

Strategies for Communicating Health Research Findings to Members of an Arctic Aboriginal Community

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"A lot of times I know in the past, people from universities have done studies, they take all information from us, go, and never come back. And never talk to the people."

Introduction:

The CANHelp Working Group is a group of Alberta and Northwest Territories investigators, health officials, and community health leaders. It was established in 2006 to address community concerns about *Helicobacter pylori* infection, recommend clinical management strategies, and reduce health risks associated with the infection. This research was piloted in the community of Aklavik in the NWT (Figure 1). Aklavik was chosen because the community had expressed concern regarding health risks from *H. pylori*, the community wanted research to help find answers. This poster describes one section of a five component process (Figure 2) specifically determining effective knowledge translation strategies for communicating research findings to the community.

Methods:

A qualitative study was undertaken in April of 2008, including three group discussions and four individual interviews. Each group discussion had four to five individuals participate. Thematic analysis was completed on transcriptions of interviews and discussions. Validation of the analysis took place in July 2008 through discussions with community members and stakeholders.

Results

Strategy: Know Expectations

Motivations:

People in Aklavik were motivated to start this research project because they perceived a high rate of stomach cancer in their community; they believed *H. pylori* to be the cause. Community members are hopeful that the *H. pylori* research will generate more questions about health in their community as well as answer questions about why such a small community has such a high rate of cancer.

Self-awareness:

Community members felt the project would increase awareness of individual health, as well as, factors in determining their health. They expect research to provide recommendations on how they can change their behaviours to improve their health. Community members are curious about what is the underlying cause of their perceived high incidence of gastric health problems.

Recommendations:

Community members look forward to receiving recommendations from the *H. pylori* project. They are interested in how they can change their behaviour, lifestyle and/or eating habits in order to maintain their gastric health. They would also like more information about treatments available to deal with this type of health issue.

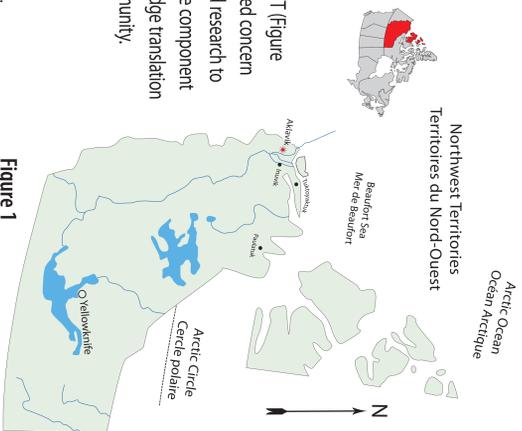


Figure 1

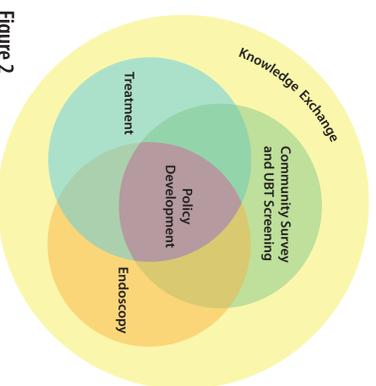


Figure 2

Strategy: Provide messages frequently

Past experiences

Aklavik residents have had negative experiences with researchers. They are concerned about researchers taking information from communities and not communicating the results back to them. Some community members have been reluctant to participate in the study due to other experiences with arctic researchers; they are leery about what kind of information the researchers are taking away with them.

Reassurance

Due to past experiences the community wanted reassurance that the research was continuing even if there was no new data to share; they wanted to know that researchers had not forgotten about the community or its concerns.

"I think a lot of people, the biggest concern right now is that people say they're infected but there's nothing being done right now. It's a slow process. Some people understand that, some people don't understand that, so just need to let them know it's a slow process and that it's on going and that we haven't forgotten about the people that are infected"

Despite being careful about how information is explained, sometimes inaccurate messages get out!

Media is a common source of inaccurate messaging, and for this project, the emphasis on the potential to impact stomach cancer rates in the community has been common. It is very important to reinforce the correct information frequently.



Strategy: Use local infrastructure

Organizations

Researchers used three local organizations to disseminate information; they were Hamlet Council, Aklavik Community Corporation (Inuvialuit Representation) and Aklavik Indian Band (Gwich'in Representation).

Radio

Community members suggested that the local radio station would be a good way to get information out to the community. Community members liked hearing local staff and researchers together on the radio.

Newsletters & School presentations

Utilization of newsletters and school presentations also helped keep community members informed.

Strategy: Combine new knowledge with existing interests

Loss of language

Many community members spoke of sadness over the loss of their language. Community members thought that having translations would be valuable for the elders.

Traditional lifestyle

Incorporating and understanding tradition is important for the communities. A holistic approach to disseminating research findings is valuable for a community.

Youth & Elders

Knowledge transfer that links youth and elders together effectively addresses the communities concerns regarding loss of traditional lifestyle and values. The community accepts this communication model as a method for communicating study results. Community members also state that youth must first approach the elders and make an individual choice should they wish to use this communication model. Lack of opportunity or interest for such interactions is a barrier for this method of delivery.

Strategy: "Demystify" the research

How researchers take data and biological samples from the community and turn it into knowledge is a process that is not easily understood by most people. Breaking down this process so that community members are aware of how this happens will help them to understand why the process takes so long, and also help in understanding the results once they are generated

Create visual media to communicate results

Production of visual media assists in communicating results from the study to the community in a manner which emphasizes community involvement in the research. In addition, researchers hope to highlight that the research was conducted "with" the community and not "on" the community. Community members feel it is important to represent the collaborative nature of this project, hearing from the community members who were instrumental in bringing the project to their community. Providing the community with reassurance that the research is collaborative is achieved through continued efforts between locals and researchers.

Enhance understanding of the research process and results

Enhancing the understanding of the research process is a crucial part of reassuring the community. Creating transparency within the project will ease community anxiety about researchers coming to their community and taking information without providing results and recommendations.

CONCLUSIONS:

When initiating the Aklavik *H. pylori* Project, community members wanted research that would not only help provide answers about why they suffered from what they believed was poor, but what they could be doing to improve their own health. Any recommendations resulting from the results of this study need to be utilized by the community to have an impact. Through keeping Aklavik informed of the results as they are generated and incorporating traditional knowledge, the community will feel ownership over the results and this will likely increase the chance of the recommendations being adopted by individuals. Strategies that include linking youth and elders may be particularly well received due to the concern in the community about loss of traditional language and lifestyles. The successful collaboration between locals and outside researchers that drove the research project will also drive the creation of a documentary that highlights how research done with a community can generate information the community can utilize itself.

Ethics:

This study was approved by the University of Alberta's Health Research Ethics Board and the Aurora Research Institute in the NWT

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