

ARCTIC INSTITUTE OF COMMUNITY-BASED RESEARCH

First Annual Conference

March 20-21, 2012 Whitehorse, Yukon



Who We Are

The Arctic Institute of Community-Based Research (AICBR) is an incorporated Canadian non-profit organization that was established in February 2007. The original name of organization was the Arctic Health Research Network-Yukon. The name was changed in October 2011 to better reflect the evolution of the organization.

The vision of AICBR is the meaningful engagement of Northerners in health research focused on Northern health priorities, with results contributing to lasting health improvements. AICBR works to build capacity of Yukon residents, particularly Yukon First Nation citizens, to facilitate meaningful involvement in all stages of research projects. As well, AICBR has an ongoing focus on knowledge translation to ensure transfer of results to inform the development of Northern policies and programs, as well as ethics.

Friendship, K., Blottner, B., Jackson, S., Butler Walker, J. 2012. 36 pp. Arctic Institute of Community-Based Research.

ISBN 978-0-9809736-9-3

Funding by Kloshe Tillicum is gratefully acknowledged.

www.aicbr.ca



Arctic Institute of Community-Based Research YUKON, CANADA

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 - (2) Presentation: Rebuilding Food Sovereignty in Nishnawbe Aski Nation, Joseph LeBlanc
 - (3) Presentation: Dawson Community Food Survey & Market Expansion Project; Danielle Palmer

Executive Summary

The Arctic Institute of Community-Based Research (AICBR) hosted their first annual conference on March 20 and 21st 2012. In total 78 people registered for the conference and attended various components over the two days.

Three sessions were offered: Community-Based Research, an H. pylori research project in the Yukon, and Food Security. Outcomes included: developing a greater understanding of what community-based research is with conference participants; developing community-based research principles relevant for the Yukon; learning more about H. pylori and the possibility for Yukon First Nation communities to participate in this research project; discussing and sharing knowledge related to food security issues in the North; and the recommendation to develop a sustainable network for people to stay connected and share information related to ensuring food security for the Yukon.

Based on feedback and the evaluation forms, it is clear that Yukoners are interested in learning more about Community-Based Research. Participants expressed an interest in research opportunities related to the bacterium H. pylori. Participants were all very clear that continued knowledge exchange and action about food security is integral for the Yukon. AICBR looks forward to the opportunity to bringing people together again in the near future. See you in 2013!

Introduction

The Arctic Institute of Community-Based Research (AICBR) hosted their first annual conference on March 20 and 21st 2012. Participants came from across the Yukon, five Canadian Universities, Northwest Territories and northern Ontario. They included Yukon First Nations, territorial and federal government representatives, rural and local food growers and producers, several non-government organizations, and academics. The purpose of the conference was to discuss and develop a Yukon/Northern perspective for community-based research, and to share information about an H. pylori project, and various opportunities for collaboration related to Yukon food security. Participants were seated so that each of the 13 tables had at least one representative from a Yukon First Nation community, at least one health practitioner or NGO, and at least one academic researcher. This way, they had the opportunity to network, share their ideas and experiences, and learn from each other, and to begin to plan for action and identify next steps in the topic areas.

In total 78 people registered for the conference and attended various components over the two days.

Goals & Objectives

The overall goal for the conference was to be responsive to identified interests and needs in the Yukon and to create a greater understanding of AICBR's approach and focus through the offered sessions. Each session had particular objectives. The goal of the conference was also to identify training needs from participants in order to support participation in various projects and future initiatives.

Community-Based Research:

To further develop a shared understanding of community-based research in the Yukon and to share and discuss some project opportunities.

H. pylori Project in the Yukon:

To share information about a project opportunity regarding H. pylori in the Yukon.

Food Security:

To share information about food security activities in the Yukon and to hear about food security activities in 3 First Nation communities in Northern Ontario. To discuss ways of moving forward collaboratively with food security in the Yukon.

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Dr. Suzanne Jackson with Clara Winnepetonga

Main Activities

Community-Based Research

Dr. Suzanne Jackson from the Dalla Lana School of Public Health, University of Toronto and advisor to AICBR presented the principles of community-based research with Jody Butler Walker, Executive Director of AICBR. Here, definitions of 'community', 'research', and 'community-based' were discussed. Groups then worked together to 'Yukonize' those principles. AICBR has taken the recommendations from the small group discussions and we will be adopting the improved principles as our approach to community-based research.

