## MAMOW AHYAMOWEN

Northern Ontario Indigenous Health Information Partnership

FALL 2017, ISSUE 4



### SUDBURY PLANNING MEETING

Mamow Ahyamowen held its annual planning meeting in Sudbury on November 7&8 this year. The objective of the meeting was to plan our future together. The group was able to reflect on the past year's achievements and begin to set out a vision for our future work together. Several informative speakers helped set the stage for our discussions.

Cai-lei Matsumoto from the Sioux Lookout First Nations Health Authority presented on some of her work as an Epidemiologist. She focussed on several different approaches that SLFNHA is using to begin to get communities the data they need as they manage their health programs. Cai-lei shared her experience gaining access to the IntelliHealth datasets, negotiating data sharing agreements for data such as Non-Insured Health Benefits, working through organizations who currently hold data such as the Institute for Clinical Evaluative Sciences, and supporting First Nations to collect their own data locally with tools like Mustiumuhw. Cai-lei reminded meeting participants that no single approach to data will answer all our

(Continued on page 2...)

### INSIDE THIS ISSUE

- Sudbury Planning Meeting.
  Planning our future together.
- 2 **Progress Updates.** Highlights from the last couple of months.
- 3 **Meeting Outcomes.** What were the themes that arose from our meeting and why are they important?
- 4 Training Opportunities in Epidemiology for Indigenous Health. Some initiatives for people with a passion for data and Definitions. Knowledge translation
- 5 Looking Forward. What are our next steps

MAMOW AHYAMOWEN 2

questions, that each data source has strengths and limitations, and that it is important to know how you want to use data in order to choose the most appropriate approach.

Jen Walker and Laura Rosella are two epidemiologists from the Institute for Clinical Evaluative Sciences. They have been working closely with Mamow Ahyamowen and provided us with an overview of how epidemiology work can help to improve wellbeing. Laura reminded us that good epidemiology takes time—sometimes it takes 20 years or more and many different types of epidemiology work before a problem is well understood, a solution is identified, and the supporting evidence is strong enough for a solution to be implemented. Laura reminded us that modern day sanitation, seatbelts, cell-phone and driving regulations, child car seats, smoking regulations, and food safety regulations all came about from epidemiology observations and investigations that gained momentum and support and ultimately led to steps to protect our wellbeing. Many of these policies and practices that came about because of epidemiology seem so obvious today that we forget that each one required years of careful epidemiology and advocacy work.

Amanda Sheppard is a Scientist from Cancer Care Ontario. She presented on the work that CCO has been doing with Indigenous people in Ontario to better understand and improve Indigenous peoples' cancer experience. She presented examples like the recent 2016 report on Cancer in First Nations in Ontario: Risk Factors and Screening<sup>1</sup> that was developed in partnership with Chiefs of Ontario. Amanda also shared work that CCO is doing on developing community cancer profiles with 14 Ontario First Nations. These profiles summarize the cancer data available for a particular community. CCO is also working on projects to help First Nations use data that is already available. In one project CCO is working with Aamjiwnaang First Nation to consolidate all the previous research studies they have been part of and then use digital story telling to connect the community's experiences with the research findings. In another project CCO has developed some short educational videos to help explain cancer epidemiology concepts<sup>2</sup>.

Thanks to all the thoughtful presenters who helped make the meeting informative and interesting.

### **Progress Updates**

Mamow Ahyamowen partners continue to work hard towards our vision of being a trusted Northern voice providing the health information our communities need to achieve health equity. Since our last newsletter we have:

- Continued to engage communities to determine which communities would like to participate in the mortality analysis. So far 24 communities have chosen to be part of the analysis.
- We are working to define our indicators in ways that are meaningful to the communities we serve. This may include moving away from thinking about our communities in terms of on-reserve or off-reserve communities.
- We held our second annual face-toface planning meeting in Sudbury and developed five themes that will guide our work in the year(s) ahead.
- We submitted an abstract for a panel discussion to the Canadian Public
   Health Association conference in 2018 to allow us to continue to communicate why communities need data and how to respectfully support communities' data needs.

We look forward to the busy winter months ahead!

## **MEETING OUTCOMES**

Through group work sessions meeting participants identified themes to guide our future work together. The themes are:

- Communicating data in ways that change our programming
- Telling our stories along with the data
- Accessing data and analysing data
- Advocating for community electronic health records
- Community engagement and capacity building

The theme of *communicating data in* ways that change our programming is closely tied to the mortality analysis that we are planning with ICES. Mortality data will allow Mamow Ahyamowen to undertake community engagement and capacity building focused on interpretation and use of epidemiology data. It may also offer opportunities to tell our stories along with the data. Meeting participants felt we need to be different than other data initiatives. One way to do that is to connect the data stories generated through epidemiology with the existing knowledge and wisdom in the stories our communities already have. By telling them together both the

community stories and data stories are richer and more informative than either would be on their own.

