First Nations Health Information Governance in Action:

First Nations Inclusion in the BC Panorama Joint Stewardship Data Governance Model

June 2015

A helpful definition…

*"**First Nations Health Information Governance**" is a component of First Nations Health Governance and refers to the structure, process and protocols 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.*

Another helpful definition…

A legal entity that employs health staff to deliver services to member First Nations

Multiple organizational variations exist

FNHSO

Required to meet the same eHealth "conformance" standards as a regional health authority

FNHSOs in BC provide service to First Nations who hold an agreement with FNHA

"First Nation Health Service Organization"

A strong Data Governance Model that supports First Nations Health Information Governance means more FNHSOs are likely to use Panorama

Panorama then enables the sharing of information between FNHSO and RHA nurses and…

- Supports nurses with critical information they need to provide safe and effective care
- Prevents double immunizations due to lack of information around immunizations received
- Improves ability to understand the state of health and service levels for First Nation communities
- Improves public health surveillance, program management and population health at multiple levels
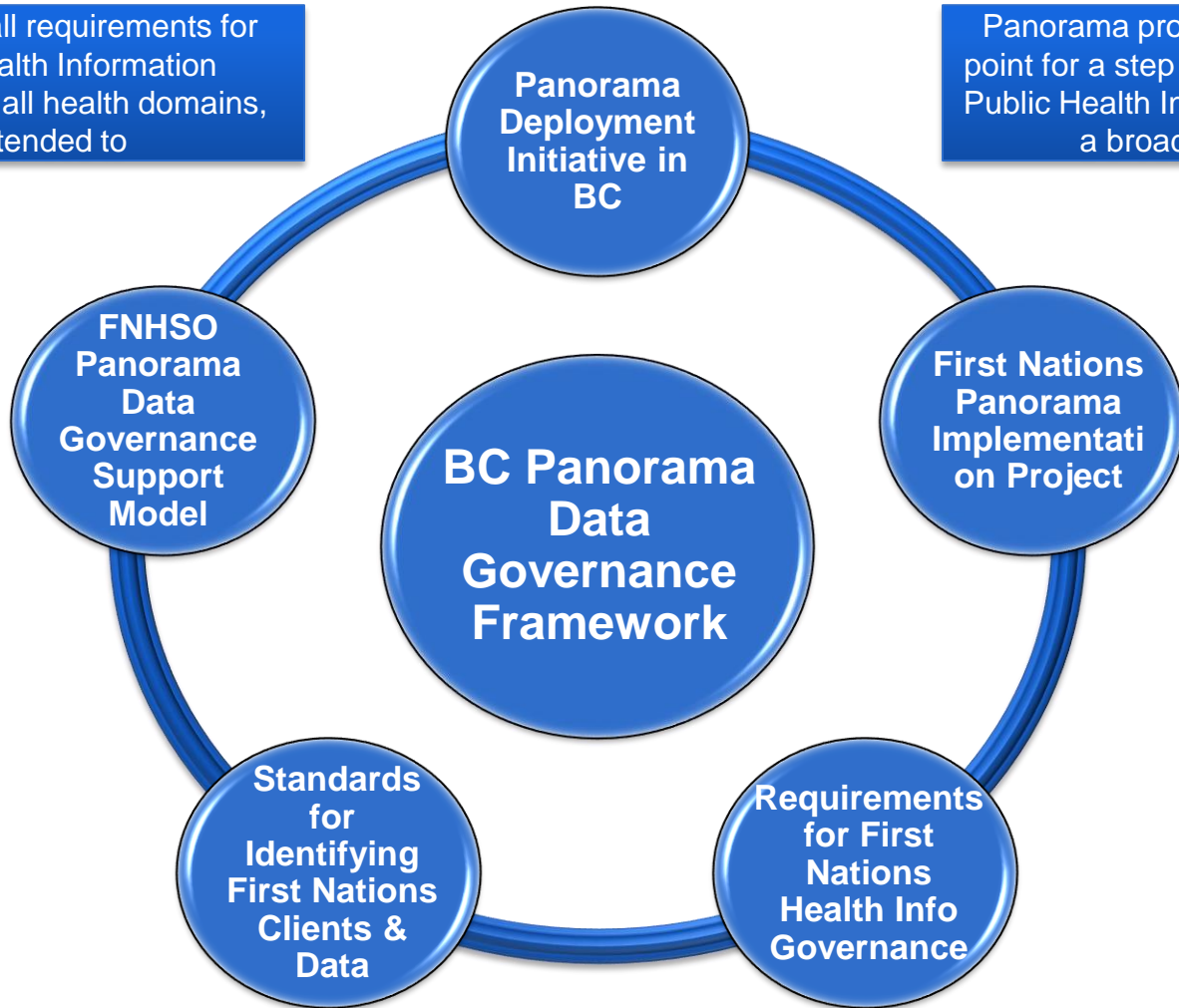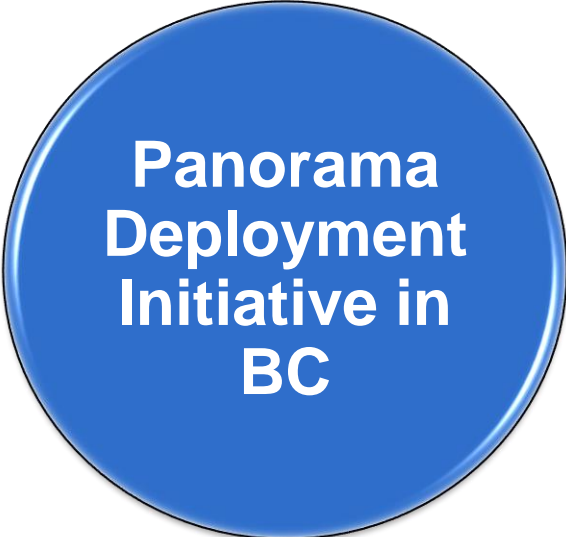
Question…

