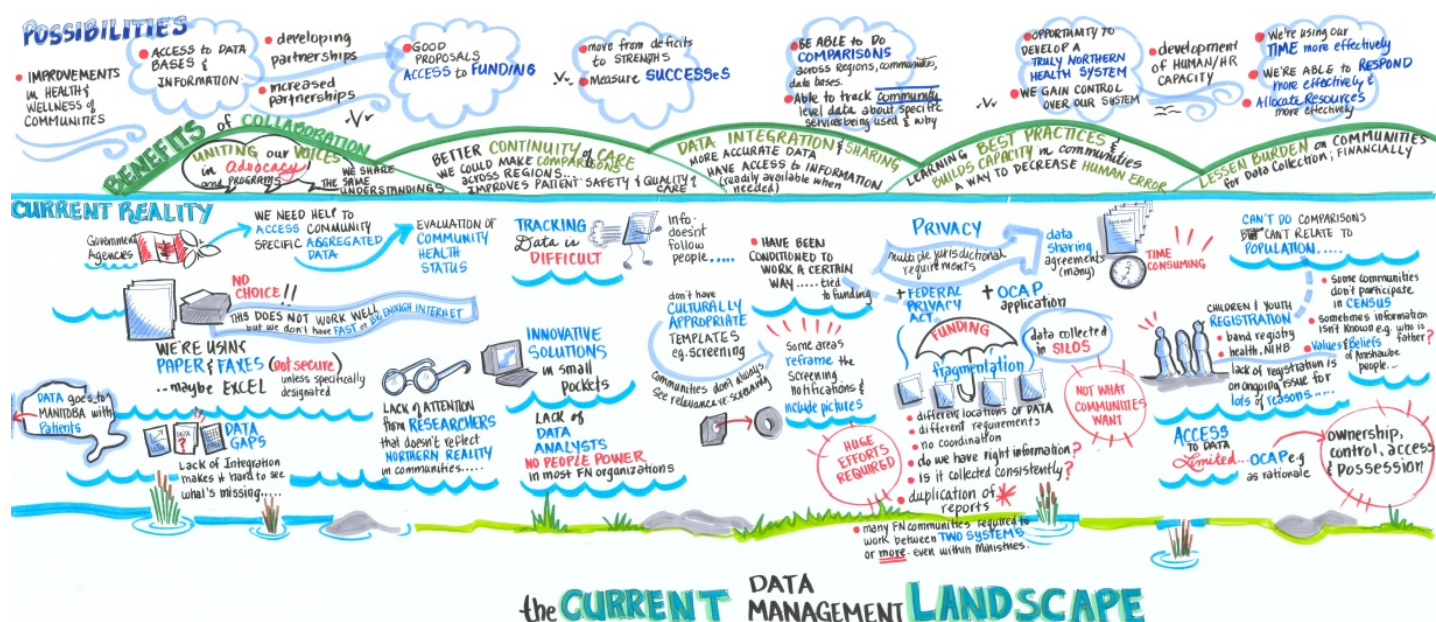


MAMOW AHYAMOWEN

Northern Ontario Indigenous Health Information Partnership

WINTER 2017, ISSUE 1



Welcome to the first quarterly newsletter of Mamow Ahyamowen. In early 2016 a group of seven First Nations health service organizations from across Northern Ontario came together in recognition of a common need. The organizations realized that the leadership of the 68 First Nations they represent did not have access to the information they needed to make informed decisions about the health of their communities.

These seven organizations submitted an application to Health Canada's Health Services Integration Fund (HSIF) in March 2016. The application received \$150,000 of funding per year for two years to form the First Nations Centre of Excellence in Epidemiology

(FNCEE). The FNCEE name was chosen quickly during a three week proposal writing window. Recent feedback from First Nations found the FNCEE name had little meaning to community members.

Responding to this feedback we decided to call our partnership Mamow Ahyamowen. In Oji-Cree, Ojibway, and Cree this means *everyone's voices or voicing something together*. Epidemiology and health status reporting which is at the core of our partnership's work is really about collecting and communicating the voices of our people in ways that will help our needs and goals to be heard and understood in a new light.

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INSIDE THIS ISSUE

- Welcome to Mamow Ahyamowen.** What is the partnership and how was it formed
- How to use this Newsletter.** Why am I receiving this and what do I do with this information
- Introducing Stephen Moore** our Project Manager and **Thunder Bay Planning Meeting Updates**
- Learning from Others** about governance models for Indigenous data partnerships and **Our Governance** about our Steering Committee's Terms of Reference
- Defining Our Work** with practical epidemiology definitions and **Progress Updates** on what we have achieved so far
- Looking Forward** to what our partnership is focused on in the coming months and **References**

The seven partner organizations that make up Mamow Ahyamowen are:

- Fort Frances Tribal Area Health Services (FFTAHS)
- Kenora Chiefs Advisory (KCA)
- Maamwesying North Shore Community Health Services (MNSCHS)
- Shibogama First Nations Council
- Sioux Lookout First Nations Health Authority (SLFNHA)
- Wabun Tribal Council
- Weeneebayko Area Health Authority (WAHA)

Together these seven partners represent First Nations communities that span the geography from the boarder of Manitoba to the border with Quebec and from the north shore of Georgian Bay to Hudson Bay.

