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DATA SHARING  
AGREEMENT

## DATA SHARING AGREEMENT

THIS AGREEMENT made this 5th day of April, 2010

**BETWEEN:**

### **INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES**

a corporation having its head office at  
2075 Bayview Avenue, in the City of Toronto

[hereinafter referred to as "ICES"]

-AND-

### **THE OUR HEALTH COUNTS GOVERNING COUNCIL ONTARIO FEDERATION OF INDIAN FRIENDSHIP CENTRE ONTARIO NATIVE WOMEN'S ASSOCIATION TUNGASUVVINGAT INUIT MÉTIS NATION OF ONTARIO**

[hereinafter referred to as the "GOVERNING COUNCIL"]

-AND-

### **CENTRE FOR RESEARCH ON INNER CITY HEALTH/ST. MICHAEL'S HOSPITAL**

70 Richmond Street East  
Toronto, ON  
M5C 1N8

[hereinafter referred to as "CRICH"]

**WHEREAS** ICES was established in 1992 in order to carry out research with respect to physicians' services and related health services on behalf of the Ministry of Health and Long Term Care (MOHLTC) and the Ontario Medical Association;

**WHEREAS** ICES' mandate now includes the conduct of clinical evaluative studies and health services research in order to improve the efficiency and effectiveness of physicians' services and related health care services;

**WHEREAS** MOHLTC has entered into an agreement with ICES to provide annual funding to ICES for the purpose of conducting such research;

**WHEREAS** ICES has entered into a data sharing agreement with the MOHLTC for access to information, including personal health information, that is in the custody or control of MOHLTC for the purpose of conducting clinical evaluative studies and health services research;

**WHEREAS** ICES is a prescribed entity under section 45(1) of the *Personal Health Information Protection Act*, S.O. 2004, c. 3 Sched. A (the Act) and O. Reg. 329/04 section 18(3) and warrants and represents that the personal health information requested in this agreement is necessary to conducting clinical evaluation studies and health services research;

**WHEREAS** pursuant to section 45(1) of the Act, the Health Information Custodian may disclose to a prescribed entity personal health information for the purpose of clinical evaluation studies and health services research if the entity meets the requirements under subsection (3). 2004, c. 3, Sched. A, s.45 (1);

**WHEREAS** ICES has in place the practices and procedures necessary under subsection (3). 2004, c. 3, Sched. A, s.45 (1) to protect the privacy of individuals and the confidentiality and security of personal health information it receives;

**WHEREAS** the Information & Privacy Commissioner/Ontario has reviewed the privacy, confidentiality and security practices and procedures of ICES and approved them in October 2008;

**AND WHEREAS** the First Nations, Métis, and Inuit people in Canada have inherent rights to self-government, specific rights as negotiated in the numbered Treaties and rights as outlined and enshrined in the Constitution Act of Canada (1982);

**NOW THEREFORE** in the consideration of the promises and the mutual covenants hereinafter contained, the parties hereto agree as follows:

### *1.0 PURPOSE OF THE AGREEMENT*

The purpose of this agreement is:

- 1.1 to set out the terms and conditions governing the provision of data, including personal health information, to ICES to enable it to conduct clinical evaluative studies and health services research on behalf of the GOVERNING COUNCIL and CRICH.

### *2.0 INFORMATION TO BE PROVIDED*

- 2.1 CRICH and GOVERNING COUNCIL have agreed to provide to ICES a copy of the Our Health Counts Respectful Health Survey dataset, (henceforth the OHC RHS dataset). The database will contain the name, gender, date of birth, OHIP number, and Respectful Health Survey response data of self-identified First Nations people living in Hamilton and Inuit and Métis people living in Ottawa (variables lists will be attached before data is transferred). There will be three linkages of the OHC RHS Database to the ICES database at baseline (2010) and in 2 (2012) and 5 (2015) years from baseline. Following the completion of the project, in 2017 the OHC RHS Database will be permanently erased from ICES files.

