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# Community Data Governance: From Frameworks to Practice

PHO Learning Exchange

August 12, 2024

## Land Acknowledgement

- This webinar is being hosted and recorded in Toronto on the traditional territory of many nations, including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples.
- We also recognize the enduring presence of many diverse First Nations, Inuit and Métis peoples across the regions to which this webinar is being delivered.

## Today's Speakers

- **Jemal Demeke**, Researcher, Wellesley Institute
- **Emily Akerman**, Equity Consultant, Equity Unit, City of Toronto
- **Roxane Gillis**, First Nations, Inuit, and Métis Data Governance Consultant, Data for Equity, City of Toronto
- **Christian Daboud**, Manager, Health Equity and Indigenous Reconciliation, Middlesex-London Health Unit

# Agenda

- 5 minutes ● Overview and objectives
- 45 minutes ● Panel presentations:
  - **The Wellesley Institute**
  - **City of Toronto**
  - **Middlesex-London Health Unit**
- 15 minutes ● Q&A with participants
- 5 minutes ● Closing

# Learning Exchange Objectives

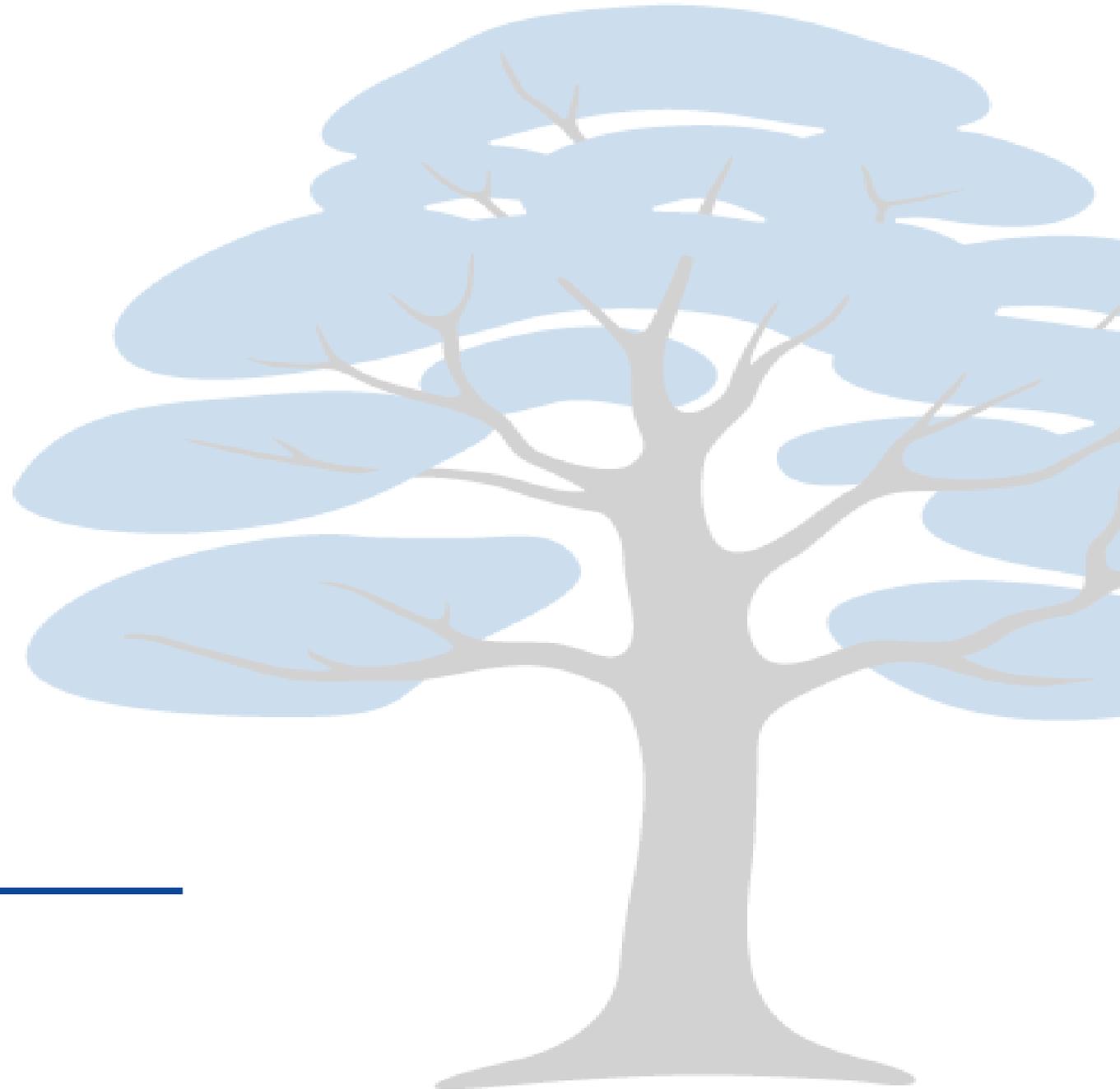
Describe the role of community data governance as being central to the responsible collection and use of race-based data.

Describe promising practise for engaging communities in data governance at the local public health level.

Understand examples of meaningful collaborations with community to inform institutions' responsible collection and use of race-based data.

