

Amendment to Record-Level Information Request for Secondary Use

Name of Initiative/Study:

Reason for Request:

- | | |
|---|--|
| <input type="checkbox"/> Research | <input type="checkbox"/> Quality Assurance |
| <input type="checkbox"/> Program Evaluation | <input type="checkbox"/> Translational Personalized Medicine Initiative (TPMI) |
| <input type="checkbox"/> Health System Planning | |

Supporting Documentation Checklist (as applicable)

- Copies of Research Ethics Board applications and approvals have been attached.
- Authorizing letters for use of additional data for the initiative have been attached.
- Copies of privacy policies or statements of information practices have been attached.
- A variable list with rationale has been attached
Variable List: https://www.nlchi.nl.ca/images/Variable_List_for_Record-Level_Request_for_Secondary_Use.docx
- The application is **signed** and **dated**.

*** All applications must be completed electronically and kept in original format.
 *** Once completed, this application, and all accompanying documents must be submitted to the Information Request Coordinator, Newfoundland and Labrador Centre for Health Information (NLCHI):
InfoRequests@nlchi.nl.ca

***Submission dates and deadlines may be found at:
https://www.nlchi.nl.ca/images/PDFs/Submission_Dates_Deadlines_-_2017.pdf

*** *By signing and submitting this application to request data, I understand that the content of the application and all submitted attachments will be used to evaluate the request. Any use of the data granted in response to this request is provided under the expectation of adherence to the representations made within the application and attachments. I further understand that additional conditions may be specified in relation to the use of this data.*

Signature of Applicant:

Signature of Program Director/Principal Investigator/Academic Advisor:

X _____

X _____

Print/type name:

Print/type name:

Date (yyyy/mm/dd):

Date (yyyy/mm/dd):

Part A: Contact Information

A.1. Provide contact information for the applicant

Name:

Organization:

Position:

Telephone:

E-Mail:

Part B: Amendment Parameters

B.1. Please indicate if any of the following parameters associated with your project/initiative have changed since the most recent information request to the Centre for Health Information.

Objectives	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Methodology	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Sponsoring/participating organizations or individuals, and their roles	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Data sources required	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Variables required	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Uses, or potential uses, of the information	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Disclosures, or potential disclosures, of the information	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Data linkages that are being performed	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Organizational privacy policies or statements of information practices	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Organizational reporting structures relating to the protection of personal information	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Method of storing the requested information	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Privacy compliance and privacy breach reporting procedures	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
The list of individuals authorized to access the information	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Timelines associated with information destruction or the alteration of information to prevent re-identification	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Procedures associated with information destruction or the alteration of information to prevent re-identification.	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>
Expiry dates associated with Research Ethics Board approval	Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>

Part C: Requested Information and Services

C.1. Briefly summarize your original information request, as well as the changes requested.
(Provide details C.3.)

C.2. Will data be provided to the Centre for use in the requested linkage/analysis/etc.?

Yes No

If Yes, Please provide details and list any data sources/variables that will be included; as well as the name and contact information of the person who will be sending/receiving the data via secure data transfer

(attach additional pages, if required)

****Note: All transfers of record-level data must be completed via the Centre's secure Managed File Transfer (MFT) system.***

C.3. Do you require a comparison group? Yes No

If Yes, please provide details:

C.4. Specify what data services will need to be provided by the Centre (i.e. data linkage, data analysis, study key retention, etc.) including a description of the proposed data flow.

C.5. How are you requesting to receive the data?

***Identifiable** (information that could be used to re-identify an individual through a combination of indirect identifiers (e.g., date of birth, place of residence or unique personal characteristics) using reasonably foreseeable means)

***De-Identified/coded** (information that is created when identifiers are removed and replaced with a code. Depending on access to the code, it may be possible to re-identify specific individuals (e.g., individuals are assigned a code name and the custodian retains a list that links the code name with the particular individual's actual name so data can be re-linked if necessary.) Custodians who have access to the code and the data will be considered to have identifiable information.

***Anonymized:** (information is irrevocably stripped of identifiers, and a code is not kept to allow future linkages.)

(*Source: Government of NL PHIA Policy Development Manual)

C.6. Describe how the requested data will be stored, as well as the physical, administrative and technical safeguards that will be used to ensure limited access.

C.6. Do you have a specific timeline for desired receipt of the final dataset? Yes No

If yes, please provide details:

C.7. Please specify the format of the final dataset:

SPSS **SAS** **Excel** **Other** *Specify:*

Additional Notes: