“NEVER SAY DIE!”
AN ETHNOGRAPHIC EPIDEMIOLOGY OF *HELIcobacter pylori* INFECTION AND RISK PERCEPTIONS IN AKLAVIK, NWT
“Never Say DIE!”

By
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A Thesis
Submitted to the School of Graduate Studies
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TITLE: “Never Say DIE!” An Ethnographic Epidemiology of *Helicobacter pylori* Infection and Risk Perceptions in Aklavik, NWT  

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NUMBER OF PAGES: xiii, 252
DEDICATION

In loving memory of Miles E. Richardson (1932-2011),
who was a good friend, a brilliant anthropologist, and an
even better human being.

This thesis is dedicated to the people of Aklavik. I thank this
generation for your hospitality, kindness, and generosity. I have loved
learning about your ancestors, and I look forward to meeting your
future children and grandchildren!

Quyanainni.

Mahsi cho.

Thank you.
ABSTRACT

*Helicobacter pylori* is a bacterial infection of the human stomach lining known to cause peptic ulcer disease and stomach cancer. This infection has become a major concern of Indigenous peoples living in the Mackenzie Delta region of the NWT, where both *H. pylori* infection and stomach cancer are more prevalent relative to much of southern Canada and the United States. I joined the Canadian North *Helicobacter pylori* (CANHelp) Working Group in 2010 to conduct participant observation in the Aklavik *H. pylori* Project (AHPP) and identify ways that ethnography can be integrated into the ongoing research that incorporates epidemiology, microbiology, gastroenterology, knowledge translation, and the development of public health policy.

Between September, 2011 and June, 2012, I lived as a participant observer in Aklavik. During this time I led an epidemiological study of the incidence and re-infection of *H. pylori* infection (Chapter 4). I examined how different risk perceptions emerge from processes of “making sense” of *H. pylori* as a “pathogen” or as a “contaminant” and described how these different constructions influence people’s behaviours (Chapter 5). Indigenous residents perceive historical colonization as the source of contemporary social inequities. Narratives of cancer as well as *H. pylori* reference contamination that has been brought to the Arctic through the physical and cultural pollution of successive colonial and boom-and-bust projects. This clashes with epidemiological narratives citing that human health improves overall (and that *H. pylori* infection decreases) when a society modernizes their socio-economic system. Ethnography, in this way, can make visible the lenses through which different groups of actors perceive, experience, understand, and react to *H. pylori* infection. The recognition that the social inequities most strongly associated with *H. pylori* infection and re-infection that exist today are the result of approximately a century of colonial history in Aklavik is one example of a space in which different lenses can be brought into a shared focus. From such shared understandings, consensus knowledge can be built collaboratively between outside researchers and Indigenous Arctic communities as these actors work together in an ongoing, and community-driven, research project. In a second way, ethnography can be used to identify more locally-valid ways of identifying and measuring the distribution of *H. pylori* infection and its associated risk factors. To that end, I critically examined the definition and use of the “household” as a level-unit of risk assessment and have outlined steps for assessing possible risk factors as these are distributed across multi-household extended kin groups that can be identified and followed in long-term research (Chapter 6).

Although my recent incidence and re-infection study revealed the burden of *H. pylori* infection has been reduced amongst AHPP participants, the settlement as a whole remains very concerned – particularly because there are new cases of stomach cancer recently diagnosed in Aklavik. Opening *H. pylori* infection research up to a broader anthropological perspective allows for a critical consideration of the ways in making sense of *H. pylori* and constructing risk shapes (and limits) the forms that treatment strategies and healthcare policy should take.
ACKNOWLEDGEMENTS

I owe gratitude to so many. The research, and the writing, have only been possible because I am fortunate to have so many wonderful colleagues, family, and friends to help me along the way. I have been privileged to be co-supervised by Drs. D. Ann Herring and Wayne Warry, who have supported my decision to pursue an aggressive writing schedule while simultaneously launching an ambitious job search. Go big or go home – you only (hopefully) do a PhD once!

Thank you to my committee members, Drs. Herring, Warry, Kue T. Young, and Karen J. Goodman, who have given me much freedom in the designing of my research methods, analysis, and writing; and thank you for prompt feedback with all of my drafts. Particularly, I wish to acknowledge Dr. Goodman for serving as my field supervisor while I lived and worked in Aklavik; and for her thoughtful feedback on my ethnographic work from an epidemiologist’s perspective. Beyond my committee, several people have contributed to this research. Thank you Janis Weir for your superb performance as an all-knowing administrative assistant.

I am indebted to the several staff members of the CANHelp Working Group, who all have supported my desire to conduct extensive ethnographic research in Aklavik. Particularly, thank you Amy Colquhoun for numerous chats surrounding knowledge translation and cross-cultural communication, and for collaborating with me during my own data dissemination planning. Thank you Laura Aplin, for your tireless efforts to coordinate equipment, supplies, and data collection logistics – you make field research happen! Thank you Laura, as well as Megan Lefebvre, for traveling to Aklavik in November, 2011, to assist me with administering breath tests in Aklavik. Thank you Hsiu-Ju Chang for assistance with the data analysis and interpretation, and revisions for our co-authored paper; and for your careful work in reviewing manuscripts and poster presentations for me. Thank you Janis Geary, for initially putting me in touch with Dr. Goodman.

There are so many people from Aklavik who have helped me along the way. It would not have been possible to do the work I have done without the expertise and guidance of the Aklavik Health Committee. Billy Archie was central in forming the original health committee and in getting H. pylori research started in Aklavik. Thank you for informing me of your concerns and desires for the research; and for providing invaluable feedback on drafts. Billy also runs an ice road taxi in the winter, which delivered the breath test samples safely to Inuvik for air transport to the project offices at the University of Alberta. Robert Buckle of the Aklavik Indian Band always made himself available to assist with planning research activities and community events. His wife, Annie Buckle, made sure I was getting around town and on the land to meet as many people as possible, and ensured I had plenty of food to eat!

In Aklavik, several people at Moose Kerr School, the Aurora Learning Centre, and the Joe Greenland Centre provided in-kind donations of space, coffee, tea, and their time so I could host community events and hold focus groups. Principal Velma Illasiak, Vice Principal Frank Galway, and Bobbie Jo Greenland helped me coordinate educational
events for high school students. Thank you to my students from Moose Kerr School, Tara Lee Steinwand, Steven Gruben, Curtis Illasiak, and Jordan Illasiak, for sharing your knowledge of Aklavik and your perspectives on growing up in the Mackenzie Delta. Elder Day Program Coordinators Karla Smith and Rhonda John helped me host presentations, activities, and interviews with seniors. Elders Mary Kendi, Ellen Arey, Barbara Allen, Arny Steinwand, Wilbur and Hugh Papik, Ruth Stewart, Sadie Whitbread, Walter Bennett, and Archie Elanik provided stories, humour, and a wealth of first-hand information about contemporary and historic Aklavik. Thank you to the Recreation Committee for donating use of the Sittichinli Recreation Complex for research-related events; and to the Bingo operators at that arena for use of the radio to communicate research updates to listeners.

I would not ever have been able to administer so many breath tests and questionnaires in such little time without the generosity and support of the numerous staff of the Susie Husky Health Centre in Aklavik. Nurse-in-Charge Rachel Munday was always willing to take time to consult with me, and ensured health centre office supplies and equipment were made available – not to mention many enjoyable but competitive rounds of Scrabble™ that helped us to pass the chilly evenings. Thank you to staff members Kathy Greenland and Gladys Edwards, for sharing your expertise concerning local history and kinship, and for all your entertaining stories! A big thank you to the Home Support Workers Diane Joe, “Charlie Boy” Kalinek, and Judy Semple for making sure I always got where I needed to go in the clinic van, and for transporting seniors back and forth to events I hosted. Thank you Tara Lee Joe, for assistance with hosting health committee meetings and other events at the clinic; and for your good company and conversations!

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My field research has been supported in part by CANHelp Working Group funds. I received external funding through the Arctic Institute of North America’s Grant-in-Aid program; the McMaster University Indigenous Health Research Development Program Graduate Scholarship and Research Grant, funded by the Canadian Institutes of Health Research – Institute of Aboriginal Peoples’ Health; and The Ontario Graduate Scholarship. I received internal funding from the Department of Anthropology at McMaster University, the Graduate Students’ Association, and the School of Graduate Studies.
ABBREVIATIONS

ACC
Aklavik Community Corporation

AHC
Aklavik Health Committee

AHIS
Alberta Health – Innovates Solutions

AHPP
Aklavik *H. pylori* Project

AIB
Aklavik Indian Band

AINA
Arctic Institute of North America

AHRN
Arctic Health Research Network

ALC
Aurora Learning Centre

ARI
Aurora Research Institute

BMI
Body mass index

CANHelp Working Group
Canadian North *Helicobacter pylori* Working Group

CEGIIR
Centre for Excellence in Gastrointestinal Inflammation and Immunity Research

CFI
Canada Foundation for Innovation

CIHR
Canadian Institutes of Health Research

COPE
Committee for the Original People’s Entitlement

CRI-O
Collaborative Research and Innovation Opportunities research grant

CSDH
Commission on the Social Determinants of Health

EBV
Epstein-Barr Virus

GCLCA
Gwich’in Comprehensive Land Claim Agreement
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>GNWT</td>
<td>Government of the Northwest Territories</td>
</tr>
<tr>
<td>GSA</td>
<td>Gwich’in Settlement Area</td>
</tr>
<tr>
<td>HBC</td>
<td>Hudson’s Bay Company</td>
</tr>
<tr>
<td>HPV</td>
<td>Human Papillomavirus</td>
</tr>
<tr>
<td>IBD</td>
<td>Inflammatory Bowel Disease</td>
</tr>
<tr>
<td>ICHR</td>
<td>Institute of Circumpolar Health Research</td>
</tr>
<tr>
<td>IFA</td>
<td>Inuvialuit Final Agreement</td>
</tr>
<tr>
<td>IRC</td>
<td>Inuvialuit Regional Corporation</td>
</tr>
<tr>
<td>IRIS</td>
<td>Infra-Red Isotope Spectrometry</td>
</tr>
<tr>
<td>ISR</td>
<td>Inuvialuit Settlement Region</td>
</tr>
<tr>
<td>KT</td>
<td>Knowledge translation</td>
</tr>
<tr>
<td>LANWT</td>
<td>Legislative Assembly of the Northwest Territories</td>
</tr>
<tr>
<td>NCCAH</td>
<td>National Collaborating Centre for Aboriginal Health</td>
</tr>
<tr>
<td>NIH</td>
<td>National Institutes of Health (United States)</td>
</tr>
<tr>
<td>NWT</td>
<td>Northwest Territories</td>
</tr>
<tr>
<td>RCMP</td>
<td>Royal Canadian Mounted Police</td>
</tr>
<tr>
<td>TCPS2</td>
<td>Tri Council Policy Statement 2</td>
</tr>
<tr>
<td>U. of A.</td>
<td>University of Alberta</td>
</tr>
<tr>
<td>UBT</td>
<td>13-carbon Urea Breath Test</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</tbody>
</table>
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Chapter 1: Introduction

This thesis is a multi-disciplinary, mixed-methods project in applied medical anthropology. Between September, 2011 and June, 2012, I lived as a participant observer in Aklavik, NWT conducting research for the Aklavik *Helicobacter pylori* Project (AHPP). *Helicobacter pylori* is a bacterial infection of the human stomach lining. Known to cause peptic ulcer disease and stomach cancer, *H. pylori* occurs has the highest prevalence amongst socio-politically and economically marginalized populations throughout the world, in both developing nations (Khalifa, Sharaf, Aziz, *et al.* 2010) and developed nations, including Canada (Jacobson 2005). *H. pylori* infection and stomach cancer, for instance, are much more prevalent in the Arctic regions of the United States, Canada, Scandinavia, and Russia compared to southern Canada and the United States. Settlements in the Northwest Territories (NWT) and Nunavut, where *H. pylori* is highly prevalent, are largely populated by Indigenous people who live with a range of social inequities that are the result of more than a century of colonialism, including poor access to quality housing, jobs, income, education, quality produce and other store foods, and adequate sanitation infrastructure.

Initial AHPP research revealed that *H. pylori* infection occurs most frequently in Aklavik residents of Indigenous identity, lower socioeconomic status, less education, and living in crowded housing (Aplin, Fagan-Garcia, Chang *et al.* 2011). Thus, in many ways, the picture that emerges in the Canadian North reflects the same relationship between *H. pylori* prevalence, social inequities, and poverty seen in many other world regions.
Under the umbrella of the AHPP, I had wonderful opportunities to address theoretical issues in Indigenous health, medical anthropology, and *H. pylori* epidemiology. Some of these opportunities result from the curious nature of *H. pylori* itself – an infectious microorganism that causes cancer and whose “natural history” is not yet completely understood. Other opportunities are owed to the structure of the AHPP, which is a community-driven project that makes Knowledge Translation (KT) and community-partnership central components of the research process. Finally, some of these opportunities are owed directly to Aklavik’s people, who make up a community that will “Never Say DIE!”\(^1\)

For this dissertation research I used a mixed-methods ethnographic epidemiology to critically explore the links between *H. pylori* infection and associated risk factors previously identified in the AHPP. I investigated how culturally-defined constructions of health, *H. pylori* bacteria, and risk inform and motivate different segments of the population to engage in what I term “risk-avoidance” behaviors, including more direct approaches to avoiding infection through filtering one’s water, and including more broadly an individual’s or family’s decision to participate in a long-term research project. Sometimes the risk perceptions of Aklavik residents and of CANHelp Working Group researchers clash, presenting challenges to developing effective KT, and that could potentially negatively affect research participation and healthcare delivery. There is a need to better understand the socio-cultural roots of epidemiological perceptions of Indigenous societies and health, and of *H. pylori* infection and its associated risk factors.

\(^1\)“Never Say DIE!” is the official motto of the Hamlet of Aklavik and was adopted as the AHPP motto. The history and cultural significance behind this motto are discussed in detail in Chapter 2.
There is also a need to better understand Indigenous perceptions of health, infection, and contamination and how various risk constructs are understood (or not understood) by epidemiologists and Aklavik’s Indigenous residents. I argue that the cultural processes underlying the construction and response to risks must be considered in the ongoing development of regional health policy regarding *H. pylori* surveillance and treatment.

### 1.1 The Aklavik *H. pylori* Project

The [Canadian North Helicobacter pylori (CANHelp)](https://canhelp.org) Working Group is a team of researchers, health officials, and community leaders and organizations who collaborate to investigate *H. pylori* infection and associated stomach diseases in the Yukon and Northwest Territories. This group was formed in 2006 to address several goals (Cheung, Goodman, Munday, *et al.* 2008:912):

1. Investigate the influence of *H. pylori* infection upon remote Arctic communities
2. Develop effective treatment strategies that respond to the particular needs of regional communities
3. Develop recommendations for health policy focused on managing *H. pylori* infection and decreasing the burden upon human health

---

2 To date, there has been some application of AHPP findings in the development of regional health practice. In Inuvik, incoming physicians are advised to prescribe a treatment regimen based on results from the AHPP treatment trial and the Inuvik pharmacies are now prescribing treatment in easy-to-use blister packs to facilitate patient adherence to a multi-drug regimen that is taken four times a day for ten days. Most recently (2013) the CANHelp Working Group earned a Collaborative Research and Innovations Opportunities (CRIO) grant through Alberta Health – Innovates Solutions (AHIS) to support future KT and policy development that includes incorporating community values into regional policy analysis for *H. pylori* management. I am continuing to work for CANHelp as an the new Ethnographic Fieldwork Lead to assist with data dissemination to participating communities (including Aklavik), KT, and to work directly with community planning committees like the AHC to draft community-informed policy recommendations that are to be delivered to regional and territorial health authorities.
Table 1.1: Aklavik *H. pylori* Project timeline

<table>
<thead>
<tr>
<th>U. of A</th>
<th>Northern territories</th>
<th>Aklavik research</th>
<th>Aklavik cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000-2004</td>
<td>Billy Archie urges officials to investigate <em>H. pylori</em> in Aklavik</td>
<td>AHC reestablished in 2004</td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>Goodman recruited to CEGIIR</td>
<td>U. of A. CEGIIR reps meet medical directors in Yellowknife</td>
<td>Local woman dies of stomach cancer</td>
</tr>
<tr>
<td>2006</td>
<td>CANHelp established</td>
<td>Goodman meets AHC</td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td></td>
<td>AHPP data collection begins (surveys, UBT)</td>
<td>Local woman dies of stomach cancer</td>
</tr>
<tr>
<td>2008</td>
<td>CANHelp begins research in Old Crow, Yukon</td>
<td>AHPP survey data collected</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>AHPP endoscopy component</td>
<td></td>
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<td></td>
<td></td>
<td>AHPP treatment component begins</td>
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<tr>
<td>2009</td>
<td></td>
<td>AHPP survey data collected</td>
<td></td>
</tr>
<tr>
<td>2010</td>
<td></td>
<td>AHPP survey data collected</td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td>CANHelp begins research in Tuktoyatuk, NWT</td>
<td>Carraher arrives in Aklavik to</td>
<td>Local man dies of stomach/pancreatic cancer</td>
</tr>
<tr>
<td>2012</td>
<td>CANHelp begins research in Ft. McPherson, NWT</td>
<td>Treatment and follow-up provided</td>
<td>Local woman diagnosed with stomach cancer</td>
</tr>
</tbody>
</table>

(www.canhelpworkinggroup.ca; Goodman 2012, personal correspondence; Huntington 2012, personal correspondence; Munday 2012, personal correspondence).

The Aklavik *H. pylori* Project (AHPP) is the pilot project in the CANHelp Working Group’s total program of research. The CANHelp Working Group developed their protocols for all research planning, data collection, analysis, publication, and data
dissemination activities in consultation with the Aklavik Health Committee (AHC) (Goodman 2011).

The AHPP is frequently referred to in the epidemiological literature as a “community-driven” project. This term emphasizes that demands for applied research originated amongst Indigenous community members: a call from residents of Aklavik came up through the ranks of regional, and then territorial, health officials, requesting an investigation of the high prevalence of *H. pylori* infection which local people had heard was causing stomach cancer. In fact, several events in Aklavik and Yellowknife, and at the University of Alberta in Edmonton, led to the initiation of a project in Aklavik (Table 1.1).

1.1.1 The birth of the Aklavik *H. pylori* Project

At the University of Alberta, the Director of the Division of Gastroenterology had secured a large Canada Foundation for Innovation (CFI) grant with which led to the development of the new Centre for Excellence in Gastrointestinal Inflammation and Immunities Research (CEGIIR). The project aimed to take an integrative approach by combining basic, clinical, and population-based research projects. In 2005, Dr. Karen J. Goodman was recruited from the United States to lead and develop a comprehensive program of *H. pylori* research within CEGIIR (Figure 1.1). Goodman was chosen because of her expertise in conducting research on *H. pylori*, and because of her experience in leading community-based epidemiological research in the United States and South America.
Figure 1.1: Organization of the CANHelp Working Group community projects within the Division of Gastroenterology, Department of Medicine, University of Alberta.

After arriving in Edmonton, the Division of Gastroenterology Director encouraged Goodman to head up a response to requests from NWT medical directors, who wanted research to be conducted on *H. pylori* in the territory’s remote communities. A number of other professionals with knowledge and experience in *H. pylori* studies and medicine were, in essence, in the right place at the right time to contribute to the development a new kind of multi-disciplinary research program. Microbiologists Diane Taylor and Monika Keelant were working at the University of Alberta and had significant experience with *H. pylori* bacteria – particularly in antibiotic susceptibility testing and the
genetics of bacterial virulence. The Division of Gastroenterology’s incoming Director, Dr. Sander Veldhuyzen van Zanten, had extensive experience in clinical research on *H. pylori*. At that time, the Director of the Northern Health Services Network – a network that acts as a liaison between Alberta Health Services and the Northern Territorial Health Services – and the Director of the Stanton Territorial Health Authority for the NWT were both gastroenterologists who were acutely sensitive to requests for *H. pylori*-focused research coming from some of the residents of Aklavik.

“So [the] Medical Director and [the] Northern Health Services Director were regularly meeting. And so, when they would say, ‘Oh, there’s this concern about *H. pylori* infection’; ‘Oh, we’ve had these cases of stomach cancer in Aklavik, and people are all worried about it.’ They had been asking for a couple of years for the Division to send people, to do research” (Goodman 2012).

1.1.2 Local concerns prompt action

By the early 2000s, there was a perception amongst community members in Aklavik that cancer in general was a growing problem and that the debilitating disease was beginning to replace previous epidemics of tuberculosis and influenza as the top killers of community residents (see Chapter 2). In some communities, like Aklavik, health centre nurses informed regional physicians and medical directors that they were seeing high numbers of *H. pylori*-infected patients suffering with a number of gastrointestinal disorders ranging from mild gastritis to abdominal pain, heart burn, nausea and vomiting, and peptic ulcers. From 1990 to 2000, stomach cancer diagnoses in the NWT, though rare compared to other *H. pylori*-associated pathologies, were three times higher than the national average for Canadian men (NWT Health & Social Services 2003). Between 2001
and 2007, seven individuals in Aklavik died from cancer, two from stomach cancer. As fearful patients in Aklavik learned from their nurses that stomach cancer has been linked to \textit{H. pylori} infection, people began to identify a target for community and medical response: the call to action on \textit{H. pylori} infection in the NWT was sounded. Following a 2005 meeting in Yellowknife between CEGIIR researchers and territorial medical directors, Susan Chatwood, then the Director of the Arctic Health Research Network (AHRN) and currently the Director of the Institute of Circumpolar Health Research (ICHR), informed Mayor Billy Archie of Aklavik that a research project was finally going to be initiated. Archie, who was also a member of the AHRN, headed up the re-establishment of the Aklavik Health Committee in 2004 specifically to organize the community around attracting researchers to investigate the bacterial infection. He had become very vocal about the need to address \textit{H. pylori} infection in Aklavik, making the issue part of his 2004 mayoral campaign platform (May 2010). Since that time, \textit{H. pylori} research in Aklavik has become well known throughout the North (Curran 2008; Thomas 2008; CBC News 2009). Dr. Robert Bailey visited Aklavik in the summer of 2006 to see if the Susie Husky Health Centre facilities would be sufficient for carrying out an extensive breath test and endoscopy project, and the companies Olympus Canada and Olympus America donated in-kind use of specialized transnasal endoscopes.\footnote{Standard endoscopes used in gastroenterology are passed through a patient’s mouth into the esophagus and down into the lower GI tract. The transnasal scopes provided by Olympus are smaller in diameter and can be passed through the nasal passages into the esophagus, which is intended to make the procedure easier for patients and can be used safely on very young children.} Archie organized the first AHC planning meeting in Aklavik in November, 2006 for Goodman to
attend. By February, 2007, the Aklavik *H. pylori* Project began recruiting participants and collecting data.

1.1.3 Aklavik *H. pylori* Project timeline

**Figure 1.2:** Research components of the Aklavik *H. pylori* Project.

<table>
<thead>
<tr>
<th>Aklavik <em>H. pylori</em> Project research timeline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feb. 2007          Community approval for project</td>
</tr>
<tr>
<td>May 2007           Community workshops held</td>
</tr>
<tr>
<td>Sept. 2007         NWT research license obtained</td>
</tr>
<tr>
<td>Nov. 2007          Aklavik <em>H. pylori</em> Project begins recruiting and testing people</td>
</tr>
<tr>
<td>Feb. 2008          Endoscopy in Aklavik</td>
</tr>
<tr>
<td>April 2008         Scope results reported back to individuals</td>
</tr>
<tr>
<td>Summer 2008        <em>H. pylori</em> tested to design best treatment options</td>
</tr>
<tr>
<td>Nov. 2008          Treatment trial begins in Aklavik</td>
</tr>
<tr>
<td>2009-2010          People are treated, more data is collected</td>
</tr>
<tr>
<td>Nov. 2011          Re-infection study begins, participants get breath tests</td>
</tr>
<tr>
<td>May 2012           Re-infection study completed, Results reported to individuals, treatment provided</td>
</tr>
<tr>
<td>Fall and Winter 2012</td>
</tr>
<tr>
<td>Ongoing            Data collection, follow-up breath tests, knowledge sharing, Expanding project to other northern communities Policy development</td>
</tr>
</tbody>
</table>

(Reprinted from Carraher 2012).

Research began in Aklavik in 2007 with activities in the community planned in consultation between Goodman and other CANHelp Working Group investigators and staff from the University of Alberta, nursing staff at the Susie Husky Health Centre in
Aklavik, and the AHC. Data collection components included initial screening with 13C Urea Breath Tests (UBT), followed by an endoscopy clinic in February, 2008, followed by a treatment trial in November, 2008 (Figure 1.2).

Early in AHPP planning, University of Alberta researchers learned that although people were interested in having a community-based *H. pylori* study, several had concerns about how research would be carried out. Researchers in the past have come and gone, never to return or report on their findings to the community. When there is a lapse in regular radio updates concerning the project, some residents reported feeling that the research must be over (Huntington, Fletcher, Goodman *et al.* n.d.; Huntington, Goodman, Munday *et al.* 2009a; Huntington, Goodman, Munday *et al.* 2009b).

University of Alberta researchers acknowledge that Indigenous residents have different world-views that influence their perceptions of what *H. pylori* bacteria and “infection” are, and recognize that there is sometimes a “disconnect” between community members and researchers that can impede communication of research findings and lead to unrealistic expectations of what kinds of questions researchers will be able to answer (Goodman & the CANHelp Working Group 2011). Perhaps the most contentious issue centers on the desires of community members that researchers determine the “source” of *H. pylori*. In response to this, I examine how people in Aklavik perceive risk for infection. Thus, a major component of my research has been to analyze and improve cross-cultural understandings and communication regarding ideas of source and risk relating to *H. pylori* infection(Chapter 5).
1.1.4 Situating my dissertation research in the Aklavik H. pylori Project

In 2010, I was invited to join the CANHelp Working Group after approaching Goodman and the AHC to offer my services as an ethnographer. My pre-doctoral research and experiences living in Alaska had led me to become interested in rural northern healthcare, Indigenous perceptions of cancer, and the link between certain cancers and infectious disease agents. *H. pylori* infection and stomach cancer are a significant problem in rural Alaska, as well as in the Yukon and Northwest Territories. I was particularly interested in being able to work as part of a collaborative, community-based project focused on *H. pylori* infection that was taking place in a rural northern settlement. After consulting the AHC to see if there was local interest in follow-up research on *H. pylori* infection in Aklavik, I submitted a proposal to Goodman, the nurse-in-charge Rachel Munday in Aklavik, and the AHC. After reviewing my proposal, I was made a CANHelp Working Group research trainee, with Dr. Goodman serving as my field supervisor. At that time, Dr. Goodman became the fourth member of my doctoral supervisory committee. I spent a week in early September, 2011 meeting with Goodman and the other CANHelp Working Group project staff at the University of Alberta and arrived in Aklavik on 13 September, 2011 to begin field work.

1.2 Research Objectives

My original intent in Aklavik was to utilize ethnography to explore how *H. pylori* infection is influenced by social inequities. This core objective has evolved to a focus on
understanding culturally-patterned ways of knowing *H. pylori* and of constructing risk, and determining how risk-avoidance behaviors are mediated by cultural constructions of risk while simultaneously being limited by social inequities. Both University of Alberta researchers and Aklavik residents were excited at the idea of a researcher coming to stay for an extended period of time to work on a single project and learn more about daily life and culture in the community. I soon realized that CANHelp Working Group researchers already had preformed impressions of what anthropologists do, and what the purpose of ethnography is. Some wanted me to explain why Indigenous community members maintain beliefs about *H. pylori* that differ from their own non-Indigenous or Euro-centric (what Indigenous health literature often labels as “Western”) and biomedically-couched perceptions. My specific research goals and activities also evolved in response to the desires of Aklavik residents. For example, community members want to know why Indigenous residents experience more *H. pylori* infection than non-Indigenous residents; they want me to generate data that community leaders can use to advocate for improved health and social services provisions[^4]. Residents also want researchers to investigate whether there is an environmental source for *H. pylori* infection, while researchers want to better understand why northern Indigenous peoples so strongly believe that *H. pylori* is a form of environmental contamination[^5] (see Chapter 5).

[^4]: I will deliver a report based on my dissertation findings to the AHC and organize community presentations and Q&A the next time I return to Aklavik.

[^5]: The CANHelp Working Group is presently drafting research and funding proposals to support an ethnographic study of local perceptions surrounding environmental degradation, and to identify specific environmental exposures that are of greatest concern to residents in Aklavik and near-by Tuktoyatuk, NWT. I am a co-investigator in this study and my role will be to provide oversight of ethnographic data collection and analysis.
As a result of these consultations, the research goals for this dissertation project are to assess the relationships between *H. pylori*, social inequities, and cultural constructions of risk in Aklavik by:

1) Operationalizing the concept of “culture” in the study of the social determinants of *H. pylori* infection by:
   a. Investigating how different groups within the community and the CANHelp Working Group perceive *H. pylori* and its related health outcomes within a broader context of their knowledge and beliefs about society, environment, and health;
   b. Examining how different cultural constructions of “risk” for *H. pylori* infection amongst Indigenous residents and non-Indigenous researchers and nurses are influencing people’s behaviors within the AHPP.

2) Augmenting the descriptive epidemiology of *H. pylori* infection and social inequities in Aklavik, based on ethnographic observations of how the community is socially structured

3) Applying my results to the ongoing development of culturally appropriate and effective *H. pylori* management policies for AHPP that are responsive to the expressed needs of the community

1.3: Terminology

As Warry points out, “Words have power. A writer’s choice of words indicates political orientation and potential bias” (2007:9). Additionally, words that are often used interchangeably in one social context or academic discipline may actually mean something different in another context. Several terms employed in anthropology and epidemiology are used differently, and I outline their intended meanings and uses in this thesis here.
1.3.1: Terms for peoples and cultures

Previous CANHelp Working Group publications use “Aboriginal” to describe native populations of the Canadian Arctic, which includes Inuit, First Nations, and Métis peoples. Within Aklavik, the majority of the population identifies as Inuvialuit (Inuit) or Gwich’in (First Nations). Warry distinguishes the terms Aboriginal and Indigenous: to him, the term Aboriginal connotes a unique sociopolitical status in Canada that is distinct from non-Native Canadians and from other racial and ethnic minorities who do not originally come from Canada, while Indigenous literally means to originate in an area. I use Aboriginal in Chapter 4 (Carraher, Chang, Munday, et al. 2013, in press) so that our terminology in that manuscript stays consistent with the original AHPP prevalence study (Goodman, Munday, Huntington, et al. 2009). However, in the rest of the thesis I use the term Indigenous which (in addition to recognizing that the Native peoples of Aklavik do in fact originate from that region) stems from my personal experiences working with several Indigenous North American groups and individuals over the years who have preferred to be referred to as Indigenous (with a capital “I”) over Aboriginal. Residents of Aklavik often use Aboriginal, Native, or Indigenous interchangeably – but are careful to never call Inuvialuit or Métis people “Indians” (because these two groups are not recognized as First Nations Peoples). When describing specific cultural, linguistic, or regional groups, I use the terms preferred by those groups – for example Inuit from northwest Alaska, to whom many Aklavik families are related, call themselves Iñupiat. When describing Inuit living in the Inuvialuit Settlement Region (ISR), I use Inuvialuit. Aklavik is home to the Ehdiitat Gwich’in Band, although members of other Gwich’in
bands (Gwichya and Teetl’it) live there as well. When describing non-Indigenous peoples, I refer to nationality (Canadian, American, European) or geographic ancestry (Euro-Canadian, Euro-American).

When quoting interlocutors, I use their own terms for non-Indigenous peoples, cultures, and societies, which usually is “White”, and sometimes “Western”. Particularly in Chapter 2, when describing Aklavik’s colonial and missionary history, I use “White” to represent local and Indigenous perceptions of non-Indigenous peoples in Aklavik, as well as to discuss Indigenous perceptions that “White culture” and “White society” at large are distinct from “Indigenous culture” and “Indigenous society.” “White” in this sense embodies the uneven balance of power that emerged throughout colonialism and persists today in the contemporary social and politico-economic organization of the Hamlet of Aklavik. “White” is also used by Indigenous interlocutors when describing lifestyles, behaviors, and values introduced by missionaries and explorers, and is associated with processes of colonization and “modernization” (see Chapter 2).

1.3.2: Terms for worldviews, belief systems, and processes of change

I found terminology particularly problematic when discussing historical social change in Aklavik. Often my interlocutors discuss being forced to adopt “White” ways of speaking and living. Sometimes they refer to “Western” culture and society. Within health and social science literature, “Westernization” is used somewhat interchangeably with “modernization” or “development”. Indigenous peoples are sometimes referred to as “non-Western” (even though my interlocutors live in the Northwest Territories of the
western Arctic). Often these terms are used to establish a dichotomous relationship between Indigenous and non-Indigenous ideologies, worldviews, cultures, or societies. Moreover, the cash-based economy and sedentary lifestyles are often portrayed as “Western” and “modern” while Indigenous subsistence practices, arts and crafts, and cultural celebrations are portrayed as “non-Western” and “traditional”. In practice, it would be wrong to say that Inuvialuit or Gwich’in families in Aklavik who successfully engage in the modern cash-based economy are somehow more Westernized (thus less Indigenous) than their neighbors. On that note, while today’s generation is definitely more modern than the last, today’s generation is no less Indigenous than their forebears. Yet, the Western/modern vs. Indigenous/traditional dichotomy persists across social science, health, and Indigenous literatures. Thus, when speaking about socio-economic development in the Arctic, I use the terms Euro-centric, Euro-Canadian, Westernization, modernization, and development depending on the particular context of the sentence. Generally, Western or Euro- connotes ideologies and practices that originated out of Western Civilization and the history of European Enlightenment, exploration, imperialism, and industrialization. Modernization and development are particular socio-economic and political processes contained within these larger Western sociocultural movements – but people who engage in modern economies and political systems are not necessarily Western or European-descended and are not necessarily “untraditional”, “Westernized”, or assimilated.

I use “biomedicine” and “biomedical” when referring to theories, methods of inquiry, and ideas derived from the health sciences. However, we must recognize that
biomedicine was developed largely within Western/European schools of thought and practice; as a cultural system, therefore, biomedicine tends to favor Western ideals of objectivity and empiricism, the self, and a belief in a real, universal world history with an emphasis on the physical (over the social, emotional, and spiritual) (see Smith 1999, Chapter 2). This can make it difficult for people enculturated into biomedical culture to understand some Indigenous concepts of environment and health.

1.3.3: Terms for places and residents

Following Collings (2011), I use “settlement” to denote a spatial locale in the Arctic where people live and “community” to denote a cohesive social group. This is a flexible way to use community, as Aklavik is at once a diverse multi-ethnic community cohesive in their shared geographic remoteness, socio-economic system, and local institutions; it is also a settlement where many communities (Inuvialuit, Gwich’in, Euro-Canadian, Anglican, Baptist, the research community, the hunting and trapping community, etc.) come into contact.

Additionally, much of the health and social science literature on Aklavik (and other western Arctic places) tends to conflate Indigenous people with locals and non-Indigenous people with outsiders. This is problematic because it neglects to realize that some of Aklavik’s non-Indigenous population was born and raised in the region and some of the Indigenous population were born far away in Alaska, British Colombia, Alberta, or other more southern and sometimes in urban parts of Canada. In Chapters 2 and 5 I describe “locals” (people born and raised in the Mackenzie Delta) and “outsiders” or
“newcomers” (temporary visitors including researchers, and first-generation residents whose families do not come from the western Arctic).

1.4: Thesis format

This is a “sandwich” thesis consisting of seven chapters; three are manuscripts intended for publication in 2013 (Chapters 4 to 6). I chose to write a sandwich thesis because the data collected in each phase of fieldwork helped to raise several different – yet related – questions that speak to contemporary issues across several academic arenas, including the disciplines of anthropology and epidemiology. The data also speak to discussions of social inequities as they relate to contemporary research in *H. pylori* infection, Indigenous health, and medical anthropology. In Chapters 5 and 6, which represent stand-alone papers, I build on issues raised during my fieldwork in Aklavik and explore other dimensions of the data I initially collected for Chapter 4. Each chapter is intended to speak to issues (and be published for audiences) working in different professional circles. A summary of the manuscripts, their purpose, author contributions, and the intended journals of publication are provided below. A preface is provided before each of Chapters 4 to 6 to articulate how each article is related to the others and to highlight the major theoretical contributions of each.

1.3.1 Chapter 2

Chapter 2 provides a historical sketch of the development of the Hamlet of Aklavik since the settlement’s early days as a Hudson’s Bay Company trading post. This chapter presents a contemporary health profile for the residents of Aklavik and situates major
current health issues within a broader temporal context of socio-economic and political processes that are interwoven into people’s daily lives. Although this chapter represents only one way in which we can position *H. pylori* bacterial infection and stomach cancer within the larger picture of human health and society, it is an earnest attempt at providing a multi-vocal, multi-local history that recognizes many different positions and power relations, and respects the many different voices of those contributing to oral history, interviews, and literature.

1.3.2 Chapter 3

Chapter 3 outlines the methods of my field research, data analysis, and data dissemination obligations to both the CANHelp Working Group staff and the community of Aklavik. I used mixed methods and collaborative, participatory approaches to data collection that aim to develop a post-colonial/anti-colonial perspective toward Indigenous health. These methods include standard epidemiological prevalence and incidence studies; ethnographic interviews and focus groups; kinship study; and participant observation. All of my methods, research activities, and future data dissemination obligations were developed in collaboration with the AHC. I also worked with a local Indigenous woman hired as a field researcher. She and I designed and conducted interviews; developed research flyers and project announcements; explained the research and collected informed consents from participants; and completed initial interview analysis together.

1.3.3 Paper 1

*Helicobacter pylori* incidence and re-infection in the Aklavik *H. pylori* Project.
S. Carraher, H.J. Chang, R. Munday, K.J. Goodman, and the CANHelp Working Group

In epidemiology, “incidence” refers to “the rate of occurrence of new cases [of disease] arising in a given period in a specified population, while prevalence is the frequency of existing cases in a defined population at a given point in time” (Bonita, Beaglehole & Kjellstrom 2006:18). Previous work in Aklavik revealed a relatively high prevalence of infection compared to the national average for Canada. However, we still know little about how long *H. pylori* infection has been highly prevalent in Arctic populations\(^6\), or how quickly bacterial populations will re-establish themselves in locales following community-wide treatment programs. This paper is unique because it is the first study of *H. pylori* incidence and re-infection to be conducted in a community in the Canadian Arctic that includes symptomatic and asymptomatic participants. Working with my co-authors also served as a way for me to observe epidemiological research in action, to better understand how CANHelp epidemiologists perceive and make sense of *H. pylori* infection, and how they stratify populations for analysis. This experience provided valuable insight into epidemiological constructions of risk, which is the focus of the next two papers. I am the first author of this paper, and wrote the first draft of the manuscript, to which the co-authors provided feedback and we revised together. Our manuscript was accepted for publication in the *International Journal of Circumpolar Health* on 22 March, 2013.

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\(^6\) Studies that estimate *H. pylori* prevalence in the past must analyze large contemporary population samples that are stratified into birth cohorts. When a population exhibits more *H. pylori* infection in older cohorts, it is interpreted that prevalence was more common in the childhood years of that cohort, indicating that prevalence has declined over decades. Numerous studies indicate *H. pylori* prevalence has drastically declined in Canada and the United States following World War II. These studies typically attribute the decline to rapid technological and economic development in the latter twentieth century, which is hypothesized to be directly linked to improved standards of living in these nations.
1.3.4 Paper 2

Pathogen or contaminant? Making sense of *H. pylori* infection and risk perceptions in the Aklavik *H. pylori* Project

S. Carraher

Since the Aklavik *H. pylori* Project (AHPP) began research activities in 2006, multiple narratives about the bacterium, its “source” and suspected transmission pathways have been constructed. Many local residents believe *H. pylori* probably travels in contaminated water from southern Canada to the Arctic, while local nurses and AHPP researchers believe that person-to-person transmission facilitated by household crowding, bed sharing, and inadequate hygiene is the most likely route. Perceiving *H. pylori* as a “pathogen” or as a “contaminant” does not simply represent different ways of thinking about a bacterium. Drawing from the notion of cultural fabrics of meaning (Geertz 1957), I explore how different narratives of infection and risk between local residents and outside researchers/health providers reflect broader chasms between Indigenous and Euro-Canadian conceptions of culture change and socio-economic “development”. I explore how these culturally-mediated narratives are translated into risk avoidance behaviors as a type of coping strategy, and then outline strategies for reframing epidemiological risk factor studies by drawing on ethnographic data on local knowledge systems and perceptions, and suggest ways of improving communication of epidemiological findings back to Indigenous community members.

