

# Powering Up Data Sovereignty

Shape Your Own Research  
and Data Future

## PROGRAM

October 24, 25, & 26, 2023



CHIEFS  
OF ONTARIO



# Thanks to the Conference Committee

Carmen R. Jones, Director of Research and Data Management

Pam Johnson, Senior Research and Policy Advisor

Roseanne Sutherland, Senior Lead

Zachary Smith, Senior Lead Research Navigator

Mariette Sutherland, Executive Project Lead,  
First Nation Data Governance Strategy

Cindy Owl, Surveys Lead

Cal Stewart, Research Assistant

Sally Hare, Senior Coordinator

Courtney Cada, RHS Coordinator

**Special Thanks to TAP Resources for their conference support.**

Tuesday Johnson-MacDonald, President

Santana MacDonald, Senior Administrator



**Ahnee, Boozhooo, She:kon, Koola Maalsi, Tansi  
Conference Delgates, Speakers, Exhibitors and  
Honoured Guests:**

As the Regional Chief of Ontario I am pleased to extend a warm welcome to all who have gathered to attend the 2023 Powering Up Data Sovereignty Conference.



First Nations research and data can be used to guide the way into a future that has been defined by First Nation peoples and communities. That makes this topic of great interest as we continue to plan for and build a good life for the ones here and the ones yet to come.

Over the next three days we will be hearing from many speakers and presenters with a wide range of experience in First Nations research and data management. Whether you are new to the topic or at the top of your field there will be something to learn and friends to be made.

I am glad you are here and I hope you have a great time over the next three days.

Meeqwetch

Ontario Regional Chief Glen Hare

**Aanii, Boozhoo, Shé:kon, Koola Maalsi, Tansi  
Conference Delegates, Speakers, Exhibitors and  
Honoured guests:**



It is my pleasure to welcome you to our first Powering Up Data Sovereignty conference: Shape Your Own Research and Data Future. We want to hear from you as community members about your understanding and needs in implementing Data Sovereignty. Over the next three (3) days you will have the chance to discover and discuss relevant issues and insights into Data Sovereignty. We have some amazing speakers this year along with our keynote speakers, Gordon Peters a member of the Delaware Nation Turtle Clan who will be speaking to Sovereignty – Past and Present, Dr. Maggie Walter who is from Tasmania. She will be travelling in from South Africa to speak on the five “D’s” of Data Sovereignty and Dr. Jennifer Walker a member of the Six Nations of Grand River will discuss what is Data Literacy. It is also our honour to welcome Harold Tarbell a Mohawk from Akwesasne as our conference emcee along with Elder Vera Pawis Tabobondung from Wasuksing First Nation and member of the First Nations Data Champion Advisory Committee.

We have incorporated some additional aspects to this conference including a theatrical performance discussing Data Sovereignty and Data Governance, on Day 1. There is a Meet & Greet reception on Day 2 for you to meet the three keynote speakers starting at 6 p.m. We have ensured to create an agenda that is engaging, interactive and provides you with some time to enjoy the vibrant city of Toronto on your own on the evening of Oct. 24, 2023.

Our whole Research & Data Management Team are looking forward to meeting all of you over the next few days as we continue our journey to data sovereignty.

Sincerely,

Carmen R. Jones  
*Director of Research and Data Management*



# Agenda

## Day 1: Tuesday, October 24th

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### COURTYARD HALL

7:30 AM – 8:30 AM

BREAKFAST PROVIDED  
Exhibitors in Spadina A & B

8:20 AM – 8:30 AM

#### **Opening Drum**

- *Danielle Migwans*

8:30 AM – 8:35 AM

#### **Welcome**

- *Conference Emcee: Harold Tarbell*

8:35 AM - 8:45 AM

#### **Opening Prayer**

- *Elder Vera Pawis Tabobondung, Wasauksing First Nation, Data Champion Advisory Committee Member*

8:45 AM - 8:55 AM

#### **Welcome**

- *Chief R. Stacey LaForme, Mississaugas of the Credit First Nation*

8:55 AM - 9:05 AM	<p><b>Opening Welcome</b></p> <ul style="list-style-type: none"> <li>• <i>Ontario Regional Chief Glen Hare</i></li> </ul>
9:05 AM - 9:10 AM	<p><b>Opening Remarks</b></p> <ul style="list-style-type: none"> <li>• <i>Grand Chief Abram Benedict, Mohawk Council of Akwesasne, Data Champion Advisory Committee Member</i></li> </ul>
9:10 AM – 9:15 AM	<p><b>Opening Comments</b></p> <ul style="list-style-type: none"> <li>• <i>Carmen R. Jones, Director of Research and Data Management, Chiefs of Ontario</i></li> </ul>
9:15 AM – 10:00 AM	<p><b>KEYNOTE ADDRESS</b>  <b>Sovereignty – Past and Present</b></p> <ul style="list-style-type: none"> <li>• <i>Gordon Peters, former Grand Chief of the Association of Iroquois and Allied Indians and former Ontario Regional Chief</i></li> </ul>
10:00 AM – 10:30 AM	<p><b>SPECIAL PRESENTATION</b>  <b>Data Sovereignty &amp; Data Governance</b></p> <ul style="list-style-type: none"> <li>• <i>Little Red Barnes Production</i></li> </ul>
10:30 AM – 11:00 AM	WELLNESS AND NETWORKING BREAK
11:00 AM – 11:45 am	<p><b>THE FUTURE OF OUR DATA</b>  <b>First Nations Data Governance Strategy as a way of expressing sovereignty</b></p> <ul style="list-style-type: none"> <li>• <i>Erin Corston, Director and Executive Lead, National Data Champion Team, FNIGC</i></li> <li>• <i>Mariette Sutherland, Executive Project Lead, First Nation Data Governance Strategy</i></li> <li>• <i>Benjamin Wald, Research Analyst, Chiefs of Ontario</i></li> </ul>
11:45 AM – Noon	<b>AUDIENCE INTERACTION</b> Q&A
12:00 PM – 1:00 PM	<p>LUNCH PROVIDED</p> <p><b>LUNCH EVENT:</b> Honouring OCAP’s Founder</p>

1:00 PM – 2:00 PM

**FIRST NATIONS RESEARCH IN ACTION**  
**The First Nations Regional Health Survey –  
Past, Present and Now**

- *Kyla Marcoux, Senior Strategic Advisor, FNIGC*
- *Roseanne Sutherland, Senior Lead Research & Data Management, Chiefs of Ontario*
- *Trevor Koostachin, Research Analyst, Chiefs of Ontario RHS*

2:00 PM – 2:30 PM

**BREAKOUT SESSIONS**

**RHS National Perspectives**

Room: Wood AB

- *Kyla Marcoux*

**RHS Regional Perspectives**

Room: Alexander A

- *Roseanne Sutherland*

**RHS Analysis**

Room: Alexander C

- *Trevor Koostachin*

2:30 PM – 3:00 PM

**WELLNESS AND NETWORKING BREAK**

3:00 PM – 4:00 PM

**FIRST NATIONS RESEARCH IN ACTION**  
**– Empowering Research from a Community  
and Cultural Lens Panel**

- *Moderator: Mariette Sutherland*
- *Dr. Lorrilee McGregor, Manitoulin Anishinabek Research Review Committee*
- *Dr. Marion Maar, Northern Ontario School of Medicine University*
- *Christina Vlahopoulous, Project Manager*
- *Maureen Gustafson, Mamow Ahyamowen*

4:00 PM – 4:30 PM

## **AUDIENCE INTERACTION**

Join the panelist in a deeper conversation.

### **Research Ethics**

*Dr. Lorrilee McGregor*

Room: Wood AB

### **Empowering Research**

*Dr. Marion Maar*

Room: Alexander A

### **Mamow Ahyamowen**

*Christina Vlahopoulous*

*Maureen Gustafson*

Room: Alexander C

4:30 PM

## **Wrap Up and Door Prize Draw**

- *Conference Emcee: Harold Tarbell*



# DAY 2: October 25, 2023

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COURTYARD HALL • EXHIBITORS IN SPADINA A&B

7:30 AM – 8:30 AM      BREAKFAST PROVIDED

8:30 AM – 8:40 AM      **Opening Drum**  
*Danielle Migwans*

8:40 AM – 9:00 AM      **Welcome & Day 1 Re-Cap**  
• *Conference Emcee: Harold Tarbell*

9:00 AM – 10:30 AM      **KEYNOTE ADDRESS:**  
**First Nations Data Sovereignty**  
• *Dr. Maggie Walter (Trawlwoolay), PhD.  
Distinguished Professor of Sociology,  
University of Tasmania*

10:00 AM – 10:30 AM      WELLNESS AND NETWORKING BREAK

10:30 AM – 11:30 AM      **COVID-19 – MODELLING FIRST  
NATIONS PANDEMIC**  
**Costs, Lessons and Preparedness in  
Ontario Panel**  
• *Moderator: Linda Ogilvie, Public Health  
Advisor, COO*

**Lessons Learned: First Nations  
COVID-19 Experience**  
• *Dr. Robyn Rowe, Robyn Rowe Consulting,*

**The Cost of COVID**  
• *Dr. Jennifer Walker, Assistant Professor,  
McMaster University*  
• *Dr. Carol Mulder, Senior Scientist, COO*

**First Nations COVID Opioid-Related  
Poisoning Report**  
• *Sacha Bragg, Opioid Research  
Communications and Project Liaison, COO*  
• *Tara Gomes, Ontario Drug  
Policy Research Network*

### The COVID-19 Scenario Model

- *Dr. Sharmistha Mishra, University of Toronto*
- *Cal Stewart, Research Assistant, COO*

11:30 AM – Noon

### AUDIENCE INTERACTION Q&A

12:00 PM-1:00 PM

LUNCH PROVIDED

1:00 PM – 1:45 PM

### FIRESIDE CHAT ON DATA SOVEREIGNTY

- *Erin Corston, Director & Executive Lead, National Data Champion Team, FNIGC*
- *Gordon Peters, former Grand Chief of the Association of Iroquois and Allied Indians and Regional Chief of Assembly of First Nations for Ontario*
- *Maggie Walter, PhD. Distinguished Professor of Sociology, University of Tasmania*
- *Jennifer Walker, Associate Professor, McMaster University*

1:45 PM – 2:15 PM

### AUDIENCE INTERACTION

Breakout Session

A facilitated discussion with the panelists.

#### Group 1: Ontario Strength

Room: Courtyard

- *Erin Corston*
- *Roseanne Sutherland*

#### Group 2: Cultural Strength

Room: Wood AB

- *Gordon Peters*
- *Mariette Sutherland*

#### Group 3: Global Context & Future

Room: Alexander C

- *Maggie Walter*
- *Carmen R. Jones*

#### Group 4: Mainstream Systems

Room: Alexander A

- *Dr. Jennifer Walker*
- *Dr. Pam Johnson*

2:15 PM –2:30 PM	WELLNESS AND NETWORKING BREAK
2:30 PM – 3:15 pm	<p><b>AUDIENCE INTERACTION</b> Report Key Highlights from breakouts</p>
3:15 – 4:15 PM	<p><b>TOOLS AND RESOURCES PANEL</b> Q&amp;A</p> <p><b>OCAP 25 and the New OCAP Training</b></p> <ul style="list-style-type: none"> <li>• <i>Dr. Aaron Franks, Senior Research Manager, OCAP</i></li> <li>• <i>Zachary Smith, Senior Lead Research Navigation, COO</i></li> </ul> <p><b>Processes for Accessing Community Data at ICES</b></p> <ul style="list-style-type: none"> <li>• <i>Graham Mecredy, Staff Scientist Indigenous Portfolio, ICES</i></li> </ul> <p><b>First Nations Data Sharing Guide and Knowledge To Action Framework – Turning Research Into Action</b></p> <ul style="list-style-type: none"> <li>• <i>Dr. Carol Mulder, Senior Scientist, COO of Ontario</i></li> </ul> <p><b>Data to Drive Change</b></p> <ul style="list-style-type: none"> <li>• <i>Patrik Lowen, Education Program Lead, COO</i></li> </ul>
4:15 pm – 4:30 PM	<p><b>AUDIENCE INTERACTION</b> OCAP 25 and the new OCAP training</p>
4:30 PM - 4:45 PM	<p><b>Wrap Up</b> Door Prize Draw</p> <ul style="list-style-type: none"> <li>• <i>Conference Emcee: Harold Tarbell</i></li> </ul>
6:00 PM – 8:00 PM	<p><b>KEYNOTE MEET &amp; GREET</b> Porter Room</p> <p>Guests of Honour:</p> <ul style="list-style-type: none"> <li>• <i>Gordon Peters</i></li> <li>• <i>Dr. Maggie Walter</i></li> <li>• <i>Dr. Jennifer Walker</i></li> </ul> <p><i>Feature Musician: Herbie Barnes</i></p>

