



TRIPARTITE DATA QUALITY AND SHARING AGREEMENT

2013-2014 Annual Report on Progress



Tripartite First Nations Health Plan



Tripartite First Nations Health Plan

For more information, please visit: First Nations Health Authority | www.fnha.ca

Province of British Columbia | www.gov.bc.ca/hls

Government of Canada | www.hc-sc.gc.ca

©2015 Copyright for this publication is held jointly by the First Nations Health Authority, the British Columbia Ministry of Health and Health Canada. Any proposed amendments or changes to content in the future requires the approval of all three parties. This publication may be reproduced without permission provided the source is fully acknowledged.

ISSN 2369-6222

Table of Contents

1.0	Glossary	4
2.0	Background and Purpose	7
2.1	Purpose	7
3.0	Context of our work.....	8
3.1	Transfer of services from FNIHB-Pacific Region to the First Nations Health Authority	8
3.2	Ministry of Health Context	8
3.0	Progress to Date on Fulfilling the Purposes of the TDQSA.....	10
5.0	Progress to Date on the Major Deliverables of the TDQSA	19
6.0	Lessons Learned.....	23
7.0	Looking ahead	23
9.0	Bibliography	24
	Appendix 1 – TDQSA Annex 1 Priority Areas of Interest.....	25
	Appendix 2 – General Conditions of Use of the FNCF.....	27

1.0 Glossary

Capitalized terms used in this report have the following meanings:

- **Annex:** A document that sets out Initiatives or other programs or activities that the Partners have agreed to approve or undertake in connection with the Tripartite Data Quality and Sharing Agreement (TDQSA) and includes Annexes developed in respect of the priority areas of interest listed in Annex 1 of the TDQSA as well as any further Annexes developed and approved by the Partners in accordance with Schedule 'A' of the TDQSA (referred to as Data Access Requests (DARs)).
- **Data Access Request (DAR):** A request received by the Data and Information Planning Committee (DIPC) and subsequently the First Nations Client File (FNCF) Data Steward for approval for linkage of other data sets to the FNCF or existing FNCF Data.
- **First Nations Client File (FNCF):** The FNCF is a cohort of BC Resident First Nations people registered under the Indian Act, and their unregistered descendants born after 1986 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 AANDC Indian Registry and the BC Ministry of Health Client Registry.

The Tripartite Partners agree the FNCF is the best available method of access to accurate health information about the identifiable majority of status and eligible-for-status First Nations clients residing in BC. The FNCF is linked to other data sets to produce FNCF Data as authorized by DIPC and the FNCF Data Steward

The development of the FNCF was made possible by means of a Memorandum of Understanding (MOU) between the BC Ministry of Health and Aboriginal Affairs and Northern Development Canada (AANDC) authorizing the disclosure of information contained in the Indian Registry to the Ministry of Health on an annual basis. The FNCF was initially created in 2011 and an updated version of the FNCF is currently being developed. The intent is that the FNCF will be updated incrementally at the beginning of each calendar year using a fresh extract from the BC Client Registry and the AANDC Indian Registry.

- **FNCF Data:** Data generated in response to approved requests by DIPC and the FNCF 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, Chief Data Steward (Section 6.3). There are mechanisms for the 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.
- **Initiative:** 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 BC communities.
- **Personal Information:** Personal information as defined in the Freedom of Information and Protection of Privacy Act [RSBC 1996], c.165, and all amendments thereto.
- **Data and Information Planning Committee (DIPC):** 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. After October 1, 2013, when the FNHA assumed the programs, services and responsibilities formerly handled by Health Canada’s First Nations Inuit Health Branch – Pacific Region the committee’s name changed to the “Data and Information

Planning Committee". DIPC is responsible for providing overall policy direction under the TDQSA and for the decisions made pursuant to it. To this end, DIPC 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 FNCF Data Steward. Data Access Requests to the FNCF are approved by consensus among the Partner Voting Members of DIPC (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).

- **Data Management Working Group (DMWG):** A committee, consisting of representatives from each of the Partner organization, with responsibility for supporting the work of DIPC.
- **Partners:** The First Nations Health Authority and the Government of British Columbia (Ministry of Health). Though not a formal signatory to any FNCF DARs after October 1, 2013 the Government of Canada (Health Canada First Nations and Inuit Health Branch) continues to participate on DIPC as an observer.
- **Partner Voting Members:** Two members of DIPC, appointed by each Partner, to vote on decisions related to the approval of FNCF Data Access Requests. Decisions require the unanimous approval of each Partner Voting Member (Schedule B, Section 1.3.b).

