

# MAMOW AHYAMOWEN

Northern Ontario Indigenous Health Information Partnership

SPRING 2017, ISSUE 2



## STRENGTH IN NUMBERS: A MODEL FOR MAMOW AHYAMOWEN?

The Strength in Numbers Initiative aims to produce better health data to inform planning and policy decisions for the First Nations in Nova Scotia. The partnership developed a client linkage registry 10 years ago and have used it to produce nine reports that cover a wide range of health topics. An example of a graph from the Strength in Numbers diabetes report is on page 2 of this newsletter. The reports have helped the 13 First Nations in Nova Scotia write stronger proposals, conduct better health planning, and advocate more effectively for the health

needs of their communities.

Strength in Numbers is a partnership of the 13 First Nations in Nova Scotia together with the Nova Scotia Department of Health and Wellness, the Union of Nova Scotia Indians, the Confederacy of Mainland Mi'kmaq, IWK Health Center, and the Nova Scotia Health Authority. The project is managed by the Tui'kn Partnership and is funded by Health Canada.

The successful model that the Strength

*(Continued on page 2...)*

### INSIDE THIS ISSUE

- 1 Strength in Numbers Initiative.** Is this a model that Mamow Ahyamowen could learn from?
- 2 Progress Updates.** Highlights from the last couple of months
- 3 The Institute for Clinical Evaluative Sciences.** Who are they and how could they support our work?
- 4 Ownership, Control, Access and Possession.** What are the OCAP® principles and why are they important?
- 5 Looking Forward.** What are our next steps

in Numbers initiative has developed relies on a registry they created that contains all members of a Nova Scotia Band and their valid Nova Scotia Health Card Number. The registry contains information on 11,638 individuals and through a thorough data governance process the initiative is able to link their registry with provincial data in order to produce First Nations Health Status Reports.

Strength in Numbers follows the principles of Ownership, Control, Access, and Possession (OCAP®). Use of the First Nations Registry is governed by a Data Management Committee made up of Health Directors of the participating First Nations and a representative of the Nova Scotia Ministry of Health.

The Strength in Numbers team has been very generous with their time and insights. They joined Mamow Ahyamowen's February Steering Committee meeting to present and discuss their work. The Steering Committee is now exploring opportunities to build on their experience and implement a similar model here in Northern Ontario.

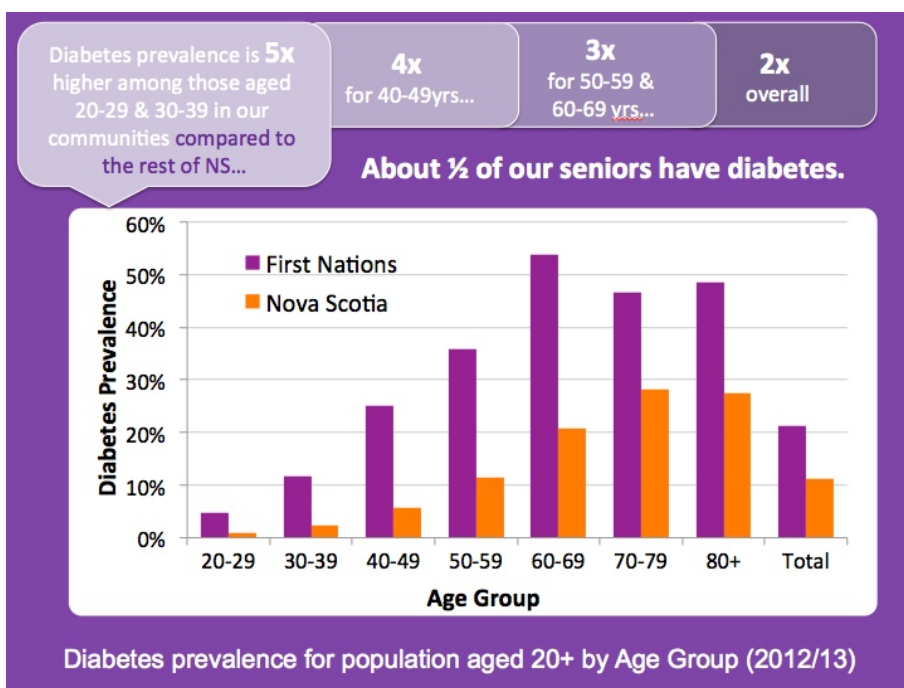
For more information on the Strength in Numbers project please visit their website. At this link you can find several examples of infographics the project has produced to clearly communicate health information to the communities they serve:

<http://www.tuikn.ca/health-information/strength-in-numbers-project/>

## Progress Updates

Mamow Ahyamowen has been busy since our last newsletter. Highlights include:

- Partners have been engaging their communities directly, through their governing boards, and at various meetings.
- Mamow Ahyamowen held its first external stakeholders call to introduce the initiative to colleagues with an interest in First Nations health in Northern Ontario.
- Information gathering for the data and IT asset mapping continues.
- The Steering Committee learned about how the Strength in Numbers project achieved their success in Nova Scotia and how they overcame some of the challenges they faced along the way.
- The Steering Committee expressed interest in exploring opportunities for Mamow Ahyamowen to operate using a model similar to the Strength in Numbers Project.
- Opportunities to work with the Institute for Clinical Evaluative Sciences (ICES) are being explored.



