Community-driven health research in NWT and Yukon: Engaging students and non-academic partners in interdisciplinary public health research

Dr. Karen J Goodman, Professor of Epidemiology
Dr. Janis Geary, Research Associate
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Northern Research Day
Our talk today

• Provide an overview of the research program
• Developing community-driven research with a biomedical focus in Northern Canada: Educating and mentoring students
• Implementing community-driven research methods into scientifically rigorous research
Overview

Canadian North *Helicobacter pylori* (CANHelp) Working Group

Research Program
Helicobacter pylori

• What is *Helicobacter pylori*?
  • A type of bacteria that can live in the stomach
  • Many people around the world have *H. pylori*

• How is *H. pylori* spread?
  • Most often during childhood
  • Most likely from an *H. pylori*-infected person who is sick with vomiting or diarrhea
Helicobacter pylori

• How common is *H. pylori* infection?
  • Believed to be common everywhere in the pre-modern world, prevalence of *H. pylori* infection was estimated in 2000* to be around:
    • 40% in developed countries
    • 70% in developing countries
  • Prevalence in developed countries continues declining, though social disparities persist within these countries

**Helicobacter pylori**

- Causes chronic stomach inflammation
- Increases risk of stomach ulcers and stomach cancer
Helicobacter pylori

- The best treatments require 3-4 drugs for 10-14 days
  - Under the best circumstances initial treatment cures ~80-90%
  - In populations where *H. pylori* is common, treatment failure is also common
Canadian North *Helicobacter pylori* Working Group

- Formed during 2006-2008 in response to:
  - Community concerns about health risks from *H. pylori* infection
  - Health care providers seeking information to improve clinical management of *H. pylori* infection
  - Public health officials wanting evidence to inform public health policy related to *H. pylori* infection
Figure 1: Locations of current CANHelp Working Group community H. pylori projects
## Participation in community projects

<table>
<thead>
<tr>
<th>Activity</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participants Recruited</td>
<td>1397</td>
</tr>
<tr>
<td>Info on <em>H. pylori</em> status</td>
<td>1333</td>
</tr>
<tr>
<td>Health Surveys Completed</td>
<td>1222</td>
</tr>
<tr>
<td>Participant Surveys Completed</td>
<td>920</td>
</tr>
<tr>
<td>Endoscopies Completed</td>
<td>405</td>
</tr>
<tr>
<td>Assigned Treatment in Trial</td>
<td>294</td>
</tr>
</tbody>
</table>
Key findings from CANHelp projects

• High prevalence of *H. pylori* infection
• High prevalence of severe disease associated with the infection
• Improved treatment regimens have increased treatment success from 60% to >90%
• Reinfection following successful treatment is infrequent
• Unique features of bacterial strains isolated from stomach biopsies
Developing community-driven research with a biomedical focus in Northern Canada by

Educating and Mentoring Students

Karen J Goodman
Professor of Epidemiology
Teaching & Learning Philosophy

- Effective teachers stimulate active learning and encourage students to be critical, creative thinkers by
  - Creating opportunities for learning-by-doing
  - Fostering critical thinking
  - Putting students in charge of their own intellectual growth as scholars and practitioners

- Graduate education aims to develop scholarly and professional abilities
Teaching & Learning Philosophy

Scholarly abilities include

- Synthesizing, integrating and applying knowledge
- Systematic observation and analysis
- Critical reflection
- Evaluation
- Depth of understanding
Teaching & Learning Philosophy

- Professional abilities include
  - Independent learning and problem solving
  - Critical review of developments in the field
  - Effective communication and collaboration with colleagues
  - Teaching and guiding others
Mentoring Philosophy

- Effective mentors cultivate professional abilities by
  - Facilitating connections
  - Modeling professional behavior
  - Facilitating opportunities for learning by doing
I’ve grown my research organically by recruiting researchers-in-training and helping them develop professionally while pursuing their interests according to their abilities.
Developing a Research Program with Research Practice Opportunities

Clinical Research Practice

- 2007-2009, Justin Cheung, MD, Gastroenterology Resident
  - AHFMR-CAG Clinical Research Fellowships:
    Designed/directed first CANHelp mobile endoscopy clinic (for Aklavik H. pylori Project)
Developing a Research Program with Research Practice Opportunities

Northern Research Training Awards

- 2008-2009, Janis Geary, MSc Global Health Student
  - NSTP-C/BAR Project: “Knowledge Transfer of Health Research Findings to Community Members of Aklavik, NWT”

- 2008, Michael Arget, MPH Student
  - NSTP-C/BAR Project: “Investigating Community Health Problems Related to *H pylori* Infection in the NWT”
Developing a Research Program with Research Practice Opportunities

