



During the Session, we invited Youth to participate in three main ways: (i) open conversation and questions (ii) an online chat box, and (iii) Jamboard, an interactive online whiteboard ([see Appendix D](#)). We also asked participants to fill out a post-Session survey ([see Appendix E](#)) to evaluate any change in knowledge and awareness, and to evaluate general satisfaction with the Session. We were honoured to have Elder Esther Diabo be a part of our Session.

This report provides a high-level review of the online Session and elements that came out through discussions. We captured valuable information for Partners and for the Partnership as a whole.

Survey Findings

Pre-Session Survey

Thirteen participants registered, and nine attended the online Session. Respondents were, on average, around 23 years old and belonged to First Nations from across northern Ontario, including some that are not served by the Partnership. Most had completed at least some college-level education. Almost half of the respondents reported being interested in a health-related career, while nearly one-third were not sure. The most common careers of interest to respondents were Outreach Worker, Youth Support Worker, and Land-Based Program Worker. There was also some interest in careers in Nursing (including as a Nurse, Nurse Practitioner, or Practical Nurse) and as a Researcher or Traditional Healer.

Post-Session Survey

Only four of the nine participants completed the post-Session survey. All four respondents felt the Session increased their knowledge or understanding of health data. Three respondents felt more comfortable talking about health data after the Session, while one was unsure. Three respondents said their knowledge about the connection between health data and the careers listed increased as a result of the Session, while one reported no change. Three respondents said that the Session increased their interest in a health-related career, while one reported no change.

Respondents were asked to rate different parts of the Session from one to five "thumbs up." On average, participants rated the overall Session at 4.5. All of the presentations received four or five thumbs up. The interactive Jamboard exercise received a mix of three, four, and five thumbs up.

What We Heard from Participants

Motivations

Participants shared a variety of reasons for being interested in First Nations health data. Several participants shared that they already worked in healthcare or for organizations that oversee First Nations health data, which made them want to learn more about it. Others reported broader interests



in data transactions and First Nations health and/or research. A few participants were very early in their educational pursuits and were curious to know more about opportunities and how their interests could align with their future education.

Priorities

Participants listed the following as the most pressing health concerns affecting their communities on the Jamboard ([see Appendix D](#)):

- Heart disease
- Prenatal Health
- Children's health and safety
- Mental health and lack of access to relevant services
- Air quality in homes / housing
- Lack of job opportunities
- Intergenerational trauma
- Substance use
- Cancer
- Access to resources
- Diabetes

When given an opportunity to elaborate on these points verbally, participants shared the following:

- Lack of job opportunities: One participant felt there was a limited number of opportunities (paid and unpaid) in their community and that those that did exist were often granted to the friends and family of people in power. They were frustrated by these displays of nepotism but excited to hear about health data-related opportunities shared by panelists.
- Air quality in homes / housing: One participant shared that overcrowding and other housing issues like air quality were major concerns in the communities in their area. This had negative effects on people's health, especially in relation to the COVID-19 pandemic.
- Mental health: One participant commented on the decreased connection to community because of the COVID-19 pandemic. Specifically, they shared that an inability to attend community events and engage in learning opportunities negatively impacted their health.

At the same time, participants also named strengths that their communities could draw on in addressing these concerns, including:

- Culture
- Relationships with others in their communities
- Connection to the land (including land-based detox programs)

Throughout the Session, participants made additional comments indicating that they are engaged in critical thinking and dialogue about the future of their Nations. For example:

- During Dr. Rowe's presentation, one participant asked if Canada had adopted the **United Nations Declaration of the Rights of Indigenous Peoples (UNDRIP)** and, if so, what implications it could have for **Indigenous data sovereignty**.



- During the same presentation, another participant asked about data on other topics such as water quality and the health of the environment. This led to a conversation about the significance of the **Land Back** movement and its ties to Indigenous health and wellbeing.
- During the Health Data Careers Panel, one participant asked the panelists about how to adopt a **decolonizing** approach in research and what that might look like in practice.

We also offered participants the opportunity to complete [The Fundamentals of OCAP® course](#) offered by the First Nations Information Governance Centre at no cost. Four participants took advantage of this opportunity, once again indicating a strong interest in Indigenous data sovereignty.



Reflections

This section will draw on what we heard from participants and speakers during the Session, results from the pre- and post-Session surveys, and discussions between members of the planning team. The following figure summarizes the themes that came up throughout the day. See below for a more fulsome discussion regarding several of these themes.