# DAY 3: October 26, 2023

## COURTYARD HALL

7:30 AM – 8:30 AM	BREAKFAST PROVIDED Exhibitors in Spadina A & B
8:30 AM- 8:40 AM	<b>Opening Drum</b> <ul style="list-style-type: none"><li>• <i>Danielle Migwans</i></li></ul>
8:40 AM-9:00 AM	<b>Welcome &amp; Re Cap Day 2</b> <ul style="list-style-type: none"><li>• <i>Conference Emcee: Harold Tarbell</i></li></ul>
9:00 AM – 10:00 AM	<b>KEYNOTE ADDRESS:</b> <b>Data Literacy</b> <ul style="list-style-type: none"><li>• <i>Dr. Jennifer Walker, Associate Professor, McMaster University</i></li></ul>
10:00 AM – 10:30 AM	WELLNESS AND NETWORKING BREAK
10:30 AM – 11:15 AM	<b>TABLE TOP DISCUSSION:</b> <b>Data Literacy &amp; Governance</b> Each table will be provided with 3 key questions to address with their table mates. At 15-minute intervals groups will move to the next question.
11:15 AM – Noon	<b>TABLE TOP REPORT BACK</b> Each table to share their key highlight per question
12:00 PM – 1:00 PM	LUNCH PROVIDED

1:00 PM-2:00 PM

## **COMMUNITY-BASED CULTURAL APPROACHES**

### **Aanish Naa Gegii: The Children's Health & Wellbeing Measure**

- Diane Jacko, Health Services Director,

### **Naandwechige-Gamig, Wiikwemkoong Health Centre**

- Sydney Chabot-Hamden, Community Outreach & Communications Coordinator, Aanish Naa Gegii Childrens Health and Well-Being Measure

### **Hope Belonging Meaning and Purpose and the Native Wellness Assessment**

- Carol Hopkins, Chief Executive Officer, Thunderbird Partnership Foundation

2:00 PM – 2:45 PM

## **COO RESEARCH INITIATIVES**

### **Risk Assessment and Danger Assessment Tools Project**

- Nancy Johnson, Director of Women's Initiatives Sector

### **Great Lakes Water Quality Agreement**

- Dr. Ryan Bowie, Program Manager, Environment Sector

### **Economic Research**

- Arvind K. Sharma, Economic Development Director, COO
- Jason Jacques, Sr. Fellow, Institute for Fiscal Studies, University of Ottawa

2:45 PM – 3:15 PM

## **AUDIENCE INTERACTION Q&A**

3:15 PM – 3:25 PM

**Closing Remarks and Door Prize Draw**

- Conference Emcee: Harold Tarbell

3:25 PM – 3:30 PM

**Closing Comments**

- Carmen R. Jones, Director of Research and Data Management

3:30 PM – 3:40 PM

**Closing Prayer**

- Elder Vera Pawis Tabobondung, Wasauksing First Nation, Data Champion Advisory Committee Member

3:40 PM

**Travelling Drum Song**

- Danielle Migwans

Thank you for joining the first  
Powering Up Data Sovereignty Conference

HAVE A SAFE TRIP HOME



# Meet Our Elder



## **Elder Vera Pawis Tabobondung**

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. She first began her life work as the Executive Director for the Parry Sound Indian Friendship Centre and has served in many prominent roles within the Friendship Centre Movement (FCM). Senator Vera is a past President of the Ontario Federation of Indigenous Friendship Centres (OFIFC), past President of the NAFC, has served her First Nation community as a Councillor and has participated on numerous boards and committees locally, provincially, and nationally.

# Meet Our Leadership



## **ORC Glen Hare**

Glen Gwiingos Hare is the Ontario Regional Chief. First Nation Chiefs elected him as a candidate for the Ontario Regional Chief on June 16, 2022. He has been happily married for 49 years to his wife Sally and with the support of my four boys, he stated he is ready to work for the Nations as the Ontario Regional Chief. He knows about commitment to family and communities. His familiarity with key Government Provincial and

Federal levels is what he brings to the table, after all the advocacy at the Chiefs of Ontario level is crucial to addressing First Nation priorities.



## **Grand Chief Abram Benedict**

Abram Benedict is currently the Grand Chief for the Mohawk Council of Akwesasne. In the position of Grand Chief, Abram leads a dynamic Council of 12 members that govern the Mohawk Community of Akwesasne. The Mohawk Council of Akwesasne is an advanced First Nation community that delivers a wide variety of services to its members. Akwesasne is uniquely located on the international boundaries of

Canada, the United States and the provincial borders of Ontario and Quebec.



As an advanced community government, one of the Council priorities is to improve the services offered to its members. By embracing change through the utilization of modern approaches and enhanced governance structures, the Mohawk Council has set out to modernize the organization through embracing its senior-level management down to its front-line staff to effect positive change. As the Grand Chief for Akwesasne Abram has successfully led several successful negotiations, including two significant land claims that will help advance Akwesasne's priorities with proceeds of over \$280 million. Other negotiations include cooperative land use agreement, union negotiations, government contribution agreements, and civil disputes.



## **Chief Stacey Laforme**

R. Stacey Laforme is the elected Chief of the Mississaugas of the Credit First Nation (MCFN). Born and raised on MCFN, Chief Laforme has served his community for over twenty years being first elected to council in 1999. Chief Laforme is committed to increasing involvement and communication between Elected Council and both on and off-reserve membership. He is very active throughout

MCFN's Treaty Lands and Territory, which encompasses 3.9 million acres of Southern Ontario, not only as a Chief, but as a notable storyteller, poet and published author. Chief Laforme has recently been appointed as honorary senior fellow for Massey College, joining the Duke of Edinburg and the Chancellor of Oxford as only the third person awarded the highest honor the college can bestow. In 2018, De dwa da dehs nye (Aboriginal Health Centre) awarded Chief R. Stacey Laforme the Walter Cooke Wisdom Keeper Award in recognition of one's capacity to exemplify significant and continuous service to our community by demonstrating integrity, generosity of spirit, humility, courage, collaboration, "The Good Mind", and traditional ways of knowing and being.