2.0 Background and Purpose

In 2006, the First Nations Health Society, Health Canada, and the Province of British Columbia (BC) – the Tripartite Partners – signed the Transformative Change Accord: First Nations Health Plan (TCA:FNHP). Action number 28 in the TCA: FNHP 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.”

To achieve this action item, the Tripartite Data Quality and Sharing Agreement (TDQSA) was drafted and signed in April 2010 by the BC Ministry of Health Services and the Ministry of Healthy Living and Sport (now the BC Ministry of Health), the First Nations Health Society (now the First Nations Health Authority (FNHA)), and Health Canada.

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

2.2 Purpose

This *Annual Report on Progress* provides a summary of progress 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.

Schedule B of the TDQSA states that: “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.” (Schedule B, section 1.8). Section 5.1(f) of the TDQSA also states that the Data Committee will: “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.” (Schedule B, Section 1.2(d))

The Data Committee referenced in the TDQSA, now referred to as DIPC, therefore respectfully publishes this report in fulfillment of our reporting requirements for calendar years 2013 and 2014.

3.0 Context of our work

Two significant events impacted the work of the Data Information Planning Committee in 2013 and 2014: (i) the transfer of services from Health Canada's First Nations Inuit Health Branch (FNIHB)- Pacific Region to the First Nations Health Authority in October 2013, and (ii) a privacy incident and subsequent investigation at British Columbia's Ministry of Health (MOH).

3.1 Transfer of services from FNIHB-Pacific Region to the First Nations Health Authority

In October 2013 the FNHA assumed responsibility for all of the programs and services formerly delivered by Health Canada's FNIHB - Pacific Region. This transition had an impact on the relationships of the Tripartite Partners as per the TDQSA, as well as their respective roles and responsibilities on the Tripartite Data Quality and Sharing Committee. The FNHA and the MOH became the Partners responsible for approving DARs that were presented to the new committee - the Data Information Planning Committee. Although no longer a signatory, Health Canada continues to be an engaged Partner through membership on DIPC.

The transfer of services from Health Canada to the FNHA also required the development of data-related initiatives for the establishment of an eligibility list for the Non-Insured Health Benefits Program that was being transferred to the FNHA (now referred to as First Nations Health Benefits within the FNHA). This work touched upon issues of identity management and the potential use of the FNCF or the "Indian Registry" to support the Health Benefits program. The FNCF was not ultimately used; however, this became a priority for many DIPC members who were involved in the discussions and working group leading up to the creation of the FNHA's Eligibility List for Health Benefits.

3.2 Ministry of Health Context

In May 2012 the BC Ministry of Health initiated an investigation relating to contracting irregularities and security concerns regarding research grant processes¹. An investigation report by the Information and Privacy Commissioner for BC was released in June 2013².

¹ Deloitte. Ministry of Health Security Enhancement Roadmap. Available online at: <http://www.health.gov.bc.ca/cpa/mediasite/pdf/deloitte-report.pdf>

The issues identified did not relate to the FNCF, however, the investigation did affect the work of the DIPC committee insofar as MOH staff were otherwise engaged in the investigation or the subsequent implementation of recommendations. As a result, the FNCF was not updated in 2013 or 2014.

Although resources were limited during the investigation the MOH Information Management and Knowledge Services branch worked with DIPC to prioritize the work and a few high priority projects were able to move forward.