This paper analyzes interview and focus group data collected between September 2011 and June 2012 during my field research in Aklavik and at the CANHelp Working Group project office at the University of Alberta. I draw information from my daily
journal and personal experiences as a participant observer. I am the sole author of this paper, which will be submitted to *The International Journal of Epidemiology* after I graduate. Recommendations resulting from this segment of my dissertation analysis are currently being drafted for delivery (in three audience-specific reports) to CANHelp Working Group lead investigators and project management staff and the Aklavik Health Committee.

1.3.5 Paper 3

**Ethnographic Epidemiology in the Aklavik *H. pylori* Project: A Case Study of Extended Kin Networks, Socioeconomic Conditions, and *H. pylori* Infection**

S. Carraher

Within epidemiology, populations are often stratified into household groups to assess the shared living conditions of individuals who presumably have the most frequent and regular contact with each other. AHPP research conducted between 2007-2010 collected data on socio-economic living conditions for participating individuals and households in Aklavik, which revealed that *H. pylori* infection is strongly associated with poor socio-economic living conditions at both the individual and household levels. However, little was known by other CANHelp researchers about how different households are related to each other within Aklavik’s Indigenous population, or whether health-influencing factors such as annual household income, education, and housing quality vary across larger kin networks that span multiple households.

In this paper I present an in-depth examination of *H. pylori* infection and living conditions for three extended Indigenous kin groups that represent the broad spectrum of
socio-economic status in Aklavik. This study provides the groundwork from which future
*H. pylori* infection and re-infection studies can be developed to combine participant
observation, kinship and social organization, and qualitative analysis with *H. pylori*
screening and epidemiological surveys. Based on this work, I make recommendations for
future extended-kin analyses that can be incorporated into long-term follow-up studies at
Aklavik, and may be adapted for other research as the CANHelp Working Group is
expanding *H. pylori* Projects to additional communities in the Yukon and NWT. This
paper will be submitted to the journal *Arctic* after I graduate.

1.4.6 Chapter 7

The project motto for the Aklavik *H. pylori* Project (AHPP) is “Never Say DIE!” I used a
mixed-methods ethnographic epidemiology to investigate perceptions of *H. pylori*
infection and risk are constructed, contested, or resisted – and how different culturally-
patterned perceptions shape the actions researchers and community residents take in
response to *H. pylori* infection. Within Aklavik, these actions include a collection of what
I term “risk-avoidance” behaviors that include more direct approaches to avoiding
infection through filtering one’s water, as well as an individual’s or family’s decision to
participate in a long-term research project. To approach different ways of perceiving *H.
pylori* infection and risk as processes of “making sense” of *H. pylori* within particular
places at particular times facilitates the development of culturally-appropriate data
dissemination, KT, and effective *H. pylori* surveillance and healthcare policies in western
Arctic settlements.
In the concluding chapter, I summarize the major findings of each paper and discuss my work’s broader contributions to Indigenous health studies, cultural epidemiology, and *H. pylori* infection and social inequities research. I describe the importance of acknowledging and attempting to understand the many different ways of knowing *H. pylori* infection (and subsequently, different ways people respond to it) in order that we can continue to improve the descriptive epidemiology of the AHPP, further contribute to capacity-building and KT, and improve the effectiveness of local *H. pylori* management policies. I conclude with an overview of recommendations for incorporating ethnographic methods into ongoing and future community-based studies of *H. pylori* infection and risk.
Chapter 2: Field site

2.1 Writing Aklavik

In this chapter, I aim to provide a multi-vocal, multi-local description, one that appreciates the many journeys through which different people come to live in and through the Arctic hamlet known as Aklavik. This ethnographic description provides a context in which to understand Aklavik’s changing health profile over time. I discuss how Aklavik is an Indigenous community that has always been defined through its relationship to Settler-Canadian society, politics, and projects, and how it is also a place where Indigenous peoples have resisted colonial labels and agendas while making and remaking their own traditions and cultural identities. In this historical sketch, I focus on how particular events and people’s responses to these events have shaped the place (culturally and geographically) that exists today. Successions of healthcare providers and scientific researchers coming to the North is a part of this history that is not often written about, but their presence has contributed in multiple intertwined ways to the development of Aklavik over the twentieth and early twenty-first centuries. By purposefully writing Aklavik\(^1\) in a way that positions it as a field site, we are able to begin

\(^1\) I am drawing from Clifford and Marcus’ (1986 [2011]) collection of essays called *Writing Culture*, in which several authors explore how ethnographers actually create new cultures through writing about their field sites. When ethnographers (or other scholars engaged in field research) neglect to describe a place’s history of being explored, studied, and written about, we are perpetuating colonial imaginations of non-Western places as exotic and unexplored, and thus are failing to acknowledge the ways in which the contemporary social structures have already been greatly affected through contact with the Western world, which includes contact with Western researchers. In the social science and health literature pertaining to Arctic communities the legacy of colonialism is almost universally described, while the history of previous researchers, their
asking how *H. pylori* infection and stomach cancer fit into the larger picture of Aklavik’s environment and society, and how the Aklavik *H. pylori* Project (AHPP) fits into Aklavik’s historical association with Western institutions, including the scientific research community.

2.2 Aklavik as a “field site”

Thinking of Aklavik as a field site has serious consequences for what outsiders know about Aklavik and its people. Aklavik is usually described in the literature in much the same way as other NWT settlements are described, as “a remote Aboriginal community”. To speak of “field sites” as places where subjects are encountered and studied serves to create the “other” and render exotic the places “they” live in. The tendency to describe Aklavik as “remote” is a case in point. This refers to physical remoteness as the settlement is not on a road system and is 60 kilometers away from Inuvik, a 5-hour flight from Yellowknife, and up to a two-day journey from Edmonton. Food, supplies, medicine, and mail must be shipped in by barge and planes in the summer, or over ice road in the winter. As a result, everything is expensive. To speak of “remote” Aklavik is to recognize affiliations with colonial institutions, and their engagements within these communities are rarely mentioned. In Aklavik I was challenged by some interview respondents why I wanted to ask them the “same questions” they already answered before (to previous researchers for different studies). In reviewing historical literature and contemporary health studies, I found most authors write in ways that serve to remove themselves from the snapshots they present of Aklavik. What is missing is a serious discussion of the ways in which Aklavik’s writers over the years have influenced residents’ lives – either directly through their actions while visiting the hamlet, or indirectly through the policies for Indigenous service provisions (including health care delivery) that are informed by what gets written about Aklavik. Failing to initiate this discussion contributes to the imagining of Aklavik as a place where social inequities have emerged out a presumably local (only) history; and fails to illuminate the more distal origins of inequities imposed through what Naomi Adelson (2005:S46) has called “tortured relations” between Indigenous societies and the Canadian nation-state.
these conditions. However, it also makes Aklavik seem isolated from the rest of the world, which can make it seem as if events there are unconnected to events elsewhere; in Yellowknife, Edmonton, Ottawa, or globally. The reality is Aklavik was historically the largest settlement in the Mackenzie Delta and a vital trading centre in the Western Arctic that brought together different Indigenous groups, and non-Indigenous entrepreneurs, missionaries, and military personnel from Alaska, Yukon, Vancouver, Edmonton, Toronto, Ottawa, and Europe.

Aklavik is also labeled in the literature as an “Aboriginal community.” While this is true, referring to a place as “Aboriginal” sets it up to be understood in opposition to White, Western, or “main-stream” Canada. Thus, to be “Aboriginal” or “Indigenous” is as much about not being White as it is about being Native; a theme I explore in section 2.3 of this chapter. It is not incorrect to label Aklavik as an “Aboriginal” or “Indigenous” community, especially as this is how local residents refer to their home. However, researchers should ask what impact this label might have, especially when “Aboriginal identity” is considered a statistically-significant marker of potential risk for a bacterial infection. What is it about an “Aboriginal community” (as opposed to a non-Aboriginal community) that makes it a place prone to infection and disease? Dene activist, artist, and writer Antoine Mountain raised this question particularly in reference to initial publicity regarding AHPP data dissemination, which included speculation about fecal-oral transmission:
“Let me just put it this way, would these same professionals expect a community with a non-Native majority to believe these same findings...?” (Mountain 2008).

The AHPP is in a challenging position: people want to know why Indigenous residents suffer from higher infection and cancer rates relative to their non-Indigenous neighbors, but they are also concerned that research findings can paint negative images of Indigenous peoples, cultures, and communities. In this thesis I aim to provide an explanation of Indigenous health in Aklavik, one that devotes as much effort to defining “Indigenous” as to defining “health.” To do so requires understanding the relationship between Indigenous societies and the Canadian nation-state:

“Indigenous health connects inextricably with matters of geography and colonisation [sic]...the effort to identify some special Indigenous essence or type ultimately is futile since the status emerges out of political subordination under settler colonialism” (Anderson 2007:144).

In other words – and to address Mr. Mountain’s question above – it is not Aklavik’s Indigenous population, nor their “culture”, that possesses some quality that makes them more prone to infection relative to Aklavik’s non-Indigenous population. Rather, I would argue that the focus of inquiry should be on understanding how Indigenous health inequalities today have been built up from generations of “tortured relations” (Adelson 2005:S46) with non-Indigenous settlers and the Canadian government. Gross social inequities in income, education, and access to employment and housing exist within Aklavik. These sharp and wide disparities appear to be contributing directly to the unequal
distribution of \textit{H. pylori} infection both between Indigenous and non-Indigenous residents, as well as within Aklavik’s diverse Indigenous population (see Chapter 6).

Jacklin (2009) finds troublesome the way “culture” is employed into the social determinants of health model, particularly in the context of Indigenous health research in Canada, as distinct collections of “cultural attitudes” that are held by dominant or subordinate groups. This obscures the unequal and marginalizing relationship between the dominating Settler culture\textsuperscript{2} and Indigenous cultures and contributes to the justification of paternalism and institutional racism. Health inequities arise not from particular attitudes perceived by outside observers to be inherent in Indigenous cultures, but rather through the historical and continuing devaluing of Indigenous cultures by the dominating society (Jacklin 2009:982). Scholars can contribute to this damaging legacy by neglecting to acknowledge the role of this power imbalance when they describe their field sites. Thus, in order to study “Indigenous” health, it is necessary to study the ways in which the research population has been defined uniquely as “Indigenous” in terms of historical colonial contact, and in terms of ongoing structural inequalities.

I have encountered Aklavik-as-a-field-site twice, first through the literature of other researchers, and then in person as a participant observer. My

\footnote{In reality groups identified as “Indigenous” and “Settler” (or “White”) are not homogenous, and to speak of these as discreet, cohesive groups creates a false dichotomy. Inaccurate as this dichotomy may be for reflecting peoples’ actual heritages, there does continue to be a grossly unequal relationship of power and wealth between Indigenous and non-Indigenous governments and populations in Canada – which as Jacklin argues, needs to be critiqued in Indigenous health literature.}
initial impressions of Aklavik, which derived from reviewing the literature, sometimes were at odds with my experiences living in the community. Early on in fieldwork I began to ask myself how these earlier readings might be affecting my perceptions on the ground. This chapter is in part a “field site” report, a form of ethnography that has traditionally dealt with places merely as settings in which people live, and often written without critically reflecting upon how places have been affected by the presence of previous explorers, ethnographers, or other researchers (Clifford 1986 [2011]). However, describing a place can become a powerful tool in applied ethnography and applied medical anthropology, when “place” is recognized as a spatially-anchored social collection of lived experiences that are multi-vocal and multi-local. To attend to place in this way, ethnographers can “empower place” (Rodman 2003) for the people(s) who constitute the communities present in the field site. I intentionally describe Aklavik as a “field site” because I wish to acknowledge the hamlet’s long history of association with explorers, historians, physicians, and researchers. This is especially important as local people have often told me they have been “over researched” and “researched to death” on the one hand, and on the other hand, these same people continue to request or even demand research be conducted in their hamlet. A multi-vocal and multi-local history of Aklavik can help us (outsiders) better understand complex and seemingly contradictory sentiments regarding research within the AHPP.

2.3 Historicizing Aklavik

2.3.1 A barren-ground meeting place: 1860-1920
Aklavik is located at 68° N latitude, 135° W longitude, at a sharp bend in the Peel Channel of the Mackenzie River Delta. Aklavik stands on the border between two Indigenous settlement areas. The communities of Tsiigehtchic and Fort McPherson to the south are Gwich’in Dene (First Nations); and the communities of, Tuktoyaktuk, Paulatuk, Ulukhaktok, and Sach’s Harbour to the north are Inuvialuit (Inuit). Only one other community, Inuvik, is built upon the borderline between the Inuvialuit and the Gwich’in settlement areas (Figure 2.1).

The word “Aklavik” from Inuvialuktun means “barren-ground grizzly bear” (aklak) “place” (vik). Throughout its history, the community has been recognized as a meeting place not only for grizzly bears, but for Inuvialuit from down the river, Gwich’in from up the river, and non-Indigenous people from the south. Like several other settlements in the NWT, the early history of Aklavik revolves around the development of the Canadian fur trade. American whalers and
Canadian fur entrepreneurs came to meet Inuvialuit and Gwich’in hunters and trappers. In so doing, this part of the Arctic met with the expanding Western free market. Smith (1977) acknowledges that the Canadian government did not assert an active interest in the North until after World War II, but emphasizes that even the earliest presence of Euro-Canadians in the North was dominated by competitive economic interests – interests which hardly changed over the decades even while policies toward Indigenous peoples did. Other scholars recognize the complexities of the North’s early history of Euro-Canadian contact, which include entangled notions of Christian charity, racist superiority, economic opportunity and pragmatism, the need for cooperation in order to survive, and compassionate interpersonal relationships between individual Whites and Indigenous persons (Waldram, Herring & Young 2006). This is the same complex web of significant relationships in which today’s healthcare system and contemporary health problems are suspended – and Aklavik’s historic role as an important nexus within the fur trade network makes it a place where new diseases and modern healthcare innovations have emerged in concert.

In the 1780s, the Hudson’s Bay Company (HBC) introduced fur trading to this region. The post that would later become Aklavik was set up by John Firth, a Scotsman who managed a larger post established in 1840 at the present-day settlement of Ft. McPherson. Firth and his men had decided they needed a new post further down the river (which runs to the North, out to the Arctic Ocean) in
order to increase trade in the winters with Inuit who travel seasonally along the northern coast from Alaska, past Yukon, to the Mackenzie Delta in the NWT.

Figure 2.2: Present-day Aklavik is situated on the northern bank of the Peel Channel. Remnants of early cabin homes can still be seen today in “Old Aklavik” (Pokiak) and along the Enoch Channel (Barker 2008).

Kenneth Stewart, a White trader and carpenter who had also worked at Ft. McPherson, traveled to set up the new post at Aklavik. When he arrived in 1911, Stewart starting dealing with an Inuit man called Pokiak from a nearby camp. The spot where Pokiak told Stewart to build the post, and the river channel alongside it, now bear Pokiak’s name (Campbell & Benyk 1987; see Figure 2.2). Today, the Stewarts and the Firths are Gwich’in families with kin living in Aklavik, Ft. McPherson, and other Gwich’in Settlement Area (GSA) communities. By 1912,
Aklavik became a permanent settlement with buildings that sprang up around the HBC trading post on the Pokiak side (also known as “Old Aklavik”). The Pokiak and Greenland families are reported to have been the first families to move there permanently. While early Aklavik was beginning to bloom, trade at Herschel Island was dwindling, prompting several Inuit trappers and whalers from Alaska to set up camps farther inland, where they could travel to trade in Aklavik (Campbell & Benyk 1987). Several of Aklavik’s Inuvialuit families are related to these Inuit – some seniors living today are their direct descendants. By 1922, the RCMP arrived, and by 1924, the Anglican Church of Canada established a mission, followed by a Roman Catholic mission in 1925 (Campbell & Benyk 1987). By the 1920s, the NWT (which at that time included all of Nunavut), had a total of six RCMP stations, two Indian Agents, and 16 church missions across the entire territories (Dickerson 1992). Aklavik was thus one of the most substantial settlements in the territories.

The health of Inuvialuit, Gwich’in, and Métis peoples during this period has been described by missionaries, explorers, early doctors, and in local stories. Written histories characterize this as a period of struggling with successive

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3 In contemporary Aklavik the term “elder” is used in different ways. On the one hand, it has come to be recognized by certain organizations and governmental bodies in the NWT as legally referring to any resident who is 60 years or older. Certain local and territorial benefits are reserved for these seniors, such as being able to use free transportation provided by the local health centre; as well as the territorial-wide benefit of paying reduced rent for public housing. A smaller number of seniors are recognized as being “Elders” in a sense of being an older community member from a local family who holds a great deal of wisdom and traditional knowledge. I use “senior” to refer more broadly to people over the age of 60; and use “Elder” to refer specifically to Aklavik residents who are recognized as being Elders with great cultural knowledge and authority.
infectious epidemics, most notably influenza in 1928, 1945, and 1949; chicken pox in 1949; measles in 1950; and tuberculosis starting in 1945 and continuing well into the 1970s; and (Table 2.1). Historical accounts of Aklavik lack significant details about the earliest of these epidemics; neither do they discuss other indicators of health, such as non-epidemic infectious or chronic diseases, maternal or childhood health. A common theme among seniors today memorializes the Aklavik of their grandparents as prosperous and happy but challenging. Infant mortality seems to have been more common in the nineteenth and early twentieth centuries. These stories indicate that in previous generations Inuvialuit, Gwich’in and Métis families were larger, often with 7 to 15 children, and that families and extended kin networks had to work together to share food and resources, especially in times of rough weather or declining animal populations.

2.3.2 “Two worlds” in one place: 1920-1950

From its strategic location on the river bend near prime trapping, hunting, and fishing areas, and serving as a major milepost between the Arctic Ocean to the north, and emerging towns like Whitehorse and Yellowknife, Aklavik boomed in the mid-century, reaching a peak population of about 1,600 people. By the early 1950s, this major Arctic centre included: two hospitals, several churches, trading posts, Anglican and Roman Catholic residential schools, hotels and inns, a Royal Canadian Legion, a bakery, a large RCMP station (with a police yard), a post office, a sawmill, a liquor store, a Native Hall, and a theatre (Campbell & Benyk
1987; Kendi 2012). Between the 1920s and 1950s, Aklavik served as the administrative centre for the Mackenzie Delta region. Supplies and workers from the south came to Aklavik on the S.S. Distributor, which sailed the Mackenzie River and its major channels to several Delta settlements. A few of Aklavik’s seniors have shared with me their childhood memories of excitement, because seeing the Distributor come down the river meant new supplies and people were arriving into town. However, the name “Distributor” seems sinister in retrospect, as the ship is now recognized for having spread Influenza in the summer of 1928, bringing the feared epidemic into the North from southern Canada (Piper 2009:43).

Dickerson (1992) describes Ottawa’s policies toward the North between 1920 and 1950 as focused on creating and maintaining “two worlds”: one for White development and a separate one for Indigenous peoples, keeping them out of development’s way. This segregated system persisted for three decades largely because Ottawa felt little pressure for change from Northerners. The few White residents were largely transient; Indigenous peoples were not yet organized as a political force. The missions were concerned largely with “saving the Natives” for the next world, rather than enabling them to participate on equal terms in this one; the HBC opposed changes that would affect Indigenous trapping activities and thus threaten the fur trade market (Dickerson 1992:57-59). This attitude toward Indigenous populations is reflected in how authority figures (including physicians) wrote about Aklavik in reports and journals, as shown below.
In 1921, the Canadian federal government established the Northwest Territories Branch of the Department of the Interior as the new administrative body for the North, which had to sort out, among other things, what to do about Inuit health. The Inuit were recognized as Indigenous people but did not have Indian status. In 1926, the Roman Catholic and Anglican Churches opened two hospitals in Aklavik, and shortly after the first physician to live and work in the western Canadian Arctic was stationed at Aklavik. Dr. J. A. Urquhart’s role involved more than just attending to the sick; he also worked in the schools. In an influential report Urquhart submitted to the Territorial Council in 1934, his opinion that Indian and Inuit children should learn just enough to be civilized yet keep to their “natural native custom” was clear:

“From a purely academic standpoint, [education] should be limited very much to the Three R’s, and manual training... These children, whether boys or girls, are going to have to live out their lives in the country. It is, therefore, necessary that everything possible should be done to avoid having the boys over-educated in a scholastic way, particularly if this is to be at the expense of their ability to make a living off hunting, trapping, and fishing” (in Dickerson 1992:38).

Urquhart’s multiple roles in administration, education, and medicine (the latter two operating under missionary control) exemplifies the interconnectedness of colonial institutions in the North. Because both hospitals were affiliated with mission schools and located in the same building, many Mackenzie Delta children first came to hospital through the residential school system. Starting in the 1940s, children were x-rayed for tuberculosis and monitored for the first fifteen days at
the beginning of the school year. Anyone diagnosed with tuberculosis was immediately sent to the hospital for treatment (Lemier 2005; Cooper 2010), and some were ultimately sent south to Charles Camsell Sanatorium in Edmonton (Stewart 2012). Thus, the schools, churches, and hospitals provided various forms of care perceived by Whites to be needed by Indigenous peoples, while acting collectively to maintain socio-economic, political, and cultural segregation.

Indigenous residents speak of two worlds or two cultures in Aklavik and refer to “tension”, or “clashing”, or “war”, between the two worlds. Residents perceive that a cultural war has permanently altered the social structure and the physical geography of Aklavik, causing many of today’s social and health problems. Prior to the 1950s, Aklavik was much more segregated – culturally, ethnically, and geographically. According to Gwich’in Elder Ruth Stewart:

**Sally Carraher:** You told me Gwich’in and Inuvialuit and Whites used to live in different places. Can you tell me where different people, I mean the different cultures, lived before in Aklavik?

**Ruth Stewart:** Some people lived across the river at Pokiak. These were Métis. And the Inuvialuit lived on one side of the creek, same as Pokiak.

**Sally Carraher:** And did the Gwich’in live on this side of the river?

**Ruth Stewart:** [Raises eyebrows meaning ‘yes’] *The Gwich’in lived on this side,* on the Hudson’s Bay Company side.

**Sally Carraher:** Where did the White people live?

**Ruth Stewart:** *Same side as Gwich’in!* But in their own houses [laughs].
Aklavik looked very different then; one’s ethnic and cultural identity could be surmised according to where along the Peel and Pokiak channels one lived. However, the different groups living in Aklavik and Pokiak would come together during certain times of the year, as Stewart explained in the same interview:

*But, July 1st was the big day. Canada Day. They’d clean the sidewalks and put tablecloths around and have a big feast. All the peoples came together and do their sports. And June 15 is the end of ratting season*. Everyone comes into town by then. July, it’s too hot to do anything. By August, you go back and fish. Everyone would go as a family. It was just automatically like that. Like, we knew that’s what you’re supposed to do.

To say that Gwich’in, Inuvialuit, and Métis families “automatically” knew how they were to organize seasonal subsistence activities for families paints a different picture from early missionary accounts that describe destitute populations in need of civilizing. According to Stewart, two of the biggest mistakes of White development in the North have been disruption in the flow of seasonal activities, and intergenerational disruption experienced when children who were needed to help with family hunting and fishing were forced to attend mission schools. Stewart sees culture clash – the collision of two worlds – as the root of many of Aklavik’s social and health problems. Because her description reflects the interconnectedness of numerous social and political issues, I quote her at length here:

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*Aklavik was known in the twentieth century as the “Muskrat Capital of the World” and muskrats are still hunted seasonally for meat and fur.*
Ruth Stewart: When people started coming into town the government said your kids have to stay for school. Next thing, we had houses in town. Next thing, the government gave people houses. Then they give you oil...That was a big mistake.

Sally Carraher: Why?

Ruth Stewart: It disrupted the families! And disrupted family activities. Education wasn’t important to the Native people. We didn’t read. “You can’t eat a book!” the parents would say to their kids. And our parents already experienced residential school in Hay River. So, we had no motivation to get an education at that time. You could still make a living without an education. But then, the kids had to stay in the hostel for the residential school, and the parents go out on the Land. At that time, we got family allowance until your kids are 16 to send them to school. We were really caught in cross culture. People tell us don’t be too White and other people tell us don’t be too Indian. It ripped the families apart. Parents started to drink. And suicide too. Before that, there was no suicide because people are really religious...I was angry at my parents for sending me to mission school. When I became a parent, I saw what a war it is and I understood why they drink.

Stewart’s narrative elucidates the tangle of socio-political institutions that first produced, then maintained, dependency upon the modern welfare system that exists in rural Indigenous communities in the Canadian Arctic. It is a knot that cannot be easily untangled: To seek a formal education and live in town year around may confer future benefits via employment but is also perceived as “acting White”, which means to adopt White customs and in so doing to give up (perhaps against one’s will) essential pieces of one’s “Indigenous” identity. This way of thinking about what it means to be Indigenous leaves many residents feeling they are being pulled in opposite directions, and that they must choose one side to stand on, despite the fact that many of Aklavik’s Indigenous families have
European, Euro-American, and Euro-Canadian ancestors who married into local lineages. In fact, while residents do recognize distinct “Indigenous” and “White” segments of today’s population, it may be more accurate to speak of “locals” (people born and raised in the Mackenzie Delta) and “outsiders” (first-generation residents whose families do not come from the western Arctic).

The lasting impact of residential schooling upon the social structure and geography of Aklavik is perhaps the biggest wedge between local (largely Indigenous) and outsider (largely non-Indigenous) groups, and so deserves attention in any attempt to understand contemporary health there. Historical accounts from the Anglican Church of Canada (2008) and the GNWT (Campbell & Benyk 1987) provide chronological details and descriptions of the mission schools, though they are presented in a sterile way that leaves out any mention of misconduct on the part of the churches or resistance on the part of pupils and their families. Residential schooling was a much-talked about subject during my stay in Aklavik, as the Canadian federal government’s Truth and Reconciliation Commission brought lawyers and counselors to Inuvik for people to apply for counseling services and cash settlements. Articles filled the territorial newspapers and airways (ATPN National News 2011; CBC News 2010, 2011a, 2011b; Stokell 2011a, 2011b). I learned a lot just from daily conversations, and I attempted to learn more about residential school experiences in my own interviews. My brief outline of residential schooling in Aklavik uses first-hand accounts as much as
possible and relies on church and secondary sources largely for dates, names, and other historical details.

In 1919, the All Saints Anglican Mission was founded in Aklavik by Bishop James Richard Lucas of the Diocese of the Mackenzie River. At this time students were predominately Gwich’in from the immediate surrounding areas. With the signing of Treaty 11 in 1921, which assured government funds for treaty-status children, more Gwich’in from Aklavik began to attend the residential school in Hay River, along with “some children, especially orphans and those from destitute native families in the delta area” (Anglican Church of Canada 2008:n.pag.). Inuviialuit children did not have to leave their families until the residential school at Shingle Point opened in 1929 after the Federal-Order-in-Council transferred administration of “Eskimos” (Inuit) to the Commissioner of the NWT (Anglican Church of Canada 2008:n.pag.).

By 1936, All Saints in Aklavik was responsible for First Nation and Inuit children, taking transfers from Shingle Point and Hay River schools, which soon closed. All Saints continued as a school until 1952 when the Federal Day School (eventually renamed Moose Kerr School) was opened in Aklavik. However, while some White children remained living at home with their families, All Saints continued as a hostel for Indigenous children from all around the delta until it was closed in 1959. After 1959, some Gwich’in children were relocated to Fleming Hall, the Anglican hostel in Ft. McPherson (Anglican Church of Canada 2008). Well into the 1990s, many of Aklavik’s Indigenous children lived at Stringer Hall.
(Anglican) or Grollier Hall (Roman Catholic) in Inuvik while attending Sir Alexander Mackenzie Day School or Samuel Hearne High School for grades 10 through 12. Stringer Hall housed Inuit, First Nations, and some Métis and White children; while Grollier housed mostly Inuvialuit children (Illasiak 2012).

As occurred in many residential schools in Canada, there are reports of physical, psychological, and sexual abuse, which has profoundly negatively affected several Aklavik residents and their families. According to locals, as soon as the nursing staff in Aklavik heard about abuse by one teacher, that employee was fired, left the community, and committed suicide shortly thereafter (Cooper 2010:50). However in 2002, 28 former Grollier Hall students from Inuvik received a historic out of court settlement in a large lawsuit accusing four hostel staff of repeated sexual and physical abuse. One of the four accused was convicted on numerous charges and sentenced to ten years imprisonment (Struzik 2002).

In my interviews with several Aklavik residents aged 40 and older, residential school is often identified as a continuing source of pain that still affects school survivors and their families today. In residents’ stories, there is evidence of perpetuated psycho-social stress that spans multiple generations and is exacerbating a number of contemporary health and social problems including alcoholism, depression, under-utilization of healthcare services, poor nutrition, and chronic diseases.
Two Gwich’in sisters told me of their younger sibling’s attempt to escape from residential school in Inuvik, which is over 70 kilometers away on foot through winding rivers, lakes, and marshes. One Inuvialuit man remembers that teachers and missionaries attempted to control every aspect of students’ lives, including their daily schedule, prayer, language, and what they could eat. Several blame residential schooling for interrupting the normal processes of childrearing which prepare a person for how to live properly in a family, have a healthy relationship with a spouse, survive rough winters, and take care of one’s parents as they age. For that reason, many see residential school as having collectively damaged all former students and their families, although to different degrees.

Several Aklavik youth who have heard these stories from their older relatives have become frustrated with their own experiences attending public school today, as they are continually told they should be grateful that things are better nowadays. This is one example of how discourses focusing on past colonialism neglect to recognize the ways ongoing (neo)colonialism affects contemporary society and health in subtle, deeply embedded ways (Wexler 2009:2).

In the 1950s and 1960s, several indicators reveal the health effects of socio-economic, political, and cultural segregation that had marked Aklavik since the 1920s. Epidemic diseases continued to emerge in Aklavik (and other northern settlements) that served as major trading centres, often transported along waterways (Waldram, Herring & Young 2006). However, while influenza
epidemics continued to reappear from the 1920s to 1940s, these gradually gave way to tuberculosis (Table 2.1). The role of the churches, mission schools, mission hospitals, and the beginnings of a welfare policy toward Indigenous peoples contributed to Indigenous health in complex, nuanced, and at times, contradictory ways.

**Table 2.1: Major epidemics in Aklavik in the 20th century.**

<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1928</td>
<td>Influenza epidemic in Aklavik and across the Mackenzie Delta was spread by the ship SS Distributor</td>
</tr>
<tr>
<td>1945</td>
<td>Major tuberculosis epidemic throughout the Mackenzie Delta region. Aklavik’s hospital filled to capacity. Many people were sent to the Charles Camsell sanatorium in Edmonton. Many died in Edmonton and family back home do not know where they are buried</td>
</tr>
<tr>
<td>1949</td>
<td>Influenza outbreak in Aklavik</td>
</tr>
<tr>
<td>1949</td>
<td>Influenza and chicken pox epidemic in Aklavik</td>
</tr>
<tr>
<td>1950</td>
<td>Measles epidemic in Aklavik</td>
</tr>
<tr>
<td>1950</td>
<td>Aklavik’s hospital expanded to house more tuberculosis patients</td>
</tr>
<tr>
<td>1952</td>
<td>Aklavik’s hospital again expanded to house 130 patients</td>
</tr>
<tr>
<td>1952</td>
<td>Federal government’s Indian Health Services provides a second physician to work in Aklavik’s hospital</td>
</tr>
</tbody>
</table>

(Campbell & Benyk 1987; Piper 2009).

For example, the influx of various Indigenous families into settlements like Aklavik exposed many Mackenzie Delta people to influenza, measles, chicken
pox, and tuberculosis; however it was only in these settlements that people could be diagnosed and treated for a variety of other ailments, such as otitis media (middle ear infection) and tooth decay and abscess. Through schools and mission hospitals (which may not have been recognized as separate institutions because they were staffed by the same people, like Dr. Urquhart), children received important immunizations, but many were also taken further away from their families to tuberculosis sanatoria in the south. Many of these children died while in Edmonton, and their families back home do not know where they are buried (Stewart 2012). This happened throughout the Delta, and across the North American Arctic (see Grygier 1994; Fortuine 2005; Cowall 2012).

Health is not only a physiological condition brought on by life events, but a means by which people are better or less able to make a living (Kiefer 2006). Krech III (1978) posits that periods of epidemic disease and starvation in the 1800s played significant roles in shaping the social organization of northern Athapaskans prior to European contact. Zaslow (1984) argues that the increasing prevalence of tuberculosis and other epidemic diseases in the 1930s combined with decreasing animal availability, dropping fur prices, and periods of hunger and malnutrition created what today could be recognized as a syndemic crisis (Herring & Sattenspiel 2007; Singer 2009), in which multiple social, environmental, and health conditions interact synergistically to compound deleterious health effects. Stephens (2009a, 2009b) has created the term psychosyndemic to refer to the intergenerational psycho-social trauma of
colonization against Indigenous peoples, which continues to influence contemporary Indigenous health. The fact that Aklavik was segregated into a world for Whites and a world for Indigenous peoples directly contributed to the social inequities that persist today. But the people of Aklavik have not given up, a community-wide attitude that makes Aklavik a place of survival and resilience.

2.3.3 The people who “Never Say DIE!”

Dickerson (1992) describes a shift in federal policies toward the Canadian North away from keeping Indigenous peoples out of the mainstream toward actively developing the region and its inhabitants. However, this shift in federal policies did not correspond to any major changes in the colonial process. Many of the programs and services aimed at Indigenous communities in the 1950s and 1960s were still devised by non-native people in Yellowknife or Ottawa, continued to be based on social and economic structures developed in the south, and took a top-down approach to program delivery. Little to no input was requested from local northern communities. The different value systems of northern Indigenous cultures, many of which emphasize community well-being over individualism, and stewardship over the lands and waters rather than ownership, were largely ignored. During this period when the Canadian government wanted Indigenous peoples to assimilate, Aklavik became the community that will “Never say DIE!” More than just a saying, this motto was adopted for the Aklavik *H. pylori* Project, and deserves discussion here.
“Never Say DIE!” captures more than just the refusal of some families to be relocated by the government. Aklavik has always been prone to flooding after spring break up. This became a serious issue mid-century when the settlement, nestled as it is in a sharp and narrow bend in the rushing Peel River, was crowded with 1,600 residents trying to manage with an inefficient and failing sanitation system (Anglican Church of Canada 2008). Furthermore, national eyes were beginning to look far more critically at the North in mid-century. U.S. military presence in northern Alaska and Canada as a response to the perceived threat of invasion during World War II, and increasing paranoia as the Cold War took hold of the worlds’ governments, prompted Canada to beef up military and police presence in the western Arctic. Largely in response to increased U.S. military presence in the Yukon and NWT, Canada was suddenly faced with criticism in domestic and international media (Bonesteel 2006). So, while Aklavik has always been prone to seasonal flooding, the attempt to move the whole community came at a point not only when the local population was at an all-time high, but when the Canadian federal and territorial governments began to face international scrutiny for their treatment of Indigenous peoples (Dickerson 1992; McFadyen

Figure 2.3: Aklavik’s hamlet flag, depicting a book and a muskrat. The official motto “Never Say DIE!” appears at the bottom (Legislative Assembly of the NWT 2010).
In the early 1950s, the territorial government urged people to relocate to Inuvik. This new town was applauded in domestic, national, and international circles for providing innovative solutions to common structural problems that had long plagued colonial settlements in the North, particularly for the development of the “utilidors” that act as an above-ground sewage system. Keeping the utilidor pipes above ground makes them easier to access for service and resists the freezing that would occur if pipes were laid underground just above the permafrost. During the late 1950s and 1960s, many families and individuals did leave Aklavik for Inuvik. The government promised jobs and houses to all who would relocate (Stewart 2012).

Aklavik has always been a multi-local place, meaning it has been imagined and re-imagined by different peoples, including its Indigenous and European-descended founders. Scholarly and government discourses have long contributed to these imaginations, and research historically has been embedded within colonial and assimilative projects there. Two examples include Dr. Urquhart’s perspectives on educating Natives in the 1930s, which was used to inform territorial policy, and the survey research of the 1950s for the purposes of

5 Inuvik was originally was called “E-3” meaning “East 3” because it was the third of six sites along the Mackenzie River that surveyors had explored as possible locations for a new regional administrative centre. In the Aklavik Journal, a newspaper that ran between 1955-1957, “E-3” was sometimes referred to as “New Aklavik” (Brown 1996), but that name was not well-received by the residents of the original Aklavik. Furthermore, it is a confusing name, because Pokiak is often referred to as “Old Aklavik.” “Inuvik” in English means “place of” (vik) “the people” (Inu from Inuit).
relocating Aklavik’s populace to an entirely new town built by the government. Another researcher, who came to in the 1950s, had different things to say about Aklavik during the government’s relocation campaign. Arnold James “Moose” Kerr, for whom the current school in Aklavik is named, is one of those who stayed behind. Kerr was a Euro-Canadian, and originally from Edmonton, but had lived in the North working in lumber camps in the summers and was interested in learning as much as he could about the many Indigenous groups that lived in the NWT. “Moose” Kerr had completed a master’s thesis in Cree food use behaviors for the Department of Anthropology at the University of Toronto, and wanted to do further social anthropological research in the NWT in the early 1950s, but also needed a job to support his wife and twin girls. Thus, in 1952, Kerr took the opportunity to move with his family to Aklavik to take a teaching position at the new Federal Day School. By the time Kerr arrived in Aklavik, he found the settlement to be a “polyglot community of Inuvialuit and Gwich’in,” some of whom “were the descendants of, or married to, men from all around the world – Scandinavians, Germans, Americans, Hawai’ians, and Scots” (Usher & Brody 2010:121-122). The Kerrs lived in Aklavik for 12 years, staying long after Aklavik successfully resisted the government’s attempt to relocate the community. Although locally he is remembered more as a teacher, church-goer, and family man rather than an anthropologist, Kerr contributed to a re-imagining of Aklavik as a place of strength, resilience, and resistance.
Kerr is credited in local history as the first person to coin the phrase “Never Say DIE!”, which was popularized and quickly adopted as Aklavik’s community motto. This motto served as a rallying cry in which local residents organized together to “[defy] an order to die” – a cry that echoed as far away as the New York Times (Waltz 1966). “Never Say DIE!” contributes to a radical (re)imagining of Aklavik as a place where Indigenous residents, and not the government, decide what is best for themselves. “Never say DIE!” reflects Aklavikers’ desires to stay in their home settlement no matter what, “come Hell or high water, and even after that!” as one resident told me after a community flood emergency preparedness meeting in the spring of 2012. As Cooper (2010:3) points out, Aklavik’s “refusal to die” was not a new idea in the late 1950s, but rather crystallized a long-standing tradition of local families determined to decide how

**Figure 2.4:** Aklavik’s motto “Never Say DIE!” is displayed on the sign to Moose Kerr School.

(Photo by Carraher, 2011).
and when to use social and health services provided first by the missions and later by the government.

Important changes in healthcare infrastructure and policy also occurred in the Mackenzie Delta during the 1950s and 1960s. Many Indian hospitals and sanatoria were closed in the 1960s, while throughout the 1970s, the number of nursing stations and community health centers drastically increased (Waldram, Herring & Young 2006). Tuberculosis continued to be a major problem, although large influenza outbreaks were relegated to memory. The refusal to move to Inuvik meant that Aklavikers lost some access to health services to which Indigenous residents only recently had officially gained legal rights. In 1945, the Department of National Health and Welfare took over healthcare provisions for all First Nations and Inuit, establishing the Northern Health Services to serve all residents of the northern territories, Indigenous and non-Indigenous (Young 2008:49). However, the hospitals at Aklavik were closed and replaced by Inuvik Regional Hospital, to which people must now travel by boat or plane in the summer, or by ice road in the winter. Although the move of resources and services to Inuvik can be seen as a significant limiting factor in peoples’ abilities to access health care, Aklavik’s residents have traditionally engaged in “acts of resistance and acts of agency as they chose when to travel to Aklavik, when to travel to Inuvik, and when to stay in their homes on the Land” (Cooper 2010:101).
2.4 Contemporary Aklavik: 1970s to 2012

If the early 1900s in Aklavik can be described as a time of little outside concern in getting involved with Indigenous peoples (beyond trading for furs), the 1970s should be described as a period of intensifying interest in observing, documenting, and engaging with Indigenous communities and governments. Increasing research in the 1970s coincides with several critical politico-economic changes in Aklavik and the NWT. In the 1970s, the Canadian North gained renewed and expanded interest from southerners, resulting in tensions between traditional land-based economic activities such as the fur trade and modern national and international industrial developers that had awakened to the potential for oil and gas exploration in the Arctic. Diamond, gold, and uranium mining have also been renewed from early “Rush” days into large multi-national corporate industries – powerful industries increasingly confronted by Indigenous communities and governments demanding consultation, cooperation, and adherence to Indigenous priorities for development. During the Mackenzie Valley Pipeline Inquiry, Aklavik resident Charlie Furlong, who has served a Director for the Métis Nation and later President of the Mackenzie Delta Regional Council (now called the Gwich’in Tribal Council), demonstrated how vast regional projects would likely affect Aklavik’s people:

...I would like to speak to you today on behalf of my people. The people are not ready for land development. By people, I mean the Indians, Eskimo and the Métis. The oil companies want to build a pipeline down the Northwest Territories. They want to take our gas, our oil. We will not even use our gas. It will go past our
homes, our communities, to heat southern Canada and our big brother, the United States of America...

