



# Tripartite Data Quality and Sharing Agreement

## 2012 Annual Report on Progress





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# Tripartite Data Quality and Sharing Agreement

## 2012 Annual Report on Progress

### Purpose

The Annual Report on Progress provides a summary on the commitments and principles laid out in the Tripartite Data Quality and Sharing Agreement (TDQSA), as well as the progress towards implementing First Nations Health Information Governance capacity within First Nations communities, as called for in the TDQSA<sup>1,2</sup>

<sup>1</sup> Schedule B of the TDQSA states that the Data Quality and Sharing Committee (now the Tripartite Data and Information Planning Committee) will produce "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 Fiscal Year end." TDQSA, Schedule B, section 1.8

<sup>2</sup> Schedule B of the TDQSA states that the Data Quality and Sharing Committee (now the Tripartite Data and Information Planning Committee) will be responsible to "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" TDQSA, Schedule B, Section 1.2(d)





# Tripartite Data Quality and Sharing Agreement

## 2012 Annual Report on Progress

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# Glossary

**Annex:** A document that sets out Initiatives or other programs or activities that the Tripartite Partners have agreed to approve or undertake in connection with the TDQSA and includes Annexes developed in respect of the priority areas of interest listed in Annex 1 of the TDQSA and any further Annexes developed and approved by the Parties in accordance with Schedule 'A' of the TDQSA.

**Data Access Request (DAR):** A request received by the Tripartite Data and Information Planning Committee and subsequently the First Nations Client File (FNCF) Data Steward for linkage to the FNCF.

**First Nations Client File (FNCF):** The First Nations Client file is a cohort of BC Resident First Nations people registered under the Indian Act, and their unregistered descendants for whom entitlement-to-register can be determined, linkable on their BC Ministry of Health Personal Health Number. The First Nations Client File is the product of a record linkage between an extract of the Aboriginal Affairs and Northern Development Canada (AANDC) Indian Registry and the BC Ministry of Health Client Registry.

The Tripartite Partners agree the FNCF is the best method of access to accurate health information about the identifiable majority of First Nations clients residing in BC. The FNCF is used in a process of record matching to produce FNCF Data.

The development of the FNCF was made possible by means of a Memorandum of Understanding (MOU) between the BC Ministry of Health and AANDC authorizing the disclosure of information contained in the Indian Registry to the Ministry of Health on an annual basis. The First Nations Client File is updated

incrementally at the beginning of each calendar year using a fresh extract from the BC Client Registry and the AANDC Indian Registry. The first version of the FNCF was created in November 2011.

**FNCF Data:** Data generated in response to approved requests by the Tripartite Data and Information Planning Committee and Data Steward through linkages of the FNCF to other data sources and may contain Personal Information.

**FNCF Data Steward:** The agency appointed by the Tripartite Partners to have custody and control of the FNCF. The responsibilities of the Data Steward are to create the FNCF, as authorized in the MOU, and perform linkages with the FNCF to create FNCF Data (Section 6.1.a). At this time, the FNCF is under the stewardship of the BC Ministry of Health (Section 6.3). There are mechanisms for the Tripartite Partners to recommend a different Data Steward for the FNCF (Schedule B, Section 1.2.c).

**First Nations Data:** Data regarding the health and demographic characteristics of the First Nations population in BC, including the socio-economic determinants of health.

**First Nations Health Information Governance:** A structure, process and protocol by which First Nations in BC 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.

**Personal Information:** Personal information as defined in the Freedom of Information and Protection of Privacy Act [RSBC 1996], c.165, and all amendments thereto.

**Tripartite Data and Information Planning (TDIP) Committee:** Originally referred to as the “Data Quality and Sharing Committee” in the TDQSA, this committee’s name changed to the “Tripartite Data and Information Planning” committee in April 2011. The TDIP Committee is responsible for providing overall policy direction under the TDQSA and for the decisions made pursuant to it. To this end, TDIP has developed standards and procedures required for the overall administration and coordination of the TDQSA and its Annexes, and makes recommendations on research activities and access to data to the Data Steward. DARs to the FNCF are approved by consensus among the Tripartite Partner Voting Members of the TDIP Committee (Schedule B, Section 1.2.b (iii) and Schedule B, Section 1.3.b) and ultimately signed-off by the FNCF Data Steward for the purposes of compliance with privacy legislation (Section 6.4).

