

# Negotiation, Reciprocity and Reality: the Experience of Collaboration

*Innovation in Community-based Primary Health Care (CBPHC) Supporting Transformation in the Health of First Nation and rural/remote communities in Manitoba (iPHIT) program of research*

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# Introduction

- 5 year study funded by the Canadian Institute of Health Research (CIHR) CBPHC Team Grant in 2013
- collaboration between University of Manitoba and, Assembly of Manitoba Chiefs (now the First Nations Health & Social Secretariat of Manitoba FNHSSM)
- 8 First Nation community partners
- Elements of healthcare system communities perceive as important; document/build CBPHC models; test these model(s) for effectiveness and ultimately, improve the scope and delivery of CBPHC services in FN & Rural & Remote Communities in Manitoba.



# Collaborating Partners

- Academic researchers from U of M
- AMC First Nation Health & Social Secretariat:  
Coordinating project/data management.
- 8 First Nation Communities:
  - Geographically dispersed, various health care models;  
representing 4 spoken dialects



# The Program of Research

- 4 distinct research projects, running over the course of 5 years utilizing both Qualitative and Quantitative Methods:
  - Community-based Participatory Research (Data analysis/interpretation/writing)
  - Mapping Hospitalization for ACSC in FN & R&R Communities (Data analysis)
  - Cross Sectional Surveys – Patient, Provider & Organizational (Data collection).
  - Multiple Case Studies (2016-18)

# Our Approach

The iPHIT project committed to:

- 1) Authentic engagement and partnership with Manitoba First Nations
- 2) Abide by First Nation 3 Ethical Guidelines
  - 1) Free prior and informed consent;
  - 2) Ownership, Control, Access and Possession of data (OCAP)
  - 3) Respect for FN or community specific ethical principles

# Authentic FN

## Engagement/Participation

- Joint planning/decision making for research project;
- Creation of joint Indigenous and University co-lead research teams; creating sub-project teams,
- Formation of Local Advisory Committees; critical for obtaining community support and provide direction to LRA's.
- Community involvement in data collection, validation, analysis, interpretation and writing.
- Ongoing communication/workshops between researchers and community leadership;
- Establishment of unique role for the Nurse Research Manager; hiring and building skills locally (Local Research Assistants);
- Respect for FN controlled data management & protocols

# Joint planning/decision making

- Involvement of Dr. Kathi Avery Kineu, and FNHSSM (AMC) research team (Wanda Phillips-Beck, Leona Star).
- FNHSSM involvement researching background community information/negotiating with community
- FN design of research project, based on community and lived experience
- FNHSSM involvement in proposal writing
- FNHSSM facilitating & obtaining appropriate approvals.

# Community Involvement

## Data Collection

- Data collection (LRA from community/employed by community through Statement of Participation Agreement with FNHSSM.



## Analysis & Interpretation



- Utilizing indigenous methods.
- Future writing utilizing community appropriate protocols

# Community Involvement

## Community Workshops



- validation of findings/data in community workshops

## Team Workshops



- Joint workshops with research team & community leadership (Oct 2013 & Jan 2015)

# First Nation Controlled Data Management

## Also, fits in with 1<sup>st</sup> of FN Ethical Principles

Data collected by communities is housed on secure server at FNHSSM

### 1. OCAP

- Ownership (Communities own and keep copies of their own data)
- Control (Communities have control of this data set – FNHSS has control of aggregate data set)
- Access (have control over who has access to data)
- Possession



# Benefits of Collaborating with FN

- FNHSSM have established relationships with community; and in many cases have direct access to community;
- or can facilitate and help establish relationships with communities;
- First Nation and individuals within FNHSSM have community and lived experience – can tell you what approaches will work and those that do not
- Very familiar with community dynamics/ intercommunity dynamics
- Communication – can facilitate ongoing communication with communities



## Benefits

- Developing the skills for communities to undertake own research
  - Some developing protocols for research
  - LRA's provide education to community on benefits of research.
- Opportunity to learn from communities – greater respect for Indigenous/local knowledge
- Opportunity to be co-creators of knowledge: more meaningful for communities.

# More of what we have learned

- no “one tried and true” recipe for successful collaboration; nor one recipe on how to apply the concepts of self-determination into research
- To be successful we all have to have be able to listen, understand and utilize respectful approaches in working together
- Ongoing communication is essential; face to face contact is necessary, on a quarterly basis to maintain enthusiasm and maintain both researcher and community engagement;
- Must have clear sense of the roles and responsibilities of research team members and communities, but these roles have to sometimes be fluid & flexible (ie. NRM/Post Doc as interviewers/focus group facilitators)

## And more;

- negotiation and compromise is necessary with collaborators/partners
- Sometimes have to just “trust the process” e.g. indigenous and alternative methods as valid and useful
- Central coordination is key; with FN ideally outside of University.
- Conflicts or disagreement are bound to arise, but there is always a solution if all parties are willing to listen and hear each other.
- Most importantly, the relationships between all partners have to be nurtured just as any relationship

# Concluding Remarks

- Negotiating and pioneering new research arrangements is critical as FN's are establishing research hubs/centres and gain more independence in the research world;
- Research collaboration with FN will result in knowledge that is more meaningful and applicable to FN context and environments
- Collaborations are about building relationships - they require long term commitment and nurturing;
- This project has the potential to leave a new footprint on fresh ground, particularly on how to successfully engage communities and conduct research in a way that is respectful of both western and traditional methods and systems.