...White men will come from the south to build the pipeline, and again white men will come into the communities, take our daughters, our wives...

...I would like to see a land settlement between the Government and the people of the Northwest Territories, a land settlement where the native people will control their land and development (in Smith 1977:222-223).

The Gwich’in and Inuvialuit eventually secured land claim settlements with the Canadian government, granting each group specific rights in exchange for giving up exclusive ownership of lands and resources on and under lands. What became the Inuvialuit Final Agreement (IFA) is the result of 10 years of negotiations between the Canadian government and Inuvialuit people spearheaded by a group of Elders and youth established the Committee for the Original People's Entitlement (COPE). On 5 June 1984, the Canadian government and the Inuvialuit signed the IFA, making this the first comprehensive land claim agreement signed in the Arctic and only the second in Canada.

In the IFA, the Inuvialuit agreed to give up their exclusive use of their ancestral lands in exchange for certain other guaranteed rights from Canada: land; wildlife management; and money (Inuvialuit Regional Corporation 2007). Although no specific provisions are outlined regarding healthcare services, as all citizens and permanent residents of Canada today have universal health coverage, IFA annual reports do frequently reference community-based health and socio-economic projects that will “ensure long-term benefits to the health of the Inuit”.

54
In 2003, the Inuvialuit Regional Corporation (IRC) directed a range of “Inuit-specific” research within broader Indigenous programs including in the health field (IRC 2004:9). Land settlement came soon after for Dene. In 1975, the Dene had published the “Dene Declaration” asserting their identity as a sovereign nation of people whose rights to traditional lands, self-determination, and special status should be recognized by the Canadian territorial and federal governments and the Canadian constitution. In 1987, the Gwich’in Settlement Area (GSA) was recognized by Canada, and Aklavik sits upon its northern border. The Gwich’in Comprehensive Land Claim Agreement (GCLCA) does assert a right to negotiate in the future regarding self-government of health services provided in the GSA (Gwich’in Tribal Council 1992).

In many important ways, the current situation of healthcare services and accessibility in Aklavik, a place that sits on the border of two Indigenous land claim settlements, represents a significant move toward Indigenous self-determination and governance. In other ways, healthcare services and resources still reflect social and political structures left over from the days when Aklavik was home to “two worlds”, one for Indigenous peoples, and one for Whites.

In 1926, the Roman Catholic and Anglican Churches opened two hospitals in Aklavik. These provided care for all patients from in and around Aklavik (White, status Indian, Inuit, and Métis), and reflect the intimate relationship between medicine and Christianity that characterizes the earliest form of Canadian
health care for Indigenous peoples (Waldram, Herring & Young 2006), a relationship that persists in some ways with the current healthcare system. The Susie Husky Health Centre, the nursing station established in Aklavik in 2002, currently employs three local residents as Home Support Workers and one as the Community Health Representative. However, in large part due to a lack of Indigenous people entering and completing medical training, the nursing staff are all outsiders and are all non-Indigenous. The Susie Husky Health Centre is a government-funded institution, but a relationship between Church and medicine persists. This relationship means different things to those providing and those receiving care. Cooper interviewed numerous Aklavik seniors who all self-identify as Christians and found that for many Indigenous residents:

“Church was centered within social relations, rather than dogmatic beliefs. People participated in mass and services as it provided an opportunity for interacting with other community members and seeing friends they might not have seen for a long time” (2010:43).

From my experiences attending Church in Aklavik, it is evident that services fill an important social role. However, while most residents identify as Christians, regular church attendance and adherence to Church dogma is not typically viewed as important as prayer, which can be done anywhere. Interestingly, there is a sign taped to the inner doors to the All Saints Anglican Church today, which reads:

ALL SAINT’S ANGLICAN CHURCH, AKLAVIK

WE ARE A HOSPITAL FOR SINNERS. ALL ARE WELCOME TO SEEK HEALING HERE.
Posted by a nurse who is an active member of the congregation, the sign represents one end of a spectrum where Christian concepts of morality and health are juxtaposed against immorality and illness. The role of the hospital and of the Church are considered in varied (but not always opposing) ways through an Indigenized Christian lens, in which biomedicine is accessed for bodily sickness, while poor Church attendance is not seen as jeopardizing spiritual health.

### 2.5 Contemporary health in Aklavik

It is evident that the Indigenous peoples in Aklavik do not represent a static or homogenous group of people (Table 2.3). Non-Indigenous residents still are the most transient subpopulation (Table 2.4) and still take most of the high-paying employment opportunities.

#### Table 2.2: Aklavik population and ethnicity, 2001-2012.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Indig.</th>
<th>Inuit</th>
<th>First Nat.</th>
<th>Métis</th>
<th>Non-abor.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>505</td>
<td>450</td>
<td>375</td>
<td>140</td>
<td>35</td>
<td>55</td>
</tr>
<tr>
<td>2006</td>
<td>585</td>
<td>545</td>
<td>350</td>
<td>180</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td>2011</td>
<td>655</td>
<td>583</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>72</td>
</tr>
<tr>
<td>2012(^1)</td>
<td>625</td>
<td>569</td>
<td>390</td>
<td>162</td>
<td>17</td>
<td>49</td>
</tr>
</tbody>
</table>

\(^1\)Estimates taken from the Spring 2012 Flood List, maintained by the Nurse-in-Charge at Aklavik.

-- Indicates data are not available for that year.

Table 2.3: Persons in community for less than 1 year (%); and less than 5 years (%).

<table>
<thead>
<tr>
<th></th>
<th>Less than 1 year</th>
<th>Less than 5 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Indigenous NWT</td>
<td>7.9 6.8 5.4</td>
<td>18.0 16.4 15.0</td>
</tr>
<tr>
<td>Indigenous Beaufort Delta</td>
<td>7.9 7.5 5.0</td>
<td>17.7 14.9 13.2</td>
</tr>
<tr>
<td>Non-Indigenous NWT</td>
<td>12.7 11.5 9.7</td>
<td>39.1 33.2 33.0</td>
</tr>
<tr>
<td>Non-Indigenous Beaufort Delta</td>
<td>22.3 19.1 16.5</td>
<td>54.8 50.2 45.8</td>
</tr>
</tbody>
</table>

(Compiled from Statistics NWT Data Portal).

For some scientific indicators of health, the NWT statistics reflect patterns similar to Nunavut, the eastern Arctic Canadian territory with the largest Indigenous population (over 80%). For other health indicators, the NWT reflects patterns more similar to southern Canada. For example in the early 2000s, while the NWT had the second-highest regional rate of tuberculosis incidence (21.1 cases per 100,000 people per decade) after Nunavut, the NWT simultaneously displayed an age-standardized prevalence of diabetes (4% of the population) that more closely approximates the Canadian national average (4.8%) (Table 2.5).

The idea that Aklavik society and health are in the process of changing is discussed by local Indigenous and non-Indigenous residents. There is a perception that illnesses, in general, have increased following the shift from a seasonally-mediated, subsistence-based lifestyle to living in a sedentary settlement with a mixed cash and subsistence-based economy. As one Gwich’in woman put it:

“I remember, like when I was growing up, I knew of like, only one person that had diabetes. But like I said before, we didn’t know..."
Ph.D. Thesis – S. Carraher, McMaster University -The Anthropology of Health

what was that illness. We were just told that people were sick, and that’s all. And didn’t know what they had. But you know we never, uh, I think diabetes is new. It’s just new, like new information. Because like, when I was growing up too, we didn’t know anything about any illnesses. Because we were active. We were living on the Land. We didn’t live in town.”

Table 2.4: Selected health indicators for northern territories compared to Canadian national averages.

<table>
<thead>
<tr>
<th>Health Indicator</th>
<th>Yukon</th>
<th>NWT</th>
<th>Nunavut</th>
<th>Canada</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life expectancy (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>75.0</td>
<td>73.7</td>
<td>66.6</td>
<td>77.1</td>
</tr>
<tr>
<td>Female</td>
<td>80.5</td>
<td>78.1</td>
<td>70.0</td>
<td>82.1</td>
</tr>
<tr>
<td>Diabetes (age-standardized prevalence %)</td>
<td>3.8</td>
<td>4.0</td>
<td>1.3</td>
<td>4.8</td>
</tr>
<tr>
<td>ASMR ischemic heart disease</td>
<td>117.3</td>
<td>95.9</td>
<td>79.7</td>
<td>111.2</td>
</tr>
<tr>
<td>ASMR stroke</td>
<td>61.9</td>
<td>76.2</td>
<td>111.7</td>
<td>48.7</td>
</tr>
<tr>
<td>Age-standardized prevalence of overweight/obesity</td>
<td>50.5</td>
<td>53.7</td>
<td>48.6</td>
<td>48.2</td>
</tr>
<tr>
<td>Age-standardized incidence all primary cancers (per 100,000)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>324.1</td>
<td>339.4</td>
<td>359.6</td>
<td>456.2</td>
</tr>
<tr>
<td>Female</td>
<td>297.1</td>
<td>323.4</td>
<td>500.3</td>
<td>347.9</td>
</tr>
</tbody>
</table>

(Young 2008:47).

From her observation, it seems that the transition to living in town year-around triggered an increase in diabetes, and several other diseases, in a double-way: coming off the land “into town” both caused an absolute increase in “Western” diseases, and increased Indigenous peoples’ awareness of Western classifications for different diseases (see Table 2.5).
Table 2.5: Selected health and social indicators for Aklavik compared to NWT averages.

<table>
<thead>
<tr>
<th>Indicator</th>
<th>NWT</th>
<th>Aklavik</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Population that smokes tobacco (2009)</td>
<td>35.2</td>
<td>60.1</td>
</tr>
<tr>
<td>% Population reporting hunting and fishing (2008)</td>
<td>39.4</td>
<td>53.7</td>
</tr>
<tr>
<td>% Population reporting trapping (2008)</td>
<td>6.2</td>
<td>18.3</td>
</tr>
<tr>
<td>% Households consuming country meat (half or more of reported meat consumption) (2008)</td>
<td>28.1</td>
<td>51.3</td>
</tr>
<tr>
<td>% Population receiving income assistance (2010)</td>
<td>5.3</td>
<td>21.6</td>
</tr>
<tr>
<td>% Households with 6 or more people (2009)</td>
<td>6.7</td>
<td>7.0</td>
</tr>
<tr>
<td>% Unemployment (2009)</td>
<td>10.3</td>
<td>32.3</td>
</tr>
</tbody>
</table>

(Statistics Canada 2007).

2.6 Locating cancer and \textit{H. pylori} infection

When I asked one of the health centre staff what she thinks are the biggest health issues in Aklavik today, she told me:

"Cancer is the biggest. Biggest one right now. One year, I say we had about seven funerals just from people dying from cancer."

In small communities where everyone knows everyone, a single death can exact a heavy social toll. In the last decade, nearly one quarter of all deaths in Aklavik are due to cancer (22.1/1,000 people per decade), making it the number-one killer over even cardiovascular and respiratory diseases (Table 2.6). Cancer rates are perceived as rising by the majority of Aklavik’s residents, and the local
fears of cancer should not be divorced from any discussion of *H. pylori* infection there. Indeed, the Aklavik *H. pylori* project was a response to address urgent community concerns that were voiced in 2004, first to local, and shortly thereafter, to territorial health officials over a perceived local epidemic of stomach cancer (Archie 2012; Goodman 2012; Munday 2012). This urgency felt by Aklavik residents is occasionally rekindled, as it was in the late summer of 2011, when three community members died of cancer in rapid succession. The first was an Inuvialuit man who had participated in the initial AHPP *H. pylori* breath test (UBT) component in 2008. Prior to this, the Aklavik nursing staff knew he often complained of stomach pains and because of this considered he would particularly benefit from being involved with the AHPP research. However, as a traveling oil company worker, he was absent during the AHPP endoscopy component. Outside of the research project, the man traveled to Inuvik and to Edmonton, and underwent four gastroscopic examinations in his search for a diagnosis. Signs of stomach cancer were only found in 2009 during the fourth and final scope. He, his wife, and their children continued to participate in AHPP research activities, even while he was recovering from radiation therapy. In 2010, the man submitted another UBT to the AHPP, which came back with an inconclusive result. He died and was buried in August, 2011, just weeks before my arrival at the community to begin research.
Table 2.6: All-cause mortality in Aklavik, 1 Jan., 2002 - 31 Dec., 2012.

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>Total</th>
<th>%</th>
<th>Rate per 1,000 per decade</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancers</td>
<td>14</td>
<td>21.5</td>
<td>22.1</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Cardiovascular Diseases</td>
<td>13</td>
<td>20.0</td>
<td>20.5</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Respiratory Diseases</td>
<td>10</td>
<td>15.4</td>
<td>15.8</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Unintentional Injuries</td>
<td>9</td>
<td>13.8</td>
<td>14.2</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Alcohol-Related Diseases</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Intentional Injuries</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Renal Failure</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Dementias</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Neo-Natal Deaths</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Subdural Hematoma</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>No Cause Recorded</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td><strong>Total Deaths</strong></td>
<td><strong>65</strong></td>
<td><strong>100%</strong></td>
<td>--</td>
<td><strong>44</strong></td>
<td><strong>21</strong></td>
</tr>
</tbody>
</table>

1 Excludes lung cancer; 2 Includes CO poisoning, fire, drowning, motor-vehicle collision; 3 Excludes liver cancer; 4 Includes suicide and homicide.

* mortality rate was calculated per 1,000 people per decade using mid-decade population estimate (n=633 in 2008).

-- GNWT suppresses data reporting when there are fewer than 5 cases from a single settlement in a given time period.

(Munday 2012).
One month later, two more community members died from cancer on the same
day (albeit not stomach cancer). On our way back to town after berry picking in
the Bush with some residents in September, 2011, we passed one of three
cemeteries in Aklavik. This cemetery contains all the recent burials from the last
few years. Two sisters invited me to join them in the cemetery to see the grave
markers of their relatives. The elder sister showed me the row of markers for the
most recent deaths, and pointed out all of the graves with people who passed away
from cancer. She pointed to the marker of the man who died of stomach cancer
just before I arrived in Aklavik, and told me a story about him and his family. She
told me my being in Aklavik was very important, and that I should stay as long as
I can, so I can learn. I have learned that cancer, a disease that further disrupts
families and makes it difficult to engage in important cultural activities within the
settlement as well as on the land, is the number-one health concern people have
regarding *H. pylori*.

Like earlier epidemics of tuberculosis and influenza, many of Aklavik’s
Indigenous residents perceive cancer as having come to Aklavik from the south
and they perceive cancer as being directly linked to historical and ongoing
development projects in the Arctic, which are introduced and largely controlled by
non-Indigenous outsiders (see Chapter 5).

Aklavik has a reputation (both within and outside of the community) for
having a lot of cancer. As Ruth Stewart told me one day:
“My brother [from Ft. McPherson] says he won’t come to Aklavik because he’s scared to get cancer. There’s so much cancers in Aklavik.”

Residents of Aklavik also perceive that stomach cancer is much more of a problem in their community than it is for the rest of Canadian society. In July, 2012, a new case of stomach cancer was diagnosed in an Aklavik resident, bringing the total of new stomach cancers cases in the last decade up to seven. It is difficult to draw conclusions based on statistics from small populations. However, the rate of stomach cancer diagnoses is three times higher in the NWT than the national Canadian average (Goodman, Jacobson, & van Zanten 2008).

Several residents believe stomach cancer has been present for a long time in Aklavik, but that it is also on the rise. Two Gwich’in women I interviewed, both in their late 40s, told me they are concerned they are at increased risk of getting stomach cancer, because they each have grandparents who are said to have died of stomach cancer when they were very young. Less than two months after our interview, one of them was diagnosed with stomach cancer and has been undergoing aggressive treatment. While writing this dissertation, another individual in Aklavik was been diagnosed with stomach cancer, bringing the incidence up to three new cases between 2009 and 2013. As one of Aklavik’s stomach cancer patients explained to me:

“H. pylori is a life or death situation for me, for this community”
2.7 Summary

This chapter situates *H. pylori* infection within local experiences with cancer more broadly, which currently is responsible for a quarter of all deaths in Aklavik, making cancer the number-one cause of mortality. The introduction of colonial institutions including residential schooling, missions, a cash-based economy and government welfare, and a biomedically-based healthcare system, are major components of Aklavik’s history and its contemporary cultural identity. These institutions are interconnected and have shaped the physical and social structure of Aklavik. These changes coincide with changes in health trends over the last 100 years, from an epidemiological profile punctuated by influenza and tuberculosis epidemics, to the rise of cancer and other chronic diseases. Local experiences with and perceptions of cancer cannot be understood without attending to the historical influence of these institutions, a point I unpack and theorize more fully in Chapter 5.

I address the important issue of how Indigenous health is written about (usually by outsiders) to draw more clearly the relationships between researchers, government, colonialism, social inequities, and health. In so doing, this chapter describes Aklavik as a “field site” where there is an ongoing relationship between researchers and other institutions introduced during early colonialism. In response to that history, the AHPP was developed as a “community-driven” research program incorporating policy recommendations, community education and data sharing, local consultation, and local capacity building. This project was initiated
on behalf of residents and born out of collaboration with local Indigenous organizations and individuals, a fact that represents more recent changes toward Indigenous self-determination in governance as well as research. Chapter 3 builds on this context to describe the methods used for my own research within the AHPP.
Chapter 3: Methods

3.1 Legacies of colonizing research

Aklavik today is a diverse, multi-cultural community with an Indigenous population that varies ethnically and economically. The community that stands in the place where people “Never Say DIE!” has been built out of approximately a century of colonialism in the Mackenzie Delta. Initially, the colonizing process was directed largely by missionaries. Throughout much of the twentieth century, there was an attempt to assimilate Indigenous peoples by introducing residential schooling and enticing people to settle permanently in government-provided housing. In some ways, this increased Indigenous access to biomedicine and other resources available only in settlements. However, as interviews with Aklavik seniors reveal, families felt coerced, even forced, to live in town. The normal Indigenous ways of teaching children to live on the land in harmony with the seasons were disrupted, leading to a perceived loss of culture. Outsiders, including fur traders, missionaries, physicians, and scientific researchers, have contributed to colonization in Aklavik – as education, housing, welfare, and healthcare policies enacted in Aklavik were based on outsider’s reports written about Mackenzie Delta Natives. Since the 1970s, more and more people have come to see and write about Aklavik, and Indigenous residents have started demanding consultation, accountability, and participation in research conducted on their lands, waters, animals, and their own peoples.
**Table 3.1:** Number of research projects in Aklavik licensed by the NWT, 1974-2010.

<table>
<thead>
<tr>
<th>Year</th>
<th>Human health</th>
<th>Climate change/geology</th>
<th>Wildlife</th>
<th>Water/snow/ice</th>
<th>Social science</th>
<th>Tech./nat. res.</th>
<th>Gov. research</th>
<th>Uni. research</th>
<th>Corp. research</th>
<th>Research by Indigenous groups</th>
<th>Total projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1974-1980</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>13</td>
</tr>
<tr>
<td>1981-1985</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>10</td>
<td>0</td>
<td>8</td>
<td>1</td>
<td>1</td>
<td>24</td>
</tr>
<tr>
<td>1986-1990</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>1991-1995</td>
<td>1</td>
<td>9</td>
<td>10</td>
<td>4</td>
<td>11</td>
<td>1</td>
<td>36</td>
<td>17</td>
<td>10</td>
<td>1</td>
<td>83</td>
</tr>
<tr>
<td>1996-2000</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>9</td>
<td>1</td>
<td>5</td>
<td>0</td>
<td>23</td>
</tr>
<tr>
<td>2001-2005</td>
<td>0</td>
<td>6</td>
<td>6</td>
<td>0</td>
<td>6</td>
<td>4</td>
<td>22</td>
<td>5</td>
<td>6</td>
<td>9</td>
<td>22</td>
</tr>
<tr>
<td>2006-2010</td>
<td>16</td>
<td>14</td>
<td>10</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>51</td>
<td>14</td>
<td>21</td>
<td>6</td>
<td>130</td>
</tr>
</tbody>
</table>

*Total* | 19 | 31 | 31 | 10 | 31 | 12 | 134 | 37 | 52 | 17 | 24 | 130 |

x indicates data are not available for that year (compiled from www.data.nwtresearch.com/community/13).

In the late twentieth century, amidst the formation of Indigenous land claims and political organizing, Aklavik began to be increasingly researched (Table 3.1). In 1974, the Government of the Northwest Territories (GNWT) began issuing research licenses for all projects conducted in the Territories. Although the total number of projects fluctuates from year to year, there has been a steadily increasing number of studies over the last four decades. More than ever, researchers make up a significant component of the transient
population of Aklavik, and scholarly imaginations of Aklavik are increasingly being disseminated across disciplines and nations. In 1984, the Legislative Assembly of the Northwest Territories (LANWT) created the Science Institute of the Northwest Territories, which was divided geographically in 1995, and merged with Arctic College in Nunavut and Aurora College in the NWT. Now known as the Aurora Research Institute (ARI), this division of Aurora College is a research center that reviews proposals, grants territorial research licenses under the Scientists Act (1988), and facilitates communication between researchers, Indigenous offices, and local communities (ARI 2012). The nearest office to Aklavik is in Inuvik.

While substantial changes to research planning and activities have been made over the last few decades, there are still several barriers to developing participatory and community-based research projects in the NWT. Increasingly since the 1970s, studies report utilizing community-engagement and participatory approaches, which reflects changing attitudes within Indigenous and northern research. However, often such projects are still embedded in hierarchal power structures inherited from early colonial institutions, including governments and universities. In fact, government- and university-sponsored research continue to predominate in Aklavik, although the number of corporation-sponsored studies and studies conducted by Indigenous bodies are also on the rise. Technology and natural resource development studies are primarily conducted by corporations, while social science projects are increasingly being conducted by Indigenous governments and organizations. Still, universities and the territorial and
federal government continue to lead research in the NWT, both in the number of studies and total funding.

Human health research in Aklavik has increased dramatically from 2006 to 2010, with 10 university-affiliated projects (including the AHPP) and 6 government-affiliated projects, for a total of 16 projects. In the period 1991-1995, Aklavik began to see research projects initiated and conducted by Indigenous bodies, such as the Inuvialuit Cultural Resource Centre, the Gwich’in Tribal Council, and The Gwich’in Renewable Resource Board. These Indigenous-sponsored studies focus on climate change/geology, wildlife, water, and social science (Table 3.1). It will be interesting to see how Aklavik is written in the future by people who have different relationships to it, i.e. when more is written by its own residents. Ideally, projects increasingly will be initiated and run by local and Indigenous researchers, although it would be naïve to expect that their work will be free of notions inherited from the long history of descriptions written by outsiders.

For my own work, I situate the AHPP within the broader, deeper history of research in Aklavik; and reflect critically on how *H. pylori* infection is known and imagined by the many different individuals and groups that have been brought into contact through this research program. I was able to explore these varied modes of risk-knowledge production through a mixed methods approach that combines three distinct, but interrelated, studies within the Aklavik *H. pylori* Project.

### 3.2: Decolonizing methodologies
To explore the cultural context of *H. pylori* bacterial infection and different understandings of risk in this diverse Indigenous community, I draw on emerging post-colonial/anti-colonial perspectives in anthropology and public health – growing bodies of theory that see collaboration with Indigenous communities as vital to the decolonizing process (Browne, Smye & Varcoe 2005; Kelm 2010). Community-based and participatory approaches to Indigenous health research are an important step in decolonizing research methodologies (Smith 1999) because the appointment of local field researchers purposefully blurs the line between researcher and the researched (Lantz, Israel, Schultz *et al.* 2006:239). However, it can be difficult to realize these goals. The choice of research methods, which is usually constrained by Western ideologies and institutions, is an indicator of the power dynamics at work within a project. Ensuring meaningful participation and partnership, especially in community-based research, requires mitigating these power differentials so that Indigenous priorities and values are understood and respected, both politically and through the day-to-day pragmatics of research (Brown 2005; Kovach 2009). The Aklavik *H. pylori* Project (AHPP) is a *community-driven* project, meaning research was requested by the people of Aklavik; thus, the project’s goals, questions, methods, data dissemination, and publication protocols have been developed through collaboration with the Aklavik Health Committee (AHC).

The AHC is a locally-organized committee with members from the Inuvialuit government at the Aklavik Community Corporation (ACC), the Aklavik Indian Band (AIB), and other community representatives – one of whom (Billy Archie) also serves on the Board for the Institute for Circumpolar Health Research (ICHR) and the Arctic Health
Research Network (AHRN). In 2004, the AHC was reconvened by Archie, an Inuvialuit resident then serving as Aklavik’s mayor. Archie wanted the AHC to work on applied health research in response to the alarmingly high rates of *H. pylori* infection and stomach cancer occurring in Aklavik (Archie 2012; Munday 2012). The AHC meets as needed to review proposals from professionals wishing to do health research in Aklavik and strategizes about initiating research and grass-roots projects for community members\(^1\). In this way, the AHC is a resource for addressing political and pragmatic considerations in research\(^2\) (see Kovach 2009). While living in Aklavik, I met regularly with the AHC to assist in planning all phases of my fieldwork and to receive feedback on all presentations and publications generated from this work. I will continue to consult with the AHC regarding the final data dissemination and future publications from my dissertation. In my own work within the AHPP, I strove to develop collaborative and participatory approaches to doing ethnography in ways that respond to the perceived research needs of the AHC and the community more broadly.

My research methodology for working within the AHPP was developed iteratively with the AHC, following guidelines outlined in *Chapter 9: Research Involving the First Nations, Inuit, and Métis Peoples of Canada* in the second *Tri Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2). This Tri-Council Policy

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\(^1\)Recent projects include the 2007 “Dietary Choices in Aklavik: Youth and Elders Promoting Change” video study (Archie, Koe, Sempleet al. 2008) and a video study on climate as a determinant of health (ICHR 2012).

\(^2\) In fact, most communities in the NWT do not have locally-appointed health committees. Because the Aklavik *H. pylori* Project is the pilot study within the CANHelp Working Group’s larger program of research in the Canadian Arctic, each new CANHelp project involves the formation of local “planning committees” that resemble the structure and roles of the AHC. For communities within the Inuvialuit Settlement Region (ISR), there is one regional-wide planning committee that has been formed. Called the ISR planning committee, it is organized through the Inuvialuit Regional Corporation, with offices in Inuvik.
Statement was updated in 2010 to include, among other substantive changes, improved guidelines for conducting ethical research with Inuit, which have been endorsed by the Aurora Research Institute (ARI) and the Inuvialuit Regional Corporation (IRC) in the NWT. Changes in the 2010 policy that are salient to conducting research in the NWT include guidelines for obtaining and maintaining community consent to participation and publication (ICHR, NSERRC & SSHRC 2010). Historically, Western\textsuperscript{3} scientific research has concerned itself only with obtaining individual consent from participants (Smith 1999; Sunseri 2007; Kovach 2009). The amended Tri-Council policy requires that I inform Aklavik residents publically (which I did via radio, flyers, community presentations, and by word of mouth) about my research and the nature of participant observation, while always remaining conscious and respectful of individuals who decline to be interviewed, photographed, or to tell their personal stories (Appendices B and C). I have also maintained contact with key informants since leaving Aklavik, including contacting individuals to show excerpts from my dissertation drafts and, in some cases, to clarify whether certain individuals wish to be named or kept anonymous in particular manuscripts or conference presentations.

3.1.1 Data Dissemination and Community Obligations

Data dissemination and knowledge translation make up a core component of the AHPP goals (Huntington, Goodman, Munday et al. 2009; Colquhoun, Aplin, Goodman et al. 2011; Wynne, Huntington, Goodman et al. 2011), and are essential to ensuring positive

\textsuperscript{3} Referring to the family of sciences that historically emerged out of the Enlightenment Era of Western Europe, which is underpinned by Eurocentric epistemologies that embrace positivism and empiricism (see Chapter 2 in Smith 1999).
collaboration and effective communication between researchers, policy makers, health
providers, and community members involved in the CANHelp Working Group. During
my fieldwork in Aklavik, I facilitated workshops to inform residents of project progress
and results (Carraher 2011; 2012a). These events served an iterative function as well,
allowing for community feedback at each stage of my research to help shape the next
updates on my progress over the radio, compiled a large bulletin board of information on
H. pylori research in Aklavik as well as in other Arctic communities in the health centre,
and mailed out a newsletter about the project, which included a Q&A section responding
to questions I was commonly asked by individuals (Carraher 2012b; Appendix F). My
obligations to Aklavik include returning in 2013 to give a series of short community
presentations; deliver a final report on my research to the AHC; and seek AHC feedback
and approval on future abstracts and manuscripts resulting from my dissertation prior to
submitting for presentation or publication.

3.1.2 A Note on Collaboration and Participatory Methods

Positive collaboration, participatory research, and community-owned/community-
controlled research are increasingly being discussed in the literature as an ideal for which
to strive because researchers are still usually outsiders to the communities where they
work. In practice, however, these ideal situations take time to cultivate, skill to realize,
and a great deal of personal commitment to see projects through from start to finish. The
people who are privileged enough to afford to bring this time, skill, and commitment to a
project most often come from formally-educated (thus, Western) backgrounds (Reason
1994). Furthermore, the people who are most disadvantaged, and most in need of research that addresses social inequities in health, are likely to remain under-represented because they may not wish to participate in research, are not likely to initiate their own research, nor to develop or participate in their own advocacy groups or organizations (Pyett 2002).

During my research in Aklavik, some of the previous participants in the AHPP who met the eligibility criteria for inclusion in the incidence/re-infection study in 2011-2012 (Chapter 4) were unreachable due to sensitive social circumstances that included alcoholism within families, domestic abuse or sexual assault, foster care and other social work issues, court proceedings, illnesses, or recent deaths in their families. Additionally, some no longer wished to participate in the AHPP for a variety of reasons, including, for some, feelings of frustration with the management of their individual test results or treatment. It is important to continue to try to address residents’ concerns, especially in cases where people feel research activities or project-related healthcare delivery was not handled correctly or with proper respect. It is equally important to allow residents to choose to end their participation at any time – but also to ensure that the community overall is aware that the CANHelp Working Group wants to hear their feedback and is dedicated to continual evaluation and program improvement. Despite the decision by some residents to decline to take part in my doctoral research, over-all participation and interest in the AHPP remains high in Aklavik, and residents often ask me informally for project updates. This continues even when I am not in Aklavik, through social media such as Facebook™, e-mail, or long-distance phone calls.
Attempts to foster participatory research in Aklavik met with an additional obstacle. The CANHelp Working Group provided funding for me to hire an Aklavik resident as a field researcher at a wage that is competitive with entry-level union wages for office/secretarial workers in the Beaufort Delta region. I met with the AHC to determine the hiring process for the position; advertised the position through a competitive application process; interviewed six applicants; and discussed the applications with the AHC before deciding whom to hire. Only women applied for the position, typical of the employment profile of Aklavik more generally. There are more women (Indigenous and non-Indigenous) working in office-based and administrative positions than men. I hired Tammy Dawn Tyrrell, a local Inuvialuit woman with a small family who was also attending the Aurora Learning Centre (ALC) as a part-time student. Tyrrell and I worked collaboratively to decide which duties we each took responsibility for during the work week, based on our individual skills and preferences. However, as I was required to follow University of Alberta hiring practices and work protocols, my relationship with Tyrrell was hierarchical rather than horizontal. She saw me as her “boss”, no matter how much I wanted us to be equal co-workers. This disjuncture smoothed out somewhat over the course of our time working together as we became more familiar and comfortable with each other. The structural imbalance between me-as-boss and her-as-subordinate was impossible to dismantle entirely. However, in many ways Tyrrell took initiative as a local expert, particularly concerning matters of contact and communication with Aklavik residents. By observing her interactions with project participants, I learned how better to describe the research and answer people’s questions by abandoning a lot of scientific
jargon, speaking more succinctly, taking my time when speaking and always being sociable (rather than formal), and learning to anticipate the types of questions participants were likely to have about the research. At the end of our fieldwork, Tyrrell took a job at the Aklavik airport and is finishing courses at Aurora College. She is interested in pursuing social work.

3.2 Ethnography, culture, and epidemiology

The terms “ethnographic epidemiology” and “cultural epidemiology” are emerging in recent literature (see; Inhorn et al. 2009; Broom, Banwell & Gardner 2013), but I want to draw a distinction between the use of ethnographic methods of observation and data collection within epidemiological research (ethnographic epidemiology) and the place of cultural theory, particularly theory from anthropology, within health research (cultural epidemiology). As I explain below, I see a benefit to using both.

First, cultural epidemiology cannot be contained solely within epidemiology, nor solely with medical anthropology. This is because cultural epidemiology is emerging, ideally, as a truly trans-disciplinary, holistic effort. “Rather than simply adding more levels to an analysis or attempting an ‘add and stir’ approach to multidisciplinarity,” I join Julie Park and Judith Littleton in arguing for an approach that “tacks between disciplines, recognizing the different logics that underlie approaches and seeing gaps between as areas for exploration” (2013:157). The end goal is not to present a single but piece-meal explanation of \textit{H. pylori} infection and risk perceptions, but to move the ongoing work of the AHPP toward a more balanced and equitable collection of research questions and
perspectives that is as much informed by Aklavik’s local history and contemporary beliefs, behaviors, and concerns as it is by the evidence-based analyses, lab results, and scientific analyses of CANHelp researchers. To do so, I found I needed both an ethnographic epidemiological approach to data collection and a cultural epidemiological approach to analysis and theory. This approach is crucial within Indigenous health studies, for two reasons. First, much research concerned with Indigenous health is still conducted by researchers who come from different places and are unfamiliar with many facets of daily life and social organization in Indigenous settlements. This is especially true in the Arctic where most researchers continue to come from the more southern and urban regions of Canada. Second, “culture” in Indigenous health literature continues to be used problematically as a marker of perceived attitudes that prevent Indigenous peoples from choosing to live healthy lifestyles.

3.2.1 What does “culture” have to do with Indigenous health?

“Culture” is recognized as playing a major role in Indigenous health. However, the term and what it represents can be understood and operationalized differently within Indigenous health, and more broadly within epidemiology and anthropology. A social determinants of health model has been adopted by several scholars working in Indigenous health (see CSDH 2007; Loppie-Reading & Wien 2008; NCCAH 2012). In applying a social determinants model to the unique context of Indigenous peoples’ health, the National Collaborating Centre for Aboriginal Health (NCCAH) states researchers must acknowledge that the disparities Indigenous peoples face today are long-standing and directly tied to “the history of their oppression and marginalization” (2012:41). Adelson
(2005) draws a critical distinction between “health disparities” as measures of a relative disproportionate burden of diseases and “health inequities” as measures pointing to the underlying causes of health disparities. Health inequities such as socio-economic status and employment opportunities, access to education, paternalism, racism, and other barriers to self-determination “sit largely outside the typically constituted domain of ‘health’” (Adelson 2005:S45) and are in fact entrenched in a long history of “tortured relations” (Adelson 2005:S46) between Indigenous peoples and Settler governments. It is precisely this over-arching, complex web of relationships that can be better addressed through integrating ethnographic and epidemiological approaches. Whereas epidemiological methods, particularly prevalence and incidence studies, can identify that inequities exist and are associated with health disparities; ethnographic methods can describe, illuminate, historicize, and problematize these inequities. What is missing from some of the social determinants of health literature is an explicit body of cultural theory; I argue that Indigenous health studies will benefit enormously from a mixed-methods cultural epidemiological approach. Initial AHPP epidemiological research revealed that *H. pylori* infection occurs most frequently in Aklavik residents of Indigenous identity, lower socioeconomic status, less education, and living in crowded housing (Aplin, Fagan-Garcia, Chang *et al.* 2011). In my own work, I utilize ethnography and epidemiology in tandem through all phases of research to construct a cultural epidemiology of *H. pylori* infection, risk perceptions, and social inequities in Aklavik.
The recent report “The State of Knowledge on Aboriginal Health” (NCCAH 2012) produces a nuanced and multi-faceted understanding of culture. First, the report defines culture as:

“a dynamic and adaptive system of meaning that is learned, shared and transmitted from one generation to the next and is reflected in the values, norms, practices, symbols, ways of life, and other social interactions of a given culture” (NCCAH 2012:57-58).

Second, the report acknowledges that biomedicine operates within a Western culture of its own, producing “cultural differences” between non-Indigenous health practitioners and Indigenous patients that can complicate diagnosis, treatment, and other service delivery (NCCAH 2012:58). However, when speaking specifically about Indigenous peoples, culture – like language – is described as being disrupted, lost, and destroyed through the processes of colonialism. To speak of threatened, dying Indigenous culture is to reference something traditional or essential that is always threatened and must continually adapt to, survive, or resist Western culture. This presents two problems: first, such statements imply that individuals, families, or communities that are recognized as practicing more “Westernized” lifestyles are perceived as being somehow less “Indigenous” or authentic; second, individuals most badly afflicted by health disparities due to their relatively worse-off socio-economic positions may be seen as having lost traditional Indigenous culture without having efficiently “adapted” to Western society. In other words, this presents a notion that Indigenous peoples have not been strong enough

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4 In reality, “Western” societies are not homogenous, although these continue to be more politically powerful and affluent compared to societies labeled “non-Western” and “Indigenous”. However, the term “Western” is often intended to define the umbrella of philosophy, epistemology, science, and a presumably broad but cohesive cultural identity that developed out of a long history of Western European exploration and imperialism.
(relative to Western peoples) to maintain and adapt their own cultures to the changing times (see Kelm 1998; 2010).

Geertz (1957) defined “culture” as an “ordered system of meanings and symbols” people use to define their world, while “social structure” is that “ongoing process of interactive behaviour” which takes place within cultural frameworks. With this distinction in mind, what the NCCAH report states is being disrupted, lost, and destroyed are what Geertz would call social structures, such as multi-generational kinship networks, traditional languages, and systems of education and child-rearing. Beyond the damage done to “pre-contact” social structures, Indigenous cultures – as ordered systems of meanings, values, and symbols – certainly have been negatively impacted by colonialism. However, Indigenous cultures today (as in the past) are living systems of syncretized, revitalized, and re-imagined meanings and symbols – like all cultures, Indigenous cultures are adaptive, fluid, and resilient. How do we attend to “culture” in a way that does not essentialize or further colonize, or dehumanize, Indigenous peoples when investigating health inequities which are themselves the products of Western essentialism and colonialism? How does “culture” actually relate to H. pylori infection in Aklavik?

I argue what is needed is a cultural epidemiology of H. pylori infection and risk in Aklavik – an epidemiology that is both ethnographic (in methods) and cultural (in theory), and one that belongs not entirely within the discipline of epidemiology or medical anthropology, but that is able to “tack” between epidemiology and anthropology (see Park & Littleton 2013). Whereas social epidemiology focuses upon the social determinants shaping health risks and resulting health inequalities (O’Campo & Dunn 2010:2), cultural
epidemiology focuses on how culturally-defined constructions of health, disease, risk, and behavior are related to the social inequities and health disparities present in a society (Trostle 2005). Drawing from post-colonial theory and a decolonizing research methodology, in this study I utilized a combination of quantitative and qualitative epidemiological and ethnographic methods. These methods evolved out of sustained and iterative consultation and a process of consensus-building with the AHC.

3.3 Epidemiologic methods

Epidemiologic studies across the globe have uncovered a strong association between *H. pylori* infection and conditions such as low socioeconomic status (SES), low levels of education, and marginalized ethnic status (Perry, de Martel & Parsonnet 2009). Over the past 10 years, *H. pylori* infection and gastric cancer have been shown to be much more frequent in the Arctic regions of the United States, Canada, Scandinavia, and Russia compared to the southern, more urban regions of these nations, and in Greenland compared to Denmark (Goodman, Jacobson, Veldhuyzen *et al.* 2008; Goodman *et al.* 2010). Research in the AHPP has revealed that similar social inequities including income, parent education level, and number of children in the household are associated with *H. pylori* infection (Aplin, Fagan-Garcia, Chang *et al.* 2011).

