CHIEFS OF ONTARIO

POWERING UP DATA SOVEREIGNTY

Shape Your Own Research and Data Future

Post-Conference Report

EVENT HELD OCTOBER 24th, 25th, & 26th, 2023

The Conference was held at the Courtyard by Marriott, 475 Yonge Street, Toronto, Ontario, Canada on the Traditional Territories of the Wendat, the Haudenosaunee Confederacy, and the Anishinaabeg, including the Chippewas and the Mississaugas of the Credit.

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CLAIRE SHANNON-AKIWENZIE

(Anishinaabe/Irish) is a proud member of the Chippewas of Nawash Unceded First Nation in Neyaashiinigmiing, Ontario. She currently resides in the traditional, ancestral and unceded territory of the Musqueam, Tsleil Waututh and Squamish peoples in Vancouver, BC. Claire is a digital artist, beader, drummer, and Indigenous educator and facilitator.

[Instagram] @zaagiidiwin_   [Web] www.zbeadwork.com

"For a millennia, First Nations ways of living, knowing, and being were protected. Our languages, our identities, and our sovereignty thrived. We were safe, and we were strong. But with colonization, our sovereignty and the right to determine our own futures came under threat. Control and ownership over our ways of knowing and being began to break down, creating a void between who we are today and who the Creator intended us to be. Yet despite these hardships, we are a strong and resilient peoples with a proud history and an even brighter future. In this era of reconciliation, a new story is being written. The story sees us taking back what is ours. It sees us exercising our rights to self-determination and self-government. But to do this, we must also exercise our rights over our information, over our Knowledge, and over our data."

— from a video describing the Assembly of First Nations' Chiefs in Assembly shared by Erin Corston

EXECUTIVE SUMMARY

The Chiefs of Ontario's (COO) Research and Data Management Sector hosted their first conference in October 2023 called the **'Powering up Data Sovereignty Conference'.** While COO has hosted many conferences over the years, this event marked a significant milestone for the Research and Data Management Sector. The event was held on October 24th, 25th, and 26th, 2023 at the Courtyard by Marriott in Toronto, Ontario, Canada on the Traditional Territories of the Wendat, the Haudenosaunee Confederacy, and the Anishinaabeg, including the Chippewas and the Mississaugas of the Credit. The conference was attended by hundreds of attendees, dozens of delegates, speakers, exhibitors, and honoured guests from a wide range of experiences and expertise in First Nations' research and data. For three days, we shared our Knowledges, learned from one another, and strengthened our connections with each other and our understandings of the importance of First Nations Data Governance and Sovereignty.

This event encourages us to "r*emember our roots and our strengths, but also to provide thought leadership around how we build on this – the hard work and the successes which our people have been able to achieve*." – Harold Tarbell

LIST OF ACRONYMS

AFN	Assembly of First Nations
AI	Artificial Intelligence
COO	Chiefs of Ontario
COVID	Coronavirus
FNIGC	First Nations Information Governance Centre
FNDGS	First Nations Data Governance Strategy
OCAP®	The First Nations' Principles of Ownership, Control, Access, and Possession
ORC	Ontario Regional Chief
RHS	Regional Health Survey

WHAT ARE THE FIRST NATIONS' PRINCIPLES OF OCAP®?

"OCAP® stands for ownership, control, access and possession, and represents the sort of rights that First Nations have over their data. ***Ownership*** *speaks to the idea that communities own their data in the same way individuals own data about themselves.* ***Control*** *talks about control over how data is collected and governed.* ***Access*** *speaks both to the idea that First Nations need the right to access their own data, as well as controlling who else has access to this data. And finally,* ***possession*** *is about the First Nations' right to physical possession of their data."*
— Dr. Benjamin Wald, Panelist

ABOUT THE CHIEFS OF ONTARIO

Chiefs of Ontario is an advocacy forum and secretariat for collective decision-making and action for Ontario's First Nations communities.

"The Chiefs of Ontario supports all First Nations in Ontario as they assert their sovereignty, jurisdiction, and their chosen expression of nationhood. Keeping in mind the wisdom of our Elders, and the future for our Youth, we continue to create the path forward in building our Nations as strong, healthy Peoples respectful of ourselves, each other, and all of Creation." – Mariette Sutherland

A FIRST NATIONS DATA GOVERNANCE STRATEGY

The FNIGC developed a First Nations Data Governance Strategy with First Nations' rights-holders. The FNDGS envisions a First Nations-led, national network of regional information governance centres. FNDGS is anchored in a robust strategic framework with:

• A clear vision and path for achieving Data Sovereignty
• A set of First Nations' guiding principles
• Nine strategic pillars where capacities must be built

Please see pages 22-23 for visuals for more information.

What is First Nations' Data Sovereignty?

The inherent rights of First Nations individuals and collectives to steward and control data on and about First Nations peoples and collectives.

What is First Nations' Data Governance?

A mechanism, framework, or tool used to assert First Nations' Data Sovereignty such as the First Nations Principles of OCAP®.

The Development of a First Nations' Data Governance Centre in Ontario

Will the Centre interfere with my Nations' Data Sovereignty?

"The centre that is being developed doesn't stop you from doing what you're doing. It's a network within and if you need, say, for example, help from that centre once it's built, absolutely. It doesn't take away from what your communities are doing. The centre is going to be developed across the country and is a network. And we can provide – no matter if you have your own Data Sovereignty in your communities – at some point, you may need help, and that's what the centre is there for." – Carmen R. Jones

Can Nations opt-out of the Centre?

"Absolutely. We don't want your data. We want to work with you. So that's a very important piece of merit." – Carmen R. Jones

DAKOTA BRANT
Six Nations of the Grand River

INDIGENOUS GRAPHIC ARTIST

DAKOTA VISUALLY RECORDED THE THREE-DAY CONFERENCE
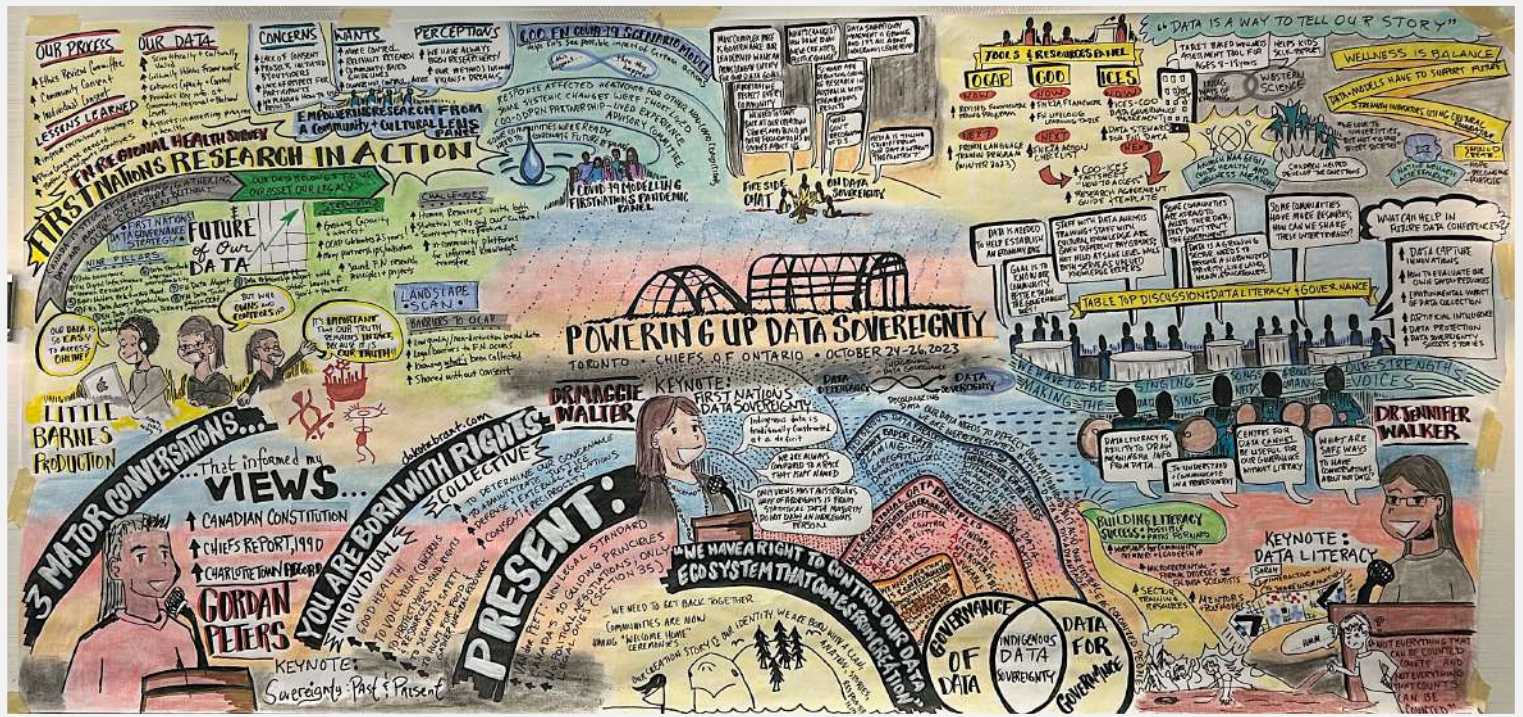
Dakota synthesized all three days on one poster, highlighting specific aspects of First Nations' Data Sovereignty.

Learn more about Dakota Brant at:

https://www.dakotabrant.com/

Turtles hold many important teachings, representing truth, Knowledge, time, seasonal changes, and moon cycles. Turtles move deliberately and slowly through life; valuing both the journey and the destination. During the *Powering Up Data Sovereignty Conference,* we came together to reflect on, and prioritize the diversity of our First Nations' teachings and perspectives. We must continue to walk the path of the turtle; taking the necessary time to reflect on truths and consider a future for First Nations' Data Sovereignty that recognizes our unique ways of knowing and doing.

CONFERENCE DAY ONE

TUESDAY, OCTOBER 24TH, 2023

Day one opened with a drum and song, land acknowledgements, and a prayer. Several welcomes and introductions followed. Speakers acknowledged the significance of Creator's gifts of land, water, and people, while acknowledging the ongoing impacts of colonialism in all our work and decisions. Day one set the context for us coming together to heal and restore our inherent roles as First Nations people; as custodians of Creator's gifts, and the significance of making wise decisions about data and AI technologies for future generations. A total of eighteen speakers spoke on day one.

DANIELLE MIGWANS

M'Chigeeng First Nation and Wiikwemikoong Unceded Territory

OPENING DRUM AND SONG

Calling on our ancestors and helpers to guide us in the three-day conference, Danielle shared a song to give thanks for the water and the good way of life that it gives us as part of the welcoming ceremony. Danielle shared this song as a gift to the attendees and as a signal of gratitude for the earth and waters. The song embraces our unified responsibility to care for the waters while having the courage to make necessary change.

Regrets were received from Chief R. Stacey LaForme from Mississaugas of the Credit First Nation. Chief LaForme had hoped to attend the event and welcome attendees to the territories but was unfortunately held up en route. We were grateful for Veronica King-Jamieson's kindness in sharing a few words of welcome in Chief LaForme's absence.

VERONICA KING-JAMIESON

Mississaugas of the Credit First Nation

LAND ACKNOWLEDGEMENT

"I want to welcome everybody here to the territory … We actually are walking data, when you think about it. Everything starts with our Creation story and especially when we weave our language into that piece of it. Now we're having to document and write everything down in the English. Someday, we can transfer that over into our language for our Youth. And that's where we have to start with."

ELDER VERA PAWIS TABOBONDUNG

Wasauksing First Nation

DATA CHAMPION ADVISORY COMMITTEE MEMBER

Senator Vera is a proud Anishinaabe woman from the Wasauksing First Nation – an Ojibway, Odawa, and Pottawatomi First Nation located on Parry Island in Georgian Bay, Ontario. As the Conference Elder and Senator, Vera provided an opening prayer with words of gratitude, remembrance, and guidance to support the attendees in opening our minds and hearts over the next few days. She shared a prayer from the *Healing our Spirit Worldwide* conference that she attended in September 2023.

A MESSAGE FROM OPENING PRAYER

"We, the Indigenous Peoples of the world have come together as part of the Healing our Spirit Worldwide movement, to declare with one voice and heart our resolve to strengthen the spirit of our Nations and Peoples. To clear from our hearts and minds the clouds of confusion and doubt.

We hold as true and as our guide, the Teachings of our Grandmothers and Grandfathers. We hold a sacred role to protect, maintain, and respect the Creator's gifts so that our children and generations of children after may live a healthy and rich life. Our responsibility to address, enhance, and restore our sacred role. As custodians of these gifts, we need to make wise decisions because we are accountable to the Creator and to generations to come.

The health and wellbeing of our People and Nations is built on our ability to maintain compassionate, functioning relationships within ourselves, with earth, each other, our families, and communities. Knowledge and wisdom are our partners, and we must enrich them both and use them well if our children are to build a meaningful future. We come in ourselves to work in unity and with resolve to strengthen and heal the Spirit of our Peoples." – Elder Vera

HAROLD TARBELL
Mohawk Community of Akwesasne

"The lessons to be learned are in the listening"

WELCOME FROM THE MASTER OF CEREMONIES

"How do we exercise our rights? How do we exercise our authority? How do we exercise our capacity, in balance with the realities of the global community that we are a part of … the power of that image and the power of this idea of ownership, control, access, and possession … and exercising that right over our own data. The idea of this conference is really to help you to sort of get re-grounded in that, but also then to start thinking about how do we apply that in your … individual community and organizational circumstances." – Harold Tarbell

"In the past five years, the movement for First Nations' Data Sovereignty has grown by leaps and bounds. We now have the OCAP® Principles to guide us in the development of our own First Nations' Information and Data Governance Centre, and an array of new partnerships whose research insights are transforming the way that we understand ourselves and our communities. The more impressive development over this time is a growing number of people like you, First Nation citizens, researchers, and technicians, whose collective effort to assert our First Nations' inherent rights to Data Sovereignty and Self-Determination in research will no doubt be strengthened by your gathering today and in these next few days." – Glen Hare

GLEN HARE
M'Chigeeng First Nation

ONTARIO REGIONAL CHIEF'S VIRTUAL WELCOME

"When together, please remember the data that we claim sovereignty over is not abstract. It is our languages, our cultural Knowledges, stories and songs. Some information about our lands, resources, our life and waters, and data about who we are today. What data captures is us. So, who better to rightfully govern that data than us!" – Glen Hare

"There's reasons to be optimistic! We still have consent, never given it up, we still have it. And it's important for us to be able to get back to some critical thinking about what it is that we want to be able to do. Get our minds back in place, get ourselves thinking about how we're going to advance things. We have got to start to be able to get to a process where we can inform our people that we can have discussions again … Our Culture is still alive. All the work that they've done to try to kill our culture, it's still alive!"
– Gordon Peters

ABRAM BENEDICT,
Grand Chief, Mohawk Council of Akwesasne

DATA CHAMPION ADVISORY COMMITTEE MEMBER'S WELCOME

"It's an interesting time in which we are in society, as we see the rise in Artificial Intelligence (AI), and the implications that will have on our people. We heard the Elder and the Regional Chief talk about our language, our traditions, and how important that is to us. But at the same time, that is a threat for us. That is why it's important that we come together and ensure we're protecting that (our Knowledges). As AI develops and evolves to enhance in so many areas, to bring so much to society and our communities, we have to make sure that we're doing our part to protect that. Because if you think about how AI works, it brings together all that information and shares it out. And I know that as a Haudenosaunee, and as a Mohawk, there are a number of our teachings in our ceremonies that belong to us and that don't belong to others." – Abram Benedict

"That's why it's equally important that today, the work we're doing here, at the Powering Up Data Sovereignty Conference, it is important that we all come together and help shape the policy for Ontario … and ensure that we're laying the framework to protect our data, to ensure that we are protecting that for the future, for our young ones to come." – Abram Benedict

"I want to welcome you all to this conference. It's been a long time coming. Powering Up Data Sovereignty is something that I think we can look towards and be able to implement in our work, in our jobs, and in our communities, over the information that you're going to be receiving." – Carmen R. Jones

For over 25 years Carmen has been an active participant in advancing First Nations' Data Sovereignty and explains: *"I've seen many of the data that have been collected, the fight for our communities to collect their own data and to have sovereignty over that data. This movement has been going on for a long time. I'm very pleased that we have our Elder Vera Pawis Tabobondung, and I'm really pleased to have her here as part of our First Nations' Data Champion Committee to be able to share her Knowledges and her experience.*

CARMEN R. JONES,
Serpent River First Nation

DIRECTOR, RESEARCH AND DATA MANAGEMENT, CHIEFS OF ONTARIO

GORDON PETERS

Lunaapeew (Lenape) of the Eelünaapéewi Lahkéewiit (Delaware Nation), Turtle Clan

Former Deputy Grand Chief, Association of Iroquois and Allied Indians and Former Ontario Regional Chief

THE IMPORTANCE OF DREAMS

"We dream all the time. And we have powerful dreams. And if you don't know what your dreams are. ask people, because there are people out there that will tell you exactly what those dreams mean; our ceremonies are the major link to the spiritual realms. So, we do those ceremonies all the time. And most of our ceremonies are done within the same cycles … And so those 13 moons, they set up the cycles for us. And that's when we conduct those ceremonies. And it's really important." – Gordon Peters

Gordon Peters shared that he was involved in three major discussions in his lifetime on First Nations' rights that impact Data Sovereignty. He attended events in the 1980s, and explains that there were several Chiefs at the time who agreed that:

"We can't depend on looking to Canada for solutions, we have to figure out what we want and how we want to be able to move forward with that. One of the first things that we want people to do is … get a name, we want them to get their own name, and stop using these English names. We want them to be able to get a clan, so they know that's where they belong and where they sit, so that they have a place. And they said we want the communities to be able to go back to that original name. So that we don't lose that identity to the land and that connection to the land." – Gordon Peters

"When we enter this world, we already have that identity. It's already there. So, we belong to a Nation. We belong to that clan family. We belong to those Creation stories that we were taught, and we're bound to our responsibilities to all of Creation … We're born into that collective. You can't function individual rights outside of the collective. That's what Canada does … And so, this idea that in the larger context of our governing bodies, the notion of our clans being able to select leaders, rather than having a group of leaders that run the whole entire community, we have all these different clans that make up the leadership process." – Gordon Peters

Speaking about the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Gordon Peters highlighted:

"*The intent was to break down barriers and combat systemic racism. It was also supposed to talk about international customary law and a few other things. It was supposed to help us to get a foot-up on Canada. Never.*

What Canada did was that they wouldn't support UNDRIP. They went back, and then Canada created Canada's 10 principles. [See Poster] … *Principle number six says, we're going to aim to secure your free, prior, and informed consent… The Minister of Justice says their federal position is free, prior, and informed consent is a series of consultations. That's no different from what they're doing right now. UNDRIP doesn't have much support for us and the things that we want to be able to do going forward … If they were really serious about trying to create a different place, a different world, and make space in their world for us right now – because they occupy all the space – they would have done all these things.*" – Gordon Peters

Source: https://www.justice.gc.ca/eng/csj-sjc/principles-principes.html

"*One of the big commitments far too underrepresented is* (when Canada said), '*we're going to implement every part of the Truth and Reconciliation Commission'. Well, they've done a whopping amount. They've done three. All of this is one process (of colonialism) that we struggle with. And it has been a part of everything that we've done in the last probably 150 years. And for lack of better words, I call it the process of dehumanization.*" – Gordon Peters

AI CONSIDERATIONS

"I think AI is a real concern, especially because Big Data has shown a worrying capacity to re-identify data that we thought was anonymous. So, the larger the data sets get, and the more different data sets you can correlate together, the more difficult it is to permanently de-identify data – to remove all the data that would make it possible to re-identify specific individuals. So, I think, yeah, the whole paradigm of de-identification is challenged by the ability of AI to sort of crunch through these huge masses of data and also, to identify groups within the data in ways we didn't previously think that we could. So even if you remove First Nation identifiers from data, there might be ways, or proxies that can be used to target First Nations and find First Nation groups within the data that we didn't think were present there."

– Dr. Benjamin Wald

Learning through Art with the
Little Red Barnes Productions

Little Red Barnes Productions took a difficult concept and turned it into an informative conversation between father and son.
Played by John Rowland and Nolan Moberly.

"I want you to want to take a deeper dive with the things that matter most like our cultures, history, our teachings, our truths, our ways of measuring growth."

"Who controls the information? Who's working out and interpreting the raw data? Who owns the information? Who holds the keys to the truth?"

"That's why it's important to control those who control telling the story, because our account cannot be misrepresented. We need to be able to obtain this information to be able to communicate this information, have access to the information, and know with all certainty we possess it."

"How do you want to approach the telling of our history? How do you get inspired to know more about where you come from and where you're going. How can we walk into the future together if we don't know where we come from, or what our past has taught us?"

Erin Corston, Mariette Sutherland, and Dr. Benjamin Wald (Left to Right)

PANEL: THE FUTURE OF OUR DATA

FIRST NATIONS DATA GOVERNANCE STRATEGY AS A WAY OF EXPRESSING SOVEREIGNTY

During the Future of Our Data panel, we learned about the future of First Nations' data in Ontario. We heard about the development of the First Nations Data Governance Strategy and the positive impacts that this will have on First Nations' Data Governance. We were also shown a health data landscape scan, highlighting how First Nations' health data is managed and collected in Ontario.

ERIN CORSTON
Chapleau Cree First Nation

**DIRECTOR AND EXECUTIVE LEAD,
NATIONAL DATA CHAMPION TEAM, FNIGC**

Speaking about the First Nations' Data Governance Strategy, Erin Corston explains: *"The Strategy, however, is not about fixing Canada's broken data and statistical system. No. It's about taking back what's ours. It's about owning and controlling, holding and leveraging our own data for our own purposes."* — Erin Corston

A First Nations' Data Governance Strategy

Using the FNDGS as a guide, FNIGC is working to establish *"fully functional, non-political, and expert-driven regional information governance centres; one in every region. Led by First Nations, these regional centres or regional hubs will provide a suite of shared data and statistical services to all communities, their governments, advocacy organizations, and service delivery agencies. Leveraging economies of scale in every region; communities and our organizations will have access to the digital infrastructure and professional expertise they need to govern, access, and repatriate their data; leveraging its power."* — Erin Corston

Implementation of the FNDGS

"Implementation will be community-driven, and nation-based, rolling out in phases. Phase one starts now with the recruitment of a dedicated Data Champion Team in every region, that will engage leadership and help them define how these regional centres will be governed, and what priority data capacities and services will they offer … With this strategy, we will build our own Data Governance and statistical institutions, and they will be equipped with the modern capacities we need to hold and use all our data. It will be our legacy for the next seven generations to come." — Erin Corston

A First Nations Data Governance Strategy

- Cultural barriers
- Lack of quality data
- Data sets are held by other governments (Fed/Prov)
- Many fragmented datasets
- **FIRST NATIONS HAVE VERY LIMITED DATA CAPACITIES**
- Important data gaps
- Jurisdictional divides between governments (Fed/Prov)
- Legislative and policy barriers to data access
- Difficulties accessing existing datasets

Leaving little ability to contribute to and benefit from Canada's statistical and information systems.

Community-driven and Nation-based

Impacting our ability to Govern, to make informed decisions, to plan and to Protect our citizens

Pillars

1. First Nations Data Governance
2. First Nations Digital Infrastructure and Human Resources
3. Rights Holders Relationship Management
4. First Nations Data Access and Repatriation
5. First Nations Data Collection, Discovery, and Gap Bridging
6. First Nations Data Standards and Intergovernmental Interoperability
7. First Nations Data Management
8. First Nations Data Trust, Ethics, and OCAP® Implementation
9. Data Relationship Management with Other Levels of Governments and Partners

The First Nations Information Governance Centre

Source: https://fnigc.ca/news/introducing-a-first-nations-data-governance-strategy/

MARIETTE SUTHERLAND
Whitefish River First Nation

EXECUTIVE PROJECT LEAD, ONTARIO – FNIGC

Decades of Advocacy leading to …

- COO Resolution 06/15 asserting jurisdiction over First Nations' data.

- AFN Resolution 57/2016 seeking sustainable investment for regional information governance infrastructure.

- COO Resolution 17/18 First Nations' data for wellness and healing and advocacy for funding.

- COO Resolution 21/27 the development of an Ontario First Nation Information Governance Centre.

"We want to make sure that our communities have the awareness of the strategy and are Knowledgeable about Data Sovereignty, before we embark on engaging them about specific questions about what they want to see in their centre. It's really important that we have a platform for informed dialogue going forward." – Mariette Sutherland

Priorities of Resolution 21/27

1. Establish an interim Data Champion Advisory Committee and develop a Terms of Reference.

2. Endorse the First Nations Data Governance Strategy, as customized to Ontario priorities and needs.

3. Support for existing forms of Data Governance until community consultations can take place.

4. Report back yearly to the Chiefs in Assembly (done quarterly).

5. This work would not prejudice or negatively impact any First Nations initiatives in research and data.

WORK TO BE ACCOMPLISHED DURING PHASE 1 (2023-2025)

Build a Data Champion Team	Define regional priority capacity needs	Ensure trust and support from leadership

Define regional Data Governance model	Secure phase 2 funding
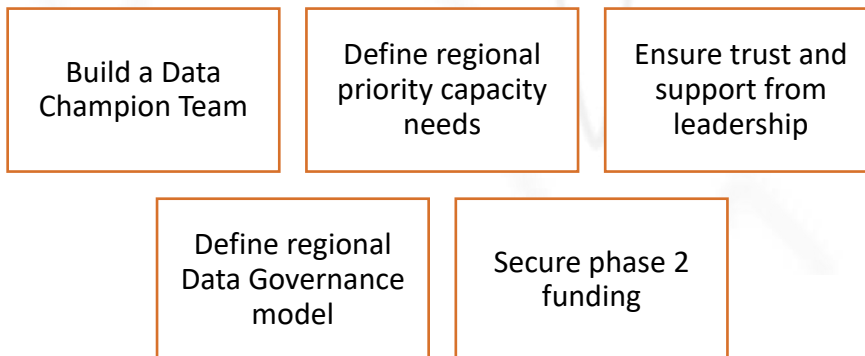
DR. BENJAMIN WALD

RESEARCH ANALYST, CHIEFS OF ONTARIO

Dr. Benjamin Wald spoke about the results of the First Nation's health data landscape scan that was recently conducted, and shared some aspirations for what Data Governance could look like.

"The aim of the landscape scan was to discover what First Nations' health information is being gathered, where it's stored, and how it's being managed. And then this information was assessed in terms of the overall trends, barriers to OCAP®, and opportunities to advance OCAP®."

"Ideally, we'd see rights-holders have control over whether or not the data is collected in the first place. So, this is important because a lot of places begin collecting data without consulting rights-holders. So, it's not just about once the data is collected, it's also, do you have the permission to collect this data in the first place? We also want to see rights-holders having control over access and use of the data so that the data isn't being used without permission, and it's not being shared with any outside groups without that permission." Dr. Wald explains that we should also see, *"First Nations themselves having access to this data when requested, so that it's available for their use.*

Community data will be protected in the same way as individual data. So, the laws do a pretty good job of protecting personally identifying information, but the laws don't really speak to community privacy. We need to see particular policies in place to protect data that's at the level of First Nation communities. And finally, ideally, we'd see capacity building for First Nation. Hopefully contributing to future increased capacity to make use of data, and to eventually possess the data themselves."

Comprehensive Data Governance
- Rights-holder control over access and use
- Community data protected in addition to individual data
- Capacity building for First Nations
- First Nations have access to the data
- Rights-holder permission for collection
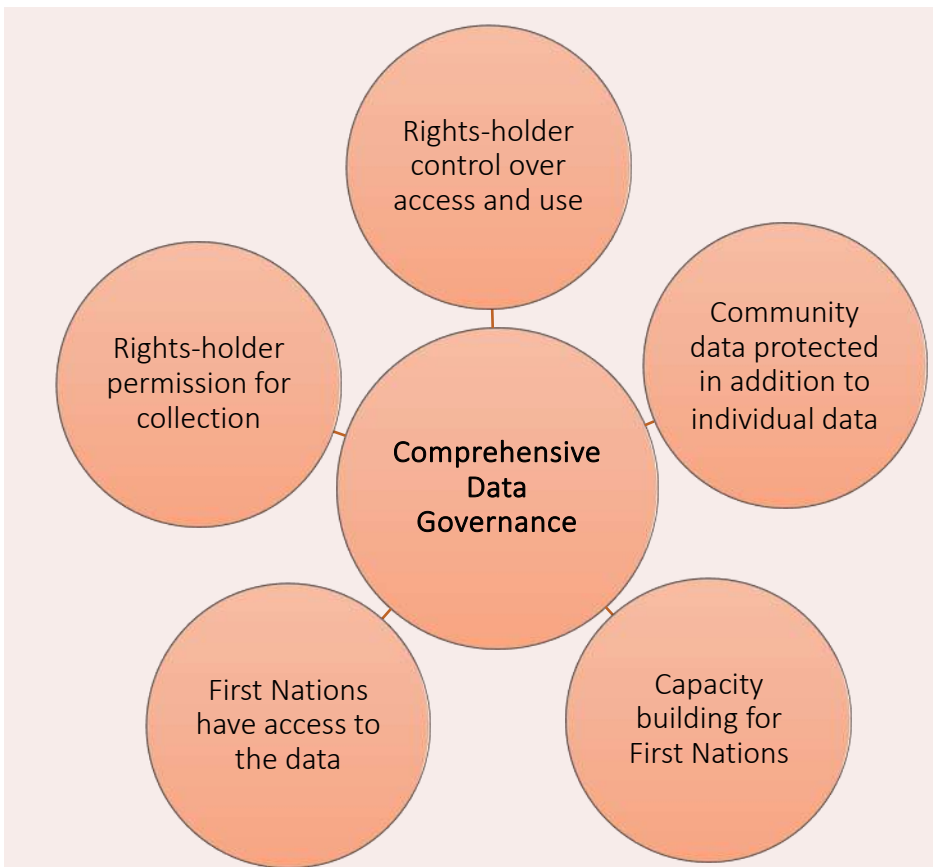
HONOURING THE LATE CATHRYN MANDOKA

CATHRYN MAY MANDOKA
1951 - 2023

The plaque reads:

In acknowledgement of the AIAI Health Director, the late Cathryn Mandoka for her contribution to the OCAP Principles and advancement of First Nations' Data Sovereignty.

In memory and in honour of the late Cathryn Mandoka, Carmen Jones shared a few words with the audience. Carmen also presented a plaque and statue that are being presented to Cathryn's family, who were unavailable to attend the conference.

"In May 2023, we lost Cathryn Mandoka. She had been quite a presence in all our lives. She was on the Health Coordination Unit, and she was the director of the Association of Iroquois and Allied Indians. Because it has now been 25-years since the time of OCA- which eventually became OCAP®. Cathryn was a big part of that, and we wanted to honour her for her contributions, and for her pioneering way." – Carmen R. Jones

Kyla Marcoux, Roseanne Sutherland, Trevor Koostachin (Left to Right)

PANEL: FIRST NATIONS RESEARCH IN ACTION

THE FIRST NATIONS REGIONAL HEALTH SURVEY – PAST, PRESENT, AND NOW

This panel highlighted the First Nations Information Governance Centre and the development of the Regional Health Survey, and the First Nations' Principles of OCAP®. The panelists highlighted the importance of First Nations' data management that prioritizes ethical research and consent, while challenging the colonial legacy of exploitative data extraction. First Nations' perspectives guide the methods and methodology of the RHS and include the involvement of a regional advisory committee and ethics review. FNIGC's data success stories include:

- Offer scientifically and culturally validated information on health and well-being
- Address First Nations' priorities within a cultural and holistic framework
- Enhance First Nations' capacity and control over research and data
- Provide First Nations with key information for planning, policy and advocacy at community, regional and national levels
- Assist First Nations in assessing progress in health, well-being and the social determinants of health

KYLA MARCOUX

SENIOR STRATEGIC ADVISOR, FNIGC

The Regional Health Survey History

"We're all familiar with the history of First Nations' Peoples and communities being the subjects of research, and much of the research literature has been written from a colonial perspective, resulting in limited representation, and often stereotypical and damaging depictions of First Nations' Peoples. And so, the way that First Nations' data is managed by governments and institutions, is very colonial. The sharing of information without consent, the commercialization of First Nations' data, the over collection of First Nations' data, as well as data being collected without the intent or capacity to improve the wellbeing of First Nations. So, the Regional Health Survey is really a response to this legacy of unethical research." – Kyla Marcoux

The First Nations Information Governance Centre

"We were incorporated in 2010 following receipt of our mandate from the Special Chiefs in Assembly, and we are mandated to support the information management, research, and training needs of First Nations. We also measure improvements to First Nations' health and wellbeing through the Regional Health Survey (RHS) and other specialized surveys. We work with 10 regional partner organizations across Canada and the Chiefs of Ontario is our partner here. These regions are really the backbone of all the work that we do. We're designed as a network of regionally controlled centres." – Kyla Marcoux

RHS Phase 4 Data collection is happening now!

[More details in Appendix]

Vision of FNIGC
The FNIGC envisions that every First Nation will achieve Data Sovereignty in alignment with its distinct worldview.

Mission of FNIGC
With First Nations, we assert Data Sovereignty and support the development of information governance and management at the community level through regional and national partnerships. We adhere to free, prior, and informed consent, respect nation-to-nation relationships, and recognize the distinct customs of Nations.

ROSEANNE SUTHERLAND
Mushkego from Kashechewan First Nation
SENIOR LEAD, RESEARCH AND DATA MANAGEMENT, COO

"There's an old Ontario Chiefs Resolution #14-10 passed, mandating Chiefs of Ontario to be keepers of RHS data for the Ontario region. We work with participating First Nation communities in Ontario to implement the survey and collect data. And we provide that linkage, as other regions do, between FNIGC and participating First Nation communities, and we prepare the final report, usually called the People's report" – Roseanne Sutherland

RHS People's Report 1, 2, and 3

The First Nations Regional Health (RHS) survey was conducted on a national level by the FNIGC with ten (10) provinces and territories participating in the survey. Chiefs of Ontario has been involved with the onset of the pilot RHS survey since 1997. Since the pilot, surveys have been conducted in 2002/03, RHS II in 2008/10 and Phase III in 2015/17. Overseen by FNIGC in collaboration with regional partners such as Chiefs Of Ontario, the RHS is the only First Nations governed national health survey in Canada.

NEW FRAMEWORK FOR THE RHS-4

There are 47 participating communities, so far.

RHS process in community

1. Complete Band Council Resolution
2. Letter of Agreement (LOA) reviewed & signed
3. Discuss the LOA (i.e., ways to pay Knowledge Gatherers)
4. Identify Community Champion
5. Hire Knowledge Gatherers-community
6. Train Knowledge Gatherers – COO
7. Review ways to do sampling
8. Collect surveys & upload to FNIGC
9. Report – COO

TREVOR KOOSTACHIN, *Attawapiskat First Nation*

RESEARCH ANALYST, COO RHS

THE REGIONAL HEALTH SURVEY

Guided by this framework, the meaning of First Nations' health is defined as "the total health of the total person within the total environment". The goal is to assist in achieving a culturally informed interpretation process that reinforces and reflects their ways of seeing, relating, knowing, and being.

RHS Cultural Framework

- Major barriers to healthcare for First Nations adults include long waiting lists, lack of available doctors and nurses, and inadequate coverage.

- First Nations' Youth with mental health challenges are less likely to contact a mental health professional.

- Unemployment rate remained steady, but other socio-economic conditions improved or worsened for First Nations people.

- Arthritis is the most common chronic health condition among First Nations adults.

In 2016, COO organized a Lessons Learned meeting with some field workers who told us about their experiences and challenges with survey work. Some of the suggestions were:

- Improve recruitment strategies i.e. Put rate of pay per survey.

- Communications: plain language materials for training, COO website use, maintain current community lists, and send toolkits early on.

- Better participation incentives and promotional materials.

- Risk management: COVID protocols, safe spaces, use of data.

- Turnover of survey staff means retraining has to occur—perhaps even exit interviews. Consider hiring already trained surveyors from past survey iterations and have community leads participate in training.

Dr. Marion Maar, Dr. Lorrilee McGregor, Christina Vlahopoulos (Left to right)

PANEL: FIRST NATIONS' RESEARCH IN ACTION
EMPOWERING RESEARCH FROM A COMMUNITY AND CULTURAL LENS

This panel shared important details about First Nations' defined research ethics processes from a cultural and community lens. Speakers highlighted concerns about research being conducted without community input, and the drive towards community action. We also learned about the Mamow Ahyamowen Partnership as an example of how communities and organizations can come together to secure First Nations' data for change.

"If you really think about the theme of this conference, Powering up Data Sovereignty, shaping our own research, and repatriating our data, that's what it's all about, that's where you start is from your Elders in your own Knowledge base." – Mariette Sutherland

MARIETTE SUTHERLAND
Panel Moderator

DR. MARION MAAR

NORTHERN ONTARIO SCHOOL OF MEDICINE UNIVERSITY

RESEARCH ON MANITOULIN ISLAND 20-YEARS-AGO

"Some of the concerns … are the same things that you might have experienced in your own communities; very little consultation, projects were initiated almost always by outsiders. Communities felt they didn't provide consent; there was potential harm to participants, inappropriate research methods, and so on. It really came to head in the year 2000, when there were two projects that really raised a lot of concerns amongst the community members, and one of them was just suddenly posters came up and they were put up in the community saying 'if you went to residential school, please, here's a number' – and it was like, I think a $50 honorarium that people would get in order to talk to them. And there was no aftercare, no consultation, nothing." – Dr. Marion Maar

BORN OUT OF COMMUNITY CONCERNS ABOUT RESEARCH

Serious ethical concerns at the community level despite the fact that the research projects had received clearances from hospital and university Research Ethics Boards.

ACTING ON COMMUNITY CONCERNS

A two-day regional community conference was conducted to gather local attitudes towards research and to create a vision for First Nations' health research in the Manitoulin area. The conference brought together community members, healthcare workers, community leadership, Elders, Traditional Healers, Indigenous and non-Indigenous researchers, and university students. A **Research Review Committee** began to meet on a regular basis to follow up on the recommendations of the conference:

- develop ethical guidelines
- continue community consultations
- promote the research review initiative with local decision makers

Elders advised on how to embed the Seven Grandfather Teachings and First Nations' Knowledges into the development of a community research ethics review board.

RESPECT, WISDOM, HONESTY, BRAVERY, TRUTH, LOVE, HUMILITY

COMMUNITY ENGAGEMENT

- Validity of Anishinaabe ways of knowing and thinking
- Naagdowendiwin (caring for each other)
- Anishinaabemowin (speaking our language)
- Ceremony
- Reciprocity
- Nbaachwe (visiting) and storytelling
- Listening & silences
- Culturally safe
- Involving Youth and Elders
- Protecting Anishinaabek Knowledge

EXAMPLES OF INDIGENOUS SELF-DETERMINATION IN RESEARCH

- Six Nations Research Ethics Committee
- Nuu-chah-nulth Tribal Council Research Ethics Committee
- Mi'kmaw Ethics Watch
- Manitoulin Anishinaabek Research Review Committee (MARRC)

Chapter 9: Tri-Council Policy Statement (TCPS) Research Involving the First Nations, Inuit and Métis Peoples of Canada

- Community engagement
- Collaborative research
- Local governing authorities
- Respect for community customs and practices
- Research agreements
- Strengthen research capacity
- Recognition of Elders and other Knowledge Holders

WE HAVE ALWAYS DONE RESEARCH, IN OUR OWN WAYS

"Our presentation focuses on research, but what I wanted to emphasize is that we, as Indigenous People have always been doing research. We've been doing research since time immemorial. We've done research in different ways; observation, experimentation. But we also gain Knowledge and do research through visions and dreams. So that's the spiritual aspect to research that most people don't really talk about."
– Dr. Lorrilee McGregor

"We actually take researchers and make them answer the question, 'how are you going to carry out or embody those Seven Grandfather Teachings while you're doing research in our community?' So, look, that's a tough one to answer for researchers, but we do expect them to answer that. We also asked them to consider how their research will benefit Seven Generations." – Dr. Lorrilee McGregor

DR. LORRILEE McGREGOR
Whitefish River First Nation
NOSM UNIVERSITY

CHRISTINA VLAHOPOULOS, *Settler Greek Ancestry*

PROJECT MANAGER, MAMOW AHYAMOWEN

About Mamow Ahyamowen

"We work with communities to find, analyze and interpret data in response to questions that they have prioritized, following a culturally respectful path." – Christina Vlahopoulos

When we work with data in a good way, it supports:

- Advocacy
- Evidence—informed decision making
- Self-determination

Working with Data to Address the Unique Needs of Northern Ontario First Nations

- Alliance between First Nations health and social service organizations serving communities across northern Ontario
- Formed in 2016
- Shared need for high quality, community-specific health data
- 11 First Nations' organizations that serve a combined total of 78 communities in the north.

