CAN *Help* WORKING GROUP

Aklavik H. pylori Project

Aklavik *H. pylori* Project

Progress Report – August 2017

The Canadian North *Helicobacter pylori* (CAN*Help*) Working Group began research in Aklavik, NT in response to concerns about health risks from *H. pylori* infection expressed by community leaders and their health care providers. Since then, other communities have invited researchers to help them learn about *H. pylori* infection in their communities. Each research project is based on input and guidance from a local planning committee.

Table of contents

When you see a *, please refer to p.19 for a definition of the term

Aklavik *H. pylori* Project Timeline

February - September 2007

- Initial project planning

November 2007 - February 2008

- Recruitment started
- *H. pylori* screening* by breath test, and questionnaires

February 2008

- Endoscopy*

April 2008

- Pathology results returned to participants

April - September 2008

- Waves 2 & 3 of recruitment
- *H. pylori* screening* by breath test, and questionnaires

November - December 2008

- Treatment started

January - March 2009

- Short-term treatment follow-up* and questionnaires

November 2011 - March 2012

- Long-term treatment follow-up* (breath test)

March 2017

- Long-term endoscopy follow-up*

Ongoing

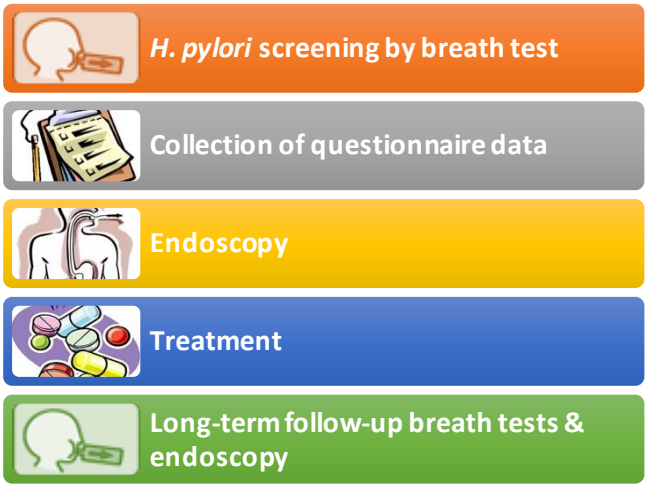
- Research results reported to community
- Long-term follow-up*
- Knowledge exchange activities

Overview of the Findings

What has been done so far?

Around **65%** of Aklavik residents have participated in this project (population ~590)

Completed components of the project include



What remains to be done?

- Knowledge exchange activities : ongoing
- Analysis of questionnaire data : ongoing
- Reporting research results back to the community: ongoing

What have we learned?

What were the scope test results?	**Almost half** of those who had a scope test and whose stomach biopsies* revealed *H. pylori**, had severe chronic inflammation of the stomach.
Does the quadruple therapy work better?	**The quadruple** (4-drug) therapy seems to work better than the conventional 3-drug therapy or sequential therapy, although we need treatment follow-up data from more participants to be more certain about this. The 4-drug therapy regimen is complex and may be difficult for some people to take as prescribed. Available treatments for eliminating *H. pylori** infection are burdensome and more research is needed to find out how to make the treatments easier to take.
How many remain free from *H. pylori*?	**Most people** who were initially free from *H. pylori** infection or successfully treated for the infection remained *H. pylori*-free for 2 years or longer.
How many tested positive for *H. pylori*?	**58%** of participants screened by breath test were positive for *H. pylori** infection.
Why some tested negative, then positive after few years?	**Some** of the people who tested negative after treatment, tested positive few years later. The reasons why this might happen include: • *After-treatment test results were false negative and they still had the infection.* • *H. pylori** *reinfection*
How do we get *H. pylori*?	The CAN*Help** Working Group research so far has not pinpointed an environmental source of *H.pylori** in Aklavik or other communities where *H. pylori* projects are being carried out; this is consistent with findings of research around the world: the evidence suggests that most people with *H. pylori* infection get it from direct contact with a person who has the infection.