**Tripartite Data Management Planning Committee (Data Management Committee):** A Tripartite committee, consisting of representatives from each Tripartite Partner organizations, with responsibility for supporting the work of the TDIP committee.

**Tripartite Partners:** The First Nations Health Authority, the Government of Canada (Health Canada First Nations and Inuit Health Branch) and the Government of British Columbia (Ministry of Health) (referred to as the “Parties” in the TDQSA).

**Tripartite Partner Voting Members:** Three members of the TDIP Committee, appointed by each of the respective Tripartite Partners, to vote on decisions related to the approval of FNCF DARs. Decisions require the unanimous approval of each Tripartite Partner Voting Member (Schedule B, Section 1.3.b).



## Background and Purpose of the TDQSA

The TDQSA was signed in April 2010 by the BC Ministry of Health, the First Nations Health Society, now the First Nations Health Authority (FNHA), and Health Canada.

The signing of the TDQSA fulfilled action item number 28 in *The Transformative Change Accord: First Nations Health Plan* (2006). The action item committed the partners to “renew the Tripartite agreement between the Province, Health Canada’s First Nations and Inuit Health Branch and First Nations to ensure federally and provincially held information on First Nations is shared.”

## Progress to Date on Fulfilling the Purposes of the TDQSA

The purposes of the TDQSA are outlined below along with the progress to date in each of these areas.

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### Article 3.1.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 questions approved in accordance with this Agreement; and*

*(iii) to ensure that FNCF is appropriately compiled, used and shared by the Parties in accordance with the principles set out in this Agreement and applicable legislation.*

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To support the implementation of the TDQSA, the Tripartite Partners have created a framework with three key Tripartite structures as well as foundational documents that guide the work of these groups.

The TDIP Committee, the Tripartite Data Management Planning Committee and the TDQSA Secretariat were established to implement the work described in Article 3.1.a:

1. The TDIP Committee has met monthly since the TDQSA agreement was signed in April 2010 to develop the processes, evaluation criteria and policies required to adjudicate FNCF DARs as well as to adjudicate fifteen requests received in 2011 and 2012.

There has been a significant amount of learning while these processes and initial Data Access Requests were reviewed as each DAR brought its own context, questions and implications to the attention of the TDIP Committee members.

The TDIP Committee has developed a work plan to guide and prioritize its work.

2. The TDIP Committee is supported by the Tripartite Data Management Planning Committee. Members of the Data Management Committee provide the detailed and time-intensive support relating to the development of TDIP policies or decisions regarding FNCF DARs.
3. The TDQSA Secretariat, created in January 2012, has been held by a FNHA staff member. The functions of the TDQSA Secretariat are:
  - To facilitate fair and impartial process and decision-making, and consistent and equitable access to information for potential applicants. The Secretariat is the conduit to information, guidance and/or advice to potential FNCF DAR applicants. TDIP Committee members refer all requests for information to the Secretariat.
  - To be a dedicated resource to coordinate the work of the TDIP committee, including preparing synopsis of research proposals and communicating with applicants to seek clarifications requested by the TDIP committee.
  - To conduct an initial review of new DARs to ensure the request is clear and that all necessary information and documentation is submitted.
  - Track the status and progress of each DAR, which, for some internal Tripartite projects, entails being the project manager for FNCF DARs.
  - Document the use, approval and outcome of FNCF decisions for reporting and auditing purposes.
  - Assist in the preparation of policies, procedures and tools that will facilitate the work of the committee, and the use of the FNCF.
  - Assist in the preparation of data sets and any in-house analysis required by FNCF DARs.
  - To be a mechanism for knowledge exchange between the current Data Steward (MOH) and the FNHA so as to facilitate the eventual change in Data Stewardship to the FNHA.

