



**May 2, 2023**  
12:00 pm – 1:00 pm

# **Recognizing the Harmful Effects of Historical Research and Building Trust with Indigenous Communities**

**FNIM Data and Indigenous Data Sovereignty Webinar Webinar Series : Part 1**

This is part of a series on Equity, Diversity, Inclusion, Indigeneity, and Accessibility in Research hosted by the Primary Care of Ontario Learning and Research (POPLAR) Network, in collaboration with the Alliance for Healthier Communities.

# Meet the Team

**Dr. Nicole Blackman, DNP, RN, MN**

**Director of Integrated Care and Clinical Services**



**Dakota Recollet**

**Director of Cultural Safety**



# About the IPHCC



The Indigenous Primary Health Care Council (IPHCC) is an Indigenous-governed and culture-based organization. It was established to support the advancement and evolution of Indigenous primary health care service provisions and planning in Ontario, through partnerships, education and advocacy.

The IPHCC uses Indigenous solutions to transform Indigenous health outcomes and decolonize health systems by:

- Empowering the voices of Indigenous peoples and communities to effect change.
- Partnering with Indigenous communities, mainstream health organizations and government agencies.
- Gathering and sharing data about the health status of Indigenous peoples in Ontario and inequitable service gaps.
- Equipping Council members with the tools, training and networks to provide quality health care.



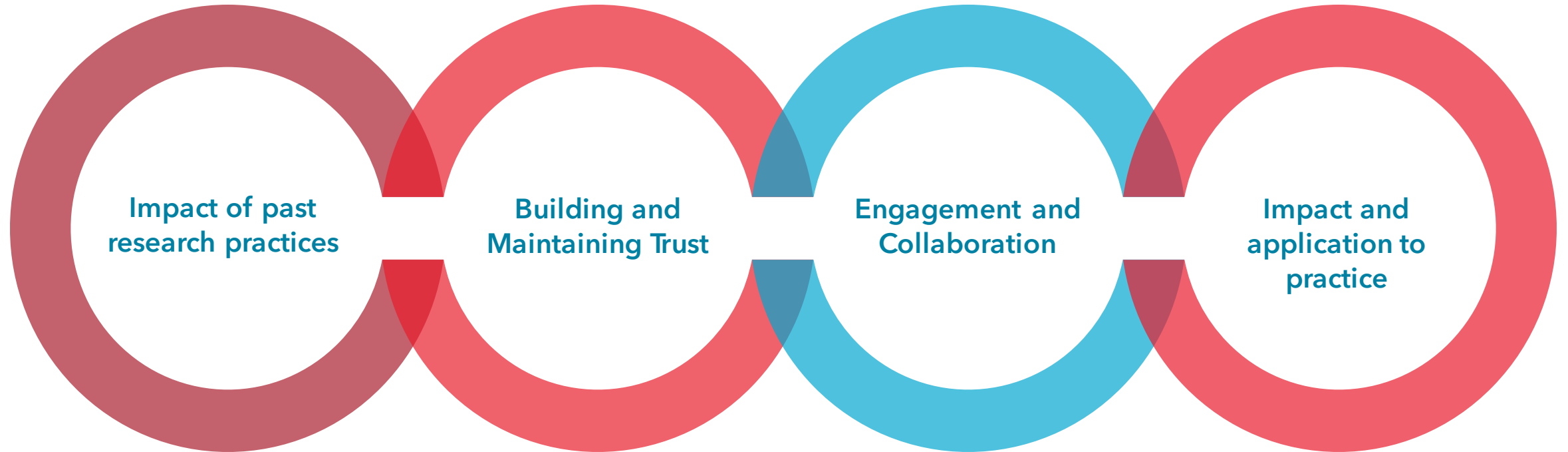
# Indigenous Health in Indigenous Hands

## Indigenous Primary Health Care Organizations (IPHCOs):

- Indigenous Community Health Centres (IHCs)
- Aboriginal Health Access Centres (AHACs)
- Family Health Teams (FHTs)
- Nurse Practitioner-Led Clinics (INPLCs)
- Indigenous Interprofessional Primary Care Teams (IIPCTs)



# Learning Objectives



**Impact of past  
research practices**

**Building and  
Maintaining Trust**

**Engagement and  
Collaboration**

**Impact and  
application to  
practice**

Acknowledge the impact of past research practices on Indigenous populations.

