

Governing Council MOU

APPENDIX A

OUR HEALTH COUNTS

URBAN INDIGENOUS HEALTH DATABASE PROJECT





Our Health Counts Governance Agreement
for
Our Health Counts: Development and Application of a Baseline Population
Health Database for Urban Aboriginal People in Ontario

between

The Ontario Federation of Indian Friendship Centres (OFIFC)

and the

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

(referred to as the parties)

1. Purpose of the Agreement

This Our Health Counts Governance Agreement is a tool to support the success of the Our Health Counts research project and the partnership between the Ontario Federation of Indian Friendship Centres, the Ontario Native Women's Association, the Métis Nation of Ontario, and the Tungasuvvingat Inuit.

The parties are to be involved as partners in all aspects of the research (community-based participatory action approaches to health data collection, respondent driven sampling, linkage to the Institute for Clinical Evaluative Services database, health assessment survey, data governance); that includes feedback, input, analysis, interpretation and communication. The development and ongoing implementation of this project is to be based on regular and respectful communication between the parties, community members, and the academic research team.

2. Research Project Description

The parties have identified a need for public health assessment data specific to the urban Aboriginal population, including the need for basic population health measures such as: primary health care access and use; infant mortality rates; emergency room visits; hospitalization rates; disease specific mortality rates; incidence rates of infectious disease; and prevalence rates of chronic disease. The collection of this data will help to achieve the main adaptation objective of Ontario's Aboriginal Health Transition Fund – to improve access to health services and result in health programs and services that are better suited to Aboriginal peoples. Clearly, health services will be neither accessible nor suited to Ontario's urban Aboriginal population until there is health assessment information available. Therefore, the project goal is to improve Ontario's health information system by working with provincial urban First Nations, Inuit, and Métis organizations and the Ontario Ministry of Health and Long Term Care. This project will enable us to provide accessible, useful, and culturally relevant urban Aboriginal population health data to local, small region, and provincial policy makers.

This research project brings together representatives from Ontario's three key urban Aboriginal health policy and service delivery stakeholder organizations (Ontario Federation of Indian Friendship Centres, Métis Nation of Ontario, and the Ontario Native Women's Association), along with Tungasuvvingat Inuit, an Inuit specific service organization in Ottawa and multidisciplinary biomedical and social science academics from five different institutions (Centre for Research on Inner City Health - St. Michael's Hospital; University of Toronto – Department of Public Health Sciences; ICES; University of Manitoba; and the Indigenous Peoples Health Research Development Program).

3. Research Project Objectives

i) Formalizing Intersectoral Partnerships and Establishing Priority Measures

- To formalize partnerships between the parties, the 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, memorandums of understanding and data management protocols. This will include the establishment of an Aboriginal Health Data Governance Council comprised of the parties.
- To confirm priority health domains and best indicators for each domain through these partnerships.

ii) Knowledge Development through Establishment of a Population Health Data Base

- To generate new health data sets reflective of priority health domains for a sample of urban First Nations, Inuit, and Métis adults and children using respondent driven sampling, secure data linkage with ICES and a health assessment questionnaire.

iii) Capacity Building, Training and Mentoring

- To strengthen capacity and leadership among the parties 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.
- 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.

iv) Knowledge Dissemination, Application, and Contribution to Future Projects

- 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.
- To build on the outcomes of this study to design future longitudinal health studies in partnership with the parties as well as additional strategies to improve the quality of First Nations, Inuit, and Métis health data in Ontario.
- 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.





4. Research Project Principles

This agreement is guided by the following principles.

- i. To maintain respectful and strong partnerships.
- ii. That the parties recognize and implement the principles of ownership, control, access, and possession with respect to all aspects of the project, including data governance and ongoing stewardship of data.
- iii. To recognize the expertise, responsibilities, mandates and accountability structures of each of the parties.
- iv. To recognize the value and potential of research that is scientifically and culturally validated.
- v. To understand and observe cultural protocols when working within particular sectors of the urban Aboriginal community.
- vi. To ensure the highest standard of research ethics, including those that have been culturally validated.
- vii. To represent the different viewpoints of the parties fairly, including viewpoints of specific Aboriginal cultural groups and those associated with different age and gender groups.
- viii. To recognize the value of capacity building at all levels.
- ix. To respect the individual and collective privacy rights of Aboriginal people.
- x. To provide respectful treatment to all persons taking part in the research project.

