10 Things You Need to Know About First Nations eHealth Projects



#### The Landscape

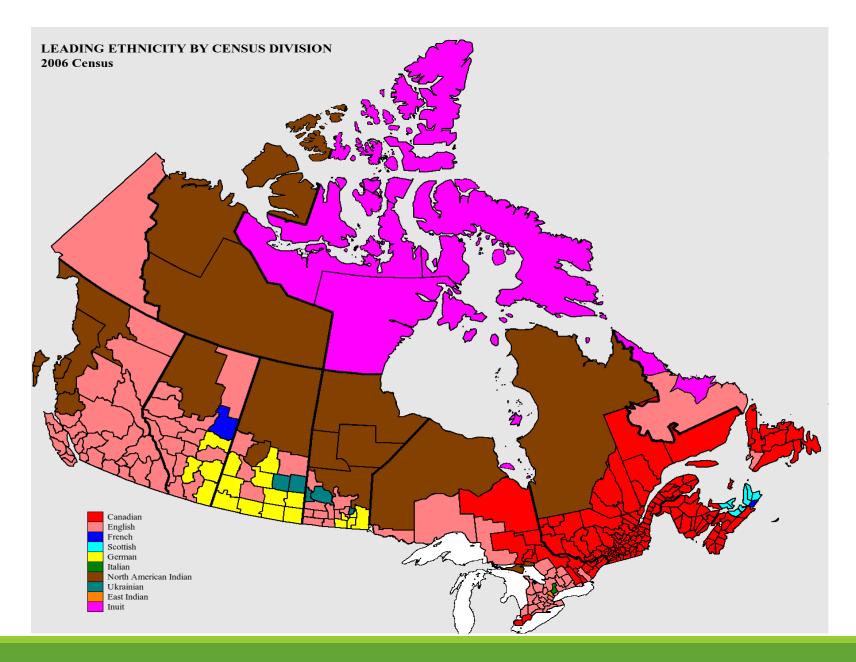
Over 1.8 million Aboriginal (2011 Census)

Over 630 First Nations Bands in Canada.

Almost half are in rural/remote locations

Isolated from health care services

Medical transportation costly (\$350 million in 2012/2013)





#### Health Status

Rate low on almost any indicator of health

High Chronic disease

Access to care is an issue

Continuity of care an issue

Paper charts in multiple places

Most adults over 50 attended residential school



#### So what's involved in eHealth?

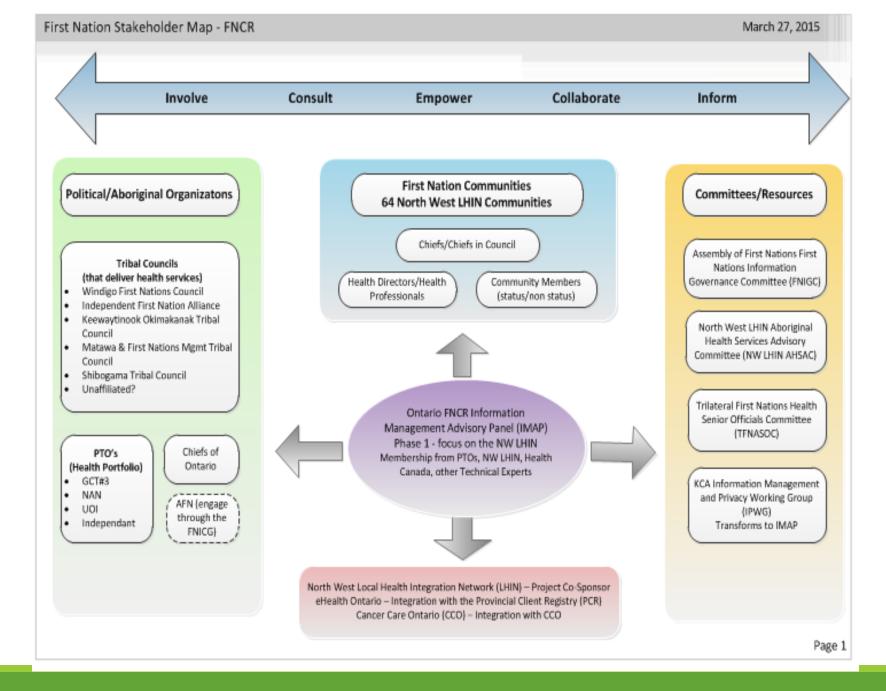
Understand the complex environment...

