

Indigenous Health Data and the Path to Healing



International Population Data Linkage Network 2018

Banff, Alberta

September 12, 2018

Jennifer Walker, PhD

Haudenosaunee – Six Nations of the Grand River

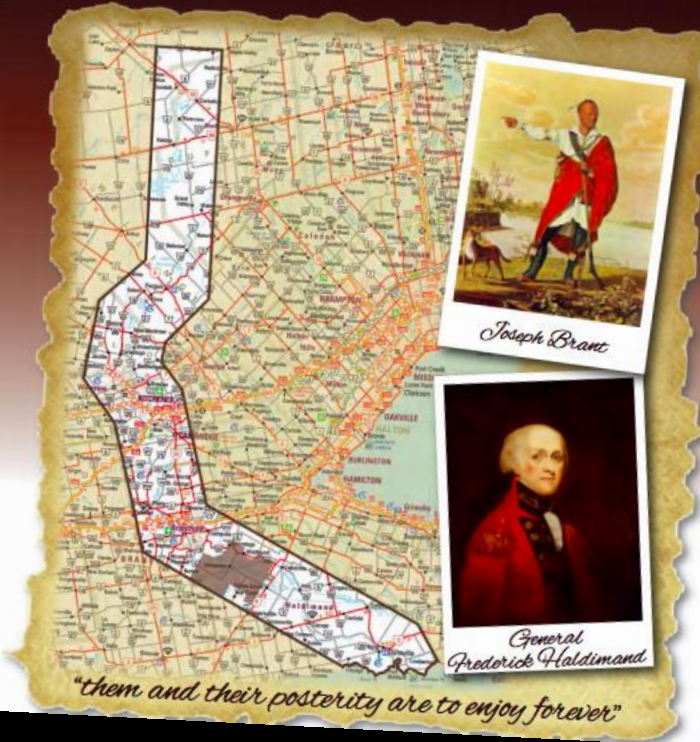
Canada Research Chair in Indigenous Health, Laurentian University

Scientist and Indigenous Lead, ICES

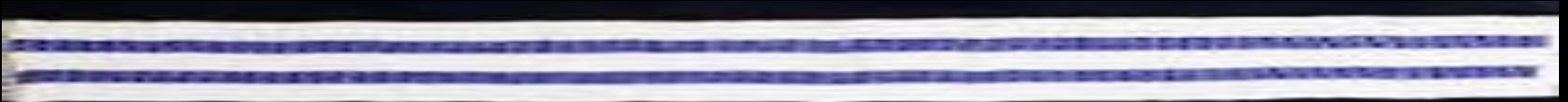


Six Miles Deep

LAND RIGHTS OF THE SIX NATIONS OF THE GRAND RIVER



Two Row Treaty of 1613



“Together we will travel in Friendship and in Peace Forever; as long as the grass is green, as long as the water runs downhill, as long as the sun rises in the East and sets in the West, and as long as our Mother Earth will last.”



Article 3 – right to **self determination**

Article 4 – right to **autonomy** and **self-government**

Article 5 – right to maintain and strengthen **distinct** political, legal, economic, social and cultural **institutions**

Article 15 (i) – right to dignity and **diversity** of cultures traditions, histories and aspirations which shall be appropriately reflected in education and **public information**

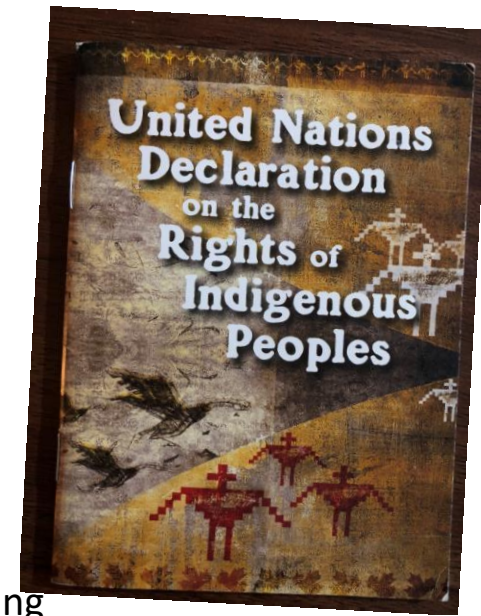
Article 18 – right to participate in decision-making in matters that would affect rights...and to develop indigenous **decision-making institutions**

