Cancer surveillance in indigenous populations: knowledge, challenges and opportunities

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Objectives

• To briefly describe what we know about cancer in indigenous populations in North America and Oceania
• To identify challenges and opportunities for enhancing cancer surveillance in these populations
Indigenous people

• UN estimates more than 370M in 90 countries speaking 4,000 languages
• Inherent in any description is the right to self-identification (ie cannot be externally defined)
• Article 33 of the UN Declaration on the Rights of Indigenous Peoples underlines the importance of self-identification, that indigenous peoples themselves define their own identity as indigenous

Source: State of the world’s indigenous people. UN 2009
Indigenous people in North America and Oceania: Canada

- Three constitutionally recognized, distinct groups
  - “First Nation” (FN) formerly “Indian”
  - Métis: mixed FN and European ancestry, especially fur traders from Scotland, Ireland & France
  - Inuit are primarily from Canada’s Arctic regions in several provinces and territories
  - Collectively referred to as “FNIM”

- 1,400,685 Aboriginal people (~4% population)

Source: National Household Survey 2011
Population autochtone par zone économique
Aboriginal Population by Economic Zone

Source of data: 2006 Census
Indigenous people in North America and Oceania: USA

- 5.2 million American Indians (AI) and Alaska Natives (AN) - 1.7% of US population
  - 3.6 million specified an AI tribe
  - 169,000 specified an AN tribe
- Largest numbers in California, Arizona and Oklahoma

Source: US Census, 2010
American Indians and Alaska Natives as a Share of the Total Population, by State, 2009-2011

Total: 2.5 million = 1% of U.S. Population

American Indian and Alaska Native includes people of Hispanic origin.
SOURCE: KCMU analysis of 2009 - 2011 ACS.
Indigenous people in North America and Oceania: Australia

- Referred to collectively as Aboriginal and Torres Strait Islander Australians
  - 670,000 (3% of population; 30% of Northern Territories)
- 632,000 are Aboriginal Australians, the original people of Australian Mainland, including Tasmania
- 38,000 identify as Torres Strait Islanders, indigenous people of the Torres Strait Islands who are of Melanesian descent
  - Most live in Queensland

Source: 2011 Census
Indigenous people in North America and Oceania: New Zealand

• 600,000 New Zealanders self-identified as being of Maori ethnicity (15% of population), originating from Polynesia
• 670,000 are of Maori descent (2013 census)
• 86% live on North Island, with 24% living in Auckland area

Source: 2013 Census
Common demographic trends

- Rapid population growth, in part due to increased identification as Aboriginal
- Young population
- Increasingly moving away from traditional lands into more populated areas
- Higher rates of poverty and unemployment
- Rapid transition to chronic diseases
- Lower life expectancy

<table>
<thead>
<tr>
<th></th>
<th>Guatemala</th>
<th>Panama</th>
<th>Mexico</th>
<th>Nepal</th>
<th>Australia</th>
<th>Canada</th>
<th>New Zealand</th>
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<tbody>
<tr>
<td>Life Expectancy Gap (in years)</td>
<td>13</td>
<td>10</td>
<td>6</td>
<td>20</td>
<td>20</td>
<td>7</td>
<td>11</td>
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</tbody>
</table>

Cancer surveillance

• Little surveillance except in a few specific environments, and mostly small studies before 2004
  • 1993-2003 there were 63 journal articles reporting some measure of cancer burden in Maori, Aboriginal & Torres Strait Islander Australians, Inuit, AI/AN, Metis, Aboriginals, Indigenous in NA/Oceania*
  • 18 so far in 2014 alone
• Shift over time from very descriptive (focus on incidence and mortality) to understanding ‘why’, looking at health services, etc.

* Includes review articles
Cancer Incidence/Mortality: Overall

- Historically, low overall cancer incidence rates
  - Especially for cancers associated with ‘western’ lifestyle, like breast, prostate, colorectal, lung and corpus uteri
- Over time, overall rates have increased and are now more similar to general population
All cancer incidence, Ontario, Canada, 1968-2001, ages 15-74

Notes:
- Rates are age-standardized to the 1991 Canadian population.
- Horizontal bars around registered First Nations rates indicate 95% confidence limits.

