Profiling Cancer within Select Ontario Aboriginal Reserves

Methods for measuring cancer burden at a local level using registry data

Maegan Prummel, MPH
Senior Research Associate, Aboriginal Cancer Control Unit, Cancer Care Ontario
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Presentation Overview

1. Background
   - Aboriginal Peoples: First Nations, Inuit and Métis (FNIM)
   - Cancer Burden in Ontario FNIM

2. Community Level Cancer Burden
   - Overview of Cancer Profiles
   - Available data sources, current practice
   - Challenges
   - Alternative Methodologies

3. Summary
Aboriginal Peoples of Ontario

301,430 Aboriginal people in Ontario (2% of Ontario population; 22% of Canadian Aboriginal population)

- 201,100 (67%) First Nations
- 86,015 (28%) Métis
- 3,360 (1%) Inuit

First Nations represent:

- Registered & non-Status Indians
- Those living on- and off-reserve

*Possible undercount due to incompletely enumerated Indian Reserves and Settlements
Cancer Burden in Ontario First Nations (FN)

- Limited information on cancer burden in Ontario Aboriginal populations (lack of identifiers in Canadian cancer registries)
- Previous studies based on cohort linked to Ontario Cancer Registry
  - Historically, cancer incidence has been lower in FN populations compared to general Ontario population
  - Cancer incidence is expected to increase more rapidly among FN compared to other Ontarians – esp. colorectal, lung
  - Survival for major cancers is significantly worse in FN people compared to the general population

Community Level Cancer Burden – Aboriginal Community Cancer Profiles

Purpose: Develop a report on cancer burden in a geographically defined area

• Typically conducted in response to community request
• Working with FN data: Need to address FNIGC OCAP™
  • Ownership; Control; Access; Possession
  • Direct Negotiations with the community

Two main approaches:

• Geographic method: based on postal code
• Cohort method: requires multiple approvals
Sample Community Cancer Profile

- Incidence & prevalence by age, sex, cancer type
- Numbers of major cancers in postal code compared to expected based on Ontario experience, 2001-2010
- Privacy: cannot disclose counts between 1-5

<table>
<thead>
<tr>
<th>Cancer Profile for Community X</th>
</tr>
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<tbody>
<tr>
<td>1) Overall Cancer Burden</td>
</tr>
<tr>
<td>a) New cancer cases diagnosed</td>
</tr>
<tr>
<td>- There were approximately 20 new cases of cancer diagnosed every year between 2001 and 2010 among an average population of 4500 residents living in Community X.</td>
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<tr>
<td>- The number of new cases diagnosed in Community X is similar to what was expected based on the experience of the Ontario population.</td>
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<tr>
<td>b) People living with cancer diagnosed between 2001 and 2010</td>
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<td>- In 2010, there were 100 people in Community X living with a diagnosis of cancer.</td>
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<tr>
<td>2) Number of new cases diagnosed by sex</td>
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<td>- In Community X, 102 cases were diagnosed in men and 88 in women. This is lower than expected for women. The number of new cases diagnosed for both men and women was lower than expected for the Ontario population.</td>
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<tr>
<td>3) Number of new cases by age at diagnosis</td>
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<tr>
<td>- In Community X, the number of cancers diagnosed in each age group, as a percentage of the population, is presented in Table 1.</td>
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<tr>
<td>Table 1: Number of cancers diagnosed in Community X by age and sex, 2001-2010</td>
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<tr>
<td></td>
</tr>
<tr>
<td>Males</td>
</tr>
<tr>
<td>Age Group</td>
</tr>
<tr>
<td>0-44</td>
</tr>
<tr>
<td>45-64</td>
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<tr>
<td>65+</td>
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<td></td>
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<tr>
<td>4) Number of new cases by type of cancer</td>
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<td>- Between 2001 and 2010 there were five types of cancer with 8 or more cases of each.</td>
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<tr>
<td>Table 2: number of cancer cases diagnosed from 2001-10 in Community X</td>
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<tr>
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<tr>
<td>Cancer Type</td>
</tr>
<tr>
<td>Prostate</td>
</tr>
<tr>
<td>Female breast</td>
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<tr>
<td>Colon</td>
</tr>
</tbody>
</table>