In addition to the Secretariat and Committees, the Tripartite Partners ground their work in foundational FNHA documents such as the 2011 and 2012 Consensus Paper's as well as feedback from community members at Gathering Wisdom for a Shared Journey Forums, and other engagement initiatives.

Finally, as each DAR brings up new questions or issues, the TDIP Committee has been developing a policy document, which is meant to serve as a guide for decision-making. The policy document for example, contains guidance on how to document amendments to approved DARs, how to document secondary data usage, and when e-signatures are permissible. This policy document is a living resource that is updated as the TDIP Committee encounters new questions or situations.

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**Article 3.1.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.*

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Tools have been developed for the purposes of adjudicating FNCF DARs. These include development of:

- Three DAR forms customized for Internal Partners, External Public Health Partners and External Researchers.
- 'General Conditions of use of the FNCF' against which each FNCF DAR is evaluated (see Appendix 3).
- A tracking mechanism, by which each application for access to the FNCF is documented so as to ensure transparency and accountability regarding the use of the FNCF.

Processes have been developed for the purposes of adjudicating FNCF DARs. These include:

- Initial review of draft FNCF DARs by the TDQSA Secretariat.
- Processes for sign-off of FNCF DARs.
- Regular and 'expedited' methods of FNCF DAR sign-off.
- Processes for amendments to already-approved DARs.
- Processes for secondary data usage of data sets created through FNCF DARs.

**Article 3.1.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.*

and

**Article 3.1.f**

*Commit the Parties to working together to develop the capacity of First Nations in BC to assume eventual custody, control and management of First Nations Data.*

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The Ministry of Health is the current Data Steward of the FNCF (Article 6.3).

Through the TDQSA, the Tripartite Partners agreed to assist First Nations in developing the capacity to assume eventual custody, control and management of First Nations Data (Article 3.1.f). It is recognized that when a First Nations Data Steward is established and able to take on the role of Data Steward, the Tripartite Partners can recommend a change in the FNCF Data Steward (Schedule B, Section 1.2 .c).

A work plan for the TDIP Committee was developed in May 2012. One of the work items included was the need to understand and prioritize the policies, safeguards and standards that will need to be in place in order for the FNHA to take over stewardship of the FNCF. This work is ongoing and will be developed over time.

One of the main mechanisms for knowledge exchange is through the TDQSA Secretariat. By working with key MOH data staff, the TDQSA Secretariat can gain knowledge and skills relating to manipulating and analyzing administrative health databases, which over time, will lead to increased capacity. Currently, direct access to and linkages of the FNCF and other key data sources are limited by data access restrictions within MOH as well as for non-MOH staff. More work is required to overcome these limitations in order to continue to develop the necessary training and knowledge exchange between the MOH and the FNHA.

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**Article 3.1.d**

*Create new data sets to enable First Nations in BC to monitor the health of First Nations and the success of programs and services provided in First Nations communities in British Columbia.*

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Fifteen FNCF DARs have been reviewed by the TDIP Committee between the creation of the FNCF in November 2011 and December 2012 (see Appendix 2 for a summary of approved DARs). Each of the approved FNCF DARs generates their own dataset on completion. These datasets are not available for any other purpose other than that described in the original application, however the TDIP Committee has established a policy on secondary data use in order to capitalize on previous work and avoid duplication of effort.

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**Article 3.1.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.*

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The principle of First Nations Health Information Governance is a central tenet of the TDIP Committee, one that the committee has been striving to flesh out as it pertains to accountability, privacy and confidentiality, wisdom from foundational FNHA documents (e.g., the 2011 and 2012 Consensus Paper's) as well as how it relates to the realities of working with administrative health data.

The Tripartite Partners are aware of their accountability to First Nations in BC for the appropriate and responsible use of the FNCF and have highlighted the need to develop clear pathways and mechanisms for insight into FNCF data access decision-making for First Nations.

The Tripartite Partners want to ensure that First Nations are involved in all decision-making regarding use of the FNCF and FNCF data; that the privacy of individuals and communities is protected; that topics of priority interest to First Nations are prioritized; that information from the FNCF be available for First Nations to plan at a community and regional level; and that the FNCF be cautiously and carefully used in an open and transparent way, recognizing the harmful realities of historical research and government surveillance.

