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Discovery  
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ICES RESEARCH  
FORUM

# WAY FORWARD

ADVANCING  
HEALTH EQUITY  
THROUGH DATA

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WAY  
FORWARD

ADVANCING HEALTH EQUITY  
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# The Role of KTE in the Application of Indigenous Data Sovereignty

Moderator: Sujitha Ratnasingham

Speakers:

Dr. Jennifer Walker

Maureen Gustafson

Christina Vlahopoulos

Aggie Mazzucco

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## Description

In this session, we will review the principles of Indigenous data sovereignty and self-determination and explore knowledge translation and exchange as an application of these principles.



## WORKSHOP #3

The Role of KTE in the Application of  
Indigenous Data Sovereignty

# WAY FORWARD

ADVANCING  
HEALTH EQUITY  
THROUGH DATA

11  
MAY  
2023



**Jennifer Walker**

ICES Indigenous Health Lead



**Christina Vlahopoulos**

Project Manager,  
Mamow Ahyamowen



**Aggie Mazzucco**

Project Manager & Research Assistant  
Prenatal Opioid Exposure and Neonatal  
Abstinence Syndrome: A Research  
Project with 13 First Nations  
Communities in Ontario



**Maureen Gustafson**


Knowledge Translation and  
Exchange (KTE) Specialist,  
Mamow Ahyamowen

# Outline

- Poll
- Overview
  - Indigenous Data Sovereignty
  - Knowledge Translation and Exchange
- Exemplar Projects
  - Mamow Ahyamowen
  - Prenatal Opioid Exposure and Neonatal Abstinence Syndrome: A Research Project with 13 First Nations Communities in Ontario
- Discussion

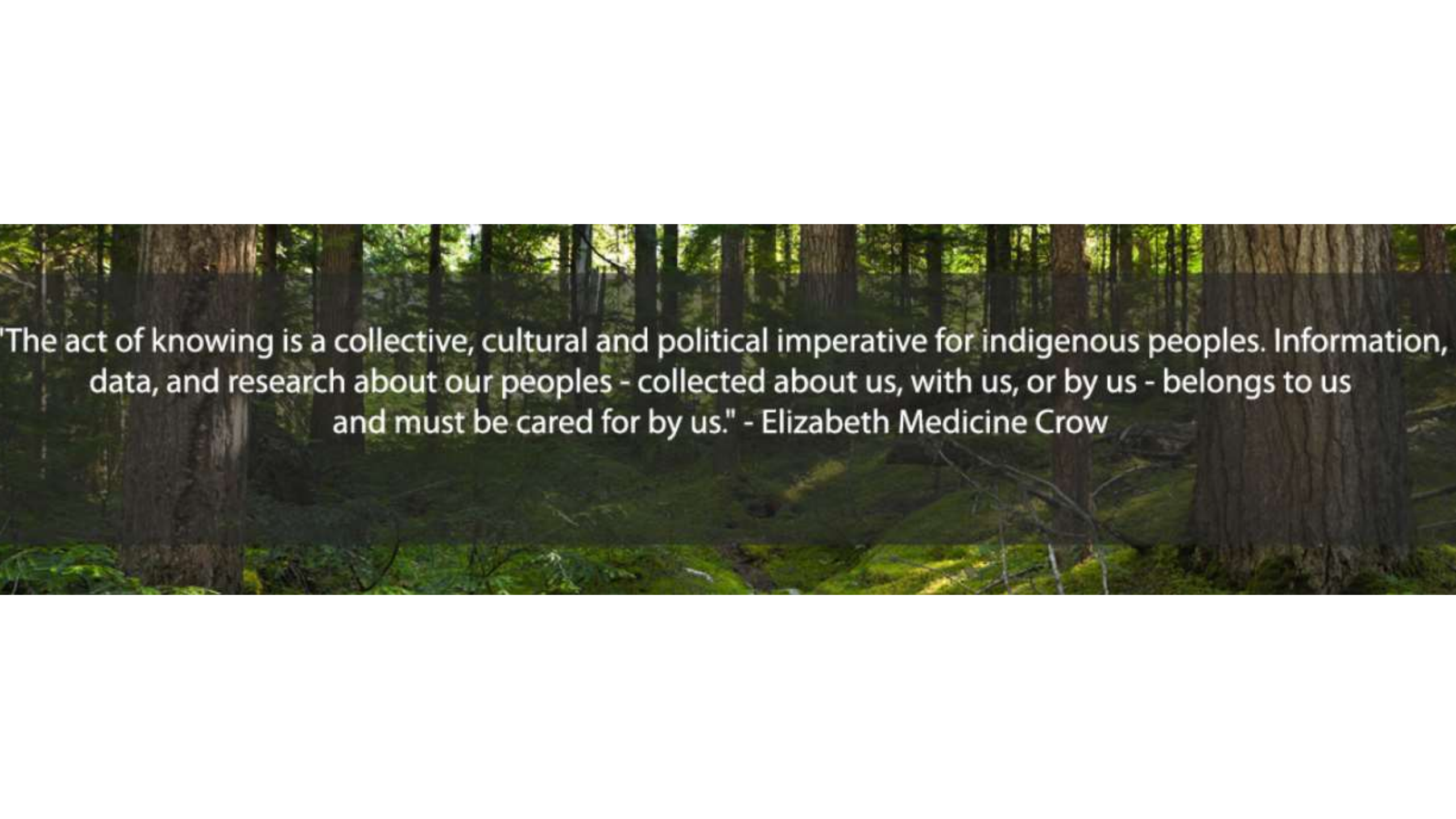


# Indigenous Data Sovereignty and KTE

A scenic landscape of a mountain valley. In the foreground, a river with milky, turquoise water flows over a rocky, gravelly bed. The river is surrounded by dark, forested slopes. In the background, majestic mountains rise, some with patches of snow or light-colored rock. The sky is overcast and hazy. A semi-transparent text box is overlaid on the right side of the image, containing the text:

*Indigenous Data Sovereignty:  
The right of Indigenous Peoples and nations to govern the  
collection, ownership, and application of their own data*





'The act of knowing is a collective, cultural and political imperative for indigenous peoples. Information, data, and research about our peoples - collected about us, with us, or by us - belongs to us and must be cared for by us.' - Elizabeth Medicine Crow





# Indigenous Sovereignty: What does UNDRIP have to say?

Article 4 – right to **autonomy** and **self-government**

Article 5 – right to maintain and strengthen **distinct** political, legal, economic, social and cultural **institutions**

Article 15 (i) – right to dignity and **diversity** of cultures traditions, histories and aspirations which shall be appropriately reflected in education and **public information**

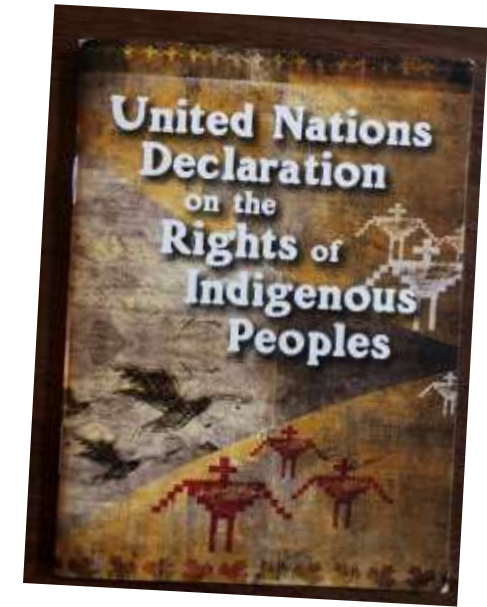
Article 18 – right to participate in decision-making in matters that would affect rights...and to develop indigenous **decision-making institutions**

Article 19 – States shall...obtain **free, prior and informed consent** before adopting and implementing legislative or administrative measures that may affect them

Article 23 – right to determine and develop **priorities and strategies**...and to administer **programs** through their own institutions if possible

Article 31 – right to maintain, control, protect and develop **intellectual property**

Article 33 – right to **determine their own identity or membership**. Right to determine structures and select membership of their institutions



2007

# Research Ethics: What does TCPS 2 (2022) have to say?

- Article 9.1

“Where the research is likely to affect the welfare of an Indigenous community, or communities, to which prospective participants belong, **researchers shall seek engagement with the relevant community**. The conditions under which engagement is required include, but are not limited to:... **d. research in which Indigenous identity or membership in an Indigenous community is used as a variable for the purpose of analysis of the research data...**”

- Article 9.2

“The nature and extent of community engagement in a project shall be **determined jointly by the researcher and the relevant community** and shall be **appropriate to community characteristics and the nature of the research.**”



Beyond individual consent → Importance of collective consent



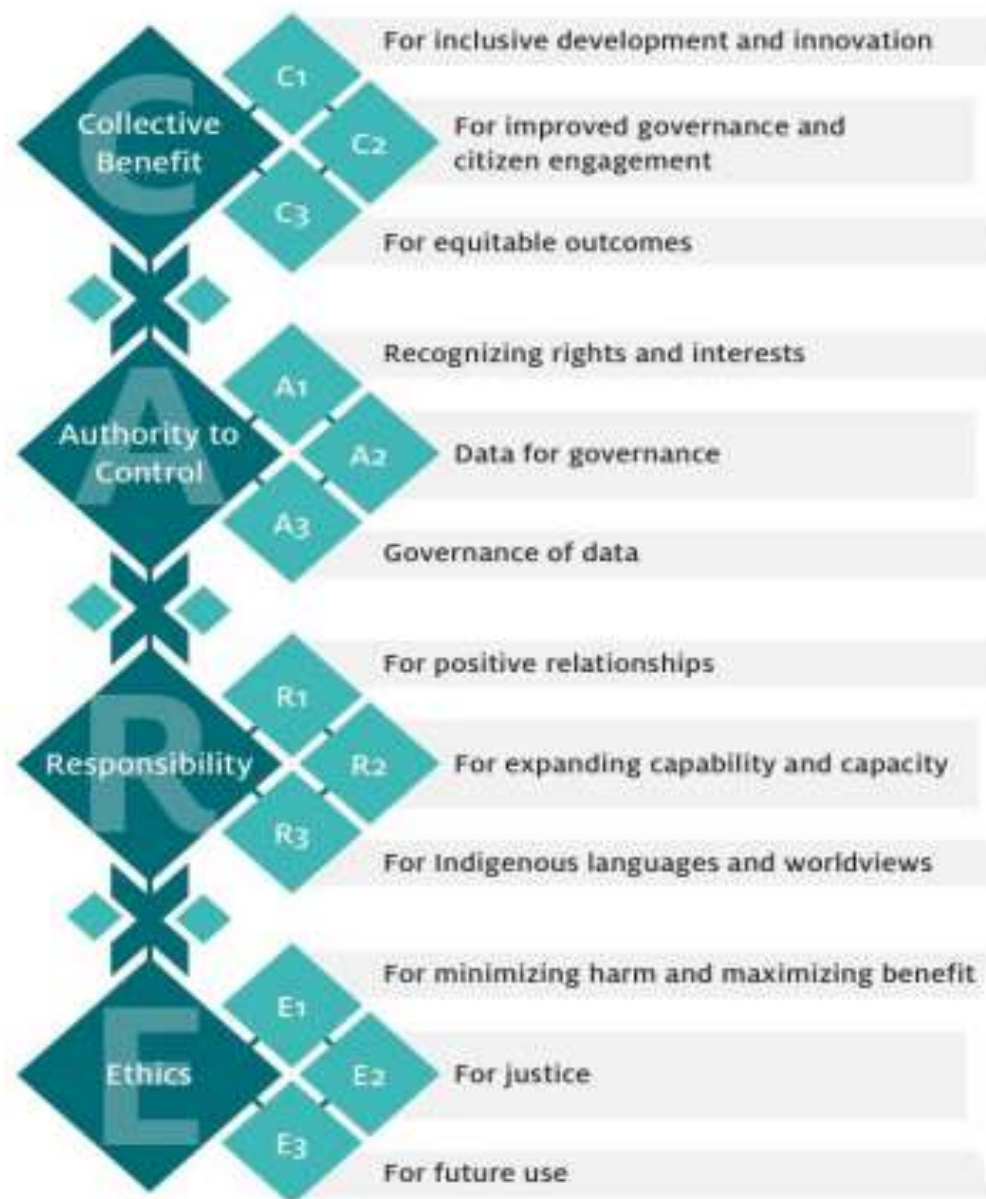
Indigenous data sovereignty → Indigenous data governance