² Office of the Information & Privacy Commissioner for British Columbia. Investigation Report F13-02. Available online at: <https://www.oipc.bc.ca/>

3.0 Progress to Date on Fulfilling the Purposes of the TDQSA

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

Purpose	Progress to Date
<p>Article 3.1.a</p> <p><i>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</i></p> <p><i>(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</i></p>	<p>To support the implementation of the TDQSA, the Partners created a framework with three key structures as well as foundational documents that guide the work of these structures.</p> <p>The Data and Information Planning Committee, the Data Management Working Group (DMWG) and the TDQSA Secretariat (now referred to as the DIPC Secretariat) were established to implement the work described in Article 3.1.a:</p> <ol style="list-style-type: none"> 1. DIPC met 7 times in 2013 and 7 times in 2014, and worked on eight separate FNCF data linkage projects (see Table 1 on page 12 for more details). <p>As in 2012, there has been a significant amount of learning while these processes and initial DARs were reviewed, as each DAR brought with it its own context, questions and implications.</p> <ol style="list-style-type: none"> 2. DIPC has, in the past, been supported by the Data Management Working Group. The DMWG did not meet in 2013 because of the transfer of FNIHB-Pacific Region to FNHA in October 2013 and the resulting shift in Tripartite working groups. The DMWG began meeting again in November 2014. A Terms of Reference was prepared in December 2014. The DMWG is made up of representatives from FNHA and the MOH. Its purpose and responsibilities are to: <ol style="list-style-type: none"> a. Provide detailed project management support relating to proposed and/or approved First Nation Client File Data Access Requests. Each FNCF DAR will be managed by an assigned project lead who will provide overall leadership to a project, including leading and/or assigning work relating to individual projects.

	<ul style="list-style-type: none">b. Develop processes and tools to facilitate the work of DIPC, including project tracking, as well as appropriate management and use of FNCF datac. Provides a forum for discussion of partner data issues, projects and supports. <p>3. The DIPC Secretariat role, created in January 2012, has been undertaken by an FNHA staff member. The functions of the DIPC Secretariat are:</p> <ul style="list-style-type: none">- Support the work of DIPC and the Data Management Working Group.- To facilitate fair and impartial process and decision-making, and consistent and equitable access to information for potential applicants.- To be a dedicated resource to coordinate the work of the DIPC, including preparing synopsis of research proposals and communicating with applicants to seek clarifications requested by the DIPC.- Conduct an initial review of new DARs to ensure the request is clear and that all necessary information and documentation are submitted.- Track the status and progress of DARs, which, for some 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 determine future options for the ongoing use of First Nations Data by the FNHA.
--	--

	<p>In addition to the Secretariat and Committees, the Partners ground their work in foundational FNHA documents such as the Consensus Paper³</p> <p>DIPC is currently updating their policy document. The policy document serves as a guide for decision-making relating to DARs and contains guidance on processes for DAR approval and sign-off, changes to FNCF DARs, secondary uses of data, sharing of unpublished data with external partners, sharing of data held by partners, community-level disaggregation of data, use of data for one-time vs. ongoing projects, and data destruction. This policy document will be a living resource that is updated as DIPC encounters new questions or situations.</p>
<p>Article 3.1.b</p> <p><i>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.</i></p>	<p>Tools have been developed for the purposes of adjudicating FNCF DARs. These include :</p> <ul style="list-style-type: none"> - Three DAR forms customized for Internal Partners, External Public Health Partners and External Researchers. External research requests have not been accepted since 2012 due to the limited resources available for data analysis and linkage to the FNCF. The forms have been updated and edited as the work of the committee identifies important information to be captured in the application process. - 'General Conditions of use of the FNCF' against which each FNCF DAR is evaluated (see Appendix 2). - A tracking mechanism, by which each application for access to the FNCF is documented so as to ensure transparency and accountability regarding the

³ The results of more than 120 regional and sub-regional caucus meetings with First Nations Chiefs, leaders and senior health professionals to inform the discussions and negotiations of a new governance arrangement for health programs and services utilized by First Nations in BC were rolled into the 2011 'Consensus Paper: British Columbia First Nations Perspectives on a New Health Governance Arrangement'. The Consensus Paper outlines Seven Directives that describe the fundamental standards and instructions for the new health governance relationship.