Practically speaking, what's required to create a strong Panorama Data Governance Model that integrates First Nations Health Information Governance, provides clear rules and processes and creates trust?

Consider what we have available to work with in the environment…

Does not address all requirements for First Nations Health Information Governance across all health domains, nor is it intended to

Panorama provides a practical starting point for a step forward with First Nations Public Health Information Governance as a broader model evolves

Panorama Deployment Initiative in BC

FNHSO Panorama Data Governance Support Model

First Nations Panorama Implementation Project

BC Panorama Data Governance Framework

Standards for Identifying First Nations Clients & Data

Requirements for First Nations Health Info Governance

OUTBREAK
MANAGEMENT

NOTIFICATION
MANAGEMENT

FAMILY
HEALTH

VACCINE/MATERIALS
INVENTORY
MANAGEMENT

WORK
MANAGEMENT

COMMUNICABLE
DISEASE INVESTIGATION
MANAGEMENT

IMMUNIZATION
MANAGEMENT

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First Nations Panorama Implementation Project

Objective: Support Panorama Deployment to FNHSOs

Objective: Support First Nations Data Stewardship

Objective: Support the development of First Nations eHealth capacity

Objective: Improve public health clinical and business process coordination between FNHSO and provincial public health professionals
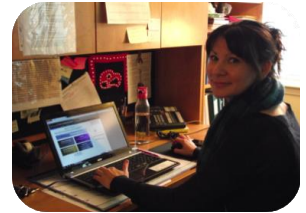
Brief Summary of Project Outcomes

Successful adoption started Fall 2013

Canadian Health Informatics Award in June 2014

Continuing to deploy to BC First Nations Health Service Organizations

Success has come through a focus on **people**, **relationships** and **clinical requirements**

Accessing Panorama

In order to access the Panorama system FNHSOs need to (in summary):

- Strengthen and/or develop their Privacy & Security Framework
- Conduct a Privacy and Security Impact Assessment
- Obtain eHealth Conformance approval from BC Ministry of Health
- Ensure staff are trained to use the system and technical and workflow alignment occurs
- Sign the information sharing agreement (ISA) to enable data governance and info sharing though membership on the Panorama Data Governance Committee