### *3.0 USE OF THE INFORMATION*

ICES shall use the personal health information collected under this agreement only as necessary for the following purposes:





- 3.1. To link the OHC RHS Database with the Registered Person Database (RPDB) to create a cohort of First Nations people living in Hamilton and Inuit and Métis people living in Ottawa. This cohort will be linked with the other administrative data, and a variety of measures will be determined and analyses will be conducted for the First Nations cohort in Hamilton and the Inuit and Métis cohort in Ottawa. These may include, but will not be limited to:
  - 3.1.1. The incidence and prevalence of chronic diseases such as diabetes, cardiovascular disease, arthritis, COPD, cancer, and stroke.
  - 3.1.2. Emergency care
  - 3.1.3. Physician care (visits with and continuity of primary care, visits with specialists)
  - 3.1.4. Age and gender specific hospitalization rates
  - 3.1.5. Medication use (glucose-lowering medications, cardioprotective medications)
  - 3.1.6. Participation in preventative care activities (as defined by ICES)
  - 3.1.7. Access to mental health care (as defined by ICES)
  - 3.1.8. The relationship between social determinants of health and acute and chronic health status outcomes
  - 3.1.9. The relationship between social determinants of health and access to health services
  - 3.1.10. Chronic disease complications (myocardial infarction, bypass surgery/angioplasty, heart failure, stroke, amputation, dialysis)
- 3.2 ICES will only release requested measures and analyses to CRICH and the GOVERNING COUNCIL in an aggregated format that prevents the identification of individuals. This does not preclude the release of First Nations, Inuit, Métis specific datasets to CRICH and the GOVERNING COUNCIL if so directed by GOVERNING COUNCIL.
- 3.3 At the request of Tungasuvvingit Inuit, ICES may release Inuit specific measures and analyses in an aggregated form to CRICH and Tungasuvvingit Inuit if so directed by Tungasuvvingit Inuit.
- 3.4 At the request of Métis Nation of Ontario, ICES may release Métis specific measures and analyses in an aggregated form to CRICH and Métis Nation of Ontario if so directed by the Métis Nation of Ontario.
- 3.5 Research reports and publications, including peer reviewed scholarly manuscripts, will be created at the discretion of the GOVERNING COUNCIL and CRICH.
- 3.6 All research reports and publications will credit the GOVERNING COUNCIL, relevant CRICH staff and the relevant ICES scientists/staff with authorship.
- 3.7 The GOVERNING COUNCIL will have the opportunity to review all research reports and publications that are prepared by CRICH before they are made public, submitted to the MOHTLC as per 3.8, or submitted for publication. The GOVERNING COUNCIL will be provided a minimum of 30 days for this review unless otherwise agreed by GOVERNING COUNCIL. Representatives of GOVERNING COUNCIL shall be able to provide a dissenting opinion of findings and any dissenting opinions will be included as part of the overall report in all publications and/or pertinent published or produced materials.
- 3.8 Under its contractual obligation to the MOHLTC, ICES will provide the MOHLTC with copies of all reports that have required the use of health care data obtained from the MOHLTC for the purposes of compiling the information 30 days prior to submitting such reports for publication or making such reports public, as the case may be. The MOHLTC shall keep all such reports confidential.

#### 4.0 MECHANISMS FOR TRANSMISSION

- 4.1 The parties shall mutually determine the method, medium, frequency and timetable to be used with respect to the provision of information under this agreement. These parameters shall enable ICES to meet its IPC-approved standards, must fit with available technology, and with availability of staff to effectively and securely manage the PHI.

#### 5.0 CONFIDENTIALITY

- 5.1 The personal information disclosed under this agreement is confidential and mechanisms for maintaining the confidentiality of this information are described in Article 5.4.
- 5.2 Before disclosing any personal health information under this agreement, CRICH, the GOVERNING COUNCIL and ICES shall exercise due caution in providing only that personal health information that is determined to be necessary for the purpose set out in Article 3.1.
- 5.3 ICES, in requesting personal information under this agreement, warrants and represents that the personal information is necessary for the purposes set out in Article 3.1.
- 5.4 ICES agrees to the following precautions and safeguards in handling confidential personal information and personal health information:
  - 5.4.1 ICES will give access to personal health information in a form in which the individual to whom it relates can be identified only to the following persons: Mr. Don DeBoer, Director, Data Management, Mr. Nelson Chong, Health Data Administrator, and Mr. Nicholas Gnidziejko, Health Data Administrator.
  - 5.4.2 ICES will keep the personal health information in a physically secure location to which access is given only to the persons mentioned in Section 5.4.1, above.
  - 5.4.3 Identifying numbers on linked OHC RHS Database will be encrypted immediately after the data are first read, and all working files will have only the encrypted number on them.
- 5.4.4 The data from CRICH, the GOVERNING COUNCIL and MOHLTC with identifying information about an individual will be copied by ICES to electronic media and stored separately in a locked safe in a room with security locks. The original media will be returned to the source or destroyed.
  - 5.4.5 ICES linked working files will not contain identifying information about an individual.
  - 5.4.6 Other than the individuals named in Article 5.4.1, the staff in ICES Information Systems, the members of ICES' Programming and Biostatistics team and ICES Scientists will be accessing the working files only in an anonymized form and will be producing analyses required for reports from such files.





