

# Indigenous Data Governance Principles & New Approaches to Race-Related Data

Dominique Legacy & Laura Ferreira-Legere

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# **ICES Strategic Plan**



#### Indigenous Partnerships, Data & Analytics Department

Support Indigenous Data Sovereignty through formal collaborations and partnerships with First Nations, Métis and Inuit organizations and communities.

#### Public and Community Engagement, Knowledge Translation Team at ICES

Meaningfully engage the public and equity deserving communities to inform how we carry out our work.

Empower employees and scientists to engage the public and diverse communities as part of their research and analytics.

Communicate findings with the public in a way that is accessible, meaningful, and impactful.

## ICES Public & Community Engagement, Knowledge Translation

As part of the ICES Science Office, our goal is to support ICES scientists, trainees, and staff to capture and incorporate the values of Ontarians in ICES activities and research.



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www.ices.on.ca/our-organization/public-and-community-engagement/

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# **Terms used in our Presentation**

The term **"race and related data"** will be used in the latter half of this presentation and refers to any data held at ICES that can **identify or infer race, including race, ethnicity or indirect variables. What we are referring to is distinct from Indigenous data**, which requires separate pathways and processes, guided by our Indigenous Partnerships Department.

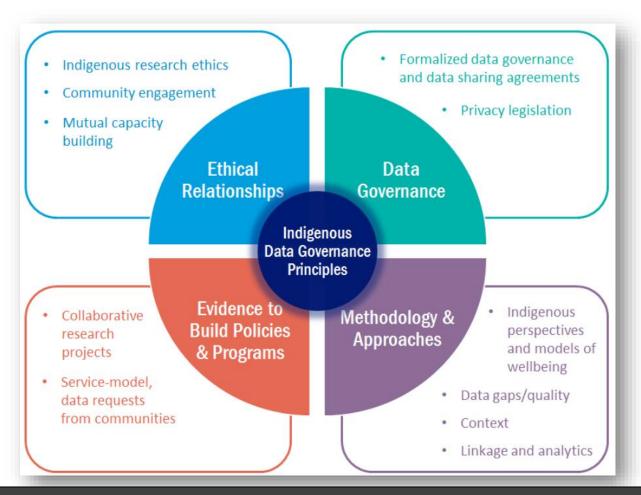
We also want to acknowledge the **distinction between Indigenous communities and broader use of the term 'community/ies'**. The term 'communities' will be used throughout the presentation, however, Dominique will be speaking specifically to Indigenous communities, whereas Laura will be primarily referring to Immigrant and Newcomer communities.

For the purpose of this presentation, the term "Indigenous" will be used as an umbrella term to collectively refer to First Nations, Métis, and Inuit peoples. However, using a distinctions-based approach is essential to properly recognize the unique cultures and identities of each group.

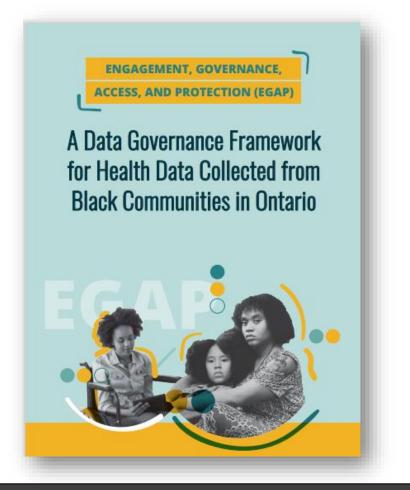


# Background

# **Foundational Work**



Developed in collaboration with Chiefs of Ontario (COO)



Developed by the Black Health Equity Working Group



#### **Indigenous health**

In January 2024, ICES formalized its Indigenous Portfolio into a new department: Indigenous Partnerships, Data and **Analytics.** This change underscores the recognition of the unique rights of **Indigenous Peoples and ICES'** commitment to Indigenous Data Sovereignty. Through the Indigenous Partnerships, Data and Analytics department, ICES will:



Support Indigenous-driven use of ICES data.



Be a trusted partner for Indigenous organizations, scholars and communities in their use of data to promote wellbeing, healing and effective policy.



