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April 8, 2010

Joe Gallagher  
Chief Executive Officer  
First Nations Health Society  
1205 – 100 Park Royal S  
W Vancouver BC V7T 1A2

Dear Joe Gallagher:

Please find enclosed the First Nations in British Columbia Tripartite Data Quality and Sharing Agreement. Please sign on page eight of this Agreement.

Once signed, you could mail this Agreement to Yousuf Ali at Health Canada in Vancouver or return it to our office. If you choose to return the signed copy back to us, we would then send it to Yousuf Ali to sign.

Thank you.

Sincerely,

Robert Hart  
Director

Enclosures



**FIRST NATIONS IN B.C. TRIPARTITE DATA QUALITY AND SHARING  
AGREEMENT**

This Agreement is dated for reference April 16, 2010

BETWEEN:

**THE FIRST NATIONS HEALTH COUNCIL** as represented by the  
FIRST NATIONS HEALTH SOCIETY ("FNHS"), a society incorporated  
pursuant to the *Society Act* of British Columbia with an incorporation number S  
0042755

("FNHS")

AND:

**HER MAJESTY THE QUEEN IN RIGHT OF CANADA**, as represented by  
the Minister of Health

("Canada")

AND:

**HER MAJESTY THE QUEEN IN RIGHT OF THE PROVINCE OF  
BRITISH COLUMBIA** as represented by the Minister of Healthy Living and  
Sport and the Minister of Health Services ("MoHS")

("B.C.")

(Jointly "the Parties")

WHEREAS:

- A. The First Nations Leadership Council (FNLC), which is made up of representatives of the First Nations Summit, the British Columbia Assembly of First Nations and the Union of British Columbia Indian Chiefs, established the First Nations Health Council to implement the Tripartite First Nations Health Plan on behalf of B.C. First Nations. The First Nations Health Council incorporated the First Nations Health Society (FNHS).
- B. On November 27, 2006, the FNLC and B.C. signed the Transformative Change Accord: First Nations Health Plan in which they agreed, among other things, that (1) the Provincial Health Officer will issue reports on Aboriginal health in British Columbia every five years, with interim updates every two years; and (2) the tripartite data sharing agreement entered into on February 25, 2002 among B.C., Canada (as represented by Health Canada's First Nations and Inuit Health Branch) and the First Nations Summit (operating through its then First Nations Chiefs' Health Committee Department), will be renewed to ensure federally and provincially held information on First Nations located in British Columbia ("First Nations in B.C.") is shared.
- C. On June 11, 2007, FNLC, Canada and B.C. signed the Tripartite First Nations Health Plan ("TFNHP") to improve the health and well-being of First Nations in B.C. through

measures that support the full involvement of First Nations in B.C. in decision-making regarding their health.

- D. FNLC, Canada and B.C. have agreed in the TFNHP that their priorities are: governance, relationships and accountability; health promotion and disease and injury prevention; health services; and performance tracking.
- E. FNLC, Canada and B.C. have agreed in the TFNHP to work together to develop such First Nations Data as is desirable and necessary to monitor and report on the health status of First Nations to improve health services for First Nations in B.C..
- F. FNLC, Canada and B.C. have also agreed in the TFNHP to collaboratively increase the involvement of First Nations in B.C. in decision making concerning their First Nations Data and health services, through innovations in governance.
- G. FNLC, Canada and B.C. have further agreed in the TFNHP to cooperate in developing the capacity of First Nations in B.C. in the area of health information governance, so as to improve First Nations Data access and promote meaningful research for the benefit of First Nations in B.C..
- H. Indian and Northern Affairs Canada (INAC) and B.C. will enter into a Memorandum of Understanding (the "MOU") to share information to authorize the creation of the First Nations Client File.

NOW THEREFORE the Parties, in consideration of the terms and conditions, contained herein, agree as follows:

**Article 1. Definitions**

1.1 Capitalized terms used in this Agreement have the following meanings:

- a) "**Annex**" means a document that sets out Initiatives or other programs or activities that the Parties have agreed to approve or undertake in connection with this Agreement and includes Annexes developed in respect of the priority areas of interest listed in Annex 1 appended to this Agreement and any further Annexes developed and approved by the Parties in accordance with Schedule "A".
- b) "**Data Access Request**" means a request received by the Data Quality and Sharing Committee and subsequently by the Data Steward for access to FNCF Data for the purposes of an Annex or Initiative.
- c) "**Data Quality and Sharing Committee**" means the committee established in accordance with Article 6.2 and Schedule A and Schedule B of this Agreement.