Understand the importance of building trust with Indigenous communities.

Discover what meaningful engagement and collaboration from an Indigenous perspective.

Consider the impact and application of knowledge shared today within your own practice.



**Let's Get Started...**



## Truth & Reconciliation Commission of Canada (TRC) Report (2015)

- Identified 94 Calls to Action
- Highlighted the important role of research to advance the understanding of reconciliation.
- Ten principles of reconciliation were provided
  - #4: reconciliation requires constructive action on addressing the ongoing legacies of colonialism.
  - #9: reconciliation requires political will, joint leadership, trust building, accountability, and transparency, as well as a substantial investment of resources.

## Federal Response

- 2017 - the Canada Research Coordinating Committee was created and reaffirmed the federal agencies commitment to the Calls of Action
- 2018 - the federal government committed \$3.8M to SSHRC, who in collaboration with other federal granting agencies, began implementation of the Strengthening Indigenous Research Capacity initiative.

# FINAL REPORT OF THE TRUTH AND RECONCILIATION COMMISSION OF CANADA VOLUME ONE: SUMMARY

*Honouring the Truth,  
Reconciling for the Future*



# Historical Approach to Indigenous Health Research

- Objective
- Top-down
- Researcher controlled

...Reflecting colonial research ideology





**Uncovering the  
dark history of  
research and  
Indigenous  
communities...**

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# Early Research on Indigenous Peoples and Communities

- Use of Indigenous knowledge and expertise to aid European explorers in navigating the land and surviving in harsh environments.
- Was often exploitative and did not recognize or value Indigenous knowledge and expertise on its own terms.

# Assimilation Policies and Research

- Indian Act
  - Residential school system
  - Indian hospitals
  - Child welfare interventions - resulted in Sixties Scoop and ongoing Millennial Scoop.
- Sexual Sterilization Act
- Inuit Relocation





# Experimentations at Residential Schools

## Drug testing

- Residential school in Kenora tested experimental drug on children with ear problems

## Vaccination

- Trial of BCG vaccine for tuberculosis

## Nutrition research

- Performed by Indian Affairs
- Lead researcher was Lionel Pett – primary architect of Canada's Food Guide



\* VI. POINTS TO BE CONSIDERED

1. Why the Study is to be Carried Out in Residential Schools:

- (a) It is, first of all, important to know what can be done with children rather than adults in such a study because many adult troubles really begin in childhood.
- (b) It has always been found to be more convenient to conduct such a study in schools rather than amongst the general public; this is certainly true among Indian bands who may often be hard to contact.
- (c) The contact for several years is important, and for this reason Residential Schools offer more stability than Day Schools or the reserves.
- (d) Better cooperation can be expected within the Residential Schools.

# Experimentations at Indian Hospitals



## Vaccine testing

- Fort Qu'Appelle Sanatorium, Fort San Saskatchewan
- BCG vaccine trial on Indigenous infants was funded by the National research Council.
- Patients were used to test new vaccines, medications, painful procedures and surgeries.

## Tuberculosis treatment

- Lung removals with local anesthetic only
- Partial lung removal long after antibiotics became the standard treatment.



# Additional examples of research-related harm

## **Misuse of blood samples**

- Samples taken to test for diabetes but also used to test for genetic schizophrenia.
- Samples thought to explore high rates of arthritis used to determine ancestry.
- Sample sold or given to other researchers for unknown use.

## **Accessing data without permission**

- In Labrador, researcher accessed local suicide statistics without permission and presented findings at a conference and never to the community.



# Harmful Research Practices

- Misconception of voluntary consent
- Apathetic towards Indigenous priorities
- Limited to no community involvement
- Did not seek approval with interpretation
- Unreciprocated compensation
- Helicopter research
- Lack of cultural safety or appropriateness with informed consent process
- Issues with confidentiality
- Disrespect of basic human dignity
- Conducted genetic research demeaning to Indigenous dignity
- Presence of alternative motives
- Theft of human remains and cultural property
- Inappropriate commercialization
- Deficit-based

“the researchers are going to assimilate all of us into one box”

“the word ‘Indigenous’ should never be used because it tells you nothing: who’s Indigenous?”