Work with communities to Access data and analyse data remains important because there are large amounts of data that communities do not currently have access to. These could be datasets held by Federal or Provincial data custodians. Some of this work might be able to be prioritized once we see the mortality data. Meeting participants expect the mortality data may raise many questions for communities and these questions could form the basis of another round of data analysis.

We also recognized that our epidemiology work is constrained by an important data gap. Most First

Nations Nursing Stations and Health Centers are currently using paper based records. Physicians who visit these sites often use a physician Electronic Medical Record (EMR) but these physician EMRs are not typically accessible to nurses, mental health workers, or other community based health workers. Furthermore, the EMRs are often not designed for the important programmatic reporting to funders that community Health Directors are responsible for. Meeting participants felt Mamow Ahyamowen has an important role to advocate for community electronic health records.

The Steering Committee will now work to develop these themes into funding proposals to sustain the partnership beyond March 2018.



Figure 1: Word cloud of all the words meeting participants wrote on their meeting evaluation forms

MAMOW AHYAMOWEN 4

# TRAINING OPPORTUNITIES IN EPIDEMIOLOGY FOR INDIGENOUS HEALTH

Epidemiology is a way to learn about what makes us sick and how we can keep ourselves healthy. Our health is often affected by the complex connections between individuals, their community, and society. This increasing complexity makes it important that Indigenous epidemiologists are trained to do this work and tell the stories that are important to Indigenous communities.

There are many different types of epidemiologists. Often professionals like social workers, mental health workers, nurses, or physicians become interested in a challenge or opportunity they see in their work. This leads them to seek out training in epidemiology that can help them to better understand and communicate the challenge or opportunity they see. Sometimes these professionals take a course or two and learn a few basic epidemiology skills. If they want to call themselves an epidemiologist they usually enroll in a Masters in Public Health program with a specialization in epidemiology.

In Sudbury, Jen Walker from the Institute for Clinical Evaluative Sciences provided information on some exciting initiatives that might be of interest to community members who have a passion for data.

In January 2018, there is expected to be a launch for the Indigenous Mentorship Network Program. This program is designed to support Masters and PhD students at a number of participating universities including Laurentian, Lakehead, Nipissing, and the Northern Ontario School of Medicine.

Laurentian University is also developing an interdisciplinary PhD program in Rural and Northern Health. This program will have an Indigenous stream which is currently being developed. The Indigenous stream could include landbased learning, community based approaches, and integration of Elders and other community knowledge

keepers.

The Institute for Clinical Evaluative
Sciences will be establishing its
Indigenous Internship Program in early
2018. The program will be a one to
two year part-time program with a
mix of on-site learning and webinars.
It will provide applied training in
epidemiology, data, and statistical
analysis. This program could be
appropriate for team members with an
interest in analyzing health data or for
University students with an interest in
health data analysis.

If you would like more information on any of these initiatives please email <a href="mailto:indigenous@ices.on.ca">indigenous@ices.on.ca</a>

#### **Definitions**

As Mamow Ahyamowen thinks about how to communicate data in ways that change our programming the term Knowledge Translation often arises. **Knowledge Translation** is the process of putting knowledge into action. Knowledge translation involves thinking about how new information fits with other existing knowledge. Successfully putting knowledge into action requires that knowledge holders identify who they should share their knowledge with and how to share their knowledge. This step is sometimes referred to as **Knowledge Exchange**. When knowledge is shared it might start to be put into action. Once new knowledge begins to be used it is important to continue to evaluate and understand whether the use of the knowledge is having the beneficial impact that was originally envisioned. The term **Implementation Science** is sometimes used instead of Knowledge Translation.

MAMOW AHYAMOWEN SUMMER 2017, ISSUE 3

### LOOKING FORWARD

In the months ahead we will continue our important community engagement work to try to make sure that all the communities we serve have the opportunity to participate in the mortality analysis if they would like to. We will keep working on indicator definitions that will make sure that we analyze the mortality data in the ways that are most useful to our communities. We will develop the themes that emerged from our Sudbury planning meeting. These themes will form the basis of our plans beyond March 2018. As we develop these plans we will seek the funding support we will need to achieve our goals. Thank you to everybody who has supported our partnership in 2017. We look forward to your continued support through another productive year in 2018.

### REFERENCES

- <sup>1</sup> Chiefs of Ontario and Cancer Care Ontario. Cancer in First Nations in Ontario: Risk Factors and Screening. Toronto, 2016 available at: <a href="https://www.cancercareontario.ca/en/statistical-reports/cancer-first-nations-ontario-risk-factors-and-screening-report">https://www.cancercareontario.ca/en/statistical-reports/cancer-first-nations-ontario-risk-factors-and-screening-report</a>
- Available at:
  <a href="https://archive.cancercare.on.ca/about/programs/aborstrategy/how\_we\_measure\_cancer\_in\_first\_nations\_\_inuit\_and\_m\_tis\_populations/?redirect=true">https://archive.cancercare.on.ca/about/programs/aborstrategy/how\_we\_measure\_cancer\_in\_first\_nations\_\_inuit\_and\_m\_tis\_populations/?redirect=true</a>

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