Because a large proportion of Aklavik’s community participated in screening and treatment for *H. pylori*, I was able to work with CANHelp Working Group epidemiologists to design an incidence and re-infection study, having identified participants who were negative for infection at the start of the study period. Our aim in
this analysis was to estimate the incidence of new *H. pylori* infections in AHPP participants who initially tested negative (baseline-negative) and the re-infection frequency in initially positive participants who were successfully treated during the project (*H. pylori*-cleared). To measure incidence and re-infection, I worked with Tyrrell and two CANHelp Working Group researchers, Laura Aplin and Megan Lefebvre, to collect 13-carbon Urea Breath Tests (UBT). I also analyzed household and individual demographic information from AHPP questionnaires collected between 2008 and 2010, and collected ethnographic information, including kinship and household data, while administering UBTs in the clinic.

### 3.3.1 Urea Breath Test (UBT)

To estimate incidence, *H. pylori* infection was detected by collecting CO\textsubscript{2} samples from eligible project participants using the UBT, which is a safe, non-invasive outpatient procedure lasting approximately 30 minutes. Participants are advised to fast for fours prior to the test. Participants exhale a normal breath into a bag (for a reference sample); then drink 100 ml of a labeled-urea solution, which allows for the detection of the products of urease hydrolysis in the participant’s exhaled breath. Urease hydrolysis only occurs if *H. pylori* bacteria are present in the stomach. After waiting 25 minutes, the participant exhales again, into a second bag. CO\textsubscript{2} samples were shipped to the CANHelp Working Group laboratory at the University of Alberta in Edmonton, where these were analyzed using an Infrared Isotope (IRIS) machine. CANHelp project staff, tabulated the results in Edmonton and sent reports back to me to deliver to individual participants.
Antibiotic treatment was prescribed by CANHelp Working Group physicians and offered to those participants testing positive for the infection. Tyrrell and I provided Aklavik residents with counseling about *H. pylori* infection, symptoms, gastric diseases, treatment, and the potential risks and benefits of participation. The counseling we provided followed CANHelp protocols developed in consensus with the Aklavik Health Committee during initial project work in 2007-2008. All testing and treatment of *H. pylori* infection was paid for by CANHelp Working Group project funding, and all services related to this research and community data dissemination are provided free of charge to Aklavik residents.

### 3.3.2 AHPP questionnaires

Between 2008 and 2010, the AHPP collected clinical, individual, and household questionnaires from project participants to assess which social and environmental factors are most strongly associated with *H. pylori* infection in Aklavik. Household questionnaires included questions about housing conditions, household dietary and water-use practices, water storage and sanitation facilities, and measures of socio-economic status. Questions assessed conditions such as household ownership and rental, number of persons currently residing in the home, and number of bedrooms and beds. Socio-economic status questions assessed conditions such as highest level of adult education, annual household income, and vehicle ownership. I analyzed these results along with kinship data to explore how *H. pylori* infection and re-infection is distributed within kin networks in Aklavik (see sections 3.4.3, this chapter and Chapter 6).

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5 See Chapter 4 for detailed discussion of antibiotics provided through the treatment trial.
3.4. Ethnographic methods

I have been a participant-observer on two related levels within the AHPP: 1) at the Susie Husky Health Centre (SHHC) I learned first-hand how epidemiological field research is conducted within the AHPP, and; 2) within the larger community of Aklavik I attempted in ten months to learn as much as possible about the many different people, families, and institutions that make up the hamlet of Aklavik.

3.4.1 Participant observation in the clinic

Like other clinic staff at the Susie Husky Health Centre (SHHC), I worked Monday through Friday, 9am to 5 pm, in the dentist’s office. During the few times that the dentist, eye health team, or other visiting health providers needed to use the office, Tyrrell and I worked outside of the clinic, usually conducting interviews in people’s homes. By working in the clinic, I was able to observe the daily routines of SHHC staff and interactions between Indigenous staff and the nurses. I was also able to engage with several residents through SHHC-hosted activities, including the monthly Elder’s Tea parties, and other community events, including an open-house party for the 10th anniversary of the SHHC. Working in the SHHC naturally put me into contact with seniors, new mothers, and parents with young children; while it prevented me in some ways from meeting older children and young, healthy adults, or residents who choose not to seek care at the clinic.

3.4.2 Participant observation in the community
As a result of my role as a participant observer I got to experience Aklavik in a very different way than the other CANHelp researchers who have done shorter-term field work there. I lived in a log cabin home that I shared with a new teacher from southern Canada. This was a good experience for both of us, as we were able to share our daily news and thoughts about being newcomers to Aklavik. The cabin is a private rental on the opposite side of town from the SHHC. Living there I was able to experience the same types of sanitation and water-supply issues that all residents live with, as all buildings in Aklavik use water-tanks and septic tanks which must be pumped out three days a week. Outside of the SHHC, I spent as much time as possible socializing with different groups in Aklavik. One of the easiest ways for me to meet new people was through sewing. I have always been a capable artist and seamstress, and upon arrival one of the AHC members invited me to her home to sit in on a traditional sewing course that she organizes for local youth. From there, I met other women in Aklavik who are skilled sewers, and soon was invited to other homes to sew on evenings and weekends. Conversations about leathers, furs, and beads led organically to discussions of caribou migrations, climate change, the historic fur trade, women’s and men’s roles, Aklavik’s history, and what it means to live well and be healthy. By sewing in other women’s homes, I was able to meet their children, partners, and other extended family. In a couple of families the men I met invited me to go ice fishing, duck and rabbit hunting, or for snow machine rides. The day-to-day conversations I observed and participated in added invaluable depth and detail to the information I collected more formally through interviews. I also watched local hockey games and participated in Aklavik’s volleyball season, which allowed me to socialize.
with several members of the young adult population who do not regularly visit the SHHC. I volunteered as a geography teacher in the afternoons for the high school during the Winter 2012 term and attended numerous community events, such as the Halloween and Valentine’s Day dances, Christmas and Easter Carnival events, fishing derbies, Aboriginal Day, and community sing-a-long. I occasionally attended church services at the All Saint’s Anglican Church and the Aklavik Baptist Church, and attended weddings and some funerals. I was unable to engage with some residents, for example seniors who were sick and bedridden, some unemployed adult males, or with school-children between the ages of about five to 14 years old.

Many ethnographers feel the longer a field trip, the better. In fact, several write that they only gain access to important aspects of other people’s livelihoods after several months of their first trip, or sometimes even only after multiple extended trips to a particular site over many years (see Bernard 2006:349-353). Although the information in this thesis has helped to raise questions and directions for future research as I continue to work within the CANHelp Working Group over the next several years, my initial time in Aklavik was long enough that by the end of my dissertation fieldwork, I had attended four funerals for people with whom I had established a comfortable level of rapport. It is through all of these activities that occur outside of the health centre, from berry-picking to volleyball to funerals, that I gained some of the richest, contextualized understandings of local history, cultural values, local government, social organization, and systems of reciprocity.

3.4.3 Kinship and household social structure
Aklavik’s population is predominantly Indigenous, made up of Inuvialuit, Gwich’in, Métis, and a small number of other First Nations peoples. Although the settlement is largely sedentary and contains modern housing, the population continues to be organized in large extended families. I observed that many of these extended kin networks contribute to the social and economic activities of several households. To better understand how kin networks are organized in Aklavik, and how these systems affect individual and household behaviors which may be related to *H. pylori* prevalence, I worked with Tyrrell and several other community members to record the genealogy of all current residents, tracing some lineages back to the first families that originally settled in Aklavik in the early 1900s. After consulting with the AHC, we came up with a plan for collecting information about residents’ family trees. It was agreed no medical information would appear in the charts and that I am to deliver copies of printed family trees back to Aklavik for cataloguing at the local library. To record kinship information, I updated a basic genealogy chart covering three generations (Appendix E) and asked adult participants to fill it out with Tyrrell or me. All participants were informed prior to giving consent that kinship data appearing in publications or reports is de-identified, and that only I would examine *H. pylori* infection and kinship data together.

After planning with the AHC and the Joe Greenland Centre Elder Day Program Coordinator, Karla Smith, I hosted a family tree and story-telling event with seniors. A few seniors and their relatives showed up and we made large, colorful paper trees to show family relationships. The seniors got to keep their trees, which were displayed on the Joe Greenland Centre walls for a time, and I asked permission to record the same information
from their trees for my genealogy charts. All participants consented to have their information included in my charts. This was especially useful to me because I was then able to connect several families living today back to the first families that settled permanently in Aklavik.

In the last month I was in Aklavik, I worked with Tyrrell and Community Health Representative Gladys Edwards to lay out extended families from the charts I collected, and correct mistakes I had made (e.g. spelling or incorrect names and birthdates). I used the most-current flood list, maintained by the Nurse-in-Charge in case of a spring-time flood evacuation, to identify all current residents living in Aklavik and check that against my genealogical reconstruction. During this process, I began to notice *H. pylori* infection clustering not only in particular households, but also in larger kin groups that span several households (Chapter 6).

### 3.5 Interviews

Interviewing techniques in Aklavik included the full spectrum of approaches, from unstructured to semi-structured, to fully structured interviews (Bernard 2006:211-212). I interviewed 41 individuals in Aklavik between the ages of 17 and 73 (Appendix C).

Interviews were not limited to incidence study participants or previous AHPP participants. Participants represent a broad cross-section of the community, including:

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6 Several people have the same first, middle, and/or surname, which I had to distinguish from each other by their first, second or third middle names, or by birth date. Furthermore, some residents have two sets of names, an Indigenous first and surname along with a different English first and surname. Because many Indigenous families did not have surnames prior to Euro-Canadian contact, several family surnames in town are taken from early Euro-Canadian fur traders who married into families, for example the Firths and Stewarts. Some Inuvialuit surnames were adopted in the twentieth century from the Inuvialuktun or Iñupiat first names of prominent family Elders (for example, the Pokiaks) (see Chapter 2).
nurses, health clinic staff, teachers, seniors and Elders, RCMP, local politicians, labourers, the unemployed, and college and high school students. Interview participants also reflect the ethnic and cultural diversity of Aklavik, including: Inuvialuit; Gwich’in, Métis, Western and Eastern European, and non-Aboriginal Canadian peoples. A majority of these interviews were conducted with women, and some people requested to be interviewed as couples. Among the couples interviewed, usually the women had the most to say. This may be due in part to the fact that I am a woman and men may prefer to be interviewed by men. This is probably largely due to local gender roles, as many of my questions asked about household living conditions. Reasons for declining to be interviewed included being busy, not wishing to participate in \( H. pylori \) research, not wanting to talk about cancer, and not wanting to be interviewed again. Some people who declined did not provide a reason.

I offered to conduct interviews wherever informants wanted. A majority wished to be interviewed in their homes in the evening, rather than at the SHHC or during the day. I held five focus groups in Aklavik: one with nurses (4 people), one with other health centre staff (2 people), one with adult community residents (9 people), one with Moose Kerr High School students (2 people), and one with non-Aboriginal newcomers who have lived in the community for less than one year (9 people). Focus group interviews centered around discussing participants’ knowledge of \( H. pylori \) infection, its origins in the community, in what ways the infection causes disease, and what kinds of information they want the AHPP to be provide to the community in the future (Appendix

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7 Aklavik has a long history of being researched and several adults and seniors have been asked similar questions by dozens of investigators over the years.
C). I also asked participants to discuss which health problems currently are most important in Aklavik and what services, resources, and activities people think they need to have in order to be healthy.

In September, 2011, at the project offices at the University of Alberta, I administered semi-structured interviews to five epidemiology researchers and held one focus group with seven CANHelp Working Group team members (Appendix C). All are women (the CANHelp Working Group staff, research associates, and trainees are predominately female). Four of these five women are around the same age as myself and everyone possesses at least bachelor degrees. None of the team members is Indigenous, though we all work in the field of “Indigenous health”. These individuals were chosen for interviews because they have spent the most time “out in the field”; Four have been to Aklavik for AHPP research at various times since 2007, while one had not been to Aklavik but has been to most of the other communities that are now participating in CANHelp Working Group projects. Focus group questions in Edmonton centered on individuals’ experiences doing H. pylori research in northern communities; perceptions of local residents’ knowledge about H. pylori infection; methods of explaining H. pylori infection to northern community residents; and how researchers respond to the types of questions that residents most frequently ask them.

3.6 Sequencing of papers

By using mixed methods grounded in a participant observation approach, the data collected in each phase of fieldwork helped to raise the questions that drove each paper in this sandwich thesis. Working in the health centre retesting AHPP participants for H.
pylori infection (Chapter 4) provided a space in which several people voiced their beliefs, concerns, and questions about what H. pylori is, and what the sources of infection are – information that prompted me to investigate local narratives of H. pylori, stomach cancer, and risk (Chapter 5). It also led me to become interested in how people actively attempt to minimize their risk for infection, which provided data on beliefs and behaviors that are useful for developing locally-acceptable and effective knowledge translation and treatment policies within the CANHelp Working Group. Previous individual and household questionnaires reviewed while re-testing participants for infection (Chapter 4) helped me to formulate questions for in-depth interviews with Aklavik residents and also guided my attention toward several features of people’s daily lives in the home, both raising the question of how several households are linked in extended kin groups, and providing direct observations from which I developed interview questions about kinship and residence patterns (Chapter 6). Finally, while conducting interviews on local perspectives of H. pylori infection and risk I became aware that some residents take issue with what they have heard about its relationship to household occupancy and bed-sharing, which they perceive as external judgment upon Indigenous kinship organization and social norms (see Chapter 5). This, in turn, prompted me to take a closer look at how risk is measured at a household level (Chapter 6). Thus, mixed methods were used throughout all phases of my fieldwork, while the analysis of the different forms of data I collected led to the particular sequence of the three papers presented in this thesis.

3.7 Summary
This thesis combines several methods of quantitative and qualitative inquiry commonly used in epidemiology and ethnography. My methodology was designed in consultation with the AHC, and this research was developed iteratively at all stages. My research draws upon post-colonial frameworks and centers around theorizing how culture, as an adaptive system of meanings and symbols that informs group as well as individual beliefs and behaviors, affects the construction of knowledge surrounding *H. pylori* infection and risk and how this, in turn, affects behaviors of people engaging with the AHPP. Later in 2013, I am to return to Aklavik to deliver reports based on this dissertation, provide copies of family trees to the local library, and present my research to community members. I will also return to the University of Alberta to present on my dissertation and deliver recommendations for research and policy development to the CANHelp Working Group.
Preface to Chapter 4


Incidence is difficult to estimate for chronic infections like *H. pylori*. Urea Breath Tests (UBT) only indicate that a person is actively infected, while antibodies present in blood samples only indicate if someone’s immune system has ever been exposed to *H. pylori*. Neither diagnostic tool is capable of determining at what point a person becomes infected. In Aklavik, because the AHPP followed up with project participants after community treatment trial was offered from 2008 to 2010, we knew who was negative for the infection (and therefore susceptible to becoming newly infected) during the study period of 2008 to 2012.

By participating in this multi-authored study, I was able to witness first-hand how CANHelp epidemiologists construct risk through the process of performing research. This added much to the data I collected in interviews with CANHelp researchers, enriching my understanding of epidemiological constructions of *H. pylori* infection and risk (Chapter
5). This study also provides incidence and re-infection data used to investigate the distribution of *H. pylori* across extended kin networks (Chapter 6).

While living in Aklavik and working at the Susie Husky Health Centre for 10 months, I worked with a field researcher, Tammy Tyrrell, hired from the community. We collected UBT samples to ship to the CANHelp Working Group offices at the University of Alberta. Co-author Hsiu-Ju Chang analyzed the samples and together we analyzed the statistical data. I wrote the first draft of this paper. Chang, Aklavik Nurse-in-Charge Rachel Munday, AHPP Principal Investigator Dr. Karen J. Goodman, and I each contributed to the final manuscript. A poster of our preliminary results was presented at the 15th International Congress on Circumpolar Health in Fairbanks, Alaska, in August, 2012. The final manuscript was accepted for publication in the *International Journal of Circumpolar Health* on 22 March 2013 and will be published this August.
CH 4

Helicobacter pylori incidence and re-infection in the Aklavik H. pylori Project

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Abstract

The Aklavik \textit{H. pylori} Project (\url{www.canhelpworkinggroup.ca}) is a community-driven project examining \textit{H. pylori} infection and its influence on health in a diverse Aboriginal community in the Northwest Territories. Initial research revealed 58\% of 333 participants with a urea breath test between 2007-2010 were \textit{H. pylori}-positive. From 2008-2010, we offered treatment to \textit{H. pylori}-positive participants, and 113 consented to treatment.

Objectives. We estimated \textit{H. pylori} incidence in Aklavik \textit{H. pylori} Project participants who initially tested negative and the re-infection frequency in initially-positive participants who were successfully treated to clear the infection.

Methods. Participants who were initially \textit{H. pylori}-negative or negative after treatment during 2008-2010 were eligible for inclusion. From November, 2011 through June, 2012 participants were offered UBT and the samples were analyzed using infrared spectroscopy (IRIS). Participants with a positive test result were classified as new cases for estimating incidence among participants testing negative at baseline and re-infection among those successfully treated for \textit{H. pylori} infection.

Results. Among 38 initially-negative participants, follow-up UBT showed 33 remained negative, 3 were positive, and 2 had uncertain status. The estimated incidence proportion during the follow-up period was 8.3\% (95\% CI: 1.8-22.0\%). Among 43 participants with a negative post-treatment UBT, 41 remained negative and 2 were positive. The estimated re-infection proportion during the follow-up period was 4.7\% (95\%CI: 0.6-16.0\%). The frequency of new cases was similar in males and females. Aboriginal participants had a combined re-infection/incidence rate of 2.4\% per year (95\%CI: 0.8-5.9\% per year). All 9 non-Aboriginal participants remained free from infection throughout the study period, as did all 23 participants aged 55 years and older.

Conclusions. The Aklavik \textit{H. pylori} Project has substantially reduced the burden of infection in Aklavik since 2008. Continued monitoring, treatment, community-engagement, and knowledge translation activities are needed to ensure a lasting benefit of the project.

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Keywords. Helicobacter pylori infection, Aboriginal health, collaborative research, epidemiology, incidence, Arctic

4.1: Introduction

The Aklavik H. pylori Project (AHPP) is a community-driven project examining Helicobacter pylori infection and its influence on health in a diverse Aboriginal hamlet in the Northwest Territories, conducted by the Canadian North Helicobacter pylori (CANHelp) Working Group (http://www.canhelpworkinggroup.ca). The CANHelp Working Group brings together health care providers, Aboriginal government representatives, the Aklavik Health Committee (AHC), and University of Alberta researchers to address community concerns regarding the high prevalence of H. pylori infection in Aklavik and the association of this infection with stomach cancer.

Aklavik is an Arctic community of 633 people (according to the 2008 census) including predominately Inuvialuit and Gwich’in peoples, along with smaller numbers of Métis, other First Nations, and non-Aboriginal residents. Over-all project goals include: Investigating the impact of H. pylori infection on Canadian Arctic communities; identifying effective treatment strategies; developing recommendations aimed at H. pylori infection management; and effectively communicating research findings to address community concerns (Cheung, Goodman, Munday et al. 2008; Huntington, Goodman, Munday et al. 2009). Currently, there is no standard recommendation for community surveillance of H. pylori infection or, more generally, for testing and treating people who are not seeking medical care for relevant symptoms. However, the Maastricht IV/Florence Consensus Report on clinical management of H. pylori infection recommends, “A screen-
and-treat strategy of *H. pylori* should be explored in communities with a significant burden of gastric cancer” (Malfertheiner, Megraud, O’Morain *et al.* 2012:657). With guidance from the locally-organized AHC, the AHPP developed approaches to participant recruitment, enrollment, *H. pylori* screening, and treatment in order to provide answers to community questions about the infection and its potential health consequences. During initial project planning, the AHC wanted all residents of Aklavik to be invited to undergo screening for *H. pylori* infection and treatment to be made available to all participants testing positive. A treatment trial conducted from 2008-2010 was designed to accommodate this request as well as to find effective treatments for the strains of *H. pylori* that exist in Aklavik, and generate information that may be useful to regional health authorities in future policy development.

Initial research revealed that of 333 project participants who were screened between November 2007 and June 2010, 193 (58%) were *H. pylori*-positive by urea breath test (UBT). From 2008-2010, the project offered treatment to *H. pylori*-positive participants. The aim of this new project component was to estimate the *H. pylori* incidence and re-infection rates in Aklavik since the treatment component of the Aklavik *H. pylori* Project was conducted.

4.2: Background

*H. pylori* are gram-negative spiral-shaped bacteria uniquely adapted to live in the stomach lining of humans. *H. pylori* infection is often chronic and usually established during childhood. While a majority of those with chronic infection remain asymptomatic and
free of disease consequences, it has been estimated that chronic *H. pylori* infection is responsible for over 90% of cases of peptic ulcer disease in developing countries where infection rates are high, and 65% of all gastric cancers worldwide (Walker, Teare, & McNulty 2008; Perry, de Martel & Parsonnet 2009). While the bacterium’s pathogenic role in initiating gastritis, peptic ulcers, and gastric cancers was described soon after *H. pylori* was identified in the late 20th century, *H. pylori* research in the public health sector has developed much more slowly. Because the exact transmission pathway(s) remain unconfirmed, much current research aims to identify potential risk factors for specific populations and communities, and to investigate the success and cost-effectiveness of particular surveillance and treatment programs.

Epidemiologic studies across the globe present a strong association of conditions such as low socioeconomic status (SES), low levels of education, and marginalized ethnic status with *H. pylori* infection frequency (Khalifa, Sharaf & Aziz 2010). Particularly in early life, poverty and related issues including household crowding are commonly associated with higher *H. pylori* prevalence (Malcolm MacKay, Shepherd et al. 2004; Wizla-Derambure, Michaud, Ategbo et al. 2001). Relatively high prevalence of *H. pylori* infection today exists in southeast Asia, Africa, Central and South America, and throughout the Arctic. Over the past 10 years, we have learned that *H. pylori* infection and gastric cancer are much more frequent in the Arctic regions of the United States, Canada, Scandinavia, and Russia compared to the southern, more urban regions of these nations; and in Greenland compared to Denmark (Goodman, Jacobson, van Zanten et al. 2008; Goodman & the CANHelp Working Group 2010).
Research in the Aklavik *H. pylori* Project has revealed that similar social issues including income, ethnic status, parent education level and household crowding are associated with *H. pylori* infection (Aplin, Fagan-Garcia, Chang *et al.* 2011). While we know that *H. pylori* is highly prevalent in several remote Arctic communities such as Aklavik, we know very little about *H. pylori* incidence re-infection rates in the north. A systematic search reveals just one report of *H. pylori* incidence in northern Canada – from a follow-up study of Aboriginal children in northern Manitoba (Sinha, Martin, Sargent *et al.* 2002) – and no reports on re-infection. Because a large proportion of Aklavik’s community participated in screening and treatment for *H. pylori*, we were able to design an incidence and re-infection study, having identified participants who were negative for infection at the start of the study period. Our aim in this analysis was to estimate the incidence of new *H. pylori* infections in Aklavik *H. pylori* Project participants who initially tested negative (baseline-negative), and the re-infection frequency in initially positive participants who were successfully treated during the project (*H. pylori*-cleared).

### 4.3: Methods

In 2008, the Aklavik *H. pylori* Project offered UBT screening to all Aklavik residents without restriction. During 2008-2010, 333 participants received a UBT to assess their infection status. The ages of the 333 project participants ranged from infancy to 80 years; 54% were females and 87% of them were Aboriginals (56% Inuvialuit, 27% Gwich’in and 4% other Aboriginal groups). A previous analysis compared demographic characteristics of project participants and the community population (Jayanthan Tweedie, Lazarus *et al.* 2009, unpublished). Characteristics of the community population of
Aklavik were estimated by the community profile of 2006 Census. The findings suggested that the study population was older and comprised a slightly greater proportion of females than the community population.

From 2008-2010, the AHPP offered treatment to *H. pylori*-positive participants, and 113 consented to treatment. Details and results of the trial have been presented elsewhere (Morse, Goodman, Munday et al. 2009). Participants were randomized to receive either the standard triple therapy used across Canada (rabeprazole 20mg po bid, amoxicillin 1 gram po bid and clarithromycin 500mg po bid for 10 days) or a sequential therapy (10 days of rabeprazole 20mg po bid, days 1-5 amoxicillin 1g po bid, days 6-10 clarithromycin 500mg po bid and metronidazole 500mg po bid), unless antibiotic susceptibility testing showed evidence of resistance to clarithromycin. For clarithromycin-resistant cases, individuals were randomized to receive either the sequential therapy or a quadruple therapy (ten days of bismuth 2 tablets qid, tetracycline 500mg po qid, metronidazole 500mg po tid and rabeprazole 20mg po bid). Treatment success was assessed with a post-treatment UBT at least 10 weeks after the completion of treatment. Participants with treatment failures were treated again with a different regimen and reassessed at least 10 weeks after the completion of treatment.

For the new AHPP component aimed at estimating *H. pylori* incidence and reinfection rates, participants aged 15 years or older who were previously shown to be free of *H. pylori* infection were eligible for inclusion. All Aklavik *H. pylori* Project participants (n=179) who initially tested *H. pylori* negative (n=107) or were negative after treatment (n=72) as of Oct 31, 2011 were invited to undergo a repeat UBT to classify
their current *H. pylori* status. From November 2011 through June 2012, we offered participants UBT screening for *H. pylori* infection at the Susie Husky Health Centre in Aklavik. Breath samples were analyzed using infrared spectroscopy (IRIS) at the University of Alberta. We classified UBT results as positive (delta-over-baseline test values $\geq 4$), negative (delta-over-baseline test values from -2 to 2.5) or borderline (test values between 2.5 and 4). For borderline results or breath samples with insufficient CO$_2$ concentration, participants were asked to repeat the test. If a sample with a sufficient CO$_2$ concentration could not be obtained, the result was considered unclassifiable and the participant was excluded from the analysis. When a repeat result was borderline, the borderline classification was retained. Participants with a positive test result were classified as new cases: incident cases in the baseline-negative group and re-infection cases in the *H. pylori*-cleared group.

We estimated two incidence measures: 1) the incidence proportion (the number of new cases divided by the number of infection-free participants who were retested for the incidence study) pertaining to the time between the negative UBT and the subsequent UBT; 2) and the incidence rate (the number of new cases divided by the person-time at risk). For estimating rates of incidence and re-infection events, we define the person-time at risk as the time period between the date of the last negative test and the date of the follow-up test for each person, subtracting half of this interval for participants with new infection onsets. We calculated the incidence rates by dividing the number of positive cases by the sum of person-time at risk.
**Figure 4.1:** Participation of the incidence/reinfection study among participants aged $\geq 15$

- 333 tested in initial UBT screening
- 1 uncertain result screening
- 194 initially *H. pylori* (+)
- 138 initially *H. pylori* (-)
- 29 participants aged < 15
- 38 dropped out
- 126 treated for *H. pylori* (113 enrolled in a treatment trial)
- 31 participants aged < 15
- 54 had positive, uncertain, or no test results after treatment
- 107 eligible for retesting for new cases of *H. pylori*
- 72 *H. pylori* (-) after treatment: eligible for retesting for reinfection
- 38 retested
- 43 retested
Given its community-based research design, the Aklavik *H. pylori* Project is guided by community priorities. Previous analysis has shown that *H. pylori* infection is less frequent among non-Aboriginal community residents, and some community members requested that we examine whether there is a difference in infection frequency between the various Aboriginal groups residing in Aklavik (classified as “Inuvialuit”, “Gwich’in”, and “other Aboriginal”).

We report estimated incidence and re-infection frequencies with 95% confidence intervals (CI) for the total study population (n=79) and for demographic subgroups by age, sex, and self-identified ethnicity. To compare incidence across groups, we estimated incidence rate differences and 95% CI. Because individual follow-up periods vary, we do not compare incidence proportions in our analysis.

### 4.4: Results

We retested 81 participants for this study (Figure 4.1). Of these 81, age at entry into this study period ranged from 18-80 years (mean: 43, median: 44); 45 were female (56%); and 66 self-identified as Aboriginal (81%). Among the 38 participants who had tested negative on initial screening, 33 remained negative on the follow-up UBT, 3 were positive and 2 had uncertain results. In this group, the estimated incidence proportion during the follow-up period was 8.3% (95% CI: 1.8-22%). Among the 43 participants with a previous negative post-treatment UBT, 41 remained negative and 2 were positive. The estimated re-infection proportion during the follow-up period was 4.7% (95% CI: 0.6-16.0%). We report person years and mean and median person years-at-risk in (Table
4.1). Because individual follow-up periods vary, we report both incidence proportions and rates, but only compared rates in our analysis.

Among the participants with follow-up results (n=79), the estimated rate of new cases was 2.1% per year (Table 4.1) over an average follow-up of 3 years. Among people with a negative UBT at study entry, the estimated incidence rate was 1.8% per year; among people who had previously cleared an infection, the estimated re-infection rate was 2.4% per year. The rates in the two groups are similar, with the 95% CI for the rate difference of -0.6% per year comparing re-infection to new cases in those who were infection-free at baseline ranging from -4.2% to 3.0% per year.

Results across groups: Sex, Age, Ethnicity

Among participants with classifiable follow-up results, incidence proportions and rates (combining new cases of infection in participants who were _H. pylori_-negative at baseline and those who were successfully treated) were estimated for categories of sex, age, and self-reported ethnic status. The estimated incidence proportion for the follow-up period was 3.1% (95% CI: 0.1-16.0%) in males and 8.5% (95% CI: 2.4-20%) in females. The estimated incidence rate was 1.1% per year in males and 2.8% per year in females. The estimated incidence rate difference comparing males to females was -1.7% per year (95% CI: -5.1-1.7% per year).

Age cohorts were grouped by two-decade intervals starting at age 15 (15-34; 35-54; 55+). The rate of new cases declined notably by age: 7.3% per year (95% CI: 1.5-21.0% per year) in those aged 15-34; 1.6% per year (95% CI: 0.2-5.8% per year) in those aged 35-54; and 0 (97.5% CI: 0.0-5.0% per year) in those over age 55.
Table 4.1: Frequency of new *H. pylori* infections among participants in the Aklavik *H. pylori* Project, Northwest Territories, Canada

<table>
<thead>
<tr>
<th></th>
<th>Tested N</th>
<th>New cases</th>
<th>Person-years at risk</th>
<th>Mean (median) years at risk</th>
<th>Incidence Proportion (%), 95% CI</th>
<th>Rate (%/year), 95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>79*</td>
<td>5</td>
<td>239.3</td>
<td>3.0 (3.0)</td>
<td>(6.3), 2.1-14</td>
<td>2.1 (0.7-4.9)</td>
</tr>
<tr>
<td>Baseline-negative</td>
<td>36*</td>
<td>3</td>
<td>126.4</td>
<td>3.5 (3.8)</td>
<td>(8.3), 1.8-22</td>
<td>2.4 (0.5-6.9)</td>
</tr>
<tr>
<td>*H. pylori-*cleared</td>
<td>43</td>
<td>2</td>
<td>112.9</td>
<td>2.6 (2.8)</td>
<td>(4.7), 0.6-16</td>
<td>1.8 (0.2-6.4)</td>
</tr>
<tr>
<td>Male</td>
<td>32</td>
<td>1</td>
<td>94.8</td>
<td>3.0 (3.0)</td>
<td>(3.1), 0.1-16</td>
<td>1.1 (0.3-4.7)</td>
</tr>
<tr>
<td>Female</td>
<td>47</td>
<td>4</td>
<td>144.6</td>
<td>3.1 (2.8)</td>
<td>(8.5), 2.4-20</td>
<td>2.7 (0.03-5.9)</td>
</tr>
<tr>
<td>Age 15-34 years</td>
<td>15</td>
<td>3</td>
<td>41.1</td>
<td>2.7 (2.8)</td>
<td>(20), 4.3-48.0</td>
<td>1.5 (1.5-21.0)</td>
</tr>
<tr>
<td>Age 35-54 years</td>
<td>41</td>
<td>2</td>
<td>124.7</td>
<td>3.0 (3.0)</td>
<td>(4.9), 0.6-17.0</td>
<td>1.6 (0.2-5.8)</td>
</tr>
<tr>
<td>Age 55+ years</td>
<td>23</td>
<td>0</td>
<td>73.5</td>
<td>3.2 (3.0)</td>
<td>(0), 0-15.0</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Inuvialuit†</td>
<td>41</td>
<td>4</td>
<td>121.5</td>
<td>3.0 (2.9)</td>
<td>(9.8), 2.7-33.0</td>
<td>3.3 (0.9-8.4)</td>
</tr>
<tr>
<td>Gwich’in†</td>
<td>23</td>
<td>1</td>
<td>68.3</td>
<td>3.0 (2.8)</td>
<td>(4.3), 0.1-22.0</td>
<td>(1.5)</td>
</tr>
<tr>
<td>Other Aboriginal†</td>
<td>2</td>
<td>0</td>
<td>7.6</td>
<td>3.5 (3.8)</td>
<td>0 (0)</td>
<td>0-49.0</td>
</tr>
<tr>
<td>Non-Aboriginal†</td>
<td>9</td>
<td>0</td>
<td>28.6</td>
<td>3.2 (3.2)</td>
<td>0 (0)</td>
<td>0-13.0</td>
</tr>
</tbody>
</table>

*excludes two with uncertain results

†one-sided, 97.5% confidence interval

†of 79 with classifiable results, excludes # who declined to identify ethnicity
Aboriginal participants had a combined re-infection/incidence rate of 2.5% (95% CI: 0.8-5.9% per year), while all non-Aboriginal participants remained free from infection during the study period. Of 41 self-identified Inuvialuit participants, the rate of new cases was 3.3% per year (95% CI: 0.9-8.4% per year); among 24 self-identified Gwich’in participants the rate of new cases was 1.5% per year (95% CI: 0.4-8.2% per year). The estimated incidence rate difference comparing Gwich’in to Inuvialuit is -1.8% per year (95% CI: -6.1-2.5% per year); the wide confidence interval indicates that this study is too small to accurately estimate the difference between these groups in the rate of new cases. The two participants who identified as “other Aboriginal” remained free from infection during the study period. Four of 79 participants chose to not report their ethnic status.

4.5: Discussion

Among participants in the AHPP aged 15 years and older we observed an incidence proportion of 6.3% over an average follow-up of 3 years. In this population, the rate of new cases of *H. pylori* infection declined notably with age and was similar in males and females. Of note, all participants in this study aged 55 years and older remained free from infection throughout the study period, as did all non-Aboriginal participants. Due to the low incidence of new cases, we do not have enough data in this population sample to precisely estimate differences between ethnic and age groups. More data is needed from additional Canadian Arctic communities so we can increase the size of regional population samples.
In this study, our results suggest that most AHPP participants treated for \textit{H. pylori} infection remained free of infection during the follow-up period. Thus, we can infer that there was a corresponding decrease in the prevalence of \textit{H. pylori} infection, bringing the prevalence in Aklavik closer to the average seen in southern Canada. This suggests a potential for reducing the burden of infection in communities like Aklavik through the application of screen and treat programs with long-term follow up. Before recommending such a strategy at the community level, however, a full assessment of costs and benefits is needed. Widespread antibiotic treatment may pose a risk to populations by increasing antibiotic resistance among \textit{H. pylori} strains as well as other bacteria in the community.

Our choice to screen and offer treatment to all positive participants is the result of consultation and consensus building with the AHC, and is appropriate in this community for a number of reasons. The AHPP has documented that \textit{H. pylori} infection is highly prevalent in Aklavik, as is severe chronic gastritis and precancerous conditions of the stomach. The pattern observed in Aklavik fits with the observation that men in regional centres of the Northwest Territories have three times the rate of gastric cancer compared to men across Canada (Department of Health and Social Services GNWT 2003). The AHPP is part of a research program that is gathering similar data from other Canadian Arctic communities. In addition to assessing the burden of disease from \textit{H. pylori} infection in this region, we will assess the cost-effectiveness of regional health care practices which currently include testing for and treating \textit{H. pylori} in patients presenting with a wide array of gastric symptoms that can be caused by factors other than \textit{H. pylori} infection. The adoption of community health strategies aimed at reducing health risks
from *H. pylori* infection requires careful generation and analysis of the full array of evidence that must be considered for effective public policy. An international analysis of reported re-infection rates estimated summary rates of 2.7% for developed countries (3,014 patients followed for 24-60 months) and 13.0% for developing countries (2,071 patients followed for 12-60 months) (Niv & Hazazi 2008; Parsonnett 2003), but there is extensive variation within these groupings depending on the population studies. One study, for example, estimated the reinfection rate at 1.8% per year in a population of Brazilian patients with dyspeptic diseases (Silva, Navarro-Rodriguez, Barbuti *et al.* 2010). The AHPP is one of a very few sources of data on *H. pylori* incidence and re-infection rates in the circumpolar north. Our literature search identified just one report from this region. A two-year prospective study of urban Alaska Native gastroenterology patients 18 years of age or older yielded an estimated re-infection proportion following successful treatment for *H. pylori* infection of 5.1% at 4 months, increasing to 7.2% at 6 months, 10.3% at 1 year, and 14.6% at 2 years (McMahon, Bruce, Hennessy *et al.* 2009). Among Aklavik project participants who were treated for *H. pylori* infection, the estimated re-infection proportion was considerably lower at 4.7% over an average of 2.6 years at risk. Some of this difference may be attributable to differences between gastroenterology patients and a community-based study population as well as random variation; the Aklavik study population was younger on average than the Alaskan study population, so if *H. pylori* incidence decreases with age, differences in age distribution would not explain the observed difference re-infection frequencies. While *H. pylori* infection is generally more prevalent throughout North American Arctic communities for which we
have data, compared to southern Canada and the United States, these findings suggest variation across Arctic communities, and demonstrate the need for data from additional communities to add to our knowledge of *H. pylori* infection and its related human health outcomes in the North.

### 4.6: Conclusions

This incidence and re-infection study indicates that the screening and treatment components of the Aklavik *H. pylori* Project have substantially reduced the prevalence of *H. pylori* infection among project participants since the treatment component began in 2008. The CANHelp Working Group is continuing to collect data on determinants of treatment success as well as benefits of treatment in order to achieve our collaborative team’s goals of addressing community concerns about health risks from *H. pylori* infection, and ultimately reducing these risks. Participant follow-up in Aklavik combined with epidemiological and ethnographic assessments of associated risk factors, and ongoing community engagement and knowledge translation activities, are continuing in order to assess the long-term implications of community-wide test-and-treat programs for controlling *H. pylori* infection.

### 4.7: Acknowledgements

The Aklavik *H. pylori* Project is made possible through partnerships with territorial health authorities (NWT Health and Social Services; Stanton Territorial Health Authority; Beaufort-Delta Regional Health and Social Services Authority; and the Arctic Health Research Network); and local government and organizations (the Hamlet of Aklavik; the
Aklavik Indian Band; the Aklavik Community Corporation, and the Aklavik Health Committee).

This study was developed in consultation with the AHC and approved by ethics review boards at the University of Alberta and McMaster University. The Aklavik *H. pylori* Project has current research licenses from the Aurora Research Institute for the NWT, as well as letters of support from the Aboriginal governance bodies and the Hamlet of Aklavik. Prior to publication, our results were shared with the AHC, who provided us with helpful feedback from a community perspective.

The authors would like to acknowledge several Aklavik community members: Aklavik resident Tammy Tyrrell for her excellent services as a field research assistant; the staff at the Susie Husky Health Centre and the Joe Greenland Centre; Adult Education Coordinator Katie McRae at the Aurora Learning Centre, and Principal Velma Illasiak and Vice-Principal Frank Galway of Moose Kerr School, Aklavik. Thank you, Quyanainni, and Mahsi cho, to everyone for making this study possible!

