

1.7 Community-driven research on *H. pylori* infection in the Inuvialuit Settlement Region (*H. pylori* Infection)

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ABSTRACT

Despite limited systematic data on its presence in northern Canada, *Helicobacter pylori* infection has been an emerging health concern in northern Aboriginal communities, where people are becoming aware of its health risks. In many such communities, people worry about the link between *H. pylori* and stomach cancer, a cancer that occurs more frequently in this region than on average across Canada. Physicians in the north view this infection as a major challenge because it is found in many patients with common stomach complaints and standard treatment is often ineffective in this setting. Health authorities have identified the need for research aimed at developing *H. pylori* control strategies appropriate for the north. This research program seeks to generate knowledge about how health care decision makers can effectively manage *H. pylori* infection in a manner that addresses community concerns. To achieve these goals, the applicants formed the Canadian North *Helicobacter pylori* (CANHelp) Working Group, a collaborative team that links the University of Alberta with northern health officials and community organizations. While the research goals require data from multiple northern settings, the team conducted a pilot project as a starting point in Aklavik, NWT, where they found that 62% of participants had *H. pylori* infection, and among those infected, there was a high prevalence of precancerous stomach conditions. This research program, developed at the request of the Inuvialuit Regional Corporation, aims to: 1) Expand the research to additional communities in the Inuvialuit Settlement Region to obtain representative data required for developing regional public health strategies pertaining to *H. pylori* infection; 2) Identify cost-effective and culturally appropriate *H. pylori* management strategies for northern communities; 3) Create knowledge exchange strategies to help community members understand *H. pylori* health risks and currently available solutions.

KEY MESSAGES

- Health risks from *H. pylori* infection include chronic digestive problems, stomach ulcers and in rare instances, stomach cancer
- Chronic *H. pylori* infection induces chronic inflammation of the stomach lining, glandular atrophy and intestinal metaplasia, which are all associated with increased risk of stomach cancer
- Communities in the Inuvialuit Settlement Region (ISR) are concerned about health risks from *H. pylori* infection
- Community leaders seek research to understand the health risks and develop locally appropriate strategies for reducing these risks throughout the Inuvialuit Settlement Region
- The Canadian North *Helicobacter pylori* (CANHelp) Working Group was formed to link University of Alberta investigators with northern community leaders and health care providers in the conduct of research aimed at addressing community concerns about health risks from *H. pylori* infection
- The Aklavik *H. pylori* Project, the initial project of the CANHelp Working Group, found that:
 - Of 355 participants, tested, 62% were *H. pylori*-positive
 - Around 90% of *H. pylori*-positive participants had moderate to severe inflammation of the stomach lining
- Information from additional northern communities is needed to fulfill the research goals of the CANHelp Working Group
- The Inuvialuit Regional Corporation (IRC) asked the CANHelp Working Group to expand the research to additional ISR communities
- The regional IRC leadership requested the development of a research agreement between the Inuvialuit Regional Corporation and the University of Alberta for the ISR *H. pylori* Project
- During February and March 2011 a pilot recruitment and data collection phase was initiated in Tuktoyaktuk
- During the Tuktoyaktuk pilot project, 86 people were recruited and tested for *H. pylori* infection

and questionnaires were pilot tested on approximately 25 participants

- Planning for the ISR *H. pylori* Project progressed slowly due to changes in community leadership and the need to identify new members for the regional project planning committee
- During July 2011, CANHelp staff returned to Tuktoyaktuk to disseminate information to the community about the planning process for the ISR *H. pylori* Project
- In August 2011, IRC partner Crystal Lennie, who collaborated with the CANHelp Working Group beginning in 2007 and throughout the Aklavik *H. pylori* Project, was replaced by Billy Turner
- During August to November 2011, the CANHelp Working Group held meetings with Beaufort-Delta health officials, the new Nurse-in-Charge of the health centre in Tuktoyaktuk, and the ISR *H. pylori* Project planning committee representative from Tuktoyaktuk to obtain input for planning the full launch of the ISR *H. pylori* Project
- During November 2011, CANHelp staff returned to Tuktoyaktuk to distribute *H. pylori* test results and hold information sessions in the community
- By the end of 2011, the research agreement was signed by representatives of Aklavik, Tuktoyaktuk, Sachs Harbour, Paulatuk, and Uluhaktuk
- Planning by the ISR *H. pylori* Project planning committee is underway and field work is scheduled to resume in Tuktoyaktuk in March 2012

OBJECTIVES

Helicobacter pylori infection, linked to peptic ulcer disease and stomach cancer, is a health concern in northern Aboriginal communities, where people are aware of its health risks. Health care providers in the north view this infection as a major challenge because it is found in many patients with common stomach complaints and standard treatment is often ineffective in this setting. This research program seeks to generate knowledge

about how health care decision makers can effectively manage *H. pylori* infection in a manner that addresses community concerns. While the research goals require data from multiple northern settings, the team conducted a pilot project as a starting point in Aklavik, NWT, where they found that a high prevalence of *H. pylori* infection, and among those infected, a high prevalence of precancerous stomach conditions.