Figure 1: Word Cloud summarizing main themes from Youth Engagement Session



The Power of Coming Together

In general, post-Session survey respondents had positive things to say about the Session. They rated the individual presentations and the overall Session highly and reported positive outcomes based on their attendance, including:

- Increased knowledge or understanding of health data
- Increased comfortability talking about health data
- Increased understanding of the connection between health data and various health-related careers
- Increased interest in health-related careers

During the Session, one participant shared that it would have been very helpful to have the knowledge they gained from the Session before they worked on a recent research project. Panelists, too, shared that they valued the opportunity to come together and hear about what others in the field were doing. We were also grateful to receive positive feedback from the Elder for the event.

With everything going on in today's world, the fact that we received positive feedback from participants and speakers highlights the power of slowing down and coming together in relation to First Nations health data.

What We Learned About Hosting Events

What Worked Well

The lessons we learned as a planning team can be applied to help improve future events. Some things that worked well included:

- **Promotion:** We reached most of our registrants on Facebook. While the best way to promote events and opportunities will vary depending on the target audience, social media is a valid option that should be considered in the initial stages of event planning.
- **Panel Discussions:** We were intentional in reaching out to prospective panelists with a wide variety of roles and at different points in their career journeys. This seemed to work well, as panelists were able to speak to different aspects of First Nations health data while still building on each other's points. The panelists stated several times that they enjoyed the Session, which we took as an indicator of success.
- **Online Facilitation Tools & Strategies:** We used several tools and strategies that were successful in helping to facilitate the Session, including:



- On-screen timer: this helped participants to know how long was left in each break.
- Jamboard: this allowed participants to reflect on and respond to our discussion questions throughout the day.
- Music: this helped let participants know when we were getting ready to start things up. From our perspective as a planning team, it also helped to dispel tension and create a fun environment.
- Working with an Elder: In addition to opening and closing the Session, Elder Esther stayed throughout the day to listen to and reflect on what was being shared. The teachings and stories that she shared, as well as her use of Anishinaabemowin, were grounding for everyone.

What To Do Differently

There are also some things we would do differently in the future, such as:

- Evaluation: Given that so few participants completed the post-Session survey, our evaluation is limited. In the future, we will consider offering an incentive to survey respondents to encourage their participation. Another option is to conduct a poll at the end of the meeting.
- Panel Discussions: The Panel Discussion started out with five panelists. The Facilitator found it challenging to manage that many panelists, and there was not enough time for each of them to share their insights. Additionally, one panelist had to leave in the middle of the Session, which made things feel rushed. In the future, we would recommend sticking to a smaller number of panelists and making sure that each can stay for the entire presentation.
- Scheduling: Six hours is a long time to spend on Zoom, even with breaks. By the end of the day, it was clear that participants were not as engaged, particularly during the group discussion. The only way to avoid this would have been to cover less content or to split the Session into two half days. We considered the latter but were worried that participants might not come back for the second day. In the future, we would recommend weighing the pros and cons of each option.
- Interactive Discussion: As mentioned above, the discussion was not as fulsome as we had hoped. It is hard to determine exactly what contributed to this, but here are some ideas that may be worth considering in the future:
 - Try different facilitation method(s) (e.g. dotmocracy)
 - Break participants up into groups to discuss amongst themselves before sharing with the group
 - Give participants more time to reflect and share
 - Shorten day(s) and/or schedule the discussion earlier on in the day (but not too early)
- Coordination: We lost some time due to technology-related challenges. In the future, we would recommend performing a "dry run" before the day of the event.
- Recording: In order to make the most of engagement opportunities, it is important to have a reliable record of what participants share. We decided not to record the Session through Zoom



Appendix A: Promotional Poster circulated via Facebook

Are you a First Nations youth who is passionate about the wellbeing of your community?

Join us to learn about First Nations health data in northern Ontario and how you may be able to contribute to this important work

HIGHLIGHTS:

- Honoraria & prizes
- Health data career panel
- Learn about Indigenous data sovereignty
- Help inform our priorities



March 8, 2022 | 10AM - 4PM EST | Online

Open to First Nations youth from northern Ontario ages 18-29

Register at: <https://www.surveymonkey.com/r/mamowyouth>



By completing this form, you indicate that you consent to the following:

- We can use the information you provide on this form to prepare for the Session and to follow up with you afterwards. Once you have submitted this form, you cannot withdraw this consent.
- Participating in a group session on your views about First Nations health data and research in Northern Ontario. You can leave the Session at any time. You will still receive an honorarium for the Session if you leave before it is finished.
- We can use the information you provide to prepare findings and reports on the Session. You can withdraw this consent anytime until we finalize the reports.

If you have any questions about privacy or consent, please email us at mamowahyamowen@gmail.com.

Personal Information

First Name: _____

Last Name: _____

Age: ____

First Nation: (please keep in mind that this event is for youth who belong to northern Ontario First Nations) _____

Email Address: _____

Phone number: (we will only call you if we have trouble reaching you via email)

What is the highest level of education you have completed?

- Some high school
- Completed high school
- Some trade/technical/vocational training
- Completed trade/technical/vocational training
- Some college
- Completed college
- Some undergraduate
- Completed undergraduate
- Some postgraduate (masters or doctorate)
- Completed postgraduate (masters or doctorate)
- Other (please specify): _____

In order to help everyone get to know each other better, we would like to share participants' bios and photos ahead of the session. *Please note that this is completely optional. You will still be able to participate if you decide not to provide this information.*



Is there anything else you would like to share with us prior to the session?

Survey Complete

Miigwech (thank you) for taking the time to fill out this Registration Form. We are looking forward to connecting and talking about First Nations health data with you!

Spots will be offered on a first come, first serve basis. If all spots are filled, we will put your name on a wait list and let you know via email.

If you have additional questions please email:

mamowahyamowen@gmail.com.



Appendix C: Welcome Package

Mamow Ahyamowen Youth Engagement Session Welcome Package



March 8, 2022
10 AM – 4PM EST / 9AM – 3 PM CST



Agenda

Zoom link: <https://zoom.us/j/97668035691> (phone details below)

Time	Item	Speakers
9:55 am – 10:00 am ET (8:55 am – 9:00 am CT)	Participants join through Zoom Welcome	Maureen
10:05 am	Opening	Esther
10:30 am – 11:15 am	Introduction and housekeeping First Nations Health Data in Northern Ontario	Maureen
11:15 am	Break	
11:30 am – 12:30 pm	Strength in Numbers: Improving our Understanding of First Nations' Data Sovereignty to Better Our Collective Health	Robyn
12:30 pm – 1:30 pm	Lunch	
1:30 pm – 3:00 pm	Health Data Careers Panel	Janelle Melanie Miranda Mariette Autumn
3:00 pm – 3:15 pm	Break	
3:15 pm – 3:45 pm	Review of Interactive Exercise	Maureen
3:45 pm	Closing	Esther

To join by phone, please dial one of the following numbers:

+1 647 374 4685
+1 647 558 0588

+1 778 907 2071
+1 204 272 7920

+1 438 809 7799
+1 587 328 1099

Meeting ID: 976 6803 5691

Passcode: 753245

For one tap mobile: +16473744685,,97668035691#,,,,*753245# Canada



Getting to know Each Other

We asked if you wanted to share a bit about yourself when you registered so we could help everyone get to know each other a little bit better. Below is what you shared with us.

Please note: We omitted this information for the report for privacy purposes.



Speaker Profiles

Maureen Gustafson (Facilitator)

Maureen is an Anishinaabekwe of mixed Ojibwe and settler heritage. A member of Couchiching First Nation, she grew up nearby in Fort Frances, Ontario. She is a loving auntie, sister, daughter, cousin, and friend.

Maureen obtained a Master of Public Health with specializations in Health Promotion and Indigenous Health from the [University of Toronto](#) in 2019. Her work is informed by professional experience at Indigenous-led research institutes in both Canada and Australia as well as health and social service providers.



Maureen has been privileged to serve the [Mamow Ahyamowen](#) Partnership as a Knowledge Translation & Exchange Specialist since 2020.

Esther Diabo (Opening & Closing)

We are very honoured to have Esther Diabo opening and closing the session. Esther will share more about herself in the session.



Robyn Rowe (Keynote Speaker)

Robyn is a mother of four, a member of Matachewan First Nation, and a hereditary member of Teme Augama Anishnabai. She recently completed her PhD in rural and northern health from Laurentian University with her dissertation entitled *The Fires we Keep: Honouring the land through Indigenous-led Resistance, Sovereignty, and Data*.