- d) **“Data Steward”** means the agency appointed by the Parties from time to time to have custody and control of the First Nations Client File. The Data Steward’s role in controlling access to Personal Information will be in accordance with Article 6.4, Article 7 and Schedule B of this Agreement.
- e) **“First Nations Client File”** or **“FNCF”** means the data file containing the personal information needed to identify First Nations clients, established cooperatively and which the Parties agree is the best method of access to accurate health information about the identifiable majority of First Nations clients residing in British Columbia, who are registered Indians and their entitled children. The First Nations Client File will be created by means of an memorandum of understanding (MOU) between the MoHS and Indian and Northern Affairs Canada authorizing and governing disclosure of information contained in the Indian Registry to the MoHS. The First Nations Client File will be used in a process of record matching involving MoHS administrative data on health, or B.C. Vital Statistics Agency data on vital events, or other research data, to produce FNCF Data.
- f) **“FNCF Data”** means data generated in response to approved research requests by the Data Steward, through use of the First Nations Client File to perform linkages to B.C. Provincial databases and may contain Personal Information.
- g) **“First Nations Data”** means data regarding the health and demographic characteristics of the First Nations population in the Province of British Columbia, including the socio-economic determinants of health, and may contain personal information.
- h) **“First Nations Centre(s) of Excellence”** means a B.C. First Nations governed organization(s), supported by B.C. First Nations to provide leadership, advocacy, technical expertise and experience in the development of First Nations Health Governance, over data and research.
- i) **“First Nations Health Governance”** means a governance structure whereby First Nations participate in the design and delivery of health services to their people to ensure such services are reflective of their needs.
- j) **“First Nations Health Information Governance”** is a component of First Nations Health Governance and refers to a structure, process and protocols by which First Nations in B.C. have access to First Nations Data and are influentially involved in decision-making regarding the culturally appropriate and respectful collection, use, disclosure and stewardship of that information in recognition of the principle that such information is integral to First Nations policy, funding and health outcomes.
- k) **“Fiscal Year”** means the period commencing on April 1 of any year and terminating on March 31 of the immediately following year.

- l) **"Initiative"** means a specific project, research, program or study undertaken by any person, organization or agency for the purpose of increasing knowledge about and ameliorating the health conditions of First Nations in B.C. communities.
- m) **"Personal Information"** means personal information as defined in the *Freedom of Information and Protection of Privacy Act* [RSBC 1996], c. 165, and all amendments thereto.
- n) **"Project Approval Form"** means a document submitted for review that describes a proposed Initiative under an Annex to this Agreement.

**Article 2. Term, Modification and Renewal**

- 2.1 The term of this Agreement begins **April 16, 2010** and will expire **April 15, 2015** unless renewed in accordance with the terms of this Agreement. At the end of the term this Agreement will be automatically extended for an additional one-year term unless a Party has notified the other Parties in writing of its intention to terminate the Agreement at least two months prior to the expiration of the term.
- 2.2 This Agreement may only be amended by written agreement of the Parties. The addition of further Annexes or Schedules to the Agreement constitute amendments to the Agreement.
- 2.3 The Parties shall review this Agreement annually and identify any mutually required amendments.

**Article 3. Purpose**

- 3.1 The purposes of this Agreement are to:
  - a) Establish a framework for the Parties to: (i) continually improve the quality and availability of First Nations Data; (ii) facilitate the sharing of FNCF Data in response to research requests approved in accordance with this Agreement; and (iii) to ensure that FNCF Data is appropriately compiled, used and shared by the Parties in accordance with the principles set out in this Agreement and applicable legislation.
  - b) Create a process for the Parties to develop, promote, and act upon Initiatives, and to facilitate and control access to FNCF Data for the purposes of such Initiatives or other programs or activities.
  - c) Commit the Parties to work cooperatively toward the development of systems and protocols empowering First Nations to assume stewardship over the use of

First Nations Data, and promote the accessibility of First Nations Data and research.