Participation and Data Counts

393	•**Participants recruited**
342	•**Urea breath test screening* completed** 341 had a positive, negative, or borderline result 1 had an uncertain result that could not be classified
345	•**Interviewer-administered health questionnaires completed**
285	•**Interviewer-administered participant questionnaires completed**
147	•**Interviewer-administered household questionnaires completed** (reporting household data for 436 individuals)
195	•**Participants completing endoscopy*** (200 participants consented to endoscopy)
194	•**Biopsies* available for *H. pylori** testing**
113	•**Participants enrolled in treatment trial** (181 participants consented to treatment, and 141 were assigned treatment)
116	•**Post-treatment breath tests* completed** (115 had positive/negative/borderline results; 1 had uncertain result that could not be classified); 94 interviewer-administered post-treatment questionnaires completed
52	•**Participants completing long-term follow-up endoscopy*** (53 participants consented to endoscopy)
52	•**Biopsies* available for *H. pylori* testing** (51 available for both histopathology* and microbiology*; 1 available for only histopathology)

Findings to Date

Proportion positive* on breath test	**58% (197/341)**
Endoscopic* findings from 195 Aklavik residents	
Gastritis*	**14% (27/195)**
Gastric* erosions	**6% (12/195)**
Gastric ulcer	**3% (6/195)**
Duodenitis*	**7% (13/195)**
Duodenal* erosions	**1% (1/195)**
Duodenal ulcer	**0**
Esophagitis	**10% (20/195)**
Barrett's esophagus	**3% (5/195)**
Pathology* findings (Sydney classification) from 194 Aklavik residents	
Chronic gastritis	**68% (132/194)**
Severe	**29% (56/194)**
Moderate	**31% (61/194)**
Mild	**8% (15/194)**
Atrophic* changes	**14% (27/193)**
Intestinal metaplasia*	**8% (16/193)**
***H. pylori** positive**	**66% (129/194)**
Chronic gastritis	**100% (129/129)**
• Severe gastritis	• 43% (56/129)
• Moderate gastritis	• 47% (61/129)
• Mild gastritis	• 9% (12/129)
Atrophic changes	**21% (27/128)**
Intestinal metaplasia	**11% (14/128)**
Microbiology* findings from 194 Aklavik residents	
Culture* positive	**70% (136/194)**
Antibiotic susceptibility* tests performed on 118 isolates from culture	
Resistance* to any antibiotics tested	**32% (38/118)**
• Metronidazole:	• 29% (34/118)
• Clarithromycin	• 8% (10/118)
• Ciprofloxacin	• 2% (2/118)
• Nitrofurantoin	• 2% (2/118)
• Amoxicillin, tetracycline, rifampicin	• 0
Resistance to multiple (2 or 3) antibiotics	**7% (8/118)**
• Metronidazole and Clarithromycin	• 5% (6/118)
• Metronidazole, Clarithromycin, and Ciprofloxacin	• 1% (1/118)
• Metronidazole, Clarithromycin, and Nitrofurantoin	• 1% (1/118)
Treatment success among 85 treatment trial participants with a post-treatment breath test*	
Standard triple therapy	**62% (29/47)**
Sequential therapy	**74% (28/38)**

The breath test prevalence (proportion positive) of 58% is a better reflection of the prevalence of *H. pylori** infection in Aklavik than the 66% positive by histopathology* (or the 70% positive by culture*) among those with biopsies* from endoscopy*. Since residents who were informed of positive breath test results were motivated to undergo endoscopy, there are proportionally more positives in the group with biopsies.

Summary of Project Activities

To categorize activities, we will be using the following symbols:

Community visit

Data collection

Dissemination and knowledge exchange

Physician's visit

Planning

On-going Project Activities

1.1 Upcoming Activities

- Reporting of results of the long-term follow-up endoscopy* back to the community will start in fall 2017.
- Managing Director Janis Geary will travel to Old Crow in fall 2017 to meet with the planning committee to host an end-of-grant workshop. The workshop will discuss strategies and plans before the funding for in-community activities ends. Janis and Data Dissemination Lead Emily Walker will also be hosting a community open-house to exchange knowledge with the residents.
- Emily will travel to Aklavik in fall to share the results of her dissertation research with participants and the community members. Emily's project aims to investigate the hypothesis that chronic ingestion of low doses of mercury through fish consumption increases the risk of severe gastritis* and precancerous gastric* lesions among *H. pylori*-positive* residents of Arctic communities.
- MSc student Taylor Cromarty will travel to Aklavik in the winter 2018 for her dissertation project. Taylor will investigate the relationship between food insecurity and the prevalence of *H. pylori** -induced disease. She will begin consultation with the Aklavik *H. pylori* Planning Committee in August 2017 to obtain community input on a food security questionnaire. She will begin data collection in September 2017, which will continue through to December 2017.
- Ethnographic Fieldwork Lead Sally Carraher will return to Aklavik after the kinship analysis is complete to deliver the educational materials she is developing in collaboration with the planning committee.