Robyn is an Executive Member of the [Global Indigenous Data Alliance](#) and was involved in the co-creation of the '[CARE Principles of Indigenous Data Governance](#)' with Indigenous partners from around the world through the International Indigenous Data Sovereignty Interest Group as part of the [Research Data Alliance](#).

She is also the Indigenous Data Team Lead at [Health Data Research Network Canada](#) and a Staff Scientist at [ICES](#). Robyn's work intersects in the areas of Indigenous health and policy, Indigenous data governance and sovereignty, and social and environmental justice. Robyn's continued research efforts focus on decolonizing health data environments through the assertion of inherent Indigenous rights and interests.

Janelle Brown-Walkus (Panelist)

Janelle is from the Squamish, Heiltsuk, and Gwa'sala First Nations. Janelle currently works at the [First Nations Information Governance Centre \(FNIGC\)](#) as a statistical data analyst. Janelle recently completed her Masters degree in Dentistry, where she grew into a love for data - specifically in an Indigenous health context. During her graduate studies, she worked with the Norway House Cree Nation to develop a questionnaire to assess the quality of preventive oral health care in a First Nation community.





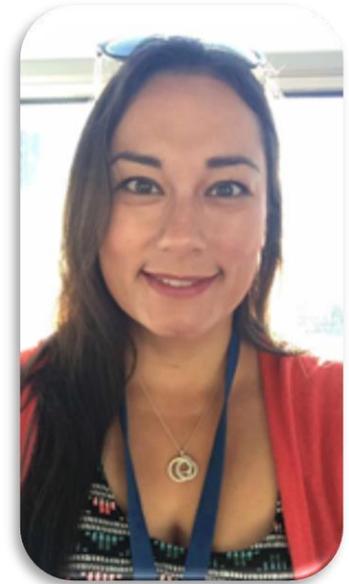
Miranda Lesperance (Panelist)

Miranda (pronouns: she/her) is an Anishinaabekwe (Ojibwe woman) from Opwaaganisiniing (Red Rock First Nation) in Ontario, Canada. She is a Ph.D. candidate at the [Dalla Lana School of Public Health, University of Toronto](#).

Her research interests include Indigenous Peoples' health, health labels and behaviours, and the social determinants of health. She has worked with the [Public Health Agency of Canada](#) for over 14 years and in her most recent contract, she was a Researcher at the [First Nations Information Governance Centre](#) working with COVID-19 data access and stewardship.

After 15 years in Toronto, Miranda has recently returned home to the Thunder Bay region to complete her Ph.D. research, titled "We are stories, not labels: Anishinaabekweg Child-rearing Experiences."

After lecturing at [Lakehead University](#), she spends as much time as possible at her home on Oliver Lake with her partner and her two children, Nodin and Waseya.



Mariette Sutherland (Panelist)

Mariette is Anishinaabe-kwe from the Whitefish River First Nation in Northern Ontario. She has been operating a private consulting practice since 2004 working to advance the self-determined health and wellness priorities of First Nations and Indigenous communities.

Mariette's consulting work has focused on the development of numerous program models, regional strategies, research and evaluation projects aimed at improving Indigenous community health and wellness.

Mariette applies a unique, culturally grounded lens as researcher, planner, administrator, and evaluator applying sound community-based engagement principles in building strong foundational relationships.



Session Support

Justice Seidel



Justice is Omushkego Cree from the Moose Cree First Nation. Justice has an undergraduate degree in Biomedical Biology and a Master's of Indigenous Relations, both from [Laurentian University](#). Justice recently moved back to her home community in Moose Factory, Ontario where she works in community as a health researcher. As the Senior Analyst of Evaluation, Research and Engagement in the Minomathasowin Public Health Department at the [Weeneebayko Area Health Authority](#),

Justice is involved in many health research projects taking place within the James and Hudson's Bay region.

Christina Vlahopoulos

Christina is of settler Greek ancestry and currently lives in the Robinson-Huron Treaty territory and the traditional lands of the Atikameksheng Anishnawbek and the Wahnapiatae First Nations (Sudbury). She graduated from the [Canadian College of Naturopathic Medicine](#) and practiced as a Naturopathic Doctor for ten years in Toronto and Kingston. During that time, Christina pursued her Masters in Public Health at [Lakehead University](#) and completed studies in health equity, vulnerable populations and social determinants of health. She took a break from private practice to work at [De dwa da dehs nye>s Aboriginal Health Access Centre](#) as the Healthy Kids Community Challenge Local Project Lead in Hamilton and Brantford. Christina is honoured to support [Mamow Ahyamowen](#) as the Project Manager.