The TDIP Committee recognizes that mechanisms for First Nations input into FNCF decision-making need to be developed over time.

Some mechanisms the TDIP Committee has adopted to address the principle of First Nations Health Information Governance include:

- FNHA representatives on both the TDIP and Data Management Committee.

- FNCF DARs decisions are made by consensus.
- TDIP committee members compare each DAR against a set of conditions (see Appendix 3), which have been developed using the feedback and insight of community members from key FNHA documents including the 2011 Consensus Paper. These general conditions of use specify that FNCF DARs should be driven by First Nation priorities, should involve relevant First Nation stakeholders throughout the project, should stimulate action leading to tangibly better services, and should be inclusive of First Nations voices during the interpretation and dissemination of project results.
- The Secretariat role filled by an FNHA staff member.
- In addition, respecting the governance of First Nations communities over their own data along with privacy issues arising from small cell size, the TDIP Committee has not authorized the release of any community-level First Nations Data. In the future, when communities express interest in community-level data for their own health and wellness planning or evaluation efforts, the TDIP Committee hopes to work in partnership with these communities in the analysis. The TDIP Committee hopes to develop these capacities through collaboration with communities over time.



## Progress to Date on the Major Deliverables of the TDQSA

The TDQSA lists seven objectives and deliverables which are provided below, along with a brief description of the results and progress in implementation.

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### Article 5.1.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 Interests.*

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Twelve priority areas of interest were identified in the TDQSA (see Appendix 1 for a complete list).

Although the priority areas of interest are not deliverables or meant to be a restrictive or exhaustive list, work has been undertaken to move several of these areas forward.

1. **Vital Statistics:** The development of a Vital Statistics Report is of interest and on the workplan of the TDIP committee, but of lower priority.
2. **On/Off-reserve (Home/Away from home) categorization:** See Section 4.0 below for an explanation of the limitations regarding work on this priority topic.
3. **Diabetes and Chronic diseases:** Chronic disease prevalence and incidence are being examined as part of a joint report on Aboriginal Women's health and wellbeing in BC by the Provincial Health Officer and FNHA, which is currently in development.
4. **Communicable Disease:** The Tripartite Partners are working with the BC Centre for Disease Control to develop a process for communicable disease reporting for the FNHA. Collaborative work is underway to develop new First Nations reports for HIV and TB. A linkage was undertaken between the FNCF and Invasive Pneumococcal Disease (IPD) data to examine IPD among First Nations children. This data was used for evidence-based immunization programming. A province-wide HIV initiative, STOP HIV/AIDS, is using the FNCF to identify the effects of the pilot project on First Nations living with HIV/AIDS.
5. **Cancer:** The Tripartite Partners are working in partnership with the BC Cancer Agency to develop a First Nations cancer report. This project is in its early stages.
6. **Injuries:** The Tripartite Partners are working together with the Tripartite Primary Care and Public Health Strategy Area of the FNHA to develop a FNCF DAR relating to First Nations injury surveillance. This project is in its early stages.

7. **Baseline data:** Work is underway to develop wellness-based indicators for First Nations. This work is ongoing.
8. **Health Care Utilization:** A Health Canada report identifying aggregate health care service and program utilization patterns and trends of First Nations at a national level was informed by FNCF data.
9. **Congenital anomalies and genetic conditions update:** A FNCF DAR is in development in partnership with Perinatal Services BC. This project may include analysis of congenital anomalies and genetic conditions.
10. **The 2008-2010 First Nations Regional Health Survey BC Provincial Report** was publicly released in 2012.
11. **Community Health Plans:** The collection of information required for community health plans is a longer-term priority of the TDIP committee. This work will require more discussion and collaboration with the First Nations Health Directors Association and the newly emerging regional tables.

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#### **Article 5.1.b**

*Achieve the goals, objectives or activities identified and agreed to by the Parties and set out in the Annexes to the TDQSA, as amended, supplemented or replaced from time to time.*

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In the TDQSA it was outlined that the Tripartite Partners were able to develop and collaborate on projects or Initiatives, which would be developed as Annexes.

