

Engagement with Aboriginal Communities during the Aklavik *H. pylori* Project

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## INTRODUCTION

*Helicobacter pylori* (*H. pylori*) infection has been a developing health concern in the Northwest Territories (NWT), and is thought to affect over half of the world's population. Primary care clinicians in the NWT report that *H. pylori* infection is a major worry to community members, many of whom know about the reported high prevalence of this infection in some northern aboriginal populations and of the reported links between this infection and stomach cancer, a cancer with a higher than expected incidence rate in this region. NWT clinicians view *H. pylori* infection as a major clinical problem, given the dilemma of frequent demand for treatment accompanied by frequent treatment failure. NWT population health authorities have identified the need for epidemiologic studies to discover the mode and frequency of transmission, and develop *H. pylori* control strategies.

Research aimed to answer questions posed by NWT community members and their health care providers has commenced in the community of Aklavik in the Northwest Territories. The long-term objectives of this research are to develop a comprehensive approach to investigating community health problems related to *H. pylori* infection in NWT communities and to identify public health solutions that respond to community health care needs as perceived by community members and health authorities. Prior to beginning data and sample collection in the Aklavik *H. pylori* Project (AHPP), a study planning committee comprising locals serving on the Aklavik Health Committee, along with Rachel Munday, Nurse-In-Charge of the Aklavik Health Centre, Billy Archie of the Arctic Health Research Network Aklavik Chapter, and Crystal Lennie of the Inuvialuit Regional Corporation was created to provide community input on study design details, informed consent documents and questionnaires. Consultation with this study planning committee has been ongoing throughout each phase of the project. The four phases of the project include: 1) screening and collecting data on disease history and risk factors, 2) endoscopy, 3) treatment, and 4) policy analysis and knowledge transfer (KT).

As outlined in the CIHR Guidelines for Health Research Involving Aboriginal People, researchers should promote the dissemination of research results, and of other knowledge that may be revealed by the research, and, if it is possible, advise the community as to what can be done to address any problems or issues brought to light as a result of the research.

A community consultation was conducted in Aklavik to determine how individuals in the community understand *H. pylori* infection, what they think about current mechanisms of KT

including the type of information being provided, and what type of information they would like to see in the future including the format of presentation. The goal of this is to provide the knowledge generated from the project in a manner that helps individuals utilize the results of the project to better understand factors that influence their health, with hopes that this will enable them to safeguard their own health, and maximize the community benefit from participating in the research project. This report describes the community consultation process, its outcomes and outlines suggested strategies for effective KT based on the consultation. It focuses on the activities occurring in the specified time period (namely the in-depth consultation for knowledge translation), but other activities outside the time period were also included for entirety.

## **PROCESSES**

### **IN-DEPTH COMMUNITY CONSULTATION**

Prior to initiating the research, a study planning committee was established in Aklavik. This committee included members of the health committee, which was already in existence. Joint workshops with the study planning committee and the research staff were held to guide the research process. In addition to the study planning committee, other key informants in the community have been consulted regarding specific areas of the study, including during initial recruitment of participants and while determining effective knowledge transfer mechanisms. While recruiting, we aimed to discover what Aklavik residents thought about the research project and how this impacted their willingness to participate. We spoke with informants to determine what factors might inhibit residents from understanding the research process and how better information could be provided to increase this understanding. We also sought to understand how the recruitment process was accepted by the community and what we could do to adapt it so it better suited the residents. This consultation was typically one-on-one.

The next in depth consultation that took place was to determine which knowledge transfer mechanisms should be used when communicating research results and information to the community. We aimed to learn about the expectations the general community had regarding the research, what information they wanted to receive and what mechanisms they thought would be most appropriate and effective. For this, both key-informant interviews and group discussions

were used. Groups were selected from existing social groups within the community to minimize discomfort in discussing potentially sensitive topics.

## COMMUNITY INPUT ON STUDY DESIGN, DOCUMENTS AND QUESTIONNAIRES

Community input on study design, informed consent documents, and questionnaires was obtained from the study planning committee. Prior to initiating each phase of the research, a meeting was held to go over documents to ensure it was acceptable to the community and understandable. While designing the study, we aimed to include components that addressed the concerns the community had regarding *H. pylori* infection. Consultation regarding informed consent documents and questionnaires aimed at ensuring that appropriate language was used, and questionnaires were further examined by the committee to determine if the questions being asked were clear.

## COMMUNICATING STUDY INFORMATION

In addition to the goal of effective transfer of final results of the study, communication of study information and preliminary results has been ongoing throughout the study. Regular updates about the project were included in health center newsletters, and *H. pylori* project-specific flyers were also generated. During initial recruitment, tables were set up at the post-office and grocery store to provide residents opportunities to ask questions and learn about the study, without having to come in to the health center. Project staff was, however, made available at the health center to answer any questions or concerns participants or potential participants had. Radio announcements informed the community on progress, and provided updated information on results, like the prevalence of the infection.