4.8: Conflict of Interest and Funding

None of the authors have any conflicts of interest to report. Additional funding to support extended accommodation in Aklavik for the lead author was provided by the Arctic Institute of North America; the McMaster University Indigenous Health Research Development Program Graduate Scholarship, funded by the Canadian Institutes of Health Research Institute of Aboriginal People’s Health; and by the McMaster University School of Graduate Studies.
References


Preface to Chapter 5

In this paper I address how perceptions of risk for getting *Helicobacter pylori* infection are imagined, produced, and responded to by the many groups of people (researchers, health providers, non-Indigenous newcomers, local Indigenous residents) involved in the Aklavik *H. pylori* Project (AHPP). Both prior to and as a result of the AHPP’s presence in Aklavik, multiple narratives about the bacterium, its “source” and suspected transmission pathways have been constructed. Many local residents believe *H. pylori* probably travels in contaminated water from southern Canada to the Arctic, while local nurses and AHPP researchers believe that person-to-person transmission facilitated by numerous other factors, including perhaps household crowding (which I suggest re-framing as “household density”). These narratives are dynamic, nuanced, multi-layered, and at times, contradictory. Drawing on the notion of cultural fabrics of meaning (Geertz 1957), I examine the opposing constructions of risk that occur simultaneously in the AHPP, and investigate how risk-avoidance behaviors emerge from processes of “making sense” of *H. pylori* as a pathogen or as a contaminant. Unpacking epidemiological narratives makes it possible to ask how non-Indigenous and biomedical world views limit the understanding of Indigenous health and risk narratives. Similarly, unpacking Indigenous narratives of contamination facilitates building a better understanding within epidemiology; one that recognizes how Indigenous concerns about contamination are spatially, historically, and socially anchored to Aklavik. This is important not only for building stronger communication and understanding between Aklavik’s residents and the AHPP
researchers, but also because local narratives reveal the cultural logic behind the risk-avoidance behaviors we observe amongst residents.

During my fieldwork (36 weeks in Aklavik, NWT and 2 weeks at the CANHelp Working Group offices at the University of Alberta in Edmonton, AB), I conducted 45 interviews and 5 focus groups in Aklavik and 5 interviews and 1 focus group at the University of Alberta. Aklavik resident Tammy Tyrrell was hired as a field researcher. She and I worked together, in consultation with the Aklavik Health Committee (AHC), to plan recruitment strategies, design interview questions, conduct and reflect on interviews, and conduct the initial analysis of interview findings. I conducted and analyzed all CANHelp Working Group researcher interviews myself, and completed coding and analyzing Aklavik interviews after leaving the field between June and October, 2012. I am the sole author of this manuscript. This manuscript will be submitted for publication to The International Journal of Epidemiology in the winter of 2013. From these narrative analyses, I am drafting reports to share with researchers and community residents. These reports provide cross-cultural explanations of the alternative views of H. pylori-the-pathogen and H. pylori-the-contaminant and will deliver recommendations aimed at improving current CANHelp Working Group data dissemination methods and materials. The conclusions in this paper also inform the recommendations developed in the following paper (Chapter 6) for reframing the descriptive epidemiology of disease patterns in Aklavik to more accurately reflect local social organization and daily lived experiences of Aklavik residents.
Chapter 5

Pathogen or Contaminant? Making Sense of H. pylori Infection and Risk Perceptions in Aklavik, NWT

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Abstract

In the early 2000s, the Indigenous community of Aklavik in the Northwest Territories urged regional health authorities to send researchers to investigate Helicobacter pylori bacterial infection and its association with a perceived higher-than-expected incidence of stomach cancer. To date, the modes of transmission of H. pylori is have not been substantiated by direct evidence, but Aklavik’s residents want researchers to identify the “source” of the infection. Since the Aklavik H. pylori Project (AHPP) began research activities in 2007, divergent narratives about the bacterium, its suspected transmission pathways, and varied understandings of risk have been constructed. Many residents believe H. pylori may travel in contaminated water, while local nurses and AHPP researchers believe that crowded housing and hygiene are probably the most crucial risk factors. Drawing on semi-structured interviews, focus groups, survey data, and 10 months of participant observation, I examine the multi-layered and interconnected processes of “making sense” of H. pylori as a “pathogen” and as a “contaminant.” I explore how these culturally-mediated narratives are translated into risk avoidance behaviors as a type of coping strategy. Policy recommendations generated from this study advocate incorporating local perceptions of human health and the environment in data dissemination materials, and outline strategies for communicating epidemiological findings in ways that do not condemn Indigenous values of living in large families.

Keywords: Arctic, H. pylori, illness narratives, ethnography, knowledge translation, risk perceptions, Indigenous health
5.1: Introduction

“Risk” has become a prominent idea within modern/Westernized societies (Beck 1992; Giddens 1999). Risk is a particularly powerful idea in epidemiology defined and measured in discipline-specific ways as a “tool for translating the findings of science-based risk management strategies” (Samet, White & Bruke 2006:126, emphasis mine). Anthropologists recognize that potential threats, dangers, and misfortunes are often perceived differently in Indigenous and non-biomedical cultures, and thus see a need for ethnographic analyses that tie risk narratives to particular places, times, and peoples (Trostle 2005:163). Being able to identify, excavate, and unpack risk narratives is useful for understanding both epidemiological and local/lay processes of defining risk, and then taking action to respond to the casual explanations making up certain risk constructs at individual, community, and public health policy levels. From September, 2011-June, 2012, I worked as an ethnographer and medical anthropologist for the Aklavik H. pylori Project (AHPP) of the Canadian North Helicobacter pylori (CANHelp) Working Group to investigate the infectious stomach bacteria called Helicobacter pylori and the different risk narratives surrounding it, in the Indigenous community of Aklavik, NWT. During my ten months of fieldwork conducted under the umbrella of the AHPP in Aklavik, NWT, I became concerned with two inter-related issues surrounding the constructions of risk perceptions. First, there is a need to theorize the cultural processes of constructing and responding to narratives of risk in public health research. Second, health research would benefit from understanding how local risk narratives influence people’s behaviors, including their acceptance or resistance to data dissemination, health policies, and health
interventions. Førde (1998) argues further that epidemiologists have a responsibility beyond ensuring the quality and soundness of their risk estimates to pay serious attention to how data, policy, and treatment are interpreted by the media and public. As Knowledge Translation (KT) and culturally-appropriate data dissemination back to the community make up a core objective of the AHPP, it is necessary to continually reflect on the processes by which researchers and participants make sense of the knowledge produced from research, particularly knowledge about “risk factors”. This is especially salient when theories about H. pylori transmission and risk factors may be understood differently, disbelieved, or rejected by AHPP participants. A cultural epidemiology of H. pylori infection in Aklavik, one that is ethnographically grounded, seeks to incorporate locally valid representations of the distribution of H. pylori infection and associated health risks into knowledge translation (KT) materials aimed at both audiences (researchers and participants). A cultural epidemiology approach integrates qualitative and quantitative methods to outline the cultural basis of risk construction and facilitate comparisons between varied perceptions of the same health conditions (Weiss 2001). Incorporating cultural epidemiology into policy development can help to diffuse epistemic tensions between research participants and researchers who come from different cultural backgrounds, and promote cooperative action for improving community health.

“Risks to health” are often understood differently by various groups and individuals in a community, and thus can be explored in studies of “lay epidemiologies” (Davidson, Frankel & Davey-Smith 1989; Petersen & Lupton 1996), “cultural models of disease” (Garro 1994; Lynch 2006), and “illness narratives” (Kleinman 1988). These
frameworks are similar in that all focus on describing emic understandings of health conditions and risk perceptions and commonly utilize narrative and thematic analyses, although lay epidemiology has been seen by some as a barrier to the empiricism of public health (see Allmark & Tod 2006). Illness narratives within anthropology are treated as “alternative explanations of the etiology, course, and treatment of disease [that are] worth exploring” (Loewe 2004:46) because these shed light on how people make sense of their illnesses\(^1\), but also because the act of narrating itself can be reflexive, therapeutic, and even transformative (Kaplin-Myrth 2007:1269).

In Aklavik, there are radically divergent narratives of risk *H. pylori*, a bacterium that lives in the human stomach and sometimes causes diseases, including stomach cancer (Perry, de Martel, Parsonnet, *et al.* 2009). The AHPP was formed in response to community concerns over perceived high rates of stomach cancer and the high prevalence of *H. pylori* infection reported by local health care providers. The AHPP is a community-driven project that brings together community leaders, health providers

\(^1\) To be fair, even some cultural anthropologists have been critiqued for presuming biomedical nosology is more authentic, real, or is the norm from which other illness narratives deviate (see Loewe 2004).
and authorities, and researchers from the University of Alberta to investigate the infection and its health consequences, assess risk factors for infection, develop regional health policy, and communicate research results back to community members.

Initial AHPP research revealed an infection prevalence of 58% (Goodman, Munday, Huntington, *et al.* 2009), while three recent cases of stomach cancer (diagnosed between 2009-2013) have occurred in residents with *H. pylori* infection (Munday 2012). This paper presents an ethnographic explanation of the interwoven, contextual, and nuanced processes of [narrating risk] for a bacterial infection whose modes of transmission have not been fully elucidated scientifically despite numerous investigations worldwide. Approaching “risk” as a type of illness narrative (Kleinman 1988), I discuss how different people involved in the AHPP are making sense of *H. pylori* infection while locating how individual biographies are woven into the history of Aklavik, which is the place where people “Never Say DIE!”

5.2: Background

5.2.1: *Helicobacter pylori and stomach cancer*

*Helicobacter pylori* is a bacterium uniquely adapted to live in the stomach lining of humans. While microbiologists and physical anthropologists have established that *H. pylori* has evolved along with our earliest *Homo sapiens* ancestors in Paleolithic Africa (Pavesi 2005; Moodley, Linz, Bond, *et al.* 2012; Velasquez-Manoff 2012), this gram-negative, spiral shaped bacterium came to be known as a serious human health concern only within the last two decades of the twentieth century. In the 1980s, microbiologist
Barry Marshall and pathologist Robin Warren demonstrated that *H. pylori* fulfills Koch’s Postulates, used to assess its role as a cause of gastritis (inflammation of the stomach lining) in humans.\(^2\) This knowledge took several years to become widely accepted in medicine due to the earlier belief that bacteria could not survive the normal acid levels in the stomach and that ulcers were caused primarily by diet and stress (Nunes, Pereira, Santos, *et al.* 2004; Nunes 2008; Meuler 2011). In 1994, however, this stance became untenable when the World Health Organization and the National Institutes of Health declared the bacterium to be a class-one carcinogen associated with multiple types of stomach cancer (IARC 1994). *H. pylori* became known to the residents of Aklavik by the early 2000s, when nurses began telling patients that this bacterium might be responsible for a number of gastric symptoms and digestive diseases, including several local cases of stomach cancer diagnosed over the past decade. In small settlements, a single death can resound throughout the community; typically in such settings, deaths cluster over time and a sporadic handful of deaths seems like an epidemic. There is a sense of urgency on the ground in Aklavik, which is reignited each time a new person is diagnosed with or dies because of stomach cancer. As one stomach cancer patient told me, *H. pylori* is a “life or death” situation for this community.

In Aklavik, 58% of the community (across all age groups) tested positive for infection (194/333 breath tests) in initial AHPP research (Goodman, Munday, Huntington, *et al.* 2009), compared to reports from other regions of Canada in which

\(^2\) *H. pylori* is actually one of only a few microorganisms, along with anthrax and *Mycobacterium tuberculosis*, found to fulfill all four of Koch’s Postulates (see Thagard 1999:57-64). In 2005, Marshall and Warren were awarded a Nobel Prize for their work in the 1970s leading to the recognition that *H. pylori* causes gastritis, which can lead to several diseases including peptic ulcers and stomach cancer.
prevalence varies in age-range from 21-38% in all age groups combined in Nova Scotia (ranging from 21% in 20-29-year-olds to 50% for 70-79 year-olds) and is approximately 35% in Manitoba adults (Goodman, Jacobson & Veldhuyzen van Zanten 2008:292).

Recent follow-up with AHPP participants reveals that the burden of infection has declined amongst long-term participants since the project’s community-based treatment trial carried out between 2008 and 2010 – particularly amongst those aged 15 years and older. Follow-up breath tests collected between November, 2011 and June, 2012 revealed an incidence rate of 1.8% per year for participants over age 15 who were *H. pylori* negative upon first joining the research (3/36 cases) and a re-infection rate of 2.4% per year for participants over age 15 who were initially *H. pylori* positive but successfully cleared the infection during the treatment trial (2/43 cases) (Carraher, Chang, Munday, *et al.* 2013, in press).

Despite this seemingly positive news, local anxieties persist – especially as two new cases of stomach cancer have been diagnosed in Aklavik residents since 2012. AHPP participants have cited stomach cancer more than any other concern associated with *H. pylori* infection (Wynne, Huntington & Goodman 2011), despite the fact that the AHPP informs participants that stomach cancers occur in less than 1% of people worldwide who are infected with the bacterium. Local knowledges of *H. pylori* infection are drawing on a rich blend of narratives as Indigenous and non-Indigenous residents, nurses, and CANHelp researchers translate existing social and cultural values into these narratives (see Williams 1984:637). As I discuss below, often there are elements of various risk narratives blended in both Indigenous and biomedical cultural ideas; yet these elements
are also entrenched in different relationships people have to Aklavik as a place that is experienced differently by (and means different things to) various groups of people.

5.2.2: “Never Say DIE!”

Aklavik is a remote Arctic community of 633 people (Statistics Canada 2008). Accessible only by air, boat, or by ice road in the winter, Aklavik is built on the border of the Inuvialuit Settlement Region and the Gwich’in Settlement Area, on the Peel River. Aklavik is home to a majority of Inuvialuit and Gwich’in peoples, with a minority of Métis, and a few other First Nations residents. About 50-60 non-Indigenous people (including Euro-Canadians, Euro-Americans, and Europeans) also live there, usually staying for a few months or a few years to work as teachers, nurses, missionaries, or RCMP. However several early European-descended settlers married into Gwich’in and Inuvialuit families and much of the Indigenous population has a mixed heritage. This culturally diverse Aklavik is known as the community that will “Never Say DIE!” – a sentiment that means different things to different people, but one that is historically and culturally anchored to this place.

Because of its location on the Peel River, Aklavik is prone to severe springtime flooding. In the late 1950s, the government of the Northwest Territories encouraged the entire population to relocate to the newly-erected town of Inuvik. About half the community’s families refused to move. Choosing to stay in their homes along the Peel River and near the Richardson Mountains, where Gwich’in, Inuvialuit, and Métis peoples have been trapping, hunting, fishing, and trading furs for generations, the people who
stayed behind adopted the community’s official motto: “Never Say DIE!” In 2007, the AHPP adopted “Never Say DIE!” as the research project’s official motto. “Never Say DIE!” should be viewed in terms of a local ideology that both represents and fosters individual and community agency. As a project motto, “Never Say DIE!” speaks to community agency that demands research in the first place, as well as to the individual agency of residents who choose to continue participating in the AHPP for long-term study.

5.2.3: Purpose of research

One of the most difficult topics for communication between CANHelp Working Group researchers and Indigenous residents centers around pinpointing H. pylori’s “source” (Figures 5.2, 5.3). Local people want to know where H. pylori comes from. In other words, they want to know where to locate the risk of getting infected by the bacteria, and ultimately, their risk of “catching” stomach cancer.³ Researchers maintain that H. pylori infection usually spreads directly from person to person, either through a fecal-oral, an oral-oral, or a gastric-oral route. Theirs is a way of locating the risk of becoming infected within the community itself, within the houses of Aklavik’s poorest families. This idea does not make a lot of sense to many Indigenous residents who have their own ways of understanding the bacteria, cancer, health, and their surrounding environment. These different cultural models of the risk of acquiring H. pylori infection may have serious

³ Some of my interlocutors speak about “catching” cancer. This reflects a cultural model of disease that dovetails Indigenous peoples’ experiences with infectious epidemic diseases that devastated northern populations in the late 19th and first half of the 20th centuries. Often these epidemics are perceived as having been brought to the north by non-Indigenous outsiders and thus are consequences of colonialism. See Cassady (2008) for discussion of how contemporary narratives of cancer and contamination in northwest Alaska reference the intergenerational damage to society and health caused by colonialism.
consequences for developing effective infection control practices that require enlisting local peoples to participate in long-term follow-up for the project or to adhere to antibiotic treatment guidelines.

Contrary to many biomedical views of *H. pylori* transmission, many Indigenous residents of Aklavik are concerned that the infection comes from an environmental source – most likely the water.\(^4\) CANHelp researchers are aware that many of Aklavik’s residents are concerned *H. pylori* is being transmitted through water:

> The current concerns that *H. pylori* may be originating from water sources appears to be an important research area for the community and has important implications for future community follow-up, health education, and water servicing (Cheung, Huntington, van Zanten, et al., n.d.).

Likewise, many of my Indigenous interlocutors report they have heard scientists and nurses say *H. pylori* is passed from person to person, through direct contact with the bacteria, or “germs”. However, they also respond that they have heard from family and friends that *H. pylori* may come from polluted water. The CANHelp Working Group found in initial surveys prior to the first round of testing for *H. pylori* infection in Aklavik in 2007 that 55% of local adults (n=132/242) reported prior awareness of *H. pylori* (Cheung, Huntington, van Zanten, et al. n.d.). Of 80 people reporting they have ideas

\(^4\) Even within biomedicine there are some who believe that water may serve as an environmental reservoir for *H. pylori* transmission. Water transmission remains difficult to study because methods for detection of viable *H. pylori* from water samples or biofilms are not yet perfected (Percival & Thomas 2009). Epidemiologists and microbiologists working within the CANHelp Working Group believe direct person-to-person transmission is the most frequent route (Goodman 2011, personal communication; Keelan 2012, personal communication).
about where *H. pylori* might come from, 40 (63%) responded that it may come from water (Wynne, Huntington, Goodman, *et al.* n.d.). Risk narratives for *H. pylori* infection, which is perceived by some residents as being inexplicably tied to stomach cancer mortality, need to be understood within their broader cultural context, as these are shaped by Aklavik’s history, current socio-economic inequalities, and contemporary cultural identity.

5.3: Methods and materials

Between September, 2011 and June, 2012, I lived in Aklavik, NWT and worked weekdays at the Susie Husky Health Centre as a research trainee for the CANHelp Working Group, and as a participant observer. During that time I worked with a locally-hired field researcher, Tammy Tyrrell. All phases of research planning and data collection were coordinated through consultation with the locally-organized Aklavik Health Committee (AHC). This paper is based on data I collected to characterize Aklavik residents’ views of their own experiences with *H. pylori* diagnosis or treatment, or more broadly concerning their knowledge of the AHPP. To collect the data, I conducted 41 semi-structured interviews and 5 focus groups in Aklavik between November, 2011 and June, 2012 (Table 5.1). I also conducted 5 semi-structured interviews and one focus group with CANHelp Working Group researchers at the project offices on campus at the University of Alberta in Edmonton. Additional observations come from my daily journal and from regular meetings with Tyrrell as well as with the AHC. Initial findings were shared with the AHC to seek feedback and local validations of my conclusions.
<table>
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<th>Total (n)</th>
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<td>5 CANHelp epidemiologists</td>
<td>n = 46</td>
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<tr>
<td></td>
<td>6 non-Indigenous teachers, nurses, or</td>
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<td>microbiologists</td>
<td></td>
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<td>(3) 9 adult community residents in Aklavik</td>
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<tr>
<td></td>
<td>&gt;1 year</td>
<td></td>
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<td></td>
<td>(4) 2 high school students</td>
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<td>(5) 9 non-Indigenous residents in Aklavik</td>
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<td>&lt;1 year</td>
<td></td>
<td></td>
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<tr>
<td>Total</td>
<td>n = 50 interviews</td>
<td>n = 6 interviews</td>
<td>n = 56</td>
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Anthropologists (Kleinman 1988; Donatuto, Satterfield & Gregory 2011) have argued for the importance of theorizing lay knowledge as narratives “which have embedded within them explanations for what people do and why…” (Popay, Williams, Thomas, et al. 1998:619). Aklavik, a place where people “Never Say DIE!” is also home to a cemetery that is filling up with cancer fatalities. Within a narrative framework, Popay
and her colleagues emphasize the importance of understanding “place” as a site where macro-social structures connect to individuals through daily life (1998:619, 633-634).

Within Aklavik, these macro-social structures help to shape the processes of cultural interpretation of *H. pylori* infection within a broader context of local ideas about cancer and contamination and Aklavik’s social memory as an Indigenous community that has been contaminated physically as well as socially from decades of colonialism. Within this larger milieu, individuals incorporate personal ideas of vulnerability, and the politics of identity (what it means to be an Indigenous resident or a non-Indigenous resident in Aklavik), into their perceptions of *H. pylori* infection risk (Nichter 2001:102). Ethnographic research can shed light on local perceptions of vulnerability that entail emotional, social, and spiritual – as well as material – aspects of daily life (Nichter 2008:112), and thus can be used to illuminate the cultural interpretative process from the macro- as well as the micro-levels. Insofar as Aklavik is viewed as a high-risk place for contracting *H. pylori* infection and stomach cancer, I have attempted to understand how Indigenous residents view contamination in terms of the community’s century-long struggles with colonialism and the perceived environmental and social degradation of boom-and-bust development in the Arctic.

5.4: Theoretical framework

Interview and focus group data for Aklavik were analyzed using qualitative narrative analysis seeking to understand participants’ views of their own experiences with *H. pylori* diagnosis or treatment, or more broadly concerning their knowledge of the AHPP. This
type of analysis aims to reveal the socio-cultural configurations of risk meanings that are dynamic, fluid, and can change over time or depending on social context (Henwood, Pidgeon, Parkhill, et al. 2011), and that sometimes occur as “contradictory layers of meaning” (Squire 2008:5). Additionally, participants were asked to speak about health and illness more generally in Aklavik, enabling them to connect their personal biographies to Aklavik’s larger, multi-vocal history.\(^5\)

Understanding Aklavik as the place that will “Never Say DIE!” is crucial for understanding local risk narratives that make up the nuanced and varied lay epidemiology expressed by local people (Jones & Moon 1993:515). To attend to risk as it is conceptualized by different groups in particular places and times requires operationalizing “culture” in a way that does not extract it from the lived contexts in which people interact with their narrative and material worlds.

Cultural anthropologist Clifford Geertz called culture a “fabric of meaning in terms of which human beings interpret their experience and guide their action” while “social structure is the form that action take[s], the actually-existing network of social relations” (1973:145). This is a useful way to consider culture in a study of risk production because it attends to how people wrap themselves up in the meanings that ultimately shape their behaviors. The term “fabric” also implies a materiality to culture. We are made of culture. This point corrects for the tendency in some of the public health

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\(^5\) Realizing that a single locale can be recognized as different kinds of places by different people, Rodman (1992) emphasizes the relevance of multi-vocality as one way to acknowledge and work around the limitations of a single writer’s account, and to correct for the tendency in ethnography to treat places merely as settings in which research subjects are encountered.
literature to treat culture merely as a collection of beliefs (DiGiacomo 1999) or as an external variable that can be somehow separated from age, sex, gender, ethnicity, or class (Trostle 2005:62). Thus, culture provides the framework of meaning from which social structures are defined, justified, and maintained (Geertz 1957).

5.5: *H. pylori* and risk perceptions

As Samet, White, and Burke (2006:126) recognize, “risk” is a specific construct in epidemiology that is used to translate evidence-based scientific findings into some sort of management strategy (e.g. a treatment or prevention strategy). As an anthropologist, I think it is equally important to understand how narratives of *H. pylori* infection and associated risk factors are translated from the “scaffolding” of previous research in epidemiology (Kelm 2010:198) that associates improved standards of living, and presumably improved population health, with the processes of Westernization/modernization\(^6\) that occurred over the 19th-20th centuries in many of today’s wealthy nations, and is ongoing in today’s “developing” nations. This is an important distinction to make because it is very much at odds with sentiments expressed by some residents of Aklavik, a place where community members have seen the damages to society and environment that can be caused by “development”, including abandoned

\(^6\) Within health and social science literature, “Westernization” is used somewhat interchangeably with “modernization” or “development”. Indigenous peoples are sometimes referred to as “non-Western”. Often these terms are used to establish a dichotomous relationship as when discussing differences in “Western” and “non-Western” ideologies, worldviews, cultures, or societies. This is problematic because it implies “non-Western” (e.g. Indigenous) societies and cultures are not modern (thus primitive). However, I use “Westernization/modernization” here to reference the myriad social, political, and economic changes that are occurring in developing nations as these adopt neoliberal politico-economic ideologies and practices.
military installations, dwindling fur prices\(^7\), and boom-and-bust mining projects in the Arctic. I now outline how “development”, standards of living, social inequities, and \(H.\) pylori infection are understood in different ways more broadly by epidemiologists across the world and by Indigenous Arctic peoples. I connect these larger meta-narratives to the particular narratives emerging within the AHPP, and then discuss how these narratives motivate and shape various behaviors in response to \(H.\) pylori infection and perceived risks.

5.5.1: \(H.\) pylori the pathogen

In much of the epidemiological literature from around the world, \(H.\) pylori is represented as a pathogen, an invasive species that causes gastritis in nearly everyone who is infected. Some science historians and philosophers point out that \(H.\) pylori does not have to be classified as a “pathogen” (Nunes, Pereira, Santos, et al. 2004). Instead, this same bacterium is

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\(^7\) Several Aklavik residents lament that fur prices have continually dropped throughout the twentieth century, to the point that most people cannot survive in today’s economy by trapping alone.
interpreted by a few scientists as a “symbiote” that maintains a “dynamic equilibrium” with its hosts. It has been hypothesized that this equilibrium may help regulate the human immune and digestive systems, and depending on the strain, and where in the human stomach \textit{H. pylori} organisms concentrate, may confer protection against a subtype of esophageal cancer (Atherton & Blaser 2009; Blaser 2006; Blaser & Kirschner 2007) (Figure 5.2). More recently, Mishra (2013) has questioned whether \textit{H. pylori} infection is “good or bad?” in light of the evidence that the bacterium only causes disease in approximately 20% of those who are infected. Thus, there is no single biomedical view toward \textit{H. pylori}, but varied cultural models that develop within the many social networks of biomedicine.

Today, there is not much dispute about whether \textit{H. pylori} is a pathogen under certain circumstances. There is also a growing awareness that \textit{H. pylori} may be part of the normal human gastric microbiome. As the plurality of biomedical views toward \textit{H. pylori} infection and its human health consequences continues to evolve, questions about how (or whether) to treat the presence of the bacterium in high- or not-so-high-prevalence populations continues to be debated.

Still, the bulk of the \textit{H. pylori} literature classifies this bacterium as a pathogen, one that is sensitive to the improvements in standards of living that are presumed to accompany national socio-economic development. Industrialization and socio-economic development following War World II in North America and Japan that led to improved national wealth, and improved public sanitation, is believed to have decreased the prevalence of \textit{H. pylori} (Ahmed, Khan, Ahmed, \textit{et al}. 2007). Epidemiological studies
within Japan often relate changing patterns in *H. pylori* prevalence to “rapid change in sanitary conditions after World War II” (Malaty, Kumagai, Tanaka, *et al.* 2000:1973), or to other similar “dramatic social transitions in Japan over the past half century” that “provide a unique opportunity to examine evidence for a cohort effect associated with changes in the standard of living” (Replogle, Kasumi, Ishikawa, *et al.* 1996:210-211). A similar narrative is constructed for post-soviet Russia. A study in St. Petersburg that followed the same children from 1995 and 2005 found significantly decreased *H. pylori* prevalence over time. The authors conclude this is likely the result of changing socio-economic conditions following the introduction of democracy to Russia (Tkachenko, Zhannat, Erman, *et al.* 2007).

These ideas are reflected in the more recent *H. pylori* literature concerning Indigenous communities in the Arctic. Initial household questionnaire data from Aklavik indicate that Indigenous ethnicity, socio-economic status, education attainment, employment, household crowding, and bed-sharing are the most significant risk factors for exposure to chronic *H. pylori* infection (Aplin, Fagan-Garcia, Chang, *et al.* 2010), although when controlled for other factors, income rather than household crowding is still the most significant factor related to *H. pylori* infection (Goodman 2013, personal correspondence). During a focus group interview, one CANHelp researcher observed that the work being done on *H. pylori* is being fitted into broader understandings of the role that “standards of living” plays in changing patterns of population health over time:

**Researcher:** *I think that* [as a result of publishing our findings] *there is a danger of perpetuating sort of the same answer of well,*
you know, poor hygiene. And a lower standard of living is related to H. pylori. And oh, look, these northern communities have a lower standard of living. Whether that’s – I mean that’s not different than anything we hear about any other diseases. You know, like, the TB literature is the same.

In Aklavik, as elsewhere, epidemiologists continue to find strong associations between deep social inequalities and deleterious health consequences. Observations like these are more broadly woven into a larger metanarrative within biomedicine – a narrative in which “under-developed” or “developing” nations and Indigenous populations are presumed to be transitioning toward more “modern” (sometimes called “Western”) socioeconomic and political organization. As Indigenous health historian Mary-Ellen Kelm eloquently puts it, this “picture that emerges is alarming not so much because it is new as because it is so old” (2010:194). Within the Indigenous health literature there emerges a picture of Indigenous peoples and cultures as vulnerable and unable to adapt to rapidly-changing circumstances. Such an image embraces ideas of social evolution, cultural diffusion, and assimilation that were abandoned in the twentieth century by anthropologists who began to re-conceptualize “culture” as fluid and adaptive systems of human meaning-making (Warry 2007:87-89). The challenge becomes how to describe obvious health inequalities in Indigenous populations without further essentializing them as static, endangered, dying cultural groups that are unable to keep up with a rapidly changing world. To understand that social inequities associated with high prevalence of H. pylori in Aklavik are the results of a long-standing relationship between colonialism and national development in Canada is to bring evidence-based epidemiological
understandings of *H. pylori* infection closer in line with local Indigenous perceptions that “development” in the Arctic has not been the gift it is perceived to be elsewhere.

Table 5.2: Comparing Indigenous narratives of cancer and *H. pylori*, Aklavik, NWT.

<table>
<thead>
<tr>
<th>Descriptions</th>
<th>Cancer narratives</th>
<th><em>H. pylori</em> narratives</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Descriptions</strong></td>
<td>Germ</td>
<td>Germ, bacteria, bug</td>
</tr>
<tr>
<td></td>
<td>Pollutant</td>
<td>Pollutant</td>
</tr>
<tr>
<td></td>
<td>Contaminant</td>
<td>Contaminant</td>
</tr>
<tr>
<td></td>
<td>Sickness caused by contamination</td>
<td>Sickness caused by contamination</td>
</tr>
<tr>
<td></td>
<td>Infection</td>
<td>Stomach cancer</td>
</tr>
</tbody>
</table>

| Perceived sources                   | Contaminated water | Contaminated water    |
|                                     | Contaminated land  | Contaminated land     |
|                                     | Contaminated animals | Contaminated animals |
|                                     | Smoking            | Germs                 |
|                                     | Bad diet*          | Kissing               |
|                                     | Bad lifestyle      | Not washing hands     |
|                                     |                   | Sharing food          |
|                                     |                   | Bad diet*             |

| Prevention strategies               | Avoid contaminated places | Avoid contaminated places |
|                                     | Filter or boil water     | Filter or boil water   |
|                                     | Avoid eating fish with red spots on the liver/belly | Avoid sharing food with people who test positive |
|                                     | Eat well, exercise      | Avoid going to houses where residents are positive |
|                                     | Quit smoking**          |                       |

| Was this a problem in the past in Aklavik? | No, not prior to the mid-twentieth century | No, not prior to late twentieth/early twenty-first centuries |

| Origins of disease/disease agent     | External | External |
|                                     | May travel down river from southern Canada | May travel down river from southern Canada |

**"Bad diet" refers to eating too many processed and junk foods from the store, or eating contaminated country foods. The high nitrate content of smoked meats and salted meats were never identified in interviews.**

**Only one resident specifically named smoking as a risk factor for stomach cancer. No residents identified smoking as a risk factor for *H. pylori* infection.**
Finally, it is important to realize that biomedical and epidemiological perceptions of *H. pylori* reach well beyond disciplinary boundaries. The biomedical narrative is fluid and flexible, but not exclusive. It may be incorporated along with perceptions of contamination. Most of Aklavik’s non-Indigenous residents (excluding nurses) hear about *H. pylori* for the first time upon arrival to the hamlet. When these newcomers hear about local concerns over water and contamination, they rationalize this information through a cultural lens that values individual responsibility for maintaining health:

**RCMP officer:** *So I’m thinking if it’s in the water, em, that a lot of us live relatively healthy lifestyles and that that’s a small contributing factor to getting any [infection]. Whereas, my view is that you’re eating healthy and you’re living a healthy lifestyle, that uh, [H. pylori] infection is pretty non-existent. Like, I wouldn’t worry about it… I just figured that it would affect more people that are not looking after themselves, or health.*

In a focus group I led with non-Indigenous residents who have lived in Aklavik for less than one year (“newcomers”), there was a general consensus that *H. pylori* bacteria might be in the settlement’s water supply, and my interlocutors reported learning this from their Indigenous neighbors. However, there was also consensus that *H. pylori* infection is not a problem in much of southern Canada *because* the rest of the nation is more economically developed. One interlocutor suggested building a road to Aklavik and opening the hamlet

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8 The majority of Aklavik’s non-Indigenous residents are Euro-Canadians who come to Aklavik to take jobs as teachers, nurses, RCMP, or missionaries and typically live in the community for a few years before moving to another northern community, or returning to southern Canada for other jobs or to be with their families.
up to tourism would improve community health by improving the economy and raising local standards of living.\textsuperscript{9}

**Table 5.3** Comparing local and outsider narratives of *H. pylori* and risk perceptions.

<table>
<thead>
<tr>
<th>Aklavik narratives</th>
<th>Outsider narratives</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Indigenous residents</strong></td>
<td><strong>Non-Indigenous residents</strong></td>
</tr>
<tr>
<td><strong>Descriptions</strong></td>
<td></td>
</tr>
<tr>
<td>Germ, bacteria, bug</td>
<td>Germ, bacteria, bug, virus</td>
</tr>
<tr>
<td>Pollutant, contaminant</td>
<td>Infection</td>
</tr>
<tr>
<td>Sickness caused by contamination</td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td></td>
</tr>
<tr>
<td>Stomach cancer</td>
<td></td>
</tr>
<tr>
<td><strong>Perceived infection sources</strong></td>
<td></td>
</tr>
<tr>
<td>Contaminated water, air</td>
<td>Contaminated water, air</td>
</tr>
<tr>
<td>Germs</td>
<td>Germs</td>
</tr>
<tr>
<td>Not washing hands</td>
<td>Not washing hands</td>
</tr>
<tr>
<td>Sharing food</td>
<td>Sharing food</td>
</tr>
<tr>
<td>Bad diet</td>
<td>Immune systems (due to bad diet, bad lifestyles)</td>
</tr>
<tr>
<td>Kissing</td>
<td></td>
</tr>
</tbody>
</table>

* excludes Aklavik’s nurses, as they possess a biomedical background that other non-Indigenous residents do not.

\textsuperscript{9}Some Indigenous residents speak about building a road to Aklavik from the Dempster Highway that goes to Inuvik, and several would also like to develop a local tourist industry. Still, others say they do not want a road because they do not want Aklavik to get too big, like Inuvik.
Further, within this focus group, there was consensus that *H. pylori* should not be much of a threat for people who choose to lead healthy lifestyles. Although accepting of local perceptions that *H. pylori* may be in the water, these non-Indigenous newcomers translate contamination through a scientific lens that emphasizes individual responsibility for minimizing risk and similarly assumes that, generally speaking, improved standards of living should accompany processes of modernization and development (Table 5.3).

5.5.2: *H. pylori* the contaminant

To many Aklavik residents, *H. pylori* is understood to be a contaminant that can infect water as well as the bodies of animals, including humans. Ideas of contamination, particularly through water, permeate conversations people have regarding *H. pylori*, as well as cancer, and are unique from non-Indigenous perceptions of contamination. Water plays an integral role in the lives of the many Indigenous peoples who call the Mackenzie Delta their home:

“For thousands of years people have travelled the trails of our ancestors on the many waterways by canoe, carrying their worldly goods on their backs over many portages. People depended on the land and water and they passed on that knowledge to assure continuity. They had an intimate relationship with the Earth as they travelled from one body of water to the next, at the same time replenishing the body with clean water...There is a sense of serenity in knowing that water is what keeps the Earth alive. This notion is quickly shattered with the reminder that the reality of modern-day living can be an increasing threat” (Zoe 2012).

In Inuvialuit and Gwich’in cultures, human bodies are connected to the many bodies of water in the Mackenzie Delta region. Human bodies travel upon the water to
move from camps to winter homes to the houses of relatives. And water travels through human bodies as well – through the water people drink and through the bodies of animals people eat. When pollutants are introduced, they follow these same paths, traveling through waterways and through human bodies, as this Aklavik resident explains:

**Inuvialuit man:** I go down whaling soon, maybe. I don’t eat whale. But I’ll hunt it if that’s what mom and them want.

**Sally Carraher:** Why don’t you eat whale?

**Inuvialuit man:** Cancer. It causes cancer, I think... That’s why people get cancer. They eat the whale and the whale ate the fish, and toxins build up and up. The herring have toxins. I don’t eat herring. And the whale eats herring.

Pollutants are often talked about in the context of development projects in the North like the old Navy base at Aklavik, or the Distant Early Warning (DEW)-line north of Aklavik, where a lot of equipment and other artifacts were left over after the sites were abandoned in the twentieth century. Contamination from the DEW-line sites is believed to have caused cancer in several people:

**Gwich’in woman:** Yeah, so they didn’t know what was happening. And they have a lot of buried stuff, eh? ...Even down at the DEW-line site, like at Shingle Point... They have a lot of um, uh, stuff, buried under the ground. A lot of stuff. And one time I know that they have hard crates and I think they tell the people down there, you can take these crates and take them apart and use them for your cabins. And some people did that. And then those crates, they were contaminated...So, a lot of those people, down there, end up with cancer. And they all died...all the people that had the cabins.

Iñupiat residents around the Kotzebue area in northwest Alaska have raised similar concerns over contamination from abandoned military and resource development
projects in the North (Cassady 2007; 2008), as have Inuit in Kivalliq, Nunavut (Tyrrell 2006). In Aklavik, contamination is also perceived to be traveling to the Arctic through processes of global climate change, through the water and the air. Viewed in this context, *H. pylori*-the-contaminant appears, literally, to travel downstream, in the Mackenzie River and its vast system of channels. Figuratively, it travels to Aklavik as local Indigenous peoples experience the trickle-down environmental and economic effects of boom-and-bust development projects in the NWT. This is a different way of understanding “development” from how it is often viewed by non-Indigenous Canadians, although several First Nations communities in southern Canada express similar concerns (see Stephens 2009). My Indigenous interlocutors often speak about being forced to adjust to “White” ways. This process is seen as having first brought infectious diseases such as influenza and tuberculosis, and now cancer, from the outside into their community.

Contaminated water is seen as a consequence of “development”:

**Gwich’in/Inuvialuit man:** The water. They add more chemicals to it. 'Specially during times of the year. More chemicals in the spring and fall, to keep the dirt out. You can smell it. Don’t know if chlorine is really good for you.

**Gwich’in woman:** Take a sample of the water. Yeah. You know when it like, floods, or...from the work sites, from around. I mean the water too, that gets used from the tap, for cooking. That also...When I do the dishes, I can smell that em, chem, chemical. Chlorine.

Many want scientists to come to the community to test the water in the river, at work sites, and in people’s homes. Some people think scientists should also look for *H. pylori* in the caribou and in the land:
Gwich’in man: Nobody knows until they start doing tests in Aklavik. All these scientists doing studies down in Edmonton and across Canada. It would be good to study stuff in Aklavik. Maybe there’s something giving it [cancer] to people.

Sally Carraher: What sorts of things do you think the scientists should study?

Gwich’in man: [shrugs shoulders].

Sally Carraher: ...Are there certain things that you’re worried might be causing cancer? Certain things that you think scientists would be able to study?

Gwich’in man: I don’t know. Get them up here and see if there’s...if it’s in the water. Food. Maybe it’s on the land.

Risk narratives contain elements that are entangled in both Indigenous and biomedical cultural contexts, but are simultaneously entrenched in the social memory that Aklavik is a place that has been damaged by Westernization, and is still vulnerable to the negative consequences of “development” (e.g. climate change, water pollution). Many of Aklavik’s Indigenous narratives of H. pylori and contamination use scientific terminology (contaminant, pollutant, bacteria, infection, transmission), and draw upon scientific concepts such as bioaccumulation, in which “toxins build up and up” in the marine food chain (Table 5.2). However, these words and concepts are used to express Inuvialuit and Gwich’in ideas that humans, animals, water, and the land are connected spiritually and culturally, as well as physiologically. If one component of this integrated system is contaminated, then all other components are at risk.