Article 19 – States shall...obtain **free, prior and informed consent** before adopting and implementing legislative or administrative measures that may affect them

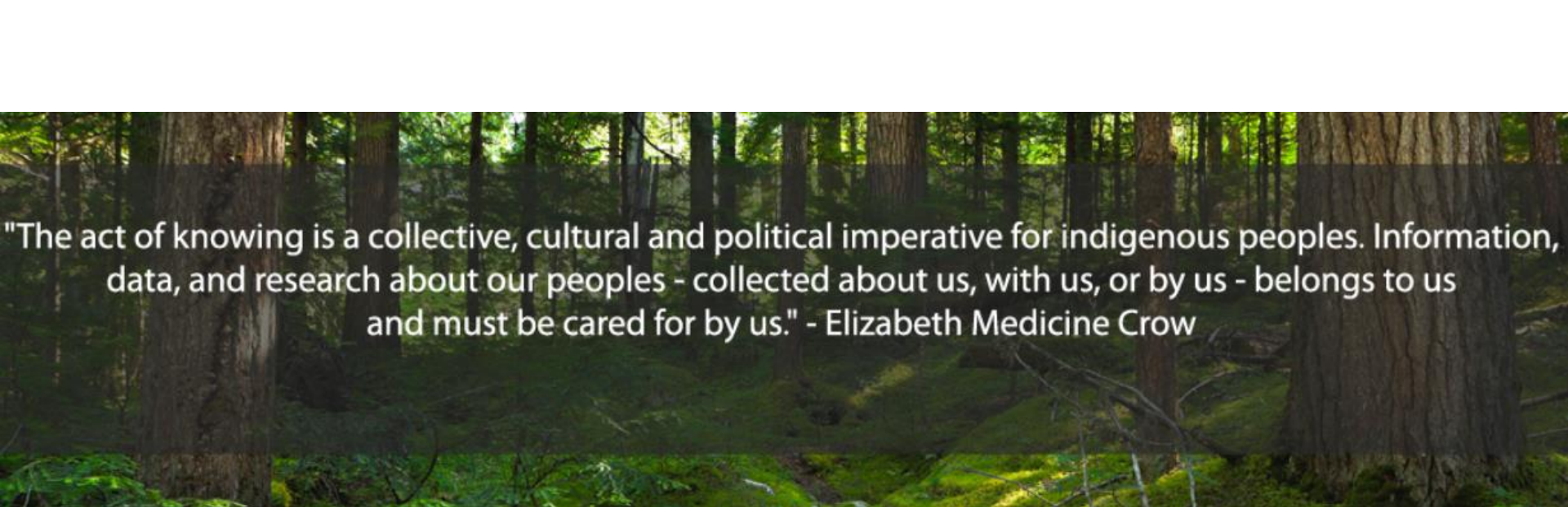
Article 23 – right to determine and develop **priorities and strategies**...and to administer **programs** through their own institutions if possible

Article 31 – right to maintain, control, protect and develop **intellectual property**

Article 33 – right to **determine their own identity or membership**. Right to determine structures and select membership of their institutions



2007

A photograph of a forest floor with moss and tree trunks. The image shows a dense forest with many tree trunks and a ground covered in green moss. Sunlight filters through the trees, creating a dappled light effect on the forest floor.