Learning from our Ancestors

- Focused on the health of people who passed away between 1992 and 2014
- 59 out of 74 communities opted in
- Multiple levels of findings:
    - Alliance
    - Organization
    - Communities

KNOWLEDGE SHARING

Four different types of reports
- Alliance level
- Organization level
- Community level
- Companion reports

MAMOW AHYAMOWEN IS CURRENTLY WORKING ON IN-DEPTH ANALYSES ON:

Chronic Conditions

Mental Health & Addictions

Injuries

CONFERENCE DAY TWO

WEDNESDAY, OCTOBER 25th, 2023

Day two opened with a drum and song. Speakers highlighted the importance of grounding sovereignty in First Nations-determined and community-based Nation-driven action. Speakers shared details of projects that contextualize data as a tool that can be used to assert sovereignty and address First Nations' community priorities. The day included a Fireside chat and opportunities for audience engagement and interaction. A total of 15 invited speakers participated in day two.

If it's data about us, we own it. How dare they say we can't have it!

- Dr. Maggie Walter, Keynote

FIRST NATIONS' DATA SOVEREIGNTY

"Everything is just always comparing – and comparing on pejorative indicators. It's almost as if it's a tick-box exercise on colonization. "Are they still the poorest?" Yeah. "Are they still the unhealthiest?" Yeah. "Are they still having the highest rates of infant mortality?" Yeah. "Do they still die younger?" Yeah. "Excellent job guys, colonization is still working exactly as planned." – Dr. Maggie Walter

SPEAKING ABOUT OCAP®

"OCAP® was the driving force for Indigenous Data Sovereignty right around the globe. So, you guys did it first. You had the bravery and the anger to say 'no, we're not doing it this way, there is a better way to do it, and what you are doing is not serving our Peoples!' So, thank you, everybody, because Data Sovereignty globally would not be here without OCAP®." – Dr. Maggie Walter

"Data are deeply political. They're not neutral. They're artifacts that reflect the realities of those whose purposes they serve. And for the vast majority of data and vast majority of data gathering history, not by us, those purposes have not been ours." – Dr. Maggie Walter

THE 5 DS OF STATISTICAL INDIGENE

Colonization is the primary frame through which Indigenous data are understood and enacted, with real life consequences for Indigenous Peoples.

Indigenous data traditionally constructs a discourse of Indigenous Peoples as deficit … measuring Indigenous Peoples as 5D:

• Difference
• Disparity
• Disadvantage
• Dysfunction and
• Deprivation (Walter, 2016)

"If all the data in those datasets is 5D data; it's all about our health problems, our poor education, then it doesn't matter how big that ball of data is, and how powerful your analytical techniques are. The only result that can come out, because that's the only indicators you've got is that Indigenous People, First Peoples, have a problem. So, it's not about how much data you've got. It's about what data you've got!" – Dr. Maggie Walter

DR. MAGGIE WALTER, *Palawa, descendant of the trawlwoolway Aboriginal people of Northeastern Tasmania, Australia*

PHD, DISTINGUISHED PROFESSOR OF SOCIOLOGY, UNIVERSITY OF TASMANIA

Dr. Jennifer D. Walker, Linda Ogilvie, Dr. Robyn K. Rowe, Dr. Carol Mulder, Sacha Bragg, Tara Gomes, Cal Stewart, Dr. Sharmistha Mishra (Left to right)

PANEL: COVID-19 MODELLING FIRST NATIONS PANDEMIC

COSTS, LESSONS, AND PREPAREDNESS IN ONTARIO

This panel, moderated by Linda Ogilvie, discussed the importance of First Nations' led data initiatives in public health, particularly during the COVID-19 pandemic. A portion of the panel focused on learning from First Nations' responses to the COVID-19 pandemic to prepare better in the future. The panelists shared diverse perspectives and experiences. This panel also highlighted the important roles of relationships and Data Governance mechanisms to ensure that First Nations are leading public health decision while controlling and owning the products of the work.

Photo Credits: Many of the photos taken during this panel were taken by Laurentian University, Indigenous Social Work Practicum Student, Nancy Sylvain.

LINDA OGILVIE
Public Health Advisor, COO
Panel Moderator

DR. ROBYN K. ROWE
Matachewan First Nation & Teme Augama Anishnabai

POST-DOCTORAL FELLOW, QUEEN'S UNIVERSITY
PRINCIPAL CONSULTANT, ROBYN ROWE CONSULTING

Lessons Learned: First Nations COVID-19 Experience

Guided by First Nations and information received from the leadership, the Chiefs of Ontario set out to determine what lessons were learned and what sorts of recommendations for future pandemic preparedness could be made, from the perspectives of individuals who were in decision-making, leadership, and advisory roles between March 2020 and December 2021.

"And I think that, you know, I kept this slide here, in part because of the art, I just really like the art. But also, in part because we really need to continue to do that, we really need to continue to prioritize ourselves, even now in this, I want to say post pandemic, it's not, we're still sort of in it in different ways. But recovery, right? Recovery and preserving our culture and ensuring that those things continue to get transmitted. Our Knowledge is continued to be passed down despite being in lockdown." – Dr. Robyn K. Rowe

REPORT HIGHLIGHTS

- Realities
- Response
- Resilience
- Repercussions
- Recommendations

Scan with your phone or device camera to open the full report

DR. JENNIFER D. WALKER, *Six Nations of the Grand River*
ASSISTANT PROFESSOR, MCMASTER UNIVERSITY

DR. CAROL MULDER
SENIOR SCIENTIST

THE COST OF COVID

Providing an overview of a CIHR-funded project that explored the costs of COVID-19, Drs. Walter and Mulder explained how this work looked at *"both the economic costs of COVID 19 to the health system, and the broader cost of having re-oriented the health system in response to COVID."* For example, *"those non-COVID things, like if you were a person living with diabetes – what did that mean for your care when services and efforts are redirected to COVID?"* – Dr. Jennifer D. Walker. The project itself was a collaboration between COO, ICES, and the University Health Network, and was formalized through an agreement, that addressed OCAP® and the ownership, control, access, and possession of the data.

Existing relationships that were ten years in the making between the COO and ICES in Ontario improved COVID-19 reporting, surveillance, and decision making during the pandemic. This project was able to use those reports to chart two years of the pandemic's trajectory and its impact on First Nations in Ontario. The experiences of people accessing the healthcare system were compared to a small number of possible contributing factors/conditions, including geography, age, and gender. Dr. Mulder explains, the *"selection of conditions was informed by not only the data – which things are common, because if they're not common enough, it's hard to look at them in the data – but also, what are priorities for First Nations? And how does this align with the kinds of things that are important for communities to know?"*

"We're not telling you anything new to say that COVID-19 caused sickness and death, that it had a direct impact on First Nations' People, and that the experience was different and somewhat worse for First Nations in Ontario and elsewhere – which is also not surprising given ongoing impacts of colonization and inequities."
– Dr. Jennifer D. Walker

"If we just keep looking at the data that we have, we're still not going to answer the questions that matter … This is our attempt to get the most value possible out of the data, understanding that is still limited." – Dr. Carol Mulder

Sample results: primary care — In-Person vs. Virtual Primary Care Visits

Sample results: substance abuse hospitalization — Hospitalizations for substance abuse Increased 40% — Hospitalizations for substance abuse increased by 40% by the second quarter of 2021 (April–June)
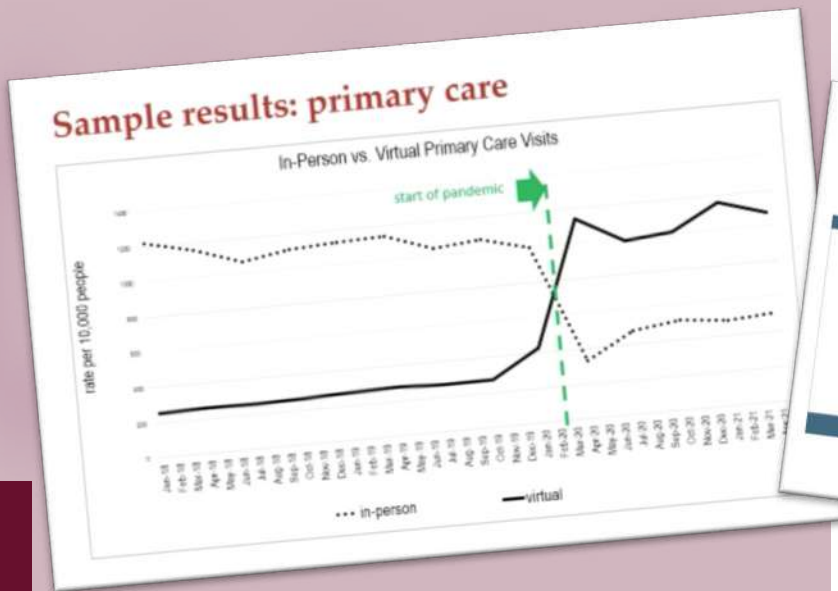
While the final report for this project is still in the works, Dr. Mulder shared a sample results graph which highlighted the exact moment that the pandemic began, explaining: *"This [graph] shows the rate of in-person visits to primary care … And many of you know, if you saw a primary care provider, which many of us do, that's the main way that people interact with the healthcare system. This is what happened with virtual visits. You started having phone calls, rather than in person visits … The point being is that this was a rapid and immediate change."* Notably, the total number of primary care visits remained relatively unchanged, suggesting that virtual care may be complementing, rather than replacing in-person visits, with potential implications for First Nations – raising several questions worth further exploration.

Some Questions Raised by the Data, so far …

- Is the change to more virtual care good?
- Were First Nations people getting primary care from providers that were not paid by the Ontario government (and therefore not included in the data for this study?).
- Were the people accessing primary care in-person before the pandemic started the same people getting virtual primary care after it started, or was the virtual care group made up of people who otherwise had not accessed primary care?
- Did First Nations have the same benefit from primary care virtual visits as others in Ontario?

SACHA BRAGG
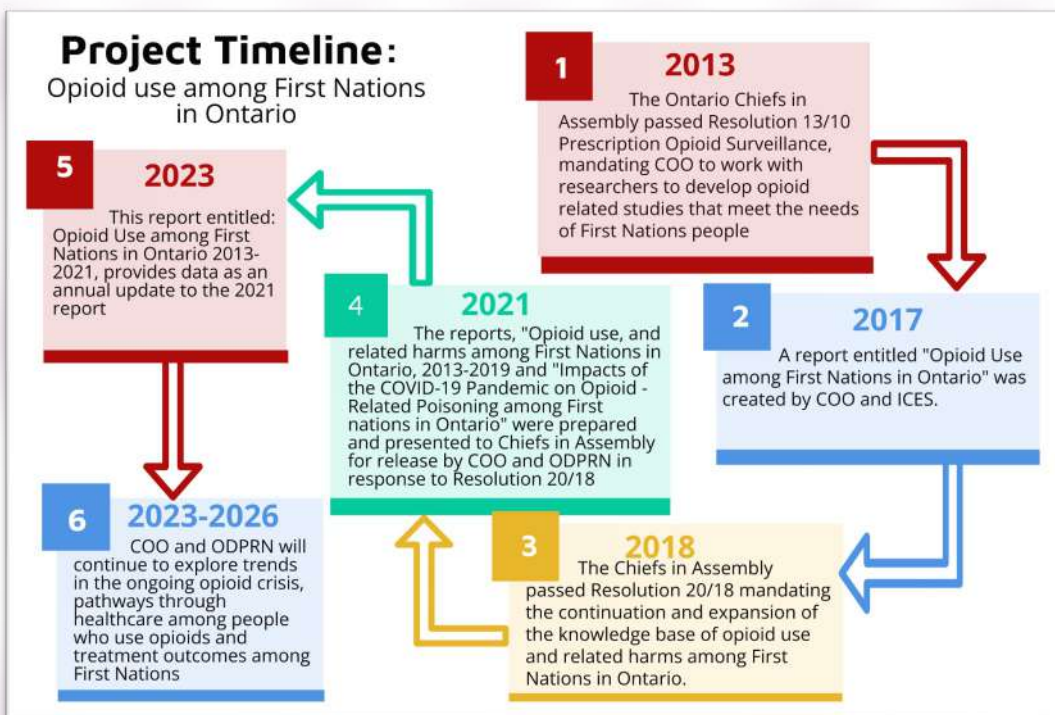**OPIOID RESEARCH COMMUNICATION AND PROJECT LIAISON, COO**

TARA GOMES
ONTARIO DRUG POLICY RESEARCH NETWORK

FIRST NATIONS COVID OPIOID-RELATED POISONING REPORT

Sasha Bragg and Tara Gomes shared information about ongoing work that continues to explore patterns of opioid use, access to treatment, and opioid-related harms among First Nations People. This work compares trends over time, and between those living within and outside of communities.

Project Timeline:
Opioid use among First Nations in Ontario

5 **2023**
This report entitled: Opioid Use among First Nations in Ontario 2013-2021, provides data as an annual update to the 2021 report

6 **2023-2026**
COO and ODPRN will continue to explore trends in the ongoing opioid crisis, pathways through healthcare among people who use opioids and treatment outcomes among First Nations

1 **2013**
The Ontario Chiefs in Assembly passed Resolution 13/10 Prescription Opioid Surveillance, mandating COO to work with researchers to develop opioid related studies that meet the needs of First Nations people

4 **2021**
The reports, "Opioid use, and related harms among First Nations in Ontario, 2013-2019 and "Impacts of the COVID-19 Pandemic on Opioid - Related Poisoning among First nations in Ontario" were prepared and presented to Chiefs in Assembly for release by COO and ODPRN in response to Resolution 20/18

2 **2017**
A report entitled "Opioid Use among First Nations in Ontario" was created by COO and ICES.

3 **2018**
The Chiefs in Assembly passed Resolution 20/18 mandating the continuation and expansion of the knowledge base of opioid use and related harms among First Nations in Ontario.

"Our first objective was funded as an interim priority project and was completed in 2021. We are currently working on the annual updated report. And we're also working on a report about treatment outcomes." – Sasha Bragg

See **APPENDIX B** for details about the 'Circle of Lived Experience Advisory Committee.'