- d) Create new data sets to enable First Nations in B.C. to monitor the health of First Nations and the success of programs and services provided in First Nations communities in British Columbia.
- e) Recognize First Nations Health Information Governance and ensure that its principles are respected in all circumstances related to the use, collection and dissemination of First Nations Data, and use of the First Nations Client File.
- f) Commit the Parties to working together to develop the capacity of First Nations in B.C. to assume eventual custody, control and management of First Nations Data.

**Article 4. Guiding Principles**

- 4.1 The Parties will undertake their obligations under this Agreement in keeping with the guiding principles set out in Schedule A to this Agreement.
- 4.2 The Parties support the principles of First Nations Health Governance and First Nations Health Information Governance as set out in the TFNHP (pp 2,3).

**Article 5. Objectives & Deliverables**

- 5.1 The Parties agree to work together in good faith to achieve the following:
  - a) Support or directly undertake Initiatives that will improve the quality and/or interpretation and use of First Nations Data, including in respect of the Priority Areas of Interest identified in the attached Annex 1.
  - b) Achieve the goals, objectives or activities identified and agreed to by the Parties and set out in the Annexes to this Agreement, as amended, supplemented or replaced from time to time.
  - c) Adopt and implement the process for: i) reviewing proposed Initiatives, as set out in Schedule B to this Agreement; and (ii) reviewing Data Access Requests, in collaboration with the Data Steward.
  - d) Oversee the development of First Nations Data in respect of the following seven performance indicators identified in the TFNHP:
    - increased life expectancy
    - mortality rates (due to all causes)
    - Status Indian youth suicide rates

- infant mortality rates
- diabetes rates
- childhood obesity (develop baseline and ongoing mechanism for collecting data)
- practising, certified First Nations health care professionals (develop baseline and ongoing mechanism for collecting data)

and establish other key indicators.

- e) Develop a plan to support and develop the capacity and self-determination of First Nations in B.C. to (i) manage the collection, use and disclosure of First Nations Data, and (ii) enhance the ability of First Nations in B.C. to conduct health research.
- f) Develop and implement a program(s) for the collection of information to assist in the development of First Nations health policy and program planning, as well as to monitor health outcomes in First Nations communities.
- g) Develop and assist other government agencies, government ministries and government departments to develop comparable data sets for non-status First Nations in B.C..

#### **Article 6. Management and Administration**

6.1 The Parties are responsible for providing overall policy direction with respect to the implementation of this Agreement and any decisions made pursuant to it.

- a) The Data Steward's responsibilities are to create the First Nations Client File, as authorized in the MOU, and perform linkages with the First Nations Client File to create FNCF Data.
- b) Health Canada's responsibilities are to be a member of the Tripartite Data Quality and Sharing Committee for the purpose of adjudicating FNCF Data requests and releases as set out in Schedule B of this Agreement. Under this Agreement, and for purposes of creation of FNCF data, Health Canada will not collect nor disclose personal information.
- c) Health Canada shall not have any access to records that include personal information as defined under the federal *Privacy Act* in the performance of its responsibilities under this Agreement.
- d) Health Canada shall have no responsibilities with respect to the collection, use and disclosure of personal information as defined under the federal *Privacy Act* which is necessary for the other Parties to comply with this Agreement and fulfill their obligations under this Agreement.
- e) Health Canada shall have no control over the responsibilities of the Data Steward that could result in Health Canada having access and control over the First Nations Client File or over personal information as defined under the federal *Privacy Act*.



- 6.2 Upon the execution of this Agreement, the Parties will cause the Data Quality and Sharing Committee to be constituted in accordance with Schedule B to this Agreement.
- 6.3 The Parties initially designate the British Columbia Ministry of Health Services as Data Steward, which designation may be amended from time to time or revoked at any time, by the agreement of the Parties in writing.
- 6.4 All requests for linkages with the First Nations Client File and release of FNCF Data will be overseen by the Data Quality and Sharing Committee for purposes of adjudication; and in conjunction with the Data Steward for compliance to privacy legislation as per Article 7 of this Agreement.

