

# DISSEMINATION OF RESEARCH FINDINGS

## – Policy –

### 1. PURPOSE

- 1.1 This Policy describes the obligations of Approved Data Users who access data from the New Brunswick Institute for Research, Data and Training (NB-IRDT) regarding the Dissemination of their findings and the required wording to be used when acknowledging NB-IRDT for use of data in a publication.

### 2. SCOPE

- 2.1 This Policy applies to all NB-IRDT Employees and Approved Data Users regardless of the format used to disseminate research findings. Signed Data Access Agreements, Data Sharing Agreements, and/or Information Management Agreements may supersede the practices and procedures within this Policy.

### 3. DEFINITIONS

- 3.1 *Aggregate Data*: Data about groups of individuals, typically provided in a table or in chart form, which combines information in such a manner as to prevent the identification of individuals. The data are combined from several measurements and groups of observations are replaced with summary statistics.
- 3.2 *Approved Data User(s)*: Individuals, such as NB-IRDT Employees, researchers, students, and government employees, who have been issued an electronic identification access card, personal identification number, and project access account following the approval of access according to all relevant NB-IRDT procedures, including a Criminal Record Check (CRC).
- 3.3 *Custodian*: As defined in the PHIPAA, an individual or organization that collects, maintains, or uses personal health information for the purpose of providing or assisting in the provision of health care, and the treatment, planning, and management of the health care system, or delivering a government program or service.
- 3.4 *Data and Research Committee*: Serves four main functions for the NB-IRDT:
  - 1) Assembles working groups (Data and Research Committee working groups (DRC-WGs)) to review and provide feedback on Data Access Requests received from researchers seeking access to

- Administrative Data Sets held at NB-IRDT, as well as draft reports from these projects.
- 2) Provides a forum to discuss issues relevant to database transfers and Data Linkage procedures.
  - 3) Serves as a forum for consultation on procedural changes.
  - 4) Organizes a forum at least once per year to present results of projects to the Government of New Brunswick (GNB) and other Stakeholders.
- 3.5 *Data Business Owner*: The entity holding legal rights and control over a Data Set(s) and its variables. In the context of a Data Sharing Agreement, this is the entity (e.g., Custodian, Public Body) who has signed the Data Sharing Agreement and who has shared/disclosed a Master Data Set(s) with/to NB-IRDT.
- 3.6 *Dissemination*: The distribution or communication of research results to facilitate research uptake in decision-making processes and practices. This includes, but is not limited to, publication in journals, posters, oral or online presentations, posts via blogs or other forms of electronic media, distribution of printed materials at educational or professional conferences and seminars, and the oral and/or written presentation of thesis material by graduate students.
- 3.7 *Employee(s) (of NB-IRDT)*: All full-time and part-time, continuing and term Employees currently earning wages or salaries from NB-IRDT (including the Director). Does not include independent contractors.
- 3.8 *New Brunswick Institute for Research, Data and Training (NB-IRDT)*: A Research Data Centre as defined in RTIPPA and PHIPAA. Like other Research Data Centres, NB-IRDT has the authority to compile and link Personal Information and Personal Health Information for the purposes of research, analysis, or evidence-based decision-making. NB-IRDT has three locations, with the hub located in Fredericton, and Satellite Sites located in Saint John and Moncton. These facilities are situated on the University of New Brunswick (Fredericton) campus (Keirstead Hall, 38 Dineen Drive; Units 316, 317, and 317-A); on the Saint John campus (Hazen Hall, 93-97 Tucker Park Road; Unit 339); and, on the Université de Moncton campus (Bibliothèque Champlain, 415 avenue de l'Université; salle 031).
- 3.9 *Qualitative Data*: Data used to explore and understand people's beliefs, experiences, attitudes, or behaviours. Qualitative Data research involves questions about how and why. It does not include information in the form of numbers (e.g., Qualitative Data are not used to reflect how many people have tried to quit smoking but to reflect their experiences in trying to quit smoking).
- 3.10 *Quantitative Data*: Data collected and used for numerical analysis. They are used to find patterns and averages, make predictions, test causal

relationships, and generalize results to wider populations (e.g., Quantitative Data are not used to reflect the personal experiences of individuals trying to quit smoking but to ask how many people have tried to quit smoking).

- 3.11 *Summary Level Data*: The result of applying statistical procedures (e.g., weighting, imputation) and analyses (e.g., means, regression) to micro level Data Sets.

