Application to Request Record-Level Information for Secondary Use

Name of Initiative/Study:

Reason for Request:

- ☐ Research
- ☐ Program Evaluation
- ☐ Health System Planning
- ☐ Quality Assurance
- ☐ Translational Personalized Medicine Initiative (TPMI)

Supporting Documentation Checklist (as applicable)

☐ Copies of Research Ethics Board applications & approval have attached. These copies must also include all supporting documentation and documentation pertaining to amendments.

☐ 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 complete variable list (with rationale) has been attached.
(Variable List found at https://www.nlchi.nl.ca/index.php/quality-information/information-requests/record-level-information

☐ 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/Submission_Dates_Deadlines_-_Revised_June_13_2016.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:

X_____

Print/type name:

Date(yyyy/mm/dd):

Signature of Program Director/Principal Investigator/Academic Advisor:

X_____

Print/type name:

Date(yyyy/mm/dd):

Form Revised: August 2016

Part A: Contact Information

A.1. Provide contact information for the applicant and primary contact.

APPLICANT:
Name:

Organization:

Position:

Telephone:

E-Mail:

PRIMARY CONTACT (if different from applicant):
Name:

Organization:

Position:

Telephone:

E-Mail:

A.2. Provide names and email addresses for all other persons associated with the initiative.

PRINCIPAL INVESTIGATOR(s)

CO-APPLICANT(s) / CO-INVESTIGATOR(s):

ACADEMIC ADVISOR(s):

OTHER(S):

Part B: Description of Project

B.1. What are the objectives of the proposed project? ***(attach additional pages, if required)***

B.2. Provide, in plain language, a brief summary of your methodology. ***(attach additional pages, if required)***

Part C: Requested Data and Services

C.1. Using the check boxes, please specify which database(s) you are requesting.

Canadian Chronic Disease Surveillance System (CCDSS) ☐

Clinical Database Management System (CDMS) ☐ **{Hospitalization Data/CIHI/DAD}**

Canadian Primary Care Sentinel Surveillance Network – EMR (CPCSSN) ☐

Client Registry (CR) ☐

Longitudinal Pediatric Research Database (LPRD) ☐

MCP Fee-for-Service Physician Claims ☐

MCP Beneficiary Registry ☐

MCP Provider Registry ☐

NLCHI Live Birth System ☐

NLCHI Mortality System ☐

Statistics Canada's Annual Mortality Data File ☐

Suicide Database ☐

Stillbirth Database ☐

Rehabilitation Database ☐

OTHER ☐ **(Please List):**

C.2. Do you have specific timeline for desired receipt of the final dataset? Yes ☐ **No** ☐

If yes, please provide details:

C.3. Will you be providing data to the Centre to use in the requested linkage/analysis/etc.?

☐ **Yes** ☐ **No**

If Yes, Please provide details and list any <u>data sources/variables</u> 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.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 <u>data flow</u>.

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. Please specify the desired format of the final dataset:

SPSS ☐	**Excel** ☐
SAS ☐	**Access** ☐
	Other ☐ **Specify:**

C.7. Will this data be required on an ongoing basis? Yes ☐ **No** ☐

If yes, please describe this requirement for data on an ongoing basis and provide rationale that explains why you require this data:

Part D: Privacy and Security

D.1. Is the data requested the minimum amount of data needed to meet the project objectives? Provide rationale.

D.2. a) Describe what linkages will be made with the requested data; that is, how will the data <u>received</u> from the Centre be combined with <u>additional</u> data?

D.2. b) Describe your authority to use this <u>additional</u> data. For each additional data source to be linked with data provided by the Centre, a letter authorizing use of the data for this project must be attached with the application.
D.3. List the individuals, or groups of individuals, that will be authorized to access the requested data as part of the project.
D.4. Describe how the requested data will be stored, as well as the physical, administrative, and technical safeguards that will be used to ensure such limited access.
D.5. For how long will the requested data be retained? Provide justification for the length of time that the requested data will be retained. If the data will be destroyed or altered to prevent re-identification, describe your procedures for doing this work.