Toolkit Implementation Methodology

Four Main Steps to enable FNHSO Panorama access

Process optimized for maximum efficiency

Tools and Templates support progress

Eight Weeks Possible Completion time

- Assumes capacity exists for all parties to meet timelines
- Does not imply continuous, full-time effort for 8 weeks
- Does not include initial engagement activities
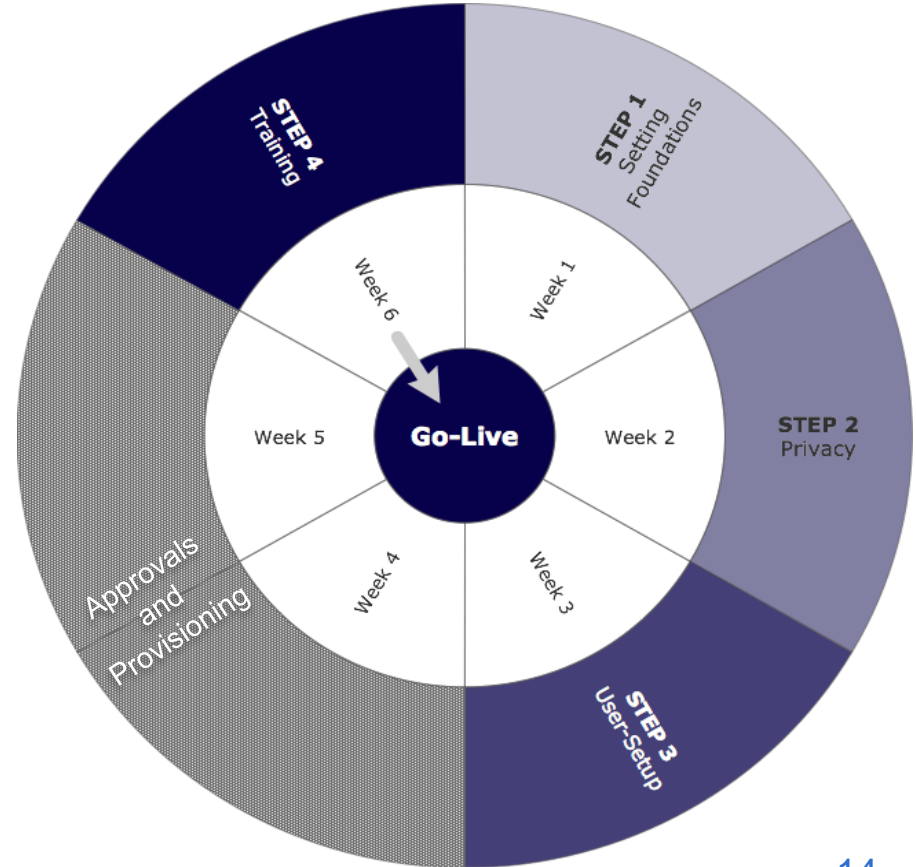
Requirements for Enabling First Nations Health Info Governance

Determining Requirements

Engaged with initial FNHSOs adopting Panorama to:

- Identify First Nations information governance requirements
- Engage legal counsel for an independent review of the BC Panorama Information Sharing Agreement and clarify legislative authorities for collection, use and disclosure of Panorama data
- Find practical and sustainable solutions for supporting First Nations Organizations to effectively steward Panorama data

In parallel, First Nations were included in the overall development of the Panorama Data Governance Framework and ISA model

- First Nations Data Governance Working Group
- First Nations Legislative Authorities Working Group
- Direct participation on provincial Data Governance Working group

Outcome: Requirements

Data in Panorama will fall under the stewardship of the appropriate First Nations Principle Data Steward(s) if it is classified as:

- First Nations client data
- First Nations Community data
- First Nations Health Organization data
- First Nations regional / provincial population data

The necessary First Nations Principle Data Stewards will hold decision making authority over this data (for purposes other than providing public health service)

Outcome: Legal Review

"…the ISA meets the requirements of the legislation and we have not identified any significant issues that would lead us to recommend that FNHSOs not sign the ISA."

