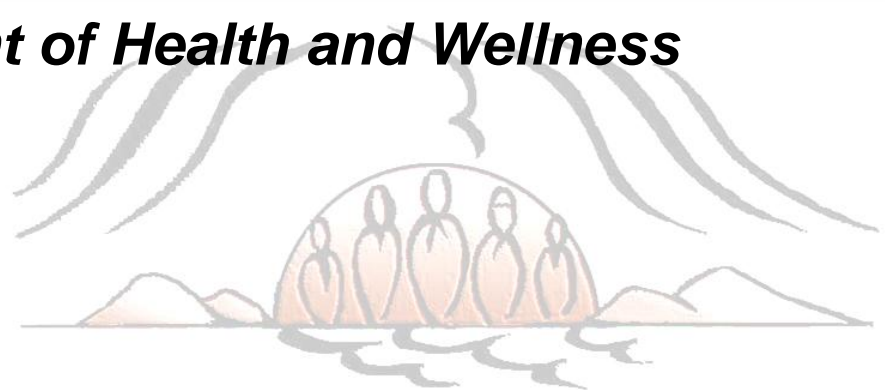


**Strength in Numbers:  
Improving Access to quality, reliable and timely  
First Nations population health information  
through partnerships**

**eHealth 2016**

**June 8, 2016**

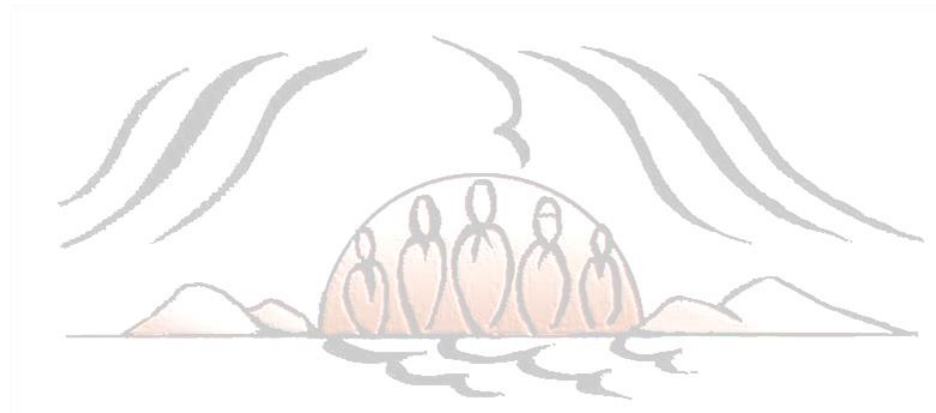
***Sharon Rudderham, Eskasoni Health Centre  
Jill Casey, NS Department of Health and Wellness***



# Strength in Numbers Project

## Goal:

- To provide First Nations in Nova Scotia with better access to reliable and comparable health surveillance data.



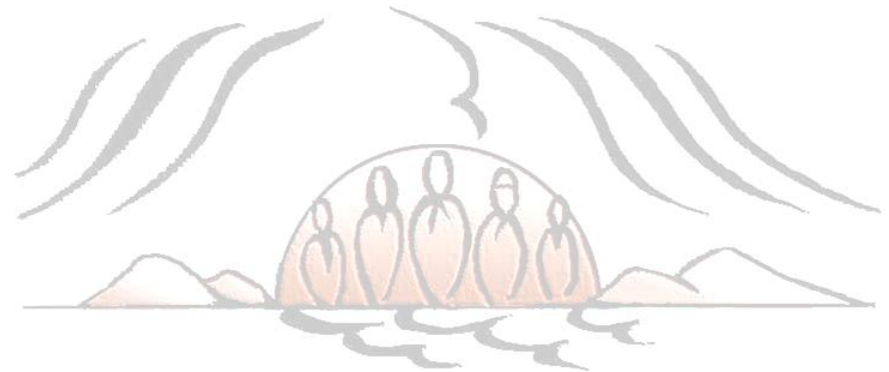
# Why?