H. pylori Project in the Yukon

Dr. Karen Goodman (Principal Investigator) and Janis Geary of the CANHelp Working Group, University of Alberta presented a project opportunity for Yukon First Nation communities to participate in researching the prevalence and treatment of Helicobacter pylori, a type of bacteria found in the stomach. They provided information about research that has been done in other Northern communities and discussed different ways of conducting the project including treatment options. Communities interested in learning more about this research opportunity can contact the CANHelp Working group. canhelp@med.ualberta.ca; 1-855-492-2525

Food Security

Discussions on the second day of the conference focused on food security and were facilitated by Heidi Marion from Foodscapers. Food security is a pressing issue across the North. The document 'Resetting the Table: A People's Food Policy' (Food Secure Canada 2011) was distributed and referred to throughout the day. Food security may be defined as the ability to access sufficient amounts of nutritious and safe foods- this affects many Northerners in different ways. The goal of the second day of the conference was to bring many people together and discuss ways food (in)security affects them, share initiatives that are currently being done, and discuss potential community-based solutions. AICBR hopes to continue to bring people together and facilitate the development of a Yukon Food Security Network that will look at the current status of food security in the Yukon, identify promising practices, and advocate for food security in the Yukon. People interested in being involved in this working group should contact info@aicbr.ca.



Dr. Karen Goodman and Janis Geary with Bree

From the Indigenous Health Research Group at University of Ottawa, Dr. Michael Robidoux discussed a food security project that his group has been working on with First Nation communities in Northern Ontario. Clara Winnepetonga of Wapekeka First Nation discussed culture programs that have been done in her community, and shared stories and pictures of community gardening and of youth and elders working together to hunt, fish and live off the land. Simon Frogg of Wawakapewin First Nation discussed the history of the area and the impacts it has had on the current lifestyle of his people. Joseph LeBlanc from the Nishnawbe Aski Nation presented a comprehensive overview of food sovereignty and the current status of the food system, as well as how to rebuild food sovereignty. This group has been working with Craig Larsen at Chronic Disease Prevention Alliance of Canada. The funding for these initiatives is through the Coalitions Linking Action & Science for Prevention. This group is hoping to build Northern partnerships in the area of food security for the purposes of knowledge exchange.

Simone Rudge from Yukon College Greenhouse and Aurora Mountain Farm shared photos and discussed her farming practices, including the raising of livestock in the Yukon. Simone also runs the Green Greenhouse Growers program under the Skills for Employment program at Yukon College. Simone's presentation included a video of her student's sharing what they've gained from taking the program and the goals they are working towards.

Matt Ball from Yukon Government Agriculture Branch discussed a different area of food security that concerns the land that is available to grow food and livestock, as well as other agricultural challenges (i.e. organic certification) that currently exist.

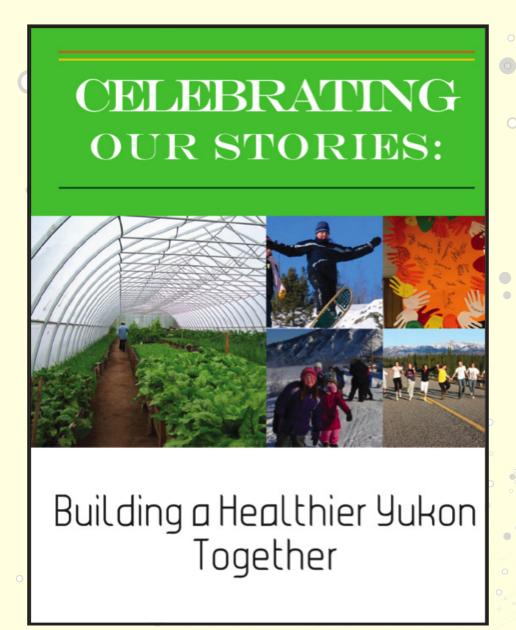
Danielle Palmer from Klondike Conservation Society (Dawson City, Yukon) discussed the Food Survey & Market Expansion Project. This project aimed to understand the current buying practices and attitudes towards local foods, as well as hurdles consumers face in supporting local agriculture in the Klondike region. It also aimed to research how to best support local farmers and facilitate the sector's ability to meet the community's growing needs for ensuring food security. The Conservation Society has been working in partnership with the City of Dawson, Tr'ondëk Hwëch'in, Robert Service School, Dawson Community Garden and Dawson Community Greenhouse.

Alice Boland of Little Salmon Carmacks First Nation shared pictures of the First Nation's Greenhouse and Farm Operation project. Alice told the story of how the project began and the learning process of finding out what would grow and what wouldn't. This greenhouse was started over ten years ago and is an inspiration to many other Yukon Communities.

Dr. Kent Mullinix, Director of Sustainable Agriculture and Food Security at Kwantlen Polytechnic University, and Dr. Scott Green from University of Northern British Columbia, introduced the proposed Yukon Food System Design and Planning project.

