



# Kenora Chiefs Advisory First Nation Client Registry (KCA FNCR)

Defining Authorities to Share  
Information with Provincial Registry

Prepared For:  
Prepared By: Donna Williams  
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# Purpose of Presentation

- Provide Background on the KCA FNCR Initiative
- Current use and management of the FNCR
- Integration with provincial registries.
- Legislative authorities for collection and sharing of First Nation information from the FNCR
- Lessons learned

# About KCA

- The Kenora Chiefs Advisory is an alliance of 7 First Nations
- Population of around 3000 people
- Located within Treaty #3 Territory in Northern Ontario
- The Kenora Chiefs Advisory's mandate is to provide programs and services in health, education and social services in a holistic, traditional way ensuring the survival of the Anishinaabe way in the present and future generations.
- Chiefs from each of the seven communities constitute a board of directors and govern Kenora Chiefs Advisory (KCA) while the day-to-day operations are managed by the Executive Director

# Health Status

- Community has been effected by high rates of diabetes, and chronic illness
- Many communities in crisis as a result of mental health issues
- Lack of housing infrastructure and safe water
- Many communities still dealing with mercury contamination and poisoning
- Water ways and food supply remain contaminated

# Why did we develop the FNCR?

- Need for communities to have an accurate source of their member information
- Support the appropriate levels of funding for health services
- Ensure health care professionals provided are based on accurate information.
- Improve coordination of health service delivery between jurisdictions (continuum of care)
- Facilitation of health planning and research
- Respect principles of OCAP
- Scalable to include other First Nations in Ontario and potentially across Canada

## Basic Components of the KCA FNCR?



- The FNCR contains a list of demographic information about an individual such as Full Name, Date of Birth, Place of Birth, Parents names, Address, etc.
- The FNCR respects the principles of OCAP™ (ownership, control, access, and possession)
- Each community inputs their own information and controls who has access to that information
- There is no Personal Health Information within the FNCR
- Can be linked with health registries to become PHI

# FIRST NATION Client Registry

*your information, your choice*

*The First Nation Client Registry (FNCR) is an electronic Registry developed by the KCA First Nations to collect Individual and community Information*

## Why are we using the FNCR?

Information from the Registry will be used by the Band and KCA in funding applications to various government programs.

Each Band Clerk and any individual authorized by the Chief in Council to access the Client Registry will be required to sign a confidentiality agreement and will be provided with training on the importance of confidentiality.

## Do I need to be a part of the Registry?

Community members have a **choice** to be part of the Registry.

If you do not want to be part of the Registry, notify the Health Data Clerk or the Health Director.

You will be asked to fill out a form and your information will be removed from the Registry.

*Please refer to the FNCR brochure for more information.*



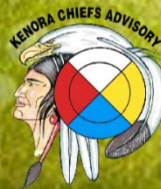
## What happens if there is a Privacy Breach?

A privacy breach is when your information is shared or viewed in a manner that is unlawful. You will be notified if there is a Privacy Breach with your information.

The community has policies in place to address any Privacy Breaches and ensure that your information is protected.

If you have any questions or would like to report a Privacy Breach, you can contact a KCA staff member at the numbers listed.

You can also call the Information and Privacy Commissioner of Ontario at **1-800-387-0073**.



for more information contact:  
Jocelyn Goretzki, KCA Health Director at 1-807-467-8144 ext. 235  
or Joe Barnes, KCA Executive Director at 1-807-467-8144 ext. 225

**KENORA CHIEFS ADVISORY FIRST NATIONS**  
Grassy Narrows, Shoal Lake 40, Noatkamewanning (Whitefish Bay),  
Ochichagwe Babigo Ining (Dalles), Obashkaandagaang (Washagamis),  
Wabaseemoong (White Dog), and Iskatewizaagegan 39

# Partnership with Cancer Care Ontario

- KCA entered into a project to link the FNCR with CCO's Registry. This will allow the following:
  - 1. Identify patients within the KCA communities that require screening for breast, cervical or colon cancer.
  - 2. Provide "Community Profiles" of cancer rates within the KCA communities.
- Data Sharing Agreements have been signed and information has been shared.
- Data Quality Analysis showed positive results for linkability with CCO's Registry. Able to identify number of KCA community members within the CCO Cancer Registry.