# THE INSTITUTE FOR CLINICAL EVALUATIVE SCIENCES

Mamow Ahyamowen is exploring options to work with the Institute for Clinical Evaluative Sciences (ICES) in much the same way that the Strength in Numbers Initiative has worked successfully with the Nova Scotia Ministry of Health. ICES is a not-for-profit research institute made up of a community of research, data and clinical experts.

ICES holds many of Ontario's health related datasets. This includes a copy of the Indian Registry System (IRS) data for Ontario. Use of all data held by ICES is protected by rigorous privacy and security measures. The IRS data is further protected by a Data Governance Agreement that requires First Nations approval before anybody can conduct an analysis using IRS data.

Policy makers and knowledge users (such as First Nations) can submit questions to ICES and if accepted ICES scientists will try to use the data they hold to provide an answer to the questions. When ICES seeks to answer questions that First Nations ask it becomes a learning opportunity that enables First Nations to assert their ownership, authorities, and rights to their data.

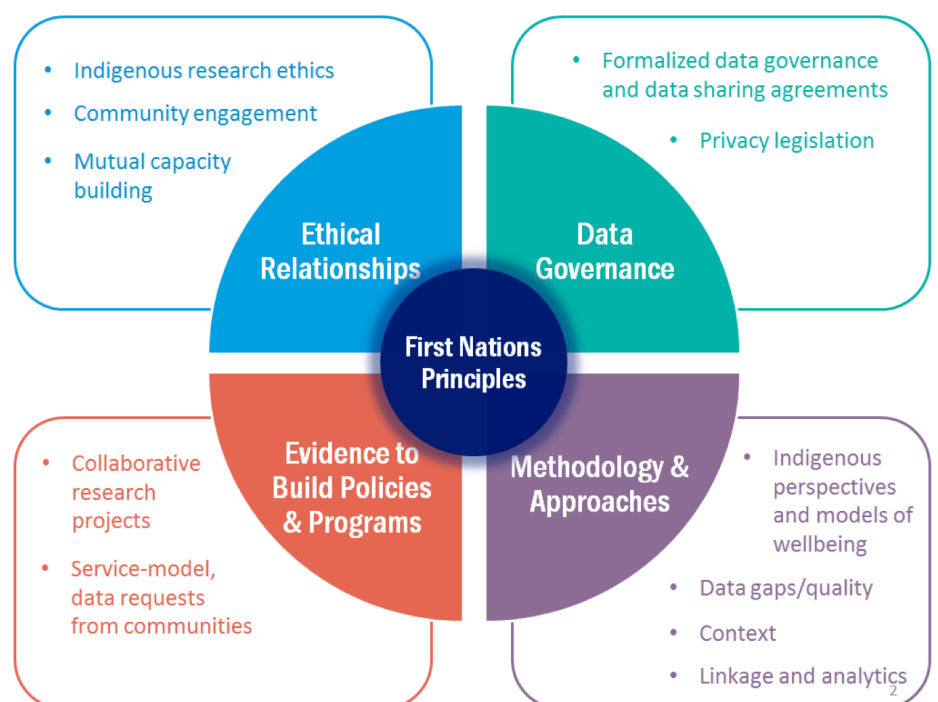
ICES has an Indigenous Health Team led by Dr Jen Walker. Jen is Haudenosaunee, has her PhD in Epidemiology, and is the Canada Research Chair in Indigenous Health at Laurentian University in Sudbury. Through Jen's leadership the Indigenous Health Team at ICES has a very respectful approach to working with First Nations to achieve their data analysis priorities. This approach is described in the image of their model on this page.

In addition to their analysis skills the ICES team also has a knowledge translation team who can help make sure that results of analyses are clearly

communicated. There are also opportunities for capacity building around First Nations data analysis. The capacity building opportunities would be particularly exciting for recently graduated First Nations epidemiologists who would like to build practical skills working with the Indigenous Health Team to analyze health data.

Mamow Ahyamowen will continue to explore possibilities of working with ICES and will provide further updates in future newsletters. For more information about ICES please visit their website:

<http://www.ices.on.ca/>



# WHAT ARE THE PRINCIPLES OF OWNERSHIP, CONTROL, ACCESS, AND POSSESSION (OCAP®)?

Mamow Ahyamowen is committed to working with data from our communities in a respectful way. Respectful use of data starts with strong data governance. Perhaps the most advanced set of principles that can guide indigenous data governance in Canada are the OCAP® principles developed by the First Nations Information Governance Centre (FNIGC). The OCAP® principles were a strong theme in Mamow Ahyamowen's early visioning work and have been incorporated as values in the Steering Committee's Terms of Reference.