OPIOID REPORT HIGHLIGHTS

In Ontario, opioid-related hospitalizations and emergency visits have been climbing among both First Nations and non-First Nations people, but at faster rates among First Nations individuals between 2009 and 2019. Suboxone has become the most common form of treatment for opioid use disorders among First Nations people in Ontario, while methadone remains more common among non-First Nations people.

Between 2013 and 2019

- Prescription opioid use for pain **decreased**
    - Higher among First Nations people compared to non-First Nations people in 2019.
- Opioid agonist therapy (OAT) use **increased**
    - Particularly, buprenorphine/naloxone (Suboxone®) rose considerably, becoming the most common type of OAT used among First Nations people living within First Nations communities in 2019.

Between 2009 and 2019

- Hospital visits for opioid-related poisoning have **increased.**
- Deaths due to opioid-related poisoning have rapidly **increased** among First Nations people
    - Higher among First Nations people compared to non-First Nations people in 2019.
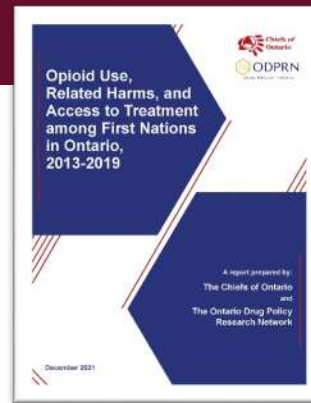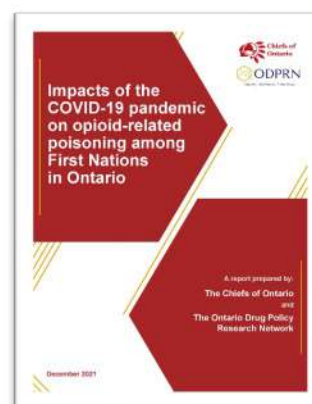
Objective

Examine trends and patterns in opioid prescribing and opioid-related poisoning among First Nations people.

2013-2019 report available here:

https://odprn.ca/research/publications/opioid-use-related-harms-and-access-to-treatment-among-first-nations-in-ontario/.

NEW 2013-2021 report available here:

https://odprn.ca/research/publications/opioid-first-nations-annual-update-2013-2021/.

Objective

Describe the impact of COVID-19 on hospital visits and deaths due to opioid-related poisoning among First Nations and non-First Nations people.

Full report available here: https://odprn.ca/wp-content/uploads/2021/11/First-Nations-COVID-Opioid-Related-Poisoning-Report.pdf.

DR. SHARMISTHA MISHRA
UNIVERSITY OF TORONTO

CAL STEWART
RESEARCH ASSISTANT, COO

The COVID-19 Scenario Model

Dr. Sharmistha Mishra and Cal Stewart discussed the First Nations COVID-19 Scenario Model that was developed by the Chiefs of Ontario in collaboration with academic partners, and its purpose to help communities reduce the spread of COVID-19 by inputting information about their community and current efforts.

MATHEMATICAL MODELING

Dr. Mishra described how mathematical modeling was used a lot throughout the COVID-19 pandemic:

"Thinking about abstracting from reality and from all of the complexity that exists, putting it into groups – grouping it into things like compartments, and then sort of walking through what might happen to individuals if they became infected with COVID-19" – Dr. Sharmistha Mishra

How to use the Model

Cal explained how to input community data into the model, including size, household composition, travel between communities, and proximity to public health units.

Section 1: Information about your Community
Section 2: Information about COVID-19 in your Community
Section 3: Efforts to Control Covid as of Today
Section 4: Future Actions your Community may take

How will the model benefit your community?

- It is an additional tool to help communities plan for the future.
- It is an opportunity to reduce the health burden of COVID-19.
- It is a way to encourage positive action.

For more details, contact Cal Stewart: cal.stewart@coo.org

FIRESIDE CHAT ON DATA SOVEREIGNTY

ERIN CORSTON,
Director & Executive
Lead, National Data
Champion Team,
FNIGC

GORDON PETERS,
former Grand Chief of
AIAI and former
Regional Chief of AFN
for Ontario

**DR. MAGGIE
WALTER**, PhD,
Distinguished
Professor of
Sociology, University
of Tasmania

**DR. JENNIFER
WALKER**, PhD,
Associate Professor,
McMaster University

PANELISTS WERE INVITED TO JOIN IN AN INFORMAL DISCUSSION WITH THE AUDIENCE

QUESTION TO ERIN: Looking across regions in Canada, what is a particular strength of the Ontario region and their track record and approach to Data Sovereignty?

RESPONSE FROM ERIN: To make a point about the availability of First Nations' information online and to take into consideration the implications of AI, Erin asked the question to ChatGPT (a natural language processing tool, driven by AI). Erin began, *"First this event is a great example of the work that the Chiefs of Ontario has been doing in the area of data and research and statistics broadly. I mean, they were able to bring this many people together in one room for three days!"* Erin also highlighted the Chiefs of Ontario's work in advocacy and policy development and the work of the COO Research and Data Management Sector in advancing the Ontario region's First Nations Data Governance Centre. The COO is building capacity in data and statistics within First Nations communities, collaborating with various stakeholders, and nurturing relationships with First Nations-led organizations to support and ensure that the Centre aligns with First Nations' priorities.

QUESTION TO GORDON: How do we link Data Sovereignty to our cultural strengths as diverse First Nations people in Ontario?

RESPONSE FROM GORDON: In response, Gordon emphasized the importance of documenting and preserving Indigenous culture, ceremony, and importantly, our languages, as they are constantly changing and at risk of being lost. He said, *"Getting back to our naming ceremonies is going to be really important for us."* Gordon also explained that there are opportunities to ensure that our stories remain ours, emphasizing the importance of controlling and deciphering one's own data to maintain cultural continuity and identity. He explained, *"we have a variety of stories in our world … there are so many stories that come off the Creation story that teach lessons in life. And we need to start back at our Creation stories. And we need to document that in our communities and hold on to that for ourselves."*

QUESTION TO DR. WALTER: Can you share a little bit more about what's happening in other countries, and what is the sort of global discourse on Data Sovereignty, and where do you see it heading in the future?

RESPONSE FROM DR. WALTER: Building upon Gordon's points, Dr. Walter discussed the value of naming ceremonies and recording family names to preserve cultural lineage. She highlighted the growth and influence of the Data Sovereignty movement as having been influenced by the First Nations' Principles of OCAP® and spoke from the perspective as a visitor from Australia, where there is a lack of Indigenous Governance structures. Dr. Walter also brought us back to Erin's talk where she used ChatGPT throughout the discussion. Dr. Walter noted, *"I have actually run ChatGPT on 'Data Sovereignty' and asked it what it is, what are its strengths, and what are its weaknesses – and what you get back, it's pretty good. And that's because we, as Indigenous Scholars all around the globe, have written all the literature that there is around Data Sovereignty, at the moment."* In explaining this, Dr. Walter highlighted the importance of Indigenous Peoples advancing Indigenous Peoples' agendas to ensure that stories written about us, including in AI generated texts, are born of Indigenous Peoples' values and priorities. In Australia, Dr. Walter is working on establishing an Indigenous Data Authority at the national level to provide a central space for Indigenous Data Governance and accountability. The proposed authority aims to provide infrastructure for storing community data, addressing concerns around Data Sovereignty and security, and promoting data-driven decision-making by and with Indigenous Peoples.

Dr. Walter also proposed the idea of planning an international Indigenous Data Sovereignty Conference to bring together Indigenous leaders and organizations from around the world to discuss and address Data Sovereignty issues as a "rolling conference" that travels around the world over a couple of weeks to ensure the highest level of engagement.

QUESTION TO DR. WALKER: What do you think is needed within academia, government, and mainstream systems for them to catch up to our understanding about Data Sovereignty?

RESPONSE FROM DR. WALKER: In consideration of the layered complexities, Jen began by noting, *"I think about academic partners like academia, its universities, our research funding structures and institutions, and there's been a long way traveled, I'd say, and there's still a long way to go."* Jen brought up the Tri-Council Policy Statement on Ethics (chapter 9) as having done a lot of work already, noting *"every research project that goes through a university has to have ethics approval and goes to a research ethics board. The Tri-Council Policy that they use to assess has a requirement that if an Indigenous data element can identify anything about an Indigenous community or an Indigenous person, it requires engagement, consultation, and collective consent. So that's in the ethics already. Now, we need people to understand that means you can say no to projects that don't do that. That means that our ethics boards and things like that, just have to catch up to understanding how to apply these things, because so much work has been done now."* Dr. Walker also noted, *"we've gone some way with advocacy, and now we have to make these things real and apply them in ways that are not creating more barriers. For example, I've worked with organizations to get their eligibility to hold research funding, then they get the research funding, and then it's paralysis – like the research can't be done – because the administrative burden is so heavy."*

Conference Registration Table: Courtney Cada, Emily Harding, Sally Hare

Image provided by COO

Following the Fireside Chat, panelists from throughout the day invited the audience to join them in separate breakout rooms. These are the highlights from those discussions.

ERIN CORSTON & ROSEANNE SUTHERLAND Ontario
Strength

Highlighting a need for authentic engagement, Dr. Corston noted, *"what sticks in my mind, is what the provinces are doing here in Ontario. We talked a lot about the initiatives that are in line with what we're trying to do by building a data centre in Ontario. Ontario is trying to do something similar, but of course they're going to own and control the data that belong to First Nations"* – Erin Corston

GORDON PETERS & MARIETTE SUTHERLAND
Cultural Strength

Mariette Sutherland shared some details about the discussion had during their Breakout Session. It included a conversation about the importance of our cultural Knowledges, explaining, *"we talked about traditional information like Knowledge of plant medicines, and the animals, and species that live in our areas. And we talked about keeping our information about that – because one of the communities was able to use that – to advocate against Greenbelt development, because they had that Knowledge"* – Mariette Sutherland

DR. MAGGIE WALTER & CARMEN R. JONES
Global Context & Future

Carmen Jones stood up to share, "We talked about First Nations' authority, and we know as we go along, there will be a lot of questions that are going to be asked, and we can't answer them all at once. It's like building blocks, as we go along. And one of the other things that resonated with me is that we do have sort of a process in Ontario about Data Governance, but at the same time, we don't have the infrastructure to do it. So now that we're going to be moving forward with the Data Governance Strategy, that will help a lot in our work that we're going to move forward on."
– Carmen R. Jones

DR. JENNIFER WALKER & DR. PAM JOHNSON
Mainstream Systems

Dr. Walker shared, "reiterating this idea that we can't start with trying to change little policies here and there without that foundation of understanding of sovereignty, otherwise it becomes really challenging to be doing anything else." – Dr. Jennifer Walker

Patrik Lowen, Dr. Aaron Franks, Zacharay Smith, Graham Mecredy, Dr. Carol Mulder (Left to right)

PANEL: TOOLS AND RESOURCES | Q & A

COSTS, LESSONS, AND PREPAREDNESS IN ONTARIO

The panelists discussed various tools and resources that are available to individuals, communities, and researchers. Panelists discussed the 25-year anniversary of the First Nations' Principles of OCAP®' and provided details on the updated OCAP® training program. Panelists also shared information about the process of accessing First Nations' community data through ICES, how Data Governance can be used to drive change and support communities, and how research can be turned into action.

"An Indigenous researcher undertaking quantitative research does not by any measure translate into Indigenous quantitative methodological practice."
- Walter and Anderson, Indigenous Statistics: A quantitative research methodology, 2013

COO Offers Condolences on the Passing of Dr. Carol Mulder

It is with great sadness that we share the news of Dr. Carol Mulder's sudden passing on December 28th, 2023. COO acknowledges her contributions and offers condolences to her family and friends during this difficult time.
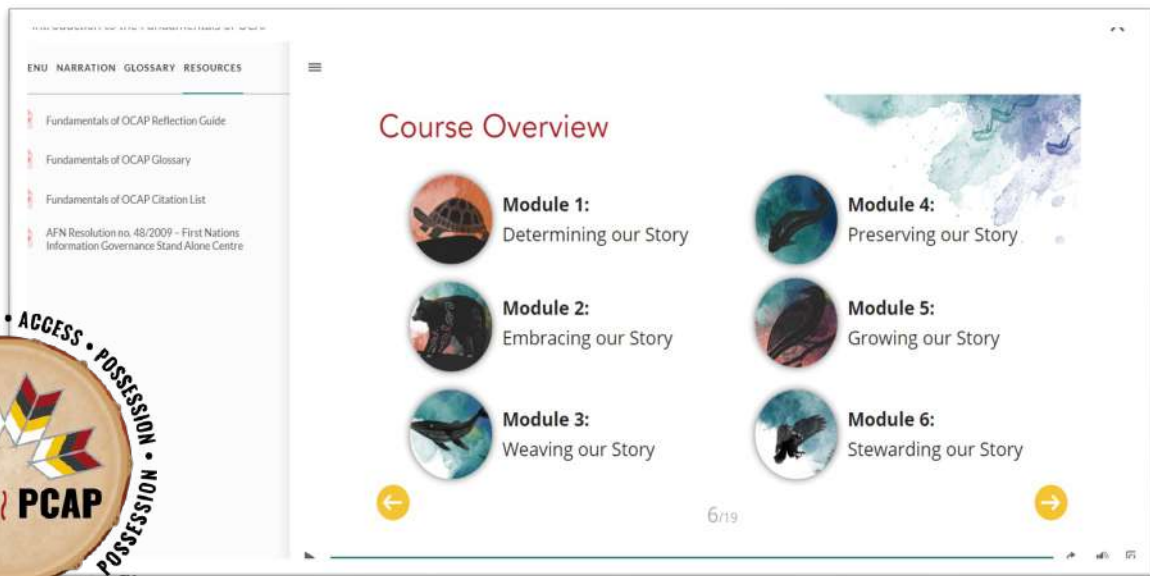
Dr. Aaron Franks

SENIOR RESEARCH MANAGER, FNIGC

FNIGC | CGIPN

OCAP® 25 and the New OCAP® Training
Contextualizing OCAP® Nationally

The First Nation's Principles of OCAP® Training Course has been revamped. Dr. Franks begins by sharing some of the details about the revamp. There are six modules that were developed and reviewed by a team of FNIGC staff and an Educational Advisory Committee. *The art in the new course was designed by two First Nations artists – Mariah Meawasige and Aaron Googoo; and is narrated by two First Nations people (Will Lafrance and Monica Ethier).*

OWNERSHIP • CONTROL • ACCESS • POSSESSION • PROPRIÉTÉ • CONTRÔLE • ACCÈS • POSSESSION

OCAP ¿ PCAP ™

Course Overview

Module 1: Determining our Story
Module 2: Embracing our Story
Module 3: Weaving our Story
Module 4: Preserving our Story
Module 5: Growing our Story
Module 6: Stewarding our Story

OCAP® TRAINING REGISTRATION DETAILS:

Webpage: https://learning.fnigc.ca

French language launch: Winter 2023

Cost: $500 CAD

Discount for First Nations organizations, First Nations students, non-profit organizations, and groups over 10.