This research program aims to:

1. Expand the research to additional communities in the Inuvialuit Settlement Region to obtain representative data required for developing regional public health strategies pertaining to *H. pylori* infection;
2. Identify cost-effective and culturally appropriate *H. pylori* management strategies for northern communities;
3. Create knowledge exchange strategies to help community members understand *H. pylori* health risks and currently available solutions.

INTRODUCTION

Helicobacter pylori infection has been a health concern in some northern Aboriginal communities, where people are aware of its health risks. In many such communities, people worry about the link between *H. pylori* and stomach cancer, a cancer that is more common in this region than on average across Canada. Northern health care providers see this infection as a challenge because it is found in many patients evaluated for stomach complaints, but treatment in this region is often ineffective. Public health authorities have identified the need for research to develop locally appropriate *H. pylori* control strategies.

This research program was developed at the request of the Inuvialuit Regional Corporation (IRC) on behalf of communities in the Inuvialuit Settlement Region (ISR) of western Canada. The goal is a comprehensive investigation of *H. pylori* infection in ISR communities

so that such communities are represented in a broader research agenda that aims to develop public health strategies for *H. pylori* infection in northern Canada. This research seeks to generate knowledge about how northern health authorities can manage *H. pylori* infection in a manner that addresses community concerns about health risks. To achieve these goals, the research team formed the Canadian North *Helicobacter pylori* (CANHelp) Working Group to link northern community organizations and health officials with University of Alberta researchers.

To develop this research, the CANHelp team initiated a pilot project in Aklavik, NWT, focused on: investigating the burden of disease and risk factors associated with *H. pylori* infection in the Aklavik population; identifying effective therapies; and developing knowledge exchange strategies that address community concerns. This preliminary research has shown that 62% of Aklavik's project participants had *H. pylori* infection, and among those infected there was a high prevalence of severe inflammation and precancerous lesions in the stomach. In a trial to compare standard treatment against a new regimen in 87 people who had not been treated before, cure rates were 74% of 39 on sequential therapy and 60% of 48 on standard therapy, a study size too small for precise estimates of the treatment effect size.

To generate study results with greater certainty, the CANHelp research program needs a larger number of participants representing additional northern communities. A second project outside the ISR was initiated in 2010. We have been working with the IRC since January 2010 on the development of a research agreement to begin projects in the remaining Inuvialuit Settlement Region communities.

This research addresses a health problem that imposes a disproportionate burden on northern communities relative to other groups in Canada. It aims to improve the management of *H. pylori* infection in northern communities, and reduce corresponding health risks. The research design conforms to principles of community-based participatory research, incorporates innovative approaches to knowledge exchange, and adheres to the

ACUNS Ethical Principles for the Conduct of Research in the North and CIHR Guidelines for Health Research Involving Aboriginal People. The effectiveness of this research will be enhanced by the collaborative research team that links scientists across a comprehensive set of scholarly disciplines with decision-makers, industry partners, and community groups toward the common goal of improving community health.

ACTIVITIES

The development of research agreements between communities and researchers regarding the conduct of community-based, participatory health research projects is a developing area in health research, with evolving standards. The elaboration of such agreements is a relatively new undertaking for researchers, university research administrators, and community organizations. As reported last year, we began developing a research agreement with the Inuviluit Regional Corporation for the conduct of an ISR *H. pylori* Project in 2010. In January 2011, it was signed by the IRC leadership. However, it took most of 2011 for the agreement to be signed by representatives from the individual ISR communities. Planning for the ISR *H. pylori* Project progressed slowly due to changes in community leadership and the need to identify new members for the regional project planning committee.

During 2011, the following activities were completed:

- In February and March a pilot recruitment and data collection phase was initiated in Tuktoyaktuk
- During the Tuktoyaktuk pilot project, 86 people were recruited and tested for *H. pylori* infection and questionnaires were pilot tested on approximately 25 participants
- In March, Maricon Hidalgo joined the research team as a graduate student field research assistant
- In April, graduate students Megan Lefebvre, Amy Colquhoun and Ashley Wynne were awarded NSTP and CCI grants they applied for in November 2010

