



## The Alberta First Nations Information Governance Centre

2<sup>nd</sup> Annual Canadian Homelessness Data  
Sharing Initiative

Bonnie Healy, RN

May 19, 2017



# Our Organization

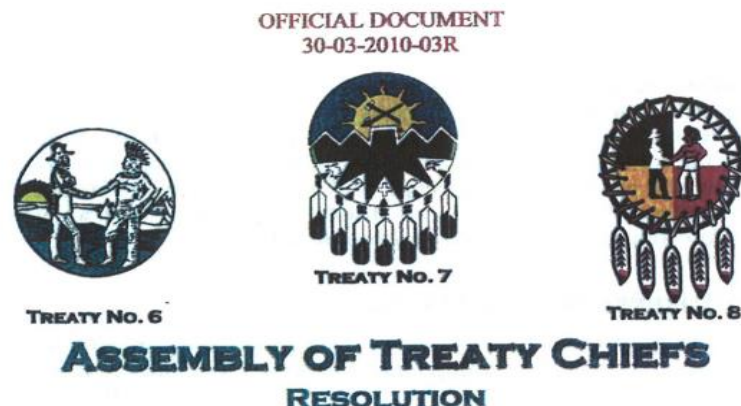
- Incorporation
- Governance
- Mandate
- First Nations Owned Servers
  - “Protecting Our Knowledge, Telling Our Stories, Strengthening Our Communities”

The Alberta  
First Nations  
Information  
Governance  
Centre



The Alberta First Nations  
Information Governance Centre

# Alberta OCAP® Resolution

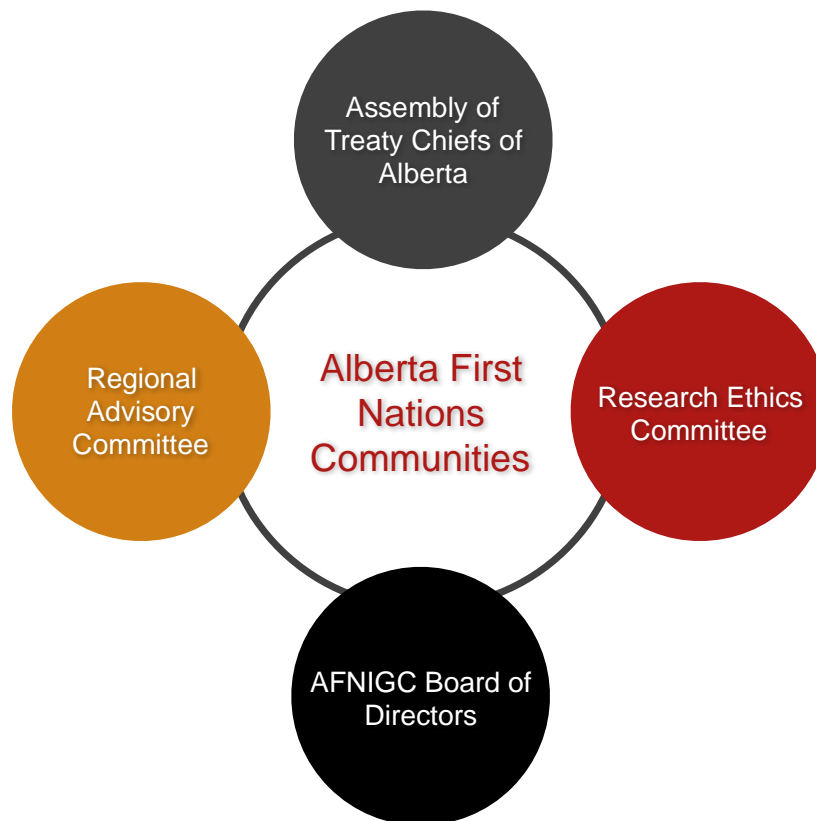


“The Centre will promote, protect and advance the First Nations Ownership, Control, Access, Possession (OCAP™) principles. The Inherent Right to self-determination and jurisdiction in research and information management.”



The Alberta First Nations  
Information Governance Centre

## Governance Structure



# 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

# Why OCAP®



- First Nation information is important for First Nation governance
- Government practice has disconnected us from building our own system of information governance
- First Nation communities set the priorities, establish ethical engagement and the right to contextualize data

OCAP® is not a checklist for non-Indigenous interactions with First Nation communities. It is a pathway forward in respectful relationship building for First Nation communities.