As part of its funding application the

partnership set out several objectives that will guide its work up until March 31st, 2018. These objectives are to:

- Establish a project management approach
- Establish the governance structure for the partnership
- Develop a data sharing or data governance agreement
- Conduct a data and IT asset mapping exercise
- Establish common data sources with a common data set
- Identify key indicators for surveillance and health status reporting
- Develop a communications plan
- Develop a sustainability plan

We look forward to working with all of you as we move forward with this exciting initiative!

HOW TO USE THIS NEWSLETTER

Mamow Ahyamowen (meaning *everyone's voices*) has identified that its success will be determined in large part by the quality of its coordination and communication. This newsletter forms an important component of our overall communications plan.

Our partnership has strong ties to the communities we support. We interact with our communities at different times and in different ways. This newsletter allows us to go to our communities and consistently communicate key information about the partnership to the 68 First Nations we represent. This newsletter will be used to generate discussion and solicit feedback from our First Nations. We will also use the newsletter as a tool through which our leadership can develop our understanding of concepts in epidemiology, health status reporting, and interpretation of the reports we will produce.

Also important is our communication with non-First Nations organizations that support and work with us. The newsletter will provide updates on progress that will help these organizations understand where we are and where we are going. It will help them to see where we need support and it will encourage feedback that will help us to grow into a successful partnership that delivers the information our leaders need when they need it.

If you have comments on what you read in the newsletter or if you have ideas on topics you would like to see covered in the future then let us know. Our contact details are on the back page.

DEFINING OUR WORK

Each quarter this section will explain terms we use in epidemiology as a way to help us build our shared language and understanding.

Data²: “A set of facts. One source of information.”

Information³: “Any stimulus that reduces uncertainty in a decision-making process”

Epidemiology⁴: A way to understand what makes us sick and how we can keep ourselves healthy. The dictionary definition is, “The study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to the control of health problems.”

Mamow Ahyamowen will use the practice of **epidemiology** to analyze and interpret **data** so that it becomes useful **information** for our communities and their leaders.

INTRODUCING STEPHEN MOORE

When the partnership received funding one of the first priorities was to identify a Project Manager. Through a competitive call for proposals Stephen Moore at Health Determinants Inc. was selected as Project Manager. We are excited to have Stephen and his 14 years of information management experience supporting the partnership.

Early in his career Stephen worked with lab data on a number of AIDS vaccine clinical trials at the University of Oxford in England. After completing an MSc in Public Health in Developing Countries at the London School of Hygiene and Tropical Medicine Stephen moved to Southern Sudan where he worked for a British NGO called the Malaria Consortium. As Country Director of the Southern Sudan program Stephen spent over 3 years leading program implementation and carrying out a number of cross sectional surveys on Malaria indicators and prevalence of Neglected Tropical Diseases.

Most recently Stephen spent 4 years as Manager of the Enteric, Zoonotic, and Vector-borne Disease Unit at Public Health Ontario (PHO) where he managed a large multidisciplinary team that included four epidemiologists. At PHO he led outbreak investigations, carried out routine surveillance, and developed provincial information management systems.

Stephen has been doing health consulting work for First Nations organizations since he and his wife moved to Sioux Lookout, Ontario in November 2015.



THUNDER BAY PLANNING MEETING UPDATES

Mamow Ahyamowen (meaning *everyone's voices*) held an information sharing and planning meeting on October 18 and 19 in Thunder Bay. Communities, tribal councils, health authorities, and external partners were represented by 46 attendees. The meeting brought together partners, potential partners, and funders to develop a shared understanding of the partnership and begin to develop foundational aspects of the partnership's governance structure.

During the meeting partners identified their current information management reality, benefits of working together, and possibilities for the future.

Partners identified key elements of Mamow Ahyamowen's vision and mission statements as well as the need to identify a name for the partnership that was more meaningful to First Nations than FNCEE. Towards the

end of the meeting attendees identified three broad goals for the partnership, which included:

- We have good governance
- We are a trusted, timely, and relevant source of information
- We use data to improve our health

Feedback from the meeting was very positive. Although not a formal outcome of the meeting, the discussions did allow views to be shared which could easily guide the development of a set of values. The thoughts shared about vision, mission, and goals formed the basis for the Steering Committee to develop a governance structure (see section on *Our Governance*).

Thanks to all who participated for your valuable time and contributions. Your support is appreciated!

LEARNING FROM OTHERS

As we began working on our own governance structures we looked for examples of how other data partnerships have been governed successfully. We found Jodi Bruhn's April 2014 article on [Identifying Useful Approaches to Governance of Indigenous Data](#).

