



# Honouring the Past, Pace and Ways of Knowing:

How to co-create space for Indigenous ways  
of knowing and being

October 16, 2024  
(1:00-2:15pm EST)

# Today's speakers

In order of appearance

- **Host:**
  - Clifford Mushquash, Advisor, Indigenous Engagement, McMaster Health Forum
- **Speakers:**
  - Jennifer Walker, Haudenosaunee member of the Six Nations of the Grand River, Lead of the research hub at the Indigenous Health Healing Lodge, and associate professor at McMaster University
  - Bernice Downey, a woman of Ojibwe and Celtic heritage, a medical anthropologist, retired nurse, researcher and the inaugural Associate Dean of Indigenous Health at McMaster University
- **Partners:**
  - Maureen Smith, Global Evidence Commission and Cochrane Consumer Network
  - Tanja Kuchenmüller, WHO EVIPNet

# Putting evidence at the centre of everyday life:

A global webinar series for citizen leaders and citizen-serving NGOs



## Available as recordings:

- [Session I](#). The big picture – Putting evidence at the centre of everyday life (June 2023 – [recording available](#))
- [Session II](#). Citizen-backed evidence – Engaging citizens in providing evidence synthesis and support (including for evidence-informed policy-making) (Aug 2023 – [recording available](#))
- [Session III](#). Battling the bunk – Bringing evidence and citizen engagement to bear in addressing misinformation (Nov 2023 – [recording available](#))
- [Session IV](#). Pushing past platitudes – from co-design to holding leaders to account for achieving real system transformation felt by everyday people in everyday life ([recording available](#))

## Today's session:

- [Session V](#) – Honouring the Past, Pace and Ways of Knowing: How to co-create space for Indigenous ways of knowing and being



## Indigenous Research - A reclamation Story

‘Honouring the Past, Pace  
and Ways of Knowing: How  
to co-create space for  
Indigenous ways of  
knowing and being’



Indigenous Health  
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## **Dr. Bernice Downey**

**BSCN, MA, PHD (OJIBWE-SAULTEAUX)**

**Associate Dean, Indigenous Health,  
Assistant Professor, School of  
Nursing & Dept. Psychiatry**



## **Dr. Jennifer Walker**

**PHD (HAUDENOSAUNEE)**

**Research Hub Lead  
Associate Professor, HEI and IHLL  
Canada Research Chair in Indigenous  
Health Data and Aging**



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The Indigenous Health Learning Lodge  
Mino Bimaadiziwin Mishkiki Aapjishnik Gamik  
'The good life; medicine recovery healing lodge.'

Tsi nón:we ayakonniyóhake táhnon  
aonsayakota'kritehake  
'The place of good life and return to health'.