Clinical Research Practice

- 2008, Amy Morse, MD, Gastroenterology Resident
  - Clinical Research Practice: Designed/directed first randomized treatment trial (for Aklavik *H. pylori* Project)
Developing a Research Program with Research Practice Opportunities

Northern Research Training Awards

- 2011, Ashley Wynne, MSc-Global Health Student
  - NSTP-C/BAR Project: “Developing efficient tools for collecting medical chart data on the burden from digestive diseases in northern community health centres”
Developing a Research Program with Research Practice Opportunities

Northern Research Training Awards

- 2011, Megan Lefebvre, PhD-Epidemiology Student
  - NSTP-C/BAR Project: “Community-driven research on barriers to successful treatment for *H pylori* infection in northern Canada”

- 2011, Amy Colquhoun, PhD-Epidemiology Student
  - NSTP Project: “Assessing common understanding among community members, researchers, and health professionals as part of knowledge translation for community-driven research on *H pylori* in northern Aboriginal communities”
Developing a Research Program with Research Practice Opportunities

Northern Research Training Awards

- 2012, Emily Hastings – MSc-Epidemiology Student
  - NSTP-C/BAR Project: “*H pylori* infection as an environmental health concern in the Inuvialuit Settlement Region”

- 2013, Emily Hastings – PhD-Epidemiology Student
  - NSTP-UANRA Project: “Community-driven research on potential environmental sources of *H. pylori* infection in northern Canada”
Developing a Research Program with Research Practice Opportunities
Northern Research Training Awards

- 2014, Kathleen Williams, MSc-Epidemiology Student
  - NSTP-UANRA Project: “Investigating exposure to antibiotics in Arctic community H. pylori projects”
Developing a Research Program with Research Practice Opportunities

Northern Research Training Awards

2016, Taylor Cromarty, MSc-Epidemiology Student
- NSTP-UANRA Project: “Studying the effect of deprivation indicators such as food insecurity on the relative frequency of $H. pylori$ infection and its consequences in female-led households compared to other households”

2016, Amrit Passi, MSc-Epidemiology Student
- NSTP-UANRA Project: “The impact of free living amoeba on $Helicobacter pylori$ infection in Indigenous Canadian Arctic communities”
Developing a Research Program with Research Practice Opportunities

Research Interns
Incorporating community-driven research methods in scientifically rigorous research

Dr. Janis Geary
Planning committees

- Composition varies between communities
- Process to set up a committee
  - Present at a community event
    - Get a sense of community interest in research
  - Work with partners to identify types of committee members
    - Community health directors
    - Band council representation
    - Municipal government
    - Community leaders
Time to starting planning workshops after initial invitation
Planning committees

• Initial planning workshop:
  • Community shares knowledge of stomach health in community and concerns about *H. pylori* infection
  • Researchers share knowledge of *H. pylori* infection
  • Community and researchers work together to determine what community questions can be answered using available research methods
Planning committees

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Example: Water
Investigating *H. pylori* and water

- **Community request:**
  - I’m worried the water is making me sick, so can you test the water?

- **Problem:**
  - Can’t just test the water for *H. pylori*
    - Could find it, but that doesn’t mean it’s infectious
    - Could miss it, but that doesn’t mean that it’s not there and infectious
Investigating *H. pylori* and water

• Solution:
  • Identify what research question the community partner is really interested in
Investigating *H. pylori* and water

• Solution:
  • Identify what research question the community partner is really interested in

• It’s not “are there *H. pylori* in the water?”, it’s “is water a source of *H. pylori* bacteria or a mode of transmission?”

• Can use epidemiology, not microbiology, to answer
Investigating *H. pylori* and water

• Epidemiologic investigation
  • Data from Aklavik and Tukoyaktuk
  • Estimate the association between consumption of untreated water and *H. pylori* prevalence

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>HP+ (%)</th>
<th>OR (adjusted)</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ever consumed untreated water</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>86</td>
<td>54 (63)</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>282</td>
<td>173 (61)</td>
<td>0.36</td>
<td>(0.14, 0.94)</td>
</tr>
</tbody>
</table>
Policies and procedures

canhelpworkinggroup.ca

Collaborative Partnerships

Guiding Principles and Research Project Guidelines

Statement on Stewardship and Dissemination of Knowledge Generated Collaboratively in CANHelp Working Group Community Projects (link to document).

Research Agreements

As the first step in planning a community project, the planning committee and the research team develop a Research Agreement (see sample agreement here).
Acknowledgements

- Other members of the CANHelp Working Group
- Alberta Innovates – Health Solutions (AIHS)
- Canadian Institutes for Health Research (CIHR)
  - Institute of Aboriginal People’s Health
  - Network Environment for Aboriginal Health Research (NEAHR)
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- Indigenous and Northern Affairs Canada
- Ualberta North