5.4.7 All personnel of ICES shall sign a confidentiality agreement to ensure that they do not disclose personal health information to any other person. In so doing, each person working for ICES acknowledges that the disclosure of personal health information is grounds for immediate dismissal or termination.

5.4.8 In accordance with its privacy policy, ICES will only present aggregated data in its reports so as to prevent the indirect identification of individuals.

This will not preclude the presentation of separate First Nations, Inuit, and/or Métis results. Information in the cells will be suppressed when they contain five (5) observations or less. Information in sparse cells may be combined with other cells to avoid cell counts of five (5) observations or less.

- 5.5 Where a person specified in Article 5.4 .1 no longer has access to identifying information, ICES shall notify CRICH and the GOVERNING COUNCIL of the substitute for that person.
- 5.6 ICES will not contact any individual to whom personal health information relates, directly or indirectly.
- 5.7 ICES will ensure that no information regarding the cohort of First Nations people in Hamilton and Métis and Inuit people in Ottawa will be used or disclosed to any other party without the prior written authority of the GOVERNING COUNCIL except to ICES employees identified in Article 5.4.1 who are responsible for encrypting the identifying numbers, doing linkages and storing, retrieving or destroying the data.
- 5.8 ICES will notify CRIHC and the GOVERNING COUNCIL as soon as it has become aware of a breach of the terms and conditions set out in this agreement and ICES will advise CRICH and the GOVERNING COUNCIL of the steps taken to correct any such default and to prevent any recurrence.

## *6.0 FINANCIAL ARRANGEMENTS*

6.1 Each party shall bear its own cost of implementing this agreement.

## *7.0 AMENDMENTS*

7.1 This agreement may be amended if the parties agree to such amendments in writing. Any amendments so made shall be consistent with the requirements of the Personal Health Information Protection Act and the CIHR Guidelines for Research with Aboriginal Peoples and shall not be contrary to any laws regarding confidentiality of health information.

## *9.0 TERMS, COMMENCEMENT AND TERMINATION OF AGREEMENT*

9.1 This agreement shall take effect on the date set out on page 1.

9.2 This agreement shall continue in effect for as long as the DATA CUSTODIAN provides data

identified in this agreement, unless there is an amendment or termination, subject to Article 10.1.

- 9.3 CRICH and the GOVERNING COUNCIL may cease disclosing any one or more data elements, without cause, by giving ICES notice in accordance with Article 11.
- 9.4 If CRICH and the GOVERNING COUNCIL cease disclosing of personal information under Article 9.3, the entire agreement is not terminated but continues with respect to the remaining data elements which CRICH and the GOVERNING COUNCIL are willing to continue to disclose.
- 9.5 This agreement may be terminated by either party without cause on at least three months notice and on breach by the other party immediately on notice.
- 9.6 This agreement may be amended or terminated on mutual agreement by the parties.
- 9.7 On termination the CRICH and the GOVERNING COUNCIL shall cease disclosing data and ICES shall cease using data.
- 9.8 On termination, ICES shall destroy all the data and all copies immediately, in accordance with ICES procedures.

#### *10.0 SURVIVAL OF OBLIGATIONS*

10.1 Terms and conditions relating to:

- (a) use and destruction of the information
- (b) confidentiality; and
- (c) indemnification shall survive the termination of this agreement.