	<p>use of the FNCF.</p> <p>Processes have been developed for the purposes of adjudicating FNCF DARs. These include:</p> <ul style="list-style-type: none"> - Initial review of draft FNCF DARs by the DIPC Secretariat - Determining priority of DAR requests on an ongoing basis by DIPC - 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.
<p>Article 3.1.c</p> <p><i>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.</i></p> <p>and</p> <p>Article 3.1.d</p> <p><i>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.</i></p>	<p>The MOH is the current Data Steward of the FNCF (Article 6.3).</p> <p>Through the TDQSA, the 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).</p> <p>Part of the work for DIPC is the need to understand and prioritize the policies, safeguards and standards that will need to be in place should DIPC decide that the FNHA should take over stewardship of the FNCF. This work is ongoing and will be developed over time.</p> <p>One of the main mechanisms for knowledge exchange is through the DIPC Secretariat. By working with key MOH data staff, the DIPC Secretariat can gain knowledge and skills relating to manipulating and analyzing administrative health databases, which over time, will lead to increased capacity.</p> <p>Direct access to and linkages of the FNCF and other key data sources have been limited by data access restrictions within the MOH as well as for non-MOH staff. In order to develop the necessary training and knowledge exchange between the MOH and the FNHA, discussions began in 2013 to second an FNHA employee to the MOH to be involved in the creation of the FNCF and production of FNCF Data through linkages. This secondment position began in November 2014 and will be in place</p>

	until November 2016.
<p>Article 3.1.e</p> <p><i>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.</i></p>	<p>Twenty-two FNCF DARs have been reviewed by DIPC since the creation of the FNCF in November 2011. Each of the approved FNCF DARs generates their own data set on completion. These datasets are not available for any other purpose other than that described in the original application, however, DIPC has established a policy on secondary data use in order to capitalize on previous work and avoid duplication of effort.</p> <p>See below a listing of projects in development in 2013 and 2014.</p>

Table 1: FNCF Data Access Requests 2013 - 2014 (in Alphabetical order of subject)

Project Title	Description	Requestor	Status
Cancer (2012-18)	To compare the descriptive epidemiology, incidence, mortality, survival, and trends over time of various cancers between Registered Status Indians Living in British Columbia (BC) and the general BC population. If differences exist, to offer recommendations in closing the inequalities, and to influence future program planning in this area.	Public Health Partner and Internal Partner	Linkage has been complete and data is being analysed
Communicable Disease (2011-7)	The purpose of this project is to conduct the analysis of communicable disease trends over time in status First Nations in BC and provide a valuable source of information for First Nations communities and their health service organizations, as well as their government partners, to inform public health programs and policy	Internal Partners	Data request has been approved. Linkage will occur when the 2014 FNCF is ready.

	<p>and to evaluate the impacts of programs and interventions aimed at reducing communicable disease burden in BC First Nations. The data linkage will follow on this previous work and provide the basis for an assessment of the epidemiology and burden of communicable disease in First Nations in BC during 2002-2012. Such an assessment is essential for the development of effective public health programs and policies and for the evaluation of programs and interventions aimed at reducing communicable disease burden among BC First Nations.</p>		
<p>FNCF Population Data (2013-19)</p>	<p>As the best source of population data for First Nations available, living at home or away from their home community, this FNCF denominator data will be used to inform the development of "Regional Envelope Guidelines" and regional profiles: to document the best current available data/estimates on how regional populations are impacted through migration patterns to inform regionally based funding and health priority setting for the FNHA.</p>	<p>Internal Partner</p>	<p>Analysis is complete.</p>
<p>Growing Up in BC report II (2014-23)</p>	<p>First Nations rates for birth weight and smoking/drinking during pregnancy are to update the "Growing Up in BC" report.</p>	<p>Public Health Partner</p>	<p>Analysis is complete.</p>
<p>Interior Health Expenditure Project (2013-20)</p>	<p>This project will provide a detailed analysis of Regional Health Authority and First Nations expenditures and service utilization in Interior Health's (IH) seven Interior Nations. Health expenditures will be interpreted and understood in the context of health service utilization, so that potential gaps in First Nations access to programs/services can be examined, and opportunities for investment or service integration between IH and</p>	<p>Internal Partners</p>	<p>Data request has been approved and PIA has been signed. Linkage is scheduled to occur in early 2015.</p>