# Needed to Define Authorities to share Personal Information to CCO

Undertook review of

- Federal Legislation
- Provincial Legislation
- First Nations

# Health Canada – First Nation Inuit Health Branch

- Responsible for on-reserve health care
- Hold vast amounts of First Nations information under control of Federal Government
- Subject to **Federal Legislation** such as the Privacy Act, Access to Information Act and Charter of Rights and Freedoms
- Must have legislated authority to collect and disclose Personal Information

# Federal Legislation

- Privacy Act (1983)
  - Applies to Federal governments and institutions
  - Defines the authorities under which the federal government can collect and disclose Personal Information
  - Applies to First Nation information under the control of the Federal Government
  - ie) Indian Registry System, Health Records within Federal nursing stations
- Personal Information Protection and Electronic Documents Act (2000)
  - Protects Personal Information that is used in electronic systems
  - Applies to Federal governments and Institutions
  - Applicable to businesses such as banking institutions
- Charter of Rights and Freedoms (1982)
  - Protects Canadian citizens from undue search and seizure
  - Protect Canadians to reasonable expectation of privacy
- Access to Information Act (1985)
  - To make governments accountable
  - Allow individuals to request Personal Information about themselves
  - Prevent unauthorized collection or disclosures of PI

# Provincial Legislation

## PHIPA

- CCO is a “prescribed entity” under Ontario *Personal Health Information Protection Act, 2004* (**PHIPA**)
- CCO is a “prescribed person” in respect of the Cancer Screening Registry under PHIPA
- CO has authority to collect information from the FNCR under PHIPA (*i.e.*, analysis and/or compiling statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system, including the delivery of services); and
- Purposes of facilitating or improving the provision of health care in relation to the Ontario Cancer Screening Registry.

# FIPPA

- CCO is an “institution” under the Ontario *Freedom of Information and Protection of Privacy Act* (**FIPPA**)
- CCO agreed to collect, use and disclose such PI in accordance with its obligations as an “Institution” under FIPPA

# First Nations

- Land First Nation communities are “tracts of land....that has been set apart by Her Majesty for the use and benefit of a band” .....Indian Act, 1876
- First Nation communities are considered federal jurisdiction
- Not a “government institution” as defined in the Privacy Act
- Not a business as defined under the Protection of Privacy and Electronics document Act
- Provincial legislation does not apply within First Nation communities
- First Nations nursing stations/health centres are not “Health Information Custodians” as defined in PHIPA.

# KCA

- No legislated designation to collect or disclose
- Legal advice to act “as if” PHIPA applied
- Needed to develop privacy infrastructure based on CSA model Codes
  1. Accountability
  2. Identifying Purposes
  3. Consent
  4. Limiting Collection
  5. Limiting Use, Disclosure, Retention
  6. Accuracy
  7. Safeguards
  8. Openness
  9. Individual Access
  10. Challenging Compliance

# OCAP™

- First Nations principles of control over their own information
  - Ownership - describes the relationship of the First Nation to its cultural knowledge, data and information in all forms. This information is owned collectively by the Nation as an individual owns their personal information.
  - Control- affirms that First Nations are within their rights in seeking to control over all aspects of research and information management processes that impact them
  - Access - First Nations must have access to information and data about themselves and their communities, regardless of where it is currently held
  - Possession of data - It refers to the physical control or stewardship of data
- These principles together with the Data Sharing Agreement (DSA) create obligations for CCO employees accessing, analyzing, linking, and creating reports/publications with First Nations' data.



# Applying OCAP™

- KCA communities have right to control what is done with their data – whether it is aggregate, de-identified or linked data.
- The KCA communities must be apprised of all activities involving FNC) data linkages and the creation of reports
- Advise KCA if linkages are desired. This is so the linked data continues to be identified as KCA Data Holding, subject to distinct access controls
- CCO employees that wish to access an KCA Data Holding must be aware of the following:
  - Any activity involving the KCA data holdings must be consistent with a project approved by the KCA via the DSA or the KCA First Nations Data Access Protocol
  - Reports of any kind created with KCA data, must be provided to the KCA for its written approval at least 8 weeks prior to submission for publication
- CCO must present results/findings contained in a report to the KCA should the KCA request it
- CCO's Data Access Committee (DAC) cannot release data to a researcher without KCA's consent
- Results must be presented in a manner respecting cultural and intellectual integrity of the participating First Nations members

# Lessons Learned

- Once Personal Information is shared, it becomes subject to the legislation within that jurisdiction
- You will need a good lawyer to confirm your authorities to collect and share First Nations data.
- Difficult to find policy experts and lawyers with experience in First Nations privacy legislation (or lack thereof)
- Difficulty explaining concepts in plain language

# Next Steps

- Continue to develop partnerships and operational model for the FNCR
- Determine if there is interest in moving forward with expansion of the FNCR
- Project under way to determine costs of expanding the FNCR to 64 First Nations within the North West LHINs (engagement, technical costs, core services)
- Looking at implications of including Health Card Numbers into the FNCR (will become Personal Health Information)

# Miigwetch



Donna Williams, RN, BScN

President

Keesic Health Strategies

[dwilliams@bellnet.ca](mailto:dwilliams@bellnet.ca)

807.728.2562