#### *11.0 NOTICE*

- 11.1 Notice of intention to terminate shall be given in writing to the other party at least three months before the date on which this agreement, or any part of this agreement, as the case may be, is to be terminated.
- 11.2 Notice shall be deemed to have been sufficiently given seventy-two hours after it has been mailed, postage prepaid, or on the date of receipt where the notice has been delivered by hand or by facsimile transmission.
- 11.3 Any notice or other communication required or permitted to be given by either party to the other shall be sent to the following addresses:

**If for ICES:**

Dr. David A. Henry  
Chief Executive Officer  
G Wing, Room 106,  
2075 Bayview Avenue,  
Toronto, ON M4N 3M5  
Phone: 416-480-4297





## DATA SHARING AGREEMENT

If for the **GOVERNING COUNCIL:**

Sylvia Maracle  
Executive Director  
Ontario Federation of Indian Friendship Centres 219 Front St.  
Toronto, ON  
M5A 1E8

Connie Siedule  
Health Director  
Tungasuuvingat Inuit  
604 Laurier Ave. West  
Ottawa, ON K1R 6L1

Donna Lyons  
Health Director  
Métis Nation of Ontario  
500 Old St. Patrick Street, Unit #3  
Ottawa, ON  
K1N 9G4

Cora Lee McGuire-Cyrette  
Executive Director  
Ontario Native Women's Association  
212 East Miles Street  
Thunder Bay, Ontario P7C 1J6

AND

If for **CRICH**

Janet Smylie  
Research Scientist  
Centre for Research on Inner City Health 70 Richmond St.  
Toronto, ON  
M5C 1N8

### 12.0 INDEMNIFICATION

12.1 ICES shall indemnify and save harmless the GOVERNING COUNCIL and CRICH and the GOVERNING COUNCIL and CRICH's Custodian's directors, officers, employees, independent contractors, subcontractors, agents, and assigns from all costs, losses, damages, judgments, claims, demands, suits, actions, causes of action, contracts, or other proceedings of any kind or nature based on or attributable to any disclosure of personal health information to whom it relates can be identified by ICES or its directors, officers, employees, independent contractors, subcontractors, agents or assigns in contravention of this agreement. This provision survives the termination of this agreement.



12.2 CRICH and the GOVERNING COUNCIL shall indemnify and save harmless ICES and ICES' directors, officers, employees, independent contractors, subcontractors, agents, and assigns from all cost, losses, damages, judgments, claims, demands, suits, actions, causes of action, contracts, or other proceedings of any kind or nature based on or attributable to any inaccuracy of the information provided by CRICH and the GOVERNING COUNCIL to ICES under this agreement. This provision survives the termination of this agreement.

**IN WITNESS WHEREOF THE PARTIES** hereto have executed this Agreement:

**ONTARIO FEDERATION OF INDIAN FRIENDSHIP CENTRES SYLVIA MARACLE**

Per: \_\_\_\_\_

Authorized Signing Officer

Witness

\_\_\_\_\_

Print Authorized Signing Officer Name

Date

**ONTARIO NATIVE WOMEN'S ASSOCIATION CORA LEE MCQUIRE**

Per: \_\_\_\_\_

Authorized Signing Officer

Witness

\_\_\_\_\_

Print Authorized Signing Officer Name

Date

**TUNGASUVVINGAT INUIT  
MORGAN HARE**

Per: \_\_\_\_\_

Authorized Signing Officer

Witness

Per: \_\_\_\_\_

Print Authorized Signing Officer Name

Date

**MÉTIS NATION OF ONTARIO  
DOUG WILSON**

Print Authorized Signing Officer Name

Date

Per: \_\_\_\_\_

Authorized Signing Officer

Witness

Per: \_\_\_\_\_

Print Authorized Signing Officer Name

Date





**CENTRE FOR RESEARCH ON INNER CITY HEALTH/ ST. MICHAEL'S HOSPITAL  
DR. ARTHUR S. SLUTSKY**

Per: \_\_\_\_\_  
Authorized Signing Officer                      Witness

Per: \_\_\_\_\_  
Print Authorized Signing Officer Name      Date

**INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES DR. DAVID A HENRY**

Per: \_\_\_\_\_  
David A. Henry                                      Witness  
Chief Executive Officer

\_\_\_\_\_  
Date

**Schedule A: Variables List**

Variables lists will be attached before data is transferred