"The act of knowing is a collective, cultural and political imperative for indigenous peoples. Information, data, and research about our peoples - collected about us, with us, or by us - belongs to us and must be cared for by us." - Elizabeth Medicine Crow

Indigenous data:

- Data about our resources and environments
- Data about us as individuals
- Data about us as Nations

Genetic researcher uses Nuu-chah-nulth blood for unapproved studies in Genetic Anthropology

 Like 13

 Share 13

 G+

 Share

 Save

 Tweet

Published on September 21, 2000



Canada's Oldest First Nation's Newspaper

For the hundreds of Nuu-chah-nulth people suffering the debilitating effects of arthritis, Dr. Richard Ward's groundbreaking study in the early 1980s was like a beacon of hope. But in the following years of no communication between medical researchers and their Nuu-chah-nulth subjects, that light has dimmed, flickered out, and has almost been forgotten.

Yet, after 15 years of waiting, many Nuu-chah-nulth people are now discovering that the blood they volunteered to help find a cure for rheumatic diseases has traveled the world, and has been used in a variety of genetic anthropology studies; outside the boundaries

of the consent forms they signed.



After months of trying to contact Dr. Richard Ward, the Oxford professor has finally responded, saying he is willing to do whatever Nuu-chah-nulth want done with their blood.

Question: You've seen the story in *Ha-Shilth-Sa* on the blood samples you took in the 1980's. What is your response to that story?

Answer: "It's always been my policy that any individual who participates in a study, who wants to withdraw from the study and have material destroyed, or who wants to have their samples placed in a repository, that those requests are always honoured. That's actually written

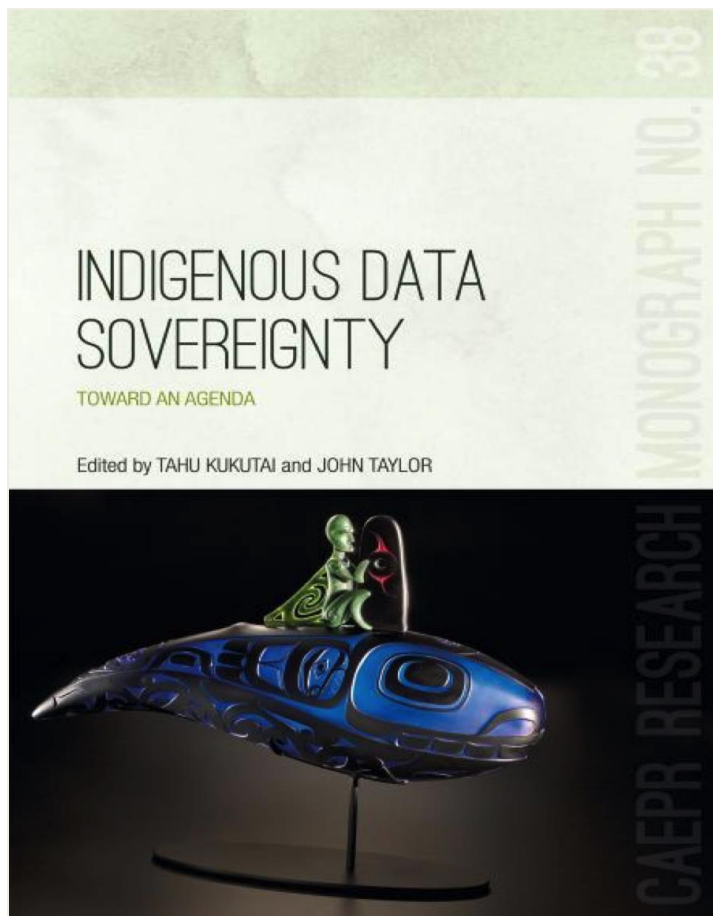
in the original consent form."

Question: But how could people do this when they had no idea where you, or their blood samples were?

Answer: "That's my fault and I accept the responsibility for that. It was not intended to be a bad thing, but that's one of the things I want to apologize for. I still accept the responsibility for not letting people know that [other studies] could be happening."

Question: So what do you see happening now?