Indigenous data governance =  
Indigenous governance of Indigenous data +  
Indigenous use of Indigenous data for  
governance



# Indigenous Frameworks

## CARE Principles for Indigenous Data Governance





# CARE Principles for Indigenous Data Governance

## Collective Benefit.

Data ecosystems shall be designed and function in ways that enable Indigenous Peoples to derive benefit from the data.

- C1. For inclusive development and innovation
- C2. For improved governance and citizen engagement
- C3. For equitable outcomes

## Responsibility.

Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous Peoples' self determination and collective benefit.

- R1. For positive relationships
- R2. For expanding capability and capacity
- R3. For Indigenous languages and worldviews

## Authority to Control.

Indigenous Peoples' rights and interests in Indigenous data must be recognized and their authority to control such data respected.

- A1. Recognizing rights and interests
- A2. Data for governance
- A3. Governance of data

## Ethics.

Indigenous Peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.

- E1. For minimizing harm and maximizing benefit
- E2. For justice
- E3. For future use



# SEEDS – Guiding Principles for Indigenous Population Health Data Linkage

- Rowe RK, Russo Carroll S, Healy C, Rodriguez-Lonebear D, Walker JD. (2021) The SEEDS of Indigenous population health data linkage. International Journal of Population Data Sciences 6:1:22



# First Nations Data Governance Principles - OCAP®

- First Nations Information Governance Centre (FNIGC)
- Refers to the rights of First Nations communities to own, protect and control how their information is used for research and other purposes

OWNERSHIP



CONTROL

ACCESS

POSSESSION



<https://fnigc.ca/ocap-training/>



# First Nations Data Governance

## A First Nations Data Governance Strategy

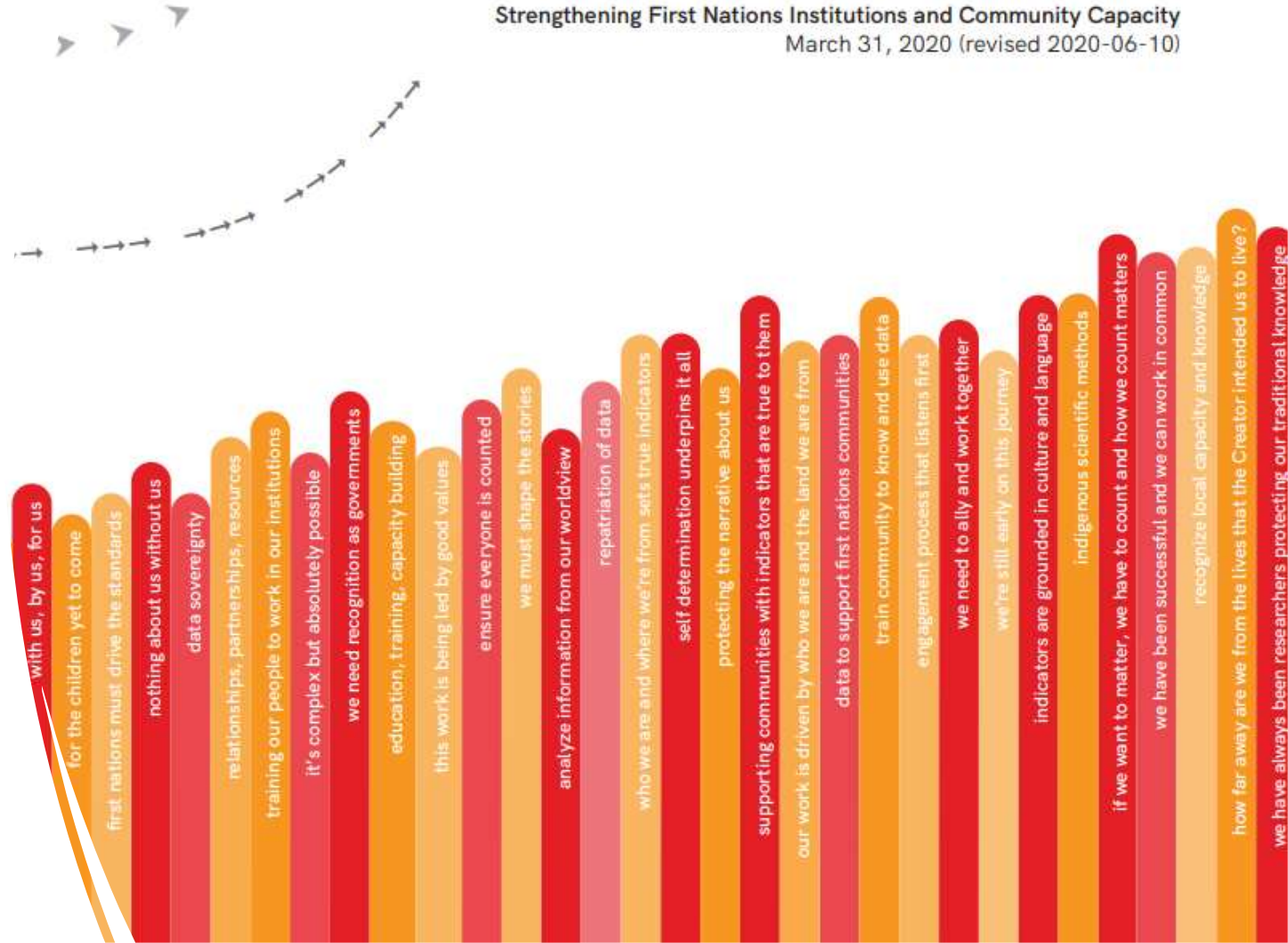
A Response to Direction Received from First Nations Leadership,  
Funded through Federal Budget 2018 in Support of the New Fiscal Relationship