A First Nation lawyer was selected by early Panorama adopters and was asked to provide a legal review that would be available to all BC FNHSOs

Outcome: Relationship Document – FNHSO Principle Data Stewards & Governance Committee Representative

A Relationship Document to define and guide the working relationship FNHSO Principle Data Stewards and the Committee Representative

This Relationship Document has received legal review

A Council, Board Resolution or some other equivalent form of authorization is required to "formalize" the relationship

THE BC FIRST NATIONS PANORAMA DATA GOVERNANCE RELATIONSHIP DOCUMENT

BETWEEN

First Nation Health Service Organization Principal Data Stewards

AND

The Panorama Data Governance Committee Representative
(Local First Nation Data Steward Representative)

FNHSO Principal Data Steward &
FNHSO Data Governance Committee Representitive

FNHSO Principal Data Steward(s) (100+)

FNHSOs (100+)

Liaison & Support Role

BC Panorama Data Governance Committee

Local Level First Nations Principal Data Steward (FNHSO Level Data Aggregation) N=1 "First Nation "FNHSO Data Governance Committee Representitive"

Figure 1 - Liaison & Support Relationship

Panorama Information Governance

FNHSO Principal Data Steward & FNHSO Data Governance Committee Representitive
Working Relationship Diagram
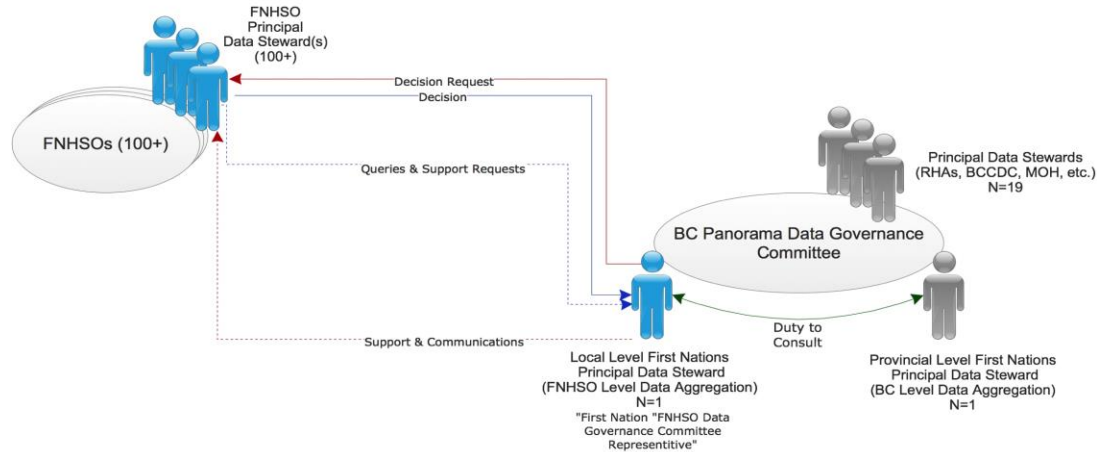
FNSHO Principle Data Stewards: Individual Data Stewards for each FNHSO in BC;

First Nations FNHSO Data Governance Committee Representative: One of two First Nations Data Stewards on committee, functions as liaison to FNHSO Data Stewards;

Provincial level First Nations Principle Data Steward: One of two First Nations Data Stewards on Committee, functions in capacity of stewarding provincially aggregated First Nations Data.

Principle Data Stewards (Other Solution Partners): Data Stewards for regional health authorities, BCCDC, Ministry of Health, PHSA, etc.

Decision Requests – when a request for disclosure of data, falling outside of that defined within the polices or in the ISA, arises, a decision request will be sent to the FNHSO Principal Data Steward, along with supporting information.

Decision Communication – formal decisions by FNHSO Data Stewards will be provided to the Committee Representative to table with the committee or the Central Data Steward as is appropriate.

Queries & Support Requests – individual FNHSO Data Stewards will communicate specific queries and/or support requests to the Data Governance Committee Representative. Various mechanisms will support this function on an ongoing basis, for example regular teleconference meeting and periodic gatherings.