How to participate on the Jamboard:

You can select a Sticky note and type your thoughts in the box - Click on the Sticky note icon to the left of your screen

You can edit your Sticky note at any time - double-click on the Sticky note, and the text box will "pop" up. You can now edit the content. Once you select "Save," or Enter your edited content will appear on the board.

You can select your Sticky note and move it around the board or re-size the note if you like.

We have a couple of boards for this exercise. You can move between Boards by selecting the Right (>) or Left (<) arrows at the top of the screen.

You can also draw circles or highlight things using the tools on the Left.

In the Text box, you can type as much as you like.

Note - if you add too much content in a Sticky note, it might not all be visible. It might be better to select the text box on the Left side of your screen.

To modify how it appears, you can use the dropdown menu beside the large "A" in the top left part of the screen and select Normal or Caption. You can also select the "A" to change the colour of the text.

You will need to double-click inside the box to get the cursor again to edit a text box.

You may need to re-size your text box to see your content.

Tap the > above and let's get started!

Are there any agreements that you would like to suggest to guide how we should interact with each other today?

Respect: listen to your fellow participants. Don't share their stories outside of this session without permission. Keep your mic on mute if you're not talking.

Avoid interrupting folks and allow them a chance to complete their thoughts before making additional comments

Try to use language that is clear and accessible

[type your agreement here]

Love: take care of yourself throughout the day, whatever that looks like for you. If differences come up, remember that we're all here out of a shared love for our people.

Humility: remember that everyone has a role to play in this work. All experiences are valid and all strengths are important.

It takes courage to speak up - let's honour others as they speak.

Mamow Ahyamowen - Youth Engagement Session - March 8, 2022

What are the most pressing health concerns affecting your community?