Kent has assembled a team of 20 specialists who are ready to work with Yukoners to co-design an integrated food system. The plan will provide farmers, food-sector entrepreneurs, consumers, and the community at large with sequential steps, drawing a roadmap to food sovereignty for the whole Yukon.

AICBR and partners have recognized through various project activities that food security and achieving and maintaining a healthy lifestyle are interrelated. On the second day of the conference, the booklet 'Celebrating Our Stories: Building a Healthier Yukon Together' was released. AICBR worked with the Recreation and Parks Association of the Yukon and Yukon Government-Health & Social Services on this initiative. Success stories that contribute to achieving a healthy lifestyle were collected and produced into a colour booklet. The publication also includes a summary from the Deliberative Dialogue on Healthy Weights for Children in the Yukon gathering hosted by AICBR and partners in December 2011, and is posted on our website (www. aicbr.ca).



Discussion Outcomes

Community-Based Research What is Community?

Based on the discussions in the Community-Based Research session, Community is described as:

In the Yukon, the primary community for AICBR work is a community of place where all living things are connected ecologically and spiritually - people, the land, animals and plants in rural and urban locations. AICBR also recognizes that all those living in the Yukon belong to several different communities – they connect to others with similar interests; like others who speak the same language, have the same history, belong to the same profession, care about the same problem, work together or go to school together. Both communities of place and communities of interest are evolving and dynamic.

Based on the discussions in this session, Community-Based Research is described as:

Community-Based research involves community members in all parts of the project or research. This relationship is built on trust, full participation of everyone, two-way communication, recognition of local expertise and community knowledge, and is driven by community agenda/issues/priorities. The researcher is a facilitator and partner rather than the leader. In the Yukon, community-based work is built on respect, caring, and sharing where communities, practitioners, and researchers have mutual goals and excitement about the work and recognize one another's strengths and contributions.



Ron Pearson (AICBR Board member) and Bree Blottner with Tami Hamilton of Carcross Tagish First Nation

Principles of Community-Based Research for the Yukon

Based on the discussions in this session, and on the four principles of Responsibility, Respect, Relevance and Reciprocity, community-based research principles for the Yukon and to be adopted by AICBR, can be described as:

- 1. Community members and researchers work together in all stages of projects. [Reciprocity and Responsibility]
- 2. Community members/research participants are actively involved in decisions about the research process from the beginning; and the process is responsive to cultural and community values. [Responsibility]
- 3. The research process strives for consensus and enables participation of all people. [Respect]
- 4. The relationship between researchers and community members is built on respect, trust, and learning with and from each other. [Respect]
- 5. The research project lays the ground for the exchange of knowledge, skills, resources, and ownership between stakeholders and within a mutual agreement. [Reciprocity]
- 6. Those involved in the research project have the responsibility to provide reciprocity. The
- 7. research process builds the capacity of community people to participate in and use the knowledge produced by the research. [Responsibility, Reciprocity, and Relevance]
- 8. There is continuous discussion/verification of data between all partners in order to generate meaningful, useful, and accessible results to inform community actions. [Reciprocity]
- 9. The research benefits and serves the community directly and addresses their interests and needs. [Relevance]
- 10. Research builds on and contributes to the strengths and resources of the community.

 [Relevance]
- 11. Health is addressed from positive, ecological and cultural beliefs and values. [Relevance]



Ashten Staffen (AICBR Volunteer) with Caitlin Dorward and Dr. Kent Mullinix of Kwantlen Polytechnic University and Dr. Paula Pasquali and Jan Langford of Yukon Government Health and Social Services

H. pylori Project in the Yukon

After the H. pylori presentation, the small groups discussed how they would start to plan a research project like this in their community, as well as, how they would plan a steering committee. Some key highlights were to first talk to Chief and Council, the Health Centre, Mayor/Village office and see if they were supportive of the project. A visual aid, such as the video that was shown at the conference (Never Say Die: The Aklavik H. pylori Project) could be a useful tool to provide a better understanding of the overall project and what it entails. Overall, if a community is interested in participating in the project, they can contact either the CanHelp Working Group (see pg. 25) or AICBR to discuss and make a plan for next steps. Other community groups (i.e. Elders Council, Health & Social, others) should also be involved, according to community capacity. It was also recognized that a key position in the community should be established, with a person responsible for managing the project at the community-level to facilitate ongoing communication and collaboration.

With respect to forming a Steering Committee, it was felt that community members, the First Nation Heath & Social director, someone from Chief and Council, the Nurse in charge, a First Nation liaison, and the researchers should be on the committee. It was recognized that it could be challenging to get community members involved because they may be intimidated by the other health professionals, and may be expected to volunteer their time, while the others are in paid positions. All in all, representation from the community (i.e. Elders, youth, etc.) was thought essential, and measures would have to be taken so they were recognized as having an equal voice to others.



