The Alberta First Nations Information Governance Centre

OCAP ® & OCAP ® in Action

Bonnie Healy, RN



Our Organization

- Incorporation
- Governance / Mandate
- Supporting Community Research
- Alberta First Nations Community Profile Initiative

"Protecting Our Knowledge, Telling Our Stories, Strengthening Our Communities"

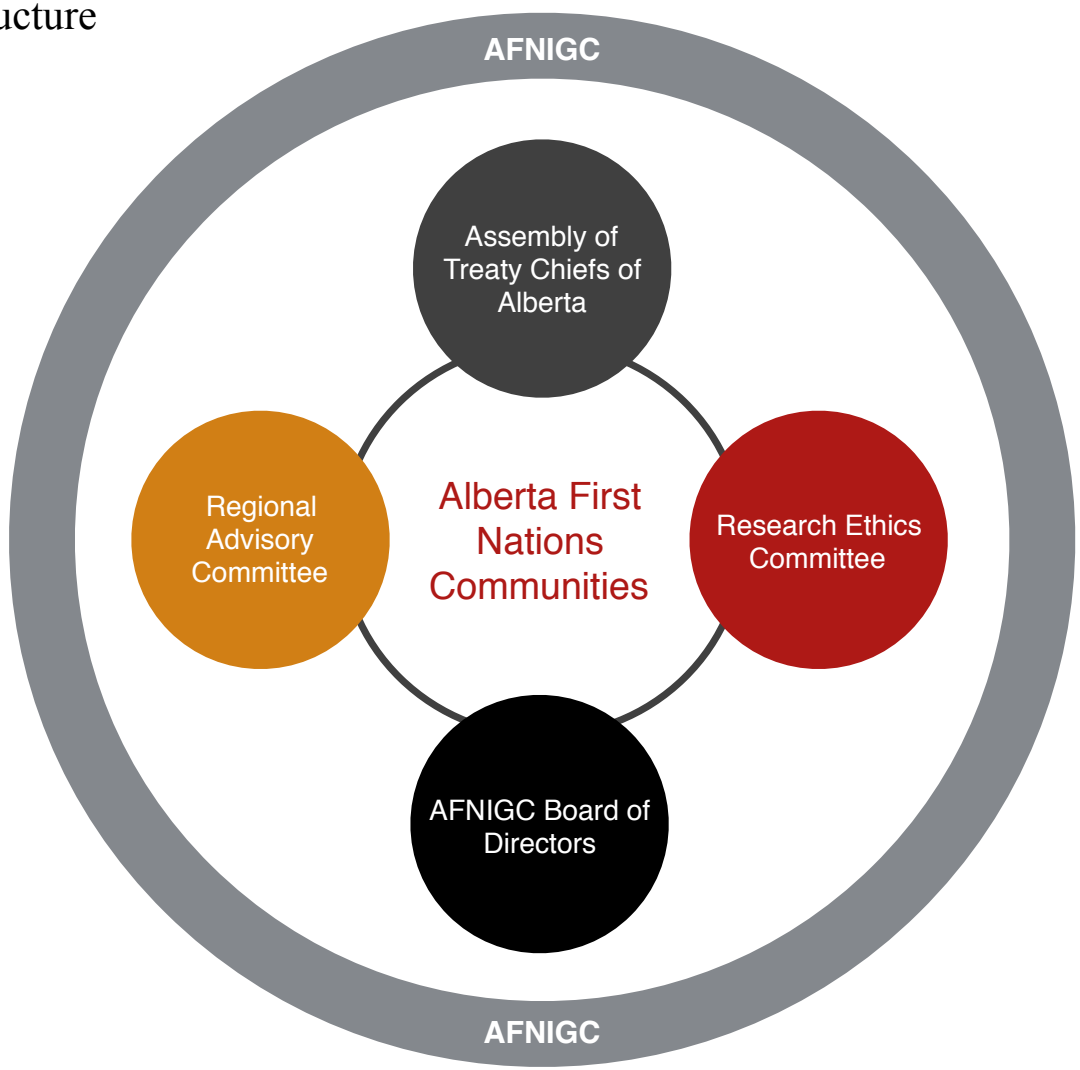
Alberta OCAP® Resolution


OFFICIAL DOCUMENT
30-03-2010-03R
TREATY No. 6
TREATY No. 7
TREATY No. 8
ASSEMBLY OF TREATY CHIEFS
RESOLUTION

"The Centre will promote, protect and advance the First Nations Ownership, Control, Access, Possession (OCAP™) principles. The Inherent Right to self-determination and jurisdiction in research and information management."

