McGill TB research methods Course
Indigenous TB – Approaches to research

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Disclosures

• No disclosures relating to this topic or presentation
Objectives

• Importance of history, geography and culture to doing research in aboriginal communities

• An example of how non Aboriginal researchers engage aboriginal communities

• Challenges to collaboration, engagement, making a lasting impact in aboriginal communities

• Emphasis will be on methods, lessons learned in the field, not on published study results
Inuit Nunangat (Inuit Homeland) is comprised of 4 regions

Nunavut means OUR LAND

Capital of Nunavut is Iqaluit
50,000 Canadian Inuit

Youngest population in Canada, 56% are under the age of 25

Inuktituk strongest aboriginal language in Canada 7/10 Inuit can carry a conversation
TB History Nunavut

- Rates of TB were some of the highest recorded in the world at the epidemic’s peak

Incident cases of active TB
- 1960 – 2500 per 100,000
- 1970 – 600 per 100,000
- 1980 – 200 per 100,000
1950s active TB cases were picked up by the survey ship CD Howe summer tour of Baffin Island.

Figure 8: Inuit watching arrival of the Eastern Arctic patrol vessel C.D. HOWE near Pangnirtung, NWT, July 1951. [11]
Figure 2. People waiting in line for medical examination on board the *C.D. Howe*. Source: Johanna Rabinowitz Collection, Archives of Hamilton Health Sciences Corporation and the Faculty of Health Sciences, McMaster University.
Figure 4. A child and an elder woman in bed on board the *C.D. Howe*. Source: Johanna Rabinowitz Collection, Archives of Hamilton Health Sciences Corporation and the Faculty of Health Sciences, McMaster University.
Patients sent to sanatoriums in Hamilton and Toronto (1 in 7 Inuit in 1956)
Figure 5. A woman sewing a parka in bed at the Mountain Sanatorium in Hamilton. Source: Johanna Rabinowitz Collection, Archives of Hamilton Health Sciences Corporation and the Faculty of Health Sciences, McMaster University.
Figure 7. Children about to begin their journey back to their home community in the North, at the Mount Hope Airport, Hamilton. Source: Johanna Rabinowitz Collection, Archives of Hamilton Health Sciences Corporation and the Faculty of Health Sciences, McMaster University.
TB History in Nunavut

Many patients died in the south and many others never returned home.

In the 1950s, the federal government shipped thousands of Inuit south for tuberculosis treatment. Many died and were buried in graves far from home.
TB incidence rates in Nunavut, 2001-2011
Taima TB program of research

Taima means STOP in Inuktitut

Mission: Taima TB is a group of research projects aimed at helping Inuit in Canada stop the transmission of tuberculosis (TB) in their communities.

Core Principles: The work of Taima TB is based on the following principles:

Collaboration
Education
Innovation
Evaluation
Collaboration

- Working together with those affected by TB and those committed to stopping it to design and test strategies intended to break the cycle of transmission

- Collaborating with patients, health care professionals, governments and Inuit regional and national representation

- Inuit involvement at each step
Challenges to collaboration

Who comes up with the research question?
- May not be what you signed up for
- Traditional paradigm that the researcher asks the question often may not apply

Who speaks for the Aboriginal group?
Who decides on what is done and is not done?
- Layers of players
- Different perspectives
Partners – Governments, Universities
Nunavut Tunngavik (NTI) ensures that the promises made under the Nunavut land claims agreement are carried out.

Inuit Tapiriit Kanatami (ITK) is the national voice of Inuit living across the Inuit Nunangat. ITK does not deliver or fund programs rather it is a national advocacy organization.
INUIT-SPECIFIC TUBERCULOSIS (TB) STRATEGY

March 2013

• “...TB Action Plan be informed by principles that include Inuit involvement, respect, commitment to health equity, transparency and accountability, and collaboration.”
TAIMA TB Partners working together
February 2012, Iqaluit, Nunavut,
Press Conference to announce the CIHR funded TAIMA TB studies:
Federal Health Minister Leona Aglukkaq, Territorial Minister Health Keith Peterson and Mr. Jack Anuak (Vice president of Nunavut Tunngavik),
Steering Committee

• Established in 2011
• Meet every 2 months, 2 x / year face to face
• 11 members from the Government of Nunavut, Nunavut Tunngavik (NTI) and the Ottawa Hospital Research Institute
• Inuit representation (NTI), policy/decision makers within Nunavut government and health care providers from territorial, regional, and local levels
• Members participate directly in decision making in the overall guidance of the studies
Education and Innovation

- Integrating Inuit culture into learning through an exchange of ideas between partners
- Learning is a two way street
- Developing educational tools that are tailored to the unique cultural and geographic aspects of Inuit communities
- Promoting learning through observation, sharing, and experience
Challenges to education/innovation

• Engagement of community members is usually an after thought in the research

• How is it done?

