

# 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 the north?     |
| <b>The Solution:</b>    | suggested future actions            |

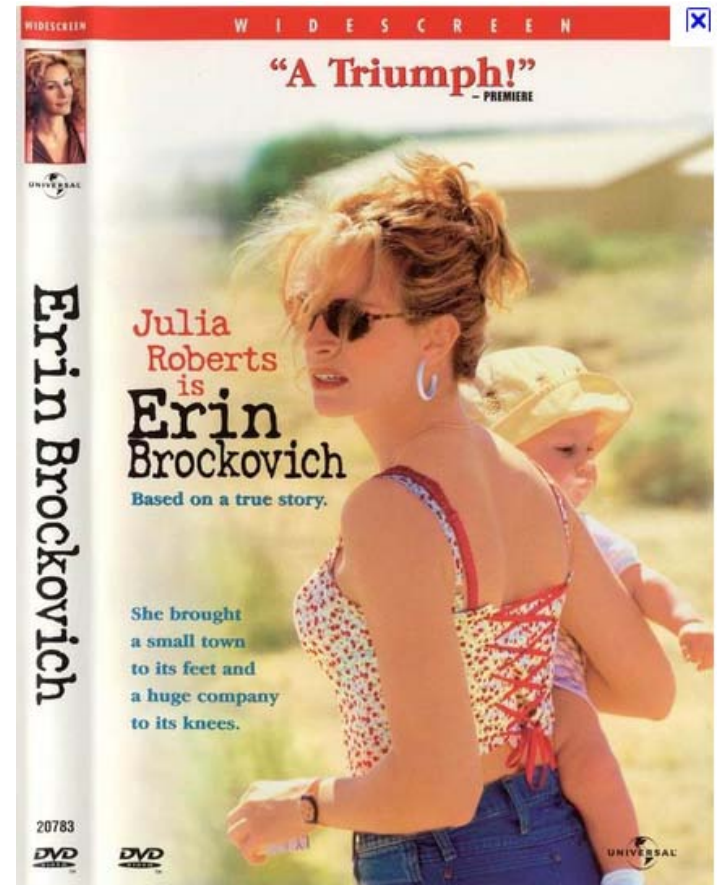


What do you see?



# 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.



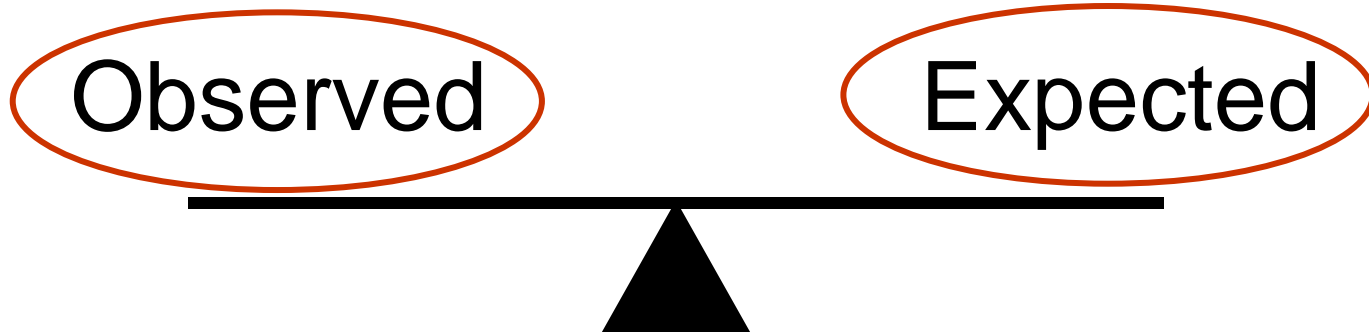
# The Situation



- 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

# The Situation

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



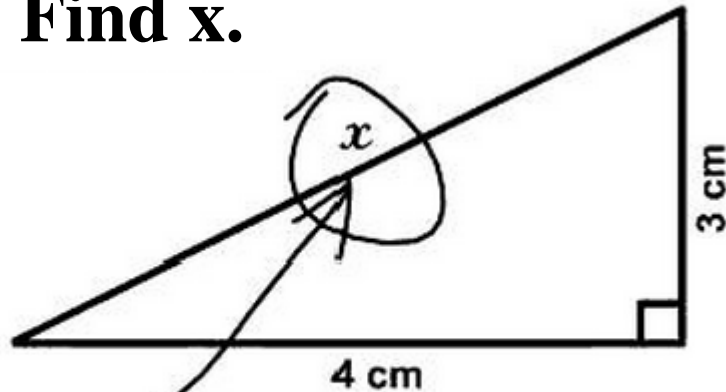
# The Problem

- **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  $x$ .**



## The Problem

- 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:

Cancer Site	Time Period	Obs	AB as Reference			
			Exp	ISIR	95% CI	
Bones, Joints & Articular Cartilage of Limbs	1. 1989-1998	~	~1	3.65	0.99	9.34
Bones, Joints & Articular Cartilage of Limbs	2. 1999-2008	~	~1	0.78	0.02	4.35
Bones, Joints & Articular Cartilage of Limbs	3. 1989-1993	0	~1	0.00	0.00	6.51
Bones, Joints & Articular Cartilage of Limbs	4. 1994-1998	~	~1	7.55	2.06	19.33
Bones, Joints & Articular Cartilage of Limbs	5. 1999-2003	0	~1	0.00	0.00	7.47
Bones, Joints & Articular Cartilage of Limbs	6. 2004-2008	~	~1	1.27	0.03	7.08

# The Problem

- 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)

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

## TOP PICKS ON RABBLE

Bell bows to pressure and backs down on usage-based billing for Internet users by Lindsey Pinto

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

- **Impact on northern communities?**
  - **Small communities**  
(= small number of outcomes)
  - **Changing environment and ways of life**
  - **Changing population structures**



# The Consequence

- 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