Support & Communications – the Data Governance Committee Representative will facilitate regular and ongoing avenues of communications, updates, training, and support to the FNHSO Principle Data Stewards as is required.

Mechanisms for Supporting First Nations Stewardship

- Specific Configuration of BC Panorama JORG and AORG models
- Data access configurations and controls (e.g. Aboriginal Access Group role-based permissions)
- ISA + policies and procedures developed for the Panorama Data Governance Committee

BC Yukon Panorama

INFORMATION SHARING AGREEMENT

BETWEEN

BC CENTRE FOR DISEASE CONTROL AND
PREVENTION SOCIETY BRANCH
(PANORAMA CENTRAL DATA STEWARD)

AND

FRASER HEALTH AUTHORITY
VANCOUVER ISLAND HEALTH AUTHORITY
NORTHERN HEALTH AUTHORITY
INTERIOR HEALTH AUTHORITY
VANCOUVER COASTAL HEALTH AUTHORITY
PROVINCIAL HEALTH SERVICES AUTHORITY
BC MINISTRY OF HEALTH

panorama — **Panorama Data Governance Committee Procedure Manual**

Data Access Request (Surveillance & Program Evaluation) Policy and Procedure

Date First Issued:	July 16, 2014	Approved by:	Data Governance Committee
Date of Last Revision:	July 16, 2014	Date of Approval:	July 16, 2014
		Record of Approval:	Minutes of June16, 2014 Data Governance Committee meeting

panorama — **Panorama Data Governance Committee Procedure Manual**

Research Policy and Procedure

Date First Issued:	May 1, 2014	Approved by:	Data Governance Committee
Date of Last Revision:	September 16, 2014	Date of Approval:	August 26, 2014
		Record of Approval:	Minutes of August 26, 2014 Data Governance Committee meeting

Panorama Standards for Identifying First Nations Clients & Data

Aboriginal Guidelines

BC & Yukon Panorama Operational Support Team

PANORAMA

Panorama Guidelines

FINAL 2.0

Aboriginal Guidelines

Please see **Panorama System Guidelines** for most current version.

Purpose

The Province of British Columbia and Aboriginal communities are working together to close the socio-economic gaps that exist between Aboriginal people and other British Columbians, with a focus on Crown–Aboriginal Relationships, Education, Housing and Infrastructure, Health and Economic Opportunities. Measuring outcomes addresses a Provincial commitment to track the social and economic outcomes of Aboriginal people in BC in order to measure progress toward closing the gaps.

For the purpose of health promotion, disease and injury prevention, and health care service delivery and program evaluation, the ability to identify a Panorama client as Aboriginal will enable health organizations to have a more effective way of:

- Identifying and locating an individual who requires health care services
- Evaluating the health of Aboriginal people by group; within a community, a group of communities; a regional area; urban versus rural; and/or provincially
- Evaluating the health of First Nations people based on whether they are status or non-status, by age group, etc.
- Comparing the health of Aboriginal people to non-Aboriginal people regionally and provincially.

The purpose of this document is to communicate the standards in which Aboriginal data is entered into Panorama to help improve reportable outcomes and care for BC clients and to provide history on field or functionality changes.

Health Authority Applicability
Fraser Health, Interior Health, Northern Health, Vancouver Island Health, First Nations, Provincial Health Services Authority

Practice Level
This data guideline is applicable to all staff documenting new or updating existing client demographics.

Policy Statement

Related Documents

Associated Guidelines

- Quick Reference Guide – Maintain Client

References

- Ministry of Aboriginal Relations and Reconciliation: Aboriginal Administrative Data Standard
- Panorama Info Bulletin 4 - Collecting and Maintaining Aboriginal Information V1.0.docx
- Immunize BC: Q&A for Hepatitis A Program

Panorama Aboriginal Guidelines   FINAL   Page 1 of 19

Aboriginal Information

* Required field

Aboriginal Information

1. Does Client wish to self identify as an Aboriginal Person:
2. Aboriginal Identity:
3. First Nations Status:
   Do Not Use:
   Do Not Use:
   Do Not Use:
4. Aboriginal Information History

Client Self Identify	Aboriginal Identity	FN Status	Do Not Use	Do Not Use	Do Not Use	Effective From	Effective To

5. Aboriginal Organization: [Clear]

To specify an Organization first click on the 'Find' button. Then search, or type the name of the Organization you wish to specify, select it and click on 'Select' button. Then click 'Close' to close.