The Alberta First Nations
Information Governance Centre

Governance Structure



Truth & Reconciliation Call 19

We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.

Supporting Community Research

Evidence Based Decision Making

- The new standard that drives policy and program development
- Technology and data are growing at a rate we have never seen before, its important for our First Nation communities to address concerns of information poverty
- To move forward at the community level, it is important to learn and master the use of data to support change
- A way in which each First Nation can articulate their needs, successes, and challenges

OCAP ®

What is OCAP®

- Exercising First Nations Jurisdiction and governance over Information/Data
- About protecting individual privacy rights as well as collective community privacy
- All privacy legislation enacted is about protecting “individual privacy rights” there is no existing legislation to protect “collective privacy rights

Principles of OCAP®

Ownership

- relationship of First Nation community to its cultural knowledge/data/information (distinct from stewardship)

Control

- First Nation aspirations and rights to maintain, regain control in all areas of their lives (including research and data)

Access

- First Nations must have access to information about themselves and their communities, wherever it is held
- First Nations have a right to determine who accesses their information

Possession

- Possession (stewardship) is the mechanism to assert and protect ownership

Benefits of OCAP®

- Helps rebuild community trust in the power of data
- More democratic methods with higher participation rates
- Promotes First Nations analyses and perspectives with minimal bias and misinterpretation
- Contributes to community empowerment, self-determination, and encourages meaningful capacity development
- Produces more relevant and useful results, which lead to change

OCAP ® in Action

Community Profile Initiative

Community Profiles are made up of indicators which identify the socio-demographics within a community (Seattle Indian Health Board, 2011)

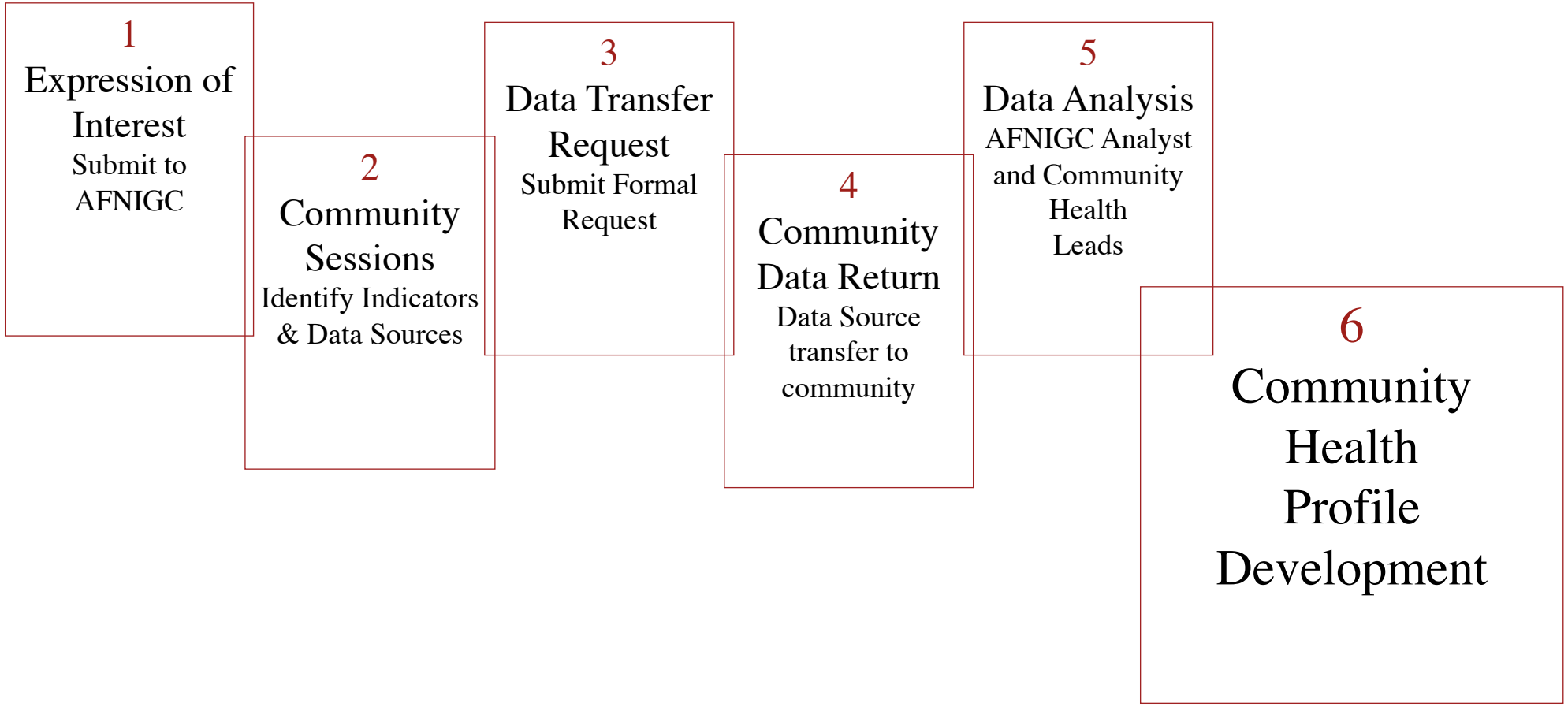
- This helps to identify areas of success and where improvements can be made (Seattle Indian Health Board, 2011)
- Used in a positive way to assist in creating better conditions to increase the health and well being of a community
- Knowing the data means knowing how to move forward