Listen to and learn from Indigenous teachings and principles so that we can strive to apply them to our relationships and collaborative projects.

### Partnerships

#### **First Nations**

- Chiefs of Ontario
- Kenora Chiefs Advisory
- Grand Council Treaty #3
- Political Organizations
- First Nations Health Authorities Irban Indigenous
- Mamow Ahyamowen
- Individual Communities

**Métis** 

Métis Nation of Ontario

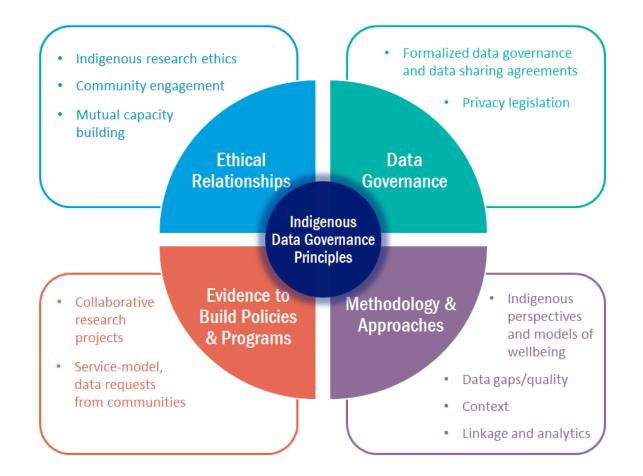
Aboriginal Health Access Centres

 Indigenous Primary Health Care Council

#### Inuit

- Tungasuvvingat Inuit
- Inuuqatigiit Centre for Inuit
- **Children, Youth and Families**
- Akausivik Inuit Family Health Team

# Framework for working with First Nation, Métis and Inuit data at ICES

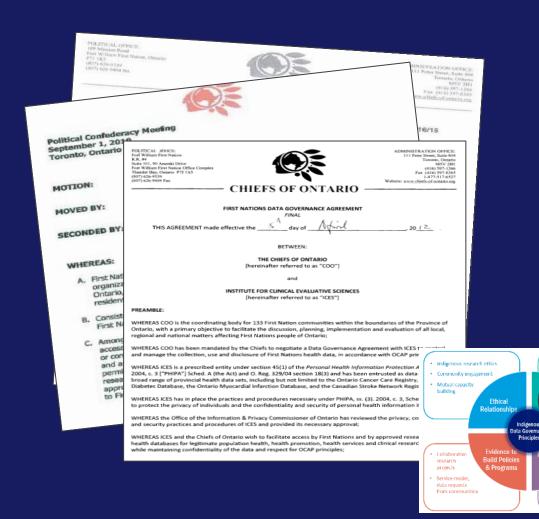




\*Initially developed with the Chiefs of Ontario for working with First Nations data

#### Data Governance

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IC/ES

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wellbeing

Data gaps/quality

Context
 Linkage and analytic

perspectives and models o

Data

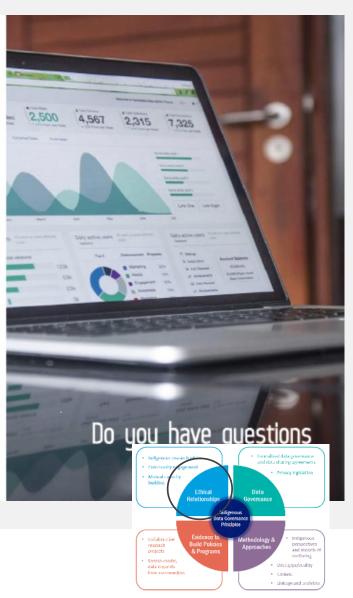


# Ethical Relationships

- Respect: Ethical and ongoing communication
- Reciprocity: Mutual capacity building- External capacity strengthening and internal capacity building
- Relevance: Processes to support community-led analysis of data (AHRQ)
- Responsibility: Upholding Indigenous Data Governance principle

Indigenous Health Data Training Program

Do you want to know how you can access health data and how you can use it?