Contact registrar@fnigc.ca for more information.

> The OCAP® Principles are the building blocks for actions (they aren't actions themselves).

> the OCAP® Principles represent commitments (they don't replace them).

"The strength of the course is that we focus on opportunities as well on ethics." – Dr. Aaron Franks

Zachary Smith

SENIOR LEAD RESEARCH NAVIGATION, COO

OCAP® 25 and the New OCAP® Training

Contextualizing OCAP® Regionally (Ontario) and through COO

OCAP® EDUCATION – CONTEXT

Communities increasingly require data for purposes related to community planning, monitoring the effectiveness of programs and services, and for advocacy.

Provincial and federal governments whose initiatives to extend the range, quality, and depth of First Nations' data remain ongoing and frequently outpace the ability of First Nations organizations to effectively respond.

Interest is also generated from the **Prominence given to First Nations' data and Data Sovereignty** in the documents such as: **The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and the Truth and Reconciliation Commission (TRC) .**

"Growing demand has raised new opportunities. It has kind of helped facilitate a closer relationship between the Chiefs of Ontario, and the First Nations Information Governance Centre; specifically, efforts to explore how regional organizations such as COO, can meet demand with greater participation in the delivery of workshops and presentations." – Zachary Smith

TOOL AND RESOURCE DEVELOPMENT

- Research to Action Framework and Checklist
- COO-ICES Factsheet (how to access community data)
- Research Agreement Guide and Template

Work at a Regional (Ontario) Level is *"guided by some very large and open-ended questions"*

- Who is the priority audience for the OCAP® message?

- What tools and resources do communities and technicians need to understand, assert and/or implement OCAP® principles?

- How can COO support your community's research and data management needs and future aspirations?

- How, and by whom, would you like to see OCAP® education delivered in Ontario?

Graham Mecredy

STAFF SCIENTIST INDIGENOUS PORTFOLIO, ICES

IC/ES

Processes for Accessing Community Data at ICES

ABOUT ICES' RELATIONSHIP WITH FIRST NATIONS' DATA

ICES is a not-for-profit research institute made up of a community of research, data and clinical experts that use data to answer important questions. ICES and the Chiefs of Ontario (COO) entered into a Data Governance Agreement (DGA) in April 2012. The DGA facilitates research, while overseeing use of First Nations' data at ICES in a manner that protects the interests of First Nations communities. ICES acts as a **data steward** for First Nations' data. First Nations approval is required from First Nations' Peoples or communities (via Chiefs of Ontario and the First Nations Data Governance Agreement). The DGA is there to protect the data and minimize potential harm.

ICES Core Data Repository: De-sensitized and Linkable

* Special Governance

People and Geography	Health Service Visits	Health Service Provider/Facilities	Disease Registries	Intersectoral Data
✓ People in Ontario eligible for healthcare since 1985	✓ Physician claims	✓ Physicians	✓ Diabetes	✓ Environmental
✓ Demographics	✓ ~In patient hospital discharge abstracts	✓ Hospitals	✓ Hypertension	✓ Transportation
✓ Deaths	✓ ~Emergency & ambulatory care	✓ Home care	✓ COPD	✓ Social Assistance
✓ Census	✓ Prescription drug claims (≥ age 65)	✓ Complex care	✓ Asthma	✓ Education (EDI)
✓ Immigration & Refugee*	✓ Home care claims	✓ Long-term care homes	✓ IBD	✓ Disability Support
✓ First Nation*	✓ Rehab Claims		✓ Cancer	
✓ Métis*	✓ Long-term care claims		✓ Stroke	
			✓ Cardiac	
			✓ POGO	
			✓ BORN	
			✓ HIV	

Connecting these databases allows us to learn about the health of registered First Nations people

Contact info: indigenous@ices.on.ca

"So, this is directed at people who are doing research with First Nations to help them comply with these ideas, and therefore do better research." –
Dr. Carol Mulder

"In terms of aligning with values, in order for the research to lead to action, you have to be intent about action from the get-go. And so, we need to focus on that, not just the Knowledge and recognize that the Knowledge coming out of the research is First Nations' Knowledge."
– Dr. Carol Mulder

Turning research into action: Knowledge to Action (K2A) Framework

BACKGROUND

First Nations' research is intended to solve problems the community is facing. There has long been a gap between research Knowledge, and how and when it is used. Many have tried to address this gap.

GOAL OF THE FIRST NATIONS' K2A FRAMEWORK

Increase the chance that First Nations' research will lead to action. The framework does not focus on how to take action. That is up to your community. K2A provides guidance for researchers who are looking to work with a community (includes First Nations' researchers or community groups), and guidance for communities considering working with a researcher.

ACKNOWLEDGING SOVEREIGNTY, RESPECTING HISTORY, AND HONOURING CULTURE

First Nations' individuals and communities hold the rights to their own data. First Nations' organizations do not hold rights over First Nations' data. First Nations' communities do not hold the rights over the data of OTHER First Nations communities. The appropriate community partner depends on the scope of your project. **You need to have a relationship before you start any data collection, access, or analysis, even if you already have received your funding.**

"When Indigenous Peoples become the researchers and not merely the researched, the activity of research is transformed. Questions are framed differently, priorities are ranked differently, problems are defined differently, and people participate on different terms."
- Smith, Linda Tuhiwai. Decolonizing Methodologies: Research and Indigenous Peoples, 2021

For more information, see Mulder et al. (2022) https://doi.org/10.12927/hcq.2022.26767

Patrik Lowen

EDUCATION PROGRAM LEAD, CHIEFS OF ONTARIO

DATA TO DRIVE CHANGE

FIRST NATION Lifelong Learning Table

First Nations in Ontario — Ministry of Education — Planning Circle — Collaboration Circle

PRIORITY AREAS AS SUPPORTED BY THE CHIEFS IN ASSEMBLY

- Curriculum
- Relationships
- Community and Student well-being
- Languages and Culture
- Information, Access, and Accountability
- Policy Development

VISION

Increased success and well-being for First Nation learners in both the provincially and federally funded education systems through a balanced, respectful, and collaborative relationship whereby collaborative work is planned, designed, implemented, and regularly evaluated.

"It's also important to know that the First Nation Lifelong Learning Table is not a decision-making table – It's an advisory table … but the Data Sharing Agreement also allows us to basically hold the province accountable." – Patrik Lowen

KEYNOTE MEET & GREET

GUESTS OF HONOUR: Gordon Peters, Dr. Maggie Walter, and Dr. Jennifer D. Walker

Featured Musician: Herbie Barnes (image at bottom right)

CONFERENCE DAY THREE

THURSDAY, OCTOBER 26th, 2023

The final day of the conference began with a drum and song about the important roles of women in First Nations' communities. The day began with a keynote discussion on data literacy. The keynote address highlighted the importance of creativity, context, and culture in data. Day three included opportunities for attendee engagement with roundtable discussions on data literacy and governance.

KEYNOTE ADDRESS

DR. JENNIFER D. WALKER
Six Nations of the Grand River
ASSISTANT PROFESSOR, MCMASTER UNIVERSITY

Sara Curley Smith,
EPIDEMIOLOGIST, SIX NATIONS HEALTH SERVICES

DATA LITERACY

Dr. Jennifer Walker and Sara Smith engaged the audience holistically, emotionally, intellectually, and spiritually through storytelling and the use of data visualizations.

*"**Data literacy**, by definition, is not so much about just the data. It's about the ability to draw meaningful information from that data. It's the ability to understand and communicate data within a proper context. So, if you think about data literacy in that context, every one of us probably has work to do in building our data literacy. So, I have a PhD in epidemiology – But am I data literate? Can I communicate the results of a model that I've run in a way that has impact? In a way that tells a story? In a way that can promote decision making, partly based on data? … We make decisions in really, complex ways. So, how do we as data scientists support that decision making, and how do decision makers work with data and integrate that into decision making?"* – Dr. Jennifer D. Walker

"It's First Nations using First Nations' data for governance, where data literacy really comes in, where we really need to build our capacity to do that."
– Dr. Jennifer D. Walker

Making the Data "Sing"

Using data to tell a compelling story – to engage, explain and have impact

- Entering quality, meaningful data;
- Preparing and analyzing the data – asking the right questions;
- Interpreting within our realities and contexts;
- Building meaningful data visualizations to support a story; and
- Building a narrative to help in decision-making.

"It's not about just summarizing data; it's about bringing life to data. It's about bringing meaning that actually touches people's hearts, and that actually moves people to change." – Jennifer D. Walker

Building Data Literacy Skills:

The importance of Creativity, Context, and Culture

"Community would ask, 'what are you going to do with this information?' … And instead of doing a graph, which is commonly what we do after events … We wanted to explore a different way of visualizing the data. So, we came up with this idea of a keychain. Every bead on that keychain represents a person that visited us that day." – Sarah Curly Smith

Spotlight on Research at Six Nations

Data Visualization Activity: Generations Linked Key Chain

On May 24th, Whitepines had a Community Awareness Open House. Community Research Coordinator Analyst and Epidemiologist had a booth to show the research process from starting a research question to providing results to community (called Knowledge Translation)

To showcase a Knowledge Translation activity we had everyone who attended our booth put a popsicle stick in jars representing their specific age category. The age categories were 0-19, 20-29, 30-39,

Rather than create a graph of the age groups that attended we tried a different approach to relay the data. We made a beaded keychain to show the ages of people at our booth. The white background is the story of different age groups connecting at our booth and shows how generations help one another while also signifying the unknown of others who did not attend our booth. Every colour bead is a person who visited us.

6 people were aged 20-29 which were positioned near 30-39 (orange beads) and 40-49 (yellow beads). There were 10 people attend aged 40-49 represented by yellow beads. The yellow beads create a path between younger generations to the oldest generation. Passing on experience both ways.

The bright sun above the young people shows their energy. While the older generations watch over the young ones. For example, kids aged 0-7 were often with adults aged 30-39 (represented by orange beads).

The two figures are for young people aged 0-19. There were 45 people aged 0-19 attend our booth. The coloured beads surrounding these figures are surrounded by the older generations representing the role each plays in imparting guidance to youth.

Age 50+ we saw 77 come through our booth. They are represented by black arrows which provide guidance and direction to the younger demographic.
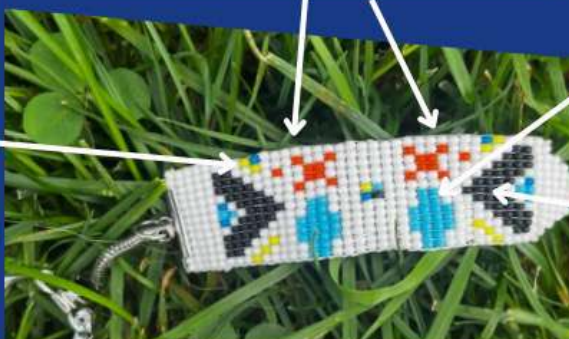
TABLETOP DISCUSSION: DATA LITERACY & GOVERNANCE QUESTIONS

EACH TABLE WAS PROVIDED WITH 3 KEY QUESTIONS TO ADDRESS WITH THEIR TABLE MATES.

1. What does Data Sovereignty mean to you in plain language and how does it help First Nations?

2. How do you envision First Nations' Data Sovereignty moving forward? What is needed to help with that? What do you see driving this forward?

3. What kind of data would you want to help address your community's needs and advance development?

4. How do you presently go about finding and accessing First Nations' data? What has worked so far for you? What makes it work well?

5. How do you see data being looked after? How do we protect it but also ensure it is always available in communities? What kind of expertise is needed to guide this?

6. How does cultural Knowledge fit in this picture? What types of information or data is needed or appropriate to include?

7. Having participated in the past 2-3 days of our conference, what is still a question mark for you? What do you need further information about? What topics would help in future conferences?

Images are pieces of Dakota Brant's Visual Conference Recording

TABLETOP DISCUSSION:

DATA LITERACY & GOVERNANCE HIGHLIGHTS

During the Tabletop Discussion, attendees were put into groups and asked to share their thoughts on some of the questions that were shared with the room. Discussions often overlapped and did not always directly respond to a single question. Attendees shared several needs and priorities to improve data literacy and governance for First Nations in Ontario.

- Advocate for access to community data to better understand needs and address gaps in existing information.
- Develop and strengthen community wellness plans to prioritize tailored services, data collection, and address access barriers.
- Improve supports for children accessing resources and education.
- Greater discussion is needed around the environmental impacts of data and technology.
- Speakers emphasized the importance of collecting data on social determinants of health, including education and geographic location, to better understand how these aspects intersect with health outcomes.
- Significance of community-led data collection and analysis.
- Need for capacity building, including in data science and management to build functional data ecosystems and ensure that data is protected and accessible to those who need it.
- Increased cultural safety training.
- Greater discussion needed to mitigate the perpetuation of racism in AI and its current and future uses.
- All discussions must be inclusive and ensure authentic involvement from diverse communities – in Ontario, this includes ensuring that Northern communities are actively included.
- The need for data protections for First Nations communities, and the significance of community-driven policy development and Data Governance development.
- Highlighted the importance of understanding cultural and traditional Knowledges as distinct but interconnected concepts.
- Researchers must be mindful of the communities that they work with and respect their values and practices and be prepared to give something in return for information shared.