5.7: Culture, agency, and pragmatics in risk-avoidance behaviors
In situations where little choice exists, people develop coping strategies that favor misfortune and illness being interpreted in particular ways (Nichter 2008:9). Some of Aklavik’s Indigenous residents reject the idea that crowded living conditions are an important risk factor in *H. pylori* transmission, favoring instead risk narratives that emphasize contaminated water. This in turn encourages water purification practices and participation in the AHPP. I now discuss how pragmatism and agency contribute to Aklavik’s contamination narrative. This is wonderfully illustrated in a conversation between two friends who grew up together in Aklavik:

**Gwich’in woman A:** Do you see the thing that kind of makes me wonder sometimes too, is like going back to what I was saying. Water. ’Cause everybody drinks water. But in a household, say if you have five people in the household, three could be positive. Two won’t. You see? So it makes you wonder sometimes. What’s really causing this *H. pylori*? The whole idea is just… [shakes her head].

**Gwich’in woman B:** Because is it overcrowding too, in the household? You know when there’s so many of them?

**Gwich’in woman A:** I think we’re OK in our community. ’Cause we’re not overcrowded people. A lot of people got their own homes. And their kids move on…That’s what I think about the household. If two could be positive and three won’t be. And then we say it’s water and then they say that’s crowding. But the reason I say water is because everybody drinks water. I thought that’s where it’s gonna come from.

Biomedical constructions of risk that emphasize household crowding and bed-sharing clash against Indigenous risk constructs that emphasize environmental contamination. The very idea that Indigenous families are “over-crowded” in the first place rubs uncomfortably against local knowledge of how Inuvialuit and Gwich’in
families have always lived and shared spaces together. Old tipis, camps, and even the first permanent houses in the early twentieth century were single-room structures in which two-, three-, and four-generations lived and cooked, talked, and slept together. Currently, everyone in Aklavik lives in at least a one-bedroom apartment with a separate kitchen and bathroom, and families today do not typically have as many children as families did 50 years ago. Because \textit{H. pylori} infection is viewed locally as a more recent phenomenon, the idea that overcrowding and bed-sharing pose a risk, in a place where people are arguably less crowded and have more private spaces today, just does not make a lot of sense. Moreover, the concept of over-crowding is \textit{frustrating} to many residents. Because Arctic settlements like Aklavik consistently experience housing shortages and a dearth of employment opportunities, there is no simple or immediate solution for crowded housing. But people \textit{can} choose where to get and how to treat their water. Thus matters of practicality, opportunity, and personal agency appear to be contributing to a contamination-risk narrative, from which water-use behaviors are developed as a coping strategy. One Inuvialuit couple explains how they minimize their risk of exposure to \textit{H. pylori}:

\textbf{Inuvialuit wife:} Yeah. Now 'lot of people are, like, buying water instead of having it through their tanks. We see different types of like, water purifiers or whatever. Like after they found out about that high rate of \textit{H. pylori}. More and more people are buying water.

\footnote{When collecting kinship and family composition data during fieldwork, I realized that families in the early 1900s often had anywhere from 7 to 15 children. Families over the last two decades often only have 3 to 7 children. However, adoption has been and continues to be common, and a foster care system was introduced in the twentieth century. I describe family composition and kinship organization in Aklavik in other work (see Chapter 6).}
Inuvialuit husband: Yeah. The way they’re saying people are really getting a lot of water that way. Boiling it quite a bit too. Boiling our water...every time we’re going to cook, we take it out of the hot water tank and let it run for a few minutes ’til it get real hot. I’ll take it out of there. Then we cook.

Pragmatic considerations also lead some of the non-Indigenous population to adopt similar coping strategies to protect themselves from contaminated water:

Non-Indigenous teacher: I also thought water, and then I did have people telling me that [H. pylori] was associated with low socioeconomic status. But then we had found out that a teacher [from southern Canada] last year contracted it, so that kind of tainted my view of where it’s coming from...The kids [at school] all say water.

This teacher also reports boiling and then filtering all the water he uses in his household for drinking, cooking, and washing the dishes.

Finally, participation within the AHPP should be considered as another coping strategy that incorporates individual as well as community agency into local residents’ risk perceptions. An overarching narrative of contamination, which is seen as a consequence of development projects and colonial history in the North, pre-dates Aklavik residents’ knowledge of H. pylori infection. This painful heritage provides much of the cultural fabric that fits H. pylori into a narrative of contamination – but it is also a heritage that has motivated the community to form the AHC, to speak up and to demand research be conducted on H. pylori in their hamlet. Although it is not a direct way to avoid H. pylori transmission, it is perceived of by residents to be a way of reducing H. pylori infection and stomach cancer for the entire community.
As Slovic points out, “Whoever controls the definition of risk controls the rational solution to the problem at hand” (1997:95). It is important to understand the ways Aklavik, home to the people who “Never Say DIE!”, exercises agency by creating a repertoire of risk-avoidance behaviors (see Table 5.2). These strategies for coping with risk range from purifying household water, to avoiding places believed to be contaminated (like the cabins made from wood crates mentioned by one Gwich’in resident above), to participating in AHPP research and submitting to numerous tests, treatments, and follow-up tests. Ultimately, peoples’ decisions to participate in the AHPP can be traced back to the community’s desire to pinpoint the source of *H. pylori*, because in accomplishing that, local people would have the power to control their own risk:

**Inuvialuit Elder:** Well, if we knew where it came it from, we’d know to avoid where to get it. You know, where we’re getting the *H. pylori* sickness? It’s stomach cancer! I tell you I’d avoid it if I knew where it was coming from.

### 5.8: Reframing risk in community-driven epidemiology

This research demonstrates that there are multiple, nuanced ways of perceiving and knowing *H. pylori* infection. Risk narratives and risk-avoidance behaviors cannot be attributed only to differences in worldview or cultural background. This is demonstrated by non-Indigenous residents who filter their water to avoid contamination, but simultaneously believe that the problem of *H. pylori* infection would be reduced if Aklavik were more economically developed and if more residents were to make healthier lifestyle choices. Sometimes, evidence-based knowledge of risk factors is rejected by Aklavik’s Indigenous residents, but not necessarily because it is perceived to be untrue.
(one Gwich’in woman quoted above acknowledges that many people must live together in small houses). Instead, “household crowding” is rejected because it is framed in a way that: 1) fails to address local concerns over contaminated water, and; 2) because the concept of crowding conflicts with Inuvialuit and Gwich’in social norms and cultural values surrounding family composition. I now describe the problems with “household crowding” and outline suggestions for reframing this risk factor to improve research communication.

5.8.1: Household “crowding” versus “density”

In the AHPP, household crowding was defined in three ways: the number of people reported living in a household; the number of children reported living in a household; and the number of people per bedroom (Fagan-Garcia, Geary, Goodman, et al. 2010). The authors found “low socio-economic status and household crowding to be associated with increased odds of H. pylori infection” (Aplin, Fagan-Garcia, Chang, et al. 2011:S230), particularly the highest odds were observed in households with three to six children, or with two or more people sharing the same bedroom.

Førde (1998) argues that epidemiologists should hold themselves accountable for how their research findings are interpreted by the public. The notion that crowding is a risk factor is rejected by some of Aklavik’s Indigenous residents. “Crowding” is a value-laden term that implies that living with many people in a single household is neither normal nor healthy. In communities that value having many children and living with extended kin, it may be more appropriate to discuss how infections can spread when
household “density” is above a certain number of persons per bedroom, or persons per bed. Density is one way to explain the strong association consistently found in epidemiology between living in relatively small spaces with numerous people and elevated prevalence of diseases; one that emphasizes the quality of housing available as a risk factor, rather than implying (even inadvertently) that there is something potentially unhealthy about Indigenous family structures. Reframing the risks of household density is not a simple matter of using a new term. KT efforts in Aklavik over the next year should aim to explain how density is defined and measured, and explain how the issues of housing quality will be discussed in policy recommendations that will emerge from the AHPP findings. I am working with other co-investigators in the CANHelp Working Group to develop follow-up study in Aklavik that will investigate local kinship organization and shifting household density over time (see Chapter 6), as well as continue to develop new KT strategies for communicating research findings and assessing community feedback.

5.9: Conclusions

In as far as Aklavik is viewed as a high-risk place for contracting *H. pylori* infection and stomach cancer, I have attempted to understand how Indigenous residents view contamination in terms of the community’s century-long struggles with colonialism and the perceived environmental and social degradation of boom-and-bust development in the Arctic. This perspective emerges as individuals who identify (and are identified by others) as *Indigenous* connect their personal biographies to the collective social memory of Aklavik as a place that has been contaminated by colonialism and Westernization. In this
sense, the contamination narrative cannot mean the same things to non-Indigenous residents who have very different personal heritages, but this does not prohibit non-Indigenous residents from borrowing the idea of contaminated water, and then adopting similar risk-avoidance behaviors. Risk narratives are living and fluid, and can be shared, adopted, reformed, or rejected as individuals incorporate their personal biographies into the larger story of the community that will “Never say DIE!”

As I argue above, one major challenge for the CANHelp Working Group is to describe obvious health inequalities in Indigenous populations that are strongly associated with *H. pylori* prevalence and gastric diseases and to communicate epidemiological knowledge of risks in ways that do not offend Indigenous cultural values and practices (e.g. family composition). To understand that social inequities associated with high prevalence of *H. pylori* in Aklavik are local consequences of colonialism and national development in Canada helps to bring epidemiological understandings of *H. pylori* infection closer in line with Indigenous understandings. To incorporate ethnography into the AHPP’s ongoing work to communicate risks in ways that are attentive to local knowledge and history helps to further project goals of building a shared foundation from which *H. pylori* research knowledge (and ultimately, policy recommendations) can be built collaboratively between researchers and participants. This is particularly important to ongoing KT work within the CANHelp Working Group, and is important for promoting long-term research participation as a type of positive coping strategy. Ethnographic research can identify, describe, and explain these different perceptions of risk and how these are translated into a particular repertoire of coping strategies, and thus
is crucial for the process of re-framing risk perceptions and methods of risk communication.

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**Kin Preface to Chapter 6**

In Chapter 5, I examined divergent risk narratives that view the *Helicobacter pylori* bacterium as a “pathogen” or a “contaminant”. After describing the range of risk-avoidance strategies that Indigenous residents have developed in response to their risk perceptions, I outlined strategies for improving ongoing Aklavik *H. pylori* Project knowledge translation (KT) and data dissemination activities. Particularly, I described why Indigenous participants reject “household crowding” (a classic risk construct within epidemiology) and I advocated for reframing crowding as “household density”. In Chapter 6, I return to the construction of risk within epidemiology and examine socio-economic risk factors from an ethnographic perspective that focuses on local kinship organization. I then outline a new model for analyzing risk factors at the multi-household kin group levels, and layout a method for collecting ethnographic and epidemiologic data that will more accurately capture family and residential dynamics than current household-level analyses. This new approach still allows for analysis of household density and *H. pylori* infection risk, but it also addresses problems in assessing shifting household residency and family composition in long-term research. This research is based on 10 months of participant observation in Aklavik, NWT, epidemiological data collected in the original AHPPH *H. pylori* screening (Goodman, Jacobson, Velhuyzen van Zanten, *et al.* 2008), and our recent incidence and re-infection study (Carraher, Chang, Munday, *et al.* 2013, in press). I am the sole author of this chapter, which will be submitted to the *International Journal of Circumpolar Health* in the fall of 2013.
Chapter 6

Ethnographic Epidemiology in the Aklavik \textit{H. pylori} Project: A Case Study of Extended Kin Networks, Household Living Conditions, and \textit{H. pylori} Infection

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Abstract

\textit{Helicobacter pylori}, the bacterium that lives in the human stomach of over half the world’s population and can cause peptic ulcer disease and stomach cancer, is most prevalent amongst the world’s most marginalized populations. Working in the Northwest Territories of Canada as an applied medical anthropologist for the CANHelp Working Group on the Aklavik \textit{H. pylori} Project, I use ethnography to explore why particular groups within Aklavik’s Indigenous population are at “higher risk” for chronic \textit{H. pylori} infection and re-infection. Epidemiologists often investigate disease and associated risks using the household as the unit of analysis. However, in many Indigenous Arctic communities, families are socially and economically organized into large extended kin networks with relatives who share resources (cash, tools, equipment, and food) and responsibilities (child rearing) across several households. Using three extended families as case studies, I present an alternate method of tracing \textit{H. pylori} infection and risk factors within multi-household kin groups that can be followed over time.

Keywords: Ethnography, risk factor epidemiology, \textit{H. pylori} infection, kinship, Arctic, social inequities in health

6.1: Introduction

To date, few medical anthropologists have contributed to research on the health inequalities associated with \textit{Helicobacter pylori}\textsuperscript{1}, the bacterium that lives in the stomachs of over half the world’s human population and causes peptic ulcer disease and

\textsuperscript{1} Physical anthropologists, along with microbiologists specializing in ancient DNA studies, have shown an interest in \textit{H. pylori} bacteria not as it pertains to contemporary human health, but rather as a means of re-tracing ancient human migrations through molecular typing of \textit{H. pylori} strains (Domínguez-Bello, Pérez, Bortolini, \textit{et al.} 2008; Wirth, Wang, Linz, \textit{et al.} 2004). Outside of physical anthropology, medical anthropologists have made passing mention of \textit{H. pylori} as a public health concern (see Brown, Armelagos&Maes 2011:255).
stomach cancer (Perry, de Martel, Parsonnet, et al. 2009). This is somewhat surprising given the discipline’s high level of concern for social inequities in health, as *H. pylori* infection and stomach cancer have been shown to be most prevalent amongst many marginalized populations in Asia, Africa, South America (Khalifa, Sharaf, Aziz, et al. 2010), and in the Arctic (Goodman, Jacobson, Veldhuyzen van Zanten, et al. 2008). Many of these populations are politically and socioeconomically marginalized, including several Indigenous communities living in the circumpolar North. Whatever the reasons for the lack of attention so far, the consistently strong association of *H. pylori* and social inequities makes this a subject ripe for theorizing in medical anthropology. Because the mode of transmission of *H. pylori* remains unknown, there is a need within the *H. pylori* literature to critically examine how socio-economic risk factors are perceived, understood, and studied – especially when researchers are working in populations from different cultural backgrounds where communities are socially organized in different ways from those of the researchers.

Anthropologists, particularly researchers using the methodology of ethnography, have traditionally utilized “vertical” methodologies, in which the ethnographer studies a few groups at the household, family, or village level in great detail to better understand how numerous social living conditions are related and influence each other (Dunn & Janes 1986:7). Inhorn and colleagues (2009:169-170), for instance, who studied traditional consanguinity, the modern fertility science industry, and high rates of male infertility in Lebanon, demonstrated the power of ethnographic epidemiology to quantify and identify social factors that place people at greatest risk for health problems, while also
interpreting *why* certain individuals, families, social strata, or cultural groups are at “higher risk” of infertility in the first place. Their work, along with that of several others (e.g., Fleck & Ianni 1958; Hahn 1995; Trostle 2005), speaks to the multiple ways in which ethnography and participant observation can be incorporated into epidemiological research. Because of the importance medical anthropologists place on explaining emic perspectives and on understanding how people organize themselves within overlapping, multi-layered social networks, ethnographic methods can be utilized in conjunction with epidemiological methods to better understand how *H. pylori* infection is distributed within high-prevalence populations. An ethnographic approach can also be highly useful in small settlements that do not lend themselves to rigorous statistical analysis.

6.1.1: The Aklavik *H. pylori* Project

The Aklavik *H. pylori* Project (AHPP) examines the high prevalence of *Helicobacter pylori* infection and its association with diseases including stomach cancer in a culturally diverse Indigenous hamlet in the Northwest Territories, conducted by the *Canadian North Helicobacter pylori* (CANHelp) Working Group. The CANHelp Working Group was formed in 2006 in response to urgent requests from community members in Aklavik to investigate the bacterial infection residents had heard was related to several local cases of stomach cancer. The AHPP is a community-driven collaborative study between health care providers, Indigenous government representatives, the locally-organized Aklavik Health Committee (AHC), and University of Alberta researchers in epidemiology, gastroenterology, pathology, and microbiology. In 2010, I joined the AHPP as a medical anthropologist and ethnographer to conduct a follow-up incidence and re-infection study.
with project participants (Carraher, Chang, Munday, et al. 2013, in press), and to work with other project investigators on knowledge translation (KT) and data dissemination efforts. I lived in Aklavik for 10 months between September, 2011 and June, 2012 and engaged in participant observation to explore in greater depth the relationship between several socio-economic risk factors and *H. pylori* infection identified previously by the AHPP (Aplin, Fagan-Garcia, Chang, et al. 2011a; 2011b). These risk factors include “low annual household income,” “education,” “crowding,” “bed-sharing,” and “Aboriginal ethnicity”.

Some risk factors are less controversial and easier to interpret (income) than others (Indigenous identity). The AHPP has one monumental challenge: people want to know why Indigenous residents suffer from higher infection and cancer rates relative to their non-Indigenous neighbors, but they are also concerned that research findings may paint negative images of Indigenous peoples, cultures, and communities. As I have discussed elsewhere (Chapter 5), classic epidemiological risk assessments can potentially be offensive to Indigenous peoples (e.g. the notion that Indigenous families are “overcrowded” implies that having large families is not normal or healthy).

Initial AHPP urea breath test screening for *H. pylori* revealed a 58% prevalence rate amongst project participants (Goodman, Munday, Huntington, et al. 2009), with 65% of Inuvialuit participants (102/157) and 56% of Gwich’in participants (45/80), but only 25% of non-Indigenous participants (9/36) testing positive for infection (Goodman and Huntington 2009). Aklavik’s Indigenous residents were found to have higher prevalence of *H. pylori* infection along with elevated frequencies of erosions and ulcers in the gastric
corpus, severe gastritis, gastric atrophy, and intestinal metaplasia (Goodman 2010). The national average prevalence for *H. pylori* infection across Canada is approximately 30% (Jones, Sherman, Fallone, *et al.* 2004), meaning Aklavik’s non-Indigenous residents display an infection prevalence close to the national average. The lower prevalence amongst the non-Indigenous residents is not really surprising, as research strongly suggests that *H. pylori* infection is chronic and often established in childhood (Lehours & Yilmaz 2007), and the majority of Aklavik’s non-Indigenous population are born and raised in more affluent areas in southern Canada.²

As I planned an incidence/re-infection study with project participants in 2011-2012, the AHC raised questions about *H. pylori* infection and risk factors within the Indigenous population. We stratified our research sample of adults over age 15 (n=81) by self-identified ethnicity into categories “Inuvialuit,” (n=41) “Gwich’in,” (n=23) “Other Aboriginal,” (n=2), “non-Aboriginal” (n=9), and “declined to identify ethnicity” (n=6) (Carraher, Chang, Munday, *et al.* 2013, in press). Overall, we found that *H. pylori* infection has decreased amongst AHPP participants since the project offered a community-wide test and treatment trial. However, *H. pylori* infection continues to disproportionately affect some of Aklavik’s Indigenous population, particularly those households identified in earlier research as the most socio-economically disadvantaged. This begs two questions: How is Aklavik’s Indigenous population socially organized? How best do we measure socio-economic risk factors within this population?

²During my fieldwork (2011-2012), Aklavik’s non-Indigenous population was approximately 50 people (in a population of approximately 630). Most of them were not born or raised in the Arctic. Most of them come from relatively more affluent towns and cities in southern Canada, but a few are from other developed nations including the United States, United Kingdom, and Australia.
Since 2007, the AHPP has analyzed *H. pylori* infection and possible socio-economic risk factors at the individual and household levels. AHPP researchers concluded that “diverse or suspected risk factors for *H. pylori* infection, assessed at the household level, appear to be strongly associated with individual *H. pylori* status among residents of Aklavik” (Fagan-Garcia, Huntington, Goodman, *et al.* 2010:n.pag.). However, when I joined the team in 2010, little was known about how different households are related to each other within Aklavik’s Indigenous population, or whether health-influencing factors such as annual household income, education, and housing quality vary across larger kin networks that span multiple households.

### 6.1.2: Challenges to risk factor research

To use the single household as a unit of analysis is problematic in the Arctic, especially for long-term follow up of research participants. Several anthropologists have demonstrated that northern Indigenous communities cannot be accurately stratified into single household units for analysis. Craver, for instance, describes how modern-day Iñupiat in Alaska live in extended kin groups utilizing several households, finding that despite the introduction of permanent housing and sedentary living in the early twentieth century, “living under one roof is rarely an independent entity, economically or in other ways” (2004:50). Magdanz and Utermohle (1998) coined the phrase “cooperation networks” to describe Alaska Native kin-based resource sharing networks, in which multigenerational families live in several households individually headed by the children of a common ancestor – often an elder parent or grandparent who still heads their own household. Cooperative socio-economic networks are built into traditional kinship
structures for Inuvialuit living in Ulukhaktok, NWT (Collins 2011), and Gwich’in living in Arctic Village, Alaska (Dinero 2003).

Drawing from AHPP data on *H. pylori* infection and re-infection, household living conditions, and my fieldwork in the community, I present a case study of three Indigenous kin groups in Aklavik to discuss how income, education, employment, and even household occupancy are, in fact, shared across several households within larger extended kin groups. Finally, I critique the use of “Indigenous” identity/ethnicity when describing risk factor research, and make a case for the inclusion of medical anthropologists in *H. pylori* research.

### 6.2: Community background and kinship organization

Like many Indigenous communities in the western Arctic, Aklavik was first settled in the early twentieth century when the Hudson’s Bay Company established a trading post in 1912 to do business with regional Gwich’in and Inuvialuit hunters and trappers. Prior to that, the Gwich’in spent their lives moving seasonally along the various channels of the Mackenzie River, named by Euro-explorers after Sir Alexander Mackenzie. Western Inuit groups at that time included Copper Inuit and several Iñupiat bands who also traveled seasonally, following whales and other marine animals along the Arctic coast and up the Mackenzie River. Today, Inuit communities in the Mackenzie Delta collectively identify as Inuvialuit and are beneficiaries of the Inuvialuit Regional Corporation (IRC), which governs the Inuvialuit Settlement Region (ISR). The region’s Gwich’in are beneficiaries of the Gwich’in Settlement Area (GSA). Aklavik sits upon the border between these two Indigenous land claims (Figure 6.1).
In 1924, the Anglican Church of Canada established a mission in Aklavik, followed by a Roman Catholic mission in 1925. Residential schooling was introduced in the NWT in 1894; by 1936, the All Saint’s Anglican residential school was established in Aklavik. Aklavik by that time had been settled by several Gwich’in, Inuvialuit, and Métis families – into which several Europeans and Euro-Canadians married and from whom several of today’s families inherited their surnames. Public housing was introduced by mid-century, along with a welfare system that paid Indigenous families monthly allowances, but mandated that children be sent to residential school until age 16. In several interviews, residents over the age of 50 told me residential schooling, public housing, and welfare collectively led to social upheaval within many families, disrupting traditional practices of communication and social bonding between the generations and
interrupting normal patterns of daily and seasonal life, which has always been family-centered.

Although rapid social, economic, and cultural change occurred in the first five decades of the twentieth century, it is important to realize how various Indigenous families have maintained much of their traditional kinship organization and the cultural values and social responsibilities that go along with it. In fact, numerous Indigenous cultures across the Subarctic and Arctic have been able to rely on traditional kin organization as a resource for adapting to the introduction of a mixed-wage economy (see Dinero 2003; Craver 2004; Collings 2011). This is not to say that kin organization and family dynamics have remained unaltered by colonization. Adoption practices are a prime example of how traditional kin organization is both maintained and adapted in response to contemporary socio-economic change in the western Arctic. It is still common in Aklavik for young mothers to give their first born to their own mothers to raise. This type of intergenerational adoption is common in Inuvialuit as well as Gwich’in families. As one Inuvialuit senior explained to me, often the grandmother receiving the newborn had to give up her first born to her own mother a generation before. Therefore, she told me, the adoption of her daughter’s first born was like getting a daughter back. Adopted children will grow up calling their biological grandparents “mother” and “father”, and calling their biological mothers their “sisters,” which they do using English, Inuvialuktun, or Gwich’in terms. Some adoptions are still informal, but increasingly adoptions are made official.
through the territorial government, and may also include adoptions of more distant relatives, sometimes from other settlements such as Inuvik. Today, Aklavik also has a Social Work office that arranges for foster care for children removed from their birth homes, and these children may be placed with a family that is distantly related or even unrelated to them.

Household occupancy ebbs and flows with the changing seasons, a phenomenon common amongst Indigenous communities in the Arctic. In the summers many parents, grandparents, and aunts and uncles take children to hunt, trap, or fish at family camps and cabins scattered along the Peel River Channel. Some families do not go out on the Land as much, and stay in town for most of the year. In the winters, people ice fish close to Aklavik. During holiday seasons, especially around Christmas and Easter, most families are home and many receive visitors from neighboring communities to participate in Aklavik’s community feasts and carnivals. In some households, young and older adult men leave for months at a time to work for oil or mining companies. These men often stay with relatives in Inuvik or other communities as they pass through on their way to or from seasonal jobs. Women are more likely to pursue educational certificates or degrees in Inuvik at the Aurora College campus – and many stay with relatives in Inuvik during the week, coming home to Aklavik on weekends. In Aklavik, it is common for children to spend many of their meal times and nights sleeping in the homes of extended kin including the houses of older cousins, aunts and uncles, grandparents, or with their half siblings at another parent’s house. Therefore, the nuclear family is not as common in everyone uses Indigenous kin terms today, I did not analyze kin terminology as a part of my doctoral research.
Aklavik compared to parts of southern Canada. Instead, Aklavik’s Indigenous families organize themselves according to numerous possible family structures and flexible residential patterns.

6.3: Methods

6.3.1: Community-based research

Between September, 2011 and June 2012, I lived as a participant observer in Aklavik, NWT and worked weekdays at the Susie Husky Health Centre as a research trainee for the CANHelp Working Group on the AHPP. During that time I worked with a local Inuvialuit woman, Tammy Tyrrell, hired as a peer-researcher. Together, we coordinated all phases of research planning and data collection in consultation with the AHC. I reviewed questionnaire data collected from individuals and households in earlier AHPP research, and working with Tyrrell, we designed semi-structured interview questions, conducted interviews, and discussed initial findings with each other. Tyrrell and I also collected C-13 urea breath tests from participants to assess *H. pylori* incidence and re-infection following the AHPP treatment trial of 2008-2010.

6.3.4: Kinship and household social dynamics

To better understand how kin networks are organized in Aklavik, and how these systems affect individual- and household-level behaviors which may be related to *H. pylori* acquisition, I worked with Tyrrell and a few other knowledgeable community members to record the genealogy of all current residents, tracing some lineages back to the first families that originally settled in Aklavik in the early 1900s. Several events were held at the health centre, the school, and during the Elder Day Program to meet with community
members, explain the kinship portion of my research in more detail, and work with residents to chart family trees. As a part of my obligations to the community and to the AHC, I will deliver printed and electronic copies of Aklavik’s family trees for archiving in the Hamlet library. No medical information about residents or their families was discussed during these activities. During the data collection process, I began to realize *H. pylori* infection not only clusters in certain households, but also in larger kin groups that span several households and regularly socialize and share resources such as food, water, clothing, and bedding.

**Table 6.1:** Aklavik *H. pylori* Project household membership data were collected in household questionnaire surveys.

<table>
<thead>
<tr>
<th>Name</th>
<th>Relation to respondent</th>
<th>Lives away</th>
<th>DOB dd/mm/yy</th>
<th>Older sibs*</th>
<th>Place of birth</th>
<th>Years in Aklavik</th>
<th>School level**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Respondent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Number of older siblings born to the mother who raised this family member; **Highest grade or level completed.

Tyrrell and I developed genealogical charts for Aklavik to record information about three generations per respondent (respondent’s parents, siblings, and children), noting which relatives reside in the same house as the respondent (Figure 6.2, third column), as well as recording siblings’ and children’s relationships to the respondent as biological, adopted, or fostered (Figure 6.1, second column). Questions about residency in and outside of Aklavik, a respondent’s history of moving, and whether respondents live in private rentals, public rentals, or privately-owned houses were asked during interviews. Thus, our kinship charts capture much of the same information regarding household residency as the AHPP’s household questionnaires regarding household residency, but
also make it possible to identify kin networks that include relatives who do not currently live in the same household.

**Figure 6.2:** Genealogical chart created for Aklavik.

* On a subsequent page, the same information in the above table was collected for the respondent’s siblings, in order of birth.

### 6.3.3: Household density as a risk factor

During my ethnographic research I found that many Indigenous residents are resistant to the idea that household crowding is a risk factor for acquiring *H. pylori* infection. Residents reported disbelief that families today are “over crowded” (which is a value-laden term that references Eurocentric social norms regarding of the nuclear family), and residents also pointed out that large families can help each other by sharing food, other supplies, and caring for each other’s children and seniors. In Chapter 5, I suggest re-
framing household “crowding” to a measure of household “density.” Density still measures important indicators, such as the relative number of individuals per house, bedroom, or bed and it can be analyzed to produce adjusted odds ratios of risks. However, framing research results in terms of density emphasizes the potentially deleterious health effects of living in cramped housing conditions without (inadvertently) condemning Indigenous cultural values of raising large families that live in cooperative extended kin groups and often share resources across numerous households as a way of mitigating income and food insecurity. In this paper, I refer to household density, rather than crowding, and below I outline a model for assessing density that will capture fluctuating household occupancy as well as identify larger extended kin groups that include multiple households.

6.4: Individual and household level risk factor epidemiology

A previous AHPP study found low socio-economic status and household density are strongly associated with an increased odds of *H. pylori* infection (Aplin, Fagan-Garcia, Chang *et al.* 2011a:105). Similar relationships have been described for larger non-Western populations in India (Graham, Adam, Reddy, *et al.* 1991) and in numerous marginalized ethnic- and racially-classified populations in Asia, Africa, and South America (Bardhan 1997). Family size and household density have been shown to positively affect *H. pylori* infection status in Aklavik (Table 6.2), as well as in Mexico (Torres, Leal-Herrera, Perez-Perez, *et al.* 1998) and Denmark (Rosenstock, Anderson, Rosenstock, *et al.* 1996). Bruer, Sudhop, Hoch, *et al.* (1996) have demonstrated that
higher numbers of children living in the household increasing the risk of infection for the adult family members.

Table 6.2: Odds ratios for the association of selected household factors with individual \( H.\ pylori \) status (n=296).

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unadjusted OR (95%CI)</th>
<th>Adjusted* OR (95%CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of children in the house</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>1</td>
<td>0.82 (0.41-1.6)</td>
<td>0.76 (0.36-1.6)</td>
</tr>
<tr>
<td>2</td>
<td>0.98 (0.42-2.3)</td>
<td>0.98 (0.38-2.5)</td>
</tr>
<tr>
<td>3-6</td>
<td>4.6 (1.4-15)</td>
<td>4.2 (1.2-15)</td>
</tr>
<tr>
<td>Number of people per bedroom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;=1</td>
<td>1.0</td>
<td>1.0</td>
</tr>
<tr>
<td>1.01-2</td>
<td>1.5 (0.84-2.8)</td>
<td>1.4 (0.72-2.8)</td>
</tr>
<tr>
<td>2.01-3</td>
<td>4.0 (0.85-19)</td>
<td>3.1 (0.63-15)</td>
</tr>
</tbody>
</table>


It is clear that Indigenous residents in Aklavik, especially those experiencing more social inequities, are more likely to have chronic \( H.\ pylori \) infection (Aplin, Fagan-Garcia, Chang, et al. 2011a; 2011b). It is more difficult, however, to trace the social networks through which certain individuals are more regularly exposed to potential infection in their daily lives. Initial research in Aklavik was concerned with discerning how \( H.\ pylori \) infection was distributed in the community \textit{at that point in time}. This prevalence study indicated the burden of \( H.\ pylori \) infection in the community that was used to develop a treatment trial as well as provide needed data for an understudied region of Canada.

AHPP household questionnaires collected demographic information on all individuals
reported to be living in a participant’s household at the time of the survey, assigning each participating resident an ID number corresponding to a number assigned based on birth order for each house included in the study (Table 6.1). This is practical in that it provides a unique identifier for each participant that shows how participants in a given household are related to each other by birth order. However, these household residence lists are problematic for long-term follow-up research on *H. pylori* infection, as they do not capture changing household occupancy over time and do not enable researchers to trace how multiple households are related to each other.

Although household level analysis presents challenges to conducting follow up research in a community with fluid and changing residential patterns, previous AHPP work correlates low socio-economic status and household density with increased odds of *H. pylori* infection, and provided me with specific data on social inequities that I could then examine in depth through ethnographic analysis. I turn to this analysis now, expanding my scope to multi-household kin groups.

6.5: Infection and risk factors in extended kin groups

Of the families who participated in the AHPP 2011-2012 incidence and re-infection study (Carraher, Chang, Munday, *et al.* 2013, in press), I retrospectively identified three extended kin groups to analyze *H. pylori* distribution within and across related households. These kin groups were chosen because each: 1) includes multiple households that participated in *H. pylori* screening in both study periods (2008-2010 and 2011-2012); 2) had complete household survey questionnaires for most if not all households; 3)
represents different socio-economic levels, and; 4) collectively, these kin groups represent the ethnic diversity of Aklavik’s Indigenous population.

6.5.1: Kin Group “A”

Kin Group “A” consists of three households headed by two sisters and one sister-in-law, each with children between the ages of 8 to 16 years at the time of the AHPP incidence and re-infection study in 2012. These families self-identify as Inuvialuit and spend a majority of their time together, at each other’s houses and around town (e.g. community feasts, hockey games, youth events). The children (cousins) spend a majority of their time eating, playing, and sleeping together. In 2008, the head of House 1 reported living with her six children in a four-bedroom public rental home with six beds. That same year, her sister-in-law, head of House 2, reported living with her husband and four children in a four-bedroom public rental home with five beds. The head of House 3 did not complete an AHPP household survey, but in another AHPP survey reported living with three children. Thus, in all three houses, the number of children (aged between 3 and 6 years old) would indicate the highest adjusted odds ratio calculated in earlier AHPP research (adjusted odds ratio of 4.2 [95%CI: 1.2-15] for 3-6 children in the home, see Table 6.2) (Aplin, Fagan-Garcia, Chang, et al. 2011a:105).

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4Following standard genealogical notations, females are represented by circles; males by triangles; and deceased individuals have a diagonal line through them. Within a family, children are displayed in birth order from eldest (left) to youngest (right). House boxes include all individuals reported as living in a house during the _H. pylori_ screening period. Kin displayed outside of these boxes were not reported to be living in the household at the time of study. Houses are numbered in each generation by birth order of the head of household.
Figure 6.3: *H. pylori* infection and re-infection in kin group “A”, Aklavik.

All of these households report less than $25,000 per year in annual household income. The female heads of households often pool resources, sharing food and feeding each other’s children. The socio-economic organization of Kin Group “A” resembles the “cooperation networks” described by Magdanz and Utermohle (1998) in Alaska Native communities, in which a multigenerational kin group often consists of multiple households individually headed by siblings of the same generation. In initial AHPP screening, all of the participating members of these households tested positive for *H. pylori* infection (14/14 participants), and all were provided antibiotic treatment through the project. In the AHPP incidence and re-infection study, only three out of the 13 participants who were re-tested remained free from infection after treatment. One child in
House 3 was not retested in 2011-2012, because the mother leaving town during the screening period. The three individuals who remained free from infection include a mother and her two children, aged 14 and 16 at the time of the 2011-2012 screening period (House 2). Everyone in House 1 and 3 who was retested between November, 2011 and June, 2012 was actively infected with *H. pylori*, and was offered treatment and follow-up through the AHPP.

In Kin Group “A”, all of the children screened from Houses 1 and 3 re-acquired the infection, as did at least one parent in each household. In House 2, the two eldest children (ages 13 and 15) remained free from infection, while the youngest (age 8) was re-infected. It is striking that this extended kin group represents one of the most socio-economically disadvantaged segments of Aklavik’s population. Furthermore, Kin Group A has the highest rate of re-infection across households, in contrast to Kin Groups B and C. The members of Kin Group A are tight-knit and support each other socially as well as economically by pooling resources and helping to raise their children together. This enables the individual heads of Houses 1-3 to take better care of their families, especially during times of social or economic hardship. However, this also likely facilitates regular and repeated exposure to *H. pylori* infection. Recent studies in several Latin American nations (Porras, Nodora, Sexton, *et al.* 2013), Iran (Muhsen, Barak, Henig, *et al.* 2010), and Brazil (Fialho, Braga, Neto, *et al.* 2010) indicate that in low-income families with multiple children, the *H. pylori* status of siblings is an important risk factor for both late childhood and parental acquisition of the infection. Although the introduction of a wage economy has altered many characteristics of social life in Aklavik (including the
introduction of permanent year-around housing), kinship structures and kin-based behavioral patterns are sustained, such as sister cooperation across numerous sibling-headed households.

While it has been demonstrated that households with numerous residents are at increased odds for *H. pylori* infection, communicating this epidemiological finding to AHPP participants can be interpreted by them as pathologizing Indigenous extended kinship organization. Framing risk in terms of household density allows epidemiological translations of risk to focus more explicitly on the deleterious health effects of inadequate housing, and leaves Indigenous kinship organization open to be analyzed for the likely positive effects conferred by living in large families that cooperate to support multiple households.

6.5.2: Kin Group “B”

Kin Group “B” includes four households of mixed Inuvialuit and Gwich’in descent and represents some of the highest-income families in Aklavik. Houses 2-5 all report owning their own homes and earning over $75,000 annually, while House 1 declined to report annual household income. The members of Houses 2-5 all live in three bedroom homes with no more than two people sleeping in the same bed. Unfortunately several individuals in this extended group declined to be re-tested in 2011-2012 and we lack data on their current *H. pylori* status. It is worth noting, however, that among family members re-tested, there were no new cases of infection, and only one case of re-infection following treatment (in the eldest child of House 4).
Canada’s National Collaborative Centre for Aboriginal Health (NCCAH 2012) uses the term “culture” to describe Indigenous social structures (such as kinship organization and languages) as being disrupted, lost, and destroyed by colonialism. While it is true that Indigenous societies across Canada continue to struggle with social inequities imposed through over a century of colonialism, to use the term “culture” in this sense signifies that Indigenous societies are always threatened and must continually adapt to the dominating society. This implies that Indigenous families and communities who have found ways to engage successfully in the “modern” economy are somehow less
authentic or “traditional” than others. Kin Group B illustrates the fault in this logic: Each household has at least one member who is employed full time, and Houses 2 and 5 have at least one parent with some college education. Also, each household engages regularly in “traditional” subsistence activities including fishing, hunting, hauling wood, and going out to family camp sites in the Mackenzie Delta. Although Kin Group B fares well in the “modern” wage-based economy, this does not make them any less Indigenous than any other family living in Aklavik.

Similar to Dinero’s (1998) description of Gwich’in living in Alaska, in today’s mixed economies in the Arctic, kin groups managing well in the capitalist economy with more formal education and higher incomes are often better able to continue practicing Indigenous subsistence activities, as wages are used to purchase necessary resources (such as snow machines, four-wheelers, ammunition, and fuel). In addition, Kin Group B’s relatively lower rate of both initial *H. pylori* infection and re-infection compared to Kin Group A indicates that socio-economic status is a more accurate indicator of *H. pylori* exposure than Indigenous identity/ethnicity.

6.5.3: Kin Group “C”

Households in Kin Group “C” represent a mixture of socio-economic status and housing conditions: Houses 2, 3, 5, and 6 all rent public units, and while Houses 2 and 6 report being unsure of their annual household income; only one person in each house works (both part-time). House 5 represents a middle-income house, reporting between $35,000-49,999 annually. While House 4 declined to report annual income, both parents were employed full-time during both study periods (2008-2010 and 2011-2012), and they own
their own home. House 4 represents a marriage between two fairly large Inuvialuit and Gwich’in families.

Figure 6.3: *H. pylori* infection and re-infection in kin group “C”, Aklavik.

Members of Houses 3, 4, and 5 spend much time eating and visiting in each other’s homes, while members of Houses 2 and 6 live next door to each other (the head of House 2 is the mother of the head of House 6). Within House 2, one female child was a foster child unrelated to the other members of House 2. She returned to live with her biological father shortly after the 2008-2010 screening. Interestingly, she is the only member of House 2 to test positive for *H. pylori*, and became re-infected some time after...
receiving treatment. Since moving out, she rarely visits with members of House 2. The mother and daughter of House 2 have never tested positive for \textit{H. pylori} in the AHPP, suggesting that before, and again after 2008-2010 screening period, the foster child acquired the infection elsewhere.