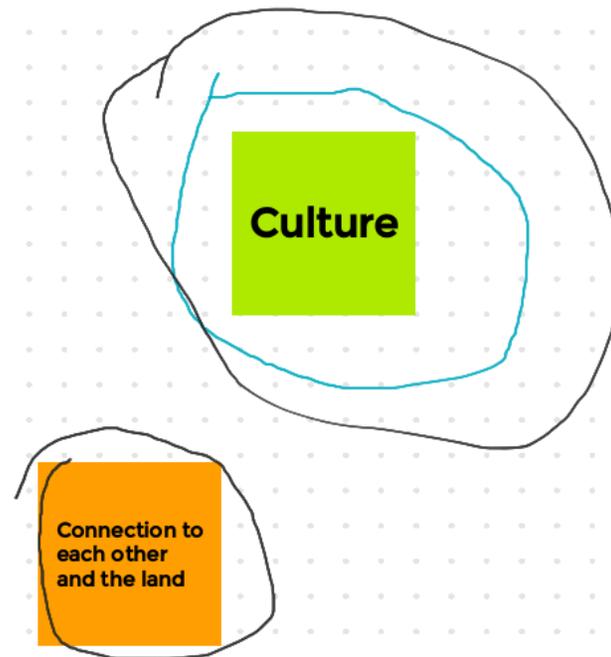


Mamow Ahyamowen - Youth Engagement Session - March 8, 2022

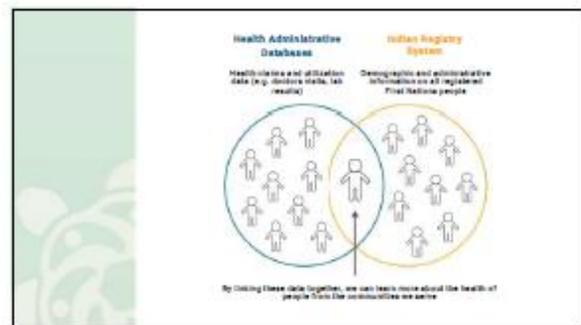
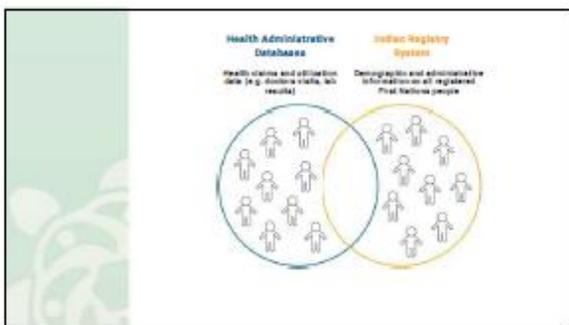
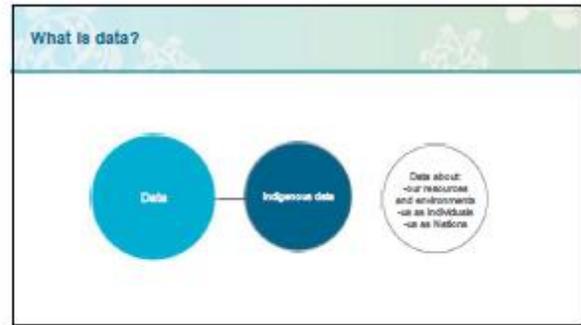
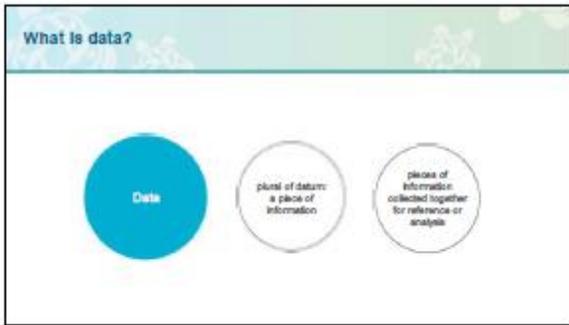
What are some strengths that your community can draw on in addressing the most pressing health concerns?

land-based
detox

eachother



Mamow Ahyamowen - Youth Engagement Session - March 8, 2022





Learning From Our Ancestors

- Our first analysis project
- Focused on the health of people who passed away between 1992 and 2014
- 59 out of 74 communities opted in
- Three levels of reports:
 - Partnership
 - Partners
 - Communities

We don't see death as something to be avoided because we do not see death as the end of life. Sure, it is the end of our material life, but our spirit lives on with the creator. Our time in the material world is temporary and then we join our ancestors in the happy hunting grounds.

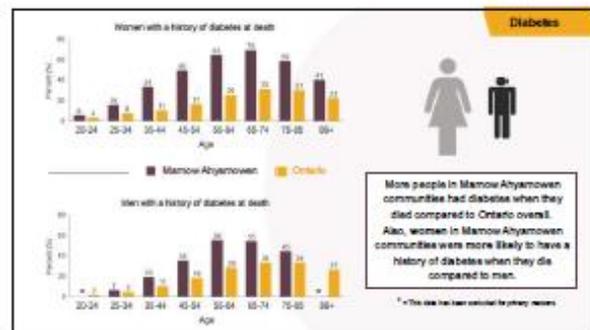
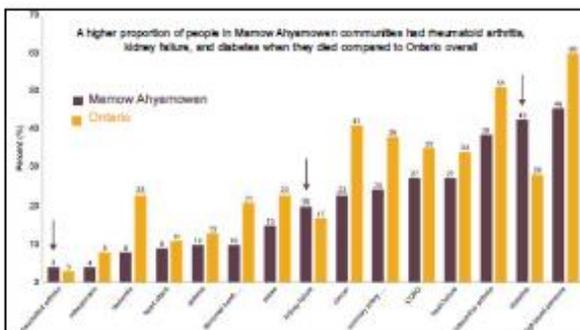
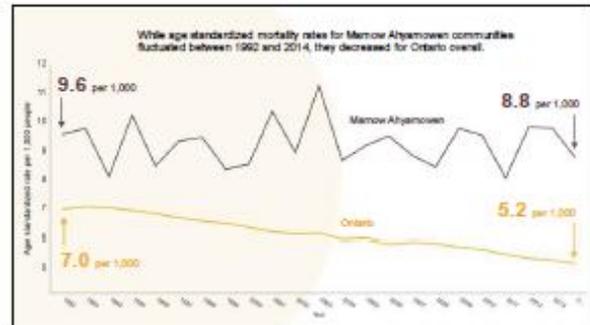
Growing up I was taught that when we see the Northern Lights it is our ancestors dancing in the spirit world.

Elder Hammond Lac Seul
 Lac Seul First Nation

Learning From Our Ancestors

Between 1992 - 2014
 There were 5,685 deaths among Mamow Ahyamowen community members. This means there were 110 deaths for every 1,000 community members.

This rate is 1.5X higher than Ontario overall.