■Tools — EMRs, EHRs, Telehealth, cEMRs, Panorama, Client Registries, Consumer Health

#### 1. There will be multiple, multiple stakeholders

In addition to provincial stakeholders such as Ministry of Health, Health Authorities, Public Health, Hospitals, you will need to involve Health Canada's First Nation and Inuit Health Branch.

First Nation involvement will include community members, Chief and Council, Elders, Youth, Political Tribal Organizations and Provincial First Nations Political Organizations.



### 2. Jurisdiction Impacts Outcomes

- •640 First Nations "Indian Reserves" in Canada
- Tracks of land set aside for First Nations
- •Under the jurisdiction of the Federal Government
- Some communities have transferred from the Federal Government and are under "First Nation Jurisdiction"
- •Most eHealth systems are provincially led and developed.
- •First Nations not recognized within provincial legislation as "Trustees" or "Health Information Custodians"

# 3. You will need to follow legislation — Even when there is no legislation...

Provincial legislation – not always clear if it applied within Federal jurisdiction

Federal Legislation – Privacy Act is applicable to agencies of the *Federal Government*. Includes Federally run nursing stations and health centres. Does not apply where Health Centres are independent from Health Canada and are run by the First Nation.

No applicable legislation within First Nation jurisdiction.

#### 4. You will need a lawyer!

Need to confirm under whose authority the data is being collected and what legislation the health facility is under

Need to confirm applicable legislation

Need to understand what legal maneuvering is required to make legislation work

Some options –

- 1. First Nations under authority of Regional Health Authorities
- 2. First Nations "act as if" provincial legislation applies
- 3. Regulated Health Professionals assume role of "Health Information Custodian" or "Trustee" of PHI

#### 5. eHealth is Complicated!

Next to impossible to translate technical terms into our language

Very challenging to build trust with communities

Fear that the information within information systems will be used against them.

Legal agreements are complex.

Many stakeholders add to the complication

## 6. First Nations do not always want to participate!

Confusing and complex systems

Requires lots of resources

Lack of funding complicates implementation by straining already limited resources

Not always a priority due to overwhelming health needs

### 7. You will need to know about OCAP

- •First Nation Principles of Ownership, Control, Access and Possession of Data
- First Nations have rights to self-determination and governance
- Extends to the application of these rights towards the control of their data and the analysis of that data
- Applies to Community-Level Information or Community-Level Health Information
- Offers an added layer of protection for the individual
- Each First Nation has the authority to choose if and how they want to apply the principles
- OCAP is an essential component to any Data Sharing Agreement or protocol development

## 8. First Nations eHealth not a priority....

First Nations often are not recognized in provincial strategies or legislation

Health Canada's First Nation Inuit Health Branch strained with other priorities such as water contamination, health crisis, outbreaks, etc.

Band aid approach to health care system

Limited or "frozen" envelopes for First Nation eHealth

Federal and Provincial eHealth leads working within their own jurisdiction

Need collaborative approach between the provinces and Health Canada

### 9. eHealth Systems are Expensive in First Nations

Bandwidth to remote locations is expensive. Telehealth dependencies on health-grade bandwidth

Limited resources

Health Canada funds are frozen

Provinces not funding eHealth into First Nations

Canada Health Infoway does not have First Nation strategy to fund projects

First Nations are expected to fund their own projects

What do you cut?

### 9. Privacy and Security Capacity is needed

- Privacy and security infrastructure foundational to eHealth applications
- Need to develop training, policies and procedures that are appropriate to First Nation environment
- •Once the infrastructure has been developed, we can build upon it to add more applications.

### 10. Need Outweighs Challenges

#### Success stories

- Telehealth Successes in ON, BC, MB, SK
- Mustimuhw First Nation Community EMR is being implemented across the country
- Panorama implementation in BC setting a Framework for First Nations in other provinces
- Manitoba implementing Telehealth, eCharting, cEMR and Panorama
- First Nation Client Registry implementation and integration projects in Northern Ontario and Nova Scotia for Health Informatics and Epidemiological Data

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