Dr. Karen Goodman presenting at the AICBR First Annual Conference

Theme	Influencing Factors
Education	Knowing how to cook and prepare food
	Food preservation
	Daycare gardening
	Media-importance of educating children on nutrition/reducing media exposure to unhealthy choices
	Making healthy choices the easy choice (providing opportunities-government, policy; normalizing healthy choices; slow food movement)
	Putting food by their actual costs (i.e. cost of growing, transporting to Yukon, etc.)
Priorities	Other Priorities
	Convenience
	Affordability
	Garden Produce to prenatal mums and children
	Making healthy choices the easy choice (providing opportunities- government, policy; normalizing healthy choices; slow food movement)
	Provide students with opportunities to make healthy life choices with careers (i.e. Relative to student debt)
	Taxation of sugar-sweetened beverages; pop should be treated like candy
	What takes away from cooking?
	Normalizing healthy choices
Theme	Influencing factors
Culture	Culture (has both positive and negative effects)
	Value Systems (relearning how to be connected to our
	food/land/community)
	Part of the land, part of the water (connection to place and to each other)
	"the Last Child in the Woods"
	Celebrating what we've done
	Build a new food culture and autonomy
	Time (body clocks vs. normal time)
	Traditional economy
Physical Environment	Growing season
	Winter
	Changing lawns and gardens
	Neighbourhood compost centre and network
	Community assessment (lack of) (Eco-trust has and assessment tool)
	Compare communities to help understand similarities
	Compete for growing

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Session Evaluation Results

Community-Based Research

Overall, the community-based session was well received. Participants enjoyed the opportunity to work in facilitated small groups, learn about community-based research, and hear different perspectives and ideas about research. The opportunity to share knowledge, stories and experiences with each other was also appreciated.

Participants identified various training interests in community-based research.

- Defining the true ethical priorities of partnerships pertaining community-based re search; First Nation protocols for research
- More on research (data/research/analysis/data management)
- Support/discussion groups specially directed at researchers (mentoring program)
- Meaningful ways to share verified results with community
- More information on research projects happening/have happened in Yukon communities
- Case studies of successful community-based investigation
- Follow-up to this session on community-based research

H. pylori Project in the Yukon

Participants in the H. pylori session found it to be very informative and it raised questions and concerns for their own community. The film Never Say Die: The Aklavik H. pylori Project was very much appreciated as a visual tool to learn about the project and about H. pylori. The main issue that some participants had with this session was that there are many unanswered questions with respect to H. pylori. For example, what are the proven causes, where and when did H. pylori come from/start? Participants noted that they would like to hear about the outcomes of the project and learn more about what the next steps are.

With respect to training, people were interested in:

- Research training for people/partners involved, including healthcare providers, Community Health Reps and nurses
- Planning
- General education and awareness workshops on H.pylori in the communities and op portunities for community discussion
- More detailed information about the issue, including facts vs. myths
- To put a great deal of energy into understanding the bacteria
- More video/visual tools to educate
- More information about the treatment

Food Security

Participants in the food security session offered a significant amount of feedback. Participants enjoyed the opportunity to come together and hear about different initiatives in the Yukon and other northern communities. Learning from each other, sharing stories, being able to have open dialogue and time for people to talk was also communicated to be very important. Participants also liked the diversity of opinions, perspectives, inclusivity, and range of discussion. A strong First Nations presence was appreciated. The Resetting the Table: A Peoples Food Policy (Food Secure Canada 2011) document was also appreciated as an opportunity to learn about food policy.

It was thought that a gathering of people interested in the Yukon food security movement should be held one or two times per year in order to continue to move forward in this area. It was also suggested that a larger conference be held that could involve others from across the country to share and build on project ideas. Topic-specific sessions could also be held. Time was a constraint with the food security session. A longer panel discussion was suggested, with more time allotted for strategizing, sharing, and networking. It was noted that no youth were present and that it would be good to know what youth are saying, feeling, asking, with respect to food security.