**Understand  
Health Status**

**Reduce Health  
Inequalities**

**Best Use of  
Resources**

**Identify  
Community Needs**

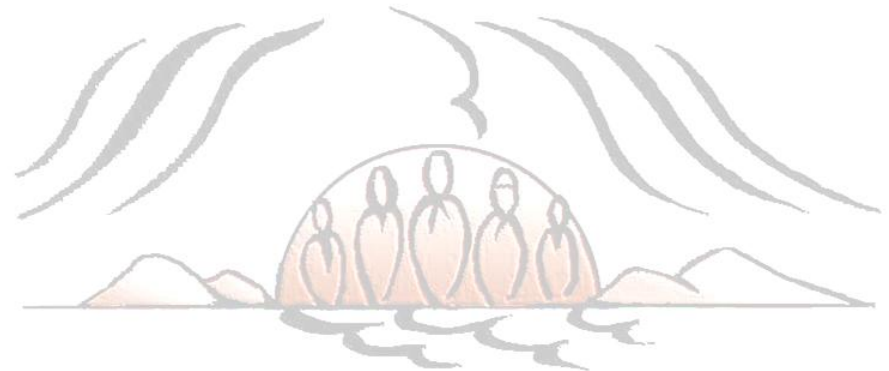


## Challenge:

Ethnic identifiers do not exist in Nova Scotia provincial health records

## Opportunity:

Build upon the success of the Unama'ki Registry

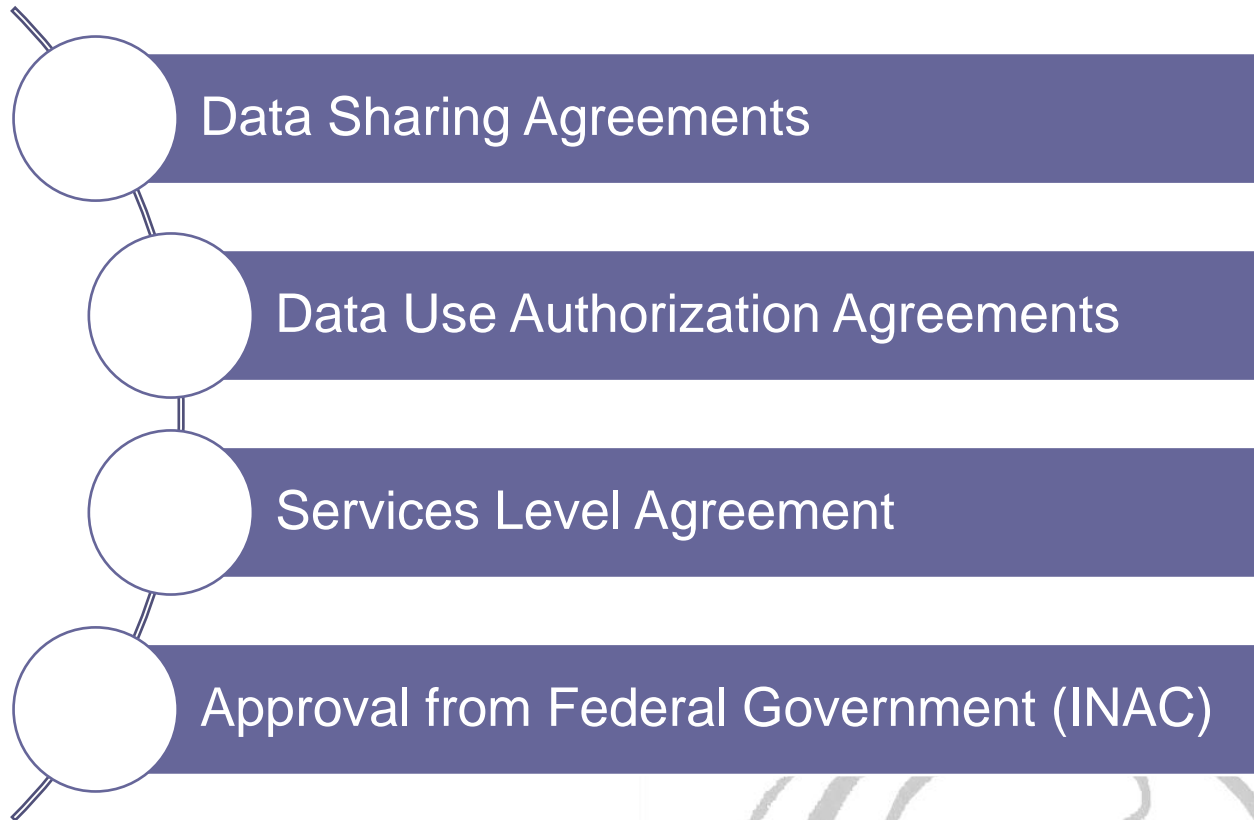


# Project Partners

- All 13 First Nations in NS
- Nova Scotia Department of Health and Wellness
- Health Canada (provided funding)
- Union of NS Indians
- Confederacy of Mainland Mi'kmaq
- Tui'kn Partnership (managed project)