# Community Data Governance

Jemal Demeke



# Outline

- Understanding community data governance
- Towards alignment on the what and how of sociodemographic data collection for health
- Moving forward on community governance of data

# Moving forward on community involvement and governance

# Community trust is an important issue in big data in Canada

- Focus on individual privacy well developed
- Some population groups concerned about impacts of use of big data on their communities
- Quality and completeness of data sets linked to community trust
- Inattention to trust can lead to data sets with insufficient quality and quantity of sociodemographic data to promote equity

# Example of Black communities in Canada

- Experience of Black communities include:
  - Data collected / extraction not used for community benefit
  - Data collected poorly or analyzed poorly leading to harm
  - Data deliberately used for harm (individual and community)
  - Lack of data used to drive equity
  - Monetization of data with no community benefit

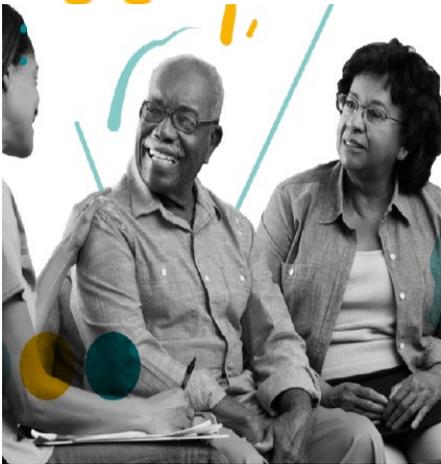
# Engagement Governance Access Protections

## EGAP framework

# EGAP framework

- The EGAP framework was created by the BHEWG as a starting point for supporting data sovereignty for Black communities to have ownership and control over their collective data.

## Engagement



## Governance



## Access

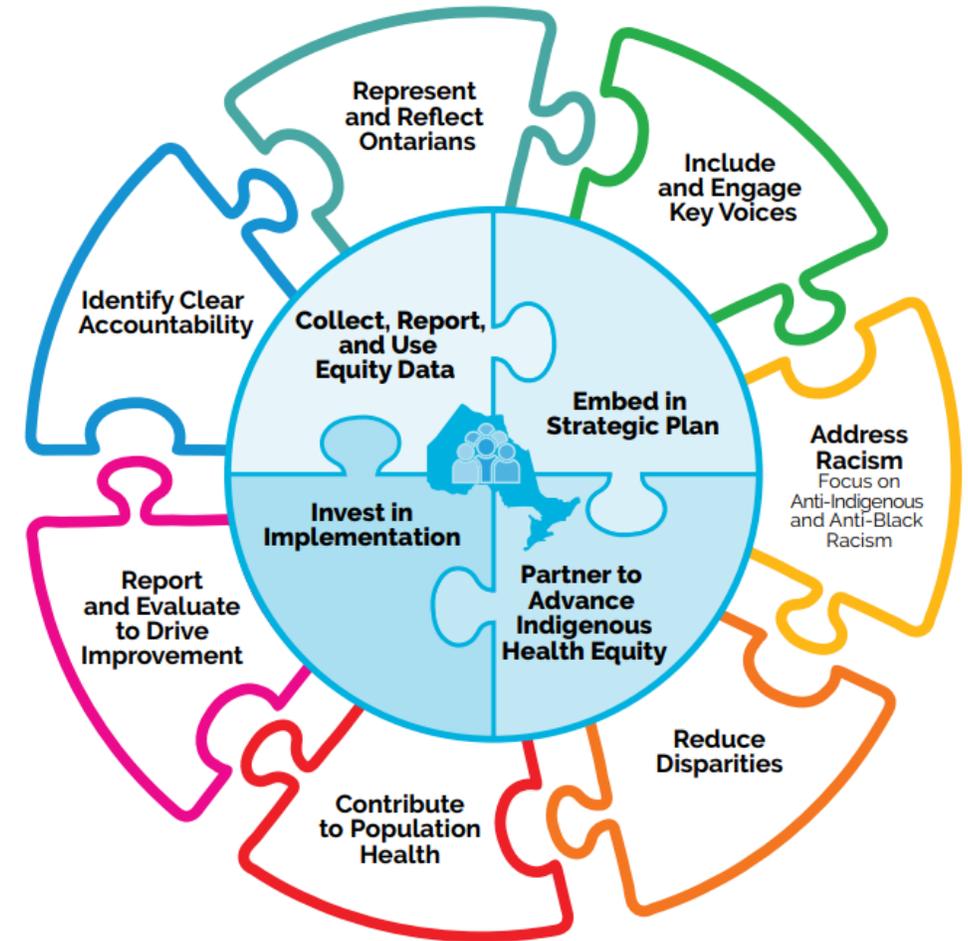


## Protection



# Ontario's EGAP implementation guide

- Multiple health service providers agreed to pilot the implementation of EGAP in Toronto Region
- We followed these early adopters to capture their narrative journey and experiences
- An implementation guide was developed to scale up regionally



# Simple pathway to implement EGAP



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Organizational agreement & readiness

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Community engagement

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Governance tables

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Supporting access

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Ensuring protections

# Reflections from EGAP implementation

- The journey to embody EGAP relies on:
  - Establishing organizational readiness and building awareness
  - Assessing technological infrastructure and personnel capacities
  - Building collaboration internally and externally

# City of Toronto Black Community Data Governance Framework

# City of Toronto and community governance

- The City of Toronto governs diverse datasets and are focused on building a strategic plan on its use to address inequities



- This data could illustrate the experiences across several systems including healthcare, housing, child welfare, and justice

# City of Toronto: Black community data governance framework

- Principles act as guiding values
- Objectives and areas of emphasis provide strategic priorities
- Outcomes outline desired benefits from implementation



# City of Toronto community governance framework implementation

- This work continues through early implementation of the framework at the city
- We will explore the establishment of community governance bodies and their role in decision-making processes

# Towards alignment of the what and the how of sociodemographic and race-based data collection

# Federal agencies are invested in race and sociodemographic data collection and use

- For instance, initiatives underway at
  - Canadian Institute for Health Information
  - Economic and Social Development Canada
  - Federal Anti-Racism Secretariat
  - Public Health Agency of Canada
  - Statistics Canada



