

Application for Access to Data for Research Purposes

Cancer Care Nova Scotia

An electronic version of this application is available on the *CCNS* website
www.cancercare.ns.ca

The information on this form will be used to evaluate the request for access to *CCNS* data. Any questions about the form should be directed to:

Pauline Hart
Administrative Assistant
Cancer Care Nova Scotia
1276 South Park Street
5th Floor, Bethune Building
Halifax, Nova Scotia B3H 2Y9
E-mail: Pauline.Hart@ccns.nshealth.ca

Items that are marked with an asterisk (*) are to be completed for **preliminary requests** (outlined in section 10.1 of the *CCNS* Data Access Policy and Procedures for Research Purposes).

Prior to final submission, please ensure that your application is complete and that attachments are clearly labeled.

If this request is approved, you may be asked to sign a contractual agreement prior to obtaining access to *CCNS* data to ensure the data is handled appropriately.

Note: Continue on separate sheets if necessary.

Cancer Care Nova Scotia **Research Request**

SECTION A: Researchers

*A.1. *Please provide the following information about the Principal Investigator. If the Principal Investigator is a student, please complete Section 2 about the Academic Supervisor. The Supervisor must also co-sign this application.*

Last Name	First Name	Middle Initial
Position:		
Organization:		
Address:		
Province	Country	Postal Code
Telephone:	Alternate Telephone:	
Fax:		
E-mail:		

A.2 *Academic Supervisor

Last Name	First Name	Middle Initial
Position:		
Organization:		
Address:		
Province	Country	Postal Code
Telephone:	Alternate Telephone:	
Fax:		
E-mail:		

A.3 Please provide the following information about Co-Investigator(s) (Add additional sections as necessary to include all Co-Investigators.)

Last Name	First Name	Middle Initial
Position:		
Organization:		
Address:		
Province	Country	Postal Code
Telephone:	Alternate Telephone:	
Fax:		
E-mail:		

Last Name	First Name	Middle Initial
Position:		
Organization:		
Address:		
Province	Country	Postal Code
Telephone:	Alternate Telephone:	
Fax:		
E-mail:		

A.4 Attach the following:

- a) The curriculum vitae for the Principal Investigator which includes education, knowledge of the subject and proposed methodology, a list of relevant successfully completed research studies, presentations and publications.
- b) The curriculum vitae for the Academic Supervisor if the Principal Investigator is a student.
- c) The curriculum vitae of the person responsible for designing the study methodology (if not the PI).

SECTION B: Description of the research project

B.1 Complete the following OR if the information is included in the research protocol, attach the research protocol. Items that are marked with an asterisk () are to be completed for **preliminary requests** (outlined in section 10.1 of the CCNS Data Access Policy and Procedures for Research Purposes).*

a) Project Title:*
b) Purpose and Objectives of the Project:*
c) Significance/benefits to be derived from the research project:*
d) Research Design:*
e) Data Request: * Years: Diagnostic Groups:
f) Please tick as appropriate the support you require from CCNS* <i>Tick as many as apply</i> <input type="checkbox"/> Identification and provision of study subjects <input type="checkbox"/> Identification and provision of study subjects plus associated dataset <input type="checkbox"/> Coordination of study process: such as mailouts, patient contacts <input type="checkbox"/> Study collaborator/partner <input type="checkbox"/> Input on study protocol/methods development <input type="checkbox"/> Preparation of study database <input type="checkbox"/> Linkage of external dataset to CCNS data <input type="checkbox"/> Chart review <input type="checkbox"/> Data analysis <input type="checkbox"/> Report writing <input type="checkbox"/> Abstract preparation <input type="checkbox"/> Other (please specify)

g)	Project budget and time schedule (include funds allocated for data acquisition and project end date):
h)	Medium in which the data is required (e.g. paper or electronic), with details about the file and/or table format (if applicable):

B.2 Attach the following information, if applicable:

a) Research Ethics Approval

At minimum, ethics approval is required for all projects requesting person-level or person-identifiable data. Ethics approval may also be required for projects requiring other data types.

i) Is Research Ethics approval required? Yes No

ii) List all involved REBs:

iii) Is the Research Ethics Board (REB) approval(s) for this project attached? If approval from more than one REB is required, copies of all approvals must be attached.

Attached _____ (Name of REB)

Not Attached _____ (Name of REB)

Decision Pending _____ (Name of REB)

If not yet available, indicate when you expect to receive approval. _____

CCNS may approve requests conditionally pending research ethics approval

b) Funding Approvals

A document confirming approved funding for this project from the funding agency.

Attached Not applicable

c) Literature review.

Attached Not applicable

SECTION C: DESCRIPTION OF THE DATA REQUIREMENTS

*C.1. *Please specify below:*

- the data holding(s) from which the data will be requested(i.e. Nova Scotia Cancer Registry; Provincial Cytology Colposcopy Registry; Patient Navigator Database) **AND**
- the level of anonymity (aggregate, person-level, person-identifiable, health-provider identifiable and institution-identifiable) for the requested data. See Section 3 of the Data Access Policy for definitions of anonymity levels.

Data Holding	Level of Anonymity

C.2. The following information is required. If it is included in the research protocol, it does not have to be re-entered.

a) Define the study population. Include selection, inclusion and exclusion criteria and sample size.*

<p>b) Identify data elements being requested and how each will be used*</p>
<p>c) Are you expecting <i>CCNS</i> to manipulate/modify any of the source data elements for this study? Describe.* (for example: verify address information or survival status)</p>
<p>d) Describe proposed linkages to be made between <i>CCNS</i> data and any other data. Include a description of the non-<i>CCNS</i> data source(s) including all data elements to which <i>CCNS</i> data will be linked.*</p>
<p>e) Target date(s) for receipt of data from <i>CCNS</i>*</p>
<p>f) Expected period of time during which access to the requested data is required.*</p>
<p>g) Plans to disseminate the information. Please tick as appropriate:</p> <p><input type="checkbox"/> Publication <input type="checkbox"/> Poster presentation <input type="checkbox"/> Oral presentation</p> <p>Please provide details about journals targeted, expected audience for Presentations</p>

SECTION D: SECURITY

D.1. In addition to the minimum safeguards outlined below, CCNS may require additional safeguards, which will be reviewed with the applicant prior to the release of the data.

In addition to the following safeguards, prior to data release, the applicant will be required to:

- Identify the secure location(s) where the data will be kept,
- Identify the named individuals who will have access to the data
- Specify procedures to prevent unauthorized access
- Specify procedures to safeguard laptops and other portable computing devices against theft and unauthorized access, if they are used.
- Specify procedures to be followed should unauthorised access or disclosure occur.

Physical Safeguards:

- All hard copies and electronic storage media will be kept in locked cabinets when not in use.
- Back up files will be made on a regular basis and will be kept in a secure location.
- Project staff will be granted access to the data on a **need-to-know** basis.

Technical Safeguards:

- Electronic files will be password protected

Person-identifiable information will not be transmitted electronically, unless encrypted
Should the applicant wish to amend the protocol or project or use of the data in any way, CCNS requires an updated copy before the data can be released.

I have been provided with, read and agree to comply with the CCNS Data Access Policy and Procedures.

Signature of Applicant

Signature of Supervisor
(if applicable)

Date

Date