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# IHI Mission Statement

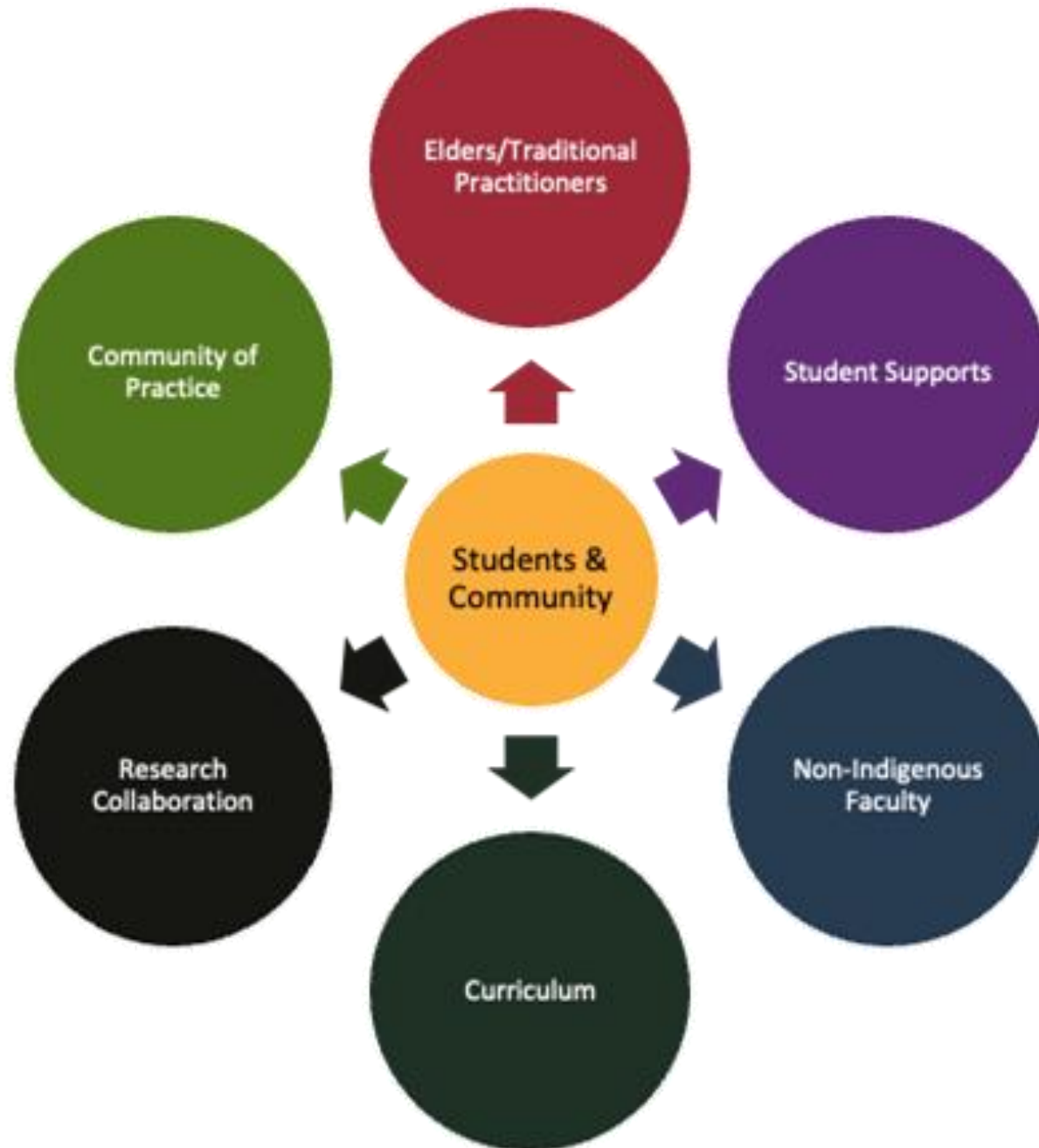
The Faculty of Health Science at McMaster University strives to **respond to the significant health disparities** that exist between Indigenous peoples and non-Indigenous Canadians.

The Faculty is **committed to the development and implementation of a comprehensive, 'whole-of-Faculty' Indigenous health initiative** that reflects the principles and values of a reconciliation-based approach as documented by the Truth and Reconciliation Commission of Canada.

The Faculty will achieve this goal by engaging local Indigenous community representatives and other collaborators and **will draw on self-determining leading practices** in post-secondary Indigenous education reform.



# Indigenous Health Learning Lodge (IHLL)



## Focus areas

- Administration
- Education & Curriculum
- Research
- Faculty Leadership & Support
- Student Supports & Services
- Indigenous Ways of Knowing



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# OVERVIEW: OBDAWIN – TRUTH TELLING

- Historical perspective: pause and reclaim
- Gathering internationally, nationally, regionally
- Initiating Indigenous Research Principles & Guidelines
- Strengthening our systems & enriching our research experience: Indigenous Data Sovereignty
- Working together with the mainstream research community: addressing the ‘how’
- The importance of relational accountability and non-interference



# DILEMMA

Western Scientific Knowledge=  
Western Scientific KT

The Dilemma: IK cannot be verified  
by scientific criteria nor can  
science be adequately assessed  
according to the tenets of IK.