Strengthening First Nations Institutions and Community Capacity

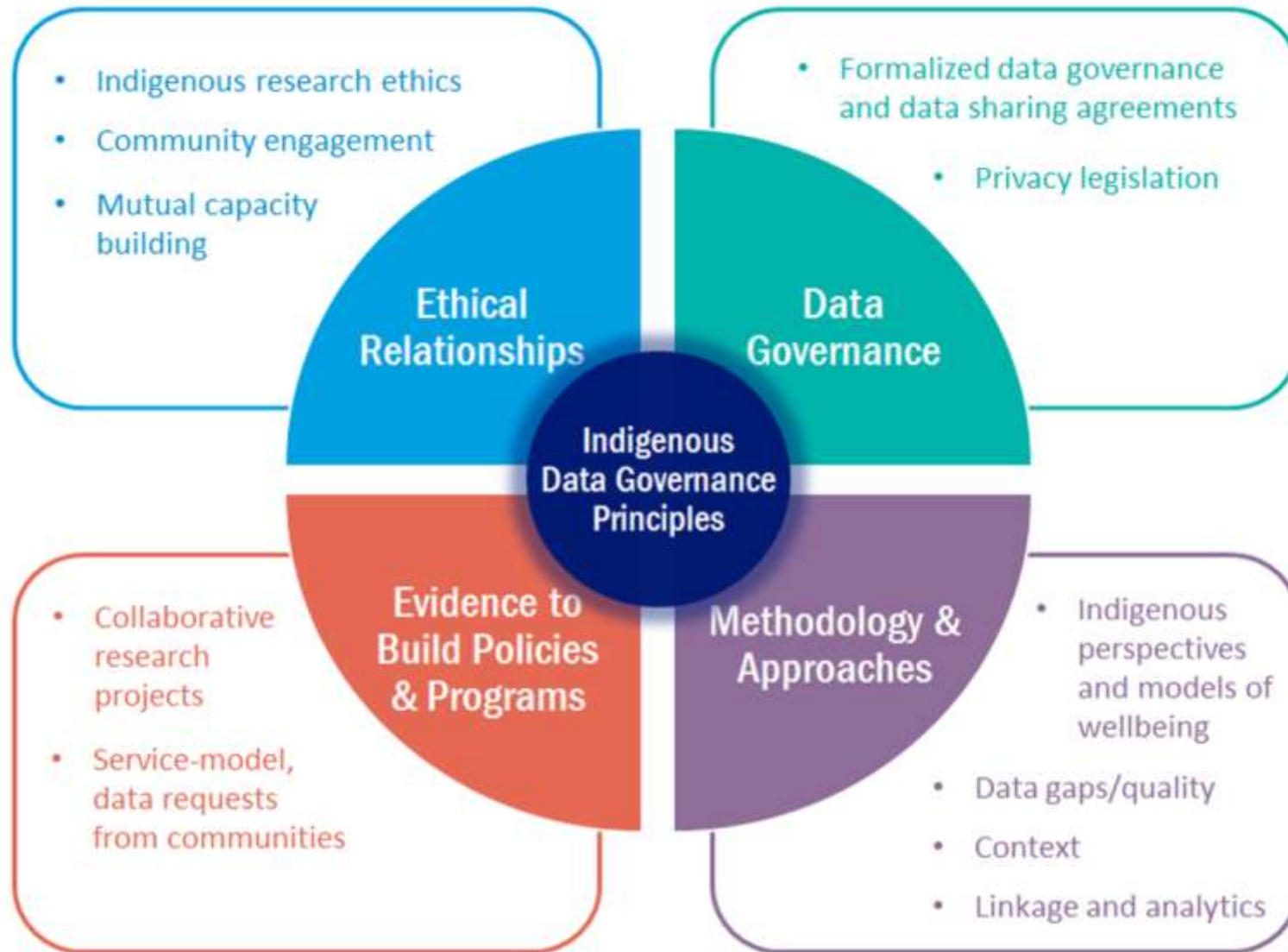
March 31, 2020 (revised 2020-06-10)

- First Nations Information Governance Centre
  - Launching National First Nations Data Governance Strategy in collaboration with regions across Canada

[Fnigc.ca](http://Fnigc.ca)



# Working with Indigenous Data at ICES



# First Nations Data Governance at ICES





# Indigenous data sovereignty and governance challenges deficit-based approaches to telling stories with data

- Harmful impacts of deficit-based approaches to administrative health services data research
  - Stereotyping and marginalization of Indigenous Peoples
  - Perpetuating narratives of despair, difference, and deprivation
- These narratives pose a risk for Indigenous people seeking health care and negatively affects how health care professionals provide care



Moves us away from using data to shine a light on “problems” ...

to Indigenous Peoples using data to find and guide a path forward.