# There are numerous provincial efforts including:



- Nova Scotia: Race-based data collection via health card (Fall 2021)
- Manitoba: Race and socio-demographic data collection at point of contact of health services (Spring 2023)
- British Columbia: Demographic survey launched for sample population (Fall 2023)

# Wellesley Institute's role in race-based data



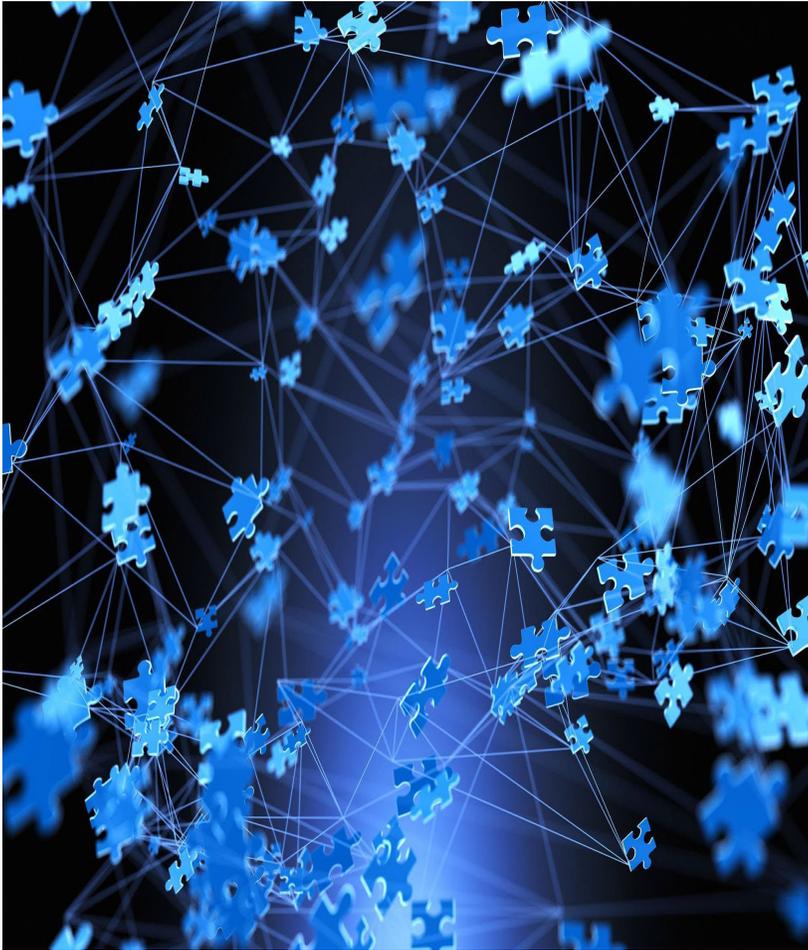
Wellesley was asked to convene a space for **cross-pollination** of ideas and **relationship building** between **national, provincial and local initiatives**



We hope to build **national consensus** in our approach to the collection, use, and governance of race-based data

# National Race-Based Data for Health Group

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- Canadian Institute for Health Information
- BC Data Services
- Federal Anti-Racism Secretariat
- Public Health Agency of Canada
- Nova Scotia Department of Health & Wellness
- Rady Faculty of Health Sciences, University of Manitoba
- Saskatchewan Health Authority
- Ontario Health
- Ontario Human Rights Commission
- Public Health Ontario
- Anti-Racism Directorate
- Information and Privacy Commissioner of Ontario

# Summary

- Collection and use of socio-demographic and race-based data can significantly improve health
- Alignment of the what and how of sociodemographic and race-based data collection could benefit Canada
- Models of community governance offer the promise of improved big data sets and data justice



# Data for Equity

**Presenters: Emily Akerman and Roxanne Gillis**

Data for Equity refers to the use of disaggregated data that is broken down by sociodemographic groups **to understand experiences, identify equity and prosperity goals, develop programs and policies** that serve residents more equitably, monitor progress, and assess equity impacts.

The Data for Equity Strategy was approved by Council in November 2020.



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## What is Data for Equity?

# How did we get here?



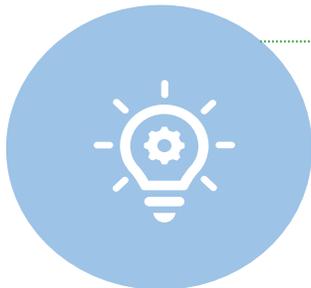
## **The Barrier**

FNIM, Black, and equity-deserving groups face systemic discrimination and barriers that impact their access to opportunities and outcomes.



## **The Need**

An approach to better amplifying, understanding, identifying and addressing those barriers using evidence and data.



## **The Response**

Enabling the City to collect and use consistent and high-quality socio-demographic and disaggregated data, with an understanding of the unique experiences of these groups, including with data itself.

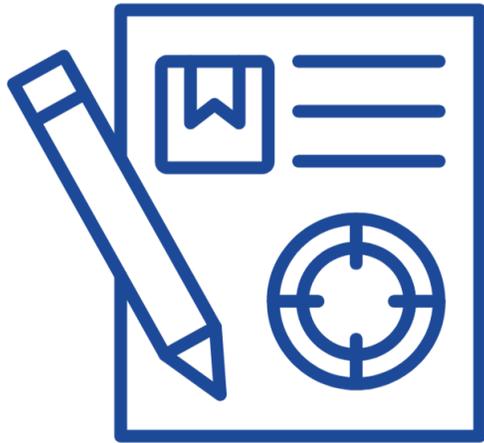
# Guiding Principles

**Data for Equity has 5 core principles:**

1. Equity and Human Rights
2. Open Data
3. Privacy and Security
4. FNIM Data Governance
5. Black Data Governance

# Objectives

The objectives of First Nations, Inuit, and Métis Data Governance Strategic Framework and Black Data Governance Frameworks are to have these communities own, analyze and report their own data away from a colonial institution. This happens through our 3 objectives.