“...stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful”

“researchers quote out of context and don’t give anything back to the community”

## Indigenous voices...

“researched to death”

“just because researchers go through ethical reviews at the university does not mean the research is ethically appropriate for Indigenous communities”

“researchers take what they want and then leave”

“jagged worldviews colliding”



# Timeline

Medical researchers began studying Indigenous peoples' health, often with the goal of identifying supposed genetic or cultural factors that contributed to their poor health outcomes.

Canadian government began conducting medical experiments on Indigenous children in residential schools and Indian hospitals, including experimental vaccines and inadequate nutrition and medical care.

1876

1920s

1928

1930s

1970s

The Indian Act is passed in Canada, which gives the federal government control over many aspects of Indigenous peoples' lives, including their health care.

The Indian Health Survey is conducted, which collects data on the health status of Indigenous peoples. This data is used to justify funding for medical services in Indigenous communities.

Indigenous peoples began challenging exploitative research leading to the development of the OCAP principles of Ownership, Control, Access, and Possession.

# Timeline

The Canadian Institutes of Health Research was established which funds health research in Canada, including research on Indigenous health.

Establishment of the First Nations Information Governance Centre (FNIGC) to ensure research in Indigenous communities was respectful and ethical.

1974

1986

1990s

2000

2010

In 1974, the National Indian Brotherhood (now known as the Assembly of First Nations) released a report highlighting poor health outcomes and called for greater control over healthcare delivery in Indigenous communities.

Research shifted to a more collaborative, community-based approach with researchers working with Indigenous communities to identify their health priorities and strengths.

The CIHR established the Institute of Aboriginal Peoples' Health to support research that is respectful and relevant to Indigenous peoples.

# Indigenous Resistance and Self-Determination



Despite the ongoing impacts of colonization and assimilation policies, Indigenous peoples in Canada have always resisted and fought back against these injustices. This includes resistance through cultural practices, political organizing, and legal challenges.

In recent years, there has been a growing movement to decolonize research and center Indigenous perspectives in all aspects of research on Indigenous peoples. This includes recognizing and valuing Indigenous knowledge and expertise, as well as acknowledging the ongoing impacts of colonization and working towards Indigenous self-determination.





# Challenges and Opportunities for Decolonizing Research



Decolonizing research on Indigenous peoples in Canada is not without its challenges. Researchers must be willing to confront their own biases and assumptions, and work in partnership with Indigenous communities to ensure that research is respectful, ethical, and beneficial.

However, there are also many opportunities for decolonizing research, including the potential for greater collaboration and understanding between Indigenous and non-Indigenous peoples, and the possibility of creating new knowledge and ways of knowing that are grounded in Indigenous perspectives and worldviews.



“

*First Nations, Métis and Inuit in  
Canada have been kept on the  
sidelines of Canadian research too  
long.*

”

— The Honourable Kirsty Duncan,  
Minister of Science and Sport



# Building and Maintaining Trust



**Recognize  
the Diversity**

**Build  
relationships  
with  
Indigenous  
Communities**

**Prioritize  
Community  
Needs**

**Obtain  
Informed  
Consent**

**Use a  
Collaborative  
Approach**

**Respect  
Indigenous  
Knowledge  
and  
Intellectual  
Property**

**Ensure  
Confidentiality  
and Privacy**

**Provide  
Feedback,  
Build  
Capacity and  
Follow-up**





# Meaningful Engagement and Collaboration

1. Relationship Building
2. Community Control
3. Reciprocity
4. Cultural Safety
5. Two-Eyed Seeing

# The Seven Sacred Values

Courage

Honesty

Humility

Respect

Truth

Love

Wisdom



# Hawk and Wolf Teachings



The Hawk can see everything; the Hawk reminds us to:

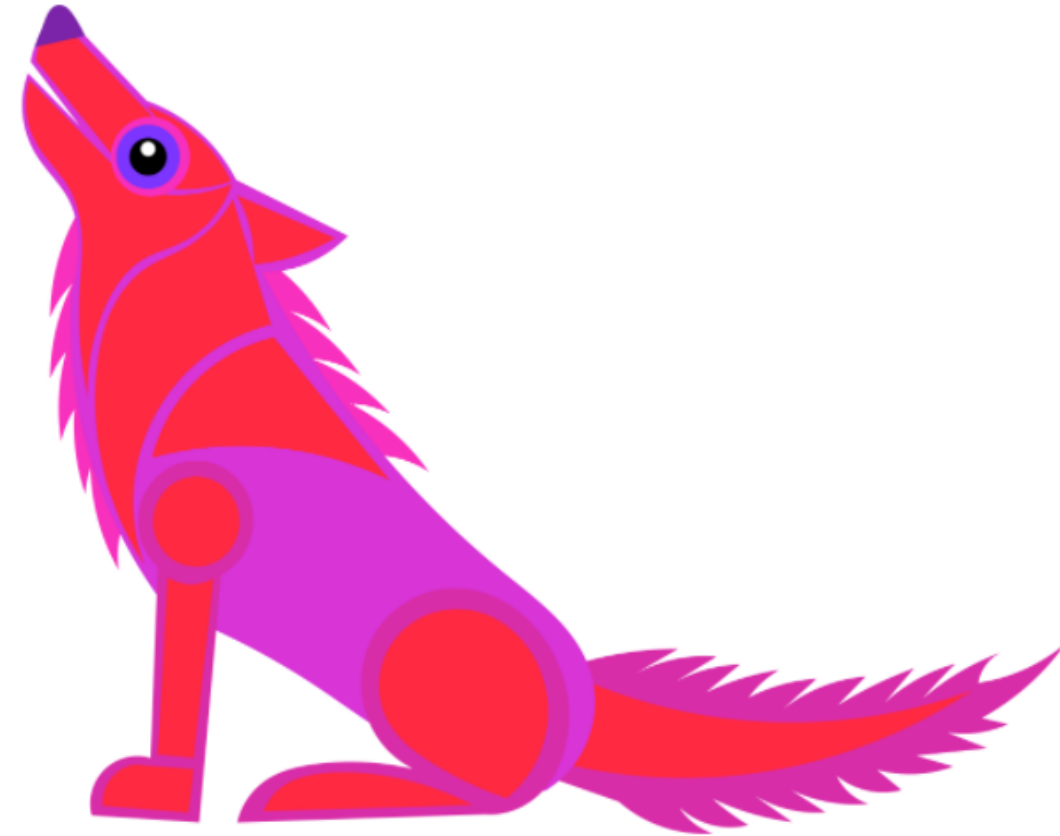
- Take a wider view
- Understand the history of colonialism and how it impacts Indigenous Peoples and populations
- Open ourselves up to new knowledge systems, as they are gifts



# Hawk and Wolf Teachings

The Wolf teaches us humility; the wolf reminds us to:

- Overcome failure. There will be challenges in relationships that will sometimes result in failure. The key is to learn from these mistakes
- Be good citizens, as you are a guest in communities
- Be humble in your relationships
- Listen and learn to communicate carefully



# Indigenous Ethics Review Boards (IERB)

Ethical review committees that are composed of Indigenous people and operate within Indigenous communities. These boards are designed to ensure that research conducted with Indigenous peoples is conducted in a culturally appropriate and safe way. IERBs may be composed of elders, knowledge keepers, community members and researchers.

1. First Nations Health Authority Ethics Review; BC and Ontario
2. Northern Ontario School of Medicine Indigenous Health Research Ethics Board
3. Sioux Lookout First Nations Health Authority Research Ethics Board
4. Six Nations Research Ethics Board
5. Waakebiness-Bryce Institute for Indigenous Health Research Ethics Review Board