# Meet Our Emcee



## Harold Tarbell

Harold Tarbell is a member of the Mohawk Nation at Akwesasne, located in Ontario, Quebec and New York State. Previous work experiences includes serving as a Tribal Chief (1987-1990), Multicultural programs coordinator, Land Claims research and community development officer, Assistant Director for Parliamentary Liaison, Executive Director of the National Aboriginal Management Board, Executive

Director of Buffy Sainte Marie's Cradleboard Teaching Project, and Chief of Staff to National Chief Ovide Mercredi during the Charlottetown Constitutional Negotiations.

Harold is Senior Partner in the Aboriginal consulting firm of Gaspé Tarbell Associates, formed in 1992. Mr. Tarbell provides group facilitation and training development services in such areas as strategic planning, consultation, policy development, team building, conflict resolution, board development, and youth programming for a wide variety of Aboriginal, corporate, and government organizations.



# Meet Our Keynote Speakers



## **Gordon Peters**

Gordon Peters is Lenape from the Delaware Nation and is of the turtle clan family. Gordon has a passion for life, culture and sovereignty which he readily transfers to others. Gord has worked with First Nations both politically and non-politically for 40 years. He has held the position of Grand chief for the Association of Iroquois and Allied Indians (AIAI), and has served in his own community as an elected

Councillor. Gord also served as the Ontario Regional Chief for 12 years, which including being a member of the AFN Executive.

He owns and operates a successful negotiation and consulting business. His hobbies include cultural undertakings, public education and writing.



## **Dr. Jennifer Walker**

Jennifer Walker is a member of Six Nations and an Associate Professor in the Department of Health Research Methods, Evidence and Impact at McMaster University. She has a PhD in Community Health Sciences with a specialization in Epidemiology from the University of Calgary. She currently holds a Canada Research Chair in Indigenous Health Data and Aging.



## **Dr. Maggie Walter**

Maggie Walter (PhD; FASSA) is Palawa, a member of the Tasmanian Briggs family. She is a Distinguished Professor of Sociology (Emerita) at the University of Tasmania and has published six books and more than 100 peer reviewed journal articles or research chapters. This body of work challenges standard explanations for Indigenous inequality, with a focus on the sub-fields of Indigenous data, Indigenous

methodologies and Indigenous Data Sovereignty. In May 2021, Maggie was appointed as one of five Commissioners with the Victorian Yoo-rrook Justice Commission. Yoorrook is Australia's first truth-telling body instructed to inquire into systemic injustices from colonisation to the present. The Commission's final report is due in 2024.



# Special Presentation

## Little Red Barnes Production Data Sovereignty & Data Governance



### Herbie Barnes

Herbie Barnes is an Anishnabe from Aundeck Omni Kaning on Manitoulin Island. He is the founder of Little Red Barnes Productions, a Producer, a Director, a Musician and a Playwright. He best known for his role of Joseph in the film Dance Me Outside, and on the CBC series The Rez. Herbie is currently the Creative Director with the Young Peoples theatre in Toronto. The first Indigenous

person to hold this prestigious position.



# Presentation Summaries

## **The Future of Our Data**

You will learn about the future of First Nations data in Ontario. You will hear about the development of the First Nations Data Governance Strategy and the positive impact this will have on First Nations data governance. You will also be shown a health data landscape scan, which identified how First Nations health data is managed and collected in Ontario.

## **First Nations Research in Action: The First Nations Regional Health Survey – Past, Present and Now**

You will learn more about the First Nations Regional Health Survey, how they collect data, and what this data is used for. You can also see how complex the process of data collection can be and how the regional health survey has been adjusted to have a successful collection rate based on lessons learned from previous surveys.

## **First Nations Research in Action: Empowering Research from a Community and Cultural Lens Panel**

This panel will teach you about First Nations research from a cultural and community lens. You will learn about the work Mamow Ahyamowen has done and how communities and organizations came together to secure First Nations data for change. You will also learn about First Nations research ethics and how they differ from mainstream research ethics.

## **COVID-19: Modeling First Nations Pandemic**

This panel will give you insight into the impacts of the pandemic on First Nations people and what has been done in response. You will learn about the impacts of COVID-19 on First Nations health and lessons we have learned from the pandemic. You will also learn about tools that were created in response to the pandemic to better prepare First Nations people for the future.

## **Tools and Resources Panel**

This panel will teach you about the numerous tools and resources available to individuals and researchers. You will learn about the past 25 years of OCAP, as well as new training that is available. You will be shown how to access community data at ICES, how data drives changes, and how research can turn into action.

## **Community Based Cultural Approaches**

You will see how community-based cultural approaches are utilized in research. These include the Children's Health and Well Being Measure and the Native Wellness Assessment.

## **COO Research Initiatives**

You will learn about different research initiatives Chiefs of Ontario sectors are working on. 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.



# Presenters



## Dr. Ryan Bowie

Dr. Bowie is a Program Manager in the Environment Sector for the Chiefs of Ontario. His work focuses on the Great Lakes region, specifically First Nations involvement with the policies and agreements that manage Great Lakes water quality and ecosystem health. He also leads engagement for the Chiefs of Ontario on the proposed Canada Water Agency.

He holds an MA in Canadian and Indigenous Studies from Trent University, and a PhD in Environmental Studies from York University.



## Sacha Bragg

My name is Sacha Bragg. I am Wolf Clan from Munsee Delaware Nation. I returned to school as a mature student as I knew I wanted to do something to help my community. I graduated from the University of Western with a Master in Public Health. I have a passion for mental health with a focus on harm reduction and how we can keep our loved ones alive. I am a mom, grandma and auntie. I have two

grandsons that are my whole world. Everything I do, I do in hopes of making this a better world for my children and grandchildren. I am also an animal lover and have 2 cats and 3 dogs. I would have many more if I could. I am hoping to someday be able to move to the country where I can have as many animals as I want.