# Health Trends First Nations Alberta



## *Partners*

Alberta First Nations, AFNIGC, & Alberta Health

## *Purpose*

Mobilize existing data sets for community use, awareness of current health trends in First Nations in Alberta

## *Implementation*

OCAP® driven practice for community data use and partnership development with the Alberta Health ministry

## Waterborne disease rates in First Nations in Alberta

### Waterborne disease rates due to drinking water by First Nations status, Alberta, 2000-2015

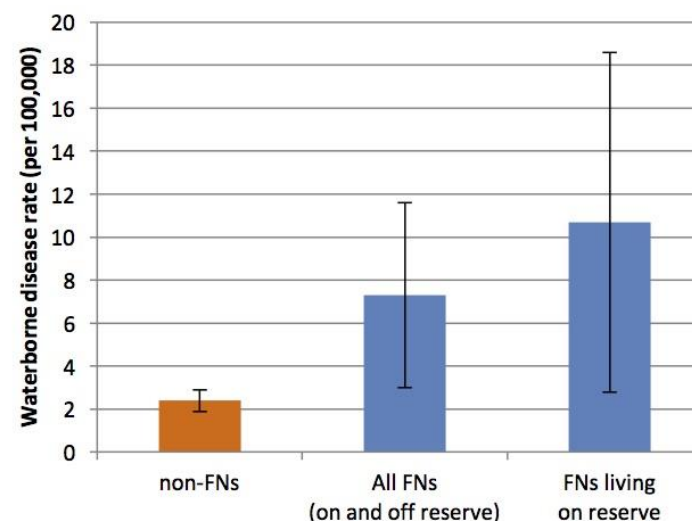
Infectious gastrointestinal diseases can cause nausea, vomiting, or diarrhea. These diseases can be contracted by humans through contact with animals, through person to person transmission, or through contaminated food. They may also be transmitted through the ingestion of untreated or inadequately treated water; when this happens, these diseases are often referred to as ‘waterborne’. The largest outbreak of waterborne disease reported in Canada occurred due to inadequately treated water contaminated with *E. coli* in Walkerton, Ontario in 2000.<sup>1</sup>

This edition of First Nations – Health Trends Alberta<sup>2</sup> describes the rate of waterborne disease likely acquired from drinking water in Alberta in First Nations people, First Nations people living on reserve, and non-First Nations people. Disease due to *Campylobacter*, *Amoebia*, *Giardia*, verotoxigenic *E. coli*, *Salmonella*, *Shigella*, *Cryptosporidium* and other waterborne diseases were included in the analysis.

### Rate of waterborne diseases attributed to drinking water in First Nations living on reserve is quadruple those in non-First Nations

Between 2000 and 2015, there were 869 cases of waterborne disease acquired in First Nations in Alberta: 11 of these cases were attributed specifically to drinking water (1.3% of total); 7 of these were observed in individuals who were living on reserve. In non-First Nations over the same time period, there were 32,343 cases of waterborne disease: 81 of these cases were due specifically to drinking water (0.3% of total).

The rate of waterborne disease due to drinking water in all First Nations in Alberta, regardless of location of residence, was 7.3 per 100,000 population in 2000-2015 (95% confidence interval (CI): 3.0, 11.6). This was three times higher than the rate observed in non-First Nations over the same time period: 2.4 per 100,000 (95% CI: 1.9, 2.9). For First Nations living on reserve, the rate of waterborne disease due to drinking water was over four times higher than the rate for non-First Nations (10.7 per 100,000; 95% CI: 2.8, 18.6).



<sup>1</sup> Waterborne outbreak of gastroenteritis associated with a contaminated municipal water supply, Walkerton, Ontario, May-June 2000. Can Commun Dis Rep. 2000 Oct 15;26(20):170-3.

<sup>2</sup> This is the third in a series of First Nations-specific Health Trends compiled in collaboration by Alberta Health and the Alberta First Nations Information Governance Centre (AFNIGC). To suggest future topics, please contact the AFNIGC ([communications@afnigc.ca](mailto:communications@afnigc.ca); 403-539-5775).