With respect to types of training people were interested in, there were multiple responses.

o CAPACITY BUILDING

- Community capacity building
- Technical information about gardening and farming in the Yukon
- Greenhouse technology
- Community garden training
- Training at Yukon College how to grow and have a harvest market later in the fall
- Alga-culture
- Mentor program and sharing of traditional knowledge between aboriginal communities
- Visual, hands-on training
- Food with the four seasons
- Food and health

o CENTRAL ONLINE HUB:

- A list of mentors and where/when mentor is available (build a database)
- Some way of knowing what's going on where?
- Opportunities to share information with each other
- Updates: Quarterly (e) newsletter to highlight projects
- Knowledge of services and supplies available in the Yukon

o RESEARCH

- What has been learned from all the research that has happened in this area
- Food security structures
- Knowledge of existing programs and initiatives that are successful, i.e. Carmacks green house
- Mapping exercise: Food activities in Yukon

o FUNDING OPPORTUNITIES

o COMMUNITY EDUCATION AND AWARENESS RAISING

• Opportunities to visit other institutions to learn

Concluding Remarks

AICBR would like to thank everyone that attended the conference. Based on feedback and evaluations it is very clear that Yukoners are interested in learning more about Community-Based Research. Participants expressed an interest in research opportunities related to the bacterium H. pylori. Participants were all very clear that continued knowledge exchange and action around food security is integral for the Yukon. AICBR looks forward to the opportunity to bringing people together again in the near future.

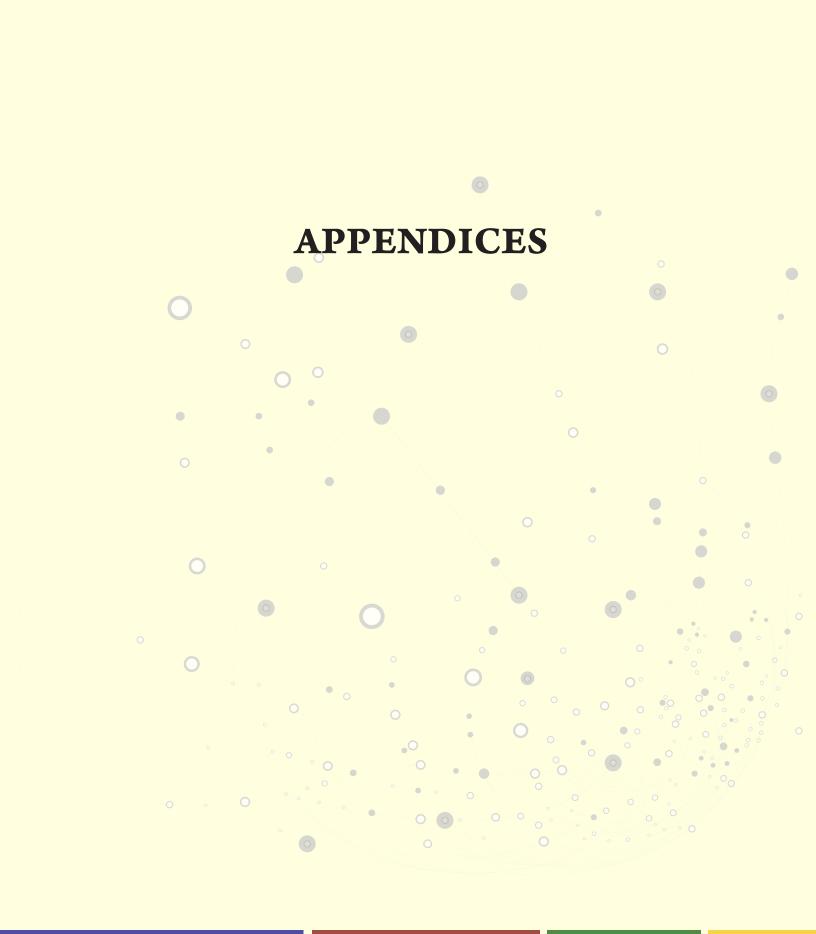








Dakka Kwaan Dancers perform for conference participants, March 21st, 2012.



Appendix A

AGENDA First Annual AICBR Conference Westmark Hotel, Whitehorse Yukon March 20-21, 2012

Tuesday, March 20th

8:30-9:00 Registration and Coffee

9:00¬-9:30 Opening Prayer

Welcoming Remarks by Minister of Health & Social Services, Hon. Doug Graham

9:45-12:00 Community-Based Research

Purpose:

To further develop a shared understanding of Community-Based Research in the Yukon and to share and discuss some project opportunities.

- o Review of key principles of community-based research
- o Small Group discussions on a Yukon perspective of the principles of community-based research

12:00-1:15 Lunch (provided)

1:15-4:00 H. pylori Project in the Yukon

Purpose:

To share information about a project opportunity regarding H. pylori in the Yukon.

- o Presentation by University of Alberta researchers (Dr. Karen Goodman)
- Overview of the Aklavik H. pylori project (Janis Geary)
- o Overview of the Old Crow H. pylori project
- o The potential role of AICBR (Jody Butler Walker)
- o Discussion of Yukon communities interest in the project
- o Questions and Answers (general discussion)

4:00 Closing of the first day

Wednesday, March 21st

8:30-9:00 Registration and Coffee

9:00-9:15 Welcoming Remarks and Review of First Day

9:30-11:45 Food Security

Purpose:

To share information about food security activities in the Yukon and to hear about food security activities in 3 First Nation communities in Northern Ontario.