	First Nations can be identified. The FNCF will be linked to the Blue Matrix databases from 2009 to 2013, and will provide essential information regarding health service utilization of Interior Nations. Comparisons between Interior Nations and the general population will inform the expenditure gaps analysis, assist in transformation, and can be used to better target future health expenditure investment and service integration in IH.		
Opioid Mortality (2014-27)	This project will assess patterns of service utilization and other measurable risk factors associated with accidental pharmaceutical opioid-related deaths.	Internal Partners	Data request is in development and has yet to be signed off by DIPC.
PHO Interim Report 2014 (2014-24)	To report on the five indicators identified in the Transformative Change Accord – First Nations Health Plan that are feasible to report on using administrative data	Internal Partners	Data request has been approved. Linkage will occur when the 2014 FNCF is ready.
Secondary Usage of Life Tables from 2011 PHO Report	The life tables for Registered Indians and non-registered persons in British-Columbia developed for the 2007 Provincial Health Officer’s report was requested to provide mortality data for the microsimulation population model Demosim under development at Statistics Canada.	External Applicant	Data request approved and life tables provided to Statistics Canada.
STOP HIV/AIDS cohort linkage (2013-21)	The STOP HIV/AIDS Program has evolved from a pilot to an ongoing province wide program of the Ministry of Health. The aim is to improve reach of HIV testing, treatment and support across BC among those at risk for infection or living with HIV. Monitoring rates of HIV/AIDS, as well as indicators of access to treatment and retention in care, among First Nations in BC is critical to determining whether and how we are able to slow transmission rates and achieve declines in morbidity and	Internal Partners	Initial linkage completed in 2012 with 2011 FNCF and data analyses are underway; linkage was updated with the new HIV/AIDS cohort, analyses pending.

mortality due to HIV disease. The DAR proposes to continue linkage on an annual basis starting Feb 5, 2014 for the next three years with an option to renew.

<p>Article 3.1.f <i>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 FNCF.</i></p>	<p>The principle of First Nations Health Information Governance is a central tenet of DIPC, one that the committee has been striving to operationalize as it pertains to accountability, privacy and confidentiality, wisdom from foundational FNHA documents (e.g., the 2011 Consensus Paper) as well as how it relates to the realities of working with administrative health data.</p> <p>The 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.</p> <p>The 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.</p> <p>DIPC recognizes that mechanisms for First Nations input into FNCF decision-making need to be developed over time.</p> <p>Some mechanisms DIPC has adopted to address the principle of First Nations Health Information Governance include:</p> <ul style="list-style-type: none"> - FNHA representatives on both DIPC and Data Management Working Groups - FNCF DARs decisions are made by consensus among the two co-signatories,
--	--

	<p>in consideration of input from DIPC discussion.</p> <ul style="list-style-type: none">- DIPC members compare each DAR against a set of conditions (see Appendix 2), which have been developed using the feedback and insight of community members from key FNHA documents including the 2011 Consensus Paper (First Nations Health Authority, 2011). 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 better services, and should be inclusive of First Nations voices during the interpretation and dissemination of project results.- The Secretariat role for DIPC is filled by a FNHA staff member (currently fulfilling this role on secondment with the Ministry of Health)- In addition, respecting the governance of First Nations communities over their own data along with privacy issues arising from small cell size, DIPC has not authorized the release of any community-level First Nations Data. In future, when communities express interest in community-level data for their own health and wellness planning or evaluation efforts, the DIPC hopes to work in partnership with these communities in the analysis. DIPC hopes to develop these capacities through collaboration with communities over time.- Resulting publications and results are to be made as accessible to First Nations as possible by disseminating publically; and researchers will be encouraged to, where possible, disseminate results in a format and method that is both accessible and meaningful to First Nations in BC.
--	---

5.0 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.

Objectives and deliverables	Progress to Date
<p>Article 5.1.a</p> <p><i>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.</i></p>	<p>Twelve priority areas of interest were identified in the TDQSA (see Appendix 1 for a complete list).</p> <p>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.</p> <ol style="list-style-type: none"> 1. Vital Statistics: The development of a Vital Statistics Report is of interest and on the work plan of the DIPC committee, but of lower priority. 2. On-/off-reserve categorization: There has been some evolution in the terminology used to describe the geographical location of First Nations since the creation of the FNCF in 2011 from 'on' and 'off' reserve to 'home' and 'away from home'. The intent is that the 2014 FNCF and Calendar Roster will include fields to capture this more current terminology. 'Home' would be defined as living in the same Local Health Area (LHA) as the band to which an individual is registered and 'Away from Home' would be defined as living outside the LHA in which the band to which they are registered is located. 3. Diabetes and Chronic diseases: Chronic disease prevalence and incidence are being explored as part of a project examining the prevalence and incidence of First Nations chronic diseases through a linkage to the provincial chronic disease registries.