Path forward: explore the interface

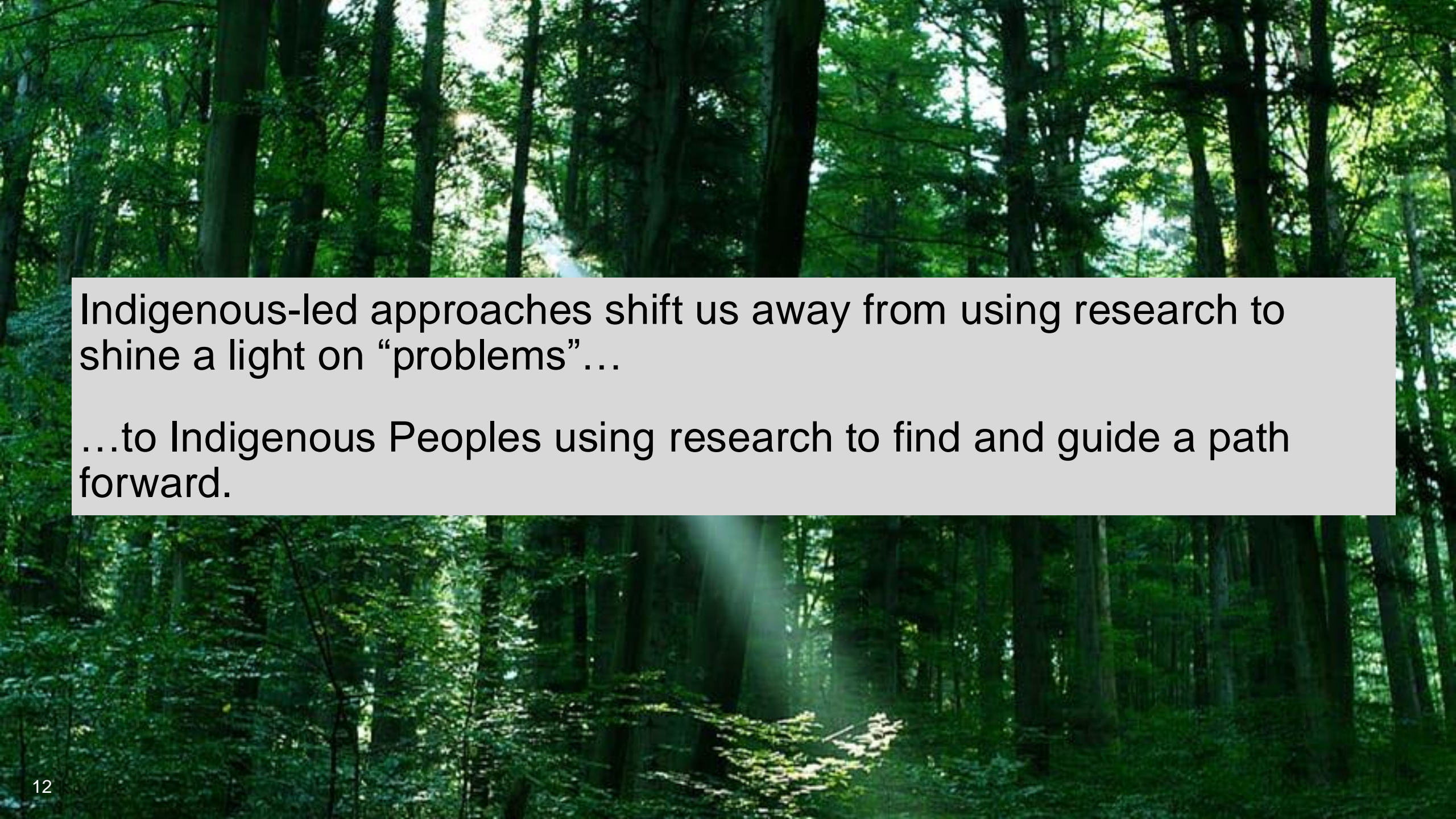


# Deficit-Based Approaches to Indigenous Health Research and Knowledge Translation & Exchange

- Indigenous research is often used to advance a discourse of:
  - Difference
  - Disparity
  - Disadvantage
  - Dysfunction
  - Deprivation
- Harmful impacts of deficit-based approaches:
  - stereotyping and marginalization of Indigenous Peoples
  - pose a risk for Indigenous people seeking services and negatively affects how professionals provide front-line care and services