Organization: Top Level > Level 2 (specific one) > Level 3 (specific one) > [Selected Level 4 Organization]   [Find]

6. Aboriginal Organization History

Name	Effective From	Effective To

Addresses   Hide Addresses

Address Type:
Country: Canada

Address Located On Reserve Administered By:

Address:
Unit No.   Street No.   Street Name   Street Type   Street Direction

P.O. Box   STN   RPO   Rural Route

Province / Territory: **City:**   **Postal Code:**

BRITISH COLUMBIA
The Best Place on Earth

GOVERNMENT STANDARD FOR

ABORIGINAL ADMINISTRATIVE DATA

Ministry of Aboriginal Relations and Reconciliation
Intergovernmental and Community Relations
Aboriginal Administrative Data Standard
Version: 1.0
March 22, 2007

FNHSO Panorama Data Governance Support Model

BC First Nations Panorama Support Material · panorama
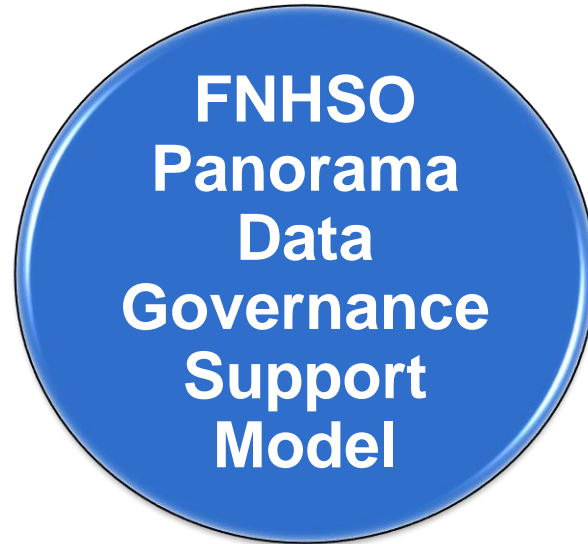
FNHSO Data Governance Forum: Terms of Reference

Background and Overview

In BC and the Yukon, a shared instance of the Panorama public health surveillance system is used by the BC Ministry of Health, BC regional health authorities, the BC Centre for Disease Control, BC First Nations Health Service Organizations (FNHSOs) and the Yukon Department of Health and Social Services. These organizations are jointly responsible for governing the data managed within Panorama through a "joint stewardship" model whereby stewardship responsibility is determined by how Panorama data is categorized and classified.

When a client in Panorama is associated to an FNHSO as their primary service delivery organization, that FNHSO's Data Steward becomes the "Principle Data Steward" and has decision making authority over how the data is used outside of standard public health service delivery activities. Others who would like to access and use Panorama data under the stewardship of an FNHSO must follow established procedures for making a request to the FNHSO Principle Data Steward. The details of this model are fully described in the Panorama Data Governance Framework.

An efficient and meaningful model has been implemented to support FNHSOs to participate in the use of Panorama and enable FNHSO-level Panorama data governance. Under this model, an "FNHSO Data Governance Committee Representative" has been established as a voting member on the Panorama Data Governance Committee. This representative attends committee meetings and advocates for FNHSO intererests, collects pertinent information to bring to FNHSO Principle Data Stewards, etc., but does not make data sharing decisions for FNHSOs.

A primary mechanism by which the FNHSO Data Governance Committee Representative will communicate and stay engaged with FNHSO Principle Data Stewards is through the FNHSO Data Governance Forum. The Forum will serve as a regularly scheduled meeting event where Panorama Data Governance Committee updates and information can be provided to FNHSO Principle Data Stewards, and as an opportunity for FNHSOs to communicate feedback and decisions back to the Committee.

