



## Steering Committee Terms of Reference

### Statement of Need

In early 2016 seven First Nations health service organizations representing 68 Northern Ontario First Nations communities came together in recognition of a common need. The communities we serve do not have access to timely, comprehensive, high quality health-related information specific to our communities. This lack of information leaves First Nations leadership unable to detect emerging issues, assess trends in health status, conduct evaluations, or make evidence informed planning, programming and policy decisions.

Our partnership has grown to eleven First Nations governed health services organizations serving 78 communities. We work in partnership to build shared capacity to generate local information to use in evidence informed decision making in the region. The partnership submitted a Health Services Integration Fund application to establish Mamow Ahyamowen as the Northern Ontario Indigenous Health Information Partnership. This Terms of Reference documents the governance arrangements for Mamow Ahyamowen.

### Vision

To be a trusted Northern voice providing the health information our communities need to achieve health equity.

### Mission

We are First Nations communities, Tribal Councils and Health Authorities in Northern Ontario who follow a culturally respectful path to use available data resources so we can

share meaningful information to support evidence-based decision making for health and wellbeing.

## Goals

- 1. Use data to develop and sustain alliances to build shared voice to strengthen community wellbeing**
  - a. Maintain strong communication within Mamow Ahyamowen
  - b. Continue to share our progress and results with external partners to support development of alliances
- 2. Measure the health and determinants of health our communities experience**
  - a. Measure health outcomes and access to health services
  - b. Measure social determinants of health and how they relate to and influence health outcomes
  - c. Identify health inequities that need to be resolved
- 3. Build community capacity for using data to achieve health equity**
  - a. Increase data literacy at the community level
  - b. Support communities to use data in funding proposals and advocacy work

## Membership

Each member of the partnership has two named representatives to the Steering Committee. Both representatives are encouraged to attend as many Steering Committee meetings as possible. When decisions are made each organization will be represented by one individual with priority given to the primary representative.

The current Members are listed below. Partners may update their named representatives as required from time to time.

1. Fort Frances Tribal Area Health Services (FFTAHS)
  - a. Kayla Caul-Chartier
  - b. Ashlee Grimard
2. Independent First Nations Alliance
  - a. Lloyd Douglas
  - b. Connor Howie
3. Kenora Chiefs Advisory (KCA)
  - a. Jocelyne Goretzki
  - b. Lucille McKenzie
4. Keewaytinook Okimakanak
  - a. Penny Carpenter
  - b. Anjali Mago

5. Maamwesying, North Shore Community Health Services
  - a. Carol Eshkakogan
  - b. Nicole Eshkakogan
6. Matawa First Nations Management
  - a. Francine Pellerin
  - b. Paul Capon
7. Mushkegowuk Council
  - a. TBD
8. Shibogama Health Authority
  - a. Howard Meshake
9. Sioux Lookout First Nation Health Authority (SLFNHA)
  - a. Janet Gordon
  - b. Emily Paterson
10. Wabun Tribal Council
  - a. Jean Lemieux
  - b. Julie McKay
11. Weeneebayko Area Health Authority (WAHA)
  - a. Loretta Loon
  - b. Robert Gagnon
12. Chair & Secretariat (Non-voting)
  - a. Christina Vlahopoulos, Project Manager

## Scope

This partnership does not create a new legal entity. It is designed as a mechanism to facilitate collaboration, learning, and pooling of resources. This partnership was established to conduct public health epidemiology. The partnership will prioritize surveillance and population health status reporting that supports First Nations communities and partners with their program planning, implementation, and evaluation needs.

From time to time the partnership may engage in advocacy where gaps are identified that are important to the success of the partnership but may not be the direct responsibility of the partnership. For example, the partnership may advocate for partners to be funded so that that all communities have electronic health information tools in their health centers and nursing stations while recognizing that funding for such tools should flow to the individual partners along with responsibility for implementation and operation of the tools.

The partnership will strive to identify and prioritize initiatives that are of interest to all partners. At the same time we recognize that not all partners will consider all the

initiatives undertaken by the partnership to be a priority. Partners will not be compelled to participate in any specific initiatives.

## Principles and Values

- **OCAP<sup>®1</sup>:** We recognize the importance of the First Nations principles of Ownership, Control, Access and Possession and we will act in accordance with these principles.
- **Respect:** Data represent people's stories. We will treat these stories with respect. This includes being respectful of privacy and being respectful of how reports are developed and disseminated.
- **Accountable:** We work for the 74 First Nations that make up our partnership. We are accountable to their leadership and our decision making will be guided by their needs and priorities.
- **Innovative:** We recognize that the information management status quo for Northern First Nations is unacceptable. We will explore new ways of producing meaningful information for our communities.
- **Collaborative:** We will work together in a strong partnership. We will also seek out key organizations that we can collaborate with to bring meaningful information to our communities.
- **Credible:** We will be a trusted source of health information. This means that we apply rigorous and objective methods in our work and we produce high quality products that First Nations leaders can confidently use to inform their decision making.

## Roles and Responsibilities

All partners agree to a core set of expectations. These include:

- Partners represent the First Nations communities they serve. The most critical role of our partners is providing the voice of our communities in all our discussions and decisions.
- All partners respect the diversity of the partnership. We embrace respectful discussion, debate, and differences of opinion as these are essential to refining our ideas and making the right decisions.
- Partners commit to review materials that are circulated prior to Steering Committee meetings so they arrive prepared to provide constructive feedback and move partnership initiatives forward.
- From time to time working groups may be needed to develop specific deliverables. Partners are expected to identify representatives from their

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<sup>1</sup> OCAP<sup>®</sup> is a registered trademark of the First Nations Information Governance Centre (FNIGC). Further information is available at [www.FNIGC.ca/OCAP](http://www.FNIGC.ca/OCAP)

organization or from the communities they serve who can participate in such working groups.