# What is Knowledge Translation?

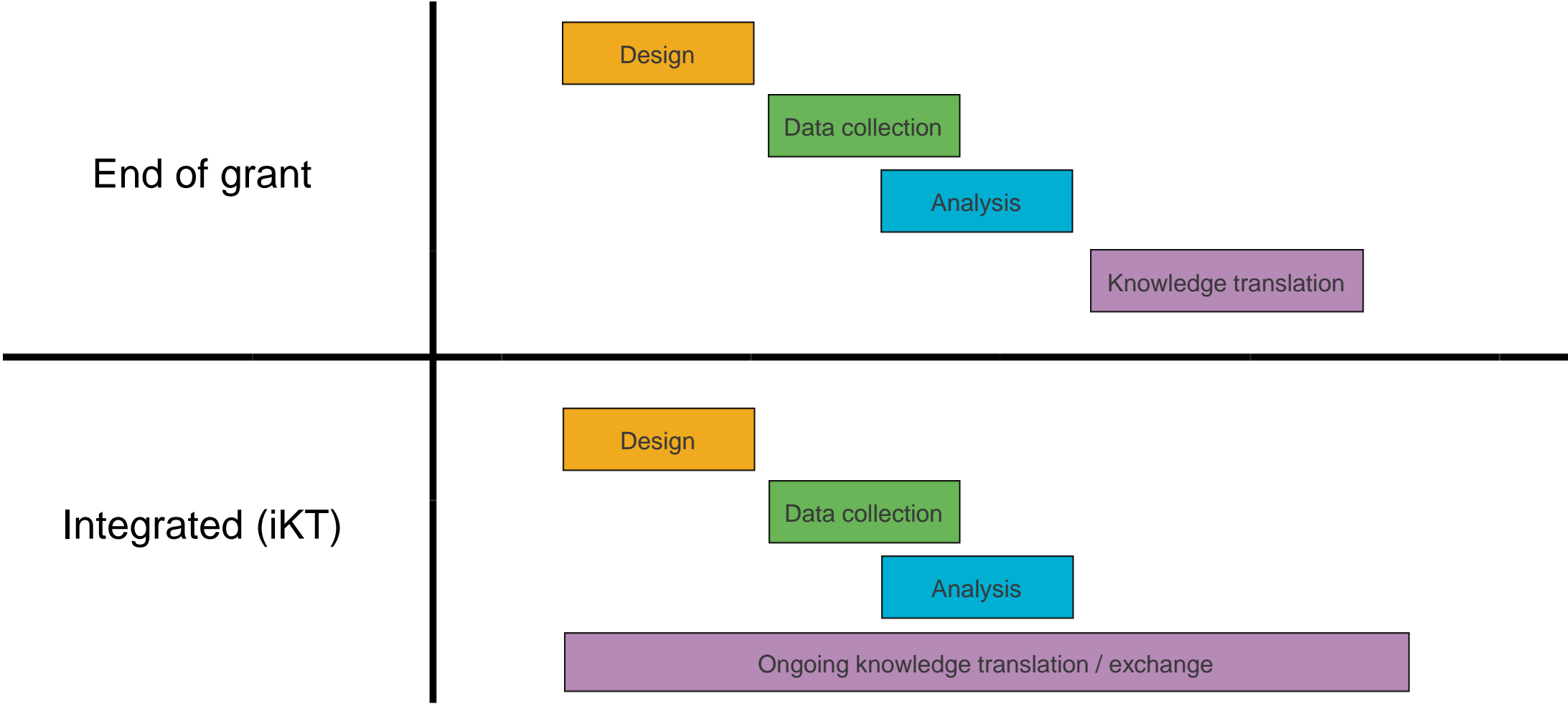


Knowledge  
Translation (KT)

Putting  
knowledge into  
action in order to  
improve health



# Approaches to KT



# Approaches to KT

End of grant

- Engaging with knowledge users after research is complete
- Cannot tailor research to users' needs
- Less likely that research will be applied

Integrated (iKT)

- Engaging with knowledge users from start
- Ability to tailor research to users' needs
- More likely that research will be applied

# What is KT?



Knowledge  
Translation (KT)

Putting  
knowledge into  
action in order to  
improve health

Sharing what we  
know about living  
a good life



# Indigenous KT

- Indigenous communities have always practiced KT
- Knowledge cannot be separated from action
- Unique knowledge pathways influenced by social, political, and physical environments
  
- We must approach KT with these things in mind
- Starting from the beginning
- Engaging as equal partners, sharing power and decision making
- Tailoring research and knowledge sharing to the community's needs and priorities

# Indigenous KT

"In contrast to the evolution of European knowledge and knowledge systems that has resulted in a separation of knowledge production from knowledge use, **in Indigenous contexts knowledge is almost always inextricably linked to action** both philosophically and practically."

Smylie J, Olding M, Ziegler C. 2014. Sharing What we Knowledge About Living a Good Life: Indigenous Approaches to Knowledge Translation. *Journal of the Canadian Health Libraries Association*, 35, 16-23.

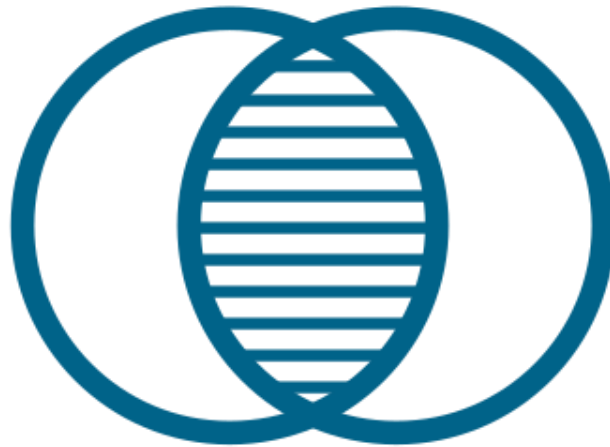
# Indigenous KT

"KT in health research is often conceptually presented as a separate and a value-added investment in non-Indigenous knowledge systems. Within Indigenous knowledge systems and contexts, **research without practical relevance or application has no merit or value.**"

Morton Ninomiya M, Maddox R, Brascoupe S, Robinson N, Atkinson D, Firestone M, Ziegler C, Smylie J. 2022. Knowledge translation approaches and practices in Indigenous health research: A systematic review. *Social Sciences & Medicine*, 301, 114898.