## Sydney Chabot-Hamden

Sydney Chabot-Hamden is an Anishinabe kwe from Kitigan Zibi, raised in Toronto, Ontario. Sydney is the Community Outreach and Communications Coordinator for the Aanish Naa Gegii: The Children's Health and Wellbeing Measure (ACHWM). She has a Bachelor of Arts in Psychology from Western University and is a Certified Holistic Nutritionist (CNP). With multiple years of experience working in

Indigenous organizations and businesses, she works to reconnect with her culture while giving back to communities across Turtle Island through health promotion and wellness-based work.



## Erin Corston

Erin Corston is a member the Chapleau Cree First Nation (Cree: ᓄᓄᓄ ᓄᓄᓄᓄᓄᓄᓄᓄ, šaplo ininiwak). She was born and raised in Treaty 9 Territory. After more than a decade in the public service, Erin shifted her professional career to the not-for-profit environment to focus on expanding her knowledge and expertise in First Nations' determinants of health. Working primarily at the national level, Erin

has contributed to the development and implementation of several major First Nations-led initiatives. Her current work at FNIGC is focused on advancing First Nations' rights over their data, through the implementation of the First Nations Data Governance Strategy.



## Dr. Aaron Franks

Aaron is the Senior Research Manager, OCAP® and Information Governance at the First Nations Information Governance Centre. He holds an MA in Social Justice and Equity Studies from Brock University and a PhD in Human Geography from the University of Glasgow. He has worked with the Centre for Environmental Health Equity (CEHE) at the University of Manitoba and Queen's University,

the Centre for Indigenous Research Creation at Queen's, SSHRC, and Universities Canada. He now belongs to a team dedicated to applied research and education in the First Nations Principles of OCAP®, information governance, and First Nations data sovereignty.

Originally from Edmonton in Treaty Six territory, Aaron is of British, Northern European, and Metis descent with roots in the Anglo-Metis communities of St. Andrews, MB, and Birch Hills, SK. He is a member of the Manitoba Metis Federation and lives on unceded Algonquin territory in Ottawa with his family.



## **Tara Gomes**

Tara Gomes is the Scientific Director of Urban and Community Health at Unity Health Toronto and holds a Canada Research Chair in Drug Policy Research and Evaluation. Her research program focuses on drug safety and drug policy research, with a specific interest in developing evidence to inform policies that address the ongoing drug toxicity crisis across Canada and that integrate perspectives of impacted communities.



## **Maureen Gustafson**

Maureen Gustafson is Anishinaabekwe of mixed Ojibwe and European settler ancestry. A member of Couchiching First Nation, she grew up nearby in Fort Frances. She is a loving auntie, sister, daughter, cousin, and friend. Maureen obtained a Master of Public Health with specializations in Health Promotion and Indigenous Health from the University of Toronto in 2019. Her work is informed by professional

experience at Indigenous-led research institutes in both Canada and Australia as well as health and social service providers in northwestern Ontario.

Maureen is privileged to support Mamow Ahyamowen as the Knowledge Translation & Exchange Specialist and enjoys working in the space between research and action.



## **Carol Hopkins**

Carol Hopkins is the Chief Executive Officer of the Thunderbird Partnership Foundation (a division of the National Native Addictions Partnership Foundation) and is of the Lenape Nation. Carol was appointed as an Officer in the Order of Canada, 2018. In 2019, she received an honorary Doctor of Laws degree from Western University. Carol has spent more than 25 years in the field of First Nations substance use and mental

health. She holds both a Master of Social Work Degree from the University of

Toronto and is 4th degree Midewiwin, a sacred Anishinaabe medicine society where she is a Chief and Teacher. Carol has throughout her career, made use of Indigenous knowledge in research, policy, practice-based evidence, teaching, and education, and in facilitating processes of decolonization specific to epistemic racism. She has co-chaired national initiatives known for best practice in national policy review and development, resulting in the: First Nations Mental Wellness Continuum Framework (FNMWC), the Honouring Our Strengths: A Renewed Framework to Address Substance Use Issues Among First Nations in Canada, the Indigenous Wellness Framework, and the Native Wellness Assessment. Her leadership has been engaged within Health and Mental Health for First Nations, Provincial, Territorial, and Federal governments serving several expert advisory and task groups.



## Jason Jacques

Jason Jacques is a Senior Fellow with the Institute for Fiscal Studies and Democracy (IFSD) at the University of Ottawa. Prior to joining the IFSD, Jason was the Director General at the Canadian Parliamentary Budget Office. He also held various positions in the Government of Canada, including the Privy Council Office, Finance Canada, Treasury Board Secretariat and Bank of Canada. Jason holds an MA in economics

from Queen's University, is a Chartered Professional Accountant (CMA), and a CFA Charter holder.



## Diane Jocko

Diane Jocko is an Anishinaabe Kwe from Wiikwemkoong Unceded Territory located on Manitoulin Island. First and foremost Diane is a mother to three daughters and one son, a grandmother to three grand daughters and two grandsons. She is a sister to her 11 siblings, an auntie, and a god mother. She is the daughter to the late Veronica Jacko (Manitowabi) and the late Arthur Jacko.

Diane graduated from Laurentian University in 1999 and attained two degrees, one in Native Studies as well as an Honors Degree in Psychology. She is a registered Psychotherapist with the College of Registered Psychotherapists of Ontario. Diane is the Health Service Director for Naandwehige-Gamig Wikwemikong Health Centre and previous to this, she was the Manager of Nadmadwin Mental Health Clinic in Wikwemikong. Diane has worked in the health field for the last 24 years with the majority being in mental health.



## **Nancy Johnson**

Nancy Johnson, M.Ed. is a member of Caldwell First Nation and Plains Cree/Métis. She has worked as a researcher and consultant in First Nations community development and as an Indigenous policy advisor for the Government of Ontario. Her first job with the Chiefs of Ontario many years ago was with First Nations youth conducting community-based research. She taught Indigenous

Studies at Centennial College prior to her current role as Director of Women's Initiatives for the Chiefs of Ontario office. She is a grandmother, singer and hand drummer.