1.2 Recent Activities – Year 2017

March 2017: Long-Term Follow-Up Endoscopy*

Ethnographic Fieldwork Lead Sally Carraher returned to Aklavik March 13 to 20, 2017, to present results from the Aklavik *H. pylori* kinship study to the Aklavik Health Committee. The study demonstrated that specific genetic sequences of *H. pylori** bacteria are being shared within extended family groups living across multiple households in the community of Aklavik. The purpose of this presentation was to ask committee members for feedback on how best to share information about local kinship and the genetics of *H. pylori* bacteria with Aklavik community members. As a result of this presentation, Sally is working with the planning committee to develop appropriate educational materials for community members of all ages.

Community Engagement Lead Ali Assi, Research Management Lead Hsiu-Ju Chang, Postdoctoral Fellow and Qualitative Research Lead Megan Highet, and Data Dissemination Lead Emily Walker travelled to Aklavik, along with Health Care Facilitator Rachel Munday, to hold the Aklavik *H. pylori* Project's long-term follow-up endoscopy* component at the Aklavik Health Centre March 20 to 23, 2017. They were accompanied by a team of three gastroenterologists*, including CAN*Help** Working Group's Lead Gastroenterologist Dr. Sander van Zanten, together with Health Care Partner John Morse (former NWT territorial medical director), and Junior Co-Investigator Amy Morse. Three Alberta Health Services (AHS) endoscopy nurses, two AHS processing technicians, and one Olympus Canada representative also travelled to Aklavik with the team.

Dr. van Zanten gave a presentation on March 20, 2017 to staff working at the local health centre (comprised of a regional physician, the Nurse-in-Charge, community nurses, and the Community Health Representative). The meeting provided an opportunity for Dr. van Zanten to present updates on *H. pylori** infection and its management and answer questions about the infection.

Ali Assi held a community meeting and dinner at Moose Kerr School to introduce Aklavik residents to the follow-up endoscopy* team on March 21, 2017. At the meeting, community members asked team members about the Aklavik *H. pylori* Project, the gastroenterologists* also addressed any questions, including specific clinical questions, community members had.

Between March 20 to 23, 2017, 53 participants enrolled for a follow-up endoscopy* at the temporary clinic in the Aklavik Health Centre. After evaluation by a gastroenterologist, one participant was not able to undergo the procedure due to medical reasons. Of the 52 remaining participants, gastric biopsies* for histopathology* and microbiology* were obtained from 51 participants. No adverse events occurred during the endoscopy procedures, and a post-endoscopy patient satisfaction questionnaire indicated that most of those scoped tolerated the procedure well and would be willing to have it in the future, if needed. The biopsies were sent back to the University of Alberta to be processed for histopathology and culture*.

Through the CAN*Help** Working Group's collaborative partnerships, a continuing medical education (CME) session was offered to two physicians based in Inuvik, NT, Dr. Mark Prins and Dr. Ryan Falk. The doctors travelled to Aklavik from the Inuvik Regional Hospital to observe the CAN*Help* Working Group's un-sedated endoscopy*

procedures. As a result of this opportunity, both physicians expressed interest in taking part in the team's future endoscopy activities in Inuvik.

The Illness Narrative Project was launched by Postdoctoral Fellow Megan Highet in Aklavik on March 20, 2017. The project aims to collect residents' stories about how *H. pylori** infection has affected them in their everyday lives. By collecting these narratives, researchers can learn more about the full impact *H. pylori* has on residents of Aklavik. The project was developed in consultation with the local planning committee. From March 20 to 23, 2017, Megan conducted interviews with 33 Aklavik residents in order to learn about their personal experiences with *H. pylori* infection and the impact it had upon their health and wellness. The results of the project will contribute to the knowledge exchange goals, and will be incorporated in the policy analysis that aims to develop locally appropriate management strategies for *H. pylori*-associated disease in northern communities.

Previous Project Activities

2.1 Year 2006

The research program was motivated by residents of Aklavik and regional health care providers who voiced concerns about health risks from *H. pylori** infection. In response, territorial health authorities invited University of Alberta researchers to investigate *H. pylori* infection in the territory. In 2006, Lead Investigator Dr. Goodman recruited an interdisciplinary team of academic investigators. Consultation with NWT health officials identified Aklavik as a suitable starting point. Consultation with the Aklavik Health Committee confirmed that community members sought such research.

In November 2006, this committee invited Dr. Goodman's team to conduct research in Aklavik; project planning began in 2007.

2.2 Years 2007 and 2008

February 2007: Initial Stages of Research Planning
Dr. Goodman worked closely with the Aklavik Health Committee to plan what would become the Aklavik *H. pylori* Project.