Answer: "As I see it we can do one of three things: we can destroy the data so it's as if they never participated, and if we have any biological material we would destroy those too. If they want biological



THE LANCET

[Online First](#) [Current Issue](#) [All Issues](#) [Special Issues](#) [Multimedia](#) [Information for Authors](#)

All Content

Search

[Advanced Search](#)

[< Previous Article](#)

Volume 390, No. 10107, p2022–2023, 4 November 2017

[Next Article >](#)

Comment

Indigenous health data and the path to healing

Jennifer Walker, Ray Lovett, Tahu Kukutai, Carmen Jones, David Henry

Published: 04 November 2017

[PlumX Metrics](#)

DOI: [http://dx.doi.org/10.1016/S0140-6736\(17\)32755-1](http://dx.doi.org/10.1016/S0140-6736(17)32755-1) | [CrossMark](#)



[Article Info](#)

Summary

Full Text

References

The health disadvantages of Indigenous peoples around the world have their roots in colonisation and discrimination and are related to a loss of autonomy over lands and culture. This history has profoundly affected social determinants of health, such as poverty and marginalisation, and contributed to higher rates of communicable and non-communicable diseases in Indigenous people, and life expectancies that are typically 5 years or more lower than in non-Indigenous populations.^{1,2} Despite persistent health inequities, Indigenous peoples are determining the path to healing their communities.

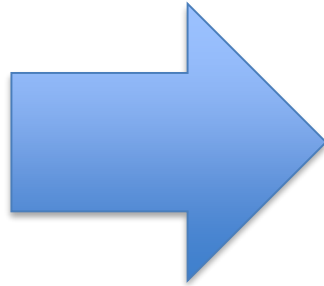
TWO CONDITIONS for Data Sovereignty

Decolonization
of Data

Indigenous
Data
Governance

5Ds of Colonizing Indigenous Data

- Disparity
- Depravation
- Disadvantage
- Dysfunction
- Difference



- Classifies us as “problematic”
- Data used to rationalize dispossession & marginalization, and to perpetuate narratives of dependency



©2014 Christi Belcourt, *The Wisdom of the Universe*

THE INTERDEPENDENCE OF NATION REBUILDING AND DATA REBUILDING



Rodriguez-Lonebear, D. and Rainie, S., (2017), JIT Law 631N, Tucson, AZ: Native Nations Institute, Udall Center for Studies in Public Policy, University of Arizona. Informed by Smith, D., (2016), Governing data and data for governance: the everyday practice of Indigenous sovereignty, in T. Kukutai & J. Taylor (Eds.), Indigenous data sovereignty: Toward an agenda (pp. 253-272), Canberra, Australia: Australian National University Press.



First Nations Information
Governance Centre in
Canada

2010

Te Mana Raraunga –
Māori Data Sovereignty
Network

2015

US Indigenous Data
Sovereignty Network

2016

Maiaṃ mayri Wingara
Indigenous Data
Sovereignty Collective in
Australia

2018

International Indigenous
Data Sovereignty Interest
Group at Research Data
Alliance

2017

DRAFT INDIGENOUS DATA GOVERNANCE PRINCIPLES

1. **Inherent sovereignty:** Indigenous peoples have the right to self-determination; with respect to data, this has implications for ownership, control, and access.
2. **Indigenous knowledge:** Indigenous data governance serves to honor Indigenous knowledge, asserting that such knowledge is of the peoples and includes relationships to the non-human world.
3. **Protection:** ethics; equal explanatory power; equitable outcomes.
4. **Intergenerational collective wellbeing:** Data need to align with Indigenous values for collective well-being across generations, and be past, present, and future oriented.
5. **Relationships:** The governance of Indigenous data requires respect, responsibility, reciprocity, and accountability between Indigenous nations and their peoples and other stakeholders.