Why Community Profiles?

- Using data that already exists can support informed decision making, target priorities for community health improvement, guide new programs, build upon existing successful programs, and enhance analysis of local data
- Data help to identify risk factors, health trends, service gaps, and the health status of a specific population

Most of all, First Nation communities have the opportunity to contextualize their data and tell their story

Alberta First Nations Community Profile Process



Data Sources

Data sources are where the data comes from and to begin collecting their information, communities should:

- Select health indicators
- Consider what data sources are accessible

Existing data are available, but communities should begin to collect new local data for themselves.

Alberta Data Sources



Existing Data Sources

Alberta First Nations Information Governance Centre

- Regional Health Survey – Phase 2 and 3
- First Nations Regional Early Childhood, Education, and Employment Survey
- Canadian Partnership Against Cancer Project
- First Nation Cancer Prevention and Screening Practices Project
- Alberta Health/AFNIGC Health Trends

Existing Data Sources

Health Canada/FNIHB

- Non-Insured Health Benefits (Utilization rates in dental, prescriptions, mental health crisis counselling, MS&E, vision care, and medical transportation)
- NNADAP, Environmental Health (Microbial Water Testing), Injury Prevention Data, Notifiable Infectious Diseases (STI's), and Immunization Data

Existing Data Sources

INAC Program Data

- Indian Registry System
- Band Governance Management System
- Indian Government Support System
- Statistics Canada
- Grants & Contributions Information Management System
- Indian Land Registration System
- Integrated Capital Management System
- Specific Claims Branch Database

Existing Data Sources

INAC Program Data (con't)

- National Additions to Reserve Tracking System
- Education Information System
- First Nations Child & Family Services Information Management System
- Integrated Environmental Management System
- Income Assistance Data

Existing Data Sources

Alberta Health Administrative Data

- AH Care Insurance Plan
- Hospital In-Patient
- Ambulance
- Pharmaceutical Information Network