“

When I look at this information it reminds me of the wisdom and knowledge that our Elders and ancestors have passed down to us. I see this information as one more way that our ancestors are able to provide us with important lessons about how we can live a good and healthy life.

Caroline Lidstone-Jones
Betchewana First Nation
Former Steering Committee Member

Why is this Important?

This data supports advocacy and evidence-informed decision making

Why is this Important?

This data supports advocacy and evidence-informed decision making

For example, Partners and communities have used information from our analyses to:

- Revise their IRS registration process
- Support a successful Jordan's Principle application
- Support a successful Long Term Care proposal
- Provide orientation to new staff members
- Inform priority setting and program planning

What's next?

At the Partners' direction, we are starting more in-depth analyses on **mental health & addictions, injuries, and chronic conditions**. So far we have:

What's next?

At the Partners' direction, we are starting more in-depth analyses on **mental health & addictions, injuries, and chronic conditions**. So far we have:

- Defined the scope of analyses with community input
- Drafted analysis plans
- Started the community opt-in process
- Identified technical experts to support the analyses

In the coming months, we will be holding ceremony to start the analyses in a good way

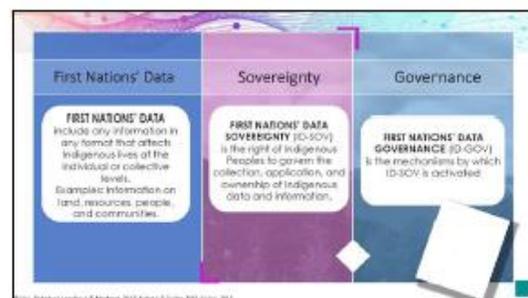
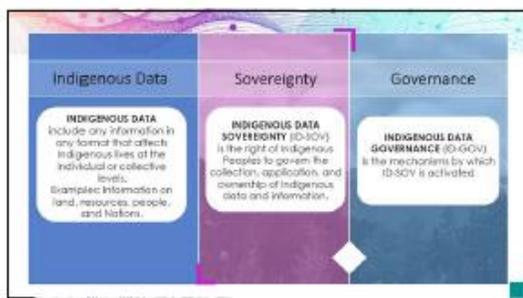
LL"° <↳Γ·Δ>
Mamow Ahyamowen
PARTNERSHIP



Miigwech ~ Thank you



Appendix G: Select Slides from Presentation – Strength in Numbers: Improving our Understanding of First Nations' Data Sovereignty to Better Our Collective Health





History of Unethical Research

Medical experiments highlight need for changed oversight

Consent for use of digital information in indigenous people

Kamsack outreach worker says people died 'daily' while authorities neglected to act

British pharmaceuticals industry based on deceptive and unfair 'toxic tests' using native sites a 'major' health inequity

Grand Chief: 'We will not' tolerate quality above organ harvesting from children who die in psychiatric care

Global Advancements in Indigenous Data Sovereignty

- Indigenous Peoples all over the world have inherent, collective rights.
- Indigenous rights are recognized in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP, 2007).
- Globally, initiatives are advancing that assert Indigenous Peoples rights over how indigenous data and research are designed, defined, owned, accessed, and controlled.

The UN Declaration on the Rights of Indigenous Peoples

- Article 3 – right to **self-determination**
- Article 4 – right to **autonomy and self-government**
- Article 5 – right to maintain and strengthen **distinct** political, legal, economic, social and cultural institutions
- Article 15 (b) – right to **dignity** and **diversity** of cultures, traditions, histories and aspirations which shall be appropriately reflected in education and public information
- Article 18 – right to **participate in decision-making** in matters that would affect rights...and to develop indigenous decision-making institutions
- Article 19 – States shall... obtain free, prior and informed **consent** before adopting and implementing legislative or administrative measures that may affect them
- Article 23 – right to **determine and develop** priorities and strategies...and to administer programs through their own institutions if possible
- Article 31 – right to **maintain, control, protect and develop** intellectual property
- Article 33 – right to **determine** their own identity or membership, Right to determine structures and select membership of their institutions

The Passing of the UN Resolution 61/295 UNDRIP

1984
1994
2006
2007

- The drafting of the UNDRIP began in 1984. There were three main drafts.
- The first version was approved by the UN Working Group on Indigenous Populations (WGIIP) and the Sub-Commission on the Prevention of Discrimination and Protection of Minorities in 1994.
- In 2006, a second version was amended by the UN Human Rights Council—despite protests from Indigenous Nations (the Sioux Nation Treaty Council who launched the work in 1984).
- The final version of the UNDRIP was passed in 2007 by the UN General Assembly, without the support from the Indigenous Peoples involved in its creation.