November 2007: First Wave of Data Collection
In November 2007, data collection started for the Aklavik *H. pylori* Project. Community coordinators Evelyn Wilson and Trevor McNutt initiated informed consent and clinical questionnaire contacts and actively recruited participants at strategic community locations.

January 2008: Community Response to Initial Recruitment Efforts
The research assistant team joined the community coordination team to boost fieldwork efforts from December 29 to January 12, 2008.

During January 2008, the team prioritized obtaining endoscopy* consents from participants regardless of breath test results and breath testing those whose willingness to be scoped depended on breath test results. At the same time, participants were told about the advantages of having both the breath test and endoscopy, regardless of test results. To increase recruitment, project staff set up recruitment posts at the supermarket and post office.

Aklavik resident Heather Stewart was hired in January to assist the community coordination team. Radio announcements to encourage participation were ongoing throughout the month of January 2008.

Initial recruitment efforts were met with a positive response from the community. Most residents contacted indicated a desire to participate. The biggest challenge was getting potential participants to follow through on scheduled appointments to complete the informed consents, questionnaires, and breath test. The field team used active recruitment with multiple invitations and reminders. A challenge for the endoscopy* phase of the project was the fraction of participants who indicated they were willing to be scoped only if they had a positive breath test. Of the initial 100 questionnaires completed, 40 respondents indicated a willingness to consent to endoscopy, another 30 or so said they would do so if they had a positive breath test, and the remainder were too young for endoscopy. The response showed that a

very high proportion of participants were willing to consider endoscopy, particularly if they had a positive breath test result. It also highlighted the need to have breath test results available before endoscopy, as well as the need to inform community members that endoscopy would provide a more thorough evaluation than the breath test, so those who were breath-test negative were also encouraged to have an endoscopy.

During January 11 to 13, 2008, Aklavik staff members were trained on the breath test protocol. The new infrared breath test analyzer (IRIS-2, Wagner, Germany) was installed in the CAN*Help** Working Group's project office in Edmonton, AB and functional by January 24, 2008. On January 28, the CAN*Help* Working Group staff began reporting breath test results to participants.

February 2008: Community Response during Endoscopy* Week

The endoscopy team arrived in Aklavik on Sunday, February 4, 2008. A well-attended community meet-and-greet was held that evening. Each evening during the week, residents were called to schedule appointments for the next day. In addition, team members went on the radio to encourage residents to come to the health centre to be scoped. Many team members engaged in outreach at various social events and during casual interactions with community residents. The activities included lunch at the preschool, a youth dance presentation at the community arena, lunch at the Indian Band offices, health career presentations by team members to high school students, curling, visits to the market and crafts shop, and evening patrols.

Upper gastrointestinal endoscopies* were performed at the Aklavik Health Centre in temporary endoscopy units equipped with rented endoscopy towers and gastroscopes, with technical support from Olympus Canada. Experienced endoscopy nurses and service workers assisted the gastroenterologists*. Study participants 15+ years of age who wished to undergo endoscopy were eligible, as were children whose parents request that they be included, at the gastroenterologist's discretion.

The number of individuals who appeared at the health centre to be scoped each day were as follows: 39 on Monday, February 4, 2008; 37 on Tuesday, February 5, 2008; 54 on Wednesday, February 6, 2008; 43 on Thursday, February 7, 2008; and 24 on Friday, February 8, 2008. Of 200 residents who appeared at the health centre to be scoped, 191 completed the ultra-thin scope procedure without sedation (mostly with transnasal insertion), 5 were sedated, 5 were not able to complete the procedure, and another 1 participant could not have biopsies* taken. No adverse effects occurred during the endoscopies, with the exception of a few minor nosebleeds and mild to moderate discomfort. A post-endoscopy patient satisfaction questionnaire indicated that most of those scoped tolerated the procedure well and would be willing to have it in the future if needed.

April 2008: Second and Third Waves of Data Collection

Dr. Safwat Girgis, the team Pathologist*, completed pathologic assessment of biopsies* in April 2008. During April 23 to 30, Dr. Justin Cheung returned to Aklavik to report pathology* findings to each participant individually.

The team's Lead Microbiologist,* Dr. Monika Keelan, processed biopsies* for culture*, encountering a number of samples that grew very slowly. Preliminary identification of *H. pylori** was performed with biochemical testing and morphology

(wet mount); confirmation was performed by 16S rRNA gene sequence analysis. Antibiotic susceptibility* testing was initiated during summer 2008.

