

# Overview of the Nova Scotia Mi'kmaw Client Linkage Registry

## BACKGROUND

The Mi'kmaq of Nova Scotia have been working together for over a decade to get better health data. Together, we have achieved unparalleled access to a broad range of population-level health surveillance data. Our communities are using this information to monitor changes in the health status of our population, measure health equity gaps, inform our health planning processes, and advocate for the services and resources that we need. Key to our success has been the ability to take advantage of administrative health data collected by the Nova Scotia Department of Health and Wellness and provincial health authorities.

## THE NOVA SCOTIA MI'KMAW CLIENT LINKAGE REGISTRY

In order to make use of provincial administrative data, we needed a way to reliably identify the Mi'kmaw population within provincial data sources. We developed the Nova Scotia Mi'kmaw Client Linkage Registry (MCLR). The MCLR is a population registry that can be linked with administrative data sources in order to provide our communities with comparable population level health surveillance data. The MCLR includes individuals who are: 1) "Status Indians", 2) members of a Nova Scotia Band, and 3) eligible for provincial medical services insurance (MSI). The MCLR includes all thirteen First Nations in Nova Scotia.

Three sources of data are used to create and update the MCLR:

- federal IRS data (authorized under an information sharing agreement between the Mi'kmaq of Nova Scotia and ISC),
- demographic data from our community health centres' electronic medical records where available (authorized through BCRs),
- provincial Health Card Registry data (authorized under a data sharing agreement between the Mi'kmaq of Nova Scotia and the Province).



The MCLR does not contain any health information except for provincial Health Card Numbers. Health Card Numbers make it possible to link the MCLR to a wide variety of provincial health data sources.

## DATA LINKAGES

Currently, eleven provincial programs are authorized by the Mi'kmaq of Nova Scotia to receive MCLR data and link it with their health data sources for the **sole purpose** of developing population health indicator reports for our communities:

- Continuing Care Branch, NSDHW
- Digital Health, Analytics and Privacy, NSDHW
- Cancer Care Nova Scotia, Nova Scotia Health Authority
- Cardiovascular Health Nova Scotia, Nova Scotia Health Authority
- Diabetes Care Program of Nova Scotia, Nova Scotia Health Authority
- Mental Health and Addictions, IWK Health Centre
- Mental Health and Addictions, Nova Scotia Health Authority
- Nova Scotia Breast Screening Program, IWK Health Centre
- Nova Scotia Renal Program, Nova Scotia Health Authority
- Nova Scotia Reproductive Care Program, IWK Health Centre
- Nova Scotia Trauma Program, Nova Scotia Health Authority

Our partners do not incorporate MCLR data into their data holdings. Rather, they use the MCLR to identify and extract data for the Mi'kmaq population. MCLR data and the resulting linked data files are kept separately and securely from the programs' other data holdings. Access to these files is limited to individuals who analyze the data and prepare the indicator reports.

This sharing of data between our First Nations and our partners is governed under two data sharing agreements (DSAs): 1) a DSA between the Mi'kmaq of Nova Scotia and the Province, and 2) a DSA between the Mi'kmaq of Nova Scotia and the two provincial health authorities.

The health indicator reports that our partners prepare for our communities contain de-identified aggregate data. Indicators are calculated at the provincial level (all 13 First Nations in Nova Scotia combined), regional level (Unama'ki First Nations and mainland First Nations), and at the community level where numbers are large enough. Reports also include comparison data for all of Nova Scotia, Cape Breton, and the mainland. This allows us to see how our communities are doing relative to the rest of Nova Scotia and to quantify health equity gaps.

## SELECTING HEALTH INDICATORS

All indicators are chosen by our communities. We work closely with our partners to select indicators that are policy, practice, and culturally relevant. We have developed a detailed indicator framework which we regularly review and update as our information needs change and as new data sources become available. Going forward, indicators will be updated at planned intervals. Together with our partners, we have developed an indicator reporting schedule to guide this process.

Our indicator reports currently include over 200 indicators that draw from 24 different provincial data sources including the following:

- Application for Notifiable Disease System
- Breast Information System
- Cancer Booking/Appointment System
- Cancer Care Application for Screening Platform & Event Relationships
- Canadian Chronic Disease Surveillance System
- Canadian Organ Replacement Registry
- Cardiovascular Health Nova Scotia Data Base
- Discharge Abstract Database
- Diabetes Care Program of Nova Scotia Registry
- Nova Scotia Drug Information System
- Fetal Anomalies Database
- Hepatitis C Enhanced Database
- Health Insurance Registry Files
- IWK Meditech
- Mental Health and Addictions Intake System (NSHA and IWK)
- National Ambulatory Care Reporting System
- Nova Scotia Atlee Perinatal Database
- Nova Scotia Cancer Registry
- Nova Scotia Trauma Registry
- Nova Scotia Vital Statistics
- Physician/NP Medical Claims Files ("Physician Billing")
- Cancer Patient Navigation Database
- Renal Service Delivery Programs
- SEAscape (Nova Scotia's home care information system)

## PRIVACY AND CONFIDENTIALITY

Protection of privacy and confidentiality is paramount. We have taken a number of steps to protect our community members' privacy, for example:

- Before creating the MCLR, we completed a comprehensive privacy impact assessment (PIA). The PIA is updated every time we modify our MCLR process.
- Our provincial and health authority partners have completed PIAs on their use of MCLR data.
- All of our agreements are compliant with applicable privacy legislation.
- **Reports do not contain individual level data;** they contain aggregated de-identified data only. Cell counts below five are suppressed to prevent the potential for re-identification of individuals.