- o Presentation by Clara Winnepetonga, Joseph Leblanc, and Simon Frogg, guests from Northern Ontario and Dr. Michael Robidoux, University of Ottawa; with Q & A period
- o Presentations and panel discussion by guests on Yukon food initiatives, including Simone Rudge (Yukon College Greenhouse), Matt Ball (Yukon Government-Agri culture Branch), and Danielle Palmer (Klondike Conservation Society)

11:45-12:00 Celebrating Our Stories: Healthy Ways of Living in Yukon Communities o Report release

12:00-1:15 Lunch (provided)

1:15-3:00 Food Security

Purpose:

To discuss ways of moving forward collaboratively with food security in the Yukon.

- o Facilitated general discussion
- How to form a Yukon food security network
- o Next steps

3:00-3:30 Roundtable Summary, Evaluation & Closing of the Day Closing Prayer

Appendix B

NAME	ORGANIZATION/COMMUNITY
Adrienne Marsh	Recreation and Parks Association of the Yukon
Alice Boland	Little Salmon Carmacks First Nation Greenhouse
Ashley Van Bibber	Selkirk First Nation
Ashten Staffen	Volunteer for Arctic Institute of Community-Based Research
Beth Mulloy	Yukon Literacy Coalition
Billie Giroux	Kwanlin Dün First Nation Elder
Bradley Barton	Yukon Government-Agriculture Branch
Bree Blottner	Arctic Institute of Community-Based Research
Cain Vangel	Yukon Young Farmers
Caitlin Dorward	Kwantlen Polytechnic University
Caroline Sparks	Contractor, C. Sparks Consulting
Charlie James	Carcross/Tagish First Nation
Christine Tapp	Yukon Government-Health & Social Services
Clara Winnepetonga	Wapekeka First Nation
Colin O'Neil	Whitehorse Fireweed Market
Craig Larson	Chronic Disease Prevention Alliance of Canada
Dana Jennejohn	Yukon College
Danielle Palmer	Conservation Klondike Society
Danny Creswell	Carcross/Tagish First Nation
Dr. Karen Goodman	CANHelp Working Group, University of Alberta
Dr. Suzanne Jackson	Dalla Lana School of Public Health, University of Toronto
Elsie DeRoose	Health and Social Services, Government of Northwest Territories
Francois Haman	Indigenous Health Research Group, University of Ottawa
Heidi Marion	Foodscapers
Helen Stappers	Council of Yukon First Nations
Ingrid Wilcox	Master Gardener
Jade McGinty	Teslin Tlingit Council
Jan Langford	Health & Social Services, Yukon Government
Janis Geary	CANHelp Working Group, University of Alberta
Jeanne Burke	Gardener; AICBR Board Member
Jen Jones	Grad Student: Public Health
Jennifer Daniels	Canadian Prenatal Nutrition Program
Joan Norberg	Food Secure Canada, local farmer
Jody Butler Walker	Arctic Institute of Community-Based Research
Johnny Mackenzie	Yukon College-Whitehorse Greenhouse Growers
Jolene Geddes	Skookum Jim Friendship Centre
Joseph Leblanc	Nishnawbe Aski Nation
Judith van Gulick	Yukon Literacy Coalition
Judith van Gulick Julia Frische	Yukon Literacy Coalition Potluck Community Co-op

Katelyn Friendship	Arctic Institute of Community-Based Research
Kawina Robichaud	Growing Ingenuity Group
Kent Mullinix	Kwantlen Polytechnic University
Kim Melton	Growers of Organic Food Yukon
Kim Neufeld	Community Dietician-Health & Social Services
Lisa Christensen	Yukon Research Centre
Lucy McGinty	Selkirk First Nation
Marie Martin	Kwanlin Dün First Nation
Marilyn Van Bibber	Arctic Institute of Community-Based Research
Matt Ball	Yukon Government-Agriculture
Michael Robidoux	University of Ottawa
Minister Doug Graham	Health & Social Services, Yukon Government
Pat Martin	Health Canada
Patrick James	Carcross/Tagish First Nation
Paula Pasquali	Yukon Government-Health & Social Services
Philip Boland	Little Salmon Carmacks First Nation Greenhouse
Rachel Byers	Little Salmon Carmacks First Nation
Rachelle Blais	Medical Student, Memorial University
Ron Pearson	Gardener, AICBR Board Member
Rosemarie Vandermeer	White River First Nation
Ryan Hennessey	Consultant
Sandy Washburn	First Nation of Na-Cho Nyak Dun
Scott Green	University of Northern British Columbia
Simon Crelli	Yukon College-Whitehorse Greenhouse Growers
Simon Frogg	Wawakapewin First Nation
Simone Rudge	Yukon College-Whitehorse Greenhouse Growers
Stephanie Starks	Family Physician
Tammy Hamilton	Carcross/Tagish First Nation
Tanya Morrison	Health Canada-First Nations & Inuit Health Branch
Tom Rudge	Growers of Organic Food Yukon, Slow Food
Valerie Whelan 。	Agriculture, Yukon Government and Agri-Food Canada
Vera Charlie	Little Salmon Carmacks First Nation
William H Venton	Yukon College-Whitehorse Greenhouse Growers
Willie Blackwater	Kluane First Nation