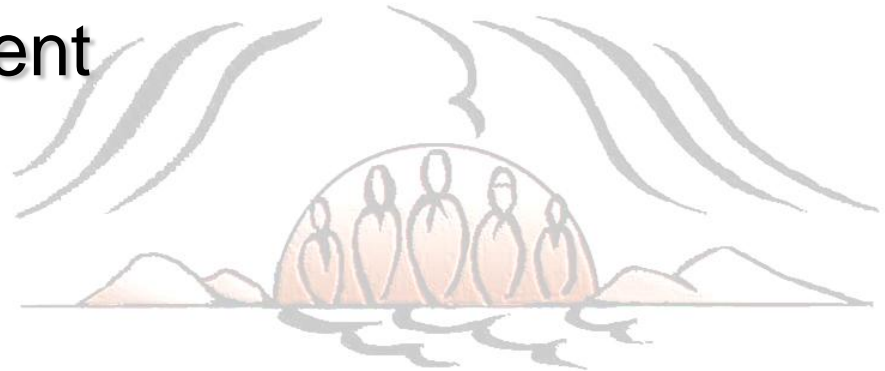


# Partnership with Clear Governance

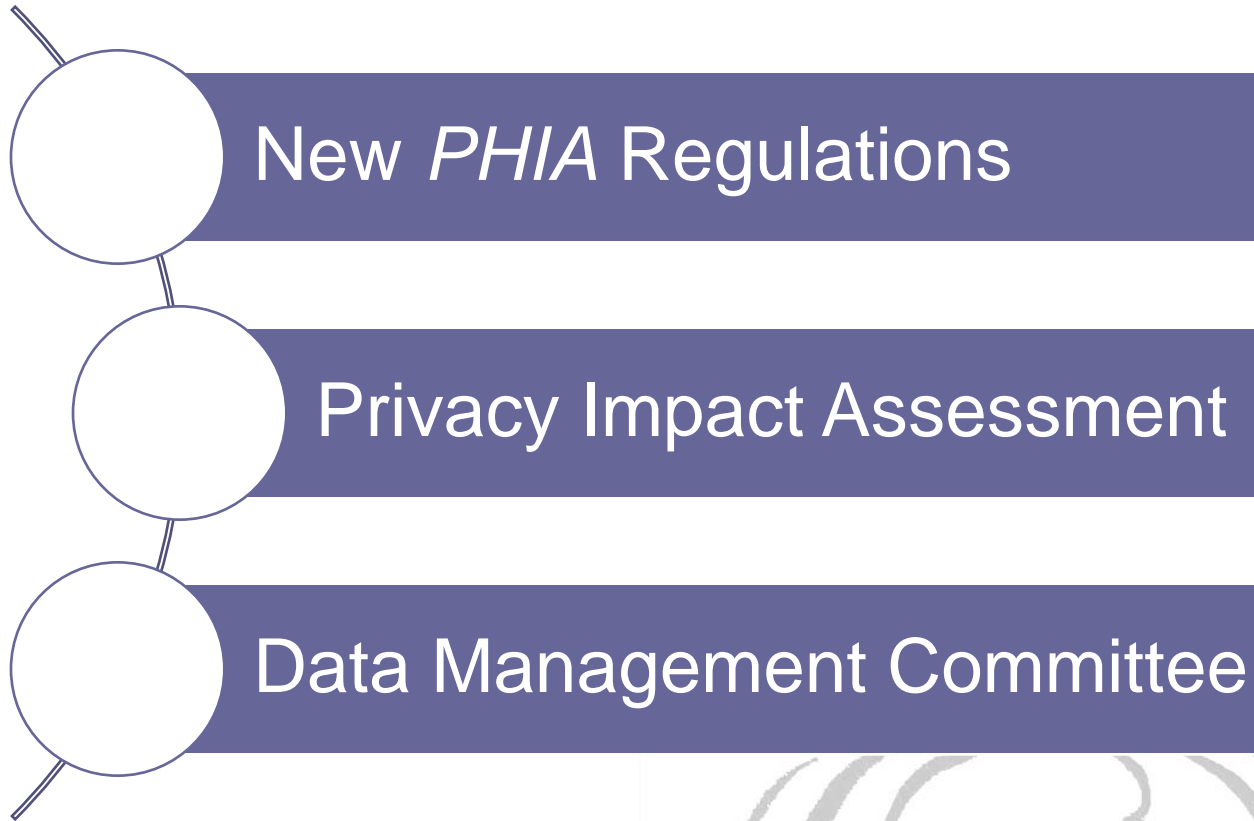




## Data Sharing Agreement Signing Ceremony



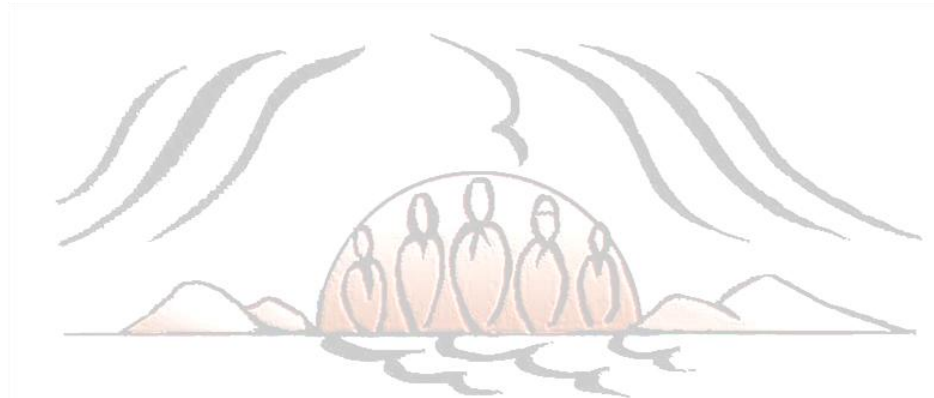
# Privacy Considerations



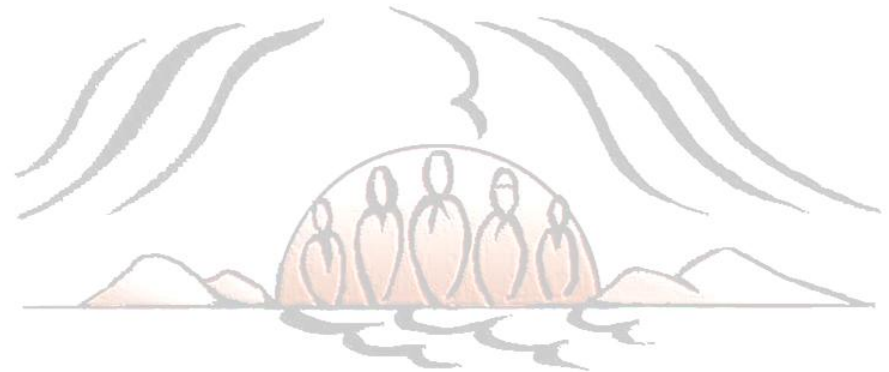


# Registry Governance

- Governance model is compliant with both privacy legislation and OCAP™ principles