These principles emerged in 1998 from the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey (RHS). The principles evolved over subsequent years and the National Steering Committee developed into the FNIGC. The principles are a response to a long history of research on indigenous people that did not consider indigenous priorities or necessarily benefit indigenous communities and people. In a number of cases such research actually did harm to the indigenous communities involved. The OCAP® principles are

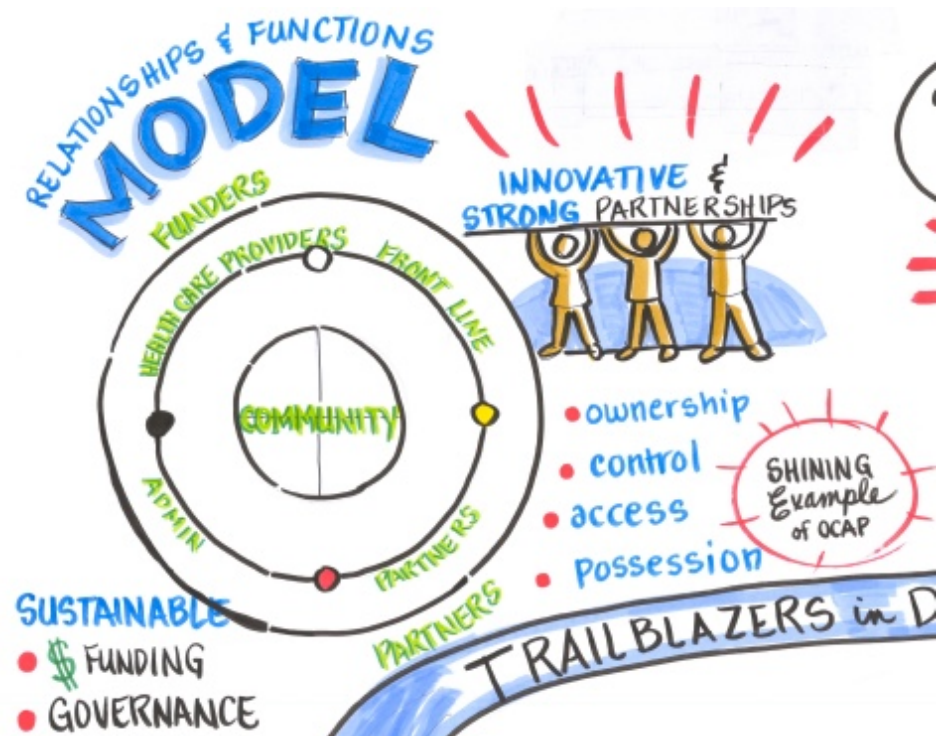
designed to ensure that future research is done respectfully and for the benefit of indigenous peoples.

The four elements of the OCAP® principles are Ownership, Control, Access, and Possession. The ownership principle refers to the relationship between a community and its information. It recognizes that communities own their information in a similar way to how an individual owns their personal information. Control acknowledges that communities and their First Nations organizations must determine whether and how their information is used. The principle of access recognizes that

communities must be able to access their data wherever it is held. The principle of possession refers to data stewardship and highlights the importance of data being within the jurisdiction of First Nations. The possession of data enables control of the data.<sup>2</sup>

The FNIGC has developed a number of resources to support the application of the OCAP® principles. This includes an online course on The Fundamentals of OCAP® developed in cooperation with Algonquin College. Further information is available on the FNIGC website:

<http://fnigc.ca/ocap.html>



## LOOKING FORWARD

Our work through the winter of 2017 was focused on understanding where our First Nations data is held and learning about information management models that our partnership could implement. Through the spring and summer of 2017 we will develop our understanding further.

In particular we will continue to explore options to work with the Institute for Clinical Evaluative Sciences. This may include the development of an analysis plan that the Steering Committee would be able to take back to the communities they serve. Developing the analysis plan will mean deciding on a dataset to focus our efforts on and developing indicators to support that analysis. In anticipation of seeking community's support to analyze data we will be continuing to engage our communities. Alongside this important work will be our continued efforts to coordinate and communicate with partners.

We look forward to continuing on this journey with you and look forward to your input and feedback.

## REFERENCES

<sup>1</sup> OCAP® 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)

<sup>2</sup> Available at: [http://fnigc.ca/sites/default/files/docs/ocap\\_path\\_to\\_fn\\_information\\_governance\\_en\\_final.pdf](http://fnigc.ca/sites/default/files/docs/ocap_path_to_fn_information_governance_en_final.pdf)

---

FOR QUESTIONS, COMMENTS, AND  
SUGGESTIONS PLEASE CONTACT:

Stephen Moore,  
Mamaw Ahyamowen Project Manager  
[Stevemoore2011@gmail.com](mailto:Stevemoore2011@gmail.com)  
76 ½ Lake Street, Sioux Lookout,  
Ontario, P8T 1E6  
Tel: (647) 205-2095