## OCAP™ PRINCIPLES

The First Nations principles of ownership, control, access and possession (OCAP™) are also of utmost importance. Some key OCAP™ features of the MCLR data governance model include the following:

- The MCLR is owned and controlled by the Mi'kmaq of Nova Scotia.
- Each First Nation retains control over their own data. A community's data cannot be used for any purpose without that community's consent.

- The MCLR is governed by a Data Management Committee which provides general oversight and management of the Registry; reviews all requests to access Registry data; ensures that maintenance and use of Registry data is consistent with OCAP principles and applicable legislation; and monitors compliance with data access agreements. The Data Management Committee is comprised of a representative from each First Nation (authorized through BCR by each Chief and Council) and one representative from the NS Department of Health and Wellness. The Committee also includes non-voting representatives from the Nova Scotia Health Authority and the IWK Health Centre.
- The MCLR is used mainly for population health surveillance purposes, but it can also be used for research that we deem to be of value to our communities. Individuals or organizations wanting to access MCLR data must submit an application to the MCLR Data Management Committee. All research requests require approval from the Data Management Committee, Chiefs, Mi'kmaq Ethics Watch, and an institutional Research Ethics Board. A signed data access agreement and non-disclosure agreement are required before any data is released.
- Aggregate data is treated like individual data. Reports containing aggregate information and statistics regarding specific Mi'kmaw communities or Nova Scotia Mi'kmaq in general are treated as confidential. Even though our indicator reports are prepared by our Provincial and health authority partners, the reports are owned and controlled by our communities. Our partners cannot use or share the reports (even internally) without our permission. Our data sharing agreements are very specific on this; the Province and health authorities are required to protect the privacy and confidentiality of all First Nations data (including aggregate data) according to the same standards and security measures as if it were personal health information.
- Third-party requests for access to indicator reports, or portions thereof, require approval from communities and a signed Data Use Authorization.

## PARTNERSHIPS

Strong partnerships have been key to our success. Together, we and our partners have been able to overcome the technical, privacy and governance challenges involved in cross-jurisdictional data sharing work. Our dedicated and solution-focused partners include:

- All 13 Mi'kmaw First Nations in NS
- Nova Scotia Department of Health and Wellness
- Nova Scotia Health Authority
- IWK Health Centre
- First Nations Inuit Health Branch, Indigenous Services Canada
- Confederacy of Mainland Mi'kmaq
- Union of Nova Scotia Mi'kmaq
- Tajiikeimik

## USING DATA TO IMPROVE HEALTH OUTCOMES AND SERVICES

Getting better health surveillance data is not our end-goal; it is only a first step. We are taking action to ensure that the data is used to improve health and well-being in our communities, for example:

- We hold workshops with staff from our health centres to build their comfort and confidence in understanding, communicating and using health data.
- We develop tools such as health information bulletins to highlight key indicators for leadership, decision makers, partners, clinicians, and community members. The bulletins contain more than just statistics, though. Statistics are only numbers. The bulletins are a way for our communities to tell the story behind the numbers.
- We have been meeting with our healthcare partners (health authorities, Province) to share key indicators, highlight health equity gaps, and explore ways that we can work together to improve access, reduce gaps and improve outcomes.

Being able to quantify health equity gaps has helped us secure new health services and programs that our communities desperately need. For example, the data was a key catalyst in helping all of our communities secure provincial funding for new primary care and mental health human resources.

The data has also sparked new **research** partnerships. For example, our surveillance data shows that ambulatory care sensitive hospital admissions are 4 times higher among our kids compared to other NS kids. Severe ENT infections and oral health conditions are among the leading causes of these admissions. We are working with researchers at Dalhousie University and the IWK Health Centre to develop community-led interventions that will improve children's ear and oral health in Mi'kma'ki.

Our communities have demonstrated that being able to access **and use** reliable and comparable data is key to reducing health equity gaps, improving health services, and achieving better health outcomes. **We have proven that there is strength in numbers.**



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**For more information about the MCLR, please contact:**

Tui'kn Partnership  
201 Churchill Drive, Membertou, NS B1S 0H1  
Phone: 902-564-6466, ext. 2820  
E-mail: [staceylewis@membertou.ca](mailto:staceylewis@membertou.ca)

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