Hyett, S., Gabel, C., Marjerrison, S. & Schwartz, L. (2019). Deficit-Based Indigenous Health Research and the Stereotyping of Indigenous Peoples. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, 2(2), 102–109. <https://doi.org/10.7202/1065690ar>

Walter M. Data politics and indigenous representation in Australian statistics. In: Kukutai T, Taylor J, editors. *Indigenous data sovereignty: towards an agenda*, CAEPR Research Monograph, 2016/34. Canberra: ANU Press; 2016.

A lush green forest with sunlight filtering through the trees. The scene is filled with tall, slender trees and dense foliage, creating a serene and natural atmosphere. Sunlight rays are visible, casting a warm glow on the forest floor.

Indigenous-led approaches shift us away from using research to shine a light on “problems”...

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

# PAUSE & RECLAIM: COMING TOGETHER

Indigenous people have been engaged in global self-determining efforts to have control over their institutions, resources, knowledge and information systems.

UN Permanent Forum on the Rights of Indigenous Peoples

United Nations Declaration on the Rights of Indigenous People (UNDRIP) (2007)

WHO COMMISSION ON THE SDOH (2005-2008)



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# 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



# 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



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## **Indigenous Data Sovereignty:**

The right of Indigenous Peoples and Nations to govern the collection, ownership, and application of their own data

Data Sovereignty is right, and it is also a responsibility for Indigenous Peoples





# Indigenous Peoples' Rights in Data

## DATA FOR GOVERNANCE

### RIGHT TO SELF-DETERMINATION

the ability to organise and control data in relation to a collective identity

### RIGHT TO POSSESS

the ability to exercise jurisdictional control over the ways that data flow/move/are queried

### RIGHT TO USE

the ability of individuals and collectives to use data for their own purposes

### RIGHT TO CONSENT

the expression of digital autonomy and the ability to assess risks and accept potential harms

### RIGHT TO REFUSE

the right to say "no" to certain uses of data

### RIGHT TO RECLAIM

the right to reclaim, retain, and preserve data, data labels, and data outputs that reflect Indigenous Peoples' identities, cultures, and relationships

## GOVERNANCE OF DATA

### RIGHT TO GOVERN

the right to lead and collaborate in the development and implementation of protocols and in decisions about access to data

### RIGHT TO DEFINE

the right to define lifeways of knowing and being including how they are represented in data

### RIGHT TO PRIVACY

the protection of collective identities and interests from undue attention, also including the possibility of requesting omission and/or erasure

### RIGHT TO KNOW

the ability to track the storage, use, and reuse of the data and who has had access to them

### RIGHT TO ASSOCIATION

the recognition of provenance and terms of attribution

### RIGHT TO BENEFIT

the opportunity to benefit from the use of data and equitable benefit sharing from derivatives of data

Global Indigenous Data alliance. (2023). "Indigenous Peoples' Rights in Data." The Global Indigenous Data Alliance. GIDA-global.org.

DOI: 10.6084/m9.figshare.22133160





## Co-creating space together: A framework that can guide us

- Non-interference, self-determination
- Working in the space in between

Hill, R. W., & Coleman, D. (2019). The Two Row Wampum-Covenant Chain Tradition as a Guide for Indigenous-University Research Partnerships. *Cultural Studies ↔ Critical Methodologies*, 19(5), 339-359. <https://doi.org/10.1177/1532708618809138>



# Indigenous Research - A reclamation Story

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Thank you



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