This model is described in detail in the "BC First Nations Panorama Data Governance Relationship Document" and summarized in the diagram below:

FNHSO P&S Framework Forum: TOR · 1

FNHSO PANORAMA DATA GOVERNANCE FORUM

Kick-off Meeting
July 8, 2014

FNHSO PANORAMA DATA GOVERNANCE FORUM

Regular Forum Meeting
August 12, 2014

FNHSO PANORAMA DATA GOVERNANCE FORUM

Regular Forum Meeting
May 12, 2015

. . .

BC Drinking Water Project
The Impact of Climate Change on Drinking Water and Health
Data Request #: PanEXT 001-2014

Principal Investigator: Dr. Tim Takaro (SFU Health Sciences)
Collaborators: Jordan Brubacher (SFU); Bimal Chetri (SFU);
                                            Dr. Diana Allen (SFU); Dr
Eleni Galanis (BCCDC)

Data Access Request Review
Panorama Data Governance Committee
July 21st 2014

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Hepatitis B Immune Globulin (HBIG) utilization data submission to the Central Transfusion Registry (CRT)

Principal Investigator: Cecilia Li, Provincial Director
                                         BC Provincial Blood Coordinating Office (CRT)

Collaborators: Chris Biantoro, Provincial Lead - Biostatistics
                                         Theresa Witt, CRT Operations Coordinator
                                         Irene Pickett, Data and Technology
Management Coordinator,
Coordinator, Business Operations   Jennifer Danielson, Technical
                                         Quality and Utilization Management

Data Access Request Review
Panorama Data Governance Committee
September 23rd 2014

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Panorama Data Quality Monitoring

Proposal to Panorama Data Governance Committee, October, 2014

Laura MacDougall
Director, Public Health Analytics

- HEP B Booster Study
- PHRDW data use
- ISA Compliance
- Data Request Triage
- Accessing FN data
- …

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BC First Nations Panorama Support

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FNHSO Data Governance Forum

This section of the website is intended to provide an overview and key reference materials for FNHSOs who are participating in the Provincial Panorama Data Governance Committee. A "Local First Nations Data Steward Representative" sits on the Committee as a voting member to support FNHSO's ongoing involvement in Panorama Data Governance. Details of how the relationships are structured to support FNHSOs are described in the "BC First Nations Panorama Data Governance Relationship Document" which is available in the Reference Material section on this webpage. The diagram below summarizes the relationships and processes whereby the Local First Nations Data Steward Representative, and the Provincial Level First Nations Principle Data Steward, support governance requirements for the First Nations data within Panorama.

FNHSO Principal Data Steward & FNHSO Data Governance Committee Representitive Working Relationship Diagram
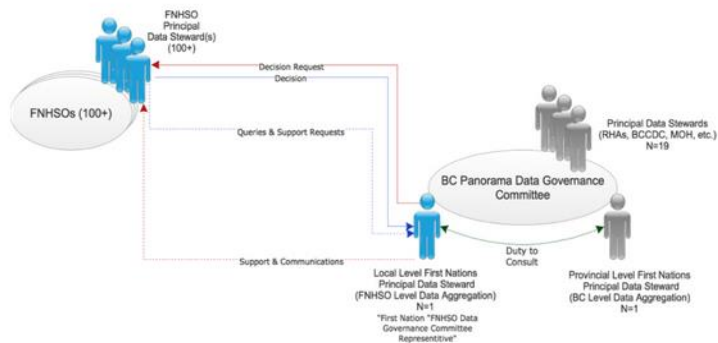
Reference Material

✓	📄	Name		Modified	Modified By
	📄	FNHSO Data Governance Forum - Terms of Reference v0.1	•••	June 17, 2014	Karl Mallory

July 2014 Meeting (DG)

✓	📄	Name		Modified	Modified By
	📄	FNHSO Data Gov Forum - Agenda - July 8 2014	•••	June 17, 2014	Karl Mallory
	📄	FNHSO Data Gov Forum - July 8 2014	•••	July 7, 2014	Karl Mallory