In House 4, both females tested positive in both screenings. However, the female head of household likely never cleared her initial infection as there were complications with her antibiotic treatments. It is possible that her daughter acquired the infection from her mother, but this cannot be determined in this study. Everyone in Houses 3 and 5 who initially tested \textit{H. pylori} positive remained free from infection following the AHPP treatment trial. Residents of House 6 declined to be re-tested and the AHPP lacks data on their current \textit{H. pylori} status. In the kin groups discussed here, all of the participants who initially tested negative for \textit{H. pylori} in 2008 remained free from infection in the 2012 screening. This is not unusual in that in the 2012 study we found only 3 new cases of \textit{H. pylori} infection out of 36 base-line negative adults over age 15 (for a reinfection proportion of 4.7\% over an average of 2.6 years at risk) (Carraher, Chang, Munday, \textit{et al.} 2013, in press). One other incidence re-infection study of Alaska Native gastroenterology patients over 18 years old revealed a much higher re-infection proportion at 2 years-follow up (14.6\%) (McMahon, Bruce, Hennessy \textit{et al.} 2009). Thus, it is evident that Indigenous populations living in the Arctic and Subarctic may display great variation in \textit{H. pylori} re-infection, and that even Indigenous residents living in the same settlement are not affected equally by \textit{H. pylori} infection.
House 2 demonstrates the difficulty of assessing household-level risk factors in Aklavik, particularly measurements of household density. During the 2008-10 screening, the female head of house reported three children living with her at the time of the questionnaire, but also reported that her son spends part of the year in living in Fort McPherson. Thus during 2008 to 2010, there were between two to three children living in a two bedroom, three bed apartment. During the 2011-12 screening, only the mother and her daughter lived in the two-bedroom home. As *H. pylori* is a chronic infection, shifting household memberships throughout the seasons and over the years can alter the ratio of persons to beds to bedrooms in a house, drastically changing the odds ratio that would be estimated if the household is assessed at different times.

6.6: Reframing risk research

Previous AHPP research at the household level has been effective at identifying several socio-economic risk factors associated with *H. pylori* infection: low-socio-economic status; low education attainment; multiple children living in the home; and multiple people who share bedrooms. However, household-level analysis as it is traditionally performed in epidemiology is problematic in Aklavik for a few reasons: 1) It does not capture daily or seasonally shifting household occupancy patterns; 2) It does not enable researchers to see how multiple houses are related to each other within extended kin groups; and 3) Estimates of adjusted odds ratios represent risk at the particular point in time of data collection (which might not reflect living conditions at the time of *H. pylori* acquisition). For long-term follow up of research participants, AHPP data collection instruments should be adjusted to follow shifting household occupancy over time and to
identify larger extended kin groups that share resources and are commonly in close physical contact across multiple households. The situation in Aklavik demonstrates, more broadly, a need to study the social organization of communities and in order to design data collection instruments that more accurately assess living conditions of epidemiological interest. Ethnographic research can fulfill this need, and ideally community-based field research should be designed in such a way that ethnographers work directly with epidemiologists and with community stakeholders throughout the length of a project.

Within the Indigenous population of Aklavik, socio-economic risk factors and *H. pylori* infection cluster within and across multiple households of extended kin groups. Realizing an ethnographic epidemiological approach to analyzing multi-household kin groups over the next few years will involve several steps. In my report to the CANHelp Working Group I propose several strategies and specific recommendations for expanding current data collection instruments:

1) Update survey instruments for individual epidemiological and household-level questionnaires to include information on kinship for a respondent’s parents, siblings, and children (see Figure 6.2). This includes kin who reside in other households in addition to individuals currently residing in a household.

2) Household density can be assessed as a range (rather than labeled as a discrete number) between the usual minimum and usual maximum number of persons residing in a house throughout a year. Some houses will have wider ranges than others.

3) Follow-up research should collect data on *current* household occupancy that can be compared to original household occupancy. It should also investigate which other relatives
household members (especially children) spend significant amounts of time.

4) Follow-up research should determine whether a household has moved since the most recent CANHelp survey, and if so collect data on the new housing (e.g. ownership or rental, number of rooms, bedrooms, beds, etc.). Current AHPP household-level questionnaires already provide a basic format that can be adapted for new questions.

5) These recommendations should be presented to community planning committees in participating CANHelp Working Group communities, and ethnographic and epidemiological data collection instruments should continue to be developed in direct consultation with locally-organized planning committees.

Planning committees should be asked to identify other possible indicators related to daily living conditions they feel may be important to explore in *H. pylori* research.

### 6.7: Conclusions

Constructions and communications of risk often present “Indigenous” or “Aboriginal” identity as if it is a risk factor in and of itself (see Kelm 1998; 2010). As this case study shows, there is great variation within Aklavik’s Indigenous population, and the factors that matter are not attributable to cultural or ethnic differences, but rather to an unequal distribution of socio-economic resources within the Indigenous population. Opening up *H. pylori* research to an ethnographic inquiry facilitates a more nuanced understanding of Indigenous identity as it relates to a shared history of struggle under colonialism that continues to shape the social inequities that exist in today’s Indigenous populations. As these cases studies demonstrate, there is great socio-economic variability within Aklavik’s Indigenous population, and there is a strong association between low socio-
economic status, high household density, and infection and re-infection. Indigenous families, just like non-Indigenous families, who fare well in the mixed-wage economy in Aklavik display less \textit{H. pylori} infection. Making this distinction is important to community members too, some of whom asked me early in fieldwork why \textit{H. pylori} infection is more common in Indigenous residents; and asked me to investigate variation within the Indigenous population.

Combining ethnographic and epidemiologic methods in follow-up research in Aklavik, or in new CANHelp Working Group community projects, allows us to draw a more detailed, nuanced picture of how this bacterial infection is distributed within the Indigenous population. Ethnographic methods make it possible to better understand how a settlement is socially structured, and how these structures order people’s daily activities, which in turn puts specific individuals (children, siblings, parents, grandparents, etc.) at increased or decreased risk of exposure to \textit{H. pylori} infection. To reframe risk research in ways that are attentive to local social organization and mindful of a place’s history presents a way of improving research methodologies and partnerships between researchers and Indigenous communities.

6.8: Acknowledgements

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Chapter 7
Conclusions

7.1: “Never say DIE!”

I joined the Canadian North *Helicobacter pylori* (CANHelp) Working Group as a medical anthropologist and ethnographer in 2010. For my dissertation research, I used a mixed-methods ethnographic epidemiology to investigate how perceptions of *H. pylori* infection and risk are constructed, contested, or resisted – and how different culturally-patterned perceptions shape the actions researchers and community residents take in response to *H. pylori* infection. Within Aklavik, these actions include a collection of what I term “risk-avoidance” behaviors that include more direct approaches to preventing infection through filtering one’s water, as well as individual or family decisions to participate in the long-term AHPP research project. I have argued that the culturally-patterned processes of constructing and responding to risks must be assessed in the ongoing development of regional health policy regarding *H. pylori* surveillance and treatment.

A central part of my work has been to understand how living with social inequities and perceiving and responding to *H. pylori* “risks” are played out in the setting of Aklavik— the place where people “Never Say DIE!” Understanding “Never Say DIE!” is crucial to understanding local risk narratives that make up the nuanced and varied lay epidemiologies (Jones & Moon 1993:515) expressed by Inuvialuit, Gwich’in, Métis, and non-Indigenous residents. In the 1950s, “Never say DIE!” sounded Aklavik’s refusal to be relocated by the territorial government to the new town, Inuvik. To the families that
stayed behind in Aklavik, “Never say DIE!” represents a collective social memory of an act of resistance. The saying has become a rallying cry for the AHPP that has taken on a new, literal meaning: Residents see controlling *H. pylori* infection as crucial to fighting back against stomach cancer, which is the leading cause of cancer mortality there. The AHPP can be seen, from the vantage point of living in Aklavik, as a manifestation of an Indigenous community’s own demands for decolonized research – research that is designed and executed to address local questions, and that revolves around taking health action in accordance to local priorities. Realization of this goal still meets with several challenges – which, in order to be overcome, require reflexivity, respect, flexibility, and a commitment to *collaboratively* producing *H. pylori* and “risk” knowledge (and treatment strategies) out of this research. Ethnography has come to be seen, by both CANHelp researchers and Aklavik residents, as a means for dismantling barriers to cross-cultural communication by providing explanations of how different groups understand *H. pylori* infection and what puts people at risk for infection. My goal for this project has been to do more than deliver this type of ethnographic service, but also to demonstrate how ethnographic research can enrich epidemiological knowledge production.

As Nichter (2008) has argued, cultural perceptions do matter in public health: the ways in which a community – any community – understands a given health issue or “risk factor” guides (and limits) any attempt at developing effective control strategies. The collaborating researchers of the CANHelp Working Group make up their own community. The team is working together to make sense of *H. pylori* infection based on
scientific evidence, and to develop control strategies in consultation with community planning committees. Thus, my work has been a crucial element not only for extending ethnographic analysis beyond Aklavik’s residents but also for critically assessing the processes of constructing “risk” as a type of measurement in *H. pylori* epidemiology.

My research approach answers calls in the emerging field of cultural epidemiology to move beyond the basic step of incorporating ethnography at the formative stages of research planning and design. Often the use of ethnography in health research focuses primarily on adapting epidemiological measurement instruments for cross-cultural communication *in one direction* to study participants (Béhague, Gonçalves, & Victoria 2008). Instead, I see ethnography and epidemiology as important approaches that should be utilized in tandem through all phases of research. As Park and Littleton (2013) have argued, a mixed methods approach that “tacks between” the disciplines of anthropology and epidemiology allows for illumination and recognition of the different logics that underlie various understandings of health and health risks, and thus allows us to see gaps between perspectives as spaces ripe for exploration. Such an approach moves beyond adopting ethnography as merely a kind of data collection method centered around conducting interviews and long-term field residence. A cultural epidemiological approach focuses attention on how “culture” is theorized and operationalized throughout all phases of research. In this community-driven project, I worked with CANHelp researchers and Aklavik’s residents to: 1) use initial AHPP epidemiological findings to inform and frame my anthropological research; 2) use ethnography in turn to augment and enrich ongoing
epidemiological risk factor assessment; and 3) construct an ethnographic context from which to begin mending divergent understandings of *H. pylori* infection and risk through developing consensus discourse on historically-produced social inequities. This ethnographic epidemiology thus contributes to contemporary discourses and addresses several key issues in current *H. pylori* research, Indigenous health, and medial anthropology.

### 7.2: Contributions to research on *H. pylori* infection and social inequities

Medical anthropology has much to contribute to *H. pylori* and human health research. An ethnographically-informed epidemiology can enhance understandings of how *H. pylori* infection is distributed within high-prevalence populations, which are typically some of the most socio-economically and politically marginalized populations of the world (Jacobson 2005; Khalifa, Sharaf, Aziz 2010). My work on three related studies: infection and reinfection (Chapter 4), risk narratives (Chapter 5), and household density within extended kin groups (Chapter 6), collectively contributes to improving explanation and accountability in *H. pylori* research.

#### 7.2.1 Explanation

Ethnographers work to describe how populations are socially organized, and a cultural epidemiology aims to explain the link between cultural systems of meaning making (i.e. the processes of narrating and perceiving risk in particular locales and social groups) and the reported and observed behaviors of social groups in these places. Understanding how individual and group behaviors are structured by social relationships and guided by
cultural meaning-making is useful in developing culturally-appropriate health policies and treatment strategies that are fitted to particular places. In working to identify social and environmental risk factors, it is important to balance assessment of living conditions that are imposed on people (and that increase the risk of infection) and culturally-patterned ways of living together (that constitute coping strategies for dealing with social inequities). I have outlined strategies for reconstructing risk measurement in the AHPP to move from an index of household crowding to assessing household density as a dynamic measure that fluctuates over time. Household density, as a measure of occupancy patterns that wax and wane throughout a year, can be studied in ways that emphasize social inequities in housing availability while recognizing the health-promoting attributes of Indigenous kinship organization, which is both traditional and a strategy for responding to contemporary socio-economic challenges.

Measuring household density better reflects local social organization than does an index of household crowding, and the former has the potential to provide a more accurate description of \( H. pylori \) distribution within Aklavik. For example, House 2 in Kin Group C (Chapter 6) illustrates the challenges involved in using traditional epidemiological approaches to assess household crowding in Indigenous Arctic communities. During the 2008-10 \( H. pylori \) screening, the female head of house reported three children living with her at the time of the questionnaire, but she also reported that her son spends time each year living in another settlement up the river. During 2008-10, there were between two to three children living in a two-bedroom, three-bed apartment. During the 2011-12
screening, only the mother and her daughter lived in the two-bedroom home, as the son was gone and the foster child had returned home to her biological father. Shifting household occupancy throughout the seasons and over the years alters the ratio of persons to beds to bedrooms in a house, changing the degree of risk that would be estimated if the household is assessed at different times of the year. Many Indigenous families in Aklavik have more or fewer people living in a given household at different times of the year, as several men leave for seasonal oil, fishing, or mining jobs and several adults (mostly women) seek secondary education or administrative job skills training in Inuvik. Also, grandparents and other extended kin often take children from a relative’s house out on the land to learn to camp, fish, hunt, trap, cook, and sew in traditional Inuvialuit and Gwich’in ways.

The three multi-household kin groups I have described illustrate a variety of ways in which Indigenous families organize themselves in Aklavik. Household occupancy is dynamic and often fluid across several households. Household size shifts throughout the year and is limited by external factors, such housing availability and a family’s socio-economic status. It is also shaped by cultural values that emphasize cooperation within extended families and social norms regarding family size. The five houses of Kin group B are some of the most affluent in Aklavik, with Houses 2-5 reporting more than $75,000 annual household income. Each of these houses also contains at least one parent who works full-time and has some college education; each family has between 3-4 children and lives in a three-bedroom home. This extended family’s position differs starkly from
that of Kin Group A. Kin Group A is composed of three sibling-headed households, each with less than $25,000 in annual income, living in rented public housing. The mother of House 1 in Kin Group A has six children and lives in a four-bedroom home, representing one of the higher household densities in Aklavik. The female siblings of this kin group spend a majority of their time together, pool resources, and help raise each other’s children.

One of the striking findings of this research is that Kin Group A displayed some of the highest rates of *H. pylori* infection in the 2008-2010 screening: all 14 participants from the three houses tested positive. Furthermore, this extended family had the highest ratio of infection in the 2011-2012 screening (10/13 participants). These results reveal how social-inequities are experienced across multiple households that are linked within extended kin groups; the data on re-infection and incidence suggests that the distribution of *H. pylori* bacteria follows the same pattern. This intriguing association is one I plan to investigate in follow-up research with the CANHelp Working Group. I aim to work with microbiologists to compare *H. pylori* cultures from participant biopsies to see if particular strains are being shared within particular houses, extended kin groups, or between multiple kin groups.

### 7.2.2 Accountability

*H. pylori* infection and associated diseases disproportionately affect many of the world’s marginalized populations. For this reason, there is a need for academic accountability for how knowledge produced about high-prevalence populations is perceived by the larger
public (see Førde 1998). Ethnography can be used to help epidemiologists see health and social issues from the perspectives of study subjects (Luby 2013), and to better understand the environments in which “at-risk” people must try to make a living (Nichter 2008:112).

The case of Aklavik residents’ reactions to epidemiological notions of “household crowding” is illustrative of the need for improved accountability in general in *H. pylori* research. AHPP researchers maintain that living with numerous occupants in a house (particularly numerous children) is one of the most crucial risk factors exposing people to chronic *H. pylori* infection. Research indicates an increased risk when three to six children live in the home (AOR 4.2; 95%CI=1.2-15), and when two to three people share a bedroom (AOR 3.1; 95%CI=0.63-15) (Aplin, Fagan-Garcia, Change, *et al.* 2011a:105). Yet, many of Aklavik’s Indigenous residents deny that person-to-person contact in multi-occupant housing is the most significant risk factor in the transmission of infection, arguing instead that contaminated water is a more likely source. I have argued that Indigenous residents are rejecting what they perceive to be a comment on being “over-crowded” in homes as a significant risk factor for two reasons. First, the ways in which the concepts of direct transmission in houses have been presented so far rub uncomfortably against local cultural values of living in large families that support each other socially and economically, which is seen as normal and healthy, rather than a risk factor for spreading disease. Second, communication of the strong evidence in favor of direct person-to-person transmission over water transmission does not adequately
demonstrate why CANHelp researchers think that *H. pylori* infection is less likely to be coming from Aklavik’s water supply. CANHelp researchers and Indigenous residents in Aklavik have different ways of “making sense” of *H. pylori* – either as a pathogen, or as a contaminant. Stories from Aklavik’s Indigenous residents overwhelmingly emphasize that the surrounding environment, and their community as a whole, has been contaminated through approximately a century of colonialism and social, political, and economic marginalization. What lies at the heart of these divergent narratives between *H. pylori*-the-pathogen and *H. pylori*-the-contaminant is a different way of viewing the consequences of socio-economic “development” in the Arctic. A first step toward reconciling differences in risk perception (that is critical for establishing improved accountability of epidemiological findings) is to acknowledge explicitly that, based on the available epidemiological evidence, it is *access to quality housing* (and not local family organization) that seems to strongly facilitate *H. pylori* transmission and persistence.

The process of creating new, shared truths in *H. pylori* research does not end with this one step. Ethnographic research works to lay bare a “geographically broad and historically deep” (Farmer 1992) understanding of how colonialism across the Arctic has shaped the social inequities that today result in a disproportionate burden of *H. pylori* infection and stomach diseases within Aklavik’s poorest families (Chapter 2). In Aklavik, *H. pylori* knowledge is being built from contemporary experiences with participation in AHPP research and knowledge translation (KT) activities, as well as from broader historic narratives of pollution, colonialism, and cultural and environmental degradation.
National development in the twentieth century does not appear to have resulted in lower *H. pylori* prevalence in the Canadian Arctic, as it is presumed to have done for much of the rest of Canada (Jacobson 2005), as well as for Japan following its economic recovery after World War II (see Repogle, Kasumi, Ishikawa *et al.* 1996), or in Russia following the “introduction of democracy” in the 1990s (Tkachenko, Zhannat, Erman, *et al.* 2007).

Thus, the situation in Aklavik appears at odds with a general narrative in *H. pylori* literature that attributes national socio-economic development with improved standards of living and a declining burden of *H. pylori* infection and stomach diseases. While non-Indigenous scientists and local Indigenous residents have different ways of knowing and understanding “contamination”, both groups of actors can (and should) acknowledge that Aklavik is the way it is today because of their long and complex history of struggle with colonialism, which has come hand-in-hand with Canadian national development in the Arctic.

7.2.3 The future of knowledge production for *H. pylori* research in Indigenous Arctic communities

One major challenge remaining for the CANHelp Working Group is to explain the obvious health inequalities in *H. pylori* prevalence and stomach diseases in Indigenous populations and to communicate epidemiological knowledge of risks in ways that do not offend Indigenous cultural values and practices, such as household and family composition and kinship structures. To reframe risks in ways that are attentive to local knowledge and history presents a shared foundation from which consensus truths, and KT
in both directions, can be built collaboratively. This is particularly relevant for promoting long-term research participation as a positive coping strategy.

Much of the Indigenous health literature focuses on describing how Indigenous peoples are vulnerable, endangered, or dying (Kelm 2010). Within the AHPP, adoption of “Never say DIE!” as a project motto represents Aklavik as a place of survival, determination, and resilience. Because H. pylori infection and its associated stomach diseases disproportionately affect many of the most socially and politico-economically marginalized populations of the world, the incorporation of ethnography with a collaborative and community-driven approach to research in the AHPP represents the beginning of much-needed shift in H. pylori research more broadly – one that works with partner communities to realize shared, consensus explanations for (and locally-acceptable, effective medical responses to) a disproportionately high prevalence of H. pylori infection.

As the CANHelp Working Group continues to study H. pylori in Aklavik, and to expand research to new partner communities in the North, new questions emerge that require growth and innovation in our research design. Initial work involves establishing the baseline prevalence rates and identifying effective treatment therapies for particular settlements. However, for long-term follow up of participants, my research points to the need to refocus on changing household occupancy over time and identifying larger extended kin groups that share resources and are commonly in close physical contact across multiple households. More broadly, my work in Aklavik demonstrates the need to
study the social organization of communities in order to design data collection instruments that more accurately assess living conditions of epidemiological importance. In so doing, community-based *H. pylori* research can be improved in Indigenous settlements when local ways of knowing and responding to perceived risks are identified and explicitly acknowledged; and when local residents are enabled to work collaboratively alongside visiting researchers to develop ethnographic and epidemiological knowledge (and KT strategies) in partnership.

### 7.3: Contributions to Indigenous health research

My work is situated in emerging bodies of post-colonial/anti-colonial theory that see collaboration with Indigenous communities as vital to the decolonizing process (Smith 1999; Browne, Smye & Varcoe 2005; Kelm 2010). The AHPP was established based on ideals of scientific partnership with the community of Aklavik. KT in both directions, data dissemination to the community, and the hiring of training of local field researchers are core components of this ongoing partnership. By consulting with the AHC and engaging in KT activities with community residents, the AHPP identifies local questions and priorities to guide the design of project studies and the delivery of *H. pylori* treatment.

My ten months of participant observation enabled me to work daily with locally-hired field researcher Tammy Tyrrell, the nurses and staff of the health centre, members of the AHC, and other residents, and to design each component of research iteratively with the AHC. In particular, cultural epidemiology can contribute greatly to decolonizing
efforts within Indigenous health research by drawing critical attention to how “culture” is defined and operationalized in Indigenous health studies.

7.3.1: Theorizing “culture” in decolonizing research

Development of a cultural epidemiology allows for the addition of explicit anthropological perspectives on “culture” that can contribute to decolonizing efforts within Indigenous health studies. Geertz (1957; 1973) defined culture as a system of symbols and meanings, a way of interpreting the world around people, and thus shaping the ways humans organize themselves and behave toward each other. This school of thought distinguishes culture from social structure (e.g. kinship). While “traditional” social structures in many Indigenous societies have been damaged or even dismantled through colonialism, Indigenous cultures – like all human cultures – are adaptive, fluid, creative, and resilient. While it is important to continue to point out the harmful legacy of colonialism – and to make explicit this legacy’s ties to contemporary social inequities (see Loppie-Reading and Wien 2008) – it is equally important to critique and correct descriptions of Indigenous peoples and cultures as pathologically vulnerable and less able than their non-Indigenous neighbors to adapt to modernization (Kelm 1998; 2010). In fact, it is Inuvaluit, Gwich’in, and Métis cultural values surrounding community, family, cooperation, and their shared heritage of what it means to be “Indigenous” in Aklavik that have enabled local families to survive residential schooling, chronic housing and job shortages, and economic and food insecurity. Extended kin groups who share resources across multiple houses exemplify how Indigenous residents maintain their cultures and
their identities while adapting their social structures in response to contemporary socio-economic challenges.

7.3.2: Dismantling false dichotomies

A cultural epidemiology responds to the artificial dichotomies produced when Indigenous health and society is compared to “Western” or “mainstream” Canadian health and society. Within the health and social science literatures, “Westernization” is used somewhat interchangeably with “modernization” or “development”. Indigenous peoples are sometimes referred to as “non-Western” (even though Aklavik is in the western Arctic). Often these terms are used to establish a (falsely) dichotomous relationship between Western and non-Western ideologies, worldviews, cultures, or societies. The world capitalist market, cash-based economies, and sedentary lifestyles are often portrayed as “Western” and “modern” while Indigenous practices of subsistence and reciprocity are portrayed as “non-Western” and “traditional”. It is wrong to presume that Indigenous families in Aklavik who successfully engage in the modern cash-based economy are somehow more Westernized, and thus less Indigenous, than their neighbors. On that note, while today’s generation is definitely more modern than the last, today’s generation is no less Indigenous than their forebears. Yet, the Western/modern vs. Indigenous/traditional dichotomy persists across social science, health, and Indigenous literatures. My work demonstrates that the more affluent households and kin groups in Aklavik are better enabled to participate in both the modern cash-economy and in traditional subsistence practices. This, combined with realization that there is wide
variation in socio-economic status within Aklavik, demonstrates that externally-produced social inequities are a stronger indicator of health than Indigenous identity in and of itself.

7.4: Contributions to medical anthropology

The origins of “cultural epidemiology” as a collaborative project that would (ideally) transcend the boundaries between cultural anthropology and epidemiology can be traced back to Trostle’s declaration that our two disciplines share a “history of benign neglect” (1986:35). Trostle, and others (Weiss 2001), have remained hopeful that a cultural epidemiology can be built, yet today, we are still working “Toward Cultural Epidemiology: Beyond Epistemological Hegemony” (see Brough 2013). DiGiacomo (1999) has lamented that ethnographers and epidemiologists have continued to maintain divergent, rather than build complementary, understandings of human health, while some others have responded by pointing to ways we can tack between the positive (though different) elements of disciplines, methodologies, and theories (Park & Littleton 2013). As Mark Brough points out, “The act of conceptualizing and practicing cultural epidemiology…brings with it a series of deep epistemological questions about the nature of knowledge production” (2013:33). Along with Western biomedicine’s position of privilege and power, he argues, comes a great responsibility to consider “critical, historical, and political reflexivity, particularly at the boundaries between dominant and oppressed cultural spaces” (Brough 2013:33) and an urgent need to pay attention to how researchers think about “culture” (Brough 2013:36). Cultural epidemiology, although often aligned with social epidemiology because of its shared interest in social justice as a
mechanism for addressing the root causes of human disease and suffering, necessarily raises issues of reflexivity regarding the “measurement” of culture.

Using ethnography as a set of methods and as critical praxis enables cultural epidemiologists to study the ways in which place, history, social memory, and personal experiences are woven together into cultural fabrics of meaning (Geertz 1973) from which particular risk narratives are cut. Such an approach is useful when varied and conflicting risk narratives exist because this approach can get to the heart of the cultural basis of risk construction and facilitate comparisons between varied perceptions of the same health conditions (Weiss 2001). Incorporating cultural epidemiology into policy development can help to defuse epistemic tensions between research participants and researchers who subscribe to different models of risk perception and, at the same time, promote cooperative action for improving community health.

7.4.1: Recognizing agency and in risk construction

Especially in situations where people have few opportunities to improve their standards of living, a pragmatics of choice influences which risk narratives are favored, and which are resisted or rejected (Nichter 2008). In Aklavik, residents cannot suddenly choose to move into larger houses with more bedrooms to avoid direct person-to-person transmission. However, they can (and they do) carefully control their water supply by drinking bottled water from the store, as well as by boiling and filtering their water. Several of my interlocutors discussed avoiding certain places in and around Aklavik they believe to be contaminated (e.g. the Distant Early Warning (DEW) line sites near Shingle Point, the
abandoned military installation in the Richardson Mountains, and a few locations within Aklavik). A few spoke about avoiding the houses of, or avoiding sharing foods with, neighbors they knew were infected with *H. pylori*.

One participant has tested positive for *H. pylori* infection four times and submitted to a stomach biopsy in 2008. Although she is frustrated that her case is proving so difficult to treat (cultures from her biopsy are multi-drug-resistant), she told me she will keep coming to “do the tests” and “take those pills” because she hopes that “you guys will eventually get it right.” This same participant reports the need for CANHelp researchers to test the water in and around Aklavik. As her case illustrates, the choice to continue to participate in long-term research, even when it has not yet worked to cure her infection, is another important coping strategy – one that she incorporates into her total repertoire of risk-avoidance behaviors. Consulting with the AHC and with other AHPP participants more broadly is necessary not only for developing locally-acceptable treatment strategies, but also for providing opportunities for residents work with researchers to develop pragmatic solutions that foster and promote community and individual agency in responding to *H. pylori* infection. A cultural epidemiological approach toward this end promises to illuminate how pragmatics, cultural perceptions, knowledge structures, and local priorities are tied to particular risk-avoidance behaviors. From there, emancipatory and empowering *H. pylori* management strategies can continue to be produced and improved – and the CANHelp Working Group can help to add volume to Aklavik’s rallying cry: “Never Say DIE!”
7.4: Next steps

I have outlined key issues in *H. pylori* research, Indigenous health research, and medical anthropology that I addressed in my dissertation through a mixed-method, community-driven ethnographic epidemiology. But in truth, I have worked alongside several scientific researchers and Aklavik residents to build a transdisciplinary body of work that will continue to grow over the next several years. Within this endeavor, ethnography and epidemiology will be practiced in concert, informing and reshaping discourses on *H. pylori* infection, risk, and Indigenous experiences with (and responses to) social inequities. The ultimate outcome of this work will not be a homogenized discourse that privileges or downplays some voices, but rather a consensus discourse informed by multiple perceptions and experiences that then is translated into direct health action and held accountable to the Indigenous communities served by the CANHelp Working Group. I now discuss the next steps to realizing this goal.

7.4.1: Data dissemination

In accordance with my obligations to the AHC and the community of Aklavik, I am drafting a final report summarizing my research findings to be delivered in person in the winter of 2013-2014. When I return, I will also discuss these findings in several community presentations (e.g. at the school, the Elder Day Program, the health centre, and the Sittichinli Recreation Complex). At that time, I will collect community feedback and answer residents’ questions using feedback questionnaires developed in consultation with the AHC, as well as conduct informal Q&A sessions during community
presentations, and as I meet and chat with individuals around town. Feedback from these presentations will inform the ongoing development of data dissemination materials and KT strategies. I will also present the community with electronic and hard copies of Aklavik’s genealogy, for archiving at the Hamlet library.

I am drafting a summary of my research findings to present to the CANHelp Working Group at our project offices at the University of Alberta. This report focuses on explaining processes of constructing risk both within the Indigenous population of Aklavik and within epidemiological literature more broadly. It will contain recommendations for ongoing ethnographic research and H. pylori infection follow-up in Aklavik, as well outline strategies for incorporating ethnography in new CANHelp Working Group projects in additional Indigenous settlements.

7.4.2: Policy recommendations

Based on my report to the CANHelp Working Group, I will work with our team members to draft policy recommendations directed to regional and territorial health officials regarding H. pylori surveillance and treatment strategies. Recently, the CANHelp Working Group earned a $2.5 million dollar Collaborative Research Innovations and Opportunities (CRIO) grant from Alberta Health – Innovates Solutions (AHIS) to support our work in all CANHelp partner communities for the next five years (2013-2018). A major component of the proposed CRIO-funded work is to collaborate with partner communities to implement effective KT strategies and conduct long-term follow-up research, and to develop cost-effective treatment strategies and regional health policy. For
this work, I am taking on a new role in the CANHelp Working Group, as the team’s Ethnographic Fieldwork Lead.

7.4.3: Ethnographic Fieldwork Lead

The CANHelp Working Group is expanding the scope and breadth of research over the next five years. We are presently restructuring staff organization to incorporate new Management Leads who oversee various arms of research activities. I am continuing my work for the CANHelp Working Group, and will serve as the team’s new Ethnographic Fieldwork Lead (http://www.canhelpworkinggroup.ca/research_staff.php#ManagementTeam). In this position I will oversee the planning and implementation of ethnographic data collection in CANHelp partner communities; collaborate with the Knowledge Translation Lead, Community Projects Lead, and Data Dissemination Lead on KT and reporting of research findings back to communities; train future research trainees and other appropriate field researchers in ethnographic research design, data collection, and analysis; and work with Principal Investigator Karen J. Goodman, our co-investigators in epidemiology, gastroenterology, and microbiology, and with the other Management Leads in designing and carrying out longitudinal research on *H. pylori* infection and risk. I see my future research within the CANHelp Working Group as a broad application of ethnography aimed at several program ends, including innovation in epidemiological measurement (e.g. developing regionally-appropriate and culturally-informed measures of household density and associated risk factors), assisting with KT and data dissemination activities,
and working with planning committees, community leadership, regional health authorities, and CANHelp researchers to develop effective *H. pylori* management strategies.

Within post-colonial studies, activist scholars have called for a “decolonized academy [that] is interdisciplinary and politically proactive. It [is one that] respects Indigenous epistemologies…as well as values cultural criticism in the name of social justice” (Denzin& Lincoln 2008:4). This call from post-colonial scholars aligns with Brough’s (2013:33) call for a critical reflexivity to be brought to the developing subfield of cultural epidemiology, especially at the margins between dominant and traditionally-oppressed cultural groups (as is often the case when non-Indigenous and relatively affluent researchers come to work in historically-marginalized Indigenous settlements). Currently, I am working with a special team within the CANHelp Working Group on a KT exchange program that brings laboratory- and clinical-based researchers to Indigenous Arctic communities, and trains Indigenous residents as peer-researchers who visit our laboratories and staff offices in Edmonton (Colquhoun, Aplin, Goodman *et al.* 2011; Carraher, Colquhoun, Keelan *et al.* 2012). This team consists of Public Health doctoral student Amy Colquhoun, Principal Investigator Dr. Karen J. Goodman, Lead Microbiologist Dr. Monika Keelan, Aklavik Nurse-in-Charge Rachel Munday, and Aklavik residents Velma Illasiak (AHC member), Bonnie Lynn Koe, and Prairie Dawn Edwards.
In 2012 we collaboratively organized an exchange program that for the first time brought laboratory personnel to Aklavik to get a taste of what life in the Arctic is like. We also brought two Aklavik youth to Edmonton to meet with CANHelp staff and researchers, visit the laboratories, and learn more about *H. pylori* research. From those experiences, our team developed data dissemination materials for reporting AHPP microbiology results back to community members in Aklavik. I then accompanied Ms. Koe and Ms. Edwards to Vancouver, B.C. in December, 2012 to present a poster on our KT project at the annual ArcticNet scientific meetings, for which we won first place in the graduate student competition (Carraher, Colquhoun, Keelan *et al.* 2012). We were recently nominated by Canadian Circumpolar Institute Director Maryann Douglas for the Arctic Inspiration Prize. We are presently putting together our nomination package, and if we receive this award, it will fund expansion of our exchange program to other CANHelp partner communities over the next two years. My role in this proposed work is to facilitate exchange logistics with planning committees in partner communities; educate CANHelp researchers in the ethnographic context for local community histories and knowledge systems prior to their community visits; contribute to collection, analysis, and interpretation of data generated during KT activities (e.g. community feedback questionnaires, interviews with residents, local health care providers, and CANHelp university researchers); and assist Arctic community team members with articulating and developing their own data dissemination materials to be shared back in their home communities, based on what they learn through the exchange program. A major
component of this work will be to assist community peer-researchers with articulating their own questions for *H. pylori* research and facilitating a collaborative process of generating answers for these questions when they come to Edmonton to visit the CANHelp project offices and laboratories.

### 7.4.4: Beyond CANHelp

I also am involved in community activist projects and some research outside of the CANHelp Working Group. In the future I plan to expand on ethnographic research in Aklavik, and nearby settlements, to study the relationships between kinship organization, social and economic reciprocity, and food-sharing networks. I recently conducted exploratory research in Aklavik, at the request of the Aklavik Indian Band (AIB), to identify local needs and priorities for a participatory-action research project that combines Indigenous subsistence practices and nutrition knowledge with innovative strategies for sustainable vegetable gardening in an Arctic environment (Carraher, Kerr, & Buckle 2012). Robert Buckle (AIB, AHC) is working this summer to provide materials and instructions for residents who wish to start their own gardens. I am working (via distance for now) with Mr. Buckle and Nurse Samantha Kerr to research nutrition and gardening projects that have been implemented in other Arctic communities, and prepare a report from which we can develop our own mission statement and project goals and needs. Promotion of traditional reciprocity practices including sharing food and knowledge within and across families has already been identified a core objective of this future
project. Ethnographic research into how traditional kinship organization functions as a contemporary economic strategy for families will be key in this work.
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Appendix A:

Interview and consent forms

LETTER OF INFORMATION

Student Investigator: Sally Carraher, Ph.D. Candidate, Anthropology, McMaster University
Peer-interviewer: Tammy Tyrrell, Aklavik

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“Social and Environmental Determinants of H. pylori Bacterial Infection in Aklavik, NWT: A Community-Based Participatory Research Project”

Hello,

My name is Sally Carraher and I am a Ph.D. student in the Department of Anthropology at McMaster University. I am conducting research in Aklavik until June, 2012. My work follows up on previous H. pylori research. I want to learn how H. pylori is related to daily living conditions in Aklavik. I also want to make sure that community concerns are answered by researchers. The results of my study will be shared with the CANHelp Working Group research team, the Aklavik Health Committee, and local health care providers.

Study Procedures
Several activities are offered. It is up to you which activities you participate in. You may be asked to:

- Participate in a personal interview asking you and your family’s experiences with H. pylori, ulcer disease, and/or stomach cancer (for about one hour). Interviews will be digitally recorded and transcribed.
- Participate in a group interview (called a “focus group”) to express your views on the research
(for about one hour) Interviews will be digitally recorded and transcribed.

- Provide information about who you live with and who you are related to in the community. Like all other activities in this research, you and your relatives will not be personally identified in any reports or publications.
- Submit a breath test to determine if you are currently infected with *H. pylori*. If you wish to submit a breath test, and it comes back positive, we can provide you antibiotic treatment free of charge.

**Other Research Activities in Aklavik:**
- **Observation:** Observation involves me watching and listening to activities going on in the community. I am living in Aklavik to learn more about who lives here, what daily life is like, and how people are related to each other and live with each other. Observation can take place in public as well as private places. If anyone sees me in public taking notes or photographs and that makes them uncomfortable, I will do my best to move out of the way, or to stop if I am asked to.

**Possible Risks**
If you agree to be interviewed, it is possible some questions may upset you or make you feel embarrassed. Tammy and I will respect your privacy, but may ask some questions you do not wish to answer. If we ask any questions that make you uncomfortable, you can tell us you prefer not to answer.

If you agree to participate in a focus group interview, there will be a room with approximately 4-8 participants, myself, and a co-researcher. While we will ask everyone to not talk about the group interview outside of that room, I cannot guarantee that they won’t. You may also feel uncomfortable answering certain questions in front of the other participants. That’s OK! You can choose not to speak during any questions, and you can even choose to quit the interview and leave the room.

**Confidentiality**
All personal records relating to this study will be kept confidential. We will not disclose your name outside the research project office. We will not identify you by name in any published report, unless you tell us that this is your wish. We will use the health information we collect only for the purpose of this research study. You will be contacted to ask for permission prior to use any of the interview data in future research after my dissertation.

Tammy has also been trained to keep your information private and safe. Please be aware that in a small community like Aklavik it is possible that family members, neighbors, or other residents may be able to identify your role in this study, especially if any interviews you participate in are held in a public place. Therefore, I cannot guarantee confidentiality. You should only participate in this study if you are comfortable doing so.

**Voluntary Participation**
Your participation in this study is strictly your choice. You can stop participating at any time. If you quit the study before I am done analyzing the interview data in 2012, I will delete your information from all my records. I cannot go back and remove information after analysis is complete in late 2012.

**Questions**
You are encouraged to ask questions about the project itself, or about how your information is being used. If you have any questions about your rights as a research participant, you may contact the
McMaster University Research Ethics Board (MREB) at (905) 525-9140 extension 23142, or e-mail ethicsoffice@mcmaster.ca.

This letter is yours to keep.

Thank you,

Sally Carraher, B.A., M.A.
Ph.D. Candidate, Department of Anthropology, McMaster University, Hamilton, Canada
CONSENT FORM FOR INTERVIEWS/FOCUS GROUP

RE. Research Project Entitled: “Social and Environmental Determinants of \emph{H. pylori} Bacterial Infection in Aklavik, NWT: A Community-Based Participatory Research Project”

Student Investigator: Sally Carraher, Ph.D. Candidate

Department of Anthropology
McMaster University
Hamilton, Ontario
Canada L8S 4L9

Telephone: (905) 525-9140 ext. 24424
Cell phone: (907) 244-1778
E-mail: carrahs@mcmaster.ca

I acknowledge that I have read the \textbf{Letter of Information}, have had the nature of the study explained to me, and I agree to participate.