Source:
Marrett & Chaudhry, Cancer Causes Control 2003; Marrett et al. unpublished data

Prepared by:
Aboriginal Cancer Control Unit, Prevention and Cancer Control, Cancer Care Ontario, May 2014
Incidence of common cancers, Ontario males, ages 15-74

1968-1991

1997-2001

* Significant Difference

Rates age-standardized to the 1991 Canadian population
Cancer Incidence/Mortality: Specific patterns

• Some notable patterns within each of the 4 countries
• Variety of methodologies adopted by cancer registries to ensure reasonably accurate and comprehensive data
New Zealand has used linkage of cancer registry to quinquennial censuses, 1981 through 2001

- High lung, similar prostate and female breast, low colorectal
- Low bladder and cancers and melanoma
- High cervix, liver and stomach

Incidence rate ratios, Indigenous Australian males, 1998-2005

Australia assessed quality of identification in cancer registries in a creative way and focused on high quality registries

- High lung, low female breast (not shown), prostate and CRC
- Low bladder cancer and melanoma
- High cervix (not shown), esophagus and liver

<table>
<thead>
<tr>
<th>IRRc</th>
<th>Tumor Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.5</td>
<td>Lip, oral and pharynx</td>
</tr>
<tr>
<td>2.1</td>
<td>Oesophagus</td>
</tr>
<tr>
<td>1.3</td>
<td>Stomach</td>
</tr>
<tr>
<td>0.5</td>
<td>Colon and rectum</td>
</tr>
<tr>
<td>1.5</td>
<td>Anus</td>
</tr>
<tr>
<td>2.7</td>
<td>Liver</td>
</tr>
<tr>
<td>1.4</td>
<td>Pancreas</td>
</tr>
<tr>
<td>1.6</td>
<td>Larynx</td>
</tr>
<tr>
<td>1.6</td>
<td>Lung</td>
</tr>
<tr>
<td>0.9</td>
<td>Bone</td>
</tr>
<tr>
<td>0.2</td>
<td>Melanoma</td>
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<tr>
<td>1.1</td>
<td>Penis</td>
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<tr>
<td>0.5</td>
<td>Prostate</td>
</tr>
<tr>
<td>0.5</td>
<td>Testis</td>
</tr>
<tr>
<td>0.8</td>
<td>Kidney</td>
</tr>
<tr>
<td>0.6</td>
<td>Bladder</td>
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<tr>
<td>0.4</td>
<td>Brain</td>
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<td>Thyroid</td>
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<tr>
<td>1.7</td>
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<tr>
<td>0.6</td>
<td>Lymphoma</td>
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<tr>
<td>0.7</td>
<td>Leukaemia</td>
</tr>
<tr>
<td>0.9</td>
<td>Others</td>
</tr>
<tr>
<td>0.8</td>
<td>All cancers combined</td>
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<tr>
<td>1.5</td>
<td>Other tobacco-attributable cancers</td>
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</tbody>
</table>

Incidence rates/rate ratios, AI/AN, 1999-2009

**IRR, Males**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Rate</th>
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</thead>
<tbody>
<tr>
<td>All</td>
<td>0.9</td>
</tr>
<tr>
<td>Prostate</td>
<td>0.8</td>
</tr>
<tr>
<td>Lung</td>
<td>1.0</td>
</tr>
<tr>
<td>Colorectal</td>
<td>1.1</td>
</tr>
<tr>
<td>Kidney</td>
<td>1.6</td>
</tr>
<tr>
<td>Bladder</td>
<td>0.5</td>
</tr>
<tr>
<td>NHL</td>
<td>0.8</td>
</tr>
<tr>
<td>Liver</td>
<td>2.2</td>
</tr>
<tr>
<td>Stomach</td>
<td>2.0</td>
</tr>
<tr>
<td>Oral</td>
<td>0.9</td>
</tr>
<tr>
<td>Leukemia</td>
<td>0.8</td>
</tr>
<tr>
<td>Pancreas</td>
<td>0.9</td>
</tr>
<tr>
<td>Esophagus</td>
<td>1.0</td>
</tr>
</tbody>
</table>

**Colorectal cancer, females**

- East
- Pacific Coast
- Southwest
- Southern Plains
- Alaska
- Northern Plains

US linked with Indian Health Service records and focused on high data quality areas

Source: White et al. AJPH 2014
Incidence of common cancers, Ontario, 1997-2001, ages 15-74

Ontario has linked its cancer registry to the Indian Registry System, 1968-2001

Notes: Rates are age-standardized to the 1991 Canadian population.
* Significant difference between registered First Nations and All Ontario rates
Source: Marrett et al. unpublished data
Prepared by: Aboriginal Cancer Control Unit, Prevention and Cancer Control, Cancer Care Ontario, May 2014

Females

Males

Notes: Rates are age-standardized to the 1991 Canadian population. Horizontal bars around registered First Nations rates indicate 95% confidence limits.

Source: Marrett & Chaudhry, Cancer Causes Control 2003; Marrett et al. unpublished data
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Registered First Nations
All Ontario

Females

Males

Notes: Rates are age-standardized to the 1991 Canadian population. Horizontal bars around registered First Nations rates indicate 95% confidence limits.

