



Data
Discovery
Better Health

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

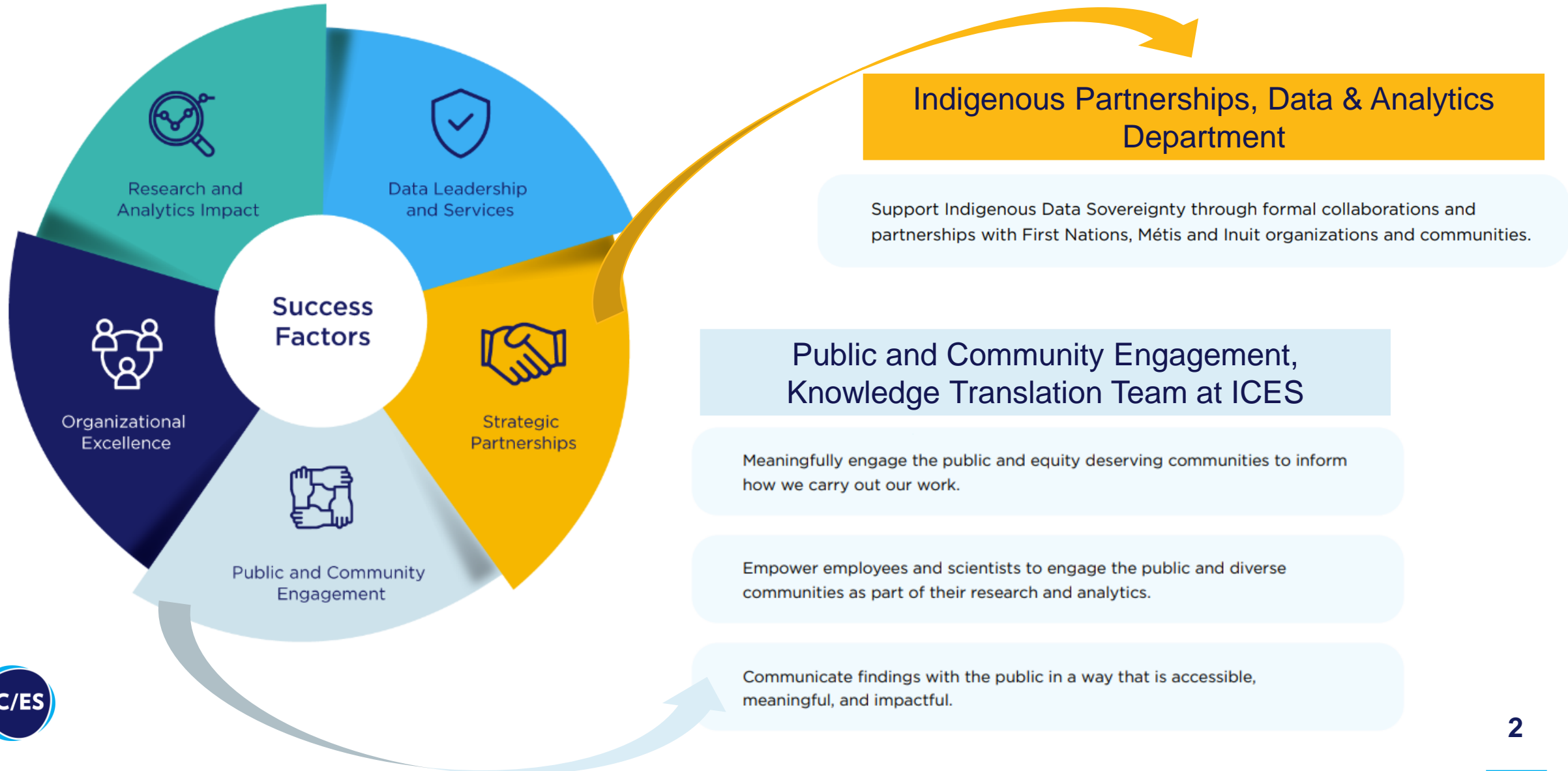
Dominique Legacy & Laura Ferreira-Legere

ICES Central

May 22, 2025



ICES Strategic Plan



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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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.