Suggested book by Chavonne White Face (2015) Indigenous Nations' rights in the Subarctic: An analysis of the declaration on the rights of Indigenous peoples

Developing the CARE Principles for Indigenous Data Governance

FAIR
Findable, Accessible, Interoperable, Reusable

CARE
Collective Benefit, Authority to Control, Responsible Stewardship

GIDA
Global Indigenous Data Alliance

Protecting Indigenous Control of Indigenous Data

For national development and innovation

For improved governance and citizen engagement

For equitable outcomes

Respecting rights and norms

Ready for government

Secure and private

For positive relationships

For increasing equality and equity

For indigenous languages and worldviews

For increasing health and maximizing benefit

For justice

For future use



The First Nations Principles of OCAP®

Ownership

Control

Access

Possession®

- Are First Nations' governing principles that highlight how data should be collected, protected, used, stored, and shared.
- FNIGC offers education and training opportunities that respect First Nations' autonomy and governance.
- Many institutions in Canada that house large administrative data sets, such as ICES are taking greater care in ensuring that the collection of First Nations data follows and respects the OCAP® principles.

To learn more about the First Nations' Principles of OCAP® visit: <https://fnigc.ca/>

Framework for working with Indigenous Data at ICES

Ethical Considerations

- Engage people early
- Community ownership
- Data sovereignty

Data Governance

- Develop data protocols and data sharing agreements
- Transparency

Indigenous-led Nations & Programs

- Collaborative research
- Community-led data management

Methodology & Approaches

- Indigenous-led data research
- Participatory
- Co-created
- Co-developed

INDIGENOUS DATA AT ICES INCLUDE...



Reports
e.g., water quality reports, water quality reports



Self-identifiers
e.g., survey data with identifiers that have been shared with or held



Geographic Identifiers
e.g., postal codes or addresses related to First Nations reserves



Indigenous-led Data sets
e.g., survey or health service delivery data

<https://www.ices.ca/about-us/about-ices/operations-and-partnerships/indigenous-partnership>

The Importance of Indigenous Data Sovereignty

Indigenous data sovereignty reinforces the rights of Indigenous Peoples to engage in decision-making in accordance with Indigenous values and collective interests.

The right to create value from Indigenous data in ways that are grounded in Indigenous worldviews and realize opportunities within the knowledge economy.

The CARE Principles are people and purpose-oriented, reflecting the crucial role of data in advancing Indigenous innovation and self-determination - complementing existing FAIR principles and encouraging open and other data movements to consider both people and purpose in their advocacy and pursuits.

How to Advance Distinct Indigenous Priorities?

- Data and research priorities must **reflect the distinct rights and interests** of Indigenous Peoples. In Canada, that means acknowledging the diversity of languages, cultures, traditions, and ways of knowing and doing of diverse First Nations, Inuit, and Métis.
- Research should be **Indigenous-led** and designed to advance Indigenous-defined rights and interests (from conception).
- Research approaches need to **honour** traditional and inherent agreements, treaties, commitments, and relationships - as **defined by Nations**.
- **Appropriate** Indigenous guidance and leadership should be integrated at every point of the decision-making process.
- Collaborations and consultations must be **meaningful** - that includes being mindful of historical contexts that have led to some Nations and diverse Indigenous people being left out of decision-making processes. Find ways to involve the most voices possible.
- The open adoption of Indigenous data and research governance models at institutional levels should be **adaptive, not prescriptive** - **inclusive, not exclusive** and lead to sustainable and relevant outcomes for and by Indigenous Nations.

What can you do?

- Stay involved in discussions about your Nations' data.
- Never stop learning.
- Grow your understanding of what data are and how they have historically been used against us as First Nations, and understand that history tends to repeat itself.
- So, really, NEVER stop learning.
- Get more involved in discussions about your Nations' data!
- In order to do really good data research and analysis that has the potential to make change, participate in conversations around how you should be identified in data, what data should be collected, and what sorts of research are needed.
- Strength in numbers is not about "data" - it's about the number of people who are willing to decolonize how they think about and use "data".

Open-Access Learning

LINKS

- Indigenous Data Sovereignty, 2016
- The State of Open Data, 2019
- Good Data, 2019
- Indigenous Data Sovereignty and Policy, 2020