## OUTCOMES

### IN-DEPTH COMMUNITY CONSULTATION

When the research project was initially started, the consultation provided a sense of ownership for the community, and helped to assure them that the research was being conducted for their benefit and not solely that of the researchers. By involving them in the design process,

they were able to see what questions the project was trying to answer, and how the study might impact their community. It also increased the knowledge of the research material, and helped to generate realistic expectations about what the research could provide for the community.

Although not all expected benefits fit within what was feasible with the research, most members of the study planning committee had a high degree of understanding about the limitations of the project.

During the beginning phases of recruitment, having local input was very beneficial. They were able to explain what the community had concerns about and what information was important for them to know to make informed choices about enrolling. This aided recruitment efforts. Through continued consultation with the planning committee, the project has benefited by having the trust and respect of the community. Although they provided important insight into local understanding of research questions and what would be most acceptable to the community, the planning committee developed trust in the research team. As the research progressed, the committee felt less and less obliged to review every aspect and often expressed that they did not feel they needed to provide any input.

The KT consultation revealed that when initiating the study, the community expected to learn more about their perceived high rates of stomach cancer, and hoped the project would provide answers regarding what they see as high rates in their community. They also mentioned they expected the project to provide information about how individual behaviours could impact their risk of *H. pylori* infection.

The main mechanism for KT of final results of the research project suggested was through the various organizations carrying out activities in the community. They believed that the three main organizations within the community (Aklavik Community Corporation, Gwich'in Band Office and Hamlet Council) would be good avenues for disseminating information. Members of the health committee, who comprise the majority of the project planning committee, recommended that all results get reported back to them first, although they clarified that the health committee would like to be aware of results and how they will be made public, but they did not wish to be the main source of publication.

The community felt very strongly that special attention should be paid to elders with regards to communication. For reporting results to elders, some participants thought discussion groups

with translators present would be the most effective way, while others again felt that the local organizations would be able to target the elders through existing boards.

All participants felt that communicating results to elders was important, as many had participated in the research project, and because they felt that elders who had not participated would also like to know the results and what has been happening in the community.

When asked about the effectiveness of a proposed video to document the project, all participants thought this would be beneficial for the community to gain understanding of the project results. Participants also agreed that the most effective way to present results would be through researchers and community members in the video.

Issues relating to traditional culture seem to be very much on the minds of Aklavik residents, as such issues were frequently mentioned in discussions of this project. Although all participants believed that English was the dominant language of communication within the community, they also all believed that having research documentation available in the two other languages of the community, Gwich'in and Inuvialuktun, was important to show respect to the elders. When speaking to a group of youth, they initially responded that it would not be necessary to provide translations, but when asked about translation for the elders, they responded that it would be beneficial for them. Other participants mentioned the regret at the loss of language within the community, and it was also noted that those who have kept the language often don't use it. Similar concerns regarding the loss of traditional diet, specifically noted was the absence of caribou for the younger generations, and their lack of awareness of traditional foods.

Communities are an important part of many Aboriginal cultures, and this was also the case in Aklavik. The concept of community was frequently mentioned during discussions and they spoke of the importance of being informed as to how other members of their community were participating in the research project.

Participants emphasized the importance of researchers working with the community, and although some participants felt that people were skeptical of researchers, others felt that the community liked to see researchers working with the community. This idea was supported by the consensus among participants that a video documenting the project should feature both the community and outside researchers.

COMMUNITY INPUT ON STUDY DESIGN, DOCUMENTS AND QUESTIONNAIRES

The community input allowed the research team to create a study that best addressed the questions and concerns the community had regarding *H. pylori* infection. Prior to starting any phases of the research, documents that were to be used were reviewed by the study planning committee. They gave suggestions on wording the information letters, but suggested reading the letters with potential participants would be more effective as people would feel intimidated by the large amount of information they were receiving. For questionnaires, they aided in ensuring the questions were understandable and helped to ensure they were obtaining the information they were targeting.

## COMMUNICATING STUDY INFORMATION

In general, participants expressed satisfaction with the current mechanisms of KT, including radio announcements and newsletters. Radio announcements included basic updates on project information as it became available, as well as mock question and answer sessions generated from anticipated questions that community members might have had. Newsletters generally included the same information as was presented in radio announcements.

The radio was often mentioned as the best way to get results back to the community. One participant noted she had not received any of the newsletters from the AHPP. Participants were particularly pleased with radio announcements during the week of endoscopy testing when project staff were on the radio giving updates frequently, and one participant noted a broadcast where the nurse-in-charge and project staff did a mock question/answer skit. There seemed to be a consensus that people understood what *H. pylori* was, but they were waiting for more answers about where it was coming from and why it caused stomach problems. Some participants noted a feeling in the community that the project had halted, as they hadn't had any updates as testing was being completed on samples that had been taken. They recommended that updates happen more frequently so the community does not feel like it has been forgotten about as the project continues. It was determined from this that even when there was no new information to update people on, it was important to continue communicating what was known, and what was being done to gather new information.