Data collection continued whenever there was an opportunity for project staff to collect more questionnaires or conduct more breath tests. The epidemiology questionnaire was launched during Dr. Justin Cheung's visit to take advantage of the large number of project participants who went to the health centre. Testing for *H. pylori* continued till September 2008 and took much longer than anticipated. Genotyping was initiated during winter 2009 and has led to new projects expected to continue for a few years.

April to July 2008: Development of Knowledge Exchange Strategies

Project Manager Janis Geary (previously Huntington) travelled to Aklavik April 4 to 15 and June 25 to July 24, 2008 to work on her funded project: "Knowledge Transfer of Health Research Findings to Community Members of Aklavik, NWT." She obtained community input to use in the development of effective knowledge exchange strategies under the guidance of anthropologist Dr. Chris Fletcher. The research identified several preferred strategies including some already being used (radio announcements, newsletters, flyers, meetings with local organizations) and some to be developed (discussion groups involving youth and elders, presentations at community events, and a video documentary).

November to December 2008: Treatment Trial

Dr. Amy Morse, University of Alberta Gastroenterology Fellow, coordinated the treatment phase of the Aklavik *H. pylori** Project. Working with Dr. Karen Goodman (Lead Investigator) and Dr. Sander van Zanten (Lead Gastroenterologist*), Dr. Morse developed a treatment protocol and study information sheet for informed consent, which were reviewed by the Aklavik Study Planning Committee, and approved by the University of Alberta ethics board.

In late November 2008, Dr. Morse went with Dr. van Zanten to Aklavik to evaluate candidates for treatment and to oversee the administration of therapy with the support of Rachel Munday, the Aklavik Health Centre Nurse in Charge. Aklavik project staff Sally Kasook and Joanna Hartley coordinated the activities at the Aklavik Health Centre. This included phone reminders to participants in the treatment trial during the course of treatment, as well as collection of bubble packs to count unused medication and administration of a post-therapy questionnaire.

The treatment trial randomized 113 participants; 95 had a post-treatment breath test*, 65% of which were negative. Used bubble packs were collected from 43 participants. Treatment was also given to 12 adults and 16 children who were not in the trial.

2.3 Years 2009 and 2010

April to November 2009: Knowledge Exchange

Christopher White, a filmmaker from Yellowknife, was hired to make a documentary as part of CAN*Help** Working Group's knowledge exchange strategies. It was filmed in Aklavik from May to June 2009, and in Edmonton from July to October 2009.

Project Manager Janis Geary travelled to Aklavik in November 2009 to present current findings from the study at a large community gathering. A news crew from CBC traveled with her to film segments for an upcoming feature on the project for a National French program called Decouverte. The Aklavik Health Committee also screened to the community members "Never say die: The Aklavik *H. pylori* Project", which is the title of the documentary produced by the CAN*Help** Working Group that aims to help community understand the research process and results. Initial reactions to the documentary were very positive.

May to July 2010: Additional Data Collection

Research assistants Ashley Wynne and Laura McAlpine (previously Aplin) traveled to Aklavik from May to July 2010 to complete additional Individual and Household Epidemiology questionnaires. The questionnaires collected data on potential risk factors for *H. pylori** infection and gastric* disease. They hired two field assistants, Kiera Smith and Charmane Elanik who helped with interviewing participants and data entry.

2.4 Years 2011 and 2012

May to June 2011: Chart Review Follow-up

Research Assistant Ashley Wynne traveled to Aklavik to complete her funded project on improving CAN*Help** Working Group's instrument for conducting chart reviews at the Aklavik Health Center. The chart review included collecting information regarding previous stomach and esophageal complaints (during the past 5 years) as well as previous testing and treatment for *H. pylori** infection.
A comprehensive assessment of the previous chart review tool was conducted, and the tool was improved based on these findings. The new chart review tool was then used to thoroughly re-review all charts with any history of gastrointestinal complaints (n=120). The first and second rounds of chart review have been merged and are ready for analysis.

September to November 2011: Treatment Follow-up

PhD student Sally Carraher (now Ethnographic Fieldwork Lead) travelled to Aklavik in September 2011 to conduct an ethnographic study of the Aklavik *H. pylori* Project. She lived in Aklavik until mid-June 2012 to conduct her study. Ethnography in the project serves as a way to augment and enrich the descriptive epidemiology of *H. pylori** infection risk factors, by exploring local kinship organization and socio-economic structure. Ethnography also serves a knowledge translation role, as important issues regarding different worldviews and understandings of current *H. pylori* research practices and findings are investigated through the use of participant observation. By strengthening communication between various parties involved in community-based research, this project aims to help promote the direct application of research knowledge into effective *H. pylori* screening* and treatment practices, both in Aklavik and other remote northern communities throughout Canada.

