

## APPENDIX B

### OUR HEALTH COUNTS

URBAN INDIGENOUS HEALTH DATABASE PROJECT





## Research, Data, Statistics, and Publication Agreement

Between  
Tungasuvvingat Inuit(TI)

and

Centre for Research on Inner City (CRICH)/ Michael's Hospital ("SMH")

**Project:** "Our Health Counts": Development and Application of a Baseline Population Health Database for Urban Aboriginal People in Ontario

THIS AGREEMENT MADE IN DUPLICATE this day (06/01/2009) WITNESSETH AS FOLLOWS:

### PURPOSE OF AGREEMENT:

The purpose of this agreement is to ensure that the project "Our Health Counts":

Development and Application of a Baseline Population Health Database for Urban Aboriginal People in Ontario is respectful to the cultures, languages, knowledge, values, and rights to self-determination of TI. This agreement will also provide a framework for the use of data collected during the Research Project. This agreement supports principles of Aboriginal collective and self-determined data management and governance. This is not a financial agreement. The agreement supports the information needs of TI, as well as acknowledging the desire of Dr. Janet Smylie, her research team to conduct this collaborative research. It defines the opportunity(ies) to develop research capacity at TI. TI anticipates this research project will assist to enhance capacity and leadership among TI communities and their policy, program and health service collaborators in the area of Inuit health information collection, analysis, and application through:

- a) the involvement of community representatives as active research team members in all aspects of this project;
- b) a series of community-based health data use workshops in program and service policy making, planning, delivery, and evaluation.

### AGREEMENT PRINCIPALS:

- Maintain mutual respect and accountability between the parties;  
Recognize the complementary and distinct expertise, responsibilities, mandates, and accountability structures of each party;

Ensure the highest standards of research ethics, including the acknowledgement of TI specific principles of self-determined data management; Respect the individual and collective privacy rights of TI staff;

- Recognize the value and potential of research that is scientifically and culturally validated;
- Recognize the value of capacity building at all levels;  
Support TI processes, including the analysis and dissemination of survey results.

**PROJECT DESCRIPTION** (see Appendix A)

**AGREEMENT:**

AND WHEREAS TI is developing a policy framework of principles for data collection, self-determined data management, analysis, and dissemination;

AND WHEREAS the TI principles will be articulated in a written format as a result of the gap in legislation applicable to TI clients and staff with respect to the collective ownership and possession of data, statistics, and information;

AND WHEREAS TI wishes to use this opportunity to build research capacity and/or provide research opportunities to its members and staff by working in collaboration with SMH and ICES;

AND WHEREAS TI would like to maintain a positive and good faith relationship with SMH and ICES;

NOW THEREFORE CRICH/SMH covenants and agrees as follows for the consideration of the sum of One (\$1.00) dollar paid to CRICH/SMH by TI, and other valuable consideration, the receipt and sufficiency of which is hereby acknowledged;

1. SMH and ICES acknowledges that any and all data collected by TI as a result of this research project is rightfully owned by TI. Utilization of the data collected for the purpose and by the means outlined in the research proposal is acknowledged and granted by TI to CRICH/SMH in accordance with the terms and conditions contained in this agreement.
2. TI agrees to undertake the research roles, responsibilities and activities described in Appendix B. Funding for these activities will be provided by Ontario Federation of Indian Friendship Centres as per their agreement with TI.
3. SMH and ICES agrees to the inclusion of project team representative(s) from TI as co- investigators and they will be acknowledged in any and all publications, reports, documents, or other written material from which this data is utilized. The representative(s) from TI will be included by CRICH/SMH in the complete research process or to the level the representative(s) is directed by TI to be involved.
4. The TI Research Project Representative(s) shall be able to provide a dissenting opinion of findings. Any dissenting opinions will be included as part of the overall report in all publications and/or pertinent published or produced materials.
5. Utilizing the data gathered from this research project by TI for secondary publishing will require specific written permission of TI. CRICH/SMH is to protect the data and act as stewards of this data on behalf of the rightful owner.
6. TI is the sole and rightful owner of all data collected from TI. CRICH/SMH will require TI consent to maintain a copy of the data set with Drs. Smylie's databank. CRICH/SMH will be required to protect the data from unauthorized use and act as stewards on behalf of the rightful owner. TI has provided consent to Dr. Janet Smylie of the Centre for Research on Inner City Health at St. Michael's Hospital to maintain a copy of the data sets generated by this project in accordance with the Study Protocol reviewed





and approved by CHRICH/SMH research ethics board and TI management for the purpose of publishing research reports as set out herein and having access to a copy of the source data of such research reports