Knowledge Translation and Indigenous Data  
Sovereignty as inseparable





## Take the Training - Open Access

Use the links below to take the public **Open Access** version of the ICRP training.



### Introduction



### Module 1

Introduction to Important Concepts



### Module 2

Key Guiding Documents



### Module 3

A Principled Approach to Research



### Module 4

Next Steps in Research Action



### Module 5 (coming soon!)

Queen's University Local Context

Online open education training resource.

Assists researchers who are new to research in partnership with Indigenous communities, or who are researchers-in-training to:

- Operationalize required regulatory policy requirements and research directives;
- Ensure equitable inclusion of Indigenous and Western-oriented knowledge in research systems;
- And, in the case of Indigenous-specific enquiry, to privilege or give primacy to Indigenous ways of knowing and doing.

Tool available at: [www.queensu.ca/indigenous/decolonizing-and-indigenizing/community-research-partnerships-training](http://www.queensu.ca/indigenous/decolonizing-and-indigenizing/community-research-partnerships-training)



Criteria \ Score	1	2	3	4	5	Criteria Score
<b>Partnership with Indigenous Stakeholder(s)</b>	<p>Indigenous stakeholders are informed by research teams about projects but are not invited to engage in any phase of the project.</p> <p>The project appears to offer no lasting or tangible benefit to the Indigenous stakeholders. The budget does not meet the needs of the indigenous stakeholders.</p>	<p>Indigenous stakeholders are named as team members who are consulted throughout the project in regard to research priorities and outcomes.</p> <p>The project offers limited, short-term benefits to the Indigenous stakeholders. It is unclear whether the budget meets the stakeholder's needs and/or financial supports are not identified.</p>	<p>Indigenous stakeholders are named as team members who are involved throughout the project in identifying research priorities and outcomes.</p> <p>The project offers tangible benefits to the stakeholders, although limited and short-term. The budget meets some of the stakeholder's needs and some financial supports are identified.</p>	<p>Indigenous stakeholders are active partners who collaborate with team members throughout the research project.</p> <p>The project offers a numerous and long-lasting tangible benefits to the stakeholders. The budget meets many of the stakeholder's needs and financial supports are identified. The project proposal is attainable and accountable.</p>	<p>Indigenous stakeholders are equal partners with decision-making autonomy over attributes of the research project (e.g. use of Indigenous research methodologies).</p> <p>The project offers meaningful and lasting benefits to the stakeholders. This includes long-term training and capacity building, policy change. The budget meets all of the stakeholder's needs and numerous financial supports are identified. The project proposal is attainable and accountable.</p>	
<b>Knowledge into Practice</b>	<p>Indigenous stakeholders are informed of knowledge translation plans and activities by research team, but do not have decision-making power in regard to their data.</p>	<p>Indigenous stakeholders are consulted and minimally involved in developing knowledge translation plans and activities with research team, but do not have decision-making power in regard to their data.</p>	<p>Indigenous stakeholders are involved in the development and application of knowledge translation activities with research team, but it is unclear whether communities have decision-making power in regard to their data.</p>	<p>Indigenous stakeholders collaborate with research team in determining knowledge translation plans that are beneficial to Indigenous stakeholders. Indigenous stakeholders have some decision-making power in regard to their data. There is a healthy research relationship, but there is no formal research agreement in place.</p>	<p>Indigenous peoples' self-determination is respected as active creators and implementers of the knowledge translation plan. A research agreement is in place, reflective of OCAP and/or Metis data-governance principles, outlining a comprehensive knowledge translation plan that is beneficial to Indigenous stakeholders.</p>	
<b>Strengths-based Approach</b>	<p>The proposed project relies on Western-colonial based health indicators that are deficit-based; as well as Western health models to identify solutions.</p>	<p>The proposed project appears to consider existing Indigenous strengths-based approaches (e.g. resiliency and wellness) but does not appear to move towards overcoming deficit-based models.</p>	<p>The proposed project appears to be aware of Indigenous historical and social realities (trauma-informed) and is informed by Indigenous resiliencies and wellness however aims to provide solutions based on Western health models. The project appears to move towards overcoming deficit-based models.</p>	<p>The proposed project is aware of historic and social realities (trauma-informed) and references and capitalizes on Indigenous resiliencies and wellness as defined by Indigenous community partners. This project appears to move towards overcoming deficit-based health research models but may be informed by Western-colonial based health indicators.</p>	<p>The proposed project is aware of historic and social realities (trauma-informed) and aims to improve quality of life and offer strengths-based solutions by building on Indigenous pathways to resiliency and wellness. The proposed project shifts perceived deficits away from the individual and places health issues into the appropriate context (e.g. colonization, systemic racism).</p>	
<b>Indigenous Knowledges and Ways of Knowing</b>	<p>Western knowledges and ways of knowing are privileged throughout the proposal. The proposal does not include any plans to include any Indigenous stakeholders in contextualizing and interpreting data.</p>	<p>Indigenous knowledges and ways of knowing are recognized, though not meaningfully engaged within the proposal. The proposal includes plans to consult Indigenous stakeholders about data, however their roles are unclear or tokenized.</p>	<p>Indigenous knowledges and ways of knowing are acknowledged and there is effort in the proposal to include them in methodologies, analysis, etc. The proposal includes plans to involve Indigenous stakeholders in contextualizing and interpreting data, their roles are clearly outlined but participation is limited.</p>	<p>Indigenous knowledges and ways of knowing contribute greatly to the proposal; this is reflected in methodologies, analysis, etc. Indigenous stakeholders help decide which knowledge and ways of knowing are used. The proposal includes plans to collaborate with Indigenous stakeholders in order to contextualize and interpret data, their roles are clearly outlined but participation is not integrated throughout the entire duration of the project.</p>	<p>Indigenous knowledges and ways of knowing are privileged throughout the proposal, methodologies, analysis, etc. Indigenous stakeholders help decide which knowledge and ways of knowing are used. The proposal indicates that Indigenous stakeholders will work closely with the research team to contextualize and interpret data, their roles are clearly outlined and participation is integrated throughout the entire duration of the project.</p>	

Total Score





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## Knowledge into Practice:

1

Indigenous stakeholders are informed of knowledge translation plans and activities by research team, but do not have decision-making power in regard to their data.