During that time, Sally Carraher also followed up with treatment participants to determine the proportion of individuals re-infected with *H. pylori** since the trial was carried out in November 2008 and with participants who did not have *H. pylori* when first tested to see if any of them have become infected.

In November 2011, PhD student Megan Lefebvre traveled to Aklavik to follow-up with treatment participants who had not yet completed a post-treatment questionnaire. She carried out an analysis of the post-treatment questionnaire data looking at adherence and barriers to completing treatment. Findings from this analysis may lead to developing community-specific strategies to improve adherence.

September to December 2012: Knowledge Exchange Program

In 2011, the CAN*Help** Working Group received a CIHR "Meetings, Planning, and Dissemination" grant to develop an innovative strategy for making microbiology* research results meaningful to community members. In consultation with the Aklavik Health Committee, team Microbiologist* Monika Keelan, Knowledge Translation Lead Amy Colquhoun and Sally Carraher launched an exchange program that facilitates sustained contact between two community members and three Aklavik *H. pylori* Project researchers, in an effort to develop an iterative, participatory data dissemination project.

Sally Carraher and Monika Keelan travelled to Aklavik in September 2012 to meet with community members and organizations and recruit two youth for the exchange project. In October 2012, two community members traveled to the CAN*Help** microbiology* lab in Edmonton to learn how the *H. pylori** bacteria and DNA were isolated, characterized, and analyzed, and how to interpret the microbiology results. They also met with the public health researchers and gastroenterologists* in the CAN*Help* and University of Alberta Hospital offices respectively.

During November to December 2012, two community members worked with Aklavik's grade 10 general science students to develop materials for educating community members about *H. pylori** microbiology* research. The resulting dissemination materials will be used to help present Aklavik *H. pylori* Project results to other interested Arctic communities. Evaluation of this exchange program will be used to improve CAN*Help** Working Group collaborative research methodologies and knowledge dissemination initiatives.

The two community members also traveled to Vancouver in December 2012 to assist Sally Carraher with presenting on the group's microbiology data dissemination project at the ArcticNet annual scientific conference, where they won an award for best poster presentation.

2.5 Years 2013 and 2014

March 2013: Dissemination Activities

Dr. Sander van Zanten, Lead Gastroenterologist*, and Emily Walker (previously Hastings), Data Dissemination Lead, travelled to Aklavik from March 25 to 31, 2013 to meet with project participants and present results from Emily's MSc thesis research on environmental exposures and transmission of *H. pylori**. Sander and Emily went on the radio to present results from the project so far and to answer questions that community members called in. They were also available to meet with community members interested in hearing more about the project and discussing results at the health center. The following is a summary of results presented to community members:

Emily's thesis results indicate that *H. pylori** infection did not occur more frequently in individuals exposed to investigated environmental sources that could potentially be contaminated with the bacteria, relative to participants who were not exposed to these sources. This includes environmental exposures such as untreated water, sewage, cats and dogs. Since contamination of local water sources with the bacteria is a commonly expressed concern in communities across the north, continued analysis of the role of environmental exposures in transmission of *H. pylori* will include testing water samples from northern communities to determine whether living *H. pylori* organisms are in local water sources.

Preliminary analysis of the effect of exposure to mice indicates that *H. pylori** infection was more frequent in individuals who reported having evidence of mice in their home, relative to those who did not report having evidence of mice in their home. Further research is needed to address whether there is a potential role for mice in transmission of *H. pylori* or if evidence of mice in the home is a marker for another source of transmission. It should be noted that a very small proportion of participants reported exposure to mice. Therefore, even if it is possible for mice to transmit the bacteria, it is not likely that this the usual route by which *H. pylori* spreads.

During this trip, Emily also completed follow-up breath tests with participants who had received treatment through the project to ensure that the infection was cleared. Individuals were then notified of their infection status and further care was arranged for participants who were still positive.

May to June 2013: Dissemination Activities

Ethnographic Fieldwork Lead, Sally Carrahar returned to Aklavik in May 2013 to meet with the Aklavik Health Committee and other community stakeholders. During that time, she provided copies of her dissertation results to community organizations and the health centre, presented the findings of her ethnographic research at different community events, and sought feedback to use in CAN*Help** Working Group's continuing data dissemination and knowledge translation efforts.

