Addressing community concerns: Individual privacy versus public wellbeing

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Northern Research Day
March 31 2011
Overview

The Situation: addressing community concerns

The Problem: barriers to effective communication

The Consequence: how does this impact the north?

The Solution: suggested future actions
What do you see?
The Situation

• Community members express concerns about health events or problems

• These may include perceived higher rates of cancer

• These concerns are reported to health officials, community champions, researchers, etc.
The Situation

- Recognized investigative process is undertaken in attempt to answer questions and address concerns

- Investigators usually attempt to determine *if* there is a problem at the beginning stages of this process
Analyses compare the experience of the community to the experience of a reference population.
The Problem

• BUT...communities may be seeking help from a different perspective

• They may *know* there is a problem and want solutions

Disconnect between health professionals/researchers involved in these investigations and community members
3. Find $x$.

* Asking different questions and solving problems in different ways can make effective communication difficult.

* Furthermore, trust can be jeopardized by the inability of investigators to share information with community members.
The Problem

- Small number of cancer cases in a small community = potentially identifiable

- Typically, <5 are suppressed:

<table>
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<tr>
<th>Cancer Site</th>
<th>Time Period</th>
<th>Obs</th>
<th>Exp</th>
<th>ISIR</th>
<th>95% CI</th>
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• Occasionally, potentially identifiable information is released because of extreme community concern.

• But...misinformation can still be a problem.
Childhood cancers have often been studied in relation to environmental exposures to carcinogens because children have a greater risk of cancer than adults from environmental toxins. (pg 34)

Example:

No cancer cases were found in children or youth. (pg 22)

Cancer Incidence in Fort Chipewyan, Alberta 1995-2006

Cancer clusters are now showing up in children in the First Nations town of Fort Chipewyan," said Barlow.

Impact on northern communities?

- Small communities (= small number of outcomes)
- Changing environment and ways of life
- Changing population structures
• Aklavik, NWT (population ~ 600)
  ▫ Varying numbers of stomach cancer cases have been reported by community members

• The CANHelp Working Group was established to investigate these concerns (and those related to the frequency of *H. pylori* and associated diseases)

• Specifically addressing concerns over stomach cancer incidence has been a challenge
The Consequence

- In addition to potentially misplaced financial resources:
  - Energy
  - Time
  - Anxiety
  - Additional health effects...
The Solution

• **Build trust**: open and bi-directional communication between investigators and community representatives

• **Build relationships**: investigators, community members, and media representatives

• **Re-evaluate data disclosure policies**: consider public wellbeing over individual privacy...after all, this information is only *potentially* identifiable
Thank You

- Canadian North *Helicobacter pylori (CANHelp)* Working Group, and in particular, support staff:
  - Katharine Fagan-Garcia
  - Janis Geary
  - Megan Lefebvre
  - Ashley Wynne

- Canadian Circumpolar Institute

- University of Alberta

- Cancer Surveillance Department
  Alberta Health Services
The Consequence

NWT Population Distribution by Age and Sex, July 1/1991 and July 1/2010