- Connections with diverse First Nations (possibly through sub-conferences) to ensure that regional variations in cultural Knowledges are taken into Data Sovereignty and Data Governance initiatives, including into the Creation of the First Nations' Data Governance Centre.

- Address the challenges of protecting First Nations' data, including government-owned data and data collected by private companies. Work on repatriation/rematriation of data.

- Emphasized the need for trust and understanding between different First Nations as crucial for addressing the existing data landscape challenges.

- A need for equal understanding of data and control of data across Nations.

- Find ways to discuss the challenges of sharing data between communities due to fear of misinterpretation and potential harm.

- The significance and importance of trust and control in data and research management.

- A need for decolonization of data.

- Find ways to bridge the gap between Knowledge Keepers and academic institutions by bringing First Nations' students into culturally based camps and vice versa for learning and sharing opportunities.

- Emphasized the importance of food and housing security and their impact on health.

- Incorporate traditional healing practices into Data Sovereignty discussions.

- Ensure emergency preparedness is included in data management and control plans.

Piece of Dakota Brant's Visual Conference Recording

Diane Jacko, Sydney Chabot-Hamden, & Carol Hopkins (Left to right)

PANEL: COMMUNITY-BASED CULTURAL APPROACHES

The panelists shared how community-based cultural approaches are utilized in research. Panelists highlighted community-led research and, when done well, how it can support the advancement of First Nations' priorities. For example, the Aanish Naa Gegii: The Children's Health and Wellbeing Measure (ACHWM) Is a self-reported tablet-based children's wellness assessment tool that was developed in part by First Nations' children. As part of the assessment, a process for real-time interventions for children who require supports, are built into the tool.

Diane Jacko, *Wiikwemkoong Unceded Territory*
Health Services Director, Naandwechige-Gamig Wikwemikong Health Centre
Aanish Naa Gegii: The Children's Health and Wellbeing Measure (ACHWM)

What is the ACHWM?

"It's a self-reported tablet-based wellness assessment too … lit is more inviting for children and Youth to complete the measure using the tablet as opposed to filling in a paper, so it was a little bit more interesting and enticing for them. The tablet can read the questions to them, or they can read it themselves. They can also plug it into headphones and if they want to do it a little bit more private, and then they answer the questions on the tablet. So, it's made for children and Youth ages 8 to 18 years old, and it generates information for the art community and for whatever community requests to use it. The information is locally controlled, and we have numerous usages for the data that we get from the measure. It's rooted in our Medicine Wheel Teachings, and again, this came from the children, so it looks at our physical, mental, emotional, and spiritual quadrants." – Diane Jacko

Origin of the ACHWM?

Developed via a partnership between Indigenous health leaders (Mary Jo Wabano) and academic researchers (Dr. Nancy L. Young) to incorporate traditional wisdom and ensure scientific credibility. The Intent was to ensure the relevance for Indigenous children across Canada.

LOCAL HEALTH WORKERS ARE ESSENTIAL

Choose someone with the skills and preparedness to support children and Youth at all levels of need and be:

- Prepared to have brief conversations with the children/Youth;
- Trusted within the community;
- Knowledgeable of community resources;
- Able to connect to natural helpers; and have
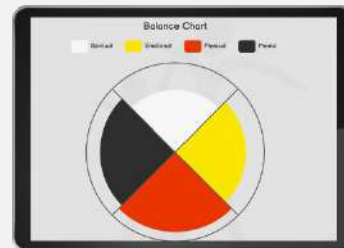- Crisis support skills.

Examples: Elder, counsellor, social worker, nurse.

KNOWLEDGE TO ACTION

A balance chart provides children/Youth a real-time visualization of their strengths and opportunities by highlighting four areas of health:

- Spiritual,
- Emotional,
- Physical, and
- Mental (intellectual)

Reflecting on how data has supported our community

- Informed health planning;
- Informing community planning; and
- Proved the effectiveness of local mental health services.

Analytic Spreadsheet

Database

Aggregated Reports

Sydney Chabot-Hamden
Anishinaabekwe, Kitigan Zibi First Nation
COMMUNITY OUTREACH & COMMUNICATIONS COORDINATOR, ACHWM, NAANDWECHIGE-GAMIG WIKWEMIKONG HEALTH CENTRE

For more information: ACHWM@cheo.on.ca

Carol Hopkins, *Lenape Nation at Moraviantown*

CHIEF EXECUTIVE OFFICER, THUNDERBIRD PARTNERSHIP FOUNDATION

Hope, Belonging, Meaning, and Purpose and the Native Wellness Assessment (NWA™)

"A DANCE ACROSS WORLDVIEWS … A DANCE OF CONVERSATION … A RESPECTFUL DANCE … OF HOW WORLDVIEW AND VALUES DIFFER."

LOCAL HEALTH WORKERS ARE ESSENTIAL

"What a great surprise, all across the country, all across the differences in language groups, the differences in culture, everybody said 'wellness is balance of mind, body, spirit, and emotions.' If you want to understand wellness, you have to look at all those quadrants. And so, it has to reflect our values and our principles. And so, setting that foundation of how you're going to approach – even where you want to go? What kind of data you want to collect? Who's going to be involved? It's really important to set that foundation. What data are we talking about and to serve who? What Knowledge-base are we going to pull from? These important conversations before you jump in the boat of doing research and collecting data." –
Carol Hopkins

https://thunderbirdpf.org/native-wellness-assessment/

https://thunderbirdpf.org/

We can connect with culture to find balance in many ways:

- Spiritually through prayer or ceremonies, such as fasting or sweat lodge ceremonies
- Emotionally by finding your Clan or going to a community event
- Mentally by learning the Creation Story or going to a talking circle
- Physically by touching the earth, spending time on the land

The NWA™ provides culturally-based information to guide treatment services which can include:

- spending time on the land;
- learning from traditional teachers and healers and joining in storytelling and dancing; and
- As more program services use the NWA™, an evidence base is being built that shows the vital role of Indigenous culture in treatment plans for substance use and wellness promotion.

Jason Jacques, Nancy Johnson, Dr. Ryan Bowie, & Arvind K. Sharma (Left to Right)

PANEL: CHIEFS OF ONTARIO'S RESEARCH INITIATIVES

During this panel, the presenters provided the audience with information about present and future research initiatives happening through sectors within the Chiefs of Ontario. These include a risk and danger assessment tool, a look at First Nations' data as it relates to the Great Lakes Water Quality Agreement, and a project on economic development.

Nancy Johnson

DIRECTOR OF WOMEN'S INITIATIVES SECTOR, COO

Nancy Johnson's presentation highlighted National Inquiry into Missing and Murdered Indigenous Women and Girls (MMIWG) and the need for more supports for victim services and community-based strategies. The Women's Initiatives Sector works to address issues of structural violence and victim services based on community input and the MMIWG. The presenter also highlighted the need for affordable housing and economic development in First Nations communities, particularly for women and girls.

For more information:
https://chiefs-of-ontario.org/priorities/womens-initiatives/

Risk Assessment and Danger Assessment Tools Project

PURPOSE OF PRESENTATION:

- To outline work being done through the Chiefs of Ontario Women's Initiatives sector to support Ontario First Nations in ending gender-based violence
- To highlight a Women's Initiatives research project on victim services that support assessment of risk and danger and safety planning

COO WOMEN'S INITIATIVES

- Women's Initiatives Sector of COO (established in 2021) provides support and coordination to FNWC and promotes the safety, well-being and empowerment of Ontario First Nations women, girls and Two Spirit/gender diverse people.
- COO Women's Initiatives supported FNWC in coordinating Ontario First Nations input into MMIWG National Action Plan.
- Women's Initiatives and FNWC convened a third MMIWG Family Gathering in 2022 and utilized input from First Nations families and front-line workers to develop an Ontario First Nations Gender-Based Violence Action Plan and work on initial priorities.

ARTIST: *Charlene Hemlock, Cayuga, Wolf Clan, Six Nations of the Grand River.*

Dr. Ryan Bowie
PROGRAM MANAGER, ENVIRONMENT SECTOR, COO

GREAT LAKES WATER QUALITY AGREEMENT

Dr. Bowie provided information about the Great Lakes Water Quality Agreement that was signed between Canada and the US in 1972, with the latest revision in 2012. What is needed is improved First Nations' input into decision making, expanding the role of traditional Knowledge, and to address the fish consumption advisories that were problematic, to effectively fulfill reconciliation commitments. Dr. Bowie explained that the environment has major data and research needs to make informed decisions and to take action for both short and long-term goals.

"Breaking from this competitive project-based funding cycle where we have First Nations competing against First Nations for a very limited pot of money – and within those discussions, data and research I think are going to be key elements that will need to be brought up about how our data is used within that program." – Dr. Ryan Bowie

ECONOMIC RESEARCH

Arvind Sharma introduced a Supply Chain and Procurement Project for First Nations businesses in Ontario that is being developed for the future. The project aims to support First Nations' business by enhancing their visibility in both public and private sectors. As Mr. Sharma explained:

"Thereby facilitating more opportunities for procurement of goods and services for these businesses. This will be achieved through the development of a comprehensive inventory of First Nation businesses and will culminate in Creation of a publicly accessible online portal … The need for the project is to understand the complex web of supply chain in goods and services for First Nations, to realize supply chain gaps that were created due to the pandemic … and to locate experts and expertise in different fields and industries among First Nation businesses."

– Arvind Sharma

Arvind K. Sharma
DIRECTOR OF ECONOMIC DEVELOPMENT, COO

Jason Jacques
SR. FELLOW, INSTITUTE FOR FISCAL STUDIES
UNIVERSITY OF OTTAWA
Economic Research

Jason Jacques highlighted the lack of economic development accommodations available for First Nations and the historical discrimination in government policies that have perpetuated poverty among First Nations, including limited access to quotas, capital, and loans for businesses, making it difficult for communities to create economic development without breaking Canadian laws. The Chiefs Committee on Economic Development aims to prioritize and address these policies and limitations.

*"I would say **data is sovereignty** and it actually puts more power and control in the hands of the people in this room and communities across the country … So, at a provincial level, tens of billions a year, similar amount at the federal level, the big game changer about 36 months ago was the fact that the federal government actually put a floor. So, they said, at least 5% of their overall procurement spending every single year needs to go to – not First Nations specifically – but Indigenous firms across the country … Needless to say, it ends up being a great opportunity on the economic development side."* – Jason Jacques

For more information, visit: https://www.ifsd.ca/en/

CLOSING REMARKS, COMMENTS, PRAYER, AND DRUM SONG

"Today it's been a very big leap for us with this conference, and I want to thank you all for being part of the story and for being there to support the communities and the work that they have to do in the area of Data Sovereignty."
– Carmen R. Jones

"As we continue to go along, I'm just remembering that you dream big, and you go there. And that really, we're creating new wampum belts ... And we started on the road that I think will see us there … it's really about great-grandchildren, and those seven generations, what are we giving to them, and I hope we are giving them new wampum belts … that will be what I see as success, for me."
– Elder Vera Pawis Tabobondung
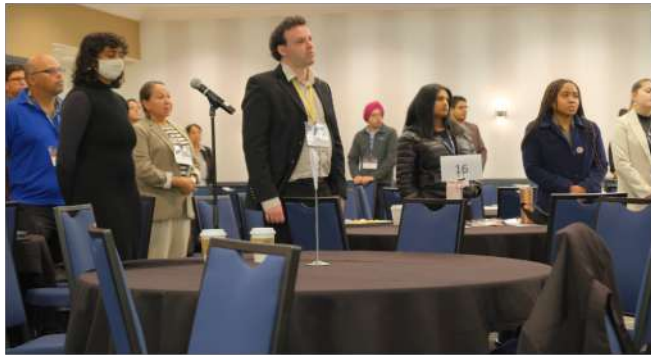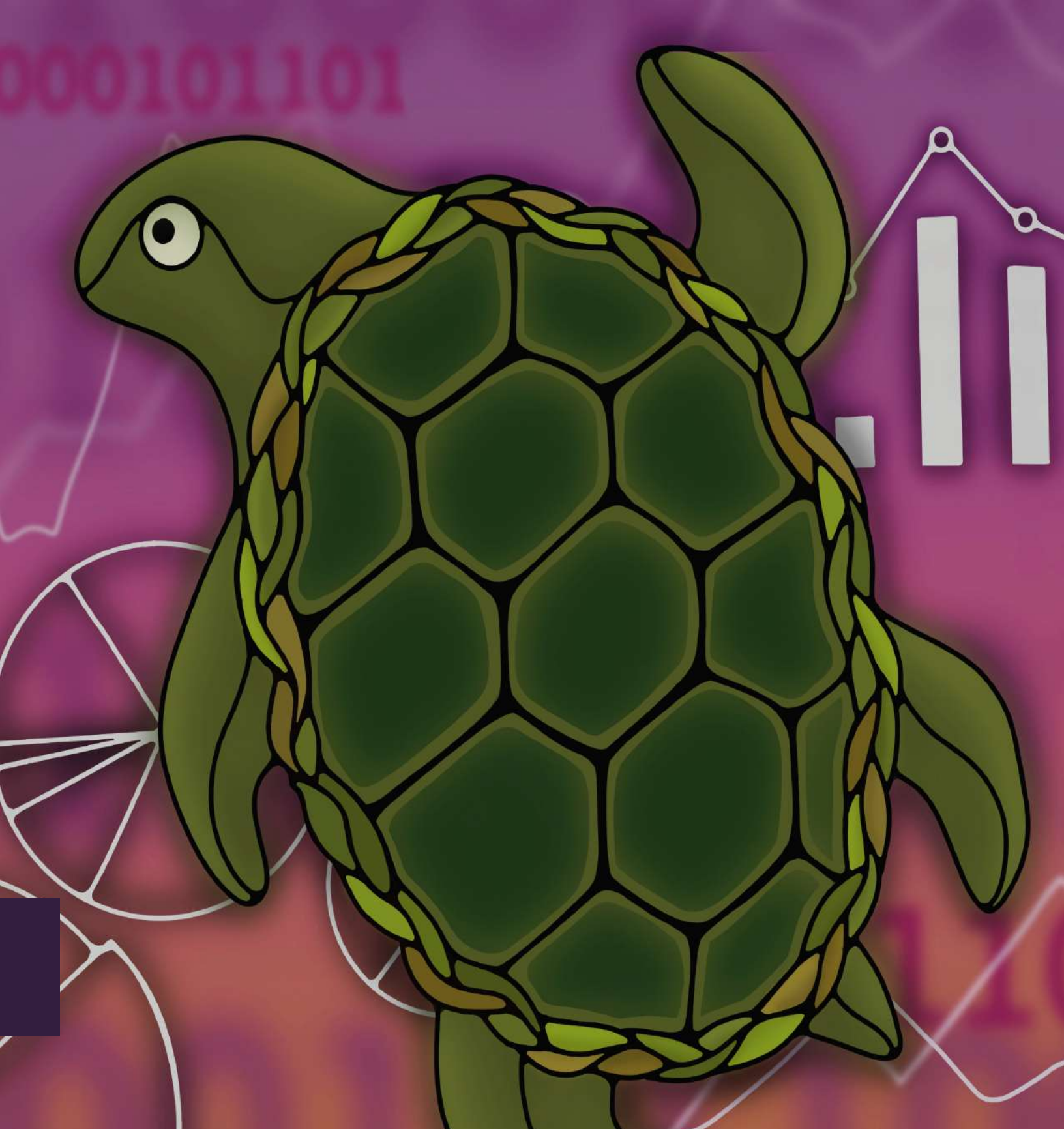
WEAVING IT ALL TOGETHER