**1. Initiation**



**2. Collaboration**



**3. Framework**

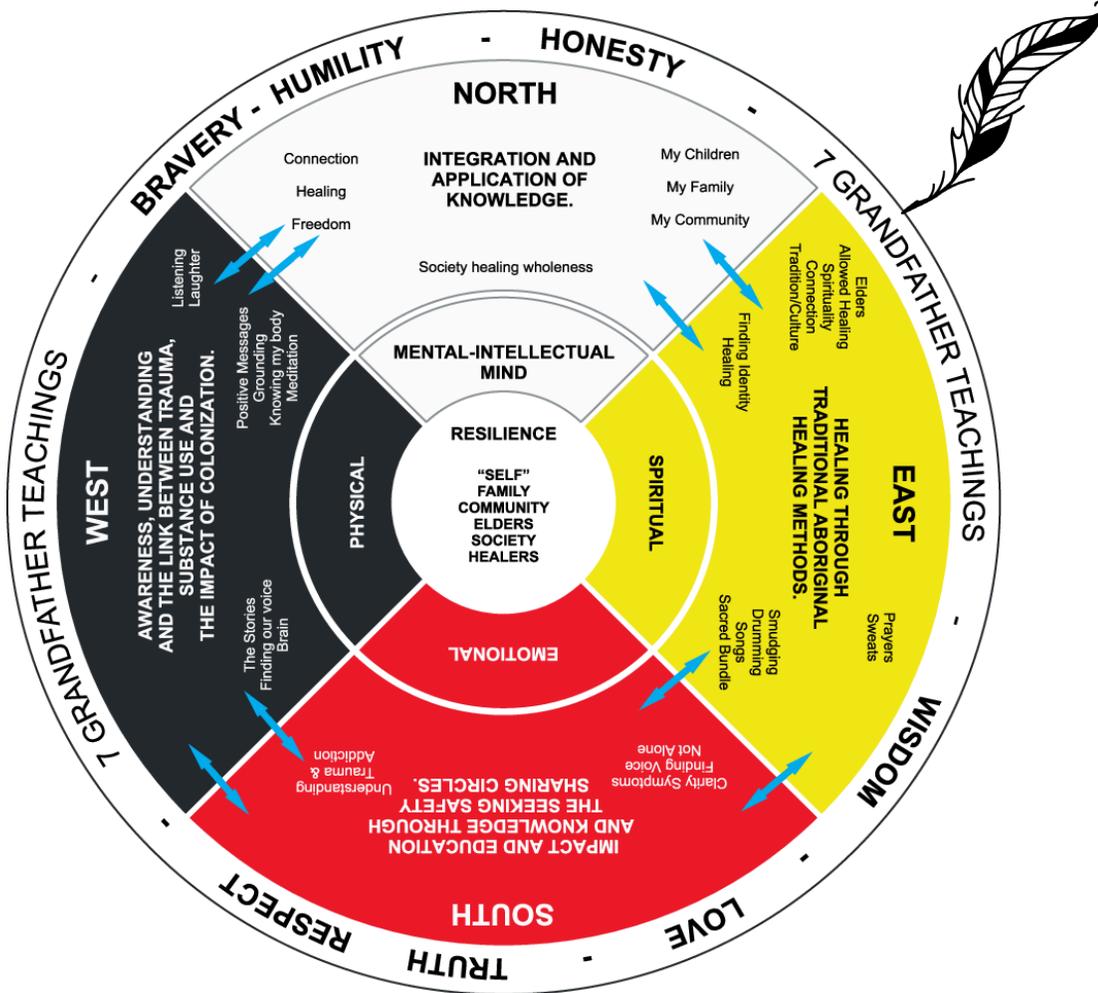
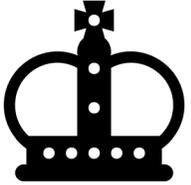
# First Nations, Inuit and Métis (FNIM) Data Governance Strategic Framework