## **Patrik Lowen**

Patrik Lowen works as an education Program Lead for the Chiefs of Ontario. This work involves K-12 provincial educational matters and close collaboration with the First Nation Lifelong Learning Table. Patrik has over 18 years of experience working in First Nation education. Patrik's educational background includes a Bachelor of Education and a Master of Arts in Counselling

Psychology. Outside of work, Patrik coaches basketball and volleyball and is busy spending time with his 3 children.



## **Kyla Marcoux**

Kyla Marcoux is a Senior Strategic Advisor at FNIGC. She has been with the organization for 10 years in various positions related to survey development, data analysis, survey coordination and management. In her current role, she is responsible for providing strategic advice, guidance and support to the Research and Information unit, bridging the survey initiatives and related research projects within FNIGC and the

FNIGC network of regional partner organizations. She is also supporting the First Nations Data Governance Strategy (FNDGS) phased implementation including the assessment and prioritization of capacity needs for FNIGC and across the FNIGC network.



## **Dr. Marion Marr**

Dr. Marion Maar is founding faculty and Professor of Medical Anthropology at the Northern Ontario School of Medicine University (NOSM U) as well as Curriculum Chair for Northern and Rural Health. She has over two decades of experience in the area of health and mental health research in collaboration with First Nations. She has supervised more than 40 graduate and medical students on research projects.

Since the inception of NOSM in 2005, Marion has co-led innovative community-engaged virtual learning with northern communities. She is the recipient of the 2011 Cancer Quality Council of Ontario's Innovation Award for her work with First Nations on cancer prevention and screening. In 2016, she was honored with NOSM's Scholar of the Year Award. Prior to her work at NOSM, Marion worked for eight years at Noojmowin Teg Health Centre on Manitoulin Island as the research and evaluation coordinator. This is where she became aware of the importance of Indigenous data to be accessible to First Nations organizations in order to support program planning.



## **Dr. Lorrilee McGregor**

Dr. Lorrilee McGregor is an Anishinaabe from Whitefish River First Nation. She is an Associate Professor at NOSM University where she teaches about Indigenous peoples' health. For the past 20 years, Lorrilee has served as the Chair of the Manitoulin Anishinaabek Research Review Committee, a community-based Research Ethics Board that has reviewed over 100 research ethics applications.



## **Graham Mecredy**

Graham Mecredy is a staff scientist within the ICES Indigenous Portfolio. He completed an MSc degree in community health and epidemiology from Queen's University, and a BSc (honours) degree in health sciences from the University of Ottawa. Graham first joined ICES in 2013 as an epidemiologist working in the Chronic Disease Program, primarily with the COPD research team. Prior to joining ICES, he worked

as a research officer at the Ontario Tobacco Research Unit for three years, conducting research on tobacco availability and smoking cessation.

In his current role at ICES, Graham works directly with Indigenous partners and communities on analytic projects to produce research outputs that are tailored to their unique challenges and needs.



## **Dr. Sharmistha Mishra**

Sharmistha Mishra is a settler and South Asian immigrant. She is an Associate Professor at University of Toronto, and works on mathematical modeling of infectious diseases.



## **Linda Ogilvie**

Linda has worked at the Chiefs of Ontario as their Public Health Advisor since 2007. Before 2007 she worked for many First Nation Communities as a clinical nurse specialist in remote and isolated areas of Ontario. Linda has a degree in Nursing from McMaster University, specializing in Public Health, and a Master of Education Degree from Brock University. She is also enrolled in part time PhD

studies at the University of Western Ontario.

Linda focuses on strengthening and advocating for improved public health services for all First Nations in Ontario. She is the proud mother of 3 adult children and five grandchildren who bring her great joy.



## **Dr. Robyn Rowe**

Dr. Robyn K. Rowe is an Anishinaabe-kwe (First Nations woman) of mixed settler ancestry, a member of Matachewan First Nation and hereditary member of Teme-Augama Anishnabai in Northeastern, Ontario. She is a mother of four and holds a PhD in Rural and Northern Health and is a Postdoctoral Fellow at Queen's University in Indigenous Digital Rights, Decolonization, and Data in Artificial Intelligence.

Dr. Rowe is a health and social scientist whose work is rooted in supporting

First Nations to advance meaningful community-led and determined data governance and data sovereignty. Dr. Rowe is the owner of Robyn Rowe Consulting and was contracted by the Chiefs of Ontario in 2022 to write a report on the Lessons Learned for First Nations in Ontario during the COVID-19 pandemic. The results of the report were shared during the 2023 COO Health Forum and will be discussed once more during the Powering up Data Sovereignty Conference. Notably, Dr. Rowe is an Executive Member of the Global Indigenous Data Alliance (Gida-global.org) and was involved in the co-development of the 'CARE Principles for Indigenous Data Governance' with Indigenous partners from around the world through the International Indigenous Data Sovereignty Interest Group.



## **Arvind K. Sharma**

Arvind Sharma functions as Director of Economic Development at Chiefs of Ontario. Before joining Chiefs of Ontario, Arvind was with Atikameksheng Anishnawbek as Director of Lands and Economic Development. Arvind experience includes interacting with First Nation Leadership, the First Nation Community, Land and Economic Development issues, negotiations with external agencies including mining proponents. Arvind is a Professional Engineer registered in Ontario.



## **Mariette Sutherland**

Mariette Sutherland, an Anishnaabe-kwe from Whitefish River First Nation is the Executive Project Lead working with the Ontario Data Champion Advisory Committee in leading implementation of the First Nations Data Governance Strategy.

Mariette is a seasoned strategist, consulting resource and project management professional with over 20 years experience in a full-time consulting practice servicing the aspirations and planning needs of numerous First Nations, Tribal Councils, PTOs, health authorities, and government partners. Over the years, Mariette has built a track record of sound community engagement, project development and providing quality intelligence to support the initiatives.



## **Christina Vlahopoulos**

Christina Vlahopoulos (she/her) is an ally of Greek settler ancestry residing in the Robinson-Huron Treaty territory, on the traditional lands of the Atikameksheng Anishnawbek and Wahnapiatae First Nations (Sudbury).





# FIRST NATIONS DATA GOVERNANCE STRATEGY

## Towards a Regional Information Governance Centre

Ontario First Nations have done leading work in data driven research projects aimed at understanding and addressing socio-economic and health outcome inequalities and strengthening their communities.