## Alberta Budget 2017: \$100M committed for clean drinking water on First Nations



By Caley Ramsay

Online Journalist Global News

Comments 13

Facebook 6.5k

Twitter

Email

Print

...



File: Tap water fills a glass.

Philippe Huguen/AFP/Getty Images

Listen

- A A +

The Grand Chief of the Confederacy of Treaty Six First Nations is pleased with the Alberta government's commitment to ensure all First Nations across the province have access to safe drinking water.

"I'm very, very encouraged. I think it's a very important step in terms of providing access to clean water," Willie Littlechild said Thursday.

"We shouldn't have had to wait this long to have access to clean water."



# First Nations Health Status Report



## *Partners*

Alberta First Nations, AFNIGC, Alberta Health MOH, FNIHB Alberta MOH

## *Purpose*

Develop a Alberta First Nations Health Status Report



The Alberta First Nations  
Information Governance Centre



Health  
Canada

Santé  
Canada



Indigenous and  
Northern Affairs Canada

# **Working together:**

## **Compiling First Nations health information through community-government partnerships**

**First Nations Health Information Governance Working Group**

# Cancer Incidence in Indigenous people in Australia, New Zealand, Canada, and the USA; comparative population-based study





**Cancer incidence in Indigenous people in Australia, New Zealand, Canada, and the USA: a comparative population-based study**

*Suzanne P Moore, Sébastien Antoni, Amy Colquhoun, Bonnie Healy, Lis Ellison-Loschmann, John D Potter, Gail Garvey, Freddie Bray*



*I acknowledge the traditional custodians of this land, the Jagara and Turrbal nations. I wish to pay respects to the elders past and present, and acknowledge the cultural heritage and beliefs that are still as important to the living Aboriginal and Torres Strait Islander people today.*



# Walking Together, Working Together



- Establishing working relationships by limiting the number of participants and seeking to maintain stable membership
- Respecting Ownership, Control, Access, and Possession (OCAP®)
- Respectful negotiations and discussions
- Building a safe/ethical space
- Shared common goal – working towards better health outcomes
- Connecting through multiple projects

A. Colquhoun, 2016

# Outline



- First Nations health information: current status, ongoing work, and proposed solutions
- Why support the compilation of First Nations-specific health information?

# Background



## Population

Total in 2011 = 3,568,000

3.3% First Nations

2.7% Metis

0.1% Inuit



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## First Nations in Alberta

1. Athabasca Chipewyan First Nation
2. Beaver First Nation
3. Bigstone Cree Nation
4. Chipewyan Prairie First Nation
5. Dene Tha' First Nation
6. Driftpile First Nation
7. Duncan's First Nation
8. Fort McKay First Nation
9. Fort McMurray First Nation
10. Horse Lake First Nation
11. Kapawe'no First Nation
12. Little Red River Cree Nation
13. Loon River First Nation
14. Lubicon Lake Indian Nation (no reserve)
15. Mikisew Cree First Nation
16. Sawridge Band
17. Smith's Landing First Nation
18. Sturgeon Lake Cree Nation
19. Sucker Creek First Nation
20. Swan River First Nation
21. Tailcree First Nation
22. Whitefish Lake First Nation (Atikameg)
23. Woodland Cree First Nation
24. Alexander First Nation
25. Alexis Nakota Sioux First Nation
26. Beaver Lake Cree Nation
27. Cold Lake First Nations
28. Enoch Cree Nation
29. Ermineskin Cree Nation
30. Frog Lake First Nation
31. Heart Lake First Nation
32. Kehewin Cree Nation
33. Louis Bull Tribe
34. Montana First Nation
35. O'Chiese First Nation
36. Paul First Nation
37. Saddle Lake First Nation
38. Samson Cree Nation
39. Sunchild First Nation
40. Whitefish Lake First Nation #128 (Goodfish Lake)
41. Blood Tribe
42. Piikani Nation
43. Siksika Nation
44. Stoney Tribe
  - Bearspaw (Eden Valley)
  - Chiniki (Morley)
  - Wesley (Big Horn)
45. Tsuu T'ina Nation



