Health Indicators for Nova Scotia First Nations Communities: the Tui'kn Initiative

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Abstract

Among the challenges facing First Nations peoples in Canada, the absence of health surveillance data specific to their communities is a barrier to understanding and gaining control of health planning issues. Five First Nations communities on Cape Breton Island, Nova Scotia have installed Electronic Patient Record (EPR) systems in each of their stand-alone community health clinics. Health practitioners serving these communities use these systems to maintain patient profiles, and facilitate billing to the single-payor provincial Medical Services Insurance (MSI) program. The Tui'kn Initiative started in 2004 to develop these separate EPRs into a single Client Registry which could be linked to various provincial administrative health data sources (including the provincial cancer registry and cervical screening registry) in order to provide community-based health indicators within a framework that would allow comparisons over time, and to the wider Cape Breton and Nova Scotia populations.

To fully enumerate the populations encompassed by the five communities, three datasets were linked: the communities' own EPRs; the provincial MSI database; and a list of First Nations' individuals living in Nova Scotia, registered in the national database of Indian and Northern Affairs Canada (the INAC database). The resulting Client Registry (CR) was then available to be linked to several different health outcome or utilisation databases available at the provincial level.

This presentation will describe the challenges of the linkage activity required for the project and the partnerships created as a result of this project to make this work a sustainable resource. Results will focus on the types of health indicators that were derived from the linkage to datasets held by Cancer Care Nova Scotia, namely the cancer registry, and the Cervical Cancer Prevention Program database.

Objectives

- Describe the creation of the Unama'ki Client Registry representing the population served within the Tui'kn communities
- Present sample reports from linkage of Client Registry to the Nova Scotia Cancer Registry and Cervical Cancer Screening Program databases

Partners

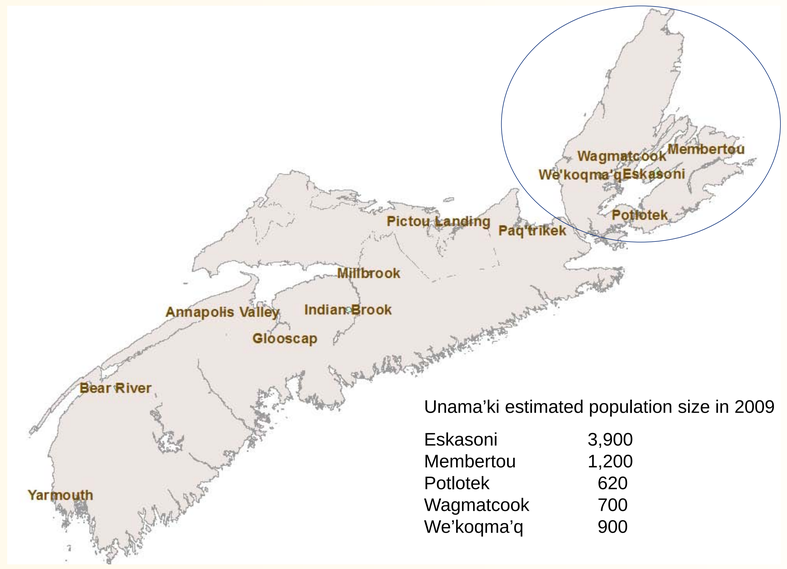
- Cape Breton First Nations communities. Together, these communities comprise the **Unama'ki Community** with a common Electronic Health Record (**EPR**) database
- **INAC** Indian and Northern Affairs Canada
- **MSI** Medical Services Insurance, managed by **Medavie** Blue Cross on behalf of the Government of Nova Scotia
- **PHRU** Population Health Research Unit of Dalhousie University, providing research expertise and access to population-based hospital and physician utilisation data
- **Provincial Health Management Programs:** under auspices of the Department of Health and Welness, Government of Nova Scotia

CCNS	Cancer Care Nova Scotia
CVHNS	Cardiovascular Health Nova Scotia
RCP	Reproductive Care Program

Data Resources (source datasets)

- **EPR** – services provided to community members by on-site health clinics
  - Client demographics (sex, date of birth, postal code)
  - Provincial Health Card Number (**HCN**)
  - Band number
- **INAC** – national database of all registered First Nations people
  - Names
  - Demographics (sex, date of birth, community name)
  - Band number
- **MSI** – provincial database of all insured persons in the province
  - Names
  - Demographics (sex, date of birth, residential address)
  - **HCN**