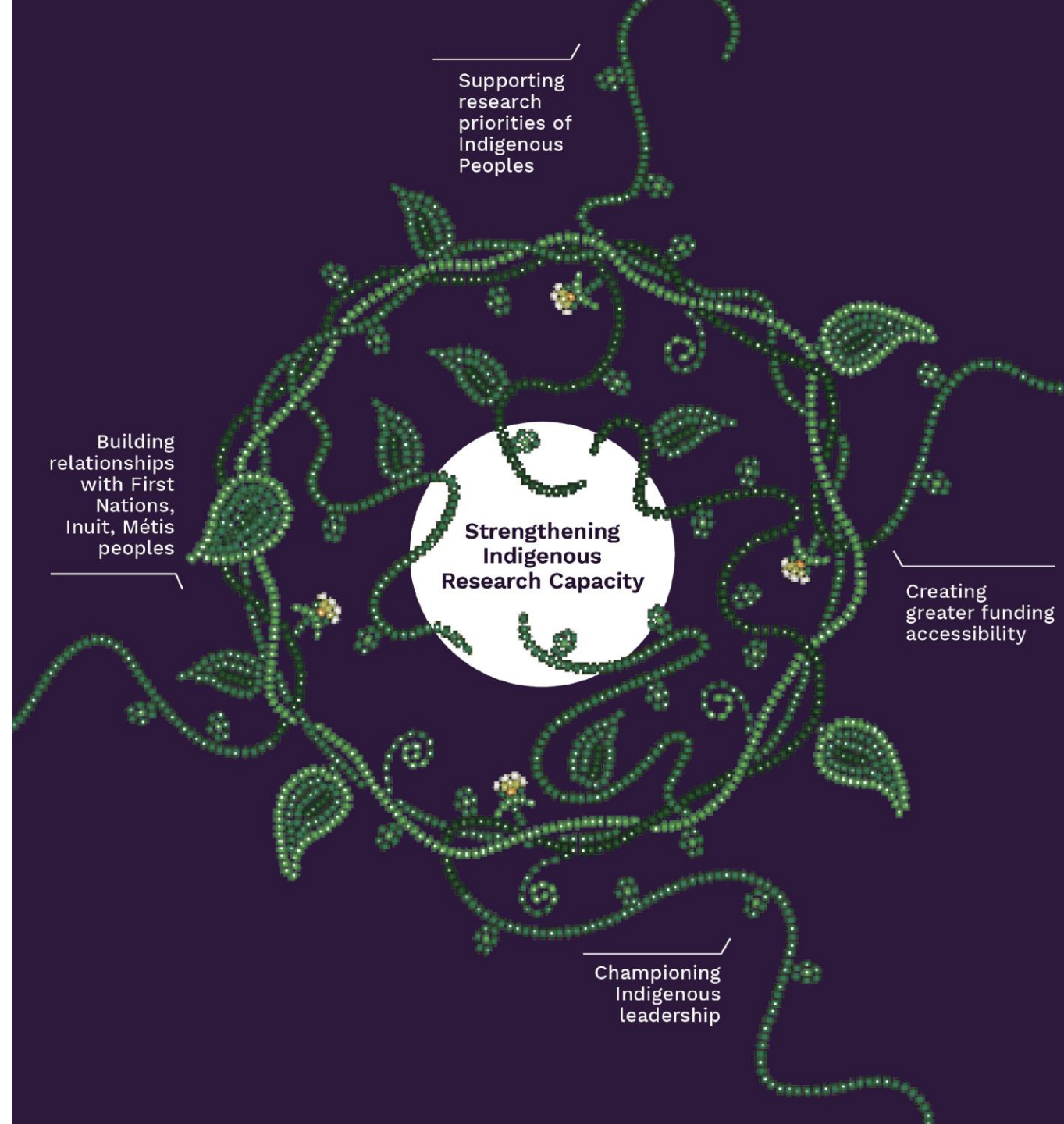


# Indigenous Research as Storytelling





# Setting New Directions to Support Indigenous Research and Training



# Conclusions

The history of research on Indigenous peoples in Canada is a complex and often painful one, but it is also a story of resilience, resistance, and hope. As we continue to grapple with the legacies of colonization and work towards Indigenous self-determination, it is essential that we center Indigenous perspectives and knowledge in all aspects of research.

By doing so, we can create a more just and equitable society that recognizes and values the diversity of Indigenous peoples and their contributions to our shared history and future.





Meegwetch  
Miigwetch  
Maarsii  
Nakurmiik  
Nia:wen!