# Background



## Alberta Cancer Registry

### Population

Total in 2011 = 3,568,000

3.3% First Nations

2.7% Metis

0.1% Inuit



### Articles

#### Cancer incidence in indigenous people in Australia, New Zealand, Canada, and the USA: a comparative population-based study



Suzanne P Moore, Sébastien Aronow, Amy Colquhoun, Bonnie Healy, Li Ellison-Loschmann, John D Potter, Gail Garvey, Freddie Bray

##### Summary

**Introduction** Indigenous people have disproportionately worse health and lower life expectancy than their non-indigenous counterparts in high-income countries. Cancer data for indigenous people are scarce and incidence has not previously been collectively reported in Australia, New Zealand, Canada, and the USA. We aimed to investigate and compare, for the first time, the cancer burden in indigenous populations in these countries.

Lancet Oncol 2015  
Published Online  
October 15, 2015  
[http://dx.doi.org/10.1016/S1473-2045\(15\)00322-6](http://dx.doi.org/10.1016/S1473-2045(15)00322-6)

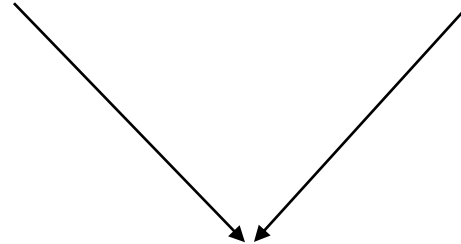
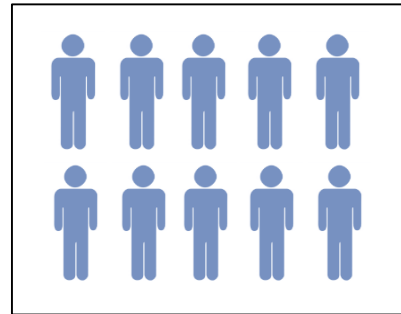
# Background



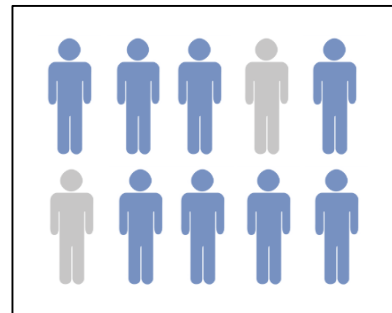
Alberta Health Care  
Insurance Plan Registry  
(First Nations Identifying  
Information)



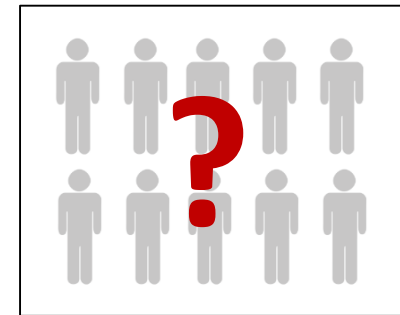
## Alberta Cancer Registry



## First Nations Individuals Identified



# Current challenges



2009

Health premiums  
eliminated

No additional  
external information

2016

First Nations  
identifiers less  
reliable

# Current challenges



- It's becoming more difficult to provide accurate First Nations-specific numbers...
  - Health premiums not collected after 2009
  - First Nations identifying information no longer updated
- Ownership, Control, Access, Possession (OCAP™)
  - Ensure that accountability, respect, ethics, values and information processes are protected and advanced



- **June 2013:** Assembly of Treaty Chiefs resolution requests that data-related issues be addressed



# First Nations Health Information Governance Working Group



## Together, we aim to:

1. Apply for access to the Indian Registration System
2. Develop an Alberta First Nations Information Governance Agreement
3. Explore options to identify out-of-province registered First Nations residing in Alberta
4. Explore options to enhance data validity with other partners and stakeholders



The Alberta First Nations  
Information Governance Centre

Alberta  
Government



Health  
Canada

Santé  
Canada

## Indian Registration System (IRS) Data Access Request

To: Aboriginal Affairs and Northern Development Canada

Submitted by: Alberta First Nations Information Governance Centre  
Alberta, Canada on behalf of the First Nations Health Information  
Working Group