First Nations Data Governance Principles

– OCAP®

- Refers to the rights of First Nations to own, protect and control how First Nations-specific data are collected, accessed and used
- Collective and individual rights are important

OWNERSHIP

CONTROL

ACCESS

POSSESSION



Inuit Qaujimajatuqangit (IQ) Principles

“that which Inuit have always known to be true”

Pijitsirniq

- The concept of serving

Aajiiqatigiingniq

- The concept of consensus decision-making

Pilimmaksarniq

- The concept of skills and knowledge acquisition

Piliriqatigiingniq

- The concept of collaborative relationships or working together for a common purpose

Avatimik Kamattiarniq

- The concept of environmental stewardship

Qanuqtuurnarniq

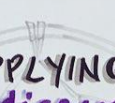
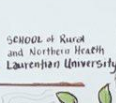
- The concept of being resourceful to solve problems

Inuuqatigiitsiarniq

- Showing respect and a caring attitude for others

Tunnganarniq

- Being welcoming to others, open in communications and inclusive in the ways of interacting



APPLYING Indigenous DATA SOVEREIGNTY PRINCIPLES

WHEN DOES ART BECOME *Spiritual*?

INDIGENOUS focus that is **ALIVE**

Research Critical Thinking Philosophy

IT CAN BE LONELY at conferences

THE TIME IS NOW

OUR KNOWLEDGE KEEPERS must Lead the Conversation

DATA COLLECTED By Us... For Us...

Traditional Data

Environment & Resources Individuals NATIONS

KNOWLEDGE belongs to the Collective

FUNDING \$\$\$ SHARING INFORMATION

WE SEEK MEANINGFUL PARTNERSHIPS

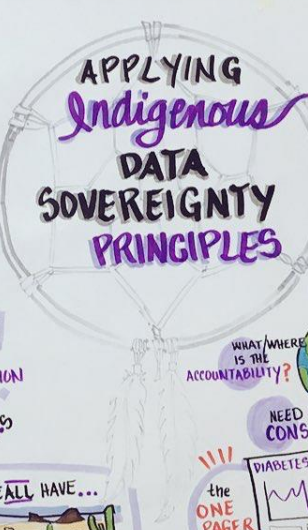
GUIDED BY OUR **VALUES & ETHICS**

INDIGENOUS PEOPLE around the world are working on DATA GOVERNANCE mechanisms

Small community data must be PROTECTED

LEGISLATION REFORM RESPECT for EACH Nation is needed

WE'LL HAVE... DATA DESERTS



WE RECOGNIZE WE ARE SOVEREIGN --- STEWARDS of the LAND --- ALL EQUAL

PATHWAYS to **SELF-DETERMINATION**

Conversations are happening at all levels of governance... community... tribal... government

DEFINE SOVEREIGNTY in our own Language

our language is **ALIVE**

CHANGE THE HOLLOW TREATY STORY

BUILDING ALLIES

community level RELATIONSHIPS

DATA MANAGEMENT SYSTEM

MAMOW AHYAMOWEN Everyone's Voices

meaningful PARTNERSHIPS

WORKING WITH PARTNERS TO HIRE & RETAIN SPECIALISTS (epidemiologists)