5. Responsibilities

The responsibility for achieving the goal and linked objectives of the project will be shared by the parties and the research/technical team. Governance of the project will be shared by the parties. The Ontario Federation of Indian Friendship Centres is the lead delivery agent and a party to this agreement.

The Parties

Responsibilities of the parties:

- Adhere to the research project principles
- Decision-making using a consensus building approach where possible
- Adhere to governance protocols and ensure individual and collective community rights are respected
- Facilitate achieving the purpose and the linked objectives of the research project
- Keep informed about the project's progress and lead the project towards meaningful results
- Act as a resource to the community on questions related to various portions of the research project

- Assist in analysis of data
- To approve research and technical team members
- To approve data users group members
- Regular communication to other parties

The Research/ Technical Team

Responsibilities of the research/technical team members:

- Adhere to the research project principles; process and agreed upon plan of action
- Adhere to governance protocols and ensure individual and collective community rights are respected
- Facilitate achieving the purpose and the linked objectives of the research project
- Enable and support the parties and the community research team in obtaining new skills (e.g. personal data collection skills, interview skills) and knowledge (e.g. respondent driven sampling, data linkage)
- Keep informed about the project's progress and help in leading the project towards meaningful results
- Act as a resource to the community on questions related to various portions of the research project
- Assist in analysis of data
- Regular communication updates to the parties
- Clear definition of roles and responsibilities and adherence to duties

The Community Research Team

Responsibilities of the community research team members:

- Adhere to the research project principles
- Facilitate achieving the purpose and the linked objectives of the research project
- Advise research project team
- Keep informed about the project's progress and help in leading the project towards meaningful results
- Supervise research project activities on behalf of community
- Assist in data collection and interviews
- Assist in analysis of data
- Regular communication updates to the research/ technical team and or parties
- Adherence to project deadlines

6. Funding

This project is funded by the Aboriginal Health Transition Fund – Adaptation Envelope through the Ministry of Health and Long Term Care. The Ontario Federation of Indian Friendship Centres is the lead delivery agent and signatory to the funding agreement on behalf of the parties with the Ministry of Health and Long Term Care. The OFIFC is responsible for the appropriate distribution of the funds to the parties.





7. Data Management and Governance (Ownership, Usage, Storage)

To ensure confidentiality for individual participants in the project, access to all data will be restricted only to those individuals involved in the project. The parties will share ownership of the data to be stored in a secure location that has been mutually agreed upon by the parties.

The data will not be used for any purpose other than which is outlined for this project without the consent of the parties.

Survey data will remain at the community research sites unless a community would prefer otherwise.

8. Secondary Publishing

Neither party shall use the name of the other party or its staff in any publication, presentation, news release, promotion, advertisement, or other public announcement, whether written or oral, that endorses services, organizations or products, without prior written consent of the party or parties whose name(s) is to be used.

9. Notices

Notices to each party shall be sent in hardcopy and by email to:

10. Commitments

We have read this agreement and understand the nature of the project and how it will be carried out. All of our questions have been answered satisfactorily. The risks and benefits have been explained. We agree to act according to the principles outlined above.

Ontario Federation of Indian Friendship Centres as Represented by the Executive Director.

Sylvia Maracle
Executive Director

Date

I have the authority to bind the Corporation.

Métis Nation of Ontario as represented by the Chief Operating Officer.

Doug Wilson
Chief Operating Officer

Date

I have the authority to bind the Corporation.

Ontario Native Women’s Association as represented by the Executive Director

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Marianne Borg
Executive Director

Date

I have the authority to bind the Corporation.

Tungasuvvingat Inuit as represented by the Executive Director

Morgan Hare
Executive Director

Date

I have the authority to bind the Corporation.