**Article 7. Applicable Laws**

The Parties acknowledge and agree that the data sharing initiatives and other activities contemplated in and by this Agreement are subject to the laws of the Province of British Columbia and the federal laws of Canada, including, without limitation, obligations of privacy arising under, as applicable, the British Columbia *Freedom of Information and Protection of Privacy Act*, British Columbia *Document Disposal Act*, the British Columbia *Personal Information Protection Act*.

**Article 8. General**

- 8.1 The Annexes and Schedules to this Agreement will be incorporated into and form part of this Agreement. In the event of any conflict between the text of the Agreement and the Annexes and Schedules, the Agreement will govern to the extent of any inconsistency.
- 8.2 The Parties acknowledge and agree that they may need to enter into further separate agreements in order to implement specific commitments made in this framework Agreement.
- 8.3 Any notice or other writing that is required or permitted to be given under this Agreement shall be sufficiently given if delivered or faxed to the Party to whom it is given, or, if mailed, by prepaid registered mail addressed to such Party at:


To: the First Nations Health Society  
Attention: Chief Executive Officer  
Suite 1205-100 Park Royal South  
West Vancouver, B.C. V7T 1A2  
Facsimile: 604-913-2081

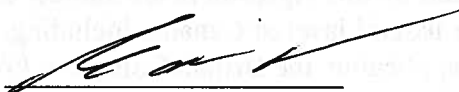
To: The Government of the Province of British Columbia  
Attention: Assistant Deputy Minister, Population and Public Health  
Ministry of Healthy Living and Sport  
4-2, 1515 Blanshard St, Victoria B.C. V8W 3C8  
Facsimile: 250-952-1570


To: The Government of Canada  
Attention: Regional Director  
First Nations and Inuit Health, B.C. Region  
757 Hastings St West, Vancouver B.C. V6C 3E6  
Facsimile:604-666-6024

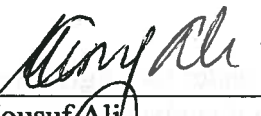
IN WITNESS WHEREOF this AGREEMENT has been executed on behalf of the First Nations Leadership Council by the Chief Executive Officer of the First Nations Health Society for the First Nations Health Council; and on behalf of Canada by the British Columbia Regional Director of the First Nations and Inuit Health, B.C. Regions and Programs Branch; and on behalf of British Columbia by the Assistant Deputy Ministers of Health Services and Healthy Living and Sport;

**PARTIES:**

  
\_\_\_\_\_  
Andrew Hazlewood  
Assistant Deputy Minister  
Province of British Columbia  
Ministry of Healthy Living and Sport

  
\_\_\_\_\_  
Elaine McKnight  
Assistant Deputy Minister  
Province of British Columbia  
Ministry of Health Services

  
\_\_\_\_\_  
Joe Gallagher  
Chief Executive Officer  
First Nations Health Society,  
operating as the First Nations Health Council

  
\_\_\_\_\_  
Yousuf Ali  
Regional Director  
First Nations Inuit Health, B.C. Regions and Programs Branch  
Health Canada

Date: Originally signed  
Expiration:

## ANNEX 1

### Priority Areas of Interest

All Parties have identified a number of common priority issues, and acknowledged the benefit of collaboration in addressing those issues. The Parties will draw on existing and new data sets, held or administered by British Columbia or Canada to support:

1. Continuation of the annual vital statistics report on birth and mortality related statistics for First Nations.
2. Identification of First Nations populations living on and off reserve, regardless of registration status, in order to better categorize health data as on or off reserve.
3. Assessment of the epidemiology of diabetes mellitus and other chronic diseases, including prevalence and complications in the First Nations people who are located in B.C..
4. Assessment of the epidemiology in First Nations of communicable diseases that are reportable under the Provincial *Health Act* including, but not limited to, HIV, TB and vaccine preventable diseases.
5. Assessment of the epidemiology of cancers in First Nations in B.C. communities, including, but not limited to, lung, breast, cervix, colon, and prostate cancers.
6. Assessment of the epidemiology in First Nations of injury related morbidity and mortality (including types of injury patterns by age group and region), including, but not limited to, motor vehicle accidents, accidental poisoning, falls, and suicide.
7. Establishment of baseline data with regard to First Nations health status so as to enable the measurement of progress by the Parties, in addressing First Nations health. Reviewing the health indicators monitored by the Provincial Health Officer, and determining what additional indicators may be needed to assess population health status of First Nations.
8. Assessment of health care service and program utilization patterns and trends for First Nations in all of Canada, including federal, provincial and regional patterns and trends.
9. Establishment of baseline data and ongoing mechanisms for collecting relevant data with respect to new indicators including, but not limited to, childhood obesity and the number of practising First Nations in B.C. certified health care professionals.
10. Collection of information about congenital anomalies and genetic conditions in First Nations.
11. Collection of information required for the First Nations in B.C. Regional Longitudinal Health Survey.
12. Collection of information required for First Nations in B.C.' community health plans.
13. Other projects as identified and agreed upon by the Parties.