Figure 1: Number of common cancers diagnosed compared to number of cases expected, from 2001-2010
Data Sources for Cancer Profiles

Information on Cancer

Ontario Cancer Registry (OCR)

- Information on all Ontario residents diagnosed with cancer (incidence, 1964-); or who have died of cancer (mortality, 1950-)

- Passive registration with four sources:
  - Hospital records from discharge abstracts and day surgeries
  - Pathology reports submitted by laboratories
  - Regional Cancer Centres (RCC)
  - Death certificates

- No Aboriginal Identity, No full addresses, postal code only
Data Sources for Cancer Profiles

Information on Population

Canadian Census (Statistics Canada)

- Annual population estimates by age, sex for census areas
- Unique census subdivision for each Indian Reserve in Ontario
- **BUT: need to estimate population of postal code area**
Data Sources for Cancer Profiles

Information on Population

Postal Code Conversion Factor Plus (PCCF+)

- Developed by Statistics Canada
- Provides correspondence between postal code and Statistics Canada’s standard geographical areas

- **Postal Code Population weight file:** population weights for each census geographic area served by a single postal code
  - Can be used to estimate population of postal code area
Example: Community Cancer Profile

- 42% of postal code population lives in community of interest (A)
- One postal code covers entire community of interest (A)
- Surrounding areas have similar population characteristics
Challenge #1: Defining population at risk

- Boundary of Reserve X(-----) does not match postal code boundary (-----)
Challenge #2: Small Sample Sizes

Privacy: can only report on groups with 6+ cases

<table>
<thead>
<tr>
<th>POPULATION SIZE OF AN ON-RESERVE FN COMMUNITY</th>
<th>PERSON YEARS 2001-2010</th>
<th>CANCERS EXPECTED* 2001-2010</th>
<th>CANCER TYPES WITH 6+ CASES†</th>
</tr>
</thead>
<tbody>
<tr>
<td>500</td>
<td>5000</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>1000</td>
<td>10000</td>
<td>25</td>
<td>0</td>
</tr>
<tr>
<td>1500</td>
<td>15000</td>
<td>38</td>
<td>2</td>
</tr>
<tr>
<td>2000</td>
<td>20000</td>
<td>51</td>
<td>2</td>
</tr>
<tr>
<td>2500</td>
<td>25000</td>
<td>63</td>
<td>4</td>
</tr>
</tbody>
</table>

*Based on the overall experience of Ontario population
†assuming top four cancers represent 15%; 15%; 10% and 10% of all cases respectively
Summary

Challenges:
• Not specific to community (postal code covers surrounding areas)
• Population of postal code is difficult, or not possible, to calculate
• Very small numbers (limits ability to provide useful information)

Alternative methods:
1. More complex mapping of cancer cases
2. Cohort method
Alternative Methods -1

Link cases from postal code to **Registered Persons Database (RPDB)**

- RPDB is a population-based register maintained by Ontario’s Ministry of Health and Long-Term Care (MOHLTC) to manage publicly funded health care services (i.e. OHIP)
- Full street address information for each person
- Suitable for communities in relatively urban neighborhoods with municipal roads…
Alternative Methods -2

Link Aboriginal cohort with Ontario Cancer Registry:

- Obtain list of residents from the community
  - At discretion of community how they define ‘resident’
  - Successful linkage requires high quality, complete data
  - Sample size requirements require multiple years of data (usually 10 years)

- Obtain access to Indian Registry System (IRS)
  - Registry of all status FN individuals, maintained by AANDC
  - Strict application process
  - Multiple approvals required
Summary: Community Cancer Profiles

- Cancer burden can be examined at an Aboriginal community level based on postal code, but there are many challenges.

- Exploring 3 potential ways to produce Aboriginal community profiles:
  1. From the Ontario Cancer Registry, based on postal code geography
  2. Linking Ontario Cancer Registry to the Registered Persons Database in more urban communities with municipal roads
  3. Cohort method: Obtaining community lists, or the IRS and linking to the Ontario Cancer Registry

- Methodology/approach dependent on consultation with community, in accordance with OCAP™
Acknowledgements & Q/A

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Questions: Maegan.Prummel@cancercare.on.ca