Nova Scotia and First Nations Communities

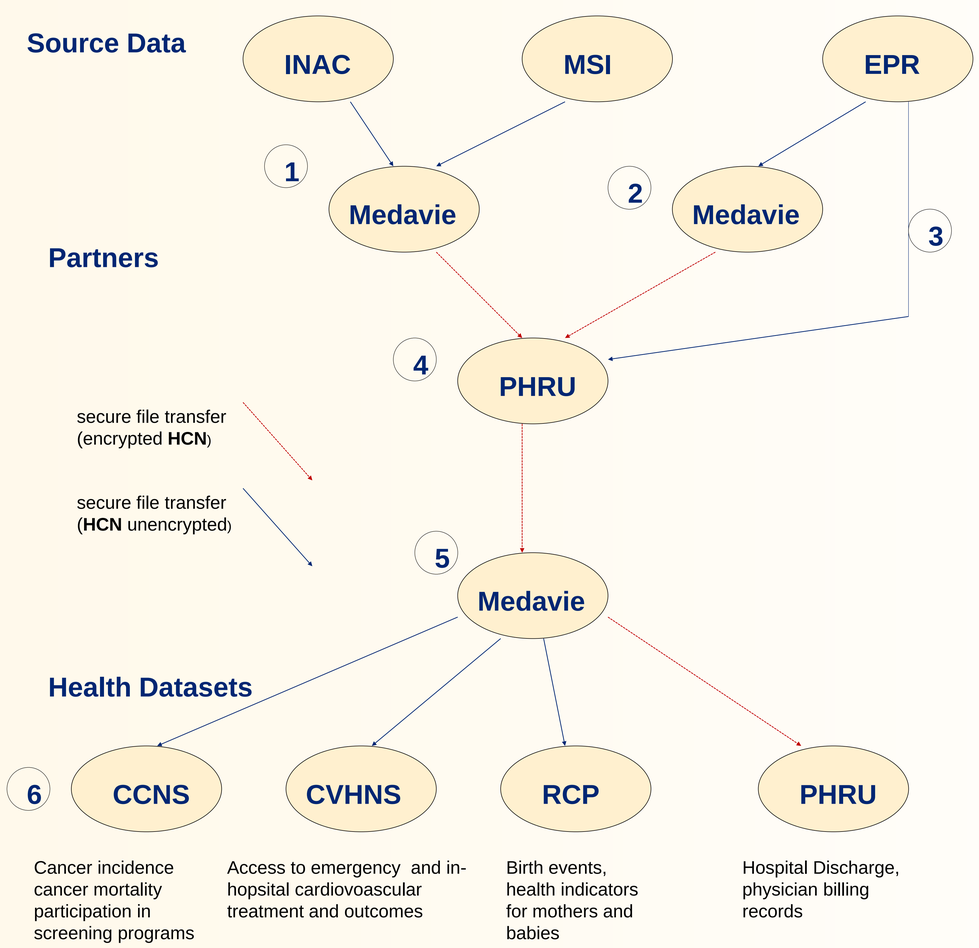


Cape Breton Island

Unama'ki estimated population size in 2009

Eskasoni	3,900
Membertou	1,200
Potlotek	620
Wagmatcook	700
We'koqma'q	900

Linkage Process
(provides both population denominators and identifies numerator events)



Linkage Steps:

1. Probablilistic linkage on names, sex, date of birth, community name. Assign encrypted Health Card Number (eHCN) and encrypt Band number with 1-time key

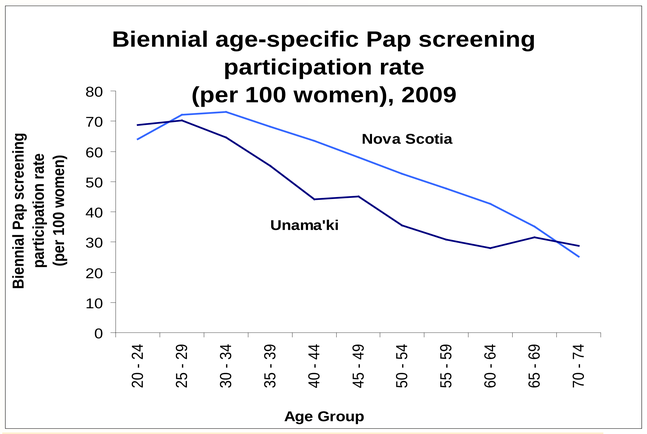
All personal identifiers removed for steps 2 – 6

2. Encrypt HCN and Band number using 1-time key. Retain unique study ID
3. EPR study data (age, sex, vital staus…) and unique study ID sent directly to PHRU
4. Merge datasets on unique study ID and eHCN, Refine linkage and reject some links formed on invalid or duplicated eHCN
5. Study dataset returned to Medavie for unencryption or for encryption with 'standard' encryption protocol
6. Linkage with provincial programs. Provincial programs retain HCN unencrypted, PHRU retains only an encrypted version ('standard protocol') of HCN

Example results from linkage to Cancer Registry, Cervical Cancer Prevention Program

Standardised Cancer Incidence (SIR), Mortality (SMR) Ratios for Members of the Unama'ki Community by sex, age and cancer site, 2000-2009

	Incidence			Mortality		
		Compared to Nova Scotia			Compared to Nova Scotia	
	Cases	SIR	95% CI	Cases	SMR	95% CI
Men	107	105.5	(84 - 125)	41	103.4	(65 - 123)
Women	147	126	(101 - 141)	41	93.6	(61 - 117)
Under 50	38	83.9	(56 - 107)	≤10	85.3	(21 - 123)
50 - 64	108	147.1	(119 - 178)	35	145.3	(91 - 181)
65 +	108	108.7	(85 - 127)	41	78.8	(53 - 100)
Colorectal	37	125.5	(81 - 162)	≤10	90	(41 - 159)
Lung	33	106	(65 - 129)	23	97.7	(57 - 134)
Breast (F)	44	134.9	(95 - 174)	≤5	72.5	(21 - 153)
Prostate	54	139.1	(114 - 196)	≤10	121.4	(49 - 202)
All Other	86	100	(77 - 121)	35	101.4	(61 - 123)
All Cancer	**254**	**116.5**	**(99 - 127)**	**82**	**98.3**	**(69 - 110)**



Lessons learned – Future steps

- Privacy concerns were paramount. Led to first ever written agreement on sharing of health data between Provincial Governement and First Nations communities
- Small populations led to wide confidence limits on estimates, difficulty in interpretation
- In future, suggest using personal identifiers and probabilistic linkage for all 3 source files, and to build in feedback loop to improve quality of identifiers.
- Project funded as 'research' but requires operational funding to be sustained
- Expand linkage to other First Nations communities and other health datasets