

# Addressing community concerns: Individual privacy versus public wellbeing

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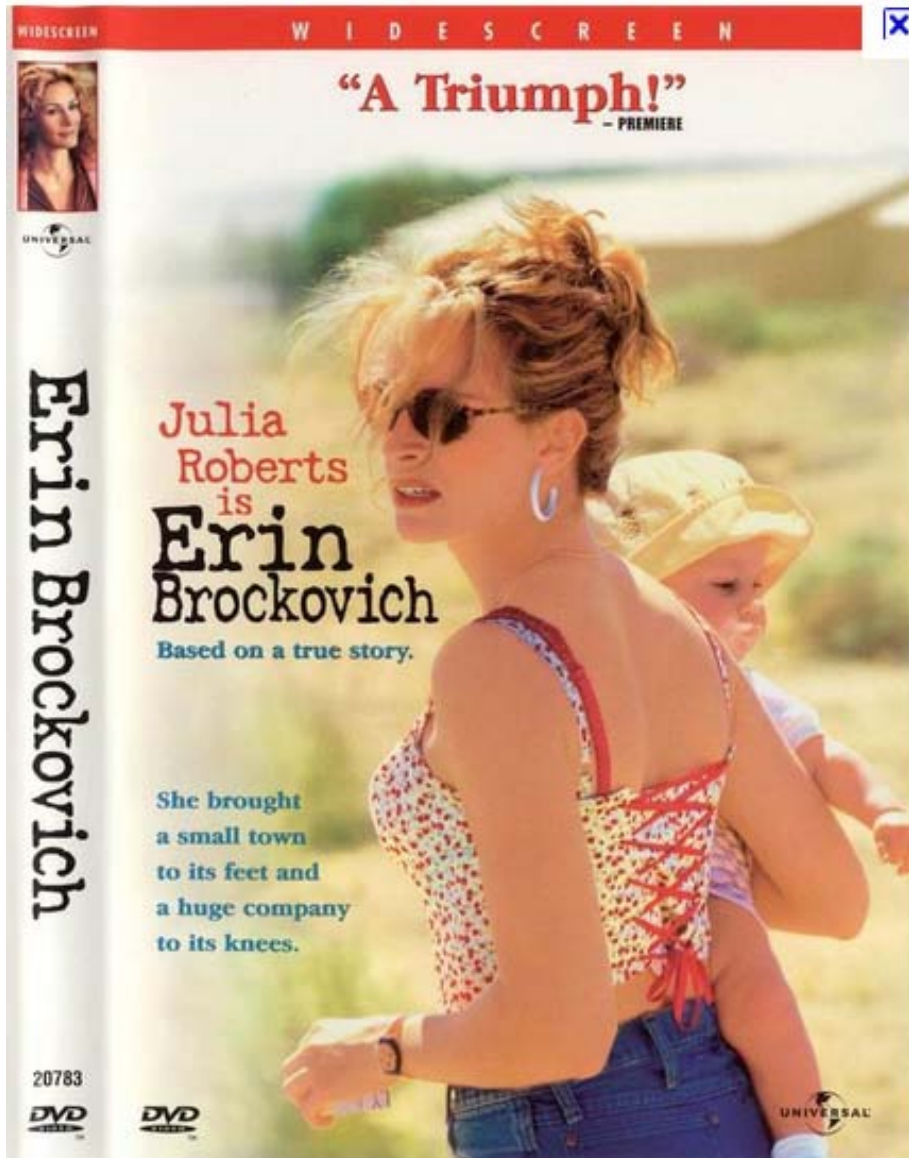
# Overview

|                         |                                     |
|-------------------------|-------------------------------------|
| <b>The Situation:</b>   | addressing community concerns       |
| <b>The Problem:</b>     | barriers to effective communication |
| <b>The Consequence:</b> | how does this impact communities?   |
| <b>The Solution:</b>    | 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.