In addition to the update on priority areas of interest (see “Progress to Date” Article 5.1.a), the TDIP committee has also reviewed and submitted additional DARs to access the FNCF for program planning purposes. These additional uses are outlined in Appendix 2 of this document.

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#### **Article 5.1.c**

*Adopt and implement the process for: i) reviewing proposed Initiatives, as set in Schedule B of the TDQSA; and ii) reviewing DARs, in collaboration with the Data Steward.*

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See “Progress to Date” description for **Article 3.1.b**

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**Article 5.1.d**

*Oversee the development of First Nations Data in respect of the following seven performance indicators 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)*
- Practicing, certified First Nations health care professionals (develop baseline and ongoing mechanism for collecting data)*

*and establish other key indicators, including wellness indicators.*

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In October 2012, the Office of the Provincial Health Officer released an interim update examining progress on the seven performance indicators from the TFNHP.

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**Article 5.1.e**

*Develop a plan to support and develop the capacity and self-determination of First Nations in BC to (i) manage the collection, use and disclosure of First Nations Data, and (ii) enhance the ability of First Nations in BC to conduct health research.*

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See "Progress to Date" description for Article 3.1.c and "Progress to Date" description Article 3.1.e

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**Article 5.1.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.*

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Processes are in place to allow Tripartite Partners to submit FNCF DARs for the purposes of program planning and monitoring health outcomes.

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**Article 5.1.g**

*Develop and assist other government agencies, government ministries and government departments to develop comparable data sets for non-status First Nations in BC.*

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The FNCF only allows for the identification of Status individuals and therefore no non-status health information can be produced using the FNCF.

The Aboriginal Administrative Data Standard is a BC government standard that allows for the collection of non-status information, but has not yet been widely implemented in the health care sector.

## Lessons Learned

The TDIP Committee identified a number of lessons learned in the first two years of implementing the TDQSA including:

- The sharing of health information is complex and is based on a framework of legislation and regulations, judicial rulings, commissioner directives and orders, agreements, policy, best practices, ethics, professional codes/standards and sound judgment. Information sharing arrangements take up a significant amount of each FNCF DAR timeline.
- With each new DAR, new processes may be created and/or revised and new questions arise that require discussion and development of additional policies, tools or processes. Over time these will be refined to improve efficiency and effectiveness and to put in place all the necessary checks and balances to ensure the principles of First Nations Health Information Governance are being respected and practiced.
- With limited time and resources prior to the transition of the First Nations and Inuit Health Branch of Health Canada to the FNHA (took place in July-October 2013), the TDIP Committee has had to balance and prioritize the types of FNCF DARs it reviews. The FNCF is a valuable resource that would benefit health partner organizations, other government departments as well as external researchers however, until the transition takes place, the TDIP Committee decided that it is unable to review or adjudicate external research FNCF DARs.
- Tripartite Partners have recognized the need to educate internal and external partners on the FNCF and the principle of First Nations Health Information Governance. Presentations have been given to First Nations Health Authority staff (Health Actions staff, Regional Health Liaisons), Ministry of Health staff (Data Access Services staff), as well as various Tripartite strategy areas (Maternal Child Health, and Primary Care and Public Health) and external partners (BCCDC staff). Tripartite Partners disseminated information on the TDQSA and FNCF to First Nation Chiefs, proxies and Health Directors at the Gathering Wisdom for a Shared Journey V Forum hosted by the First Nations Health Council May 15-17, 2012. Website content has also been developed, but not yet released publically because of the current focus on internal Tripartite priorities; it will be revisited after transition is completed in October 2013.

