Addressing community concerns:
Individual privacy versus public wellbeing

Amy Colquhoun
Laura Aplin
Janis Geary
Karen J. Goodman
Juanita Hatcher

Insights ‘11

November 16 2011
Overview

The Situation: addressing community concerns

The Problem: barriers to effective communication

The Consequence: how does this impact communities?

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

- Community members express concerns about health problems
- May be a perceived high incidence of cancer
- Concerns reported to health officials, community champions, researchers, etc.
**The Situation**

- Recognized investigative process undertaken to address concerns

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

- Community members may be asking different questions!
- They may *know* there is a problem and want solutions
The Problem

- May also have different ways to find solutions...

3. Find x.
The Problem

• We may be:
  ▫ asking different questions
  ▫ solving problem in different ways

• Also...trust jeopardized by the inability of investigators to share information with community members
The Problem

- Small number of outcomes in a small population = potentially identifiable

- Typically, <5 cases are suppressed:

<table>
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<tr>
<th>Cancer Type</th>
<th>Time Period</th>
<th>Obs</th>
<th>ISIR</th>
<th>95% CI</th>
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<td>0.00</td>
<td>0.00 1.68</td>
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<td>4. 1994-1998</td>
<td>~</td>
<td>1.66</td>
<td>0.20 6.00</td>
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<td>5. 1999-2003</td>
<td>~</td>
<td>0.92</td>
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<td>6. 2004-2008</td>
<td>~</td>
<td>1.64</td>
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</table>
The Problem

- Occasionally, potentially identifiable information is released because of extreme community concern.
- But...misinformation can still be a problem.
“...children have a greater risk of cancer than adults from environmental toxins.” (pg 34)

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

Example:

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.

The adoption of the UN's Resolution on the Right to Water and the halting of Schedule 2, a new federal bill that allows mining companies to dump toxic waste into pristine lakes.

The Council along with the Tsilhqot’in Nation fought to protect Fish Lake from Taseko Mines in British Columbia. A federal assessment panel recommended against the Fish Lake project due to adverse environmental effects, but the Council continues to oppose a similar project in Newfoundland, where Brazilian mining giant, Vale Inco.

The Consequence

- Potentially misplaced resources and arising issues:
  - Money
  - Energy
  - Time
  - Anxiety
  - Additional health effects...
The Consequence

- Aklavik, NWT (population ~ 600)
- Varying numbers of stomach cancer cases have been reported by community members
The Consequence

- Canadian North *Helicobacter pylori* (CANHelp) Working Group established to investigate these concerns

- (and those related to the frequency of *Helicobacter pylori* and associated diseases)
Specifically addressing concerns over stomach cancer incidence has been a challenge:

- Unsubstantiated number of stomach cancer cases reported by media
- Territorial cancer registry unable to release actual number of stomach cancer cases
“Between 1992 and 2000, the Northwest Territories government recorded 27 cases of stomach cancer, of which eight were centred in Aklavik.”

~Edmonton Journal (2008)

“Exact numbers are not known, but one local family is said to have lost five relatives to [stomach cancer].”

~CBC (2008)
The Solution

- **Develop strategies & tools:** Risk communication strategies and knowledge translation tools specific to health investigations.

- **Build trust & relationships:** Between community members, investigators, and media representatives!

- **Re-evaluate data disclosure policies:** Public wellbeing may outweigh individual privacy (only potentially identifiable!)
Thank You

- Canadian North *Helicobacter pylori* (CANHelp) Working Group, and in particular, support staff:
  - Hsiu-Ju Chang
  - Katharine Fagan-Garcia
  - Emily Hastings
  - Megan Lefebvre
  - Ashley Wynne

- Canadian Circumpolar Institute

- University of Alberta

- Cancer Surveillance Department
  Alberta Health Services