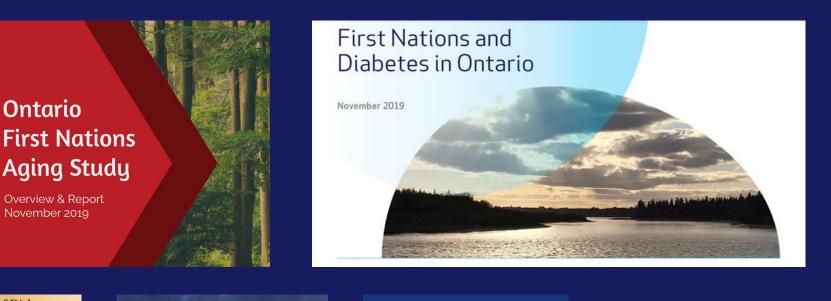
- Ontario Ministry of Health (MOH) **funding program** to produce research evidence that informs planning, policy and program development that will benefit the Ontario health system
- Dedicated resources for Indigenous partners:
  - Individual communities
  - Groups of communities
  - PTOs
  - First Nations organizations
  - First Nations leadership
  - Documents and results for First Nations projects are NOT shared with MOH or others outside of the requester

No cost to First Nations

**Applied Health Research Questions (AHRQ)** 

#### Access to Evidence to Build Policies and Program

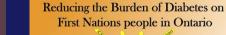
- **Collaborative Research** • projects
- Data request from  $\bullet$ communities





Learning from Our Ancestors: Mortality Experience of First Nations in Northern Ontario March 2020





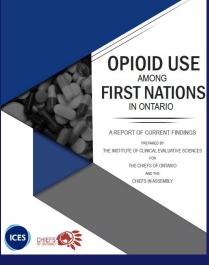
Ontario

**Overview & Report** November 2019

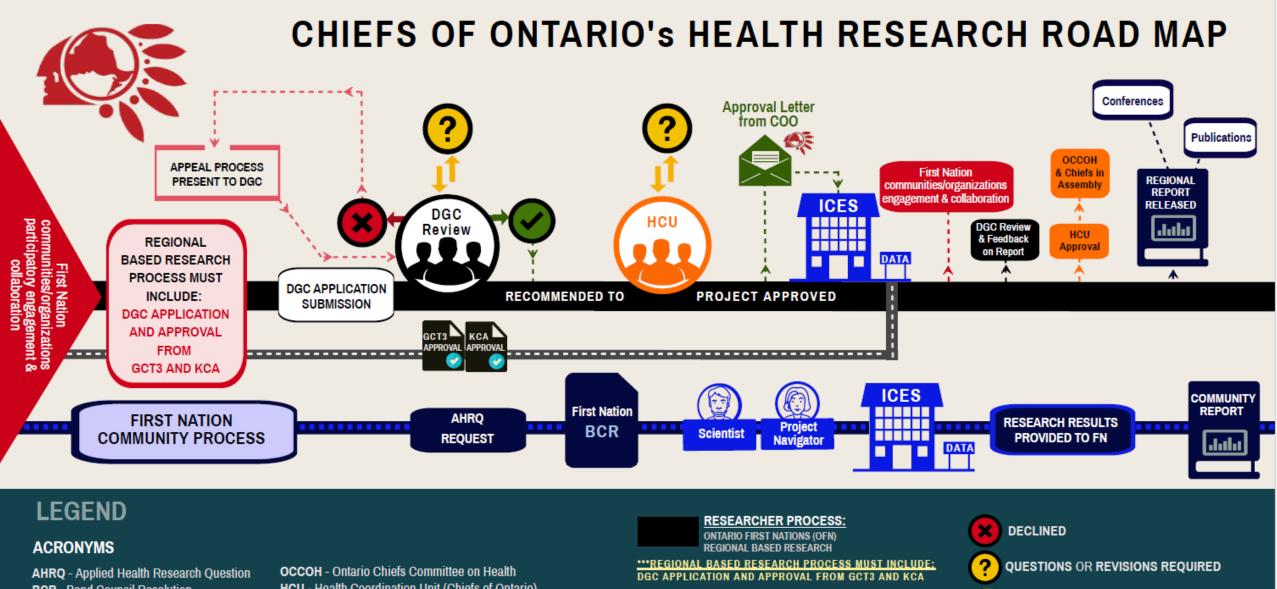


**Cancer in First Nations** People in Ontario: Incidence, Mortality, Survival and Prevalence









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RESEARCHER PROCESS:

GCT3 & KCA APPROVAL REQUIRED 💙

FOR OFN REGIONAL BASED RESEARCH

OFN COMMUNITY PROCESS:

**FN COMMUNITY BASED RESEARCH** 

DGC RECOMMENDATION OR HCU APPROVAL

BCR - Band Council Resolution KCA - Kenora Chiefs Advisory GCT#3 - Grand Council Treaty #3 FN - First Nation OFN - Ontario First Nation OCCOH - Ontario Chiefs Committee on Health HCU - Health Coordination Unit (Chiefs of Ontario) DGC - Data Governance Committee (Chiefs of Ontario) COO - Chiefs of Ontario

ICES - pronounced as letters: "eye – see – ee – ess" (F.K.A.: Institute for Clinical Evaluative Sciences)

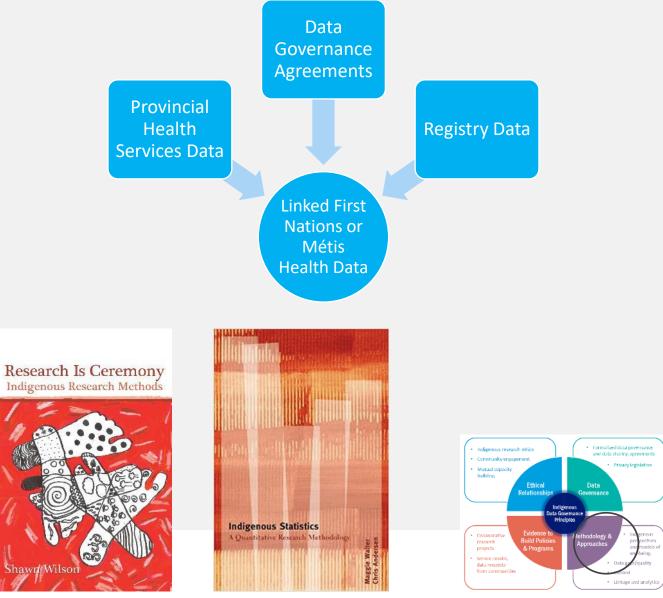


# Methodology & Approaches

C Linkage & Analytics

S Context

S Data Gaps/ quality





# How are Indigenous Peoples Identified in ICES Data?



#### **Indigenous Data at ICES**

19797			
Self-identifiers	Geographic identifiers	Registries	Indigenous- Specific Datasets
<ul> <li>Self-identifiers in data holdings at ICES.</li> <li>*Data we receive from non-Indigenous organization that has Indigenous data embedded.</li> </ul>	<ul> <li>Postal code or residence codes in community</li> </ul>	<ul> <li>Indian Register System</li> <li>Métis Citizenship Registry</li> </ul>	<ul> <li>Indigenous surveys</li> <li>Data from Indigenous healthcare providers</li> </ul>