- Access is controlled by a Data Management Committee
- Registry can not be accessed without the consent of FNs



# Technical Solution

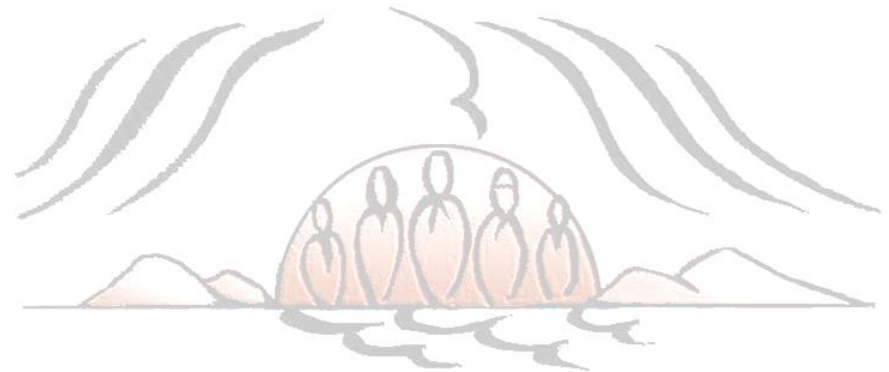


# NS First Nations Client Linkage Registry (NSFNCLR)

“Registered”  
First Nations  
Population

Linkable

Virtually  
Comprehensive



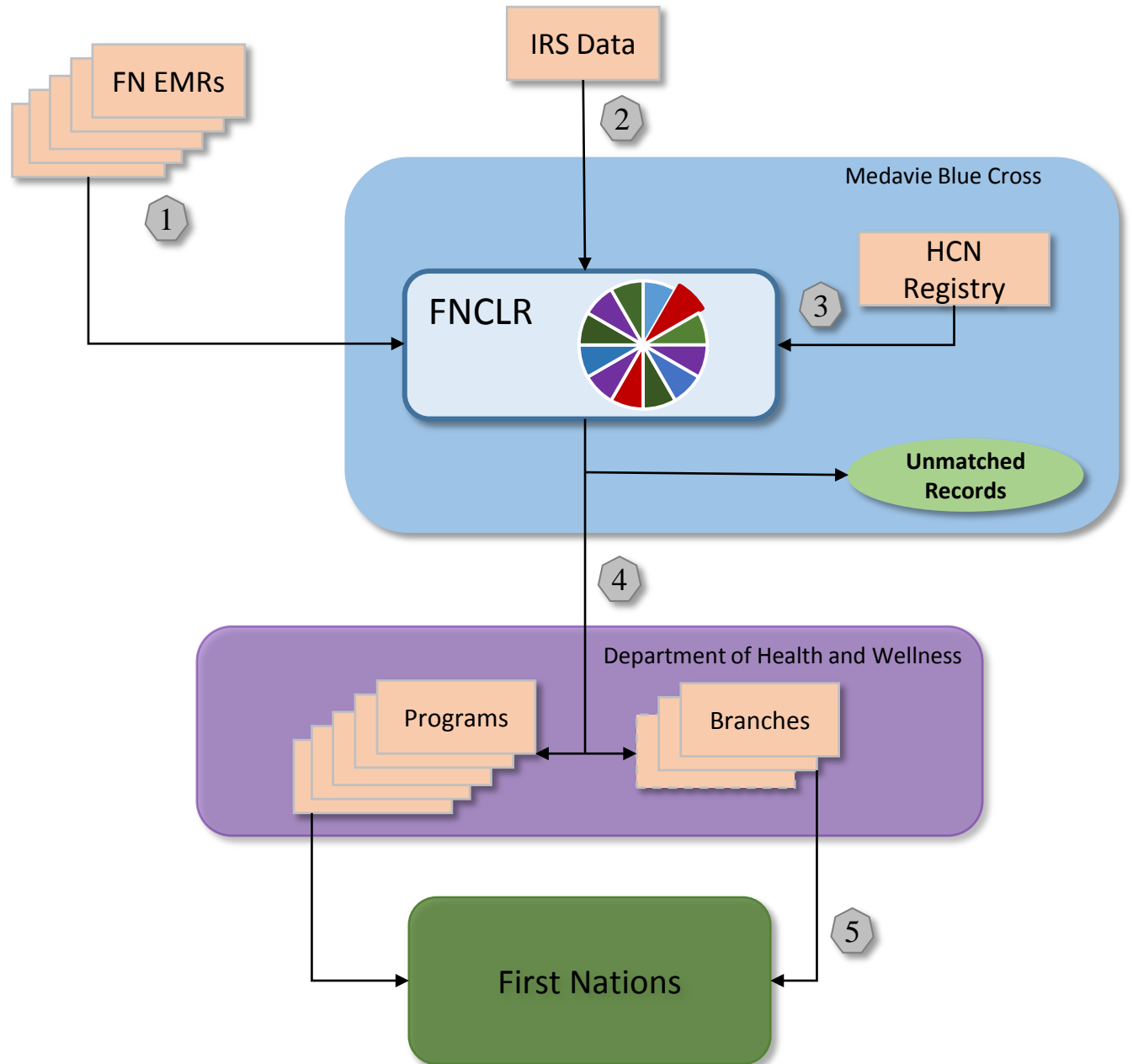
# Who's In the Registry?