## **Financial Management**

One or more partners may receive funding to support the activities of the partnership at any given time. Partners who manage funds on behalf of the partnership are expected to do so in an equitable and transparent fashion. Applications for partnership funding will be approved by the Steering Committee. The Steering Committee will then support successful applicants to deliver on the resulting contractual obligations that the funding recipient has agreed to on the partnership's behalf. Note that this support does not compel any partner or the First Nations they represent to participate in any data analyses that were proposed unless adequate community level approval was obtained prior to proposal submission.

The organization administering the funding will receive the administrative fees associated with the funding. In turn they will use their corporate policies, procedures, and services to execute the successful funding proposal. From time to time this may include the recruitment of staff or consultants who would be managed according to the hiring organization's policies and procedures.

## **Chair and Secretariat**

The Project Manager shall chair Steering Committee meetings while resources permit or until such time as the Steering Committee chooses to have an alternate Chair for the meetings. The Project Manager shall also provide Secretariat services to support the day-to-day functioning of the Steering Committee for the duration of the funding term.

The Secretariat function includes preparing and circulating agendas and meeting materials in advance of Steering Committee meetings and for circulating draft minutes following the meeting. Minutes will be confirmed at the subsequent Steering Committee meeting.

The Project Manager is a non-voting member of the Steering Committee. From time to time the Steering Committee may need to discuss sensitive matters. If requested by the Steering Committee the Project Manger will leave Steering Committee meetings to allow for such discussions to occur in their absence.

## **Decision Making**

### **Meetings**

The Steering Committee shall meet monthly at a consistent time chosen by Steering Committee members. Meetings will be block booked so Steering Committee members can book the times early in their calendars.

Members may invite guests to join Steering Committee meetings. Invited guests should be introduced at the start of a Steering Committee meeting and may be asked to leave a meeting if the Steering Committee is discussing sensitive topics.

### **Changes to Membership**

Membership may be amended from time to time. Partners may choose to leave the partnership at any time by written notice to the Chair. New partners may ask to join the partnership at any time. Prospective partners may be asked to submit a letter of interest or make a brief presentation to the Steering Committee stating why they would like to participate and how they feel they can contribute to the partnership's goals. Steering Committee members will review any statements of interest at a subsequent meeting and must agree unanimously to the addition of new members to the partnership. New members will have the same voting privileges as existing members. The membership of the Steering Committee may include a minority of non-First Nations organizations.

### **Decision Making Process**

The approval process related to decisions on whether and how to use First Nations data are outlined in the *Data Governance* section below. For other decisions the partnership will use a consensus based decision-making process. Where consensus cannot be reached the Chair may choose to hold a vote. Quorum for a vote is considered to be attendance by 50% or more of the Steering Committee organizations at the start of the meeting. A simple majority in favour of a motion will carry the motion.

### **Data Governance**

The partnership uses an opt-in approach to determine which communities would like to participate in a data analysis exercise. Communities are provided with an analysis plan that provides information on what analysis is being proposed and how results will be communicated. This process relies on the existing governance arrangements that partners have with the communities they serve.

All partners recognize that individual partners may choose not to participate in a data initiative of the partnership without expressing opposition to the initiative. The decision of a partner not to participate in an initiative will mean that none of the First Nations represented by that partner will participate in the initiative. The decision of a partner to participate in an initiative does not mean that all First Nations represented by that partner will necessarily participate. If a First Nation chooses not to participate in an initiative then their data will not be used in that initiative. The partnership recognizes

the authority of individual First Nations to control their data as outlined in the OCAP® principles.

Data governance requirements specific to any initiative will be defined in the documentation associated with the initiative. The following principles shall appear in most documentation governing the use of First Nations data:

1. Individual First Nations will be adequately informed of the purpose of the proposed initiative and will be given the choice of whether or not they would like to participate in the initiative. This will include reviewing the agreement that governs the specific initiative. Different partners use different methods to document such approval including Band Council Resolutions or Resolutions from Chiefs in Assembly.
2. Steps will be taken to adequately protect individual privacy in any initiatives, analyses, or reports produced by the partnership.
3. Results of initiatives will be reported back to participating First Nations communities.
4. Plans for dissemination of results of any data initiatives will be clearly articulated in the agreement that governs the initiative. Changes to the proposed dissemination plan requires the unanimous approval of the Steering Committee for aggregated results. Partners will be responsible for dissemination of any analyses at the level of the partner organization. Individual First Nations will be responsible for determining the level of dissemination of community level data. Partner organizations will be responsible for providing communities with their community level results. Permission to access individual First Nations data analyses may be sought from the individual First Nations after the analyses have been completed.

### **Financial Sustainability of the Partnership**

All partners are expected to monitor for new potential sources of funding to sustain the partnership. Funding opportunities often have short application periods and may require special ad-hoc Steering Committee meetings or email based review processes in order to submit a successful application.

When a potential funding opportunity is identified the Steering Committee will review the opportunity and decide whether to pursue the funding or not. If the Steering Committee decides to pursue the funding then a partner will be selected to lead the application. Typically the partner chosen to apply for the funding will be the organization that will have the greatest chance of success at obtaining and implementing the funding. Support for the final application will be sought through a Steering Committee meeting or by email prior to submission of the proposal. Attempts should be made to get approval from all partners prior to submission.