#### **4. POLICY STATEMENTS**

- 4.1 Prior to accessing data at NB-IRDT, Approved Data Users are obligated under PHIPAA and RTIPPA to enter into a written Data Access Agreement with NB-IRDT. This agreement includes obligations as stated in this Policy.
- 4.2 Approved Data Users are obligated under section 43 of PHIPAA to not publish Research findings in a form that could reasonably be expected to identify individuals whose data were used for the research project.
- 4.3 NB-IRDT is obliged under PHIPAA and in its agreements with Data Business Owners to ensure that Approved Data Users comply with the obligations regarding Dissemination of Summary Level or Aggregate Data. Therefore, a review process must be in place for advanced vetting of all proposed Disclosure of data findings to ensure data protection and privacy compliance.
- 4.4 The review process must ensure the proposed consideration for Dissemination or submission for publication is provided to the Data Business Owner/Custodian who provided the data prior to Dissemination. Provision is made to allow the Data Business Owner/Custodian to identify concerns about the interpretation of the data in relation to the circumstances in which it was collected, and to allow for the preparation of responses to the media about the research findings prior to Dissemination. The Data Business Owner/Custodian does not have the authority to veto a proposed Dissemination or submission for publication; however, the Data Business Owner/Custodian is able to identify data interpretation concerns.
- 4.5 As an Information Manager, NB-IRDT may conduct commissioned work on behalf of a government department or body as a Data Business Owners/Custodian. Since the work is for the Data Business Owner/Custodian using their data, requests for the release of aggregate interim results made for review and comment prior to the end of a regular Embargo Period will be directed to the department or body's DRC representative. The representative will instruct NB-IRDT when and to whom the interim aggregated results can be released.
- 4.6 NB-IRDT has adopted a 25-business-day Embargo Period for data disclosure request to allow for the conducting of the necessary review processes.

## 5. PROCEDURES

### 5.1 Disclosure Scenarios

Scenario	NB-IRDT Role	Length of Embargo	DRC Working Group Review Process	Rationale
Data Disclosure request, vetted results released with standard Embargo Period	Custodian	25 business days	In person or delegated	Required following the Data Access Request and Data Access Agreement process
Data Disclosure request, vetted results released with expedited Embargo Period	Custodian	7 business days	In person or delegated	Required following the Data Access Request and Data Access Agreement process – this is an exception and requires justification e.g., a grant application deadline needs to be met.
Data Disclosure request of vetted results released to government bodies/departments/Data Business Owner/Custodian of their own data before Embargo Period.	Information Manager	Not applicable	Not applicable	Commissioned work is conducted on behalf of the Data Business Owner/Custodian using only their data; they may request aggregate interim results to monitor the progress of the project. Final Disclosure of results requires 25 business day.
Data Disclosure request of vetted results released to a working group and Stakeholders, before Embargo Period.	Custodian	Not applicable	The DRC will consider an early release request only when indicated on the DAR. This request must be confirmed during the	Data Access Request including multiple Data Business Owners/Custodians <i>may permit</i> preliminary Disclosure of aggregate interim results to a working group or Stakeholders for assistance with

			DRC's review of the DAR.	interpretation of results.
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## 5.2 Data Vetting

5.2.1 NB-IRDT Employees and Approved Data Users are to request Vetting of research data results following the process as outlined in the *Standard Operating Procedure: Data Vetting Request*. Data must be vetted prior to Disclosure to anyone not on the research team.

5.2.2 If mutual agreements cannot be met with respect to Vetting results, the PI or the Database Administrator may notify the Director and/or Privacy Officer and request that the Data Vetting Committee be convened. (See *Standard Operating Procedure: Data Vetting Request Appeal* and *Data Vetting Committee Terms of Reference* for further information)

## 5.3 Data Findings Dissemination (Quantitative)

5.3.1 NB-IRDT Employees and Approved Data Users may only disseminate and/or report on Research findings at Summary Level or in Aggregate Data form. Statistical analysis must preclude the identification, either alone or with other information, of subject individuals. Findings that result in a cell size smaller than 5 (that is, the number of individuals determined to be exhibiting a specific trait or characteristic is less than 5 individuals but not 0) may not be disseminated in any format.

5.3.2 NB-IRDT Employees or Approved Data Users who plan to disseminate their findings in any format, including oral form, poster presentation, or written publication submission, must follow the procedures as stated within this Policy.