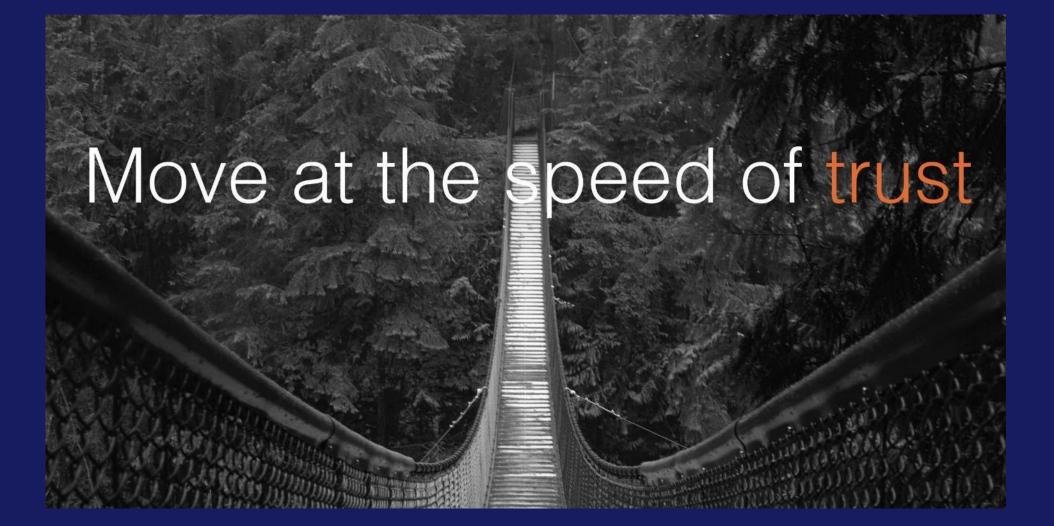
#### **Next steps**

We are...

- Enhancing knowledge translation efforts to better support ongoing projects
- **Collaborating with partners** to co-lead innovative approaches for strengthening community capacity and user-friendly access to data
- Collaborating with ICES North to co-lead a new initiative title the 'Northern and Rural Algorithm Validation initiative'



#### Relationships as the foundation of research



# Informing new approaches for race-related data governance



### **ICES Peoples' Panel**

#### Peoples' Panel Recommendation:

Level of agreement:

63%

of respondents

recommendation

Ideally, communities should have autonomy and governance over their own data. ICES should consider its role in establishing community governance. ICES researchers should partner with community organizations or representatives who are trusted, well known, and considered subject matter experts by the communities of interest.\*

\*This recommendation was updated based on comments received in the post-Panel survey.

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#### Level of importance:

4.4/5 Is the average level of IMPORTANCE respondents give to this recommendation 11-41









## Framework to Drive Anti-Racist Approaches to Health Research at ICES\*





\*Indigenous data are out of scope for this guidance. The ICES Indigenous Partnerships, Data and Analytics Department provides guidance on using Indigenous identifiers.

### Goals of Community Data Governance at ICES



- To maintain accountability and transparency to communities whose data are being used in ICES research and analysis;
- To reflect community values and perspectives in the ways we access and use race and related data; and
- To establish clear guidance for scientists
   when using race and related data, keeping
   community needs at the forefront.



# **Piloting Community Data Governance**

Who is "community" in a given time and place?

Which "data" are being used?

What "governance" processes are in place?



# **Defining Community**



#### Work to date

- Engaged community members on the Peoples' Panel
- Engaged in initial chats with 13 other community members
- Informal conversations with partner organizations and their work





## **Defining Data**

#### Work to date

- Reviewed all data holdings at ICES to see which had "race or related" pieces of information and created a repository
- Considered the data holdings that are most often used and options for a 'test or pilot'
- Selected one data holding to start with: Immigration, Refugees and Citizenship Canada (IRCC) Ontario data



# What are Immigration, Refugees and Citizenship Canada (IRCC) Data?



The Ontario portion of Immigration, Refugees and Citizenship Canada (IRCC)'s Permanent Resident Database is available at ICES. This includes immigration application records in Ontario since 1985. The data contains permanent residents' information such as country of citizenship, level of education, first language, & landing date.

Some immigrants who are currently residing in Ontario but originally landed in another province are not currently captured (but will be in the future). Immigrants who landed in Ontario before 1985 are not captured.



## How are IRCC Data used at ICES?

The information provided by IRCC to ICES may only be used for health research, evaluation and/or support for health policy and program development for this population. The data may not be used for any other purposes, such as evaluation of IRCC's programs or policies.

#### Some example projects have included:

- Prostate cancer incidence among immigrant men in Ontario, Canada
- Diabetes Prevalence Among South Asian Immigrants
- COVID-19 in immigrants, refugees and other newcomers in Ontario: characteristics of those tested and those confirmed positive



# Why start with community governance of IRCC data?

- IRCC is more often used (between 50-80 new projects initiated per year) and has individual-level race-related data.
- This approach allows us to focus on immigrant and newcomer communities and IRCC allows us to more clearly define these communities.
- This data is already controlled (meaning project teams have to submit a special request to use it) so it already has an existing and well-known pathway.
- We have **discussed our approach with the data partner** and there is support for this work.