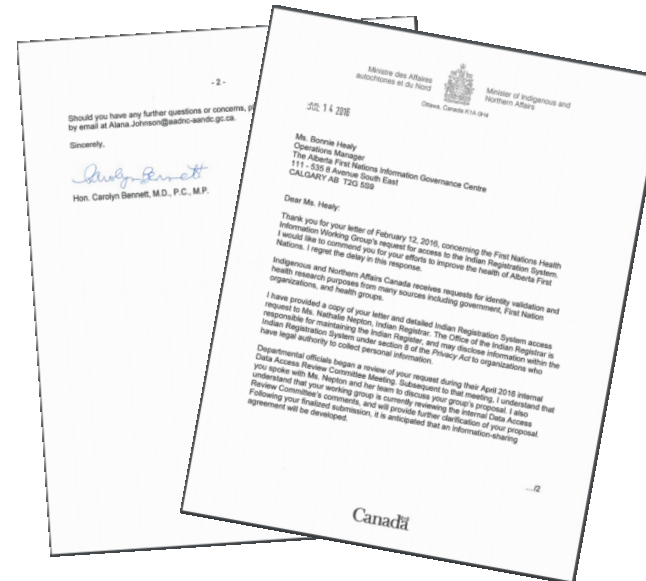
# Application process:



Support for application received from:

- Health Protection Sub-Committee
- Health Co-Management
- Grand Chiefs Alexis, Weaselhead, and Courtoreille
- Alberta First Nations Information Governance Centre
- Alberta Health
- First Nations and Inuit Health – Alberta Region
- Indigenous and Northern Affairs Canada

Also received letter of support from INAC Minister Bennett.



# Current status of application:

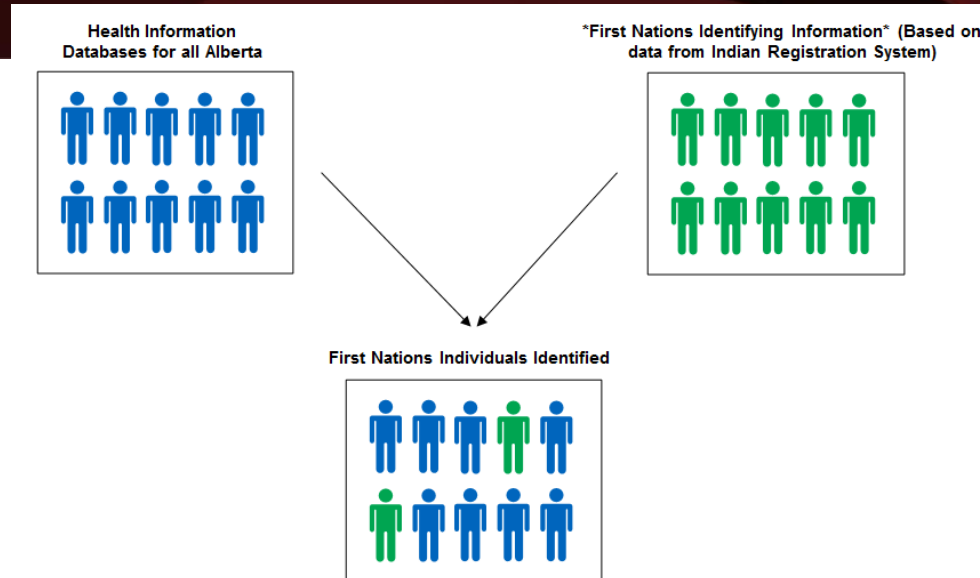


## Successful!

- INAC's Data Access and Review Committee has granted us permission to develop an information sharing agreement that will permit the movement of IRS data to Alberta Health (need to draft ISA and PIA).
- We received permission to receive IRS data from across Canada so that all First Nations residing in Alberta will be included:

In 2009, 21.1% of First Nations living in Alberta (almost 33,000 people) were affiliated with a First Nation outside of the province.