	<ol style="list-style-type: none"> 4. Communicable Disease: The Partners are working with the BC Centre for Disease Control to develop a communicable disease report. This report is awaiting the most recent version of the FNCF to begin work on the data linkage. The FNCF is also being used to assess the burden of HIV/AIDS among First Nations in BC, as well as access to treatment and retention in care, from a linkage with STOP HIV/AIDS Cohort at the BC Centre for Excellence in HIV/AIDS. 5. Cancer: The Tripartite Partners are working in partnership with the BC Cancer Agency to develop a First Nation cancer report. Data has been linked and analysis is underway. 6. Injuries: There are no FNCF DARs with respect to injuries at this time. 7. Baseline data: Many of the initiatives underway will contribute to baseline health data for First Nations. 8. Health Care Utilization: An analysis of health expenditure data is underway through a FNCF DAR being led by FNHA and Interior Health. The intent is to replicate this analysis in other health authorities 9. The First Nations Regional Health Survey BC Provincial Report: The next wave of the Regional Health Survey will take place in 2015/2016, however this survey is not under the scope of the Data Information Planning Committee 10. Community Health Plans: The collection of information required for community health plans is a longer-term priority of DIPC. This work will require more discussion and collaboration with the First Nations Health Directors' Association and regional tables.
<p>Article 5.1.b</p> <p><i>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</i></p>	<p>The TDQSA states that the Partners are able to develop and collaborate on projects or Initiatives, which would be developed as Annexes.</p>

<p><i>or replaced from time to time.</i></p>	
<p>Article 5.1.c <i>Adopt and implement the process for: i) reviewing proposed Initiatives, as set in Schedule B of the TDQSA; and ii) reviewing Data Access Requests, in collaboration with the Data Steward.</i></p>	<p>See "Progress to Date" description for Article 3.1.b</p>
<p>Article 5.1.d <i>Oversee the development of First Nations Data in respect of the following seven performance indicators in the TFNHP:</i></p> <ul style="list-style-type: none"> - <i>Increased life expectancy</i> - <i>Mortality rates (due to all causes)</i> - <i>Status Indian youth suicide rates</i> - <i>Infant mortality rates</i> - <i>Diabetes rates</i> - <i>Childhood obesity (develop baseline and ongoing mechanism for collecting data)</i> - <i>Practicing, certified First Nations health care professionals (develop baseline and ongoing mechanism for collecting data)</i> - <i>and establish other key indicators, including wellness indicators.</i> 	<p>In October 2012, the Office of the Provincial Health Officer released an interim update examining progress on the seven performance indicators from the TFNHP. These indicators will be updated when the 2014 FNCF is available.</p>
<p>Article 5.1.e <i>Develop a plan to support and develop the capacity and self-determination of First Nations in BC to (i)</i></p>	<p>See "Progress to Date" description for Article 3.1.c.</p>

<p><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.</i></p>	
<p>Article 5.1.f <i>Develop and implement a program(s) for the collection of information to assist in the development of First Nations healthy policy and program planning, as well as to monitor health outcomes in First Nations communities.</i></p>	<p>Processes are in place to allow Partners to submit FNCF DARs for the purposes of program planning and monitoring health outcomes.</p>
<p>Article 5.1.g <i>Develop and assist other government agencies, government ministries and government departments to develop comparable data sets for non-status First Nations in BC.</i></p>	<p>The FNCF only allows for the identification of Status individuals and therefore no non-status health information can be produced using the FNCF.</p> <p>The Aboriginal Administrative Data Standard (AADS) (Ministry of Aboriginal Relations and Reconciliation, 2007) is a BC government standard that allows for the collection of self-identity status and non-status information, but has not yet been widely implemented in the health care sector.</p>

6.0 Lessons Learned

The DIPC identified a number of lessons learned in the first three 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 time within each FNCF DAR project work plan.
- 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. The DMWG and DIPC are currently reviewing and updated their policy document.
- The FNCF is a valuable resource that would benefit health partner organizations, other government departments as well as external researchers however, with limited time and resources, the DIPC has decided that it is unable to review or adjudicate external research FNCF DARs at this time.
- Personnel changes heavily impacted the committee's work.