- Registered member of a Nova Scotia Band  
**and**  
Valid Nova Scotia Health Card Number
- Total = 11,638 individuals



# How Was the Registry Created?



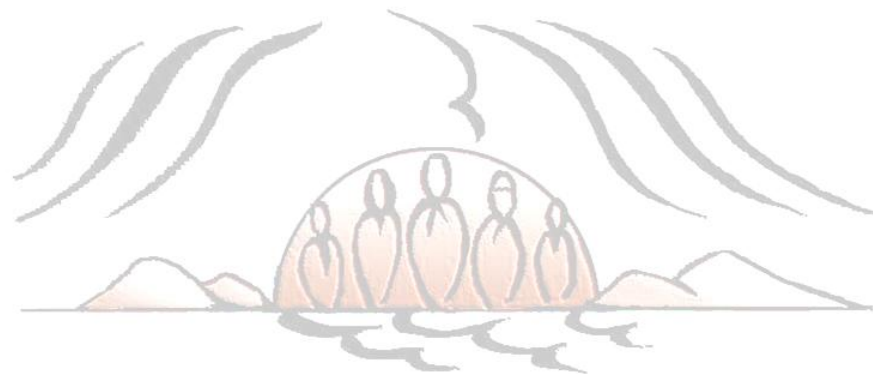
# Improving Access to Health System Data

- Cardiovascular Health
- Cancer Care
- Reproductive Care
- Renal Disease
- Breast Cancer Screening
- Diabetes Care
- Trauma and Injury
- Mental Health and Addictions
- Healthcare Utilization
- Public Health
- ...

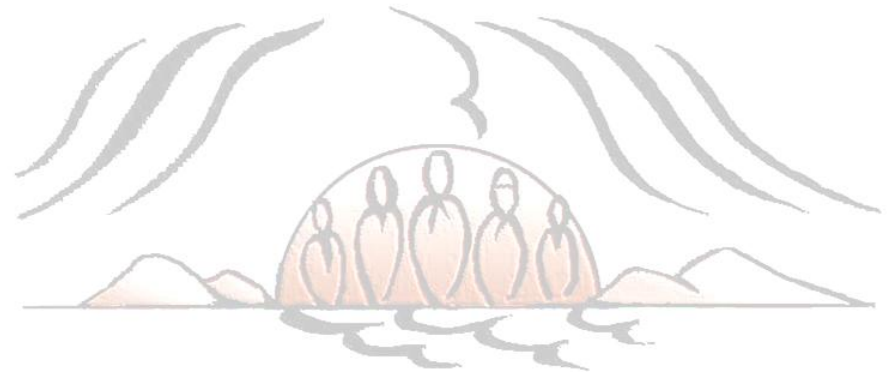


# Health Indicator Reports

200 health indicators  
chosen by First Nations  
in collaboration with  
provincial partners



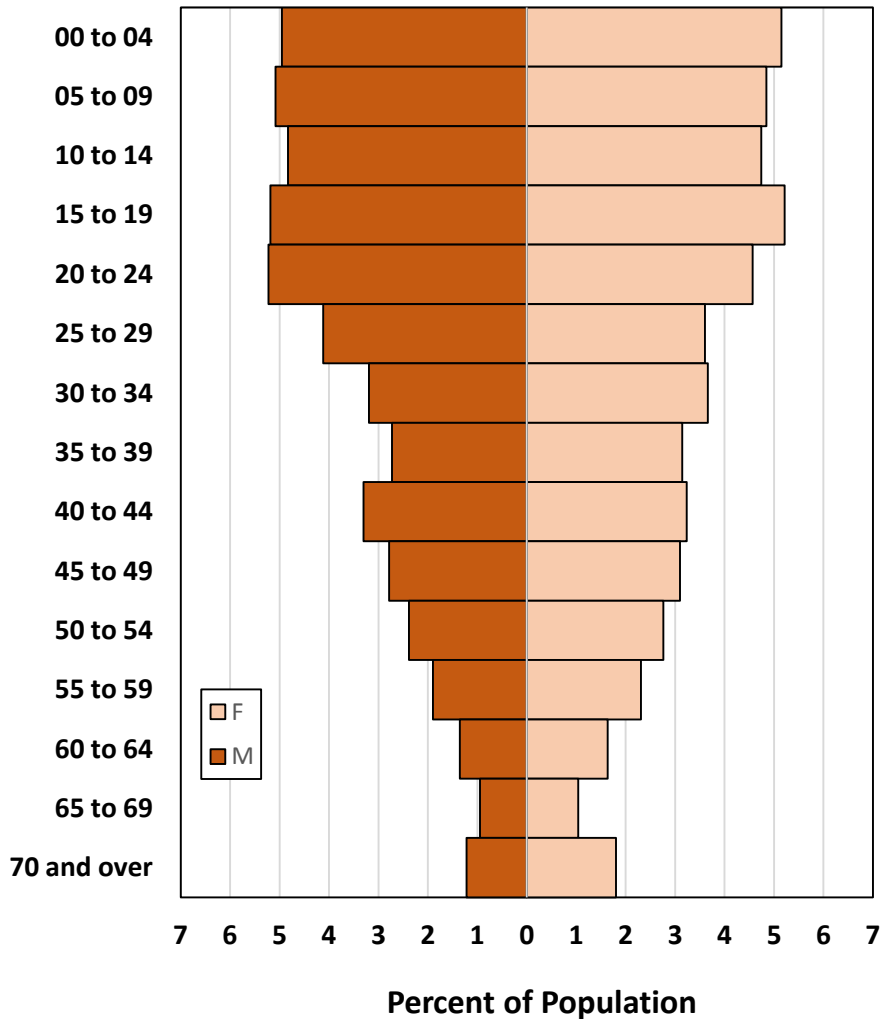
# Some examples of data...