2

Indigenous stakeholders are consulted and minimally involved in developing knowledge translation plans and activities with research team, but do not have decision-making power in regard to their data

3

Indigenous stakeholders are involved in the development and application of knowledge translation activities with research team, but it is unclear whether communities have decision-making power in regard to their data.

4

Indigenous stakeholders collaborate with research team in determining knowledge translation plans that are beneficial to Indigenous stakeholders. Indigenous stakeholders have some decision-making power in regard to their data. There is a healthy research relationship, but there is no formal research agreement in place.

5

Indigenous peoples' self-determination is respected as active creators and implementers of the knowledge translation plan. A research agreement is in place, reflective of OCAP and/or Metis data-governance principles, outlining a comprehensive knowledge translation plan that is beneficial to Indigenous stakeholders.

# Exemplar Projects



# **Mamow Ahyamowen**

**KTE in the Context of a Northern Ontario First Nations  
Epidemiology Alliance**

# History

- First Nations epidemiology alliance
- Collaboration between First Nations health and social service organizations serving communities in northern ON
- Formed in 2016
- Shared need for high quality, community-specific health data



# Organizations

Giishkaandago'Ikwe Health Services



Weeneebayko Area Health Authority

Independent First Nations Alliance



Wabun Tribal Council

Keewaytinook Okimakinak



Sioux Lookout First Nations Health Authority

Kenora Chiefs Advisory



Shibogama First Nations Council

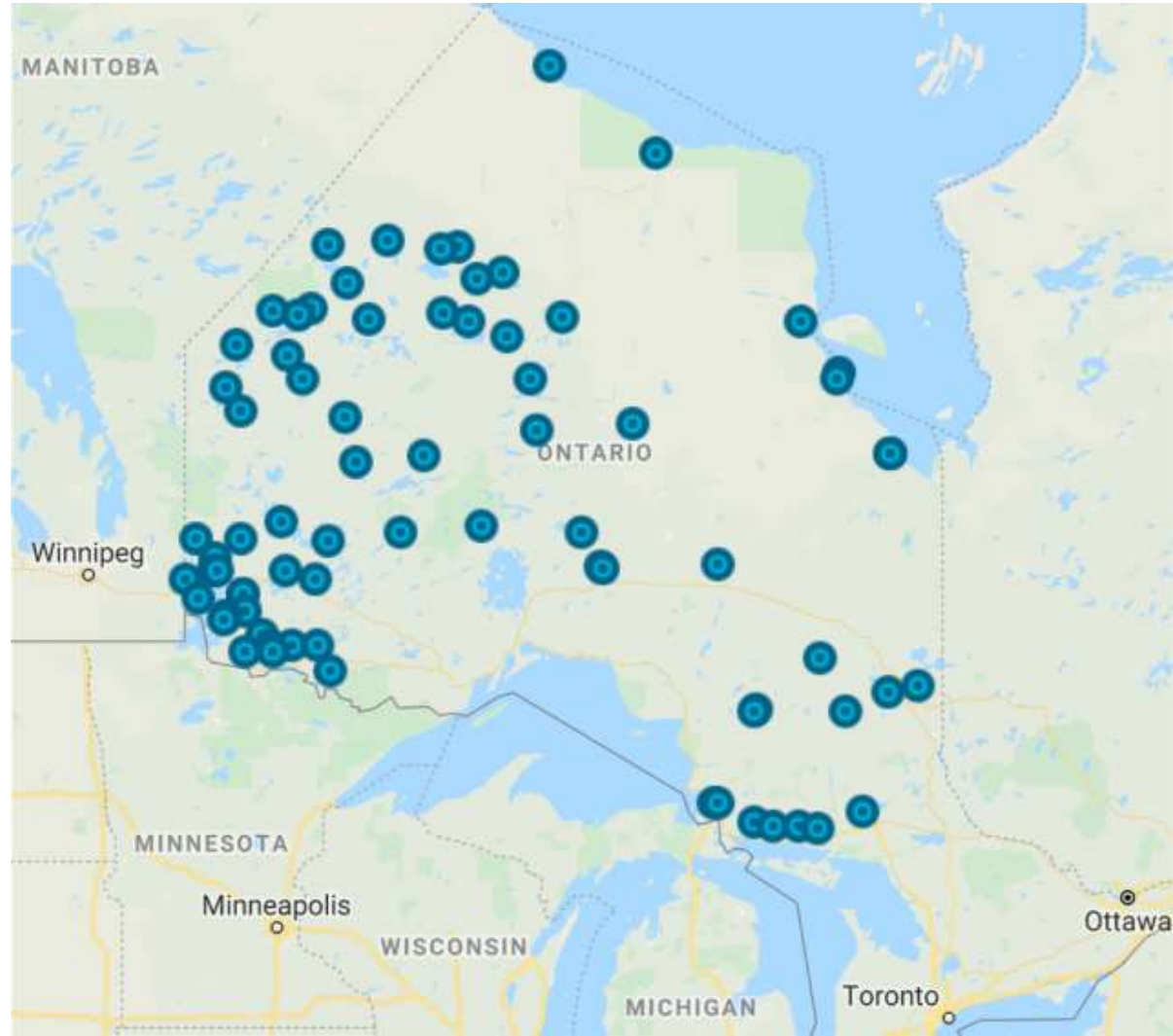
Maamawesying North Shore Community Health Services