From the perspective of a political scientist, Jodi reviewed existing data governance models, she discusses models put forward by Indigenous organizations, highlights a number of practical considerations, and then presents case studies of a number of promising Indigenous data governance models.

For our young partnership we particularly liked a section where Jodi discusses what makes data partnerships successful. She found the key ingredients are:

- Partners perceiving a mutual benefit of working together
- Trust between individuals and organizations
- Leadership providing clear direction
- Clear roles and responsibilities
- Respect of partners' autonomy
- Respectful use of authority
- Staff time to build and implement the partnership

These ingredients guided the writing of our Terms of Reference and are embedded in our values. Thanks Jodi!

Article accessed on Jan 2, 2017 at:
<http://ir.lib.uwo.ca/iipj/vol5/iss2/5>



OUR STEERING COMMITTEE GOVERNANCE

Mamow Ahyamowen (meaning *everyone's voices*) worked to develop its governance structure in the fall. Stephen met with all seven partners, visiting us in our communities when possible. In October we met as a group in Thunder Bay. We are now having monthly conference calls.

As a result, we now have a Terms of Reference for our partnership. It includes the following sections:

- Statement of Need, which is our reason for existing
- Our Vision, which is what we want the future to look like
- Our Mission, which describes how we will achieve our vision
- Goals for the partnership
- Membership of our partnership
- The Scope of what we will and

will not work on together

- Our Principles and Values that guide how we keep communities at the center of our work together
- Roles and Responsibilities that define our mutual expectations
- Our Decision Making processes

This Terms of Reference guides how the Steering Committee makes decisions. It is not a data governance or data sharing agreement. We will develop data governance agreements when we seek community approval to analyze data. Highlights of our Terms or Reference include our vision to be a trusted Northern voice providing the health information our communities need to achieve health equity. To achieve our vision, our mission states

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that we are First Nations communities, tribal councils and health authorities in Northern Ontario who follow a respectful path to collect and analyze data so we can share meaningful information to support better decision making for health and wellbeing.

Our goals were developed in Thunder Bay (see p. 3). Our membership has not changed (see p. 2). The scope of our work focuses on public health epidemiology to support surveillance and health status reporting that helps our communities do better program planning, implementation, and evaluation work. Our partnership does not create a new legal entity.

Our values include recognition of OCAP®¹, respect for our people's data, accountability to the 68 First Nations we serve, commitment to being innovative since our information

management status quo is unacceptable, we are collaborative, and we value our credibility and see it as integral to our vision of becoming a trusted Northern voice.

Our decision-making will be consensus based. We will develop data governance agreements that specify how specific data initiatives will take place. As overarching principles we recognize that not all partners may choose to participate in all the data initiatives we undertake and that if an individual First Nation chooses not to participate in an initiative then their data will not be used in that initiative.

Now our governance is documented, we start the hard and exciting work of living our values and working to get useful information in the hands of our community leaders. We look forward to your continued support—we cannot succeed alone.



PROGRESS UPDATES

Our work up to December 2016 has been very productive. As we measure our progress against the objectives we laid out for ourselves in the HSIF funding application we have already completed three of the eight deliverables and are well on our way with a fourth deliverable.

Specifically we:

- Have a project management approach established and implemented
- We have a governance model developed, agreed on by the Steering Committee, and being implemented, in part, through regular monthly meetings of the Steering Committee
- We have a communications plan which is being implemented. This newsletter is one component of how we communicate and coordinate.
- We have started data and information technology asset mapping with a focus on assets that have data representing all seven partners and as many of the 68 First Nations as possible

Perhaps more important than these tangible deliverables is the less obvious but tremendously valuable work that partners have invested in sharing ideas, identifying common interests, and building resolve to work together.



LOOKING FORWARD

We hope that the updates in this newsletter have helped you understand the work we have done. In this space we want to share with you a few words about where we are going.

Our work during the winter of 2017 is focused on understanding and mapping our First Nations data. Who holds it, who controls it, and what are the information technology systems that support it. We are also thinking about information management models that will be appropriate for our partnership. These models need to provide us with a path to ownership, control, access, and possession¹ of our data so that we can use our data to improve our health.

Alongside this work we are deepening our relationships within the partnership. Our partners are reaching out to the communities they serve to tell them about our work and seek their input and feedback. We also want to develop our communication with our external stakeholders. We recognize that our sustainability depends on continued strong relationships within our partnership and with our external partners too.



REFERENCES

¹ OCAP® is a registered trademark of the First Nations Information Governance Centre (FNIGC). Further information is available at www.FNIGC.ca/OCAP

² Accessed on January 2, 2017 at: <http://www.phac-aspc.gc.ca/php-ppsp/ccph-cesp/glos-eng.php>

³ Forsetlund L, Bjørndal A. The potential for research-based information in public health: identifying unrecognised information needs. BMC Public Health. 2001;1:1.

⁴ Last JM, ed. Dictionary of Epidemiology, Third edition. New York: Oxford U. Press, 1995:55

FOR QUESTIONS, COMMENTS, AND
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