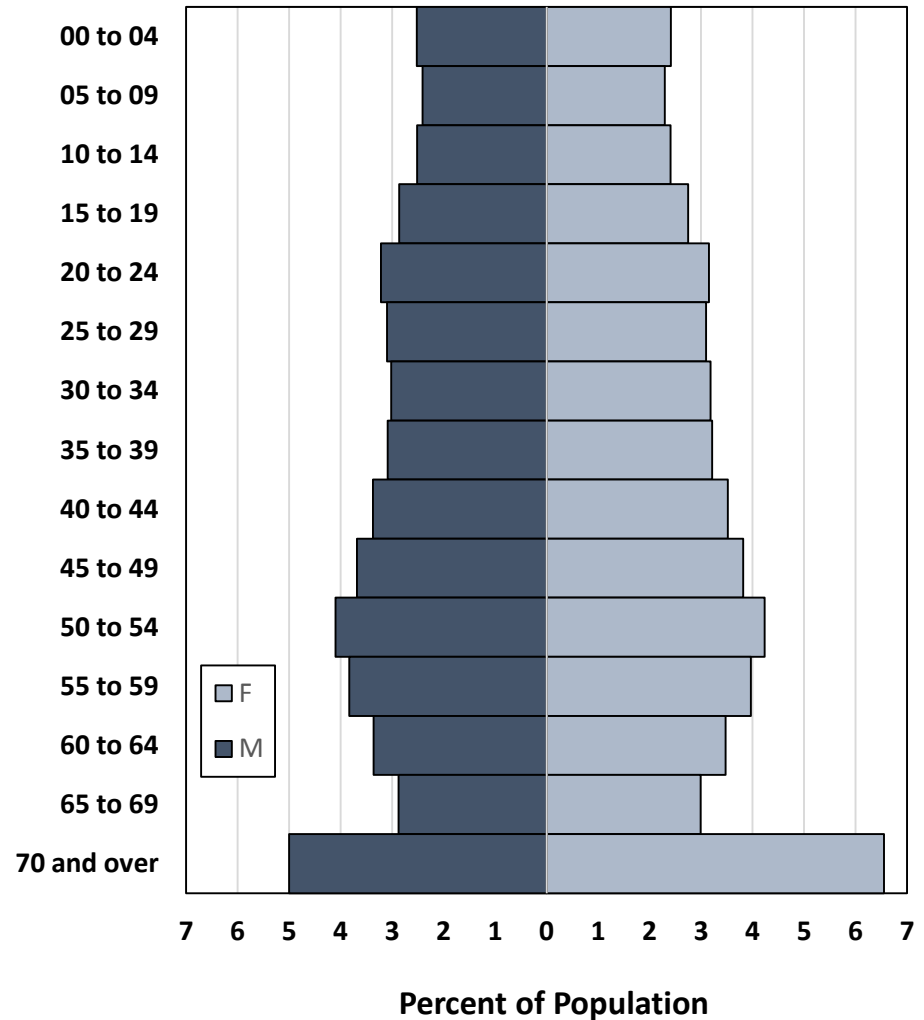


# Demographic Context

**2013 First Nations Population  
by Sex and 5-Year Age Groups**

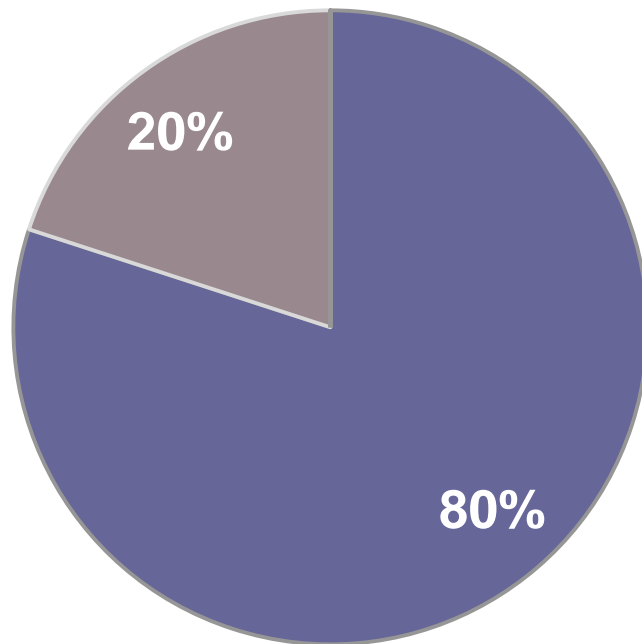


**2013 Nova Scotian Population  
by Sex and 5-Year Age Groups**



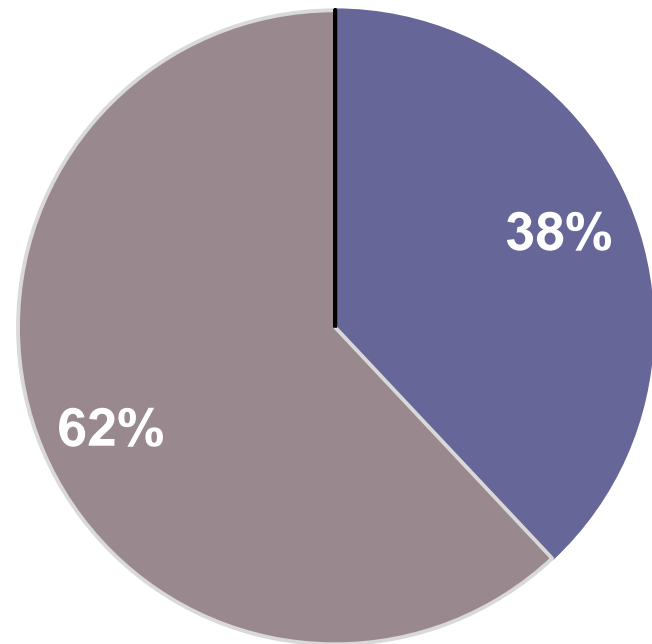
# Premature Mortality, 2004-2013

## NS First Nations



■ Under Age 75 ■ 75 and Older

## Nova Scotia



■ Under Age 75 ■ 75 and Older

# Diabetes Prevalence for Population 20+ by Age Group 2012/2013, NS First Nations

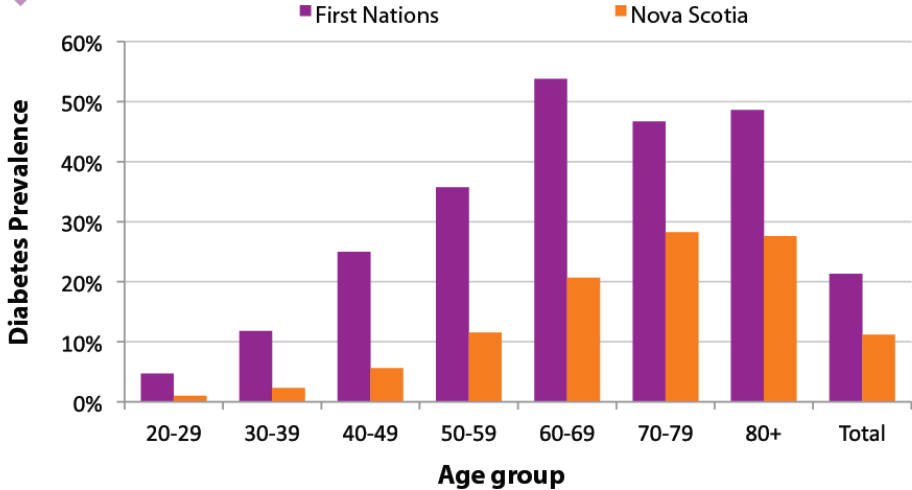
Diabetes prevalence is **5x** higher among those aged 20-29 & 30-39 in our communities compared to the rest of Nova Scotia ...

**4x** for 40-49yrs ...

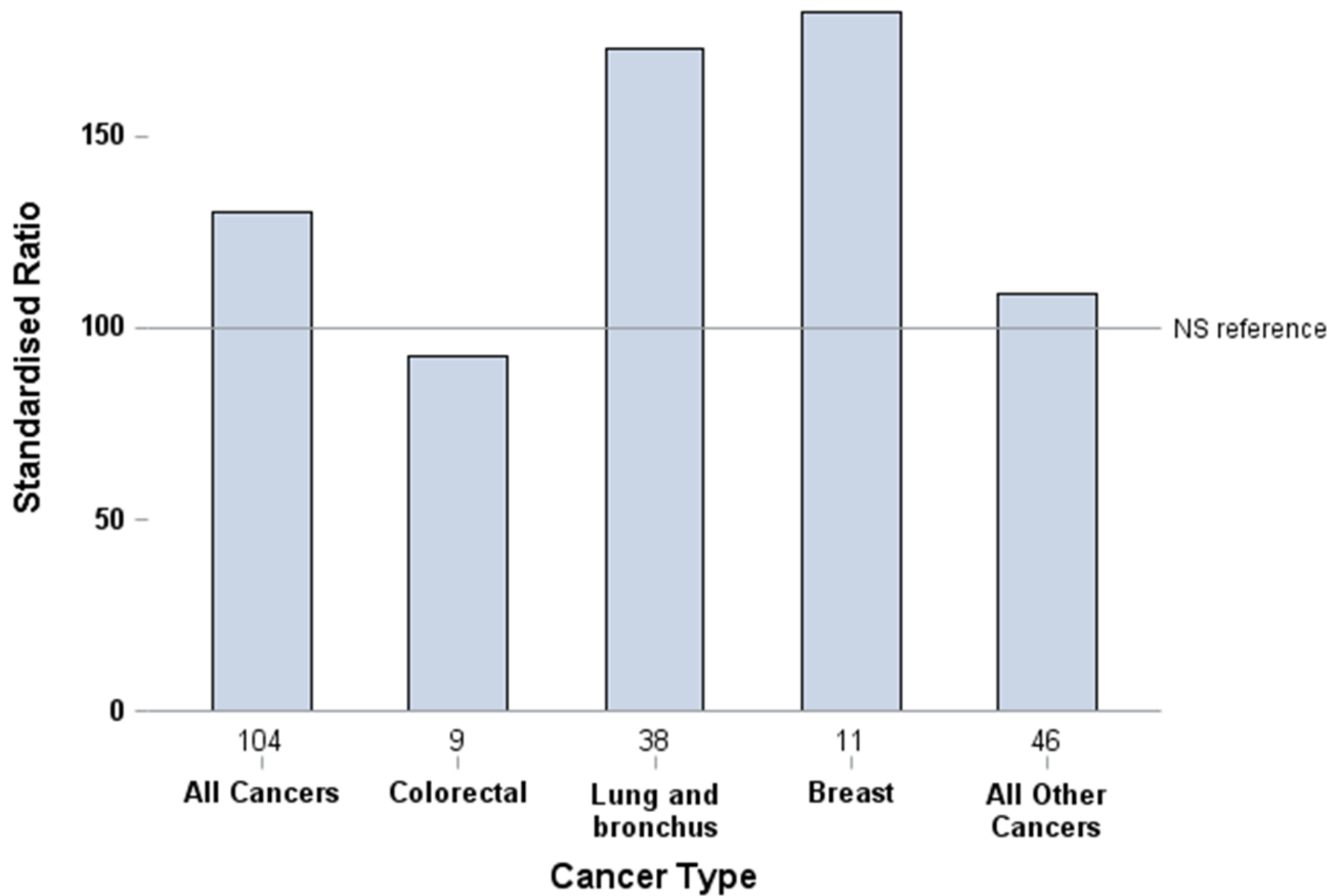
**3x** for 50-59 & 60-69yrs ...