# Why Alberta Health?



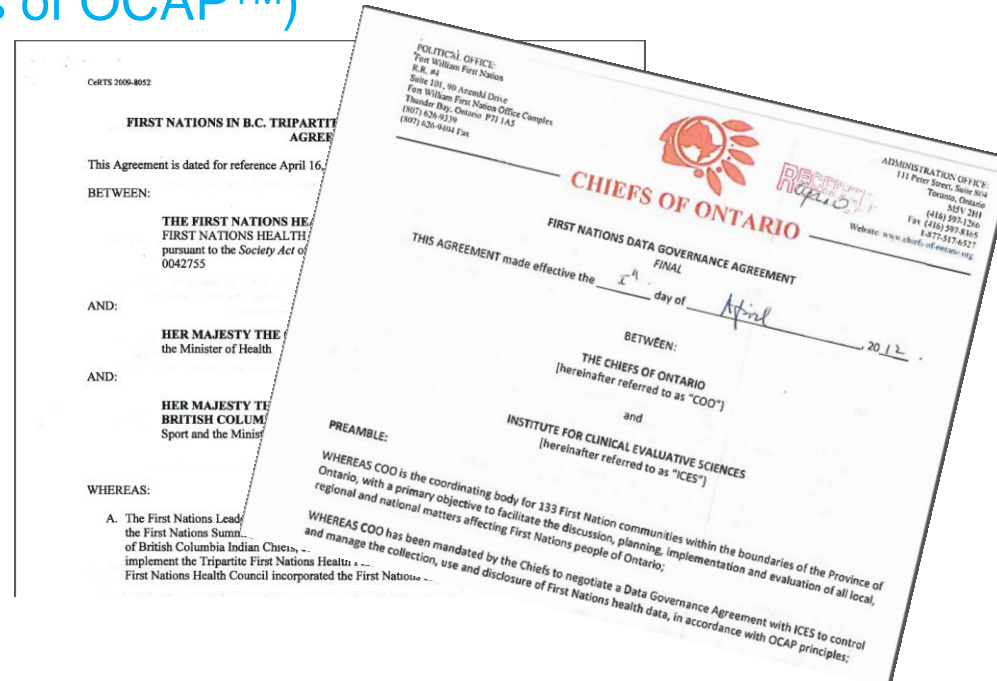
- Home of numerous health-related databases
- Privacy legislation prevents the sharing of individual-level health data
- Existing infrastructure and capacity
- Promote OCAP principles through meaningful and respectful data management and use
- Support existing data relationships with FNs communities
- Help 'clean' data (e.g. identify who has passed away)

# Together, we aim to:



## 2. Develop an Alberta First Nations Information Governance Agreement and Public Health Surveillance Framework

(ensure that data are managed and used in a way that fulfills legislative requirements while also taking into account the principles of OCAP™)



# Outline



- First Nations health information: current status, ongoing work, and proposed solutions
- Why support the compilation of First Nations-specific health information?

# Ultimate Goal



36824  
105346  
98705  
2091

**Support First Nations  
communities in Alberta  
so they can tell their  
own (data) stories**

# What is a Community Profile?



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?



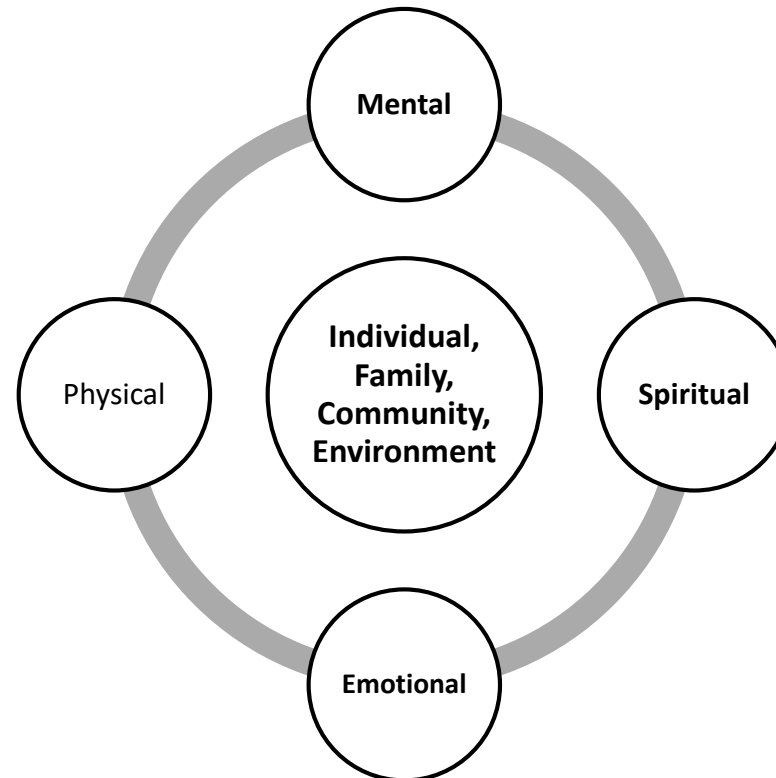
- Using data that already exists can support informed decision making, target priorities for community health improvement, guide new programs, build upon existing successful programs, and enhance analysis of local data
- Data help to identify risk factors, health trends, service gaps, and the health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