Aug 2014 Forum Meeting

✓	📄	Name		Modified	Modified By
	📄	FNHSO Data Gov Forum - Agenda - Aug 12 2014	•••	August 11, 2014	Karl Mallory
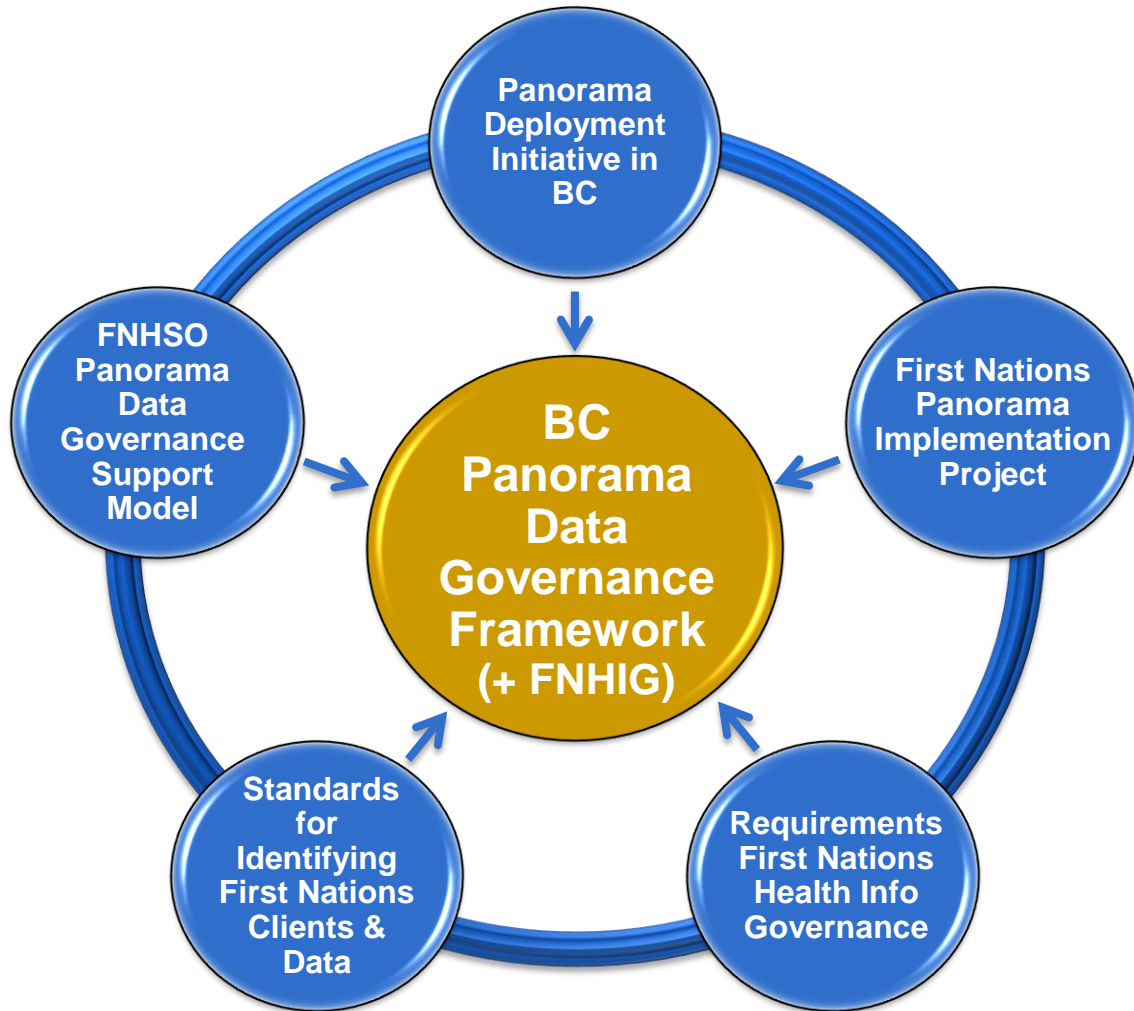
Wrap-up

- Comments?
- Questions?

- Contact info:

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Karl Mallory: kmallory@fnpip.ca