7. This agreement is in force from the date of the last authorizing signature and CRICH/SMH agrees that this agreement is irrevocable and shall ensure to the benefit of and be binding upon CRICH/SMH its employees, administrators and legal and personal representatives.
8. CRICH/SMH represents that they understand and agree to the terms contained within this agreement and such performance will not be unreasonably withheld.
9. CRICH/SMH declares that it has been given the opportunity to obtain independent legal advice with respect to the details of the terms evidenced by this Agreement and confirms that they are executing this Agreement freely and voluntarily.
10. CRICH/SMH will provide TI the opportunity for review of any research reports before the submission of reports for publication. TI will be provided 4 weeks to review the research results and accompanying manuscript. In the event that TI and Drs. Smylie cannot agree on the content of the written report, TI will be invited to write an editorial to accompany the report to be submitted for publication.
11. TI, and CRICH/SMH agree to perform their respective study activities in accordance with the research proposal as approved by the SMH REB, participant consent forms, and all applicable laws, regulations and guidelines, including without limitation, the Tri-Council Policy Statement, "Ethical Conduct for Research Involving Humans" and the Canadian Institutes of Health Research Guidelines, "Guidelines for Health Research Involving Aboriginal People", all as amended from time to time
12. TI, and CRICH/SMH confirm their respect for the privacy of individual participants in the research project. TI, and CRICH/SMH agree to follow applicable privacy laws and regulations and to notify each other if either receives a complaint about breach of privacy
13. Neither party shall use the name of the other party or its staff in any publication, news release, promotion, advertisement, or other public announcement, whether written or oral, that endorses services, organizations or products, without the prior written consent of the party whose name is to be used
14. TI, the Releasor, confirms that if they transmit this Agreement by facsimile or such device, that the reproduction of signatures by facsimile or such similar device will be treated as binding as if originals and undertakes to provide all parties with a copy of this Agreement bearing original signatures forthwith by courier.
15. Notices to each Party shall be sent to:


**SMH:**  
30 Bond Street  
Research  
Administration  
Toronto, ON  
M5B 1W8

**CRICH/SMH:**  
70 Richmond  
Street East Toronto, ON  
M5C 1N8

**Tungasuvvingat Inuit:**  
Connie Siedule  
297 Savard Ave.  
Ottawa, ON  
K1L 7S1

16. This agreement may be executed in counterpart. Copies collectively bearing the signatures of all parties shall constitute the fully executed agreement.

ST. MICHAEL'S HOSPITAL

  
\_\_\_\_\_  
For, Dr. Arthur S. Slutsky

  
\_\_\_\_\_  
Dr. Janet Smylie

TUNGASUVYINGAT INUIT

  
\_\_\_\_\_  
TI Authorized Signature

Name and title:

MORGAN HARE  
EXECUTIVE DIRECTOR

## APPENDIX A: PROJECT DESCRIPTION

### Background:

Dr. Janet Smylie is a Métis family doctor and public health researcher with an interest in improving health services and programs in First Nations Inuit and Métis communities by providing health workers, program managers, and policy makers with useful and relevant information. As a result of her experiences providing medical care to young Aboriginal families, she is especially interested in the health and wellbeing of infants, children, and families. Dr. Smylie believes that health services and programs may be improved by enhancing Ontario's health information system in order to provide accessible, useful, and culturally relevant urban Aboriginal population health data to local, small region, and provincial policy makers.

### Key Adaptations:

In order to meet our goal of improving Ontario's health information system in order to provide accessible, useful, and culturally relevant urban Aboriginal population health data to local, small region, and provincial policy makers, we have designed several key adaptations, which will be implemented and evaluated during this two year adaptation program. These include:

1. Community-based participatory action approaches to health data collection
2. Respondent driven sampling
3. Longitudinal linkages to the ICES database
4. Respectful health assessment survey
5. Data governance and management protocols





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APPENDIX B  
THE RESEARCH ROLES  
AND ACTIVITIES

**Goal:**

To work with provincial urban First Nations, Inuit, and Métis organizations and the Ontario Ministry of Health and Long Term Care to adapt Ontario's health information collection system so that it provides accessible, useful, and culturally relevant urban Aboriginal population health data to local, small region, provincial and federal policy makers.

**Objectives:**

Formalizing Intersectoral Partnerships and Establishing Priority Measures

1. To formalize partnerships between the four core urban Aboriginal provincial organizations, the multidisciplinary academic team, the Ontario Ministry of Health and Long Term Care (MOHLTC), and the Institute for Clinical Evaluative Sciences (ICES) for this project through research agreements and data management/governance protocols. This will include the establishment of an Aboriginal Health Data Governance Council comprised of the four core urban Aboriginal provincial organizations.
2. To confirm priority health domains and best indicators for each domain through these partnerships.

**Knowledge Development through Establishment of a Population Health Data Base**

3. To generate new health data sets reflective of these priorities for a sample of urban First Nations, Inuit, and Métis adults and children using respondent driven sampling, secure data linkage with ICES and a respectful health assessment questionnaire. Capacity Building, Training and Mentoring
4. To strengthen capacity and leadership among Ontario's urban Aboriginal communities and their policy, program and health service collaborators in the area of Aboriginal health information collection, analysis, and application through: a. the involvement of community representatives as active research team members in all aspects of this project; b. a series of community-based health data use workshops.
5. To provide a scientifically excellent and culturally relevant training and mentorship environment for Aboriginal health researchers at the undergraduate, graduate, post-doctoral and new investigator level.