Community-Based Research DEFINITIONS

What is Community?

There are several different definitions of the word 'community'.

- a) One is a group of people who live within certain geographical boundaries based on location. This could be people who live in one area of land, one small town or between certain city streets.
- b) Group of people who share the same interests. This could refer to a group of people from the same family background, language group, profession, or age no matter where they live. A community of interest means you connect to people with the same interest wherever they live and you can exclude people who don't share your interests. For example, there could be a community of health practitioners, farmers, Health Directors, or skiers.

What does this mean for community-based research for AICBR?

We have to be clear about what communities might be interested in working with us, and how it could take shape. This can be challenging and take time. A key aspect is being inclusive through community meetings, notices, etc. throughout the research process.

What is Community-Based?

There is a need to clarify the difference between "community-placed" and "community-based":

- a) When projects or research are located in the community, they are Community-Placed. People who live in the community are asked to participate in someone else's research or project idea. They could also be consulted to get ideas for parts of the research. Community-placed research can evolve into community-based research when Community-Based Principles are followed.
- b) Community-Based projects or research involve community members in all parts of the research or project. People who live in the community are involved from the beginning in generating the research question, who can be involved, the best ways to conduct the work, what to do with the results, how to communicate the results and what action to take because of the results. What does this mean for community-based research in AICBR? Community members need to be part of the research project from the beginning. AICBR researchers strive to work WITH the community to develop the research idea rather than bring in a fully formed research project. There are variations of this where communities decide what parts of the research they want to be part of in collaboration with other members of the research team.

What is Research?

There are several ways to think about research:

- a) The simplest definition is that research is to find out about something. You have a question like where did my ancestors come from? You do some research to find out some answers this research could be looking up information in old records and it could be talking to people who know about your family. Anyone can do this without special expertise but you can also benefit from the experience of others who have done this successfully. Research can be creating new knowledge or remembering old knowledge.
- b) Some questions are more difficult to answer and require certain kinds of expertise. There are many levels of expertise and some community members know how to do basic research or evaluations and others (like AICBR staff) have received training and can guide research and evaluation. When the research requires specialized knowledge, the community-based research team can expand to include others (e.g. government policy analysts or university researchers).
- c) When you want to know whether your project or program is working as well as it could or whether it is making a difference, this kind of research is called an evaluation. Evaluations use research tools, such as surveys, interviews, and review of notes or records.

What does this mean for community-based research with AICBR?

Both evaluation and research can be community-based and involve both community members (from geographic communities and communities of interest) and researchers. If community members have an idea for research, they can talk to AICBR or others for advice about how to do it and what level of outside expertise might be required. If AICBR has an idea for research (often coming from funding opportunities), they will talk to community members about it to see whether they are interested. AICBR staff can work with community members to increase their skills to do many kinds of research and evaluation and they know others who can also contribute.



Questions for You!

- When have you been part of community-placed projects?
- What would be different if these projects were community-based?



Implications for AICBR

- Involve the community members in the research from the beginning (maybe in the form of a Steering Committee)
- Work with the community to develop the research idea
- Collaborate with community members to decide who is involved in each research step
- Follow as many Community-Based Research Principles as possible

What is Research?

- Research = finding out about something
- Creating new knowledge or remembering old knowledge
- Some questions need special expertise and others need to be involved
- Is my program working well or making a difference? Evaluation = a kind of research

Questions for You!

- When have you collaborated on a project with others?
- What made this collaboration work?



What are the Implications for AICBR?

- Evaluation and research can be communitybased
- Research can be a collaboration between community members and research experts
- AlCBR can provide advice, talk to community members about ideas to fill funding opportunities, provide training about research and evaluation



Appendix D

Session 2: Handout

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Background of the H. pylori (CANHelp) Working Group and Project

In 2007, the Canadian North Helicobacter pylori (CANHelp) Working Group was created to link community leaders and health officials with researchers at the University of Alberta. The goal of this group is to study H. pylori infection in Northern Canadian communities and to find solutions to community concerns about health risks. The CANHelp Working Group expanded to include the Yukon when the Vuntut Gwichin First Nation began their project in 2010. With additional funding recently confirmed, there is now an opportunity for other interested Yukon First Nation communities to participate.