ONLINE TRAINING

COMMUNITIES moving... FROM PAPER to EMRs

WORKING WITH EXPERTS to BUILD Capacity

LANGUAGE Translation

KEEPING the CANOE Afloat

REAL changing PERSPECTIVES

OUR DATA isn't reflective of our COMMUNITIES

GROWING POPULATION

MOBILITY of POPULATION

JURISDICTION

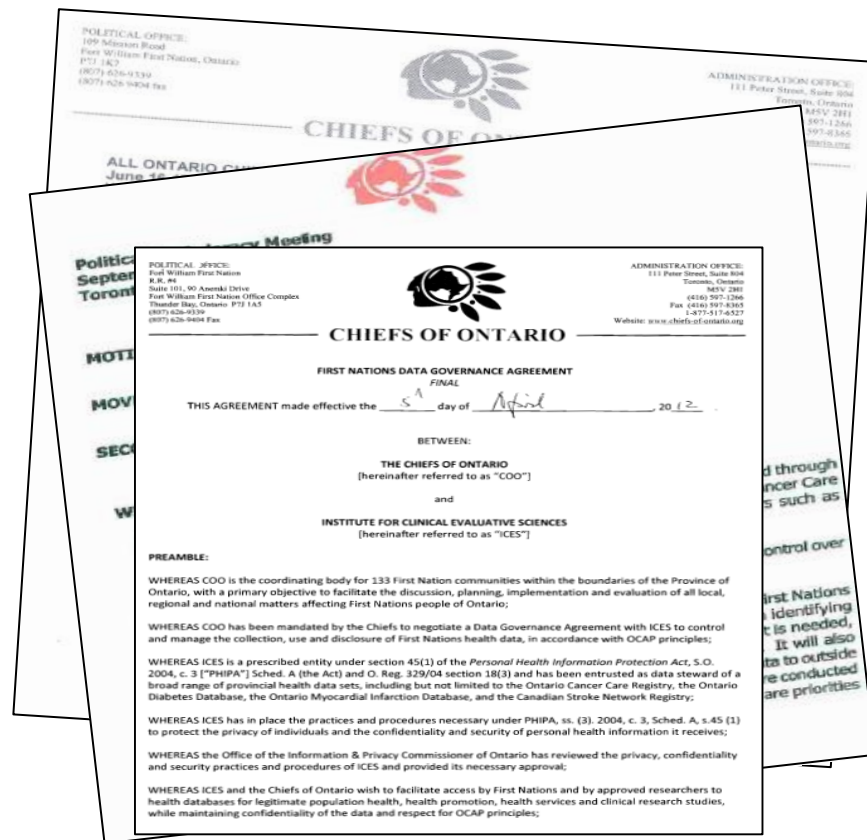
ability to ANALYZE our own DATA

making our **STORIES** REAL

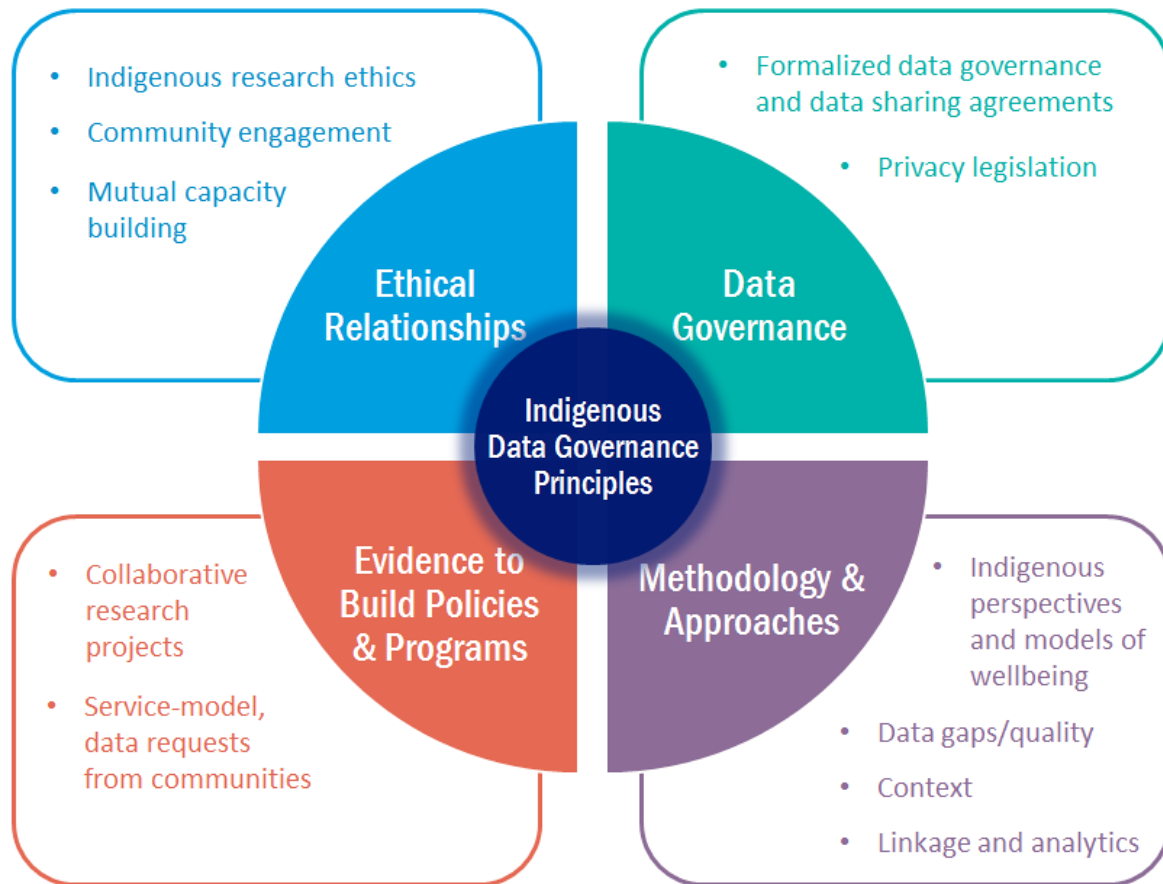
First Nations Data Linkage

- Linked data being used for surveillance and research by First Nations across Canada
 - At least 6 First Nations regions are accessing provincial data through linkage
 - Requires partnership, relationship, agreements

Building Relationships



Framework for working with Indigenous data at ICES



Initially developed with the Chiefs of Ontario for working with First Nations data

Cancer in First Nations People in Ontario:

Incidence, Mortality,
Survival and Prevalence



First Nations Long-Term Care

Tri-Partite Working Group on First Nations Long-Term Care
Final Report

House of Commons Standing Committee on Indigenous and Northern Affairs

Reducing the Burden of Diabetes on First Nations people in Ontario



OPIOID USE AMONG FIRST NATIONS IN ONTARIO

A REPORT OF CURRENT FINDINGS
PREPARED BY
THE INSTITUTE OF CLINICAL EVALUATIVE SCIENCES
FOR
THE CHIEFS OF ONTARIO
AND THE
CHIEFS IN ASSEMBLY



Liver Cancer among First Nations in Alberta

Age-standardized liver cancer incidence rates by First Nations status and sex, 2006-2015

In a previous *First Nations – Health Trends Alberta* linked to infectious disease agents. Liver cancer rates among First Nations. Globally, most liver cancer cases are due to viral hepatitis. To further describe the extent of this burden in Alberta, we present age-standardized liver cancer incidence rates by sex for First Nations and non-First Nations people.