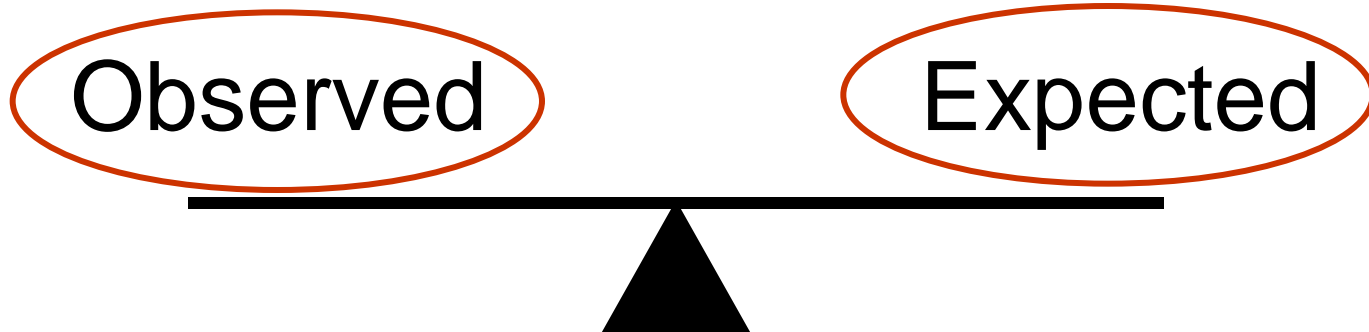
# The Situation



- Recognized investigative process undertaken to address concerns
- Investigators usually attempt to determine *if* there is a problem

# The Situation

Analyses compare the experience of the community to the experience of a reference population



# The Problem

health  
professionals/  
researchers



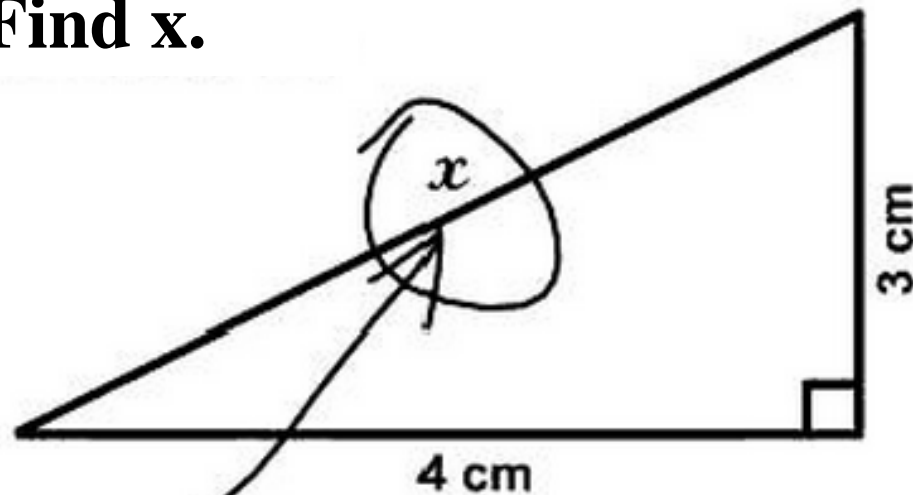
community  
members

- 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  $x$ .**



*Here it is*



# 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:

| Cancer Type | Time Period  | Obs | ISIR | 95% CI |      |
|-------------|--------------|-----|------|--------|------|
| Bladder     | 1. 1989-1998 | ~   | 0.59 | 0.07   | 2.12 |
| Bladder     | 2. 1999-2008 | ~   | 1.30 | 0.27   | 3.81 |
| Bladder     | 3. 1989-1993 | 0   | 0.00 | 0.00   | 1.68 |
| Bladder     | 4. 1994-1998 | ~   | 1.66 | 0.20   | 6.00 |
| Bladder     | 5. 1999-2003 | ~   | 0.92 | 0.02   | 5.14 |
| Bladder     | 6. 2004-2008 | ~   | 1.64 | 0.20   | 5.93 |

# 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**

<http://www.albertahealthservices.ca/rls/n-e-rls-2009-02-06-fort-chipewyan-study.pdf>

# Council of Canadians' hosts tele-town hall

BY PINA BELPERIO | FEBRUARY 28, 2011

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On Feb. 27, the Council of Canadians, Canada's largest public advocacy group held its first ever tele-town hall. The goal was to engage its 50,000+ members in an intimate forum on a cold, snowy Sunday afternoon with the Council's chair, Maude Barlow. By all accounts, the event was a huge success with over 20,000 Canadians joining in the call. Callers had a chance to learn about the Council's political campaigns, ask live questions and vote in two live polls.

In addition to celebrating its 25th anniversary last October, Barlow highlighted two big wins for the Council of Canadians, which included

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

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Election 2011: Fake lake or Lake

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

So how are the election ads doing?  
| NorthReport posted 3 min 41 sec ago

more

# 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)





# The Consequence

- **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**

# The Consequence

“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:

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Megan Lefebvre

Ashley Wynne



- Canadian Circumpolar Institute



- University of Alberta



- Cancer Surveillance Department  
Alberta Health Services