- In April, graduate students Amy Colquhoun, Laura Aplin and Megan Lefebvre gave oral presentations at the University of Alberta Northern Research Day
- In June, Emily Hastings joined the research team as a MSc student under Karen Goodman's supervision and applied for a Nasivvik MSc scholarship (awarded in September)
- In June graduate students Ashley Wynne, Megan Lefebvre, Laura Aplin, and Amy Colquhoun presented posters at the North American Congress of Epidemiology in Montreal
- In June, Karen Goodman was awarded a 5-year CIHR operating grant for the CANHelp research program
- In July, CANHelp staff returned to Tuktoyaktuk to disseminate information to the community about the planning process for the ISR *H. pylori* Project
- In August, IRC partner Crystal Lennie, who collaborated with the CANHelp Working Group beginning in 2007 and throughout the Aklavik *H. pylori* Project, was replaced by Billy Turner
- During August- November, the CANHelp Working Group held meetings with Beaufort-Delta health officials, the new Nurse-in-Charge of the health centre in Tuktoyaktuk, and the ISR *H. pylori* Project planning committee representative from Tuktoyaktuk to obtain input for planning the full launch of the ISR *H. pylori* Project
- In August, Karen Goodman was an invited speaker and session chair at the CHRO Vancouver conference
- In August, PhD students Amy Colquhoun and Megan Lefebvre, along with summer student Alvin Keng, presented posters at the CHRO Vancouver conference
- In September, McMaster University PhD student, Sally Carraher, began a year of field work in Aklavik to conduct her ethnographic thesis research to include follow-up *H. pylori* testing of Aklavik *H. pylori* Project participants
- In September, Karen Goodman, Amy Colquhoun and community collaborator Rachel Munday presented posters at the EHSG Dublin conference
- In September, Karen Goodman attended the Circumpolar *Helicobacter pylori* Working Group annual workshop in Copenhagen to update Arctic *H. pylori* researchers on the CANHelp Working Group's research progress, and to ensure that Canadian *H. pylori* research adheres to international standards and contributes to international initiatives for collaborative research aimed at reducing gastric cancer and other health risks from *H. pylori* infection across the circumpolar region
- In October, PhD student Amy Colquhoun was awarded a CIHR knowledge dissemination grant
- In November, graduate students Amy Colquhoun and Emily Hastings gave oral presentations and Janis Geary gave a poster presentation at the University of Alberta INSIGHTS School of Public Health Research Day
- In November, CANHelp staff returned to Tuktoyaktuk to distribute *H. pylori* test results and hold information sessions in the community
- In November, Sally Carraher initiated data collection for an Aklavik *H. pylori* incidence and reinfection study
- By the end of 2011, the research agreement was signed by representatives of Aklavik, Tuktoyaktuk, Sachs Harbour, Paulatuk, and Uluhaktuk
- Throughout the year, graduate students and other staff members conducted data analysis and submitted abstracts and delivered presentations at 4 international conferences, 1 national conference and 2 campus conferences
- Graduate students Janis Geary and Amy Colquhoun each had a lead-author manuscript accepted for publication
- Throughout the year, CANHelp staff developed a website to facilitate communication regarding research program activities within the CANHelp Working Group and to the public

Planning by the ISR *H. pylori* Project planning committee is underway and field work is scheduled to resume in Tuktoyaktuk in March 2012. The launch of the completed CANHelp Working Group website will be widely publicized in January 2012.

RESULTS

Community-driven research on *Helicobacter pylori* infection in Northern Canada. E. Hastings, L. Aplin, K.J. Goodman, The CANHelp Working Group. Abstract of Oral Presentation, School of Public Health Research Day, November 2011

Introduction: *Helicobacter pylori* (*H.pylori*) infection is a health concern in northern Canada due to its association with stomach cancer. In response to questions raised by community leaders and health care providers, the Canadian North *Helicobacter pylori* (CANHelp) Working Group established the Aklavik *H.pylori* Project in 2007 in Aklavik, Northwest Territories (population=590). The research has since expanded to other communities, at their request. The Old Crow *H.pylori* Project was established in 2010 in Old Crow, Yukon (population=250), and the Inuvialuit Settlement Region (ISR) *H.pylori* Project was piloted in 2011 in Tuktoyaktuk (population=870). These projects aim to address community concerns, investigate associated disease burden, and inform local policy. This abstract reports progress to date.

Methods: Projects are developed with local planning committees and typically include questionnaire-based data collection, urea breath test (UBT) screening for *H.pylori* infection, and endoscopy.

Results: The Aklavik *H.pylori* Project (n=379) yielded data on clinical factors (n=345), individual-level socio-environmental factors (n=286), household-level socio-environmental factors (n=165), as well as UBTs (n=333; positivity=58%) and gastric biopsies (n=194). Examination of biopsies revealed high frequencies of severe gastric inflammation, gastric atrophy and metaplasia.

The Old Crow *H.pylori* Project (n=179), yielded yielded data on clinical factors (n=134), individual-level socio-environmental factors (n=125), household-level socio-environmental factors (n=83), as well as UBTs (n=178; positivity=70%). Endoscopy and treatment are scheduled for 2012.