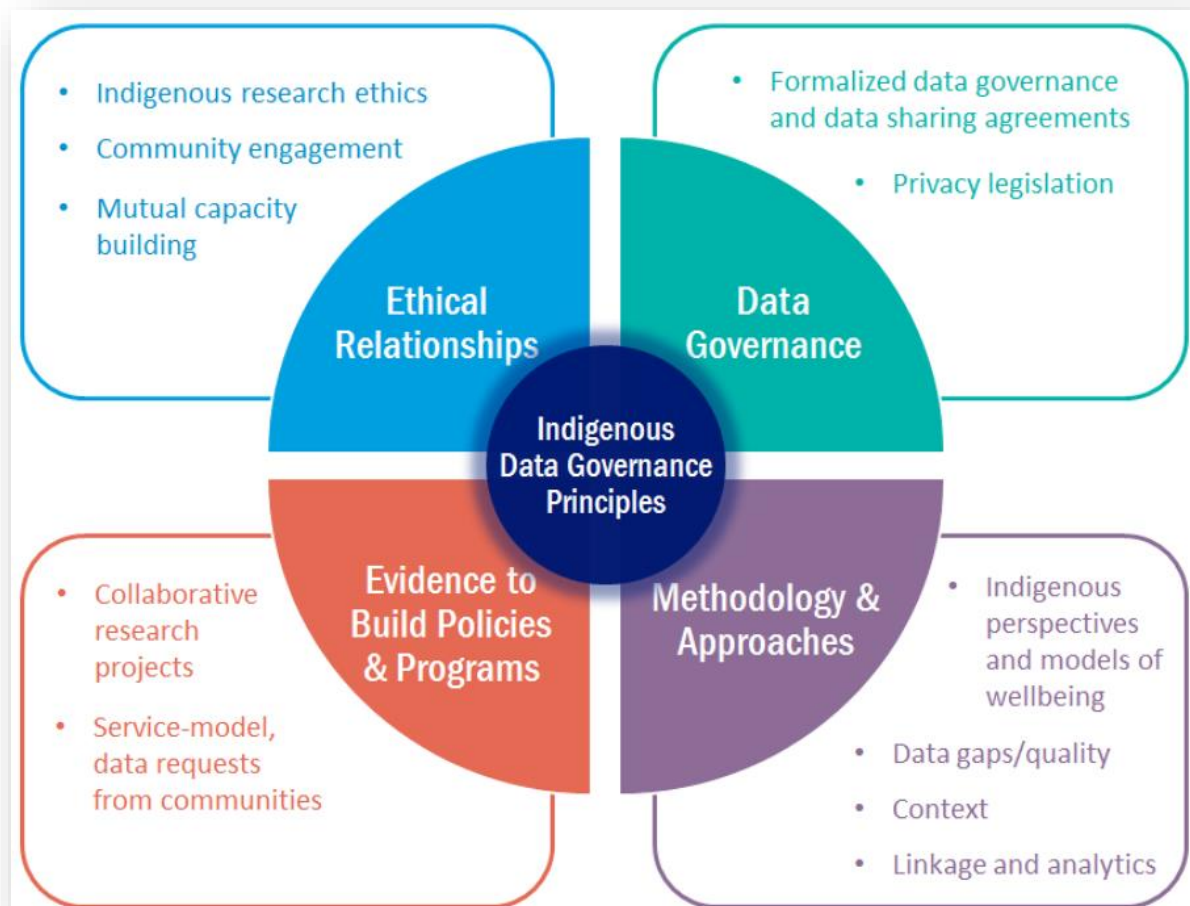
We also want to acknowledge the **distinction between Indigenous communities and broader use of the term ‘community/ies’**. The term ‘communities’ will be used throughout the presentation, however, Dominique will be speaking specifically to Indigenous communities, whereas Laura will be primarily referring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

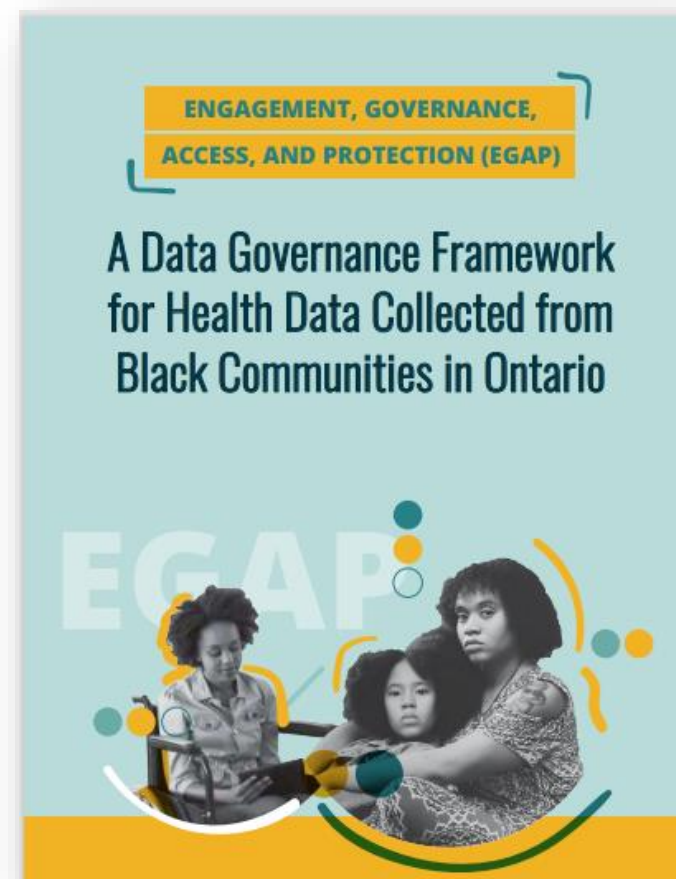


Background

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
- Mamow Ahyamowen
- Individual Communities

Métis

- Métis Nation of Ontario