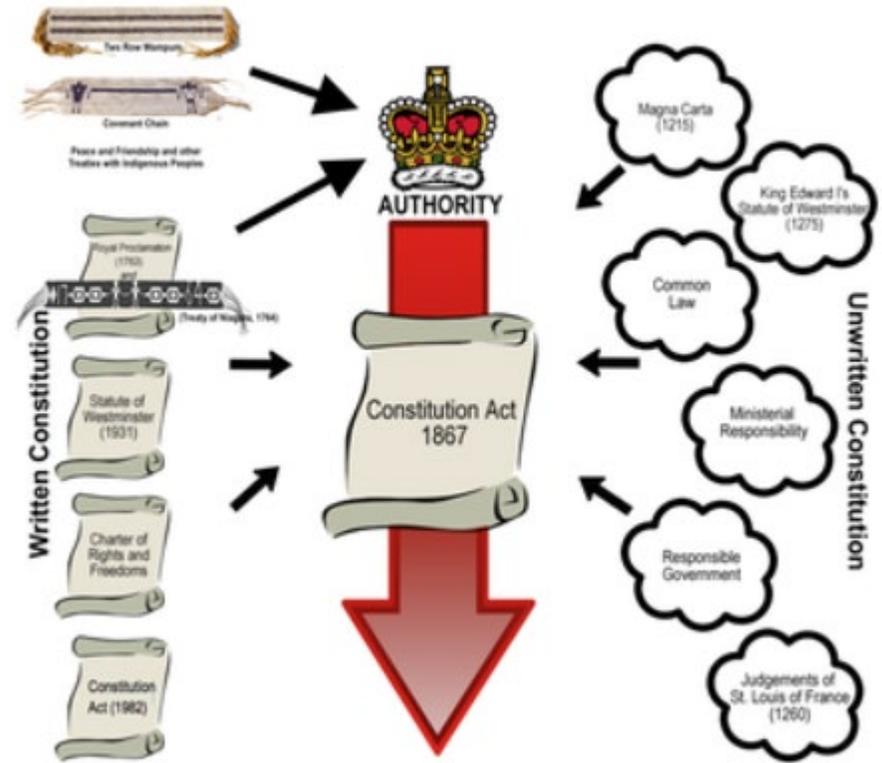
# Historical Implications



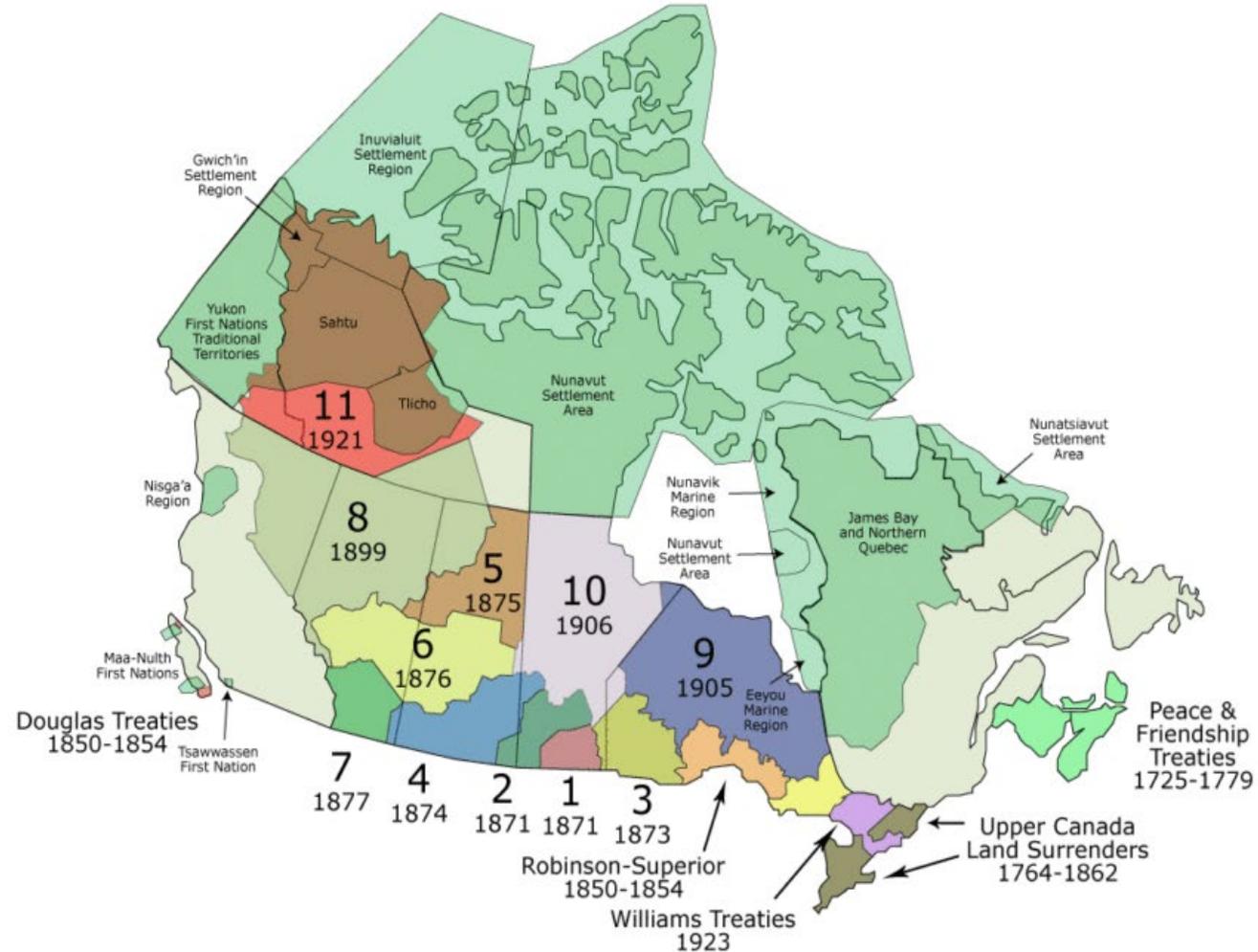
# Cultural Differences in Governance



## The Canadian Constitution



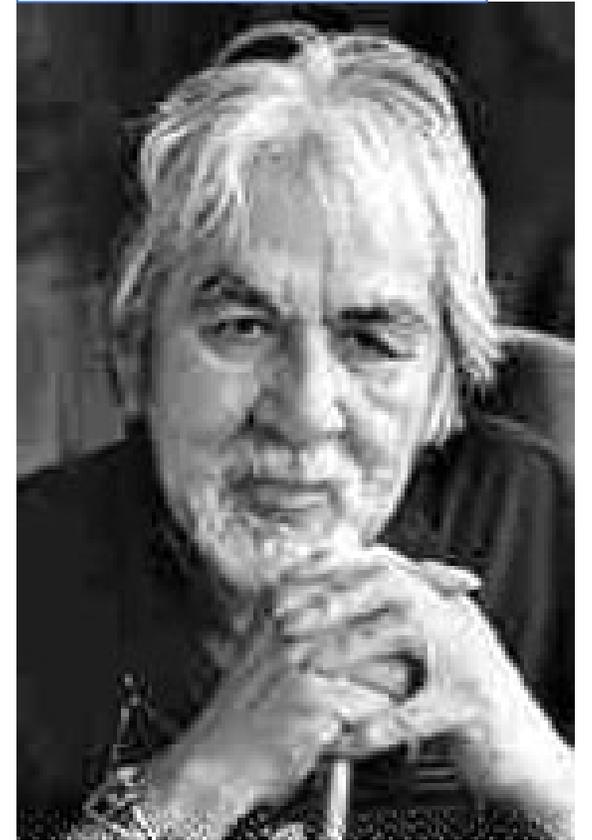
# Land Dispossession and Legal Challenges in Data