In order to advance this work, Ontario through the Data Champion Team lead by Mariette Sutherland and under the guidance of the Data Champion Advisory Committee (see attached list) has begun implementing the First Nations Data Governance Strategy (FNDGS) ([Introducing a First Nations Data Governance Strategy - The First Nations Information Governance Centre \(fnigc.ca\)](#)).

The Strategy envisions a First Nations-led regional information governance centre networked with others across the country, designed and built based on needs and priorities expressed by Ontario First Nations. The centre will provide First Nations with timely access to quality data in order to make informed decisions and plan for the future and to deliver the services needed in the community.

The Strategy, itself, is rooted in community-driven and Nation-based collaborative approaches and charts the path necessary to further advance First Nations' self-determination. This begins with putting data back into the hands of First Nations communities in keeping with the fullest expression of OCAP principles.

**A needed first step is engagement with First Nations to establish collaborative relationships, assess needs and priorities and draft a plan for the Centre. Interested in learning more? Connect with team and committee members here at the conference or email your inquiry to: [Priscilla.Nakochee@coo.org](mailto:Priscilla.Nakochee@coo.org)**





**Chiefs of Ontario  
Data Champion Advisory  
Committee Members**

**ELDER VERA PAWIS TABOBONDUNG**

**GRAND CHIEF ABRAM BENEDICT - LEADERSHIP COUNCIL**

**CHIEF SHELLY MOORE-FRAPPIER**

**MR. LARRY SAULT - ADVISOR**

**MR. GARY ALLEN - ADVISOR**

**DR. CHRIS MUSHQUASH - ADVISOR**

**DR. JENNIFER WALKER - ADVISOR**

**DR. DARREL MANITOWABI - ADVISOR**

**DR. EMILY FARIES - ADVISOR**

**DR. MICHAEL SCHULL - ADVISOR**



# Meet the RDM Staff



## **Carmen R. Jones**

*Director of Research and Data Management*

Carmen is an Anishnawbe-kwe and a member of the Serpent River First Nation. She was raised on the Garden River Reserve and now lives in Peterborough, Ontario. Carmen has been in her career for about 40 years. She has been with the Chiefs of Ontario for the past 10 years. Previous to becoming the Director of Research and Data Management, she held the position of Health Director and Research. She oversees the new Research and Data Management Sector and is overseeing the development of the First Nation Information Governance Centre for Ontario supported by the Chiefs-in-Assembly. Her portfolio includes implementing the First Nations Data Governance Agreement with the Institute for Clinical Evaluative Sciences (ICES) and is responsible for managing the work in research and data. Carmen is a Board Member of First Nations Information Governance Centre and she has a ministerial appointment to the Ontario Health Data Council. She has 7 grandchildren, is a singer-song writer and in her spare time is a behavioural dog trainer.



## **Sally Hare**

*Senior Coordinator*

Sally is a member of M'Chigeeng First Nation. She has been working and living in Toronto for the past 20 years. She is a graduate of Sault College in Executive Office Administration. Her experience in administration includes social services, health, education, economic and housing at the community, regional and provincial level. Sally is a proud grandma to seven grandchildren.



## **Dr. Pam Johnson**

*Senior Research and Policy Advisor*

Pam is a Senior Research and Policy Advisor in the Research and Data Management department at the Chiefs of Ontario. She is part of the Kanyen'kehaka Orenrehgowehe wolf clan family of the Grand River territory and has resided in community on the Six Nations of the Grand River Territory from birth. Pam has worked on a variety of First Nations issues

over the past 35 years, with her most recent focus being First Nations data sovereignty. Pam pursued both social science and the arts in her education. She earned a PhD in psychology, with an early focus on community psychology, supported by a diploma in social work; and balanced with a certification in expressive art therapy and yoga instruction. Her interests are like leaves on a tree, too many to count and ever changing. She believes we can't change the problems we face with the same consciousness that created it (I borrowed that one from Einstein) and seeks fresh perspectives in work and through play.



## **Benjamin Wald**

*Research Analyst*

Benjamin is a research analyst in the Research and Data Management sector of the Chiefs of Ontario. He has a PhD in philosophy from the University of Toronto. His current work focuses on First Nations data sovereignty, looking in particular at health data, social data, and AI.



## **Dr. Rex Roman**

*Senior Data Strategist*

Rex is the Senior Data Strategist. He recently worked with the Ministry of Health on Data governance and privacy. In the past, Rex has been Vice-Chair of the Health Professions Regulatory Advisory Council, Vice-Chair of the Women's College Research Ethics Board and Bioethicist serving a variety of Toronto hospitals. Rex has also previously worked as an IT professional in the Ontario Public Service. He likes to relax by gardening and playing guitar



## **Priscilla Nakochee**

*Executive Assistant*

Priscilla is a proud Cree woman from Fort Albany First Nation. She recently joined the Chiefs of Ontario in the Research and Data Management as an Executive Assistant for First Nation Data Strategy. She obtained her Degree in Business Administration from Laurentian University. She is excited to be part of the team!



## **Carol Mulder**

*Senior Scientist*

Carol is a scholar-practitioner currently serving Chiefs of Ontario as their Senior Scientist. She has a Doctorate in Business Administration focusing on change management related to performance measurement in primary care recently to support COVID-19 response. Her contributions in that role include producing weekly COVID-19 reports for First Nations in Ontario and collaborating on research addressing First Nations COVID-19 modelling, the impact of COVID-19 on the healthcare system and other non-COVID-19 topics like the intergenerational impact of Diabetes in First Nations, among others. Carol also leads internal COO efforts related to performance measurement and analysis of regional First Nations survey data. She is affiliated with the Department of Family Medicine at Queens University as a Lecturer and collaborating researcher. related to performance measurement in primary care. Carol supports Chiefs of Ontario remotely from her home in a yurt on unceded land of the Chippewas of Nawash on the shore of Georgian Bay, near Wiarton Ontario.



## Cal Stewart

*Research Assistant*

Cal is a Research Assistant with the Research and Data Management Sector at the Chiefs of Ontario. He previously attended the University of Toronto, graduating with a master's degree in history. He has worked at the University of Toronto, where he researched issues in Long Term Care. His work with the Chiefs of Ontario includes a Covid-19 modelling project and report, and intergenerational diabetes project.