## Looking Ahead

As the TDQSA continues to be implemented, the following can be expected in the future:

- The TDIP Committee will review the TQDSA for potential amendments. The TDIP Committee has identified a number of potential enhancements to the TDQSA for future consideration:
  - Update the TDQSA Committee Terms of Reference. The current terms of reference focus on the tasks and responsibilities in setting up the TDQSA;
  - Development of a Terms of Reference for the TDQSA Secretariat; and
  - The second Priority Area of Interest in Annex 1 of the TDQSA “Identification of the First Nations population living on and off reserve, regardless of registration status, in order to better categorize health data as on and off reserve” cannot be completed because the FNCF does not include non-status First Nations. Better categorization of First Nations with respect to Status and residency will require new tools and data standards such as the Aboriginal Administrative Data Standard.
- The development of a succession plan for TDIP resources.
- More data that increases the ability of First Nations communities and Tripartite organizations to monitor health and measure the success of programs and services provided in BC First Nations communities.
- More data on topics set out as priority areas of interest in the TDQSA.
- More knowledge exchange between the MOH and FNHA with respect to Data Stewardship of the FNCF so as to enable the eventual transfer of FNCF Data Stewardship and FNCF Data to the FNHA.

## Conclusion

There has been significant progress in the creation of high quality First Nations health data management with the development of the FNCF. Other successes in the implementation of the TDQSA include creation of: the consensus-based Tripartite Data and Information Planning Committee; Tripartite-approved processes for review of all FNCF DARs; and new data sets. The TDIP Committee seeks to continue its work in articulating and mobilizing the principle of First Nations Health Information Governance. The Tripartite Partners look forward to collaborating together on this important work in the future.



# Appendix 1

## TDQSA Annex 1 Priority Areas of Interest

### Priority Areas of Interest

In addition to First Nations-driven research that looks at First Nations health from a wellness perspective, the tripartite partners have identified a number of additional common priority issues, and acknowledged the benefit of collaboration in addressing those issues. The partners 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 BC.
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 BC 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 practicing First Nations in BC 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 BC Regional Longitudinal Health Survey.
12. Collection of information required for First Nations in BC[s] community health plans.
13. Other projects as identified and agreed upon by the Parties.

## Appendix 2

### Selection of FNCF Data Access Requests Reviewed by the TDIP Committee in 2011/2012

#### Data Access Requests (DARs) Reviewed by TDIP

The TDIP Committee has reviewed fifteen DARs on a variety of topic areas from November 2011 to December 2012. Of these, twelve DARs were approved and three were not approved. An additional seven DARs are in development.

Approved FNCF DARs are summarized in the table below:

Project Title	Description	Purpose of Project
<i>Fetal and Infant Mortality and Serious Neonatal Morbidity among 'Status Indians' in BC</i>	Quantify fetal and infant mortality and newborn illness rate among 'Status Indians' and the general BC population; study what causes of death are responsible for potential differences in fetal and infant death rates; and explore determinants for differential rates of fetal and infant mortality and newborn illness rate among Status women and infants in BC.	Research study
<i>'A Statistical Profile on the Health of First Nations in Canada' – Vital Statistics report</i>	BC Vital Statistics data for national report on First Nations, including natality and mortality indicators (e.g., birth rates, fertility rates, birth weight, mortality rates, leading causes of death, life expectancy, and potential years of life lost).	Program planning

Project Title	Description	Purpose of Project
<i>Seek and Treat to Optimally Prevent HIV/AIDS (STOP HIV/AIDS) Pilot</i>	The STOP HIV/AIDS pilot is aimed at reducing HIV-related morbidity and mortality, reducing the number of new HIV infections, and containing associated health system costs. Monitoring and evaluation of this pilot is critical to determining the impact pilot activities have on these goals. FNCF data will be used to assess the impacts of pilot activities on First Nations people in order to inform further programming to address the HIV epidemic in BC's First Nations population.	Public report / program planning
<i>Nurse-Family Partnership Program</i>	Identify the location of low income, first time mothers under the age of 25 years to structure a public health nurse program.	Program planning
<i>Epidemiology of reportable communicable diseases in BC First Nations</i>	Analysis of communicable disease (CD) trends over time in status First Nations . This data will be used to establish a baseline for CD rates in First Nations in BC and guide public health interventions around CD.	Public report / program planning
<i>Chronic disease update</i>	Chronic disease epidemiology for PHO's Aboriginal Women's Report	Public report
<i>Invasive pneumococcal Disease (IPD) in First Nations children in BC in relation to a potential pneumococcal conjugate vaccine (PCV 13) catch up program for young children</i>	First Nations cases in the IPD Enhanced Surveillance database maintained by the BCCDC were analyzed in order to determine whether BC First Nations children under the age of 59 months experienced higher rates of IPD than non-First Nations children in the same age group and whether they would benefit from a proposed vaccination program aimed at providing a catch up dose of PCV13 to those between 12 and 59 months of age.	Program planning
<i>Consumer product safety issues among Canada's Aboriginal population – an evaluation of injuries and relative risk factors</i>	To describe unintentional injury and risk factors related to consumer product safety among the Aboriginal population in Canada, including First Nations, Métis and Inuit. This work will support the goal of reduction and monitoring of injuries, including their severity and consequences where consumer products are involved.	Contract to PHAC