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

# Health Status Definition



First Nations describe health as balance between various elements. These include the Physical, Mental, Emotion and Spiritual aspects of life and include environment, culture, family and community.



# 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



# 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.

# How healthy are Canadians?



The focus of indicators is on:

- Well Being
- Health Conditions
- Health Function
- Death

Non Medical Determinants:

- Health Behaviors
- Living and working conditions
- Personal Resources
- Environmental Factors

# Indicator Frameworks

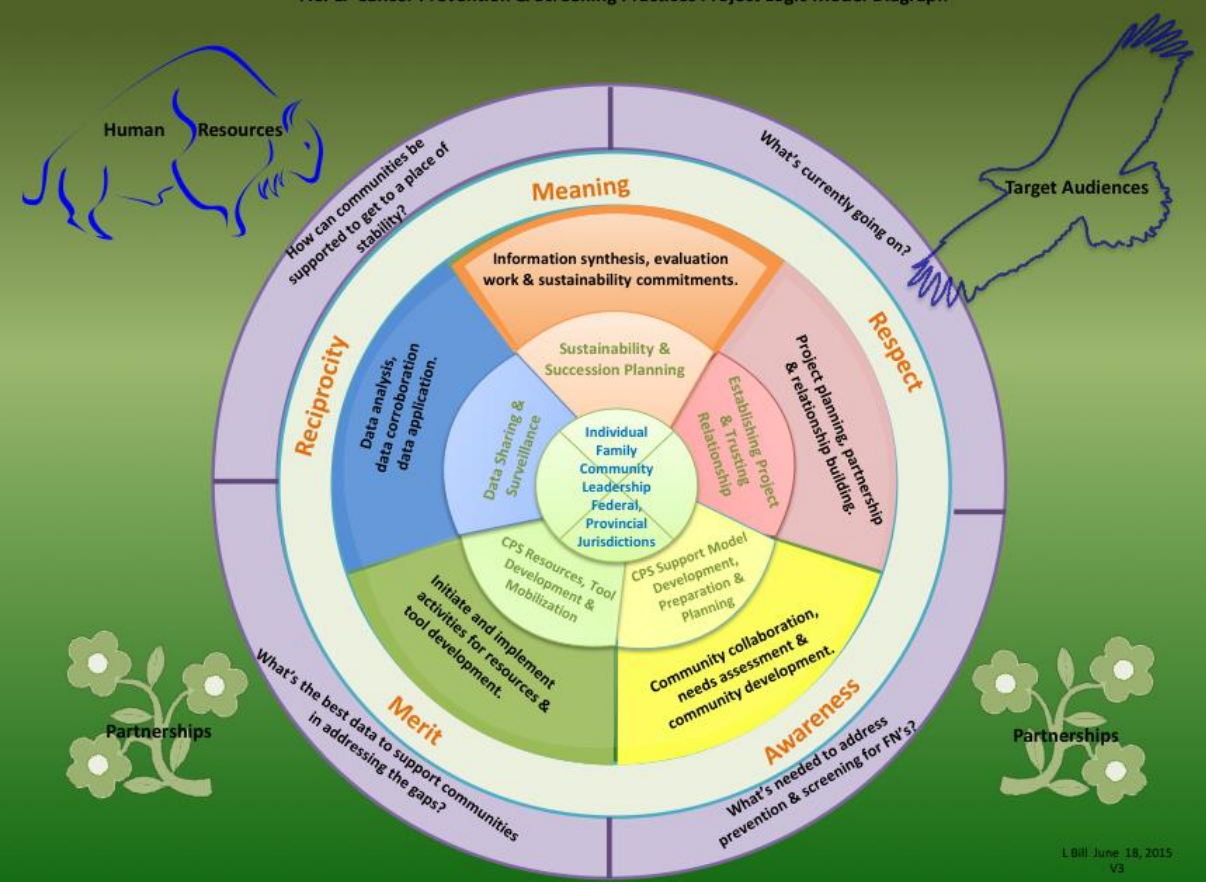


- Due to the large data sets it is best to establish a way to organize and identify health indicators
- It is equally important that communities are involved in the development of their indicator framework, as it will be the community that will establish a priority for placement of funding