Community Health Indicators

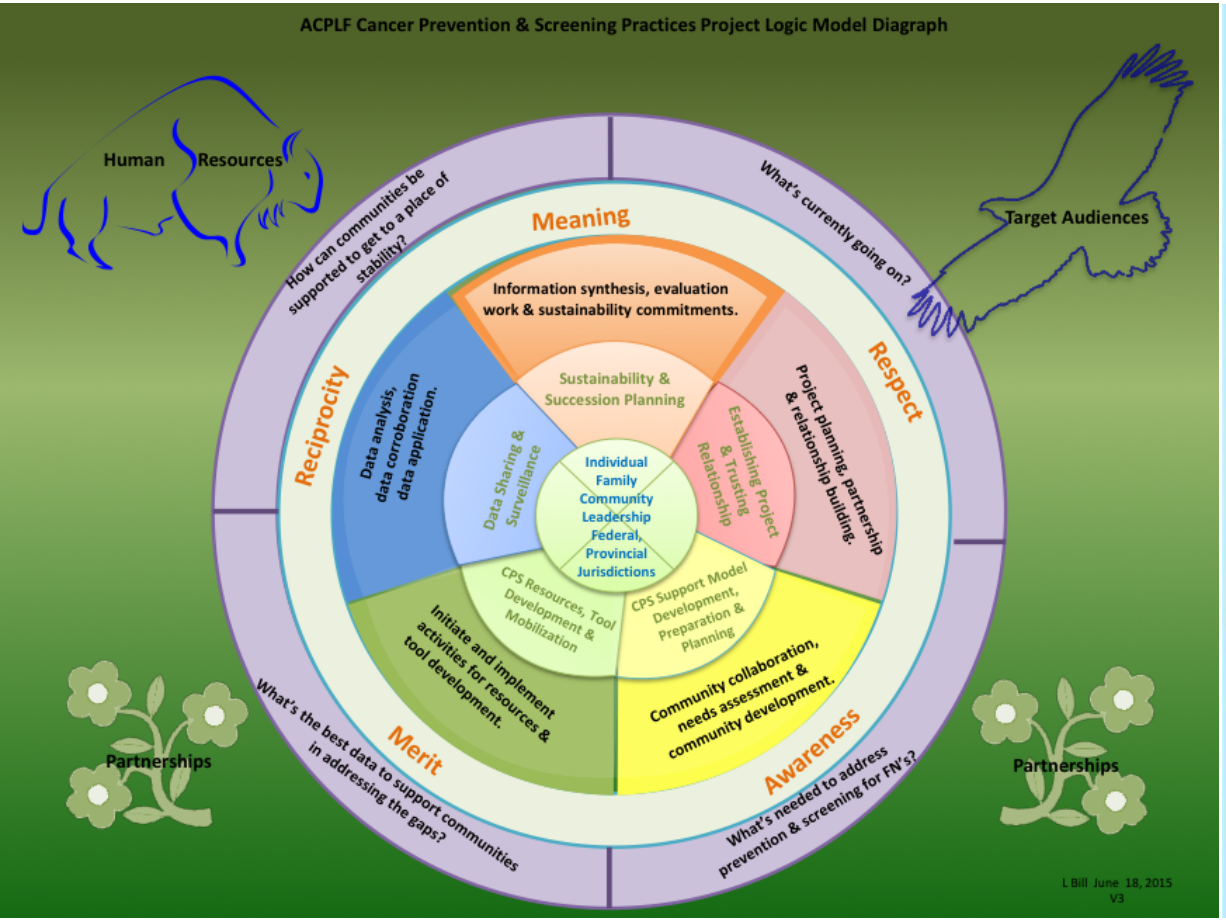
- “Disease stats and utilization data don’t tell us much about ‘health’ in a holistic and positive sense” (Rudderham, 2014)
- Many indicators measure deficits, which often overlooks the areas communities are experiencing successes.
- Therefore, communities need to choose their own indicators to contextualize their data sources and become their own data storytellers.