Project Title	Description	Purpose of Project
<i>Pathways to Child Maltreatment of Aboriginal Children in British Columbia</i>	A panel study to better understand some of the factors that contribute to the over-representation of Aboriginal children in care in BC. Objectives: ascertain the predictors of initial child maltreatment across a range of government service sectors; establish the pathways through various service systems that children and families take on their way to a report of child maltreatment; and compare the pathways of Aboriginal children and families with the pathways of other children and families.	Legislative disclosure
<i>Mental Wellness and Substance Use</i>	Support and inform strategic decision-making of the First Nations and Aboriginal Mental Wellness and Substance Use Plan.	Tripartite Request
<i>A Statistical Profile on the Health of First Nations in Canada – Health Services Utilization</i>	Health services utilization data for First Nations in BC used in a report of the fourth edition of a national report series entitled: <i>A Statistical Profile on the Health of First Nations in Canada</i> . This series is one of FNIHB's regular publications and this report will present information on health services utilization for First Nations in Canada, including hospital separation rates, causes of hospitalizations, and average length of stay. This report will focus on the health conditions that are the most common causes of hospital separations in the First Nations population.	Tripartite Request
<i>TCA:FNHP Indicator update</i>	The purpose of the project is to report on five of the seven relevant indicators identified in the TCA:FNHP that are feasible to report on using administrative data.	Tripartite Request

## Appendix 3

### General conditions for the use of the First Nations Client File

#### Involvement of appropriate community and/or Tripartite Staff

The design and delivery of public health and health care services for First Nations in BC is changing. Since 2005, a new relationship has been evolving between First Nations leadership and provincial and federal governments. The 2006 *Transformative Change Accord: First Nations Health Plan* set out a number of action items intended to facilitate closing the gap in health outcomes between BC First Nations and the general population. At the Gathering Wisdom for a Shared Journey IV Forum in May 2011, 87% of the Chiefs and Proxies in attendance voted in favour of a resolution which created the Seven Directives and established a foundation for BC First Nations the first in Canada to take over health service delivery from the federal government. The signing of the *British Columbia Tripartite Framework Agreement on First Nation Health Governance* in October 2011 set the stage for the creation of a new First Nations Health Authority in BC. In May 2012, 94% of Chiefs and Proxies approved the *Consensus Paper 2012: Navigating the Currents of Change – Transitioning to a New First Nations Health Governance Structure*. The 2012 Consensus Paper mandated transition from the interim First Nations Health Authority into a permanent form and begun planning for the establishment of Regional Offices to support health and wellness engagement with BC First Nations and Health Authorities at the regional level.

With all of these changes, First Nations and their partners will require high quality information and data to support community, regional, provincial and national action. The FNCF, FNCF data and FNCF denominator data are valuable tools that will empower public health professionals, policy-makers, clinicians, community leaders and researchers with accurate, quality data to answer any number of broad health and social questions and inform key program and policy decisions.