## Roseanne Sutherland

*Senior Lead*

Roseanne is Mushkego from Kashechewan First Nation. She has worked at Chiefs of Ontario since 2014 in surveys, health research and currently is Senior Lead in Research and Data Management. She has worked in the non-profit sector, for profit sector, First Nation organizations and in her home community. Roseanne has a Master's Degree in History and Business Administration in Accounting. Conversing in Cree, creating quilts, reading history books, and travelling to new places are joyful aspects of her life.



## Courtney Cada

*RHS Coordinator*

Courtney is a member of Mississauga First Nation and is an Ojibwa woman. She graduated from Sault College in Social Service Worker – Native Specialization in 2013. She has been living in Toronto working in multiple First Nation organizations for 10 years. Her experiences are in administration, event planning and coordinating. Courtney spends her free time drawing, playing video and board games and watching her favourite shows/movies with her cat Ori.



## Cindy Owl

*Surveys Lead*

Cindy is proud to have dedicated 20+ years working within First Nation organizations in the GTA. Cindy began working with Chiefs of Ontario in 2012 as a Health Coordinator. She is currently the Surveys Lead in the Research and Data Management Sector. Cindy is a mother, daughter and auntie of many beautiful nieces and nephews. In her spare time, she enjoys reconnecting with friends, extended family but mostly spending time with her daughter.



## Zachary Smith

*Senior Lead, Research Navigation*

Zachary is an Anishinaabe doctoral candidate in the Department of History at the University of Toronto. Born in Toronto to family originally from Wasauksing First Nation, he researches histories of Indigenous-settler relations in Canada and is currently writing a dissertation on the migration of Indigenous peoples from reserves to urban centres in mid-twentieth century Canada. Zachary previously worked as a student researcher in COO's Justice Department in 2011-2012, and is excited to be back working on projects that advance First Nations' self-determination and sovereignty. He lives in Toronto with his wife and two young sons.



## Emily Harding

*Coordinator*

Emily (Manidoo Aanakwad) is from Aamjiwnaang First Nation and from the Bear Clan. She is a registered practical nurse who has a long and varied history of assisting in her surrounding communities: Bluewater Health hospital, St. Joseph's Hospice, LTC homes, OTN walk-in clinics, Primary Care, Public Health, Aamjiwnaang and neighboring First Nations-KSPFN & Bkejwanong. She has worked initially in administrative roles supporting her local college and friendship center where she began her career as an administrative professional.



## **Trevor Koostachin**

*Research Analyst*

Watchyeh, Hello, I am Trevor Koostachin and I am a research analyst with Chiefs of Ontario. I am a proud member of Attawapiskat First Nation and I was raised in my community. I began my studies at Laurentian University. Early on in my studies, I was interested in First Nations health and with the guidance of an Indigenous Health researcher, which at the time

I wouldn't know, began the trajectory of my career in Health research. I work closely with the research navigation team with the Research and Data Management team within the Chiefs of Ontario.





# RHS

## REGIONAL HEALTH SURVEY

Phase 4 is scheduled to launch in 2023/2024

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 its 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.

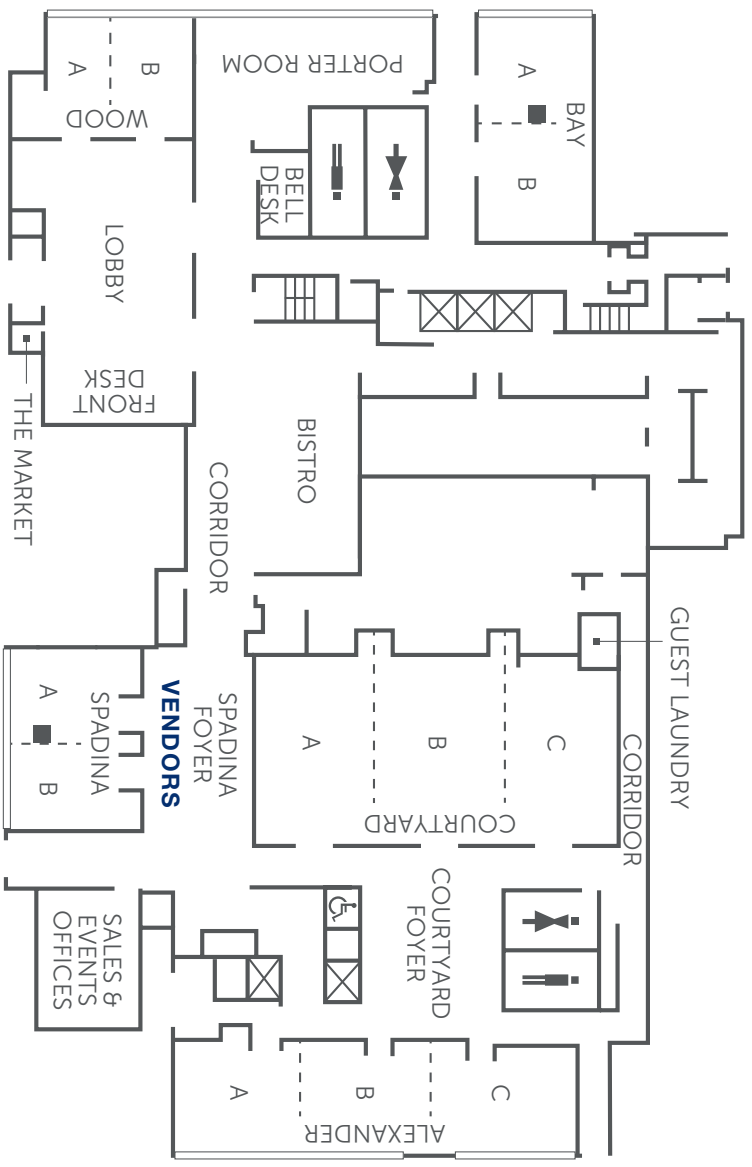


**FNIGC / CGIPN**  
First Nations Information Governance Centre  
Le Centre de gouvernance de l'information des Premières Nations



For more information, visit [www.fnigc.ca](http://www.fnigc.ca)

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t: 519 445 1794 e:president@tapresources.ca