5.3.3 Prior to the first consideration for Dissemination or submission for publication, the NB-IRDT Employee or Approved Data User must provide the NB-IRDT Data Access Coordinator with the work for publication that reports the results of Research using data accessed at NB-IRDT. The publication will undergo a Data Disclosure review.

5.3.4 The Embargo Period for Data Disclosure review begins when the NB-IRDT Data Access Coordinator receives the request for Dissemination or submission for publication.

5.3.5 The NB-IRDT Data Access Coordinator distributes the proposed consideration for Dissemination or submission for publication to the Data Research Committee (DRC).

5.3.6 The Data Business Owners/Custodians and Data Research Committee members will review the consideration for Dissemination or submission for publication and provide any comments to the NB-

IRDT Data Access Coordinator, who will forward them to the Approved Data User for their consideration, as appropriate.

NB-IRDT will defer to Data Business Owners/Custodians and the Data Research Committee representative to distribute as appropriate within their department or body for review and comment.

- 5.3.7 The NB-IRDT Director may review the consideration for Dissemination or submission for publication and provide comments at their discretion if they are not the Principal Investigator or a co-researcher for the project.
- 5.3.8 The NB-IRDT Data Access Coordinator will notify the Approved Data User at the end of the Embargo Period that publication and Dissemination is permitted.

#### 5.4 Embargo Period

- 5.4.1 Embargo Period - The Embargo Period is set at twenty-five (25) business days from the date that the request for consideration for Dissemination or submission for publication is received by the NB-IRDT Data Access Coordinator. This length of time is required to provide sufficient time to allow Data Business Owners/Custodians and the Data Research Committee to receive, review, and correspond on the data findings.
- 5.4.2 Expedited Embargo Period - In exceptional circumstances, where the applicant must proceed to the Dissemination stage faster than the standard Embargo Period, a reduced Embargo Period may be permitted (e.g., consultation with approved project patient/citizen engagement partners, deadlines for funding, etc.). A reduced Embargo Period of no less than seven (7) calendar days (1 week) may be permitted. An expedited Embargo Period is permitted at the discretion of the NB-IRDT Director in consultation with the appropriate Data Business Owners/Custodians and the Co-Chairs of the DRC. The following conditions apply:
  - Proposed data findings for Dissemination must be reviewed by the DRC, the NB-IRDT Database Administrator, and the NB-IRDT Privacy Officer.
  - Results are to be presented in the most Summary Level Data or Aggregate Data level possible.
  - The Dissemination document must clearly be marked 'not for distribution' or, in case of oral presentation, must verbally state the findings are preliminary and not be distributed.

- A regular Embargo Period of 25 business days will apply when a request for consideration for regular Dissemination or submission for publication is made.

## 5.5 Data Findings Dissemination (Qualitative Data)

- 5.5.1 For the release of qualitative findings, NB-IRDT Employees and Approved Data Users may only disseminate and/or report on Research findings as they were approved in their project's Research Ethics Board application.
- 5.5.2 The Data Vetting process, as described in 5.2 and 5.3 above, does not apply if the consideration for Dissemination or submission for publication does not include access to Administrative Data.
- 5.5.3 Review may be required by the Data Business Owner/Custodian and/or the NB-IRDT Privacy Officer for Research Ethics Board compliance following the regular Data Disclosure process.

## 5.6 Abstracts

- 5.6.1 NB-IRDT Employees or Approved Data Users who will be submitting a Research Abstract or providing an oral presentation that does not refer to actual data must notify the NB-IRDT Data Access Coordinator to inform the Data Owner
- 5.6.2 To ensure the obligations set out in this Policy and the Data Access Agreement have been met the NB-IRDT Data Access Coordinator distributes the proposed consideration for Dissemination or submission for publication to the NB-IRDT Database Administrator, NB-IRDT Privacy Officer.
- 5.6.3 The NB-IRDT Database Administrator and NB-IRDT Privacy Officer will inform the Approved Data User, with carbon copy (cc) to the NB-IRDT Data Access Coordinator, if there are any data privacy or Confidentiality issues.

