-level data sets.
- 3.2 *Cell size smaller than 5*: Data where the number of individuals exhibiting a specific trait or characteristic is less than 5 individuals.
- 3.3 *Data Access Committee (DAC)*: The Committee tasked with reviewing requests to conduct secondary data analysis for research, surveillance or health service assessment purposes using the administrative databases held by HDNS of Dalhousie University for privacy, security, and confidentiality concerns.
- 3.4 *Dissemination*: refers to publication of study findings in journals, posters, oral or online presentations, posting via blogs or using other forms of electronic media, distribution of printed materials at educational or professional conferences or seminars, and the oral and/or written presentation of thesis material by graduate students.
- 3.5 *Health Service Assessment*: activity to assess, investigate or evaluate the provision of healthcare services.

- 3.5 *Research*: A systematic investigation designed to develop or establish principles, facts, generalizable knowledge, or any combination of them, and includes the development, testing and evaluation of research.

4. POLICY STATEMENT

- 4.1 To protect the privacy of personal health information, HDNS ensures that dissemination of findings does not result in the identification of individuals whose data were used for the project.
- 4.2 Requestor(s) may disseminate findings provided the results reported include only aggregate level data and statistical analysis that preclude the identification - either alone or with other information - of subject individuals.
- 4.3 Findings which include cells smaller than 5 may not be disseminated in any format, including papers, presentations, abstracts or posters unless specific permission is provided by the Nova Scotia Department of Health and Wellness.

5. PROCEDURES

- 5.1 Within any dissemination of research findings based on data accessed through HDNS, the requestor(s) must include a disclaimer similar to this example:

"The data (or portions of the data) used in this report were made available by Health Data Nova Scotia of Dalhousie University. Although this research / health service assessment analysis is based on data obtained from the Nova Scotia Department of Health and Wellness, the observations and opinions expressed are those of the authors and do not represent those of either Health Data Nova Scotia or the Department of Health and Wellness."

- 5.2 At least two (2) weeks prior to the publication or presentation date, the requestor(s) must provide HDNS with an advance copy or draft of any publications that report findings based on HDNS data.
- 5.3 HDNS will review the publication within one (1) week to ensure that the obligations set out in this policy and any related policies have been met.

6. ADMINISTRATION

6.1 Accountability

- 6.1.1 Requestor(s) are responsible to:
- Ensure that the findings comply with section 4.2 of this policy and do not permit the identification of subject individuals.

- Comply with the timeframe of providing an advance copy of the publication to HDNS.
- Include the appropriate disclaimer.

6.1.2 The HDNS Manager or the Co-Chair of the Data Access Committee is responsible to review the publication to ensure compliance with this policy and to provide feedback to the requestor(s) one (1) week prior to the publication / presentation date.

6.2 *Monitoring, auditing and reporting*

6.2.1 HDNS will monitor the status of projects and ensure that any advance copies of publications are reviewed in a timely manner.

6.2.2 If the HDNS Manager becomes aware that a requestor(s) has not complied with the conditions for dissemination set out in this policy, they will contact the requestor(s) to highlight this contractual requirement.

7. RELATED POLICIES AND OTHER DOCUMENTS

7.1 *HDNS Policies and Procedures*

- Privacy Incident and Breach Policy

7.2 *HDNS Forms*

- HDNS Contractual Agreement for Data Access and Management (CADAM)

7.3 *Other Documents*