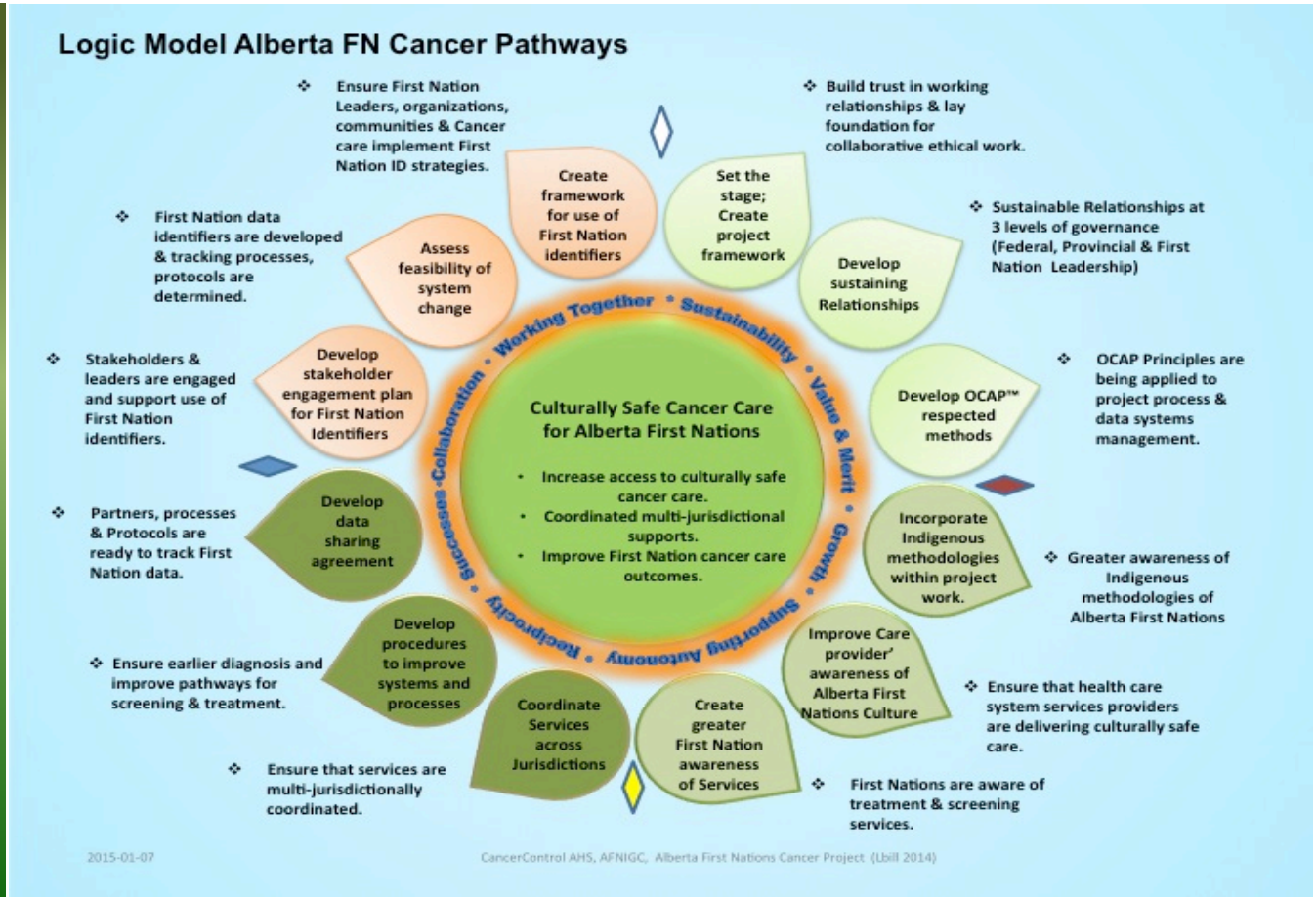
Indicator Frameworks

- Due to the large data sets it is best to establish a way to organize and identify health indicators

- It is equally important that communities are involved in the development of their indicator framework, as it will be the community that will establish a priority for placement of funding

Indigenous Logic Models





Alberta First Nations Community Profile Initiative Training

- OCAP Certification (Algonquin College)
- Ethical Space
- Evidence Based Decision Making
- Data 101
- Population Health
- Developing Indigenous Indicators
- Data Management
- Additional Training modules to be developed as requested by First Nation Communities

First Nations Health Information Working Group

- Dissolution of health premium payments in 2009 led to challenges in health surveillance for First Nations in Alberta
- Little support for actions aimed at protecting and promoting good health
- Assembly of Treaty Chiefs resolution for the formation of the Alberta First Nations Health Information Working Group (FNHIWG) to:
  - Gain Access to data held within the Indian Registry System (IRS)
  - Develop an Alberta First Nations Information Governance Agreement for data and health surveillance support
- By January 21, 2016 FNHIWG had:
  - Finalized their terms of reference
  - Drafted an application to the IRS
  - Began engagement and input from First Nation communities and leadership

FNHIWG Engagement

- Alberta First Nations Health Surveillance Work Plan – March 2016
- Support the ongoing work of the FNIHWG to respectfully engage and integrate First Nation partners
  - Phase 1 Preparations
  - Phase 2 Community Capacity Support
  - Phase 3 Implement First Nations Health Surveillance Practices
  - Phase 4 Evaluation of First Nations Health Surveillance Practices
- By February 12, 2016 the FNIHWG had
  - Finalized IRS application with signatures from Treaty 6, Treaty 7, Treaty 8 Grand Chiefs, Alberta Health, and Health Canada
  - Began preparations with communities

FNHIWG Submission

- Submission of application to INAC – Summer 2016
- Support campaign with Minister Bennett
- Community profiles support campaign for health and surveillance with First Nation partners
- By August 18, 2016 the FNHIWG had:
  - Received approval for the Indian Registry application
  - Began discussions with INAC for data transfer and size of data set

Access

- Increased access to data for health status assessment and surveillance
- Creating a wellness focused health system for First Nation communities
- Two information sharing agreements drafted:
  - Alberta First Nations Health Information Governance Agreement
  - Data Sharing Agreement between INAC and Alberta Health
- Community Profiles has begun in 3 First Nation communities with outreach for an additional 6 pilot communities

Publications

The Lancet Oncology Journal
In partnership with the World Health Organization

Rheumatology Journal

Alberta First Nations Regional Health Survey Report

Alberta Baseline Assessment Report
In partnership with the First Nation Cancer Pathways Project Team

First Nations Health Trends Alberta one-page reports
In partnership with Alberta Health

Data Resources and Challenges for First Nation Communities
Literature Review

Questions?

References

Urban Indian Health Institute, Seattle Indian Health Board. (2011). Community Health Profile: Denver Indian Health and Family Services. Seattle, WA: Urban Indian Health Institute

Rudderham, S. (2014, February 14). Moving Toward Excellence in First Nation Health Information Management: How First Nations in Unama'ki Have Increased Access and Use of Population Health Surveillance Data. Lecture presented at First Nation Story Telling Through Data Workshop Series in TCU Place, Saskatoon.



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