Mushkegowuk Health Department

Matawa First Nations Management





Map of First Nations communities served by Mamow Ahyamowen



Map of Mamow Ahyamowen service area overlaid with map of Western Europe

## We work with communities to



find, analyze, and  
interpret data



in response to questions  
that they have prioritized

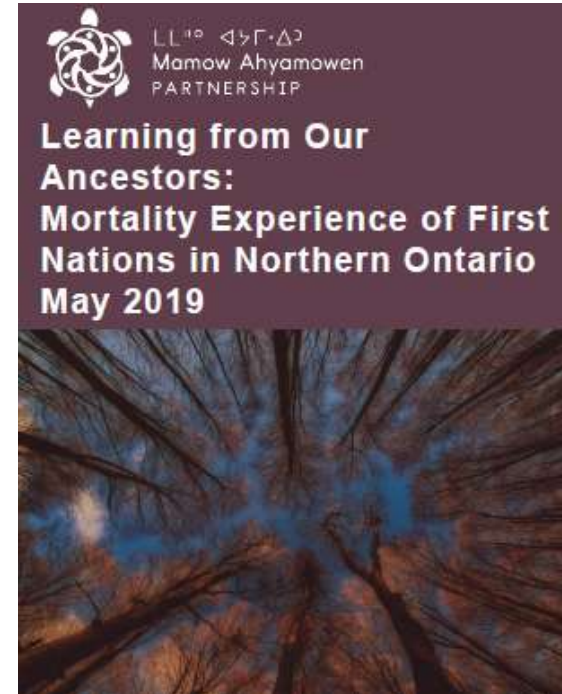


following a culturally-  
respectful path



# Learning From Our Ancestors

- Our first analysis project
- Focused on the health of people who passed away between 1992 and 2014
- Used health administrative data linked with vital statistics and population files at ICES
- 59 out of 74 communities opted in



# Knowledge Translation

## Knowledge Products

- Reports - 4 different types:
  - Partnership level
  - Partner level
  - Community level
  - Companion reports
- Slide decks
- One-page infographics
- Whiteboard video (forthcoming)



# Knowledge Translation

## Knowledge Products

- Reports - 4 different types:
  - Partnership level
  - Partner level
  - Community level
  - Companion reports
- Slide decks
- One-page infographics
- Whiteboard video (forthcoming)

## Engagement & Dissemination

- Interactive workshops
- Quarterly newsletter
- Press releases
- Presentations at academic conferences
- Webinars (e.g. NCCIH)
- Social media (forthcoming)



# Uses & Applications

Member organizations have used this data to:



Apply for funding



Inform planning



Support local initiatives

## Next Steps

We are currently planning more in-depth analyses on:



Chronic Conditions



Mental Health &  
Addictions



Injuries

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# **PRENATAL OPIOID EXPOSURE AND NEONATAL ABSTINENCE SYNDROME: A RESEARCH PROJECT WITH 13 FIRST NATIONS COMMUNITIES IN ONTARIO**





## THE NEEDS & CONCERNS OF COMMUNITIES: THE SEED

- Concerns raised by several First Nations communities about how to better support the health and wellness of school-age children with prenatal opioid exposure
- Genesis of a First Nations-centred research partnership





## PROJECT GOALS

- Build strong relationships with First Nations communities
- Gather and share community and culturally specific information about the impacts of prenatal opioid exposure and neonatal abstinence syndrome

# TWO ARMS OF THE RESEARCH PROJECT

## Quantitative

Rates of POE & NAS + maternal & baby characteristics using existing health information housed at ICES and governed by First Nations

## Qualitative

Focus groups & interviews (parents, families & caregivers, service providers, Elders)



# OUR APPROACH

Grounded in First Nations understandings of wellness and a strengths-based approach to research

Used research to shift from patterns of intergenerational trauma to intergenerational healing

Centred on community needs and interests

Embedded principles of First Nations data governance

Designed and implemented an integrated KT strategy

## COMMUNITY PARTNERS INFORMED & SHAPED ALL ASPECTS OF THE PROJECT

- Championing the project and engaging decision makers
- Participating in engagement and planning sessions
- Coordinating focus groups and interviews
- Promoting the respect, privacy, safety, and well-being of community members
- Examining project materials, adapting research methods, selecting data elements, and reviewing KT activities
- Ensuring research products and processes were community and culturally appropriate



**SHARING AND  
USING THE  
FINDINGS TO  
IMPROVE THE  
HEALTH &  
WELLNESS OF  
COMMUNITY  
MEMBERS**





# SHARING AND USING THE FINDINGS

- Community reports and presentations
  - Co-authorship & acknowledgements
- Aggregate report
- Community presentations
- Communications plan
  - Aggregate report to be posted on the ICES website with permission from all communities
  - Media release and graphics





**EXAMPLE #1:  
USE OF IMAGERY**

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**EXAMPLE 2:  
CREATING  
ADAPTABLE &  
TRANSFERABLE  
INFORMATION**





**PHASE 2:**  
**COMMUNITY-  
SPECIFIC  
KNOWLEDGE  
TRANSLATION  
PLANS  
+  
A COMMUNITY OF  
PRACTICE**



**RESEARCH FUNDING AUTONOMY**

**FIRST NATION'S RIGHTS TO  
SELF-DETERMINATION**

**FIRST NATIONS-LED  
KNOWLEDGE TRANSLATION**



# KEY TAKEAWAY

***“NOTHING ABOUT  
US, WITHOUT US”***

Brenda Johnson,  
Core Research Team member



# THANK YOU TO OUR FUNDERS



**CHILD-BRIGHT**  
Network

# Questions and Discussion

Thank you  
Miigwech  
Nia:wen