## 5.7 Acknowledgement

- 5.7.1 Within any publications in which NB-IRDT data were used, the NB-IRDT Employee or Approved Data User will acknowledge NB-IRDT and the appropriate Data Business Owner/Custodian. A disclaimer similar to this example must be included:

*"This work was supported by the Department of XXX of the Province of New Brunswick under a contract with the New Brunswick Institute for Research, Data and Training at the University of*

*New Brunswick. The results and conclusions are those of the authors and no official endorsement by the Government of New Brunswick was intended or should be inferred.”*

- 5.7.2 Any acknowledgement, as referenced in 5.7.1 above, does not replace any other acknowledgments as may be required by funders or other parties involved in the work.
- 5.7.3 For oral presentations, NB-IRDT Employees and Approved Data Users must include a verbal acknowledgment using language similar to 5.7.1.

## **6. ADMINISTRATION**

### **6.1 Accountability**

- 6.1.1 Approved Data Users are responsible to:
- Ensure that the request for consideration for Dissemination or submission for publication findings complies with this Policy and does not permit the identification of individual subjects;
  - Comply with the set Embargo Period and provide the consideration for Dissemination or submission for publication to the NB-IRDT Data Access Coordinator in a timely manner; and,
  - Include the appropriate disclaimer.
- 6.1.2 The NB-IRDT Database Administrator will remind NB-IRDT Employees and Approved Data Users of this Policy and the 25-business-day Embargo Period requires for data disclosure review prior to data release.
- 6.1.3 The NB-IRDT Data Access Coordinator will facilitate communication between Approved Data Users and those with review responsibilities (i.e., DRC, Data Business Owners/Custodians, and NB-IRDT Employees).
- 6.1.4 The NB-IRDT Database Administrator and Privacy Officer are responsible to review requests for Dissemination or submission to publication, to ensure compliance with this Policy, and to provide feedback to NB-IRDT Employee(s) or the Approved Data Users in a timely manner prior to the Dissemination date.
- 6.1.5 The NB-IRDT Director is responsible to ensure that the appropriate Data Business Owners/Custodians are provided with requests for consideration for Dissemination or submission for publication and an opportunity to meet with the Approved Data User if a briefing is requested.

### **6.2 Monitoring, Auditing, and Reporting**



- 6.2.1 NB-IRDT will monitor the status of Research projects and submitted publications for reporting to granting agencies, the Government of New Brunswick, and other funders.
- 6.2.2 If the NB-IRDT Privacy Officer becomes aware that an NB-IRDT Employee or Approved Data User has not complied with the conditions for Dissemination set out in this Policy, they will notify the NB-IRDT Director and, if appropriate, invoke the *NB-IRDT Privacy Breach Policy*.

## 7. RELATED DOCUMENTS

- *NB-IRDT Standard Operating Procedure: Data Vetting Request*
- *NB-IRDT Standard Operating Procedure: Data Vetting Request Appeal*
- *NB-IRDT Data Vetting Committee Terms of Reference*
- *NB-IRDT Glossary of Data Privacy and Security Terms*
- *NB-IRDT Privacy Breach Policy*

## 8. REFERENCES

- [Right to Information and Protection of Privacy Act, SNB 2009, c R-10.6](#)
- [Personal Health Information Privacy and Access Act, SNB 2009, c P-7.05](#)

## 9. DOCUMENT VERSION, REVIEW, AND APPROVAL HISTORY

Version	Author	Nature of Change		Date
1.0	NB-IRDT Staff	Document Creation		September 2016
Approved by		Approval Date	Effective Date	Review Date
Vice President (Research)		November 2016	November 2016	September 2017

Version	Author	Nature of Change		Date
2.0	D. Curtis Maillet	Major Revisions for 2018 Expansion & Procedural Changes		July 2018
Approved by		Approval Date	Effective Date	Review Date
Vice President (Research)		November 2019	November 2019	July 2020

Version	Author	Nature of Change	Date
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3.0	D. Curtis Maillet / A. Lavigne	Major revisions to accommodate process changes throughout.	June 7, 2022
3.1	A. Lavigne	Incorporating feedback (grammatical corrections, etc.) from NB-IRDT employee review	June 14, 2022
3.2	D. Curtis Maillet / A. Lavigne	Incorporating Director Review comments	June 28, 2022
3.2.1	NB-IRDT Staff	Content review and minor edits	May 26, 2023
<b>Approved by VP Research UNB</b>		<b>Approval Date</b>	<b>Effective Date</b>
David MaGee		July 2023	July 2023
			<b>Review Date</b>
			July 2024