PRIORITY AREA	OPPORTUNITIES
RELATIONAL	• Build and strengthen relationships with one another (across Nations, governments, and institutions. • Require authentic engagement and sustainable relationship building (particularly with government). • Ground relationships in inclusivity and collectivity. • Connect with one-another (First Nations) more often • Have welcome home ceremonies • Unite in our shared directions and uplift one another • Create safe spaces for all, embedded with culture and ceremony. • Elders and Youth must be a part of every discussion to share and transmit information from one generation to the next. • Expand relationships and connections • Build on national and international connections to support the advancement of Indigenous Data Sovereignty, more broadly.
CEREMONY AND CULTURE	• Rooted in our diverse identities, cultures, languages, traditions, and teachings. • Connect with our traditional roots through naming ceremonies. • Reclaim identity and share our Creation Stories. • The importance of storytelling, dreaming, and learning from one another. • Bring people together who have a strong cultural basis to create the change we want. • Embrace culture, context, and creativity through ceremony to tell our own stories. • Land, air, waters, and all of Creation must be cental to every decision. • Create our own plans to identify priorities that account for all our relations.
LANGUAGE	• Weave language throughout all aspects of Data Governance and Sovereignty

PRIORITY AREA	OPPORTUNITIES
DATA LITERACY	• Foster collaboration and relationships to strengthen data literacy leading to more field experts. • Aim for equity in data literacy across Nations. • Understanding and integrating the language of data in our everyday work. • Data scientists – need to understand data within context and be able to tell compelling and understandable stories. • Program / policy analysts – need to build in, understand, and rely on data cycles for evaluation and planning. • Leadership – need skills to critically assess data and become comfortable with the language of data. • To improve services, providers, educators, data collectors and users need to understand the importance of data quality and see the value in data cycles. • Being data literate also means knowing what good, quality, meaningful data is to inform compelling stories and decisions, rather than relying solely on deficit data. • Expand data capabilities at the community level.
TRUST AND TRANSPARENCY	• There are things we do not yet have the answers for, be open and honest about our own limitations and gaps in Knowledge. • Build trust across, and within First Nations. • *"Get people back to that same place again, where we have trust in our world. Hold each other accountable and use ceremony."* – Gordon Peters • Colonial government needs to follow through to help build trust.
INNOVATION AND CREATIVITY	• Shift the narrative away from deficit-based thinking and highlighting our strengths. • Dreams as part of our identity – and part of what needs to be protected. • Develop innovative ways of shaping policy and practice

PRIORITY AREA	OPPORTUNITIES
KNOWLEDGE TRANSLATION AND EXCHANGE	• Elder and Youth inclusion as part of Knowledge sharing, development, and exchange. • Find innovative ways to keep community people informed – improve communication. • Develop mechanisms for ensuring that communities know what regional organizations (i.e. COO), tribal councils, and others are doing.
EDUCATION AND TRAINING	• Hands-on, culturally safe, and relevant learning to keep people meaningfully informed. • Learning from and with Elders and Youth. • Grow and strengthen human resources capacity and data literacy. • Ensure communities are well versed in First Nations' principles of OCAP® and other Data Governance. • Increase human resources capacity.
ADVOCACY	• Protect our people, lands, and resources. • Advocate for systems change to meet First Nations' data priorities. • Work together to ensure that advocacy efforts create meaningful change. • Advocate for funding to develop community-led initiatives aimed at improving the current deficit data, i.e. infrastructure, water, housing, etc. • Non-First Nations can use their voices and platforms to support First Nation-defined priorities and to make space for First Nations to raise their own voice. • *"You have a right to protect your Nation, your people, your lands and resources. That's an international standard, the right to defend."* – Gordon Peters
FORWARD THINKING	• Consider the implications of all decisions, for generations. • Ensure that decisions account for the futures of technology and Artificial Intelligence. • Consider data priorities and changes amidst a crisis (i.e. a public health crisis).

| PRIORITY AREA	OPPORTUNITIES
GOVERNANCE	• Develop strong and informed Agreements to protect the interests of First Nations' communities. • Develop governance mechanisms that align with First Nations' Data Sovereignty priorities. • Develop governance mechanisms that ensures appropriate contextualization of research data and clear, relational, community-driven representation of First Nations. • Determine clan structures and governing bodies in charge of collectives. • Develop a process for collective decision making that may fall outside colonially-imposed structures. • Revitalize traditional leadership and traditional governance structures to strengthen and support community decision making and priority setting. • Strengthen the ways that we uplift our leadership.
GET INFORMED	• Communities and anyone doing research with First Nations must know the context of colonial history, past and present. • Understand colonial inequities and use data as a tool to address them. • Understand the data landscape (know what exists and where). • Be informed about your rights, including the right to consent. • Be open to discussion with other Nations to stay informed. • Learn what other First Nations and First Nations' organizations are doing. • Mobilize First Nations' ways and innovate new ways of sharing information. • Embed Truth, transparency, and Honesty in all processes to ensure informed decision making. • Take the time to be meaningfully informed and make sustainable decisions. • Do our own costing exercises. • Levy the tools and resources that already exist to strengthen the position.
SAFEGUARDS	• Protect our information, data, ceremonies, and stories from AI and tech advancements.

THE PATH OF THE TURTLE: PLACING PRIORITIES

Keeping in mind the wisdom of our Elders, and the future for our Youth, we continue to create the path forward in building our Nations as strong, healthy Peoples, respectful of ourselves, each other, and all of Creation.

– Chiefs of Ontario
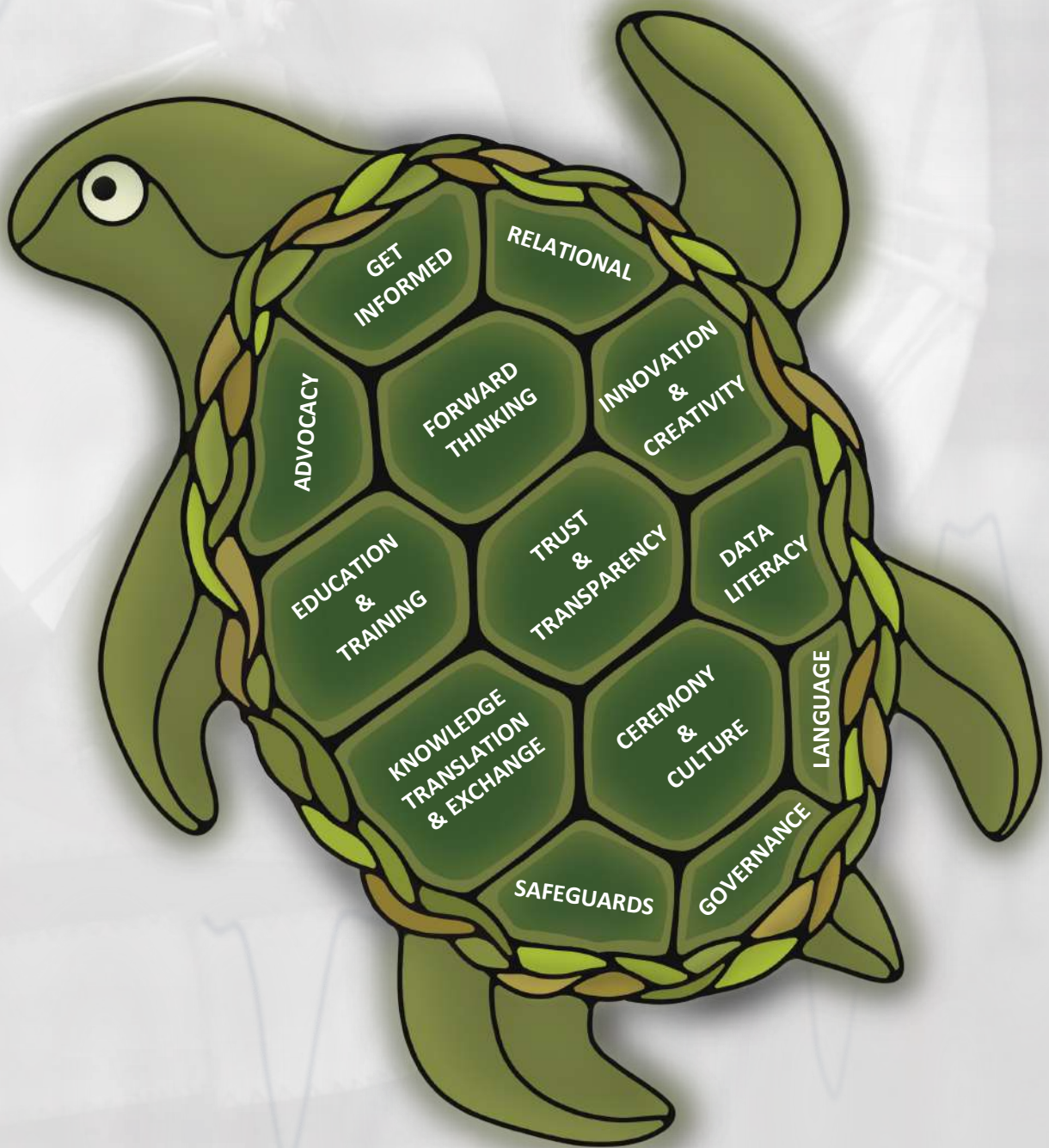
THANK YOU TO EVERYONE WHO SUPPORTED THE EVENT!

The Chiefs of Ontario Conference Committee

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Conference Support Provided by TAP Resources

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Thank you to additional support people!

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Nancy Sylvain and Sharon Snooks

Chiefs of Ontario Research and Data Management Team

Image provided by COO

THANK YOU TO ALL OF THE VENDORS WHO JOINED US DURING THE EVENT!

CIRCLE OF LIVED EXPERIENCE ADVISORY COMMITTEE

Do you or someone you know struggle with opioid use?

If so, Chiefs of Ontario is looking for First Nation people with lived experience of opioid use to become members of an advisory committee about research on Opioid Use and Harms among First Nations people in Ontario.

Your Participation will help to:
- Identify programs or policies that may be helpful for people who use opioids.
- Provide understanding how research can be used to remove barriers and provide better planning for programs and services
- Ensure that the voices of First Nation people with lived experience is incorporated into the research.

Committee Members will have the opportunity to:
- Participate in trainings that will be provided based on what the committee thinks would be most beneficial to them.
- Be involved in future research projects.
- Be part of a group that is interested in helping others who struggle with opioid use.
- Add skills to your resume

Meetings will be held virtually every three months and participants will be compensated for their time.

If you would like more information or are interested in becoming a committe member, please contact us circle@coo.org

For more information about this event, to browse presentations, watch a recording of the event, or to keep up-to-date on upcoming Chiefs of Ontario events, please visit: https://www.chiefsmeeting.com/

RHS Phase 4 | Q & A

Q: What is the Regional Health Survey (RHS)?

A: For more than 25 years FNIGC has been collecting data with First Nations communities using an approach that's built on an inherent respect for Data Sovereignty, as embodied by the First Nations principles of OCAP®. The RHS is the first, and only, national First Nations health survey, which collects wide-ranging information about First Nations living on reserve in northern communities and is based on western and Traditional understandings of health and well-being (FNIGC, 2023).

Q: Why should I participate in this survey?

A: Your participation in the survey is voluntary. However, your important contribution will directly support First Nations in Ontario and across Canada in gathering relevant information to support decision making that strengthen and develop health and wellness programs and policies.

The First Nations Regional Health Survey (RHS) is the first—and only—national health survey created, conducted, and carried out by First Nations people for First Nations people.

Now in it's fourth phase, results from the RHS have been used to support policy and programming at the community, regional, and national level.

Rooted in Traditional and western understandings of health and well-being, the RHS gathers information from First Nations people living on reserve and in Northern First Nations communities.

The RHS is carried out by the First Nations Information Governance Centre (FNIGC), a non-profit First Nations organization that has been doing surveys on reserve and in Northern First Nations communities in collaboration with its Regional Partners since 1997.

For more information visit www.fnigc.ca

Event Hosted by **COO, Research and Data Management Sector**

Event Powered by **TAP Resources**

Report Prepared by **Robyn Rowe Consulting**