• When is it done?

• Why is it so important?
The aim of the campaign was to raise awareness about TB, and to provide in-home screening and treatment for people living in residential areas at high risk for TB.

Screening was based on geographic location rather than on individual risk factors.

Our Inuit partners were involved in the design, implementation, analysis and presentation of results.
Community engagement

• Development of a steering committee

• 5 TAIMA TB facts were based on WHO facts

• Contextualized for Iqaluit by Inuit representatives (NTI), Iqaluit nurses and doctors involved in TB care in Iqaluit

• Community members were then invited to participate in a focus group regarding the 5 TAIMA TB facts
Community engagement

• Community members were then asked to develop videos in Inuktitut/English about 5 TAIMA TB facts

• The videos about the facts were then presented to the community at TAIMA TB night

• Finally, community members (salaried TAIMA TB champions) delivered the facts in the door to door campaign and answered questions in Inuktitut or English supported by TB nurse experts
Fact #38: Our body can fight the TB germ much better if we keep our immune system and bodies healthy. Quitting smoking is a good way to help make your lungs stronger.

23 hours ago · Share
Focus Group Lessons Learned

• “It is better if health messages come from Inuit rather than health care professionals”

• “It is easier for Inuit to relate to other Inuit”

• Oral versus written communication

• Street Inuktitut versus school Inuktitut
TAIMA TB NIGHT

• Inuit feast celebration night

• Introduction to TAIMA TB team and program of study

• YouTube video screening

• TB storytelling
Community engagement = success

• Spend the time LISTENING and involving community members from the conception of the idea, to the study introduction and execution, to the analysis and dissemination of the results

• TAKES TIME – I spent the first 5 years listening...2 years preparing and only the last 3 years doing studies that matter to Inuit
Other gaps in the research methods

• Transient nature of human resources in remote parts of the country

• Cost of doing studies in remote areas

• Research to policy to dollars – to changing clinical practice
TAIMA (Stop) TB: The Impact of a Multifaceted TB Awareness and Door-to-Door Campaign in Residential Areas of High Risk for TB in Iqaluit, Nunavut

Gonzalo G. Alvarez\(^1\), Deborah D. VanDyk\(^1\), Shawn D. Aaron\(^1\), D. William Cameron\(^1\), Naomi Davies\(^6\), Natasha Stephen\(^6\), Ranjeeta Mallick\(^1\), Franco Momoli\(^1\), Katherine Moreau\(^2\), Natan Obed\(^5\), Maureen Baikie\(^6\), Geraldine Osborne\(^6\)

The Feasibility of the Interferon Gamma Release Assay and Predictors of Discordance with the Tuberculin Skin Test for the Diagnosis of Latent Tuberculosis Infection in a Remote Aboriginal Community

Gonzalo G. Alvarez\(^1\), Deborah D. Van Dyk\(^1\), Naomi l Marc Desjardins\(^1\), Ranjeeta Mallick\(^1\), Natan Obed\(^5\), Ma

Sputum induction for tuberculosis diagnosis in an Arctic setting: a cost comparison

J. Sugarman, G. G. Alvarez, K. Schwartzman, O. Oxlade

The feasibility, accuracy and impact of Xpert MTB/RIF testing in a remote Aboriginal community in Canada

Gonzalo G. Alvarez, MD; Deborah D. Van Dyk, MScN; Marc Desjardins, PhD; Abdool S. Yasseen, III, MSC; Shawn D. Aaron, MD; D. William Cameron, MD; Natan Obed, BA; Maureen Baikie, MD; Smita Pakhale, MD; Claudia M. Denkinger, MD; Hojoon Sohn, MSc; Madhukar Pai, MD

Cost effectiveness Xpert study & Youth initiative TB awareness
Study results given back to community

Other modalities used to bring results back included radio, paper and presentations.
HIGH TECH Approach

Website
Facebook
Emails
All in Inuktitut

Google:Nunavut Tunngavik Inc and Taima TB
Natan Obed and Sharon Edmunds Potvin from Nunavut Tunngavik
Maureen Baikie, Elaine Randell and Geraldine Osborne from the Government of Nunavut
Sonia Marchand and all the staff at the Qikiqtani General Hospital Laboratory
Kristine Hutchison, Kate Darling and Charlene Lavalle and all the staff at Iqaluit Public Health
All the members of the TAIMA TB steering committee
Deborah Van Dyk Coordinator of the Taima TB studies