July 2013: Pilot Water Study

In 2013, with guidance from the Aklavik *H. pylori* Project Planning Committee, team Microbiologist* Dr. Monika Keelan supervised a summer student, Yashna Beesoon, in a pilot study to test local water sources for living *H. pylori** organisms. Water samples were collected from treated water and untreated surface water sources in July and filtered for DNA and RNA extraction; the filters were cultured in an attempt to grow any *H. pylori* organisms present. The cultures* did not yield *H. pylori* isolates and no *H. pylori* DNA was detected in the water samples. Failure to detect organisms, however, cannot be interpreted as ruling out water as a mode of transmission, because the methods used in this investigation might not be sufficiently sensitive. In particular, larger water sample volumes may be required to collect a sufficient number of organisms for detection. Planning committee members have requested that additional approaches to water testing be attempted to overcome the limitations of the pilot project.

December 2013: Dissemination Activities

Data Quality Lead Katharine Fagan-Garcia and Aklavik *H. pylori* Project Planning Committee member Billy Archie presented an update on CAN*Help** Working Group's community projects at ArcticNet's 9th Annual Scientific Meeting in Halifax, Nova

Scotia in December 2013. They updated the scientific community on the high prevalence of *H. pylori** infection found in Aklavik, and in other communities, the high frequencies of severe gastric* inflammation in people with *H. pylori* infection, the pattern of *H. pylori*-associated stomach disorders that indicates increased risk of stomach cancer, and the unsatisfactory cure rate of the standard therapy from the treatment trial compared to the quadruple therapy. Katherine and Billy also informed the attendees that the findings suggested that community concerns about health risks from *H. pylori* infection are warranted, and CAN*Help** Working Group's initial research in Aklavik was a start towards generating the information needed to obtain data required for developing regional public health strategies for reducing health risks from *H. pylori* infection.

March 2014: Knowledge Exchange Program

Two community members from Aklavik travelled to Edmonton in March 2014 to share their experiences as educators in the community with researchers and students at the University of Alberta. This was part of knowledge exchange activities for CAN*Help** Working Group's 2011 CIHR knowledge dissemination grant. The community partners gave two formal presentations: one hosted by the Circumpolar Students' Association and the other hosted by the School of Public Health. They presented their experiences with the knowledge exchange project, and taught academic researchers about life in their community (for example, the scope of the science curriculum in the local school) and about community perspectives on scientific research (for example, how community members talk about *H. pylori**). The two community members agreed to continue to act in an advisory capacity for other CAN*Help* Working Group knowledge exchange projects.

May 2014: Key Informant Interviews

Emily Walker travelled to Aklavik in May 2014 to conduct semi-structured qualitative interviews with key informants from the community to identify specific research questions that address predominantly-expressed community concerns about the health effects of regular exposure to environmental contaminants. Emily will use this information, along with information from similar interviews conducted in other communities, to focus her PhD dissertation work. She completed 7 interviews in Aklavik, which were recorded, transcribed and analyzed to identify major themes. Some aspects of this analysis are ongoing.

June 2014: Chart Review – Antibiotic Use

MSc Student Kate Williams visited Aklavik in June 2014 to collect antibiotic exposure histories from medical charts of participants who had *H. pylori** cultured from stomach biopsies* and tested for antibiotic susceptibility* and/or were treated and completed a post-treatment breath test*. For each of these participants, information was collected for the five-year period before project enrolment on: demographic factors; frequency of antibiotic prescriptions; type of antibiotics prescribed; and reason for prescription. Kate will use this information for her MSc thesis, to estimate associations of antibiotic exposures on two health outcomes: 1) the prevalence of antibiotic-resistant* *H. pylori* infection and 2) success of treatment to eliminate *H. pylori* infection.

2.6 Years 2015 and 2016

July 2015: Key Informant Interviews

Supported by Ethnographic Fieldwork Lead Sally Carraher, MSc student Kate Williams developed a qualitative (semi-structured) interview guide for interviewing community members in Aklavik about their views on the use of antibiotics. Kate travelled to Aklavik in July 2015 to conduct interviews where she completed 10 interviews with Aklavik residents regarding their perspectives on the value and potential harms of using antibiotics to treat infections and on factors that influence adherence to prescribed antibiotic regimens. Factors that were identified to influence adherence to prescribed antibiotics most frequently included the occurrence of side effects and forgetfulness. The information obtained from the interviews will be used in the development of local *H. pylori** control strategies.