7.0 Looking ahead

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

- Both the TDQSA and the MOU between Aboriginal Affairs and Northern Development Canada and the Ministry of Health are expiring in April 2015 and the process for renegotiation of these agreements has begun. DIPC has identified a number of potential enhancements to the TDQSA for future consideration.
- New geographical boundaries with more meaning for First Nations, namely the investigation of 'Nation-based' groupings, i.e., sub-regional geographies that group individual First Nations communities within each respective Nation as well as new 'home' and 'away' from home rather than 'on' and 'off' reserve designation.
- More data that increases the ability of First Nations communities and Partners to monitor health and measure the success of programs and services provided in BC First Nations communities and supporting regional activities and initiatives through analysis of data at regional levels.

- 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.

9.0 Bibliography

First Nations Health Authority. (2011). *British Columbia First Nations Perspectives on a New Health Governance Arrangement: Consensus Paper*. Retrieved from http://www.fnhc.ca/pdf/FNHC_Consensus_Paper_-_WEB.pdf

Ministry of Aboriginal Relations and Reconciliation. (2007). *Government Standard for Aboriginal Administrative Data*. Retrieved from http://www.cio.gov.bc.ca/local/cio/standards/documents/standards/aboriginal_administrative_data_standards.pdf

Provincial Health Officer. (2012). *The Health and Well-being of the Aboriginal Population: Interim Update*. Retrieved from <http://www.health.gov.bc.ca/pho/pdf/interim-update.pdf>

Tripartite Committee on First Nations Health. (2012, October). *Together in Wellness: Tripartite Committee on First Nations Health Interim Report*. Retrieved from <http://www.health.gov.bc.ca/library/publications/year/2012/together-in-wellness.pdf>

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' community health plans.
13. Other projects as identified and agreed upon by the Parties.

Appendix 2 – General Conditions of Use of the FNCF

Each data access request for use of the FNCF, FNCF data and FNCF denominators should consider how it can integrate the 7 Directives. Requests will be considered by DIPC in light of how the 7 Directives are integrated into the proposed project.

For example:

Principle ¹	Ways in which FNCF DARs can embody this principle
<p>Directive #1: Community-Driven, Nation-Based.</p> <p>Program, service and policy development must be informed and driven by the grassroots level.</p>	<p>DARs should be driven whenever possible by local community interests.</p> <p>The results of the project should be of use in the planning and delivery of health care services.</p> <p>The results should be made public and available to First Nations whenever possible.</p> <p>Knowledge dissemination strategies should be integrated into the project to push the results of the work into the hands of those who would reasonably be expected to enact change with the information.</p>
<p>Directive #2: Increase First Nations Decision-Making and Control.</p> <p>Increase First Nations influence on health program and service philosophy, design and delivery at the local, regional, provincial, national and international levels.</p> <p>Implement Ownership, Control, Access and Possession™ principle</p>	<p>The results of the project should be of use to the planning and delivery of health care services at local, regional, provincial, national and international levels.</p> <p>The principles of First Nations Health Information Governance guide the data management of the project.</p>

<p>regarding First Nations health data, including leading First Nations health reporting.</p>	
<p>Directive #3: Improve Services Support health and wellness planning and the development of health program and service delivery models at local and regional levels</p>	<p>Projects relate to a topic that may reasonably lead to better health or health care service delivery for First Nations in BC.</p>
<p>Directive #4: Foster Meaningful Collaboration and Partnership Foster collaboration in research and reporting at all levels. Enable relationship-building between First Nations and the regional health authorities and the First Nations Health Authority with the goal of aligning health care with First Nations priorities and community health plans where applicable.</p>	<p>Project should involve community members or relevant partner representatives including staff from First Nation communities, the First Nations Health Authority (FNHA), BC Ministry of Health (MOH), First Nations and Inuit Health Branch (FNIHB), Health Authorities or the First Nations Health Directors Association. Ideally involvement should take place throughout the project, including the analysis, interpretation and dissemination of information as determined by First Nations partners involved.</p>
<p>Directive #7: Function at a High Operational Standard Be accountable, including through clear, regular and transparent reporting. Make best and prudent use of available resources.</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. 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>



Canada 



Tripartite First Nations Health Plan



First Nations Health Authority
Health through wellness



BRITISH
COLUMBIA