As participants believed radio and newsletters were appropriate for the community, and felt they were getting information through these sources, both should be continued throughout the research project to provide updates and at the completion of the project to disseminate results to

the general population. However, concerns about the project letting up indicate that regular updates should be made in a predictable manner so members of the community can anticipate when information will be presented. For instance, members of the study planning committee could make weekly or biweekly updates on pre-determined days to let the community know if there is or is not new information. Also, AHPP updates should be included in regular health centre newsletters, regardless of the availability of novel research findings.

A video to document the research project would be a good mechanism to inform community members of the results of the project. This video should provide an overview of how the project was completed in Aklavik and UA laboratories, as well as inform viewers of results from the study that could be utilized to understand and safeguard individual health. It should highlight the effort made by the community to initiate and host this project, and the effort made by both the community and the researchers in collaboration.

All KT strategies should be a result of collaboration between researchers and local representatives. Specifically, researchers should work with community members to create sustainable strategies that can be continued when the researchers are no longer present in the community. Researchers should work in the capacity of providing accurate and transparent study results to form the basis of locally driven educational initiatives, as well as guidance for the development of these initiatives. Study documents should not be simply made available to local organizations but effort should be made to distribute relevant information and project results to each organization in a manner that calls attention to the content of the material being distributed.

The youth are an important group to the community of Aklavik, and many of their current knowledge transfer strategies include linking youth with elders and the community at large. Although there were youth who were very interested in participating in the research project, discussion groups with youth revealed that they believed the majority of youth were not interested in participating in the research, or learning about the results. The youth indicated that most students would view any information provided through the school as just a break from regular studies, but that there were some students who really wanted to learn. Knowledge gained from the AHPP could be worked into existing programs, including science lectures, to provide students with an overview of the study and what was gained from it. Also, health days organized through the school could include information from the AHPP. As communication between youth

and elders in the community is important for language retention as well as other traditional knowledge, results from the study that are relevant to traditional practices could be addressed through workshops linking the two groups of community members. CIHR guidelines recommend researchers support the protection of traditional knowledge, practices, and traditions, and this type of dialogue between youth and elders would not only serve to protect but also promote, while teaching new knowledge gained from the AHPP that will further benefit the health of the community. Within the community, this approach has been utilized to provide education about other health matters.

Youth should also be given the opportunity to participate in KT, through assisting in the organization of discussion groups, working on the documentary project, or organizing school based information sessions. In addition to increasing their understanding of the research results and providing capacity building opportunities for the youth in the community, this will enable those students who would like to be involved to do so.

Elders represent an important group within many Aboriginal communities, including Aklavik. It will be important to provide study information in the languages of the community, although not necessarily in written form. Discussion groups with elders should be arranged through elder representatives within local organizations, as well as through community health workers. During these discussion groups, it would be necessary to have a translator present. Although nearly all elders in the community speak English fluently, having information in their language would show respect and increase understanding of the results. Also, elders should be explicitly invited to any community events held as a result of the AHPP. It will not be necessary to translate all study documentation produced into the languages of the community, but it would be appropriate to have study results available in translations.

Also, exploring traditional understandings of disease and progression of illnesses may provide mechanisms for increasing the understanding of *H. pylori* infection and illness within this community. Additional work with elders to further understand local conceptualizations of diseases may be beneficial for this, including how scientific terms are translated into local languages.

## CONCLUSIONS

In keeping with CIHR recommendations for research involving Aboriginal people, this community consultation aimed to promote community understanding and involvement in the research process, uncover methods to promote dissemination of research results and advise the community about dealing with issues arising as a result of this research. The initial consultation resulted in creating a research project that was accepted and owned by the community. Learning about how the community understands *H. pylori* infection and what they expect to get from this research will help with communicating the study findings as they are generated. Issues may include finding that certain behaviours are associated with increased frequency of *H. pylori* infection – and it will be necessary to consider whether behaviours that may be risk factors for *H. pylori* infection are practiced because of some benefit they confer. It is important that study results are viewed in the context of possible risk/benefit tradeoffs and that the relevant concepts are communicated in an acceptable and understandable manner that maximizes individual ability to utilize the results to safeguard their own health and values. Part of this entails ensuring high numbers of people have access to the results. More importantly, however, is ensuring that the types of KT strategies available are appropriate to those able to access it. This consultation provided insight into expectations of the community, with regards to the AHPP and their overall health. We found that individuals are interested in uncovering reasons for the high rates of cancer and stomach ailments within the community, and would like to learn about strategies to improve their own health. Local media such as radio and community newsletters are recognized as desired mechanisms of receiving information, as well as through community based organizations. Elders represent an important group within the community, and special consideration should be paid to communicating results to them, at least partially using traditional language.