April to June 2016: Dissemination Activities

Aklavik's community representative Billy Archie, along with representatives from Fort McPherson and Ulukhaktok, visited Edmonton to meet with Edmonton-based team members in April 2016. They were joined by the Yukon Community Partnership Coordinator Reanna Mohamed, and Northern Health Research Consultant, Kathy Gilmore. During their visit, they toured the CAN*Help** Working Group's offices and labs to learn about research activities carried out in Edmonton, including the analysis of the breath test samples and laboratory testing of *H. pylori**. Additionally, the ongoing and upcoming research activities were discussed, as well as input on the updated research agreement template was obtained. Having northern-based team members and community representatives visit the CAN*Help* Working Group in Edmonton strengthened the relationships, and served as a knowledge exchange opportunity for enhancing the quality of the research activities. Global News Edmonton featured this event on their 6:00 PM evening news. They filmed meetings between Edmonton-based academic staff and the Northwest Territories community partners, and interviewed Janis Geary about the project.

In June 2016, Janis Geary, Fieldwork Coordinator Megan Lukasewich and Data Dissemination Lead and PhD student Emily Walker travelled to Aklavik to meet with the Aklavik *H. pylori* Project planning committee in person to start developing the Traditional Medicines Spotlight Project. Over two days, the planning committee discussed what the research goals of the Traditional Medicines project were, how the project will be conducted, including plans to protect the Traditional Knowledge. Janis, Megan, and Emily also discussed with the committee plans for upcoming research activities, including the collection of Indigenous traditional medicines, the recruitment of participants for Emily's dissertation project, possible collaborations with international research groups and plans for long-term follow-up endoscopy* in Aklavik in 2017.

September 2016: Knowledge Exchange Activities

Megan Lukasewich and Mitacs-Globalink summer intern Yiwen Zhenug travelled to Aklavik to collect traditional medicines, as identified by the planning committee, to assess its antimicrobial properties. She worked with the Aklavik *H. pylori* planning committee and other community members to go onto the land before winter made collection impossible. The medicines were brought back to the University of Alberta where they will be stored until they can be tested for anti-*H. pylori** activity.

Megan Lukasewich provided an opportunity for community members of Aklavik to meet and learn about upcoming traditional medicine project in September 2016. A

brief presentation and overview of the *H. pylori** project was shared, and community members were provided the opportunity to ask questions about the project. Megan also met with high school students and shared information about the *H. pylori* project, and the upcoming traditional medicine project. The meeting increased the awareness of traditional medicine among the youth, and aimed at identifying any youth interested in collecting traditional medicine with elders on the land. Some of the youths expressed interest in participating in the project.

October 2016: Key Informant Interviews

Emily Walker travelled to Aklavik to recruit participants for her dissertation project. The project aims to investigate the hypothesis that chronic ingestion of low doses of mercury through fish consumption increases the risk of severe gastritis* and precancerous gastric* lesions among *H. pylori*-positive* residents of Arctic communities. Emily collected hair samples for laboratory measurements of mercury levels and administered fish-focused food frequency questionnaires with 45 participants.

Definitions and Acronyms

Antibiotic resistance	Ability of a microorganism to withstand the effects of an antibiotic
Antibiotic susceptibility	Susceptibility/Sensitivity of bacteria to antibiotics
Atrophy	Wasting away and breakdown
Biopsy, of stomach	A tiny piece of stomach taken during endoscopy
CAN*Help*	Canadian North *Helicobacter pylori*
Culture	As bacteria are living organisms, they can be made to grow in laboratories under the right conditions. A culture test provides conditions that encourages bacteria to grow
Duodenal	Related to the duodenum (small intestine)
Duodenitis	Inflammation of the duodenum (small intestine)
Endoscopy, of stomach	Using a scope/tube to look inside the stomach
Gastric	Related to the stomach
Gastritis	Inflammation of the lining of stomach
Gastroenterologist	Stomach specialist
Histopathology	A test where biopsy material are made into slides so a pathologist can examine them under a microscope to see if *H. pylori* organisms are visible
H. pylori	Stands for *Helicobacter pylori*. *Helicobacter pylori* are bacteria that infect the stomach lining. Chronic infection with *H. pylori* occurs when the bacteria live in the stomach for a long time.
Long-term follow-up	Includes both breath tests and endoscopy. It is done few years after treatment to estimate the incidence rate of *H. pylori* infection, and to examine the change in stomach lining
Metaplasia	Abnormal change in the nature of a tissue
Microbiology	Science that studies microscopic forms of life
Microbiologist	A scientist who specializes in microbiology
Pathology	Science that identifies diseases and conditions by studying tissues and organ biopsies
Pathologist	A scientist who specializes in pathology
Positive for *H. pylori*	Have the *H. pylori* infection
Post-treatment breath tests	Tests given after the participants complete their treatment
Screening	Testing
Short-term follow-up	Breath test given starting 8 weeks after treatment