# Section 35 of the Canadian Constitution



Norval Morrisseau



# UNDRIP and Data Sovereignty



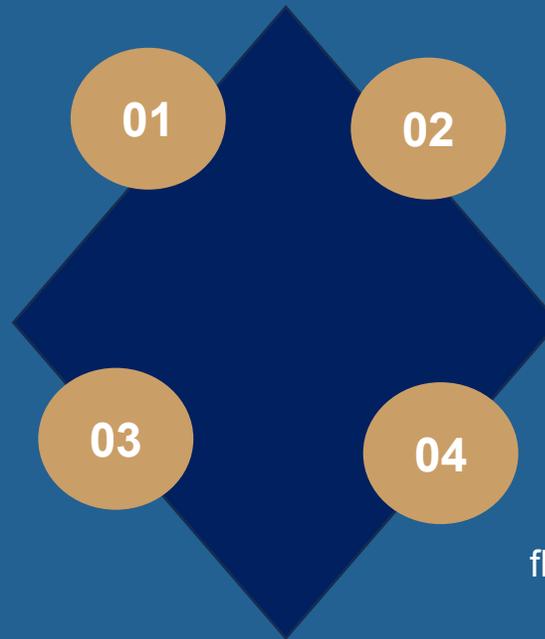
# Key Reflections

## Trust and Power Dynamics

Recognizing power dynamics, historic and ongoing harms of data and that colonial institutions should not own, store, analyze or report data from First Nations, Inuit and Métis communities

## Diversity of Communities

Understanding the vast differences of Nations and then within different First Nations because of location (including language and dialect, some traditions etc.)



## Collaboration

Driving forward this approach requires centering of communities always and a deep understanding of their contexts

## Iteration

Recognizing that the work, contexts, experiences are ever-evolving and being flexible, open in the approach, pivot as needed and always being responsive to the experiences of FNIM peoples. Having a learning approach and mindset.

# Next Steps

- Very much in the information gathering phase, and understanding what data is to FNIM peoples
- Still in the research and development phase; Consultations ongoing;
- It is council mandated to develop
- We've created an interim guide to support staff while the larger framework is being developed based on our current knowledge



**Pikogan Powwow in Abitibi-Témiscamingue, Quebec**

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# Resources

## City of Toronto

[Data for Equity Strategy – City of Toronto](#)

[First Nations, Inuit and Métis Data and Technology Circle](#)

## FNIM Resources

[Home - The First Nations Information Governance Centre  
\(fnigc.ca\)](#)

[Native-Land.ca | Our home on native land](#)

# Contact Information

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# The Evolving Story of Race Based Data Collection and Use at MLHU

Presentation for Public Health Ontario Learning Exchange  
Event

August 12, 2024

# The Geography of The Middlesex London Health Unit (MLHU)

- Situates it in proximity to:
  - The Oneida of The Thames First Nation
  - The Chippewas of the Thames First Nation
  - The Munsee-Delaware Nation
- Many Indigenous Lead organization also serve the area:
  - SOAHAC London
  - Atlohsa Family Healing Services
  - N'Amerind (London) Friendship Centre

## MLHU Foundational Documents

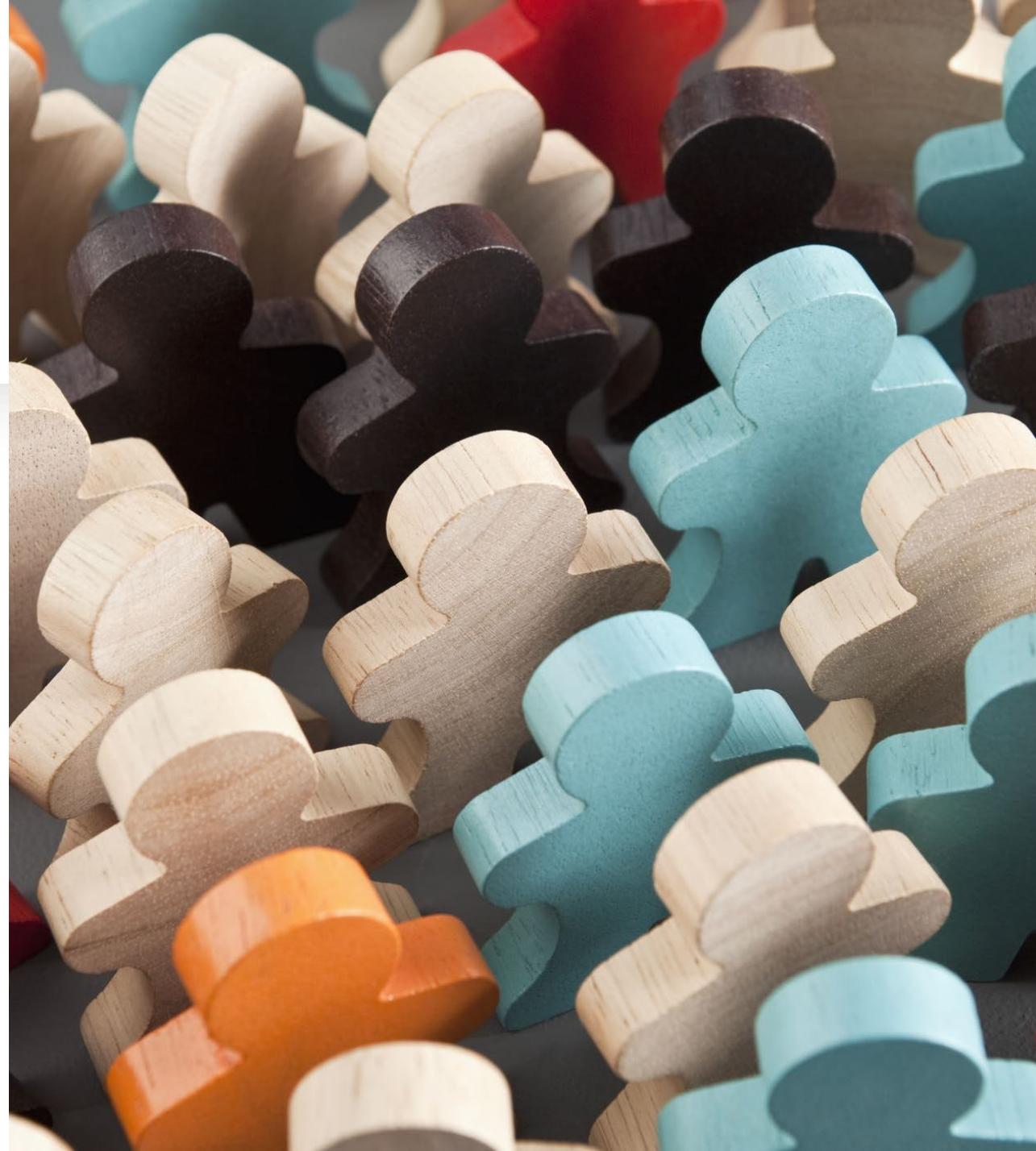
- The Taking Action for Reconciliation Plan (**TAFR**)
- The Anti-Black Racism Plan (**ABRP**)

## The Health Equity and Reconciliation Team (HEART)

- Is responsible to implement the **TAFR** and **ABRP** through strategic projects like the **SDOH Data Collection Initiative**:
  - The collection and use of race-based data is recommendation number 1 of the ABRP!
  - And aligned with the BOH strategic goals

# Our Race-based Data Collection Vision

- To increase organizational and staff capacity **to collect** race-based and sociodemographic data to achieve a client-centered and culturally humble approach to data collection.
- To increase organizational capacity **to utilize** race-based and sociodemographic data to identify health inequity and share with partners for collective action to reduce inequities.

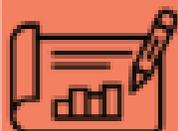


## HISTORY OF THE PROJECT TO DATE



### DECIDING WHAT TO ASK - MAY TO SEPTEMBER 2022

14 types of demographic questions considered (e.g., "race," gender)  
3 focus groups with MLHU staff



### PLANNING - APRIL TO MAY 2023

2 types of questions prioritized ("race," Indigeneity)  
4 pilot teams selected. 3 Indigenous partner meetings. 1 African Caribbean and Black partner meeting



### STAFF AND LEADER TRAINING - JUNE 2023

11 leaders trained and consulted  
Ways of asking and recording information were tested



### COLLECTING DATA (PILOT) - JULY TO SEPTEMBER 2023

4 pilot teams started asking clients  
Ways of asking continually improved based on staff and client feedback



### LESSONS LEARNED - JULY TO ONGOING

4 pilot teams started asking clients  
Ways of asking continually improved based on staff and client feedback

## **However, the Human Story Behind the History is important**

- This is where data governance development began

## **However, the Human Story Behind the History Is More Important**

We learned that:

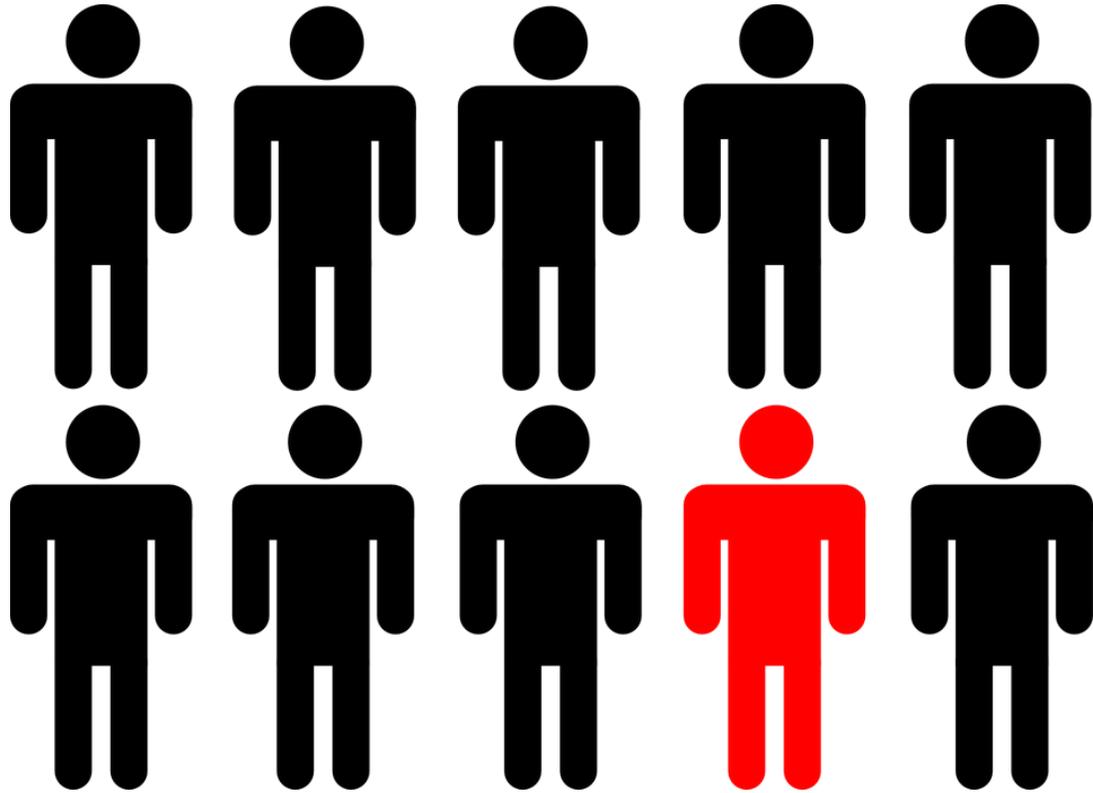
- Committed relationship that is trustworthy is the primary mechanism for data to flow in both directions

## **However, the Human Story Behind the History Is More Important**

We learned that:

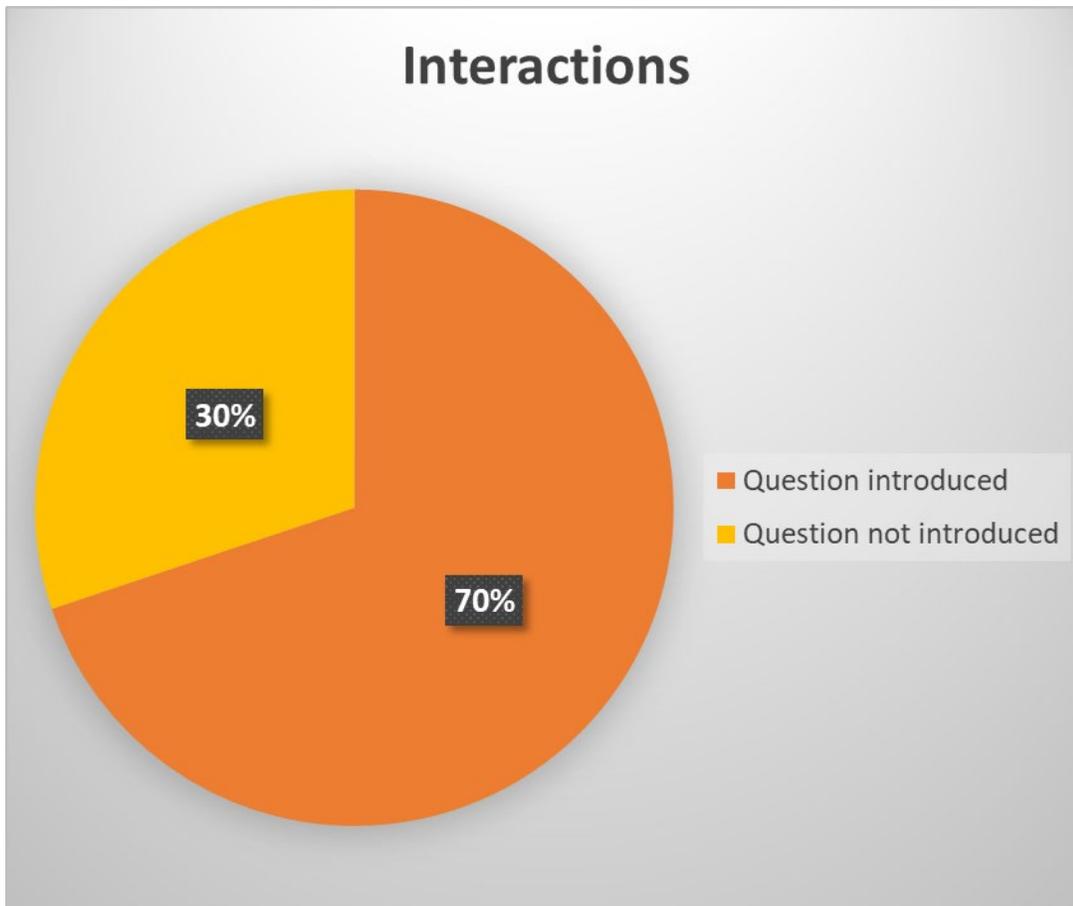
- We can only fulfil the ethical data governance principles with strong relationship independent of 'data' collection

# Client Response Rate



- 90% of clients asked were willing to respond

# Staff Participation Rate



- Staff asked about race and Indigenous Identity during 70% of client interactions

# Implementation and Change Management Lessons

- The staff capacity, technological requirements, engagement and leadership required to implement is very complex
- Give yourself time to build and nurture relationship with internal and external partners; but get started!
- We can only “**move at the speed of trust**” (Ways of Working, MLHU’s ABRP)

# Implementation and Change Management Lessons

- Courage, perseverance and support (a team) are needed to overcome inevitable fear and resistance.
- There is no template to how do this right at your organization with your potential partners but start with building relationship and let it the partners guide your decisions, but get started!
- Senior Leadership commitment is crucial to getting started and sustain the work; ‘middle management’ involvement is required to support staff fidelity to culturally safe and sufficient data collection

# Implementation and Change Management Lessons

- Engagement and relationship is crucial to sustainability and to shared governance
- Accountability to mechanism are required for sustainability (Staff Participation Rate has become a KPI in our performance management system)

## What is Next

- Linking race-based data with health-outcome data to identify differences in health outcomes attributable to inequity
- Modify or develop protocols, procedure and policy (with partners involvement)
- Formalizing the governance expectations of Indigenous and Black communities through existing collaboration, advisory and accountability mechanism such as the ABRP Advisory Committee
- Formalizing a process to generate shared meaning (analysis) from the data for collective action

# Question and Answer Period with Attendees