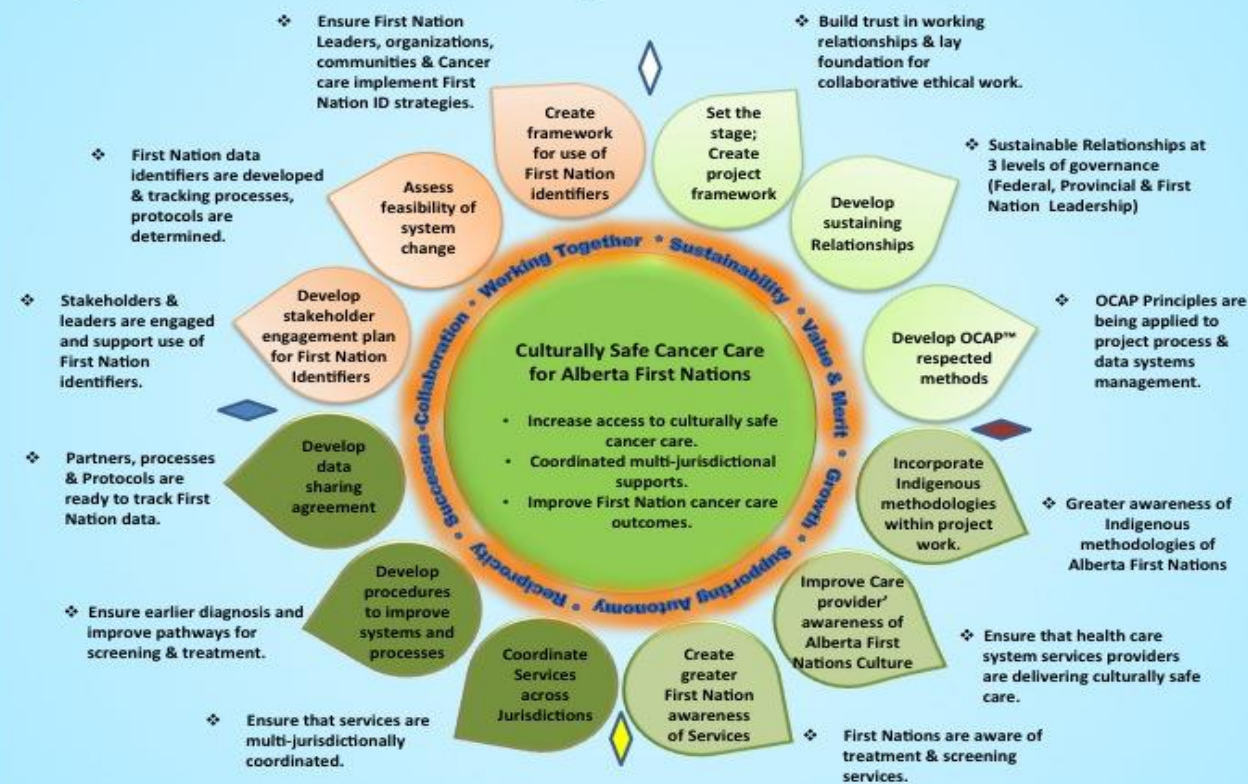
# Indigenous Logic Models



ACPLF Cancer Prevention & Screening Practices Project Logic Model Diagram



Logic Model Alberta FN Cancer Pathways



2015-01-07

CancerControl AMS, AFNIGC, Alberta First Nations Cancer Project (Lbill 2014)

# 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



Colquhoun, Amy. (2016) *Working together: Compiling First Nations health information through community-government partnerships*. [PowerPoint slides].

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.



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

## Contact Us

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