It is critical that the use of the FNCF, FNCF data and FNCF denominators be aligned with the overarching principles and Directives guiding the historic changes in health services for BC First Nations. The 2011 Consensus Paper: British Columbia First Nations Perspectives on a New Health Governance Arrangement lays out Seven Directives to guide the development of a new health governance arrangement. These Directives were developed over the course of three years by First Nations in over 120 regional and sub-regional meetings and thus represent broad guiding principles that can guide other Tripartite work, including FNCF, FNCF data and FNCF denominator data access. Principles and Directives related to the TDQSA include:

Principle/Directive <sup>1</sup>	Ways in which FNCF DARs can embody this principle
<p><b>Directive #1: Community-Driven, Nation-Based.</b></p> <p><i>Program, service and policy development must be informed and driven by the grassroots level.</i></p>	<p>DARs can be driven by local community interests and involve community members or relevant Tripartite representatives.</p>
<p><b>Directive #2: Increase First Nations decision-making and control.</b></p> <p><i>Increase First Nations influence on health program and service philosophy, design and delivery at the local, regional, provincial, national and international levels.</i></p> <p><i>Implement Ownership Control Access and Possession (OCAP) principle regarding First Nations health data, including leading First Nations health reporting.</i></p>	<p>The impetus behind DARs is driven by communities or Tripartite organizations. Community members or Tripartite partners are involved throughout the project and OCAP principles guide the data management of the project.</p>
<p><b>Directive #3: Improve Services</b></p> <p><i>Support health and wellness planning and the development of health program and service delivery models at local and regional levels.</i></p>	<p>Proposals will stimulate action leading to tangibly better health care services for First Nations.</p>
<p><b>Directive #4: Foster meaningful collaboration and partnership</b></p>	<p>Projects involve relevant Tripartite structures and staff as appropriate for the project. These include staff from the First Nations Health Authority, BC Ministry of Health, First Nations and Inuit Health Branch, Health Authorities as well as representatives from other Tripartite bodies such as:</p> <ul style="list-style-type: none"> <li>- Community Engagement Hubs;</li> <li>- Regional Caucuses and Regional Tables;</li> <li>- First Nations Health Directors Association;</li> <li>- FNHS Health Action Strategy Councils, planning and implementation groups.</li> </ul> <p>Ideally involvement should take place throughout the project, including the analysis, interpretation and dissemination of information as determined by the Tripartite partners involved.</p>

Principle/Directive <sup>1</sup>	Ways in which FNCF DARs can embody this principle
<p><b>Directive #7: Function at a high operational standard.</b></p> <p><i>Be accountable, including through clear, regular and transparent reporting.</i></p> <p><i>Make best and prudent use of available resources.</i></p>	<p>Use of the FNCF, FNCF data and FNCF denominators will enable more effective use of existing data sources to inform best practices and policy.</p> <p>Users of the FNCF, FNCF data and FNCF denominators will be accountable through clear, regular and transparent reporting that demonstrates appropriate use and interpretation of the FNCF, FNCF data and FNCF denominators.</p>

<sup>1</sup> Principle's/Directive's taken from the Consensus Paper 2011: BC First Nations Perspectives on a New Health Governance Arrangement. For the full document please visit: [www.fnhha.ca](http://www.fnhha.ca)

Each DAR for use of the FNCF, FNCF data and FNCF denominators should consider how it can integrate these principles. Requests will be considered by the Tripartite Data and Information Planning committee in light of how these principles are integrated into the proposal.

## Sharing of Results and Publications

The Tripartite Data and Information Planning (TDIP) committee, as well as additional Tripartite partners identified during the project should be consulted prior to any and all dissemination of results developed using the FNCF, FNCF data or FNCF denominators data, including, but not limited to: peer-reviewed publications, internal and external reports, abstracts, oral presentations, posters, and media releases by any of the involved parties to this evaluation. This consultation includes at a minimum, providing materials for review and comment at least 30 days prior to any such release. Electronic copies of all publications produced using the study data should be provided to the TDIP committee.

Applicants are encouraged take steps to make the results of their projects or studies available to First Nations in BC including setting aside funding to allow open-access of results in academic journals.

## Approval of other data sources

Approval of use of the FNCF, FNCF data or FNCF denominators by the TDIP committee does not imply approval for any other data sources required by the proposed research or evaluation. Additional data sources may have their own data access processes that would need to be followed in addition to the FNCF approval process.



Tripartite First Nations Health Plan



First Nations Health Authority  
Health through wellness



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