The ISR *H.pylori* pilot project (n=93), yielded 86 UBTs; the ISR-adapted clinical questionnaire was piloted with 35 participants and the individual and household socio-environmental questionnaires were piloted with 23 participants. Feedback will inform planning for the ISR *H.pylori* Project launch in 2012.

Conclusion: High prevalence of *H.pylori* infection has been observed in Aklavik and Old Crow. High frequencies of *H.pylori*-attributed stomach disorders in Aklavik indicate that community concerns are warranted. The CANHelp Working Group aims to help identify strategies for reducing the *H. pylori*-associated disease burden.

Posters:

Geary J, Colquhoun A, Lennie C, Bubela T, Goodman KJ. Developing research agreements between communities and academic researchers: A case-study from northern Canada. International Network for Circumpolar Health Research. Oulu, Finland, Jun 2011.

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Geary J, Munday R, Chang H, Girgis S, Cheung J, Keng AB, Veldhuyzen van Zanten S, Goodman KJ, CAN-Help Working Group. Symptomatic manifestations of H. pylori-associated diseases in a Northern Canadian community. XXIVth International Workshop on Helicobacter and Related Bacteria in Chronic Digestive Inflammation and Gastric Cancer, Dublin, Sep 2011.

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DISCUSSION

Analysis of data collected from the ISR community of Aklavik provides strong rationale for the need to expand this research to additional communities. Work completed by the research team (outside the scope of the ArcticNet project) in the Yukon community of Old Crow also points to this, as preliminary *H. pylori* screening suggests that this closely-related community has a high-

er prevalence than Aklavik (79% of 59 tested in Old Crow vs. 58% of 333 tested in Aklavik). This leads us to believe that there may be important inter-community differences in *H. pylori* infection risk and disease burden, even between closely related communities such as Aklavik and Old Crow.

Highlights of Preliminary Results from Aklavik

We observed high prevalence of *H. pylori* infection in Aklavik (62%) and Old Crow (70%). In Aklavik, we also observed high frequencies of severe inflammation in people with *H. pylori* infection, and a pattern of *H. pylori*-associated stomach disorders that indicates increased risk of stomach cancer. These findings suggest that community concerns about health risks from *H. pylori* infection are warranted. Additional analysis showed an association between *H. pylori* density and the severity of inflammation, both acute and chronic, as well as gastric atrophy among *H. pylori*-positive residents of Aklavik.

Our Aklavik research has revealed that general awareness and concerns about *H. pylori* infection were common, but few respondents articulated specific knowledge or reasons for concern; many had not heard of *H. pylori* infection, and few could describe illnesses caused by the bacterium, or how people got it. We will conduct further research to learn more about what communities know about *H. pylori* infection and why they are concerned about it in order to inform knowledge exchange strategies that address community concerns.

Given that northern Aboriginal communities in Canada face serious interrelated socio-environmental challenges that impact health, disentangling the effect of household environmental factors on *H. pylori* prevalence is challenging. We need additional data from diverse communities to enhance the statistical precision of analyses aimed at identifying socioenvironmental risk factors.

Our analysis of the effects of dietary factors on severe gastritis did not yield clear evidence, although our findings support further investigation of pop as a risk fac-

tor and tea as a protective factor. For more accurate results, we need more data to address key limitations of the Aklavik data for analyses of severe gastritis as an outcome (small sample, temporal ambiguity, endoscopy-associated selection factors and too few cases of mild inflammation for a sharper contrast in gastritis severity).

We also need additional data to perform analyses of associations between *H. pylori* genotypes and specific disease outcomes.

CONCLUSION

The continuing development of the ISR *H. pylori* Project has allowed our team to develop expertise in research agreements between scientists and communities for community-based, participatory research in health science.

Many factors influence *H. pylori* infection and disease risk in Arctic Aboriginal communities. Our initial research in Aklavik was a start toward generating the information needed to obtain data required for developing regional public health strategies for reducing health risks from *H. pylori* infection. Analysis of data collected from this ISR community provides a strong rationale for the need to expand this research to additional communities. Our continued progress toward including additional communities in this research will allow us to accumulate representative data from diverse Arctic communities, and in this way, we will be able to conduct policy analysis to identify cost-effective *H. pylori* management strategies that ethically, economically, and culturally appropriate for northern communities. We also continue to develop the expertise of our team in knowledge exchange strategies that help community members understand *H. pylori* health risks as well as currently available solutions and unsolved challenges for reducing these health risks.

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2011-12 PUBLICATIONS

All ArcticNet refereed publications are available on the ASTIS website (<http://www.aina.ucalgary.ca/arcticnet/>).

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