



# Challenges created by data dissemination and access restrictions when attempting to address community concerns: individual privacy versus public wellbeing



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- Community members often express concerns about perceived health threats, such as perceived higher rates of cancer in their community.<sup>1</sup>

- These concerns are usually reported to health officials, community champions, researchers, or the media.

- An investigative process is undertaken by health officials or researchers to answer questions and address concerns.<sup>2,3</sup>

- This process includes several components:

- Analyses may compare the frequency of disease in the community to the experience of a reference population in another geographic area.
- Other aspects of the investigation include the building of relationships and the maintenance of open and bi-directional communication.

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2. Guidelines for investigating clusters of health events. *MMWR Recomm Rep*. 1990;39(RR-11):1-23.

3. Kingsley SS, Schmeichel RL, Rubin CH. An update on cancer cluster activities at the Centers for Disease Control and Prevention. *Environ Health Perspect* 2007;115(11):165-171.



## (1) The Situation

## (2) The Obstacles

- The questions posed by the concerned community and those answered by investigators may differ: community members may *know* there is a problem and want to know its cause while investigators attempt to determine *if* there is a problem.

- Results of analyses may suggest to investigators that there is no evidence that disease rates are higher in the community; this finding must be communicated in a clear manner accessible to a variety of audiences.

- One obstacle to the effective dissemination of investigation results is the inability of investigators to share some information with community members due to data release restrictions:<sup>4,5</sup>
  - Occurs when there are a small number of outcomes in a small population.
  - For example, fewer than five events are suppressed to prevent the release of information on *potentially* identifiable cases.

## Case Study: The Aklavik *H. pylori* Project

The hamlet of Aklavik, with a population of ~600, mostly Aboriginal, is located in the Northwest Territories, Canada.



During a few years preceding 2006, residents expressed concerns about a perceived increase in the number of stomach cancer cases diagnosed in the community.

Many residents believed that this occurred due to a high frequency of *Helicobacter pylori*, a bacterium known to be a risk factor for gastric cancer.



In 2006, the Canadian North *Helicobacter pylori* (CANHelp) Working Group was formed:

A collaborative research initiative is underway involving community members, researchers at the University of Alberta, and Northwest Territories health care professionals, that seeks to address concerns about *H. pylori* and associated diseases.

Specifically addressing concerns over the perceived increase in stomach cancer cases has been a challenge:

- \* Exaggerated numbers of stomach cancer cases have been reported to and disseminated by the media \*
- \* Due to data disclosure restrictions, the territorial cancer registry has been unable to release information on the actual number of stomach cancer cases diagnosed in Aklavik over recent time periods to clarify circulating misinformation \*
- \* The research team is unable to give the community needed information to put their risk of stomach cancer in perspective \*

- Investigation lacks transparency:

- Hindered ability of investigators to communicate the results, interpretation, and suggested next steps.
- Difficult to maintain trusting relationships essential to investigations of health problems in communities.<sup>6</sup>

- Unable to adequately address concerns:

- Missed opportunities to decreased anxiety in the community because misinformation cannot be corrected.
- Wasted and/or misaligned resources: money, time, and energy spent to address specific concerns at the expense of other health and social issues.

- Researchers are restricted:

- Without access to data, researchers are unable to undertake studies that support public health goals.<sup>7</sup>

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7. Wartenberg D, Thompson WD. Privacy versus public health: the impact of current confidentiality rules. *Am J Public Health* 2010;100(3):407-412.

## (3) The Consequences

## (4) The Solutions

- Develop risk communication strategies and knowledge translation tools:

- Understanding community perceptions will foster relationships and aid effective communication.
- Knowledge about the research methods, results, and interpretation will enhance understanding of the investigative process.<sup>8</sup>

- Invest in building trusting and bi-directional relationships:

- Relationship-building and trust between investigators and community members will increase the likelihood that these investigations will be perceived to be successful.<sup>9</sup>

- Re-evaluate data disclosure policies:

- Data may be only *potentially* identifiable.
- Consider public wellbeing over individual privacy in situations where there is extreme community alarm.

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9. McComas KA, Trumbo CW, Besley JC. Public meetings about suspected cancer clusters: the impact of voice, interactional justice, and risk perception on attendees' attitudes in six communities. *J Health Commun* 2007;12:527-549.

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