**Knowledge Dissemination, Application, & Contribution to Future Projects**

6. To support community-based, small region, provincial, and federal uptake and application of health data generated through 1-3 above to First Nations, Inuit, and Métis health policies, programs, and services. This will include the establishment of an Aboriginal health data users group, which will have open membership and allow diverse stakeholders input and access to data generated by the project.
7. To build on the outcomes of this study to design future longitudinal health studies in partnership with First Nations, Inuit, and Métis governing/organizational stakeholders as well as additional strategies to improve the quality of First Nations, Inuit, and Métis health data in Ontario.
8. To share study results and adaptation processes with First Nations, Inuit, and Métis stakeholders in other provinces and territories and thereby contribute to the development of urban Aboriginal health data enhancement strategies.

## Team:

This adaptation program brings together representatives from Ontario's four key urban Aboriginal health policy and service delivery stakeholder organizations (Ontario Federation of Indian Friendship Centres (OFIFC), Métis Nation of Ontario (MNO), Tungasuvvingat Inuit (TI), Ontario Native Women's Association (ONWA) and multidisciplinary biomedical and social science academics from five different institutions (Centre for Research on Inner City Health (CRICH) - St. Michael's Hospital; University of Toronto — Department of Public Health Sciences; ICES; University of Manitoba; and the Indigenous Peoples Health Research Development Program). The four urban Aboriginal organizations will work together as a coalition, with OFIFC taking the lead as signatory and acting as delivery agent for OFIFC, MNO, and ONWA and CRICH, supporting the interests and financing for Tungasuvvingat Inuit. The team will build on existing longstanding research partnerships between the research director (Smylie) and the core Aboriginal organizational partners — Dr. Smylie has been engaged in community based partnership research with TI and MNO (Ottawa Council) since 2002 and OFIFC since 2004. The multidisciplinary academic research team brings together experts from the disciplines of public health, family medicine, epidemiology, health database research, biostatistics, psychiatry, internal medicine, and psychology. All of the academic team members have experience in community based Aboriginal health research and several have dedicated their careers to this area.

Core Aboriginal Organizational Partners: Ontario Federation of Indian Friendship Centres

(OFIFC), Métis Nation of Ontario (MNO), Tungasuvvingat Inuit (TI), Ontario Native Women's Association (ONWA)

Academic Research Team Members: Janet Smylie, Pat O'Campo, Rick Glazier, Marcia Anderson, Kelly McShane, Roseanne Nisenbaum, Dionne Gesink Law, Cornelia Wieman, Sanjeev Sridharan

Aboriginal Organizational Research Team Members: Sylvia Maracle (OFIFC), Connie

Siedule (TI), Donna Lyons (MNO), Marianne Borg (ONWA)

Additional Collaborators: Vasanthi Srinivasan (Director, Health System Planning and

Research Branch, MOHLTC); Fredrika Scarth (Acting Manager, Research, Health System

Planning and Research Branch, MOHLTC); Sue Vanstone (Manager, Aboriginal Health

Strategy Unit, MOHLTC); Don Embuldeniya (Manager, Health System Information and Management Branch, MOHLTC); Kelly Murphy (Director of Knowledge Translation, CRICH); Leslie McGregor, Director, Noojamawin Health Authority; Paula Stewart (Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada)





## **APPENDIX B: TI RESEARCH ROLES, RESPONSIBILITIES, AND ACTIVITIES**

### **TI Governing Council Member**

Connie Siedule

- Participate in project steering committee meetings
- Advise technical research team on issues of research governance, ethics, and broad strategic direction
- Hire TI Respectful Health Survey administrators
- Assist in linking research project activities with other community activities as required
- Assist in preparing and dissemination of project data reports
- Contribute and participate in collaborative presentation of results at regional, national and international Aboriginal and scholarly venues

### **TI Staff Project Liaison**

Connie Siedule

- Participate in concept mapping training workshop
- Identify specific content areas in the health survey domains
- Assist in refining and translating survey tools as required
- Assist in fine-tuning of survey tools based on feedback from this pilot administration
- Assist in linking research project activities with other community activities as required
- Contribute and participate in collaborative presentation of results at regional, national and international Aboriginal and scholarly venues
- Work with project co-ordinator Conrad Prince to manage implementation of project in Ottawa Inuit community

### **Community Members at large**

- Community Concept Mapping Meeting ON Brainstorming, organizing, and prioritizing Aboriginal community ideas and concepts regarding health
- Pilot administration of draft Respectful health assessment survey tool to small groups of Inuit volunteers
- Respondent Driven Sampling (RDS) o A modified snowball technique requiring data collection on the structure of the referral network.
- Conduct 500 Inuit adults and 500 Inuit children Respectful health assessment surveys

### **Community Elders**

TBD by community

### **TI Respectful Health Survey Administrators**

- Inuit staff working out of TI will be involved in the recruitment of the sample, collection/analysis of data, and documentation/dissemination.
- A Inuit health data workshop will be held at TI that is designed to interactively train local and regional health staff on practical Aboriginal health data topics