**2x** overall

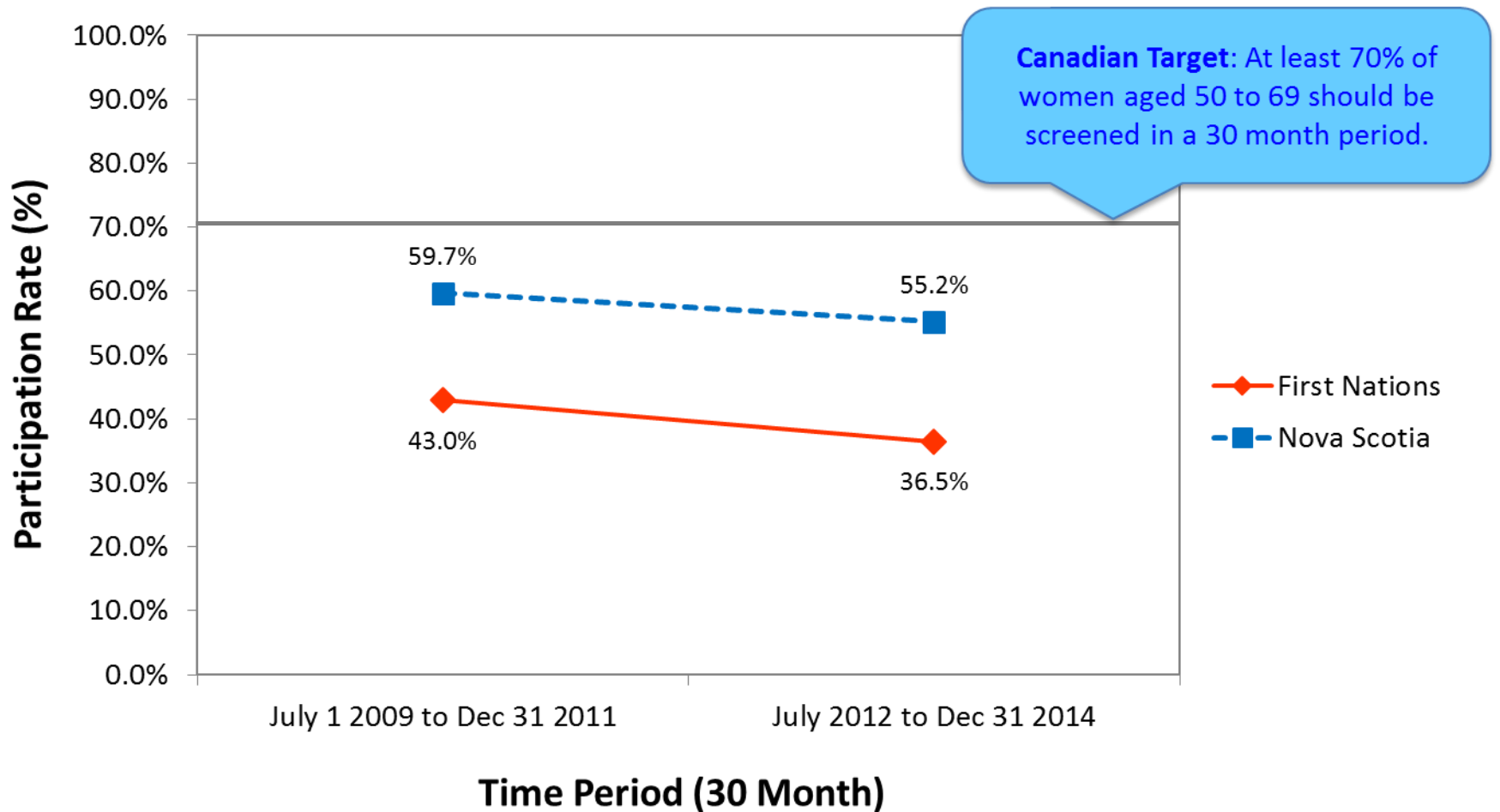
About **1/2** of our seniors have diabetes.



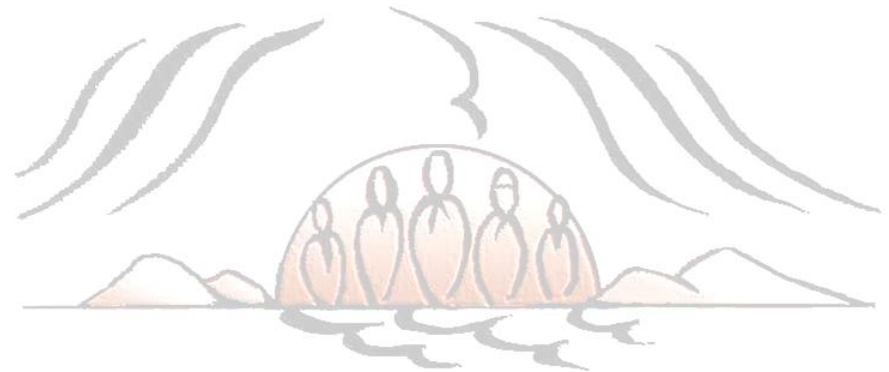
### Client Registry Cancer Profile 2004-2013: Deaths Standardised Ratio by cancer type



# Breast Screening Participation Rates in First Nations and Nova Scotia Women Aged 50-69.

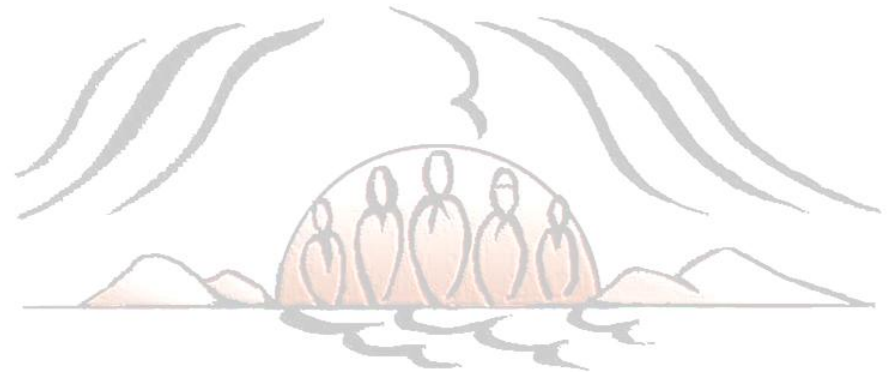


# From Data to Knowledge



# Knowledge Sharing

- Developing strategies and tool for sharing surveillance data
- Community knowledge is key to making sense of surveillance data



# Population Health Bulletins

Together, with provincial and federal partners, our Mi'kmaq communities in Nova Scotia created the **Nova Scotia First Nations Client Linkage Registry\***

This is an update to the communities about our health information, produced by the **Strength in Numbers Project (2016)**.