## **SCHEDULE A**

### **Guiding Principles**

The Parties agree that the implementation of the Agreement and the activities contemplated by it, will be undertaken in a manner that is consistent with and in furtherance of the following principles, enshrined in the TFNHP:

#### **Respect and recognition:**

- The Parties acknowledge and respect established and evolving jurisdictional and fiduciary relationships and responsibilities, and will seek to remove impediments to progress by establishing effective working relationships.
- This Agreement recognizes that First Nations Health Information Governance must be developed in accordance with the principles of First Nations Health Governance.
- The Parties agree that First Nations will have access to their First Nations Data without cost.
- This Agreement establishes cooperation in developing the capacity for First Nations in the area of health information governance, which will lead to improved data access and promote meaningful research for First Nations and does not represent an obstacle to a transition to First Nations stewardship
- First Nations local community and regional protocols will be respected and active participation by communities will be encouraged.

#### **Commitment to action:**

- The Parties recognize that the current capacity of First Nations does not permit them to have complete ownership over federally and provincially held databases containing information and data about First Nations populations. The Parties will work towards developing a capacity for First Nations in relation to First Nations data.
- The Parties will strive to ensure the results of First Nations health research are accessible and meaningful to First Nations.
- First Nations Centre(s) of Excellence will be established, to create capacity to assume the role of Data Steward and to develop First Nations privacy legislation.

#### **Nurture the relationship:**

- Each Party agrees to pursue enhanced collaboration, coordination and cooperation and commits to seeking opportunities for complementary engagement.
- The Parties respect the need for, and commit to, the evaluation of progress under this Agreement. The actions of the Parties will be based on reciprocal accountability; each Party will be responsible to the other Parties for obligations and commitments under this Agreement.

#### **Transparency:**

First Nations' Personal Information will be collected, used and disclosed appropriately according to applicable legislation and for the agreed upon purposes outlined in the Annexes to this Agreement. The Data Steward will ensure that all Initiatives approved by the Data Committee will be conducted in compliance with applicable legislation.

## **SCHEDULE B**

### **TERMS OF REFERENCE**

#### **The Data Quality and Sharing Committee (“Data Committee”)**

Unless otherwise stated, capitalized terms in this Schedule shall have the meaning set out in the Agreement.

#### **Membership**

1.1 The Data Committee is comprised of:

- a) Three Co-chairs (one Co-chair appointed by each Party),
- b) Three equal, voting members (one member appointed by each Party), and
- c) Such non-voting members appointed by the Parties as the Data Committee or the Parties may deem desirable or necessary to achieve the purposes of this Agreement.

Upon executing the Agreement, each Party will appoint one Co-chair and one voting member to the Data Committee, and advise the Parties of the names and contact information of each such representative. A Party may at any time, and from time to time, replace its appointees to the Data Committee by written notice to the other Parties.

#### **Duties of the Data Committee**

The duties of the Data Committee may be expanded or amended by agreement amongst the Parties.