From 2008 to present, CANHelp has studied H.pylori in Aklavik, NWT and is also currently working in the communities of Tuktoyaktuk, NWT and Old Crow, YT. Each community is at a different stage in the research process.

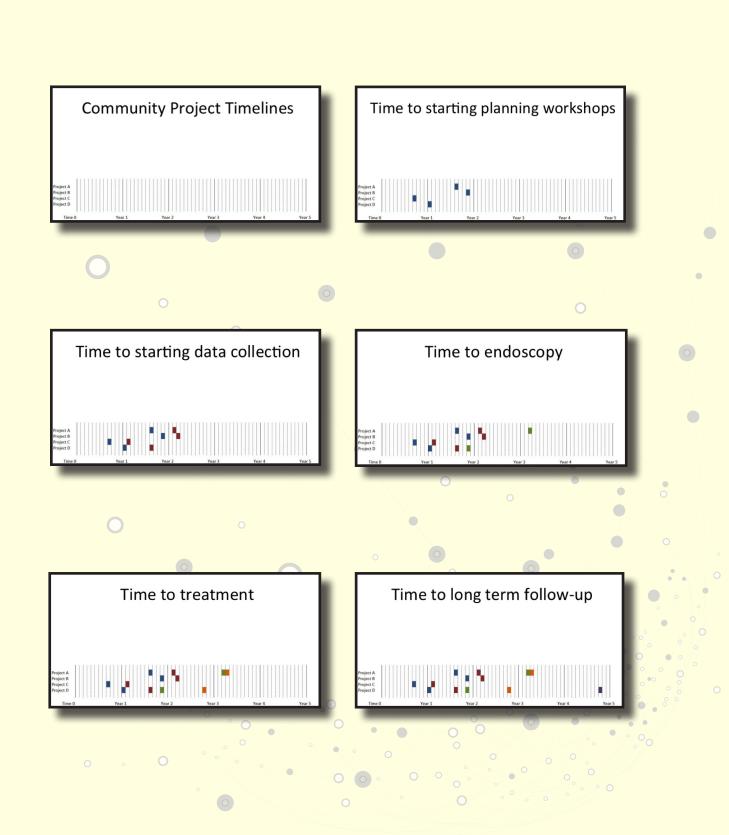
Communities may choose to work with CANHelp to:

- Actively engage community members in the research planning and project implementation
- Test consenting community residents for H. pylori
- Investigate potential risk factors for getting H. pylori infection and related stomach diseases
- Offer stomach endoscopy's (sampling of stomach tissues) to infected participants
- Establish criteria for treating and offer treatment to infected participants
- Evaluate new or alternative H. pylori treatments that may work better in communities than what is currently being used
- Follow those treated long-term to identify factors associated with treatment failure and getting infected again later-on

In the Yukon, the CANHelp team will be inviting all Yukon First Nation communities that are interested in this scientific research the opportunity to participate in the project.

For more information about H. pylori, the research team, methods and sources of support, reports of research results, progress reports etc please visit the website:

http://www.canhelpworkinggroup.ca



Participation

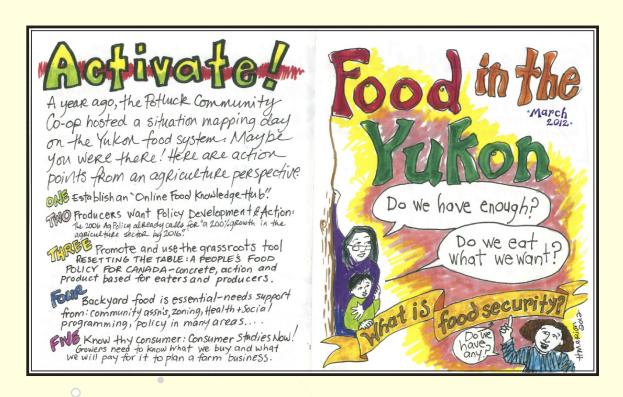
- · Aklavik: 379
 - 333 tested for *H. pylori* (193)
 - · 200 had endoscopy
- Old Crow
 - 186 tested for *H. pylori* (130)
 - · 64 had endoscopy
- Tuktoyaktuk
 - 86 tested for H. pylori

What we've learned so far

- Most of the research participants have H. pylori infection (60-70%)
- Compared to people in other parts of Canada, research participants with H. pylori are more likely to have severe inflammation in their stomach

What we've learned so far

 The treatment that is used commonly across Canada only worked on the first try in about 60% of research participants





Session 2: Presentation