Liver cancer incidence rate 2.1 times higher among First Nations compared to non-First Nations people

Between 2006 and 2015, there was an annual average of 7 liver cancer diagnoses in Alberta (7 among First Nations and 7 among non-First Nations). Over this time period, the age-standardized incidence rate for both sexes combined was 12.6 per 100,000 population for First Nations compared to 6.1 per 100,000 population for non-First Nations.

Among both populations, males had higher rates than females. Among First Nations, the rate among men was 17.0 per 100,000 compared to 17.0 per 100,000 for non-First Nations men. The rate among women was 17.0 per 100,000 for First Nations women compared to 6.1 per 100,000 for non-First Nations women. However, the disparity in rates between men and women was higher among First Nations than non-First Nations: the rate for First Nations men was 3.0 times higher than for non-First Nations men, while for non-First Nations, the rate for men was only 1.1 times higher than for women.

A major risk factor for liver cancer is infection with hepatitis B and C viruses, and alcohol consumption. While treatment is an option, reducing risk of exposure to these factors is important.

First Nations – Health Trends Alberta

May 29, 2018

Different types of Infant Mortality in First Nations in Alberta

Rate ratios comparing First Nations and non-First Nations infant mortality rates by type, Alberta, 2011 to 2017

Infant mortality is an important indicator of population health. In Alberta, the overall infant mortality rate (deaths under one year of age per 1,000 live births) is 10.6, which is higher than the national average of 9.6. This is due to socio-environmental conditions, the age of death provides a window into the health of a population.