I agree to be \textbf{interviewed} (check one) \hspace{1cm} [ ] yes \hspace{1cm} [ ] no

I agree to participate in a \textbf{focus group} (check one) \hspace{1cm} [ ] yes \hspace{1cm} [ ] no

Name (please print): __________________________________________

Signature: __________________________________________ Date: _________________

Name of Person Obtaining Informed Consent:

________________________________________

Signature of Person Obtaining Informed Consent:

________________________________________ Date: _________________
CONSENT FORM FOR PHOTOS/VIDEO

Aklavik H. pylori Project

Student Investigator: Sally Carraher, Ph.D. Candidate

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Canada L8S 4L9

Telephone: (905) 525-9140 ext. 24424  
Cell phone: (907) 244-1778  
E-mail: carrahs@mcmaster.ca

I acknowledge that I have read the Letter of Information, have had the nature of the study explained to me, and I agree to inclusion of photos or video as stipulated below:

I agree to donate photos or video of myself/family for use in research:  
(check one)  
[ ] yes  
[ ] no

I agree that my donated photos or video may be used in publications and presentations resulting from this research:  
(check one)  
[ ] yes  
[ ] no

I agree that photos/video taken of me may be used in publications and presentations resulting from this research:  
(check one)  
[ ] yes  
[ ] no

Name (please print):  ___________________________________________________________________________________

Signature: ___________________________ Date: __________________

Name of Person Obtaining Informed Consent:  
_________________________________________________________________________________

Signature of Person Obtaining Informed Consent:  
_________________________________________________________________________________ Date: __________________
**About the Researcher**

Hello! My name is Sally and I come from Alaska. I am a Ph.D. student in Anthropology at McMaster University, in Ontario.

My previous research focused on understanding why cancer is such a big problem in the Arctic in Alaska and Canada. I want to learn more about how people might catch *H. pylori*, who gets sick from *H. pylori*, and also what people think they need in order to stay healthy.

At Aklavik, I want to continue this work by learning more about how *H. pylori* and stomach cancer might be related to things in the environment and community, like food, water, housing conditions, plumbing, and other things.

**Contact Information**

If you have any questions about this study or would like to participate, please contact Sally Carraher at my local telephone:

978-2304 (weekdays 9am-4pm) or 978-2961 (weekends and evenings)

Or e-mail: carrahs@mcmaster.ca

The results of this study will be available in 2013. You can contact the researcher by e-mail if you would like to receive a copy.

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**The Aklavik H. pylori Project**

**H. pylori Bacteria Infection in Aklavik:**

A Community-Based Study

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**Researcher: Sally Carraher**

Doctoral Student
Department of Anthropology
McMaster University
Hamilton, ON
**About this Project**

Over this winter and throughout 2012, I am doing research in your community. This is my part of the Aklavik *H. pylori* Project, which you have heard of or participated in before. My study follows up on previous *H. pylori* screening and treatment, and looks at community members’ views on *H. pylori* and the diseases it can cause.

My research combines medical tests, like the breath test for *H. pylori*, with social and cultural research about how people make a living in Aklavik. I am living in town and attending local events to see what day-to-day life is like. I sometimes take notes and photos at these events. I will interview some people. I also work with a local person who I hired as a co-researcher. Together, we will learn how to improve stomach health in Aklavik!

**Want to participate?**

There are many ways you can help with this research! You may choose to do one or more of the following activities:

**Interviews:**

I invite people to come speak with me about their experiences with *H. pylori* or diseases like ulcers and stomach cancer. I want to ask people what they know about *H. pylori* and stomach health, and how they feel about their over-all health and quality of life. I also want to ask people about their family histories and what it is like to grow up and live in Aklavik. These interviews are open to everyone – even if you did not participate in *H. pylori* research before. Individual as well as group interviews will be conducted.

Interviews will last about one hour, and will be at the health centre, or another at your home if you like. You can skip questions you do not wish to answer, and you can quit the interview any time, with no penalty or judgment.

I will not disclose any private or identifying details from our interviews to other people. You may request to be interviewed by my local co-researcher instead of by me. This person is from Aklavik, and is trained by me to keep your information safe and private.

**Urea Breath Test:**

Some people are being asked to take a urea breath test at the health centre. Urea is a harmless powder that detects *H. pylori* in the stomach. For this test, you would blow into a tube or bag. You would drink a harmless drink that has urea in it and wait 20 minutes. Then you would blow into another bag. Your test results will be reported back to you later on, and will be kept private.

On the same day that you take the breath test, I may ask you to do other things:

- Answer questions about your health and digestive symptoms
- Answer questions about your family, household environment, and diet
- Allow me to look at your medical records (until December 31, 2013)
- Allow CANHelp researchers to store your breath sample from this study to use in future research; if you agree, your extra samples will be stored without any information that can identify you

You have the right to say “no” to any of these requests. You can choose to do only the breath test, and not answer any questions. You can choose to do one, some, all, or none of these activities.

**Confidentiality**

All personal information in this study will be kept private. I will not use your name outside the research project office. I will not identify you by name in anything I write, unless you tell me that this is your wish. I will use the health information I collect only for the purpose of the Aklavik *H. pylori* Project research. Information from your interview(s) will be kept in a computer file that only myself and the co-researcher will have access to. In addition to us, my field supervisor Karen Goodman, as well as the Health Research Ethics Board at the University of Alberta, may be given access to your records to monitor the research and verify the accuracy of study data.

If at any time people feel uncomfortable with my taking notes or photos at local events, they are welcome to let me know and I will make every effort to respect their privacy.

Participation in this research is voluntary. You may quit this study at any time.
You are invited to participate in an incidence study for the Aklavik H. pylori Project!!

I want to invite you to come to the clinic sometime starting Thursday, Nov. 24 to get a new breath test for an incidence study. This study will help us know if H. pylori infection rates are changing or staying the same in Aklavik since the treatment trial in 2008-10. If you take a breath test with me, and the result is H. pylori positive, we can provide treatment for you.

Hello! My name is Sally Carraher, and I am working with the Aklavik H. pylori Project. Over this winter and next spring, I am living in Aklavik and working at the Susie Husky Health Centre. I would like to re-test some of the people who participated in the H. pylori research earlier.

I am doing an incidence study of H. pylori exposure in Aklavik. An incidence study is when a researcher counts how many new cases of infection happen during a certain time period. In order to do this kind of research, we have to know who has had H. pylori and who has been H. pylori -negative before the new study starts. For this reason, I am only offering breath tests to people who meet the pre-study criteria. I am inviting you, because you are eligible to participate.

The breath test is harmless and appointments are for 1 hour. You may also be asked to answer some questions or make an appointment for an interview later on. You can choose to just do the breath test and say “no” to these other activities if you want. You can also say “no” to everything and choose not to participate at all. Participation is your choice. You are free to withdraw from this study at any time, with no penalties.

If you would like to participate in this continuing research, please make an appointment for a breath test. Or you can just stop by the clinic between 9a.m. and 11:30a.m., Monday-Friday, starting Nov. 24.

It is best to have an empty stomach during the breath test. Please fast for at least 4 hours before the test. Please do not smoke or drink anything besides water for 4 hours before the test. Smoking, drinking, or eating can mess up the test results.

If you have any questions about this research, or want to make an appointment for a breath test, please call 978-2304 or email carrahs@mcmaster.ca.

Thank you! Quyanainni! Mahsi Cho!
Appendix C:

Interview guides

Aklavik interview guide

CANHelp Interview guide

Aklavik focus group guide

Aklavik nurses focus group guide

CANHelp focus group guide
INTERVIEW GUIDE – Aklavik residents

“Social and Environmental Determinants of H. pylori Bacterial Infection in Aklavik, NWT: A Community-Based Participatory Research Project”

Sally Carraher (Ph.D. candidate, McMaster University)

Tammy Tyrrell (Peer Interviewer, Aklavik)

Introduction:

“H. pylori” is the name of bacteria that infect the human stomach. It is especially common in some Arctic communities. Scientists are not sure exactly how people get infected. Sometimes it makes people sick. Sometimes it doesn’t.

We want to learn more about how daily life in Aklavik may be related to the spread of H. pylori infection. This information will be used to improve H. pylori management in Aklavik. It will also be used to improve CANHelp research and expand the studies to other northern communities.

At any time during this interview, you may ask us to turn off the recorder. When you decide you are ready, one of us will start the recorder again. If we ask any questions that you do not want to answer, you can choose not to answer. If you want to end the interview at any time, just let us know and we will stop.

FILL IN FROM Hp FILES IF PREVIOUS PARTICIPANT:

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<tr>
<th>Completed questionnaires?</th>
<th>clinic</th>
<th>house</th>
<th>ind</th>
</tr>
</thead>
</table>

Date:

Interview location: ___ clinic ___ respondent’s home ___ other (where?)

Interviewer: ______________________________________________________

Respondent(s): ____________________________________________________

ID# ___________________ DOB: ________________________________

1a) To get started, I would like to know some basic information about you and your family: Please tell me your :
1b) Sex Male [ ] Female [ ]

1c) Are you: Single [ ] Married [ ] Common law [ ]
                      Divorced [ ] Widowed [ ]

1d) How many people live in your household today? ___ Adults 18 or older; ___ children

1e) Please tell us what is your occupation? ___________________________

1f) How long have you had this job? ____________________________

1g) If it’s OK, we’d like to know what kinds of things do you do at this job?
          - who do you work with/have contact with the most
          - how many hours a week do you work?

1h) If you don’t mind telling me, what is your annual household income?

       __ less than $25,000/yr    __ $25,000-34,999 __ $35k-49,999 __ $50k-74,999
       __more than $75,000/yr    __unsure    __ refused to answer

1i) If you don’t mind telling me, are there any other benefits from your job (like a housing allowance in addition to income, or non-cash benefits?)

1j) Do you ever make money from games like bingo, poker, or cards?

2a) What is your ethnic status?      [Inuvialuit, Gwich’in, Metis, mixed, white, other?]

2b) Is everyone in your family ____________________________?

3a) How long has your family lived in Aklavik?

3b) [if first-generation resident]: What place or places do most of your family come from?

Food

4a) Where do you get most of your store foods? (Northern, Stanton’s, Inuvik…?)

4b) Do you eat foods from the land?

4c) Do you or does someone in your household hunt, fish, or gather any food off of the land?

4d) Where do you usually get foods from the land from? How do you usually get foods from the land?
       - Do you or someone from your house hunt, fish, or gather foods from the land?
       - Do you get country food from other family members or friends?
       - Do you ever pay or trade for country foods?
4e) Do you share food with family, neighbors, or friends in Aklavik?
   - What kinds of foods do you normally share with others? How often?
   - Where or when do you get the foods that you share with other?
   - Do you ever share store-bought foods with others? If not, why not?

4f) When eating with kids and family, do you ever eat out of the same bowl or plate?
   - Do people in your household ever share spoons and forks, cups, cans, bottles, or straws when eating and drinking?

Activities

5a) What places do you spend most of your time in Aklavik?
5b) What kinds of activities do you like to do a lot in Aklavik?
   - Do you do certain activities more during certain seasons?
   - Who do you do these activities with? (like family, friends?)

5c) Who do you spend the most time with in Aklavik? (family, friends, co-workers, neighbors?)
5d) Do you ever spend the night at other people’s houses?
   - How often?
5e) Do your kids ever spend the night at other people’s houses?
   - How often?
5f) Do your kids sleep on beds or couches or mattresses on the floor?
   - Do your kids share a bed, couch or mattress?

5g) Do you spend time out on the land?
   - What do you do?
   - Where on the land do you go?
   - Who do you go with

5h) Do you spend time outside of Aklavik?
   - When (times of year?) Where do you go?
   - Who do you go with?
   - Who do you stay with?

Housing (mark their house on the map)

6a) How long have you lived in this house?
   - Do you plan on moving within the next year?
Health

7a) What do you think are the biggest health problems in Aklavik?

7b) Could you describe if you think _________________ might be related to other problems in Aklavik?

7d) Are there any resources in this community that you think people can use to stay healthy?

7d) What things do you think people need to have or do in order to stay healthy?

7c) If you don’t mind telling me, are there any particular health problems that your family has had or are dealing with now?

7e) Have you ever been told that you have \textit{H. pylori} infection?

[or, if ”no”] Do you know anyone in your family who has had or been treated for \textit{H. pylori} infection?
- How did it make you feel when you found out?

7f) Did you/that person get sick from \textit{H. pylori}? [please describe]

7g) When you were told you had \textit{H. pylori}, what was the most valuable information you got?

- Who did you get that information from? (nurse, doctor, researcher, family, or friend?)
- Did you find the information about _________________ useful?
- In what ways was it useful?

7h) Were you treated for \textit{H. pylori}? If so, what was that like?

- Did you complete the treatment? Did it work?
- Were there any problems you had with the treatment offered/given to you?
- Did you feel better after the treatment?
- What kinds of things helped you to remember to take the pills?

7i) Where do you hear the most information about \textit{H. pylori}? (at clinic, from nurses, from family, neighbors, or friends? From people in Aklavik or outside of Aklavik?)

7j) Do other people ever ask you questions about \textit{H. pylori}? (like who?)

- What kind of questions do they ask you?
- What do you tell them?
INTERVIEW GUIDE – CANHelp researchers

“Social and Environmental Determinants of H. pylori Bacterial Infection in Aklavik, NWT: A Community-Based Research Project”

Sally Carraher (Ph.D. candidate, McMaster University)

Interview location: __Katz Building offices  __respondent’s home  __other (where?)______________________________

Respondent(s):___________________________________________________

1) Background with CANHelp – in general, what is it like to work on this team?

Please describe your personal background with CH. When did you first join the working group, and how?

What kinds of work have you done for CANHelp? What do you do now?

How much interaction with planning committees in communities do you have? What is that like?

2) What communities have you traveled to for CH work?

What did you do in each community (same thing, different things)?

3) Let’s talk about your experiences in Aklavik. Let’s start with your first trip there, when that was, what you did, and what it was like, and move on from there.

i.  -Where all in the community did you do your work (only in the clinic, or other places too?)

ii. -Where in Aklavik did you spend most of your free time?

iii. -While in Aklavik, which people in the community did you spend the most time with? (during work, during free time)

iv. -Do you keep in touch with anyone from Aklavik? Who?

v. Did you feel some people living there seemed to be more or less willing to speak with you or hang out with you?

3a. I’d like to talk about how you feel about the progress of the Aklavik H. pylori Project so far?

i. Do you think this study has collected enough information from Aklavik yet?
ii. Should CANHelp focus more on expanding the research to other communities to expand the database? Or is there still more to be learned/studied about *H. pylori* in Aklavik?
   a. Given an unlimited budget, what kinds of things would you like to see researched in Aklavik or other CANHelp participating communities?
iii. What are any limitations or factors that might be or seem to be impeding the AHHP mission?

**4a. What do you think are the greatest benefits that this research will provide for the participating communities?**

In addition to learning what our work will achieve for local communities, I’d like to also talk about **what our work will add to the discipline of epidemiology.**

4.b Researchers have noted a trend in which *H. pylori* prevalence has tended to decrease in industrialized nations following the second world war. Even though we don’t have a lot of data on Arctic populations yet, **Why do you think Hp is so prevalent in the Arctic regions of the world today?**

i. Based on what we know about Hp prevalence trends in other world regions, how do you suspect, or how do you imagine that Hp became so prevalent in the Arctic?

**4c. What will our research add to the epidemiological literature on H. pylori over-all?**

4d. Do you feel our research will add anything important to the literature on Aboriginal population health?
Focus group questions: Aklavik focus groups

In attendance:

Location: ____________________________ Date/time: ______________________________

I want to start by getting a sense of what people already know about *H. pylori*, so I can get you the information you need when I make my final report to the community. I’d like to ask a couple questions about your knowledge.

1. If a family member or a friend asked you **what is H. pylori?** – in your own words, how would you explain it to them?
2. Based on what you know about it, **how do you imagine the H. pylori bacteria gets inside** of the human body?
3. We know that sometimes people get infected again after they are treated. **When people get H. pylori over and over again, how do you think this is happening? [Or why, do you think this happens to some people but maybe not other people?]**
4. OK, well, going from there, if more work was to be done on the *H. pylori* project in Aklavik, what do you think are **the most important things about H. pylori that this community needs to learn about?**

I’d like to know where *H. pylori* fits into the overall health of Aklavik – and I’d also like to know what you feel are the most important issues regarding people’s health in Aklavik.

5. There was a lot of concern voiced about *H. pylori* by some people in Aklavik in the last few years, which led to the development of this research project. I’m curious to know: In your opinions, **how important is H. pylori infection in relation to people’s overall health?**
6. What do you think are **the most important health issues** in Aklavik today?
7. What do you think are the biggest **determinants of health [or causes of these health issues __________________named above]** in Aklavik today?
8. **Why is Aklavik like ______________________ [the way they describe determinants in #2] today? [Or how did Aklavik come to be this way, like with the __________________?]**
Focus group questions: **Nurses in Aklavik**

In attendance:

Location: __________________________ Date/time: __________________________

I want to start by getting a sense of what people already know about *H. pylori*, so I can get the information people need when I make my final report to the community. I’d like to ask a couple questions about your knowledge and communication methods.

1. In general, how would you describe community members’ knowledge of health and of how to stay healthy?
   a. Do people seem well informed on health issues such as chronic diseases, infections?
   b. Do people seem to you to have a good grasp of the proximate causes of the most common illnesses?
   c. How about the social determinants of health?
   d. Within the community, which groups of people seem the most well informed on health issues? Which groups seem the least well informed on health issues? [like women, elders, men, more educated residents, locals, outsiders?]

2. When community members come to talk to you about health concerns, what are some of the most common issues that get raised? Which illnesses or health issues do people usually want to talk about?

3. Based on what you’ve experienced working in Aklavik as researchers from the Aklavik *H. pylori* Project come and go, how would you describe Aklavik residents’ knowledge of *H. pylori* infection?
   a. Do community members seem very knowledgeable about bacteria in general, or about *H. pylori* bacteria specifically?
   b. Do community members seem to you to understand the concept of “infection”?

4. What kinds of issues related to *H. pylori* do people seem the most well informed on? The least well informed on?

5. Please describe the ways in which you’ve heard community members speak about *H. pylori*.

6. What kinds of questions do community members ask you about *H. pylori*?

7. When someone asks you about *H. pylori*, how do you explain it to them?

8. Based on what you know about either the project, or about *H. pylori* in general, plus your knowledge of people in this community, what do you think are the most important things to investigate in the Aklavik *H. pylori* Project?

9. What parts of this research do you feel will be most useful to you in terms of health care delivery for the Susie Husky Health Centre?
FOCUS GROUP INTERVIEW GUIDE – CANHelp health researchers

“Social and Environmental Determinants of \textit{H. pylori} Bacterial Infection in Aklavik, NWT: A Community-Based Research Project”

Sally Carraher, Ph.D. candidate
Department of Anthropology – McMaster University

Introduction:

Hello! Most of you already know me as the anthropology student from McMaster who is working with the CANHelp Working Group on the Aklavik \textit{H. pylori} Project. For my dissertation research I am taking an in-depth look at social and environmental conditions in Aklavik which may be affecting the distribution of \textit{H. pylori}, as well as the effectiveness of the Aklavik \textit{H. pylori} Project. That may sound like two separate research goals – but actually it is my belief that because the CANHelp Working Group has been active in Aklavik for a few years now, that the social dynamics of our work there is an important factor in the current distribution of \textit{H. pylori} infection.

The purpose of this group interview is to discuss your experiences working for the CANHelp Working Group, and particularly about your memories, feelings, and opinions about working the communities. Just as I am interested in learning how northern community residents understand and perceive \textit{H. pylori} and health, I am also interested in learning how you as researchers conceptualize \textit{H. pylori} and the health of northern Aboriginal populations.

Because this is a group interview, I cannot guarantee confidentiality. I do promise that I will not attribute anything said in here to a specific individual by name or title in anything I report or publish. However, as colleagues of yours might read what I eventually publish, it is possible for someone to infer that specific statements are being made by certain people. Therefore, you should only share information with us today that you feel comfortable with the whole group – including myself, and possibly others outside of this group – knowing about. If there are any questions which a person prefers not to answer, that person may choose not to speak during that part of the interview. I will be recording this interview and taking notes throughout the process.

Thank you for participating in this part of my research!

For this first part I want us to talk about what you know about the knowledge of local communities regarding \textit{H. pylori} bacteria, infection, and related health issues:

1) Based on what you’ve each experienced in your visits to northern communities, how would you describe northern residents’ knowledge of \textit{H. pylori} infection?
   - do community members seem very knowledgeable about bacteria in general, or about \textit{H. pylori} bacteria specifically?
   - do community members seem to you to understand the concept of “infection”?

   1a. What kinds of issues related to \textit{H. pylori} do people seem the most well informed on? Least well informed o

   1b. Please describe the ways in which you’ve heard people speak about \textit{H. pylori}?
      
      i. (what do you think they mean when they say things like that? Or what does talking about _____ in that way make you think about?)

   1c. What kinds of questions do community members or partners ask you about \textit{H. pylori}?
      
      ii. (why do you think they are asking about this?)
iii. (why do you think this is on a lot of peoples’ minds?)
iv. (who/what kind of people in the communities typically ask these kinds of questions?)

1d. When you are answering individuals’ questions directly, like_______, what do you say to them? (How do you answer people’s questions about _____?)

2) Based on the data that we have from the lab work, what do you think is the most important information to report back to communities about H. pylori?

2a. Based on what you’ve each experienced in working in these communities, what are most the important messages CANHelp researchers should be relaying to community members?

2b. When you are explaining what H. pylori is to community members, how do you all describe it?

i. (pretend I’m a community member with no formal medical or health education. What kinds of things would you guys typically say to explain H. pylori infection to me?)

3) For those of you who have worked in multiple communities, is there anything about Aklavik [the clinic staff, the people, the planning committee, etc.] that seems different or unique from the other northern communities?

I’d like to finish up by discussing how we speak to other professionals about H. pylori, and the benefits of CANHelp research.

5a. What do you think are the greatest benefits that this research will provide for the participating communities?

In addition to learning what our work will achieve for local communities, I’d like to also talk about what our work will add to the discipline of epidemiology.

5b. Researchers have noted a trend in which H. pylori prevalence has tended to decrease in industrialized nations following the second world war. Even though we don’t have a lot of data on Arctic populations yet, Why do you think Hp is so prevalent in the Arctic regions of the world today?

i. Based on what we know about Hp prevalence trends in other world regions, how do you suspect, or how do you imagine that Hp became so prevalent in the Arctic?

5c. What will our research add to the epidemiological literature on H. pylori over-all?

5d. Do you feel our research will add anything important to the literature on Aboriginal population health?
Appendix D

CONFIDENTIALITY SCRIPT:  
PROTOCOL TITLE: Social and Environmental Determinants of H. pylori Bacteria Infection in Aklavik: A Community-Based Study

RESEARCHER: Sally Carraher, Department of Anthropology, McMaster University

To be used during training of peer-interviewers/translators from Aklavik.

I want to spend a few moments talking about confidentiality.

- You will be working over the next several months with people from your own community. Even though you may know each other very well, you need to be careful not to talk about what happens during interviews to anyone else, except for myself.

- As a peer-interviewer you are becoming a part of this research team. By signing this statement, you agree to not reveal the identities of any people participating in individual interviews, focus groups, or any other part of this study.

- I ask that you not reveal identities of people who have taken part in the Aklavik H. pylori Project research previously, nor anyone who will participate now, to anyone.

- Keeping people’s identities safe means more than just not using their names. It means that you should not speak about any part of what goes on during the interview process to anyone outside of the interview room. Especially in a community as small as Aklavik, it could be very easy for other people to figure out who was involved in an interview, or who said what during an interview, even if you only repeat a small part of what someone else said without saying their name.

- Interview and focus group recordings will be digitally recorded, and we will transcribe them later into computer files. These files will be saved only on my laptop computer and harddrive, and are protected with a password. As a peer-interviewer you may have access to these files. These files are not to be copied, e-mailed, printed, or otherwise given out to anyone. Only myself and you as a peer-interviewer will ever see these files. It is important that you do not talk about what you read in these files, even if it seems unimportant or not dangerous to talk about it.

- You should memorize the password for our computer files. You should not write it down where other people could ever see it, and you should not tell it to anyone else.

- The people participating in individual and group interviews are trusting us to keep their information private!

- Do you have any questions for me?

I acknowledge that I have been informed of confidentiality procedures for this study and that I understand the steps I need to take to ensure confidentiality. I have asked any questions I have at this time, and am satisfied with the answers.

I agree to become a peer-interviewer and to maintain confidentiality (check one)  [   ] yes  [   ] no

Name (please print):  

Signature: ___________________________ Date: ___________________________
Sally’s signature: ___________________________ Date: ___________________
**Aklavik H. pylori Project: Ethnographic Component**  

**GENEAOLOGY**  

Interviewer ______________________  

Date (dd/mm/yyyy) ______________________

**Location of interview**  

[ ] clinic  

[ ] respondent’s home  

[ ] other place: __________________________

**RESPONDENT**  

Respondent’s study ID: __________________________

Partnership: [ ] marriage  

[ ] common law  

[ ] co-res/dating

**PARTNER**  

**Surviving parents and any other spouses**

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Other marriages or Notes:

Appendix E: Kinship chart
Aklavik H. pylori Project: Ethnographic Component

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Notes:
**H. pylori Update**

**2011-12 Results**

**May, 2012**

It’s been a busy year for the Canadian North *Helicobacter pylori* (CANHelp) Working Group! We did a lot of new research, and got some interesting results from that!

In September of 2011, Sally Carraher moved to Aklavik to do some new work with the Aklavik *H. pylori* Project. Sally has been meeting with the Aklavik Health Committee to help plan research activities including breath tests, interviews, focus groups, and how to reach out to community members. A local person was hired to assist with research planning, breath tests, and other activities.

In November, two other CANHelp researchers, Megan and Laura, flew up to help Sally begin a re-infection study. We offered breath tests to people who had participated in the project before. We did this in order to see who has gotten new *H. pylori* infections since the treatment trial in 2008. We tested 119 people and found that only 30% of project participants have *H. pylori*! This is half of what was found in 2008 when the project began. So, we were happy to find that out!

Sally has been interviewing people, and also just talking and hanging out with a lot of people around the community, in order to learn more about daily life in Aklavik. By doing this, Sally hopes this will help the CANHelp team better understand what puts people at risk for getting *H. pylori* infection and what can be done to help prevent infection.

The CANHelp Working Group has also started projects in Old Crow and Tuk. This summer a project will be launched in Fort McPherson as well. The more people who participate in the research, the more we will be able to learn about *H. pylori* infection in this region of the North. This will help researchers, nurses, health officials, and communities work together to reduce the burden of *H. pylori* infection and the stomach diseases that it can cause.

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**What have we accomplished?**

**Research timeline...**

| Feb. 2007  | Community approval for project |
| May 2007  | Community workshops held       |
| Sept. 2007| NWT research license obtained  |
| Nov. 2007 | Aklavik *H. pylori* Project begins recruiting and testing people |
| Feb. 2008 | Endoscopy in Aklavik           |
| April 2008| Scope results reported back to individuals |
| Summer 2008| *H. pylori* tested to design best treatment options |
| Nov. 2008 | Treatment trial begins in Aklavik |
| 2009-2010 | People are treated, more data is collected |
| Nov. 2011 | Re-infection study begins, participants get breath tests |
| May 2012 | Re-infection study completed, Results reported to individuals, Treatment provided |
| Fall and Winter 2012 | Community planning for reporting microbiology results back to Aklavik |
| Ongoing | Data collection Follow-up breath tests Knowledge sharing Expanding project to other northern communities |
Ask a researcher:

This is what a *H. pylori* bacterium looks under a microscope. It has a spiral-shaped body, like a corkscrew, with little tails called “flagella”.

(Carraher, 2012)

Sally, what is *H. pylori* infection?

*Helicobacter pylori* (*H. pylori* for short) is the name of bacteria that lives in the inner lining of the human stomach. Bacteria are living things that are very small – too small to see without a microscope. There are lots of kinds of bacteria, just like there are lots of kinds of birds or fish or flowers. The species called “*H. pylori*” is just one of many kinds of bacteria. Not all bacteria live inside humans. Out of the kinds that do live inside your body, most of them are harmless. In fact, some kinds of bacteria are very useful! They help us digest our food, and keep other, dangerous kinds of bacteria and other small living things from infecting us. Because *H. pylori* can stay inside someone’s stomach for a long time, it is called a **chronic infection**.

Sally, is *H. pylori* in other parts of the world?

YES, it is! Chronic *H. pylori* infection affects about half of all the people living on Earth. But, the infection is not evenly spread across the world. This means that infection rates are much higher in some parts of the world, and much lower in other parts, as you can see on the maps (next page).

In Aklavik in 2007-2008, when the project first started, we found that 58% of the 333 people who had a breath test had *H. pylori* infection. In 2011-2012, we retested 119 of the earlier participants, and found that the infection among project participants dropped to about 30%. This means a few different things.

First, it means that large treatment campaigns, like the one we did between 2008-2010 in Aklavik, can work to reduce *H. pylori* infection in northern communities, at least in the short term. We believe that if we can continue to see a lower infection rate, then we will eventually also see a decrease in severe gastritis, stomach ulcers, and stomach cancer too.

Second, it means that Aklavik project participants, for the time being, have an infection rate that is closer to the national average of about 20-30%.

Third, we may wish to return to Aklavik in a few years and follow up with people to see if the infection rate stays the same, gets better, or gets worse again. No matter what we do, the researchers, the health centre, and the Aklavik Health Committee are committed to working together to make sure that community concerns are addressed, and that the knowledge we gain is shared back to the community.
**Top:** This map shows the prevalence of *H. pylori* across the world. Prevalence is the percentage of people in a region who have *H. pylori* infection at a given time.

**Middle:** This map shows *H. pylori* infection in the Arctic. You can see it’s a common infection in Arctic Russia, Alaska, the NWT, Nunavut, northern Manitoba, and Greenland.

The information for these maps was summarized from numerous scientific reports.3

**Bottom:** This table shows the percentage of people with *H. pylori* infection in three western Arctic communities.4

<table>
<thead>
<tr>
<th>Community</th>
<th>Time period</th>
<th>Participation</th>
<th>Population</th>
<th>No. of people tested</th>
<th>% <em>H. pylori</em> infection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aklavik, NWT</td>
<td>2008-2010</td>
<td>Open to all community members</td>
<td>~645</td>
<td>333 (breath test)</td>
<td>58%</td>
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<tr>
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<td></td>
<td></td>
<td>194 (biopsy)</td>
<td>67%</td>
</tr>
<tr>
<td>Aklavik, NWT</td>
<td>2011-2012</td>
<td>Restricted to previous participations</td>
<td>~625</td>
<td>119 (breath test)</td>
<td>30%</td>
</tr>
<tr>
<td>Old Crow, Yukon</td>
<td>2010-2011</td>
<td>Open to all community members</td>
<td>~250</td>
<td>187 (breath test)</td>
<td>72%</td>
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<tr>
<td>Tuktoyaktuk, NWT</td>
<td>2011</td>
<td>Open to all community members</td>
<td>~870</td>
<td>103 (breath test)</td>
<td>57%</td>
</tr>
</tbody>
</table>

(Carrah, 2012)

(http://www.stanford.edu)
What will happen if I get H. pylori?

One really important thing to know is that H. pylori does not make all people sick. Some people could have it for years and never get sick, or may not even know they have it. But some people will get sick.

When people get H. pylori infection, the bacteria upset the stomach lining, causing inflammation called gastritis. Gastritis causes thick, patchy changes, seen in the image below. Not everyone who has gastritis will feel it. The gastritis can be mild or severe. At first, some people may get stomach problems that stop after a few days.

Some people with chronic H. pylori infection develop long-lasting symptoms, such as stomach pain, nausea or vomiting, heart burn, and a few people develop serious diseases. These diseases can include stomach ulcers and, very rarely, stomach cancer. Out of the people with H. pylori infection, about 10% might get a stomach ulcer and about 1% (or even less) might get stomach cancer.¹

Stomach cancer is more common in this part of the North compared to the rest of Canada, which is why many people are concerned about H. pylori. But we want you to know that when stomach cancer is caused by H. pylori, it tends to happen in people who have probably had the infection for many, many years. If you ever find out that you have H. pylori, we want you to know that usually you are in no immediate danger. We know sometimes it takes a while for the treatment (pills) to come in. It’s OK to wait for the pills to come in to Aklavik – most people do not have to worry about getting a disease all of a sudden. Also, remember that most people who have H. pylori will never get stomach cancer.

Many things other than H. pylori can cause stomach problems. So if you have any stomach problems or pain, it is best to see a nurse to figure out what is causing your symptoms.

H. pylori infection can cause:

- stomach pain
- nausea
- vomiting
- heart burn

Although most people never get sick from H. pylori, a few people may get:

- stomach ulcers
- stomach cancer

Out of the people with H. pylori infection, about 10% might get a stomach ulcer and about 1% (or even less) might get stomach cancer.

Remember, ALL of these symptoms and sicknesses - including stomach cancer - can be caused by other things besides H. pylori. It is important to see a nurse if you are having stomach problems, so that you can find out what is causing it.
Sally, where does *H. pylori* infection come from?

This is a tough question! Let me explain why.

First, *H. pylori* science is relatively young. Scientists have known since 1882 that tuberculosis is caused by a bacterium called *Mycobacterium tuberculosis*. And we’ve known since 1933 that influenza is caused by a virus. Scientists didn’t know for sure that stomach gastritis and ulcers are caused by the *H. pylori* bacterium until the 1980s. We still don’t know exactly where *H. pylori* originate from, or how they spread. The CANHelp lead microbiologist Monika Keelan explains that *H. pylori* bacteria are unique in many ways – in their genes and in their behaviors. So *H. pylori* infection is proving to be a complicated issue to study. But she and her team, and all the other CANHelp team members, are up to the challenge! Here’s what we do know so far about how *H. pylori* infection works.

People get *H. pylori* infection most often during childhood. This is true in Aklavik, and it’s true in many other parts of the world. Based on research, it seems that people probably get infected when someone comes in direct contact with an infected person’s germs, especially if that person is sick with vomiting or diarrhea.

It is a good idea to always **wash your hands** before eating, after using the washroom, and after you take care of adults or children who have been vomiting or have diarrhea. This will help you avoid all kinds of germs, including *H. pylori*.

Research has shown that **humans are the only known source of *H. pylori* infection**. This means scientists have looked for *H. pylori* in other animals, and we can’t find it living naturally in other animals. Although we only find it in humans, scientists have not ruled out the possibility of an environmental source for *H. pylori* infection, like perhaps water. More research is needed.

**FACTS: *H. pylori* and water:**

- While some scientists have reported finding *H. pylori* in the water, others have not found it. When we find it in water, it is a different shape and we do not know if the bacteria in this shape are alive, or able to reproduce (make new bacteria). We do not know if these different-shaped *H. pylori* are able to infect people, so we cannot say for sure if people are getting this infection from the water.

- In Aklavik, researchers have looked at infection, gastritis (inflammation in the stomach), and water-use habits in 278 participants who submitted gastric biopsies. This study found a possible connection between drinking untreated water and having severe gastritis. However, there is not enough data yet to determine if the gastritis is caused by irritants in the water, or by something else. CANHelp is collecting data from other nearby communities to add to our knowledge of water use, *H. pylori* infection, and gastritis. CANHelp will share results of future research back to all the communities in which we work.

**FACTS: *H. pylori* in households:**

- *H. pylori* infection is strongly connected to low income and crowded housing. A lot of the people in Aklavik who have *H. pylori* live in crowded housing, because they do not make enough money to afford larger houses which cost more rent, and also because there’s not a lot of additional housing available for people to move into. Throughout the world, households with more people living in them typically have higher *H. pylori* infection rates. This makes a lot of scientists conclude that *H. pylori* infection spreads directly from person to person, because housemates are in close contact each other daily.

- Daily living conditions and economics appear to play a strong role in *H. pylori* infection. There is some evidence from South America that people with poorer nutrition may be more susceptible to chronic *H. pylori* infection. In Aklavik, income affects the quality of nutrition that families are able to get, because store foods are expensive. Also, income affects a family’s ability to buy fuel to be able to go on the Land and get country foods. In general, people with poorer nutrition are more likely to get all kinds of infections. We are continuing research into daily living conditions, environmental conditions, and *H. pylori* infection in northern communities like Aklavik.

Do you have any questions about *H. pylori* or about the research that the CANHelp Working Group is doing in the Aklavik and the North?

E-mail your questions to Sally at carrahs@mcmaster.ca.
Sally, you’re leaving soon. Who can I talk to about *H. pylori*?

You can always talk to me. I’m in Aklavik until June 11, 2012. And I will come back to Aklavik in 2013. In the mean time, you can call me, e-mail me, or add me to your Facebook friends.

**Sally Carraher**

Email: carrahs@mcmaster.ca

Phone: (907) 244-1778

**Address in Alaska** (summer time):

Department of Anthropology
Beatrice McDonald Building, Room 212
University of Alaska Anchorage
3211 Providence Drive
Anchorage, AK USA, 99503

**Address in Ontario** (fall and winter time):

Department of Anthropology
Chester New Hall, Room 524
McMaster University
2180 Main Street West
Hamilton, ON Canada, L8S 4L9

You can get more information about the Aklavik project, and the other Northern research, by visiting our web site at [http://canhelpworkinggroup.ca](http://canhelpworkinggroup.ca).

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13 May, 2012

**Dear Aklavik,**

**Mahsi Cho! Quyanainni!**

Thank you, from the bottom of my heart!

You have opened up your community to me, and shared your joys and passions and questions and concerns (not to mention all your yummy country food, music, arts, and awesome culture!) I have truly enjoyed my time living in Aklavik, and I will miss so many, many people from here.

See you again in 2013!

**Sally Carraher**

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**References:**

1. [https://canhelpworkinggroup.ca](https://canhelpworkinggroup.ca).
McMaster University Research Ethics Board (MREB)
c/o Office of Research Services, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Application Status: New  ✔ Addendum  □ Project Number: 2011 113

TITLE OF RESEARCH PROJECT:
Social and Environmental Determinants of H. pylori Bacterial Infection in Aklavik, NWT: A community-Based Participatory Research Project

Faculty Investigator(s)/ Supervisor(s) | Dept./Address | Phone | E-Mail
--- | --- | --- | ---
W. Warry | Anthropology | 23901 | warrywa@mcmaster.ca

Student Investigator(s) | Dept./Address | Phone | E-Mail
--- | --- | --- | ---
S. Carraher | Anthropology | 907-244-1778 | carrahs@mcmaster.ca

The application in support of the above research project has been reviewed by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster University Policies and Guidelines for Research Involving Human Participants. The following ethics certification is provided by the MREB:

✔ The application protocol is cleared as presented without questions or requests for modification.

✔ The application protocol is cleared as revised without questions or requests for modification.

The application protocol is cleared subject to clarification and/or modification as appended or identified below:

COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.

Reporting Frequency: Annual: Sep-01-2012 Other:

Date: Sep-01-2011 Chair, Dr. Br. Detlor:

McMaster University Research Ethics Board (MREB)  
c/o Office of Research Services, MREB Secretariat, GH-305, e-mail: ethicsoffice@mcmaster.ca  

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COMMENTS AND CONDITIONS: Ongoing clearance is contingent on completing the annual completed/status report. A "Change Request" or amendment must be made and cleared before any alterations are made to the research.

Reporting Frequency: Annual: Sep-01-2012
Date: Sep-01-2011  Chair, Dr. Br. Detlor: [Signature]

2011
Northwest Territories Scientific Research Licence

Issued by: Aurora Research Institute – Aurora College
Inuvik, Northwest Territories

Issued to: Dr. Karen J Goodman
University of Alberta
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T6G 2E1 Canada
Phone: (780) 492-1889
Fax: (780) 492-7593
Email: karen.goodman@ualberta.ca

Affiliation: University of Alberta

Funding: Alberta Heritage Foundation for Medical Research
Canadian Gastroenterology Association
CIHR
Social Sciences and Humanities Research Council of Canada
Public Health Agency of Canada
Indian and Northern Affairs Canada
Canadian Circumpolar Institute
Nasivvik Centre for Inuit Health and Changing Environments, CIHR Network
Environment for Aboriginal Health Research, Laval/Trent
Anisnabe Kekendazone - CIHR Network Environment For Aboriginal Health Research, Ottawa
ArcticNet

Team Members:
Karen Goodman; Christopher Fletcher; Carl Phillips; Sander Veldhuyzen van Zanten;
Monika Keelan; Safwat Girgis; Richard Fedorak; Justin Cheung; Amy Morse; Robert
Bailey; Robert Buckle; Crystal Lennie; Rachel Munday; Leah Seaman; John Morse;
Susan Chatwood; Kumi Kandola

Title: The Aklavik H. pylori Project

Objectives: 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.

Dates of data collection: March 15, 2011 to December 31, 2011

Location: Aklavik

Licence No. 14686 expires on December 31, 2011
Issued in the Town of Inuvik on March 15, 2011

Pippa Seccombe-Hett,
Director, Aurora Research Institute