\* At this time, our Registry does not include Acadian and Sipekwi'atik First Nations' population numbers.

## Cancer

Population-level health information gives us quality data to support community education and planning.

There were **260** new cases of cancer diagnosed in our communities between 2004-2013 (that's an average of about 26 cases per year).

**Here is the good news:**

The number of people in our communities who are diagnosed with cancer is pretty small. And, our overall rate of cancer is about the same as you'd expect to see in the general Nova Scotia population.

Even so, a cancer diagnosis is challenging news for anyone. And chances are, if you live in a First Nation community, you have been touched by cancer in some way.

The cancers that are hitting us the hardest are ones that we can either **prevent** or **beat with screening and early treatment.**

**We know what to do. We have the information to back it up.**

Data for this:

- Cancer C
- NS Brac
- NS Col
- NS Ca



Together, with provincial and federal partners, our Mi'kmaq communities in Nova Scotia created the **Nova Scotia First Nations Client Linkage Registry\***

This is an update to the communities about our health information, produced by the **Strength in Numbers Project (2016)**.

\* At this time, our Registry does not include Acadian and Sipekwi'atik First Nations' population numbers.

## Diabetes / Kidney Disease

Population-level health data gives us quality information to support community education and planning.

About **1,300** of us over 20 years old have diabetes (out of 6,100).

We already knew that our communities have high rates of diabetes.

Now we can also see that it's affecting people in our communities at a **younger** age than the rest of the Nova Scotia population.

**That means we need to:**

- do more diabetes prevention (eat better and be more active)
- screen for it sooner and
- do more diabetes management.

Let's take a closer look at our data ...

While the numbers are small, they have a huge impact. In our First Nation communities, about **1 in 4 (20 of 80) of the new cases of diabetes were in people younger than 40 (2012-2013).**

This is a **much higher rate** compared to the Nova Scotia population, where 1 in 10 of the new diabetes cases were in people younger than 40 years old.

**We know what to do. We have the information to back it up.**

Data sources for this bulletin:

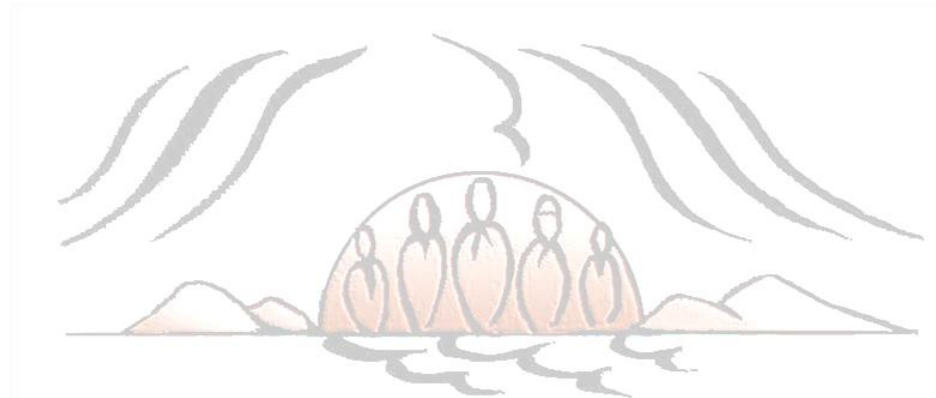
- Diabetes Care Program of NS
- NS Renal Program
- Reproductive Care Program of NS





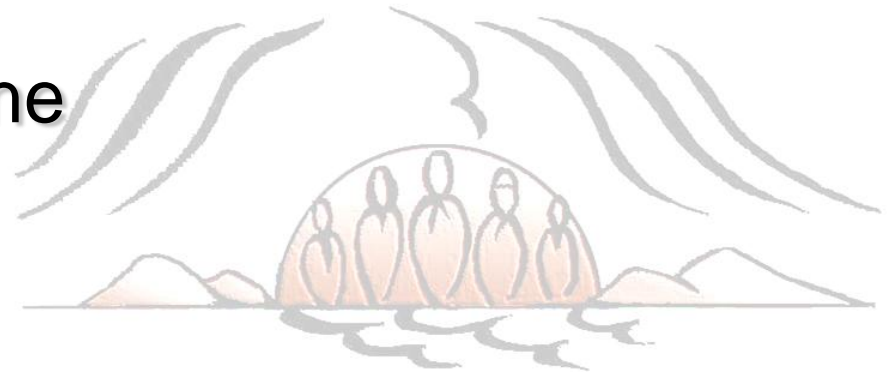
# Lessons Learned about Partnership

- Identify and recruit champions from all partner organizations
- Define roles and assign tasks as early as possible
- Formalize agreements to ensure long-term commitment
- Pay attention to policy and legislative requirements
- Balance risk and opportunity



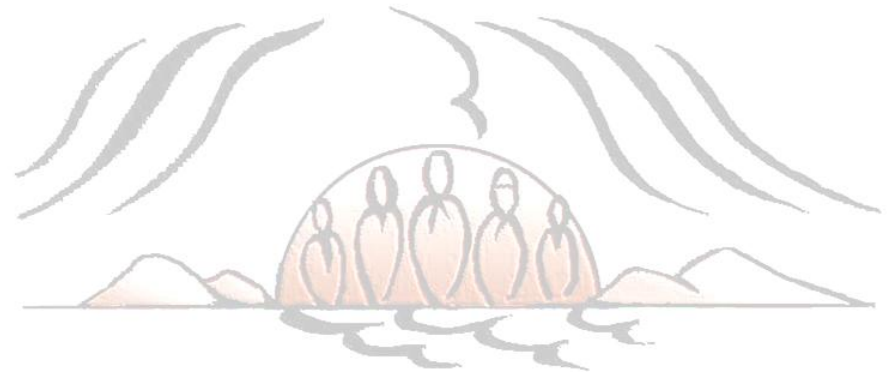
# Advice for Other Jurisdictions

- Start small, keep it simple
- Take the time to build mutual understanding
- Engage champions with the 'right' connections
- Produce accessible data products
- Be patient, remain optimistic
- Dream big
- Map out a realistic timeline



# Key Success Factors

- Incremental approach
- Well articulated data sharing agreement
- Privacy Impact Assessment
- Mutual understanding
- Data governance model
- Funding and in-kind contributions
- Stakeholder champions
- Political will



# Questions?