Perinatal mortality is the number of stillbirths and deaths in the first week of life per 1,000 total births. Neonatal mortality is defined as the number of deaths in the first 27 days following birth per 1,000 live births. Both types of infant mortality are heavily influenced by factors such as maternal health.¹ Alternatively, post-neonatal mortality occurs a little later in an infant's life. It is the number of deaths in infants aged 28 to 364 days per 1,000 live births and may be relatively more influenced by environmental factors that lead to outcomes such as Sudden Infant Death Syndrome (SIDS) or fatal injury.

Here,³ we investigate disparities across different types of infant mortality by estimating rate ratios that compare the rates of death in First Nations to the rates in non-First Nations infants. The value of this rate ratio describes the number of times higher rates are in First Nations compared to non-First Nations.

Post-neonatal mortality rate for First Nations is 1.7 times higher than for non-First Nations

In 2011-2017, the annual average number of perinatal deaths in Alberta was 1.7 times higher compared to non-First Nations (1.7 times higher compared to non-First Nations respectively). A similar disparity was noted for neonatal mortality with 3.1 per 1,000 for non-First Nations, corresponding to a rate ratio of 1.58 in non-First Nations). While perinatal and neonatal mortality rates were higher in First Nations, post-neonatal rates of death were 4.0 times higher in First Nations compared to non-First Nations.

First Nations – Health Trends Alberta

July 17, 2018

Emergency Department visits due to self-harm among First Nations youth

Rates of ED visits due to self-harm by First Nations status and age group, both sexes, Alberta, 2006 to 2017

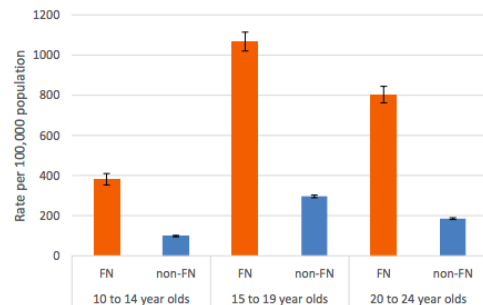
Self-harm, or self-injury, occurs when a person purposefully harms their body with a non-fatal outcome.¹ This may occur through cutting, burning, or other forms of injury. Numerous factors contribute to the risk of self-harm. These include living with mental illness, feelings of hopelessness, or other psychological factors. Risk of self-harm may be amplified in Indigenous populations that are impacted by a complex colonial history including intergenerational trauma from residential schools, higher rates of poverty, and systemic racism.²

In today's *First Nations – Health Trends Alberta*,³ we present emergency department (ED) visit rates during 2006 to 2017 due to self-harm in First Nations and non-First Nations youth separately. Rates are presented for both sexes combined and by age group.

Among 10 to 24 year olds, ED visit rates due to self-harm are 4 times higher for First Nations compared to non-First Nations

During 2006-2017, the annual average number of ED visits by 10 to 24 year olds due to self-harm in Alberta was approximately 2,080 (410 in First Nations). The ED visit rate for First Nations over this time period was 3.9 times higher than the rate for non-First Nations (rates 2250.9 and 579.2 per 100,000, respectively).

There were differences in rates across age categories: ED visit rates due to self-harm were highest in 15 to 19 year olds for both First Nations and non-First Nations during 2006-2017 (First Nations: 1066.8 per 100,000 and non-First Nations: 296.1 per 100,000). This corresponded to an annual average of 200 visits and 820 visits for First Nations and non-First Nations aged 15-19 years, respectively. Rates were lowest in 10 to 14 year olds for both groups, with an average of 70 visits annually in First Nations and 250 annual visits in non-First Nations (rate in First Nations: 381.1 per 100,000 and non-First Nations: 98.1 per 100,000). Similarly, for both First Nations and non-First Nations, rates were higher in females compared to males in all age categories.





Learning from the water.

The path to healing and data governance is a braided path – no one is stepping in exactly the same place twice.



Thank you. Niawen.

jenniferwalker@laurentian.ca