Source: Marrett & Chaudhry, Cancer Causes Control 2003; Marrett et al. unpublished data

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Variation in cancer incidence rates between Inuit, 1989-2003

Cancer survival

Notes: Rates are age-standardized to the 1991 Canadian population. Five-year age-standardized observed survival (%) by cancer site and sex comparing First Nations population to other Ontarians for cancers diagnosis between 1968-1991 with follow-up to December 31st, 2007 and censoring at age 75.


Prepared by: Aboriginal Cancer Control Unit, Prevention and Cancer Control, Cancer Care Ontario, May 2014

Notes: Rates are age-standardized to the 1991 Canadian population. Five-year age-standardized observed survival (%) by cancer site and sex comparing the First Nations population to other Ontarians for cancers diagnosis between 1968-1991 with follow-up to December 31st, 2007 and censoring at age 75.


Prepared by: Aboriginal Cancer Control Unit, Prevention and Cancer Control, Cancer Care Ontario, May 2014
Summary

• In general, overall cancer incidence and especially mortality rates have risen, reaching or approaching those of non-indigenous populations

• High and increasing rates of lung and other smoking-related cancers
  • May have stabilized in AI/AN men in the US

• Indigenous populations have lost their historical advantage vis-à-vis the common (‘western’) cancers but have largely retained their higher/similar rates for cancers of the gallbladder, kidney, stomach and liver
Summary (2)

• Generally, a reduction in disparity for cervical cancer
• Continuing low rates of bladder cancer and melanoma
• Cancer incidence patterns are not uniform across populations
  • Regional variation within US
  • Inuit across circumpolar regions
  • Inuit, FN and Métis within Canada
• Fewer studies of cancer survival, but generally poorer
• Less improvement in survival over time
What is needed: surveillance

- Build and enhance sustainable and ongoing surveillance systems and strategies
- Continuing improvements to data and methodology needed to support good surveillance
  - Creative use of administrative databases such as registers, non-traditional health files and censuses, and of modeling or other statistical techniques
  - Appropriate life tables
- Expanded metrics (e.g., prevalence, DALYs) and finer subgroups (e.g., differences by geography, subpopulations, etc)
Challenges to improving surveillance

- Data availability, access and quality
  - Many registries have either no (most of Canada) or poor quality (parts of Australia) Aboriginal identifiers
  - Access to and use of useful data may be strictly controlled (e.g., linkages to census at Statistics Canada)
- Relatively small numbers, small proportion of population, multiple important subpopulations
- Changing self-identification
  - E.g., Canada’s indigenous population rose by 20% in 2006-2011; Métis population almost doubled in 1996-2006
  - Partly due to changes in reporting of identity across Canadian censuses (‘ethnic mobility’)

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Challenges to improving surveillance

• Privacy concerns, e.g., concept of ‘community privacy’
• Governance issues, e.g., OCAP principles (Ownership, Control, Access, Possession)
• Multiplicity of political and governmental organizations
What is needed: action

• Strong linkages with indigenous organizations/communities and acknowledgement of their concerns
• More research into “why” the disparities and “what works” to reduce
  • We know about high rates of smoking and low rates of screening but what else?
  • E.g., in Ontario, poorer breast cancer survival due to higher stage and more comorbidity
• ACTION
Aboriginal Cancer Strategy (ACS II) 2012-15

• Cancer Care Ontario’s roadmap to address FNIM cancer control needs in Ontario
• Led by CCO’s Aboriginal Cancer Control Unit
• ACS III is under development

Vision
“To improve the performance of the cancer system with and for FNIM peoples in Ontario in a way that honours the Aboriginal Path of Well-being”

“The ACS II sets out a clear plan for reducing risk & preventing cancer...”
# ACS II: Strategic Priorities

<table>
<thead>
<tr>
<th>Strategic Priority 1:</th>
<th>Strategic Priority 2:</th>
</tr>
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<tbody>
<tr>
<td>Build productive relationships</td>
<td>Research and surveillance</td>
</tr>
<tr>
<td>Work with FNIM groups to formalize relationships based on trust and mutual respect</td>
<td>Data to inform programming initiatives will be compiled/developed</td>
</tr>
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<thead>
<tr>
<th>Strategic Priority 3:</th>
<th>Strategic Priority 4:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention</td>
<td>Screening</td>
</tr>
<tr>
<td>Smoking cessation efforts will be a key focus but we will begin looking at other modifiable risk areas</td>
<td>Increasing participation to cancer screening across the Province</td>
</tr>
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<thead>
<tr>
<th>Strategic Priority 5:</th>
<th>Strategic Priority 6:</th>
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</thead>
<tbody>
<tr>
<td>Palliative and Supportive care</td>
<td>Education</td>
</tr>
<tr>
<td>Help address the Palliative and Supportive care needs of FNIM with cancer</td>
<td>Increase the knowledge and awareness of cancer through cancer education and awareness initiatives</td>
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</tbody>
</table>
Thank you!
Questions?

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