# **Defining Governance**

#### Work to date

- Looked at the literature on existing structures for community governance.
- Co-developing draft 'criteria' for projects wanting to use IRCC. The criteria will outline required actions depending on how the data is being used in a given project.
- Planning for a community advisory table that could advise on our approaches.

#### **Remaining questions**

• What actions will be required of projects using IRCC data? Is community engagement the best approach for every project? What projects should engage, when and why?





# **Developing Project Criteria**

- We will be **co-developing criteria with community organizations**, **community members**, **data and governance experts** that project teams will need to follow based on how they are using IRCC.
- What these criteria will look like is under development, but there are key questions we will explore with focus groups:



# **Developing Project Criteria**

If community engagement is not required, should dissemination back to community be a priority?

What types of projects should engage community and when?

Are there other project scenarios we haven't thought of, or times when the advisory table would need to be more involved beyond general advising on our approach?

Should there be overarching criteria for any project (e.g., reflect on how and why you are using the data)?

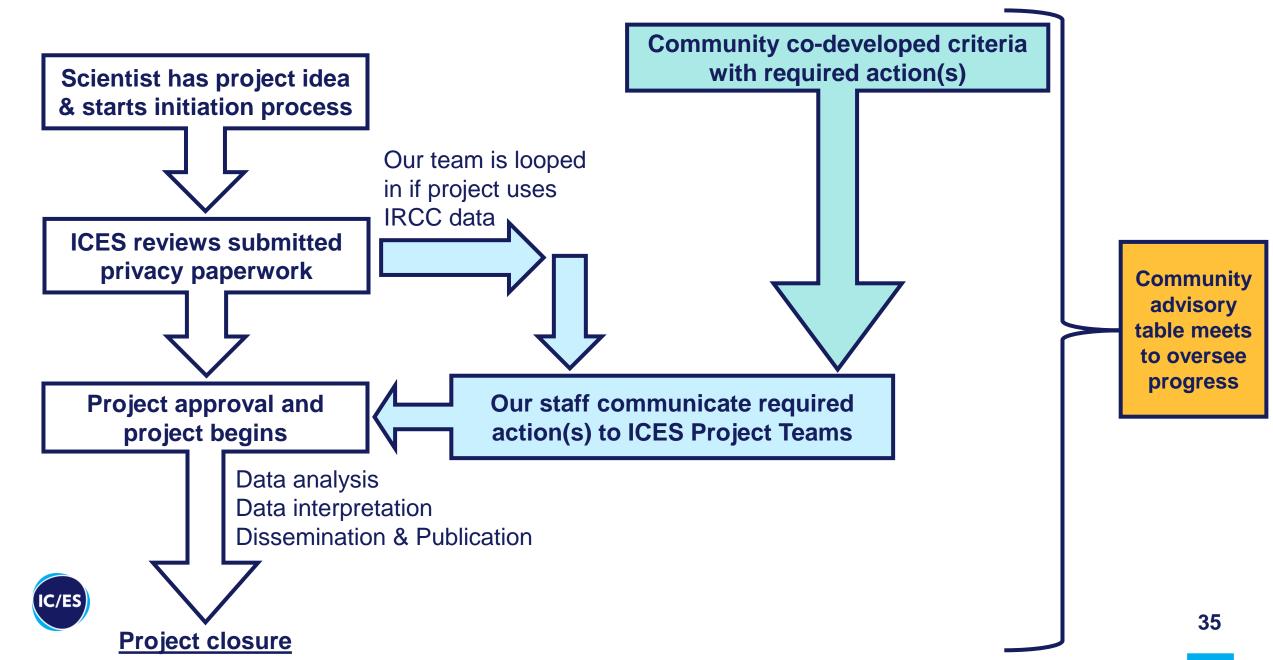


# What could this process look like in action?



#### **Existing ICES process**

#### Addition of community data governance





## Summary

We are...

- Co-developing Community Data Governance of IRCC data.
- Exploring what criteria will guide project teams in using IRCC data through community consultation.
- Convening a community advisory table to oversee our broader implementation.



# Questions?

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