1.2 The Data Committee will be responsible to:

- a) Administer and oversee the implementation of the Agreement, including by:
  - (i.) Developing standards and procedures required for the overall administration and coordination of the Agreement and of its Annexes;
  - (ii.) Approving, as required, the establishment and mandate of appropriate sub-committees to meet the objectives of the Agreement;
- b) Oversee the processing of Data Access Requests, including by:
  - (i) Developing a process for receiving and granting Data Access Requests which mandates input from and approval by the Parties and enables the Data Steward to determine additional conditions for access, as authorized

- by legislation;
- (ii) Developing criteria upon which Data Access Requests will be evaluated and granted;
  - (iii) Determining, by consensus, a response to each Data Access Request;
  - (iv) Developing a monitoring and reporting system, to report to the Parties on all Data Access Requests relating to use of the First Nations Client File;
  - (v) Notifying principal researchers or other Data Access Request applicants in writing of the Data Committee's consensus decision regarding their Data Access Requests;
  - (vi) Supporting the ability of First Nations communities to access FNCF Data, by assisting them in understanding the Data Access Request process;
  - (vii) In all of the above, the Data Committee will adhere to applicable legislation as per Article 7 of this agreement.
  - (viii) The data committee will acknowledge traditional laws and practices with regard to the protection and use of First Nations information and the context in which it is used.
- c) Recommend to the Parties a Data Steward to have responsibility for the First Nations Client File and any such further data files as agreed to by the Parties which may be created and which contain only First Nations Data;
  - d) Make an annual report to the Parties on progress toward implementing First Nations Health Information Governance capacity within First Nations in accordance with section 5.1(f) of the Agreement;
  - e) Prepare a record of decisions for each Data Committee meeting, to be circulated to members and shared with the Data Steward;
  - f) Inform related and subsidiary agencies of the Parties to enable the development of sub-agreements which authorize access to data needed to fulfill the purposes of this Agreement.
  - g) Carry out other duties, powers or functions specified elsewhere in this Agreement or, such as may be assigned to the Data Committee by the Parties to this Agreement from time to time.

### **Meetings and Decision-Making**

- 1.3 The following will apply to the exercise of the powers, duties, and functions of the Data Committee:
- a) At least one voting member appointed by each of the Parties must be present before a meeting of the Data Committee may proceed. Committee meetings may be attended in person, by teleconference or by videoconference.
  - b) The decisions of the Data Committee require the unanimous approval of those voting members present to be effective.
  - c) If the Data Committee is unable to reach a unanimous decision on a matter it will be referred to the Parties for consideration and their decision will be final.
  - d) The decisions of the Data Committee will be valid only if they are in writing and signed by the voting representatives appointed by the Parties. This will include written approval conveyed electronically.
  - e) Data Committee meetings will be held as required, but in no case less frequently than once each quarter of the calendar year.

### **Implementation of Annexes and Initiatives**

- 1.4 The Parties may decide to develop Annexes. Each Annex would include:
- a) a description of the Initiative, including the purpose and objectives of the Initiative described in the Annex, and how it supports data quality and sharing;
  - b) criteria to define eligible activities and projects that are within the scope of the Annex;
  - c) an explanation of how data quality and sharing activities and projects will be undertaken and monitored;
  - d) an approval process that includes assurance of direct input from the Parties with respect to all Initiatives, including a research proposal associated with a Data Access Request (which pertains to the First Nations Client File);
  - e) a description of how the Annex will benefit First Nations in B.C..

- 1.5 The Parties will jointly develop a process for receiving and assessing Initiatives submitted for Data Committee review under each Annex, which will include:
- a) The principal researcher's description of how the proposed Initiative satisfies the criteria set out in subsection 1.4(b), and aligns with the stated purpose and objectives of the Annex, under which the proposed Initiative is to be reviewed;
  - b) A description of the consultation and development processes undertaken prior to submission of a Data Access Request, and the mechanisms for ongoing First Nations community participation appropriate to the Initiative;
  - c) a description of issues to consider when developing communications:
    - (i) to the First Nations in B.C., other stakeholders, and the public about the Initiative described in the Annex; and
    - (ii) about the findings and implications of the Initiative contained in the Annex for the health status of the First Nations in B.C. population.

#### **Approvals**

- 1.6 Each activity or project reviewed by the Data Committee under an Annex will be described in an appropriate Project Approval Form, as determined by the Committee.
- 1.7 Copies of signed Project Approval Forms will be compiled and maintained by the Data Committee.

#### **Communications**

- 1.8 An annual report on the activities carried out under this Agreement will be developed by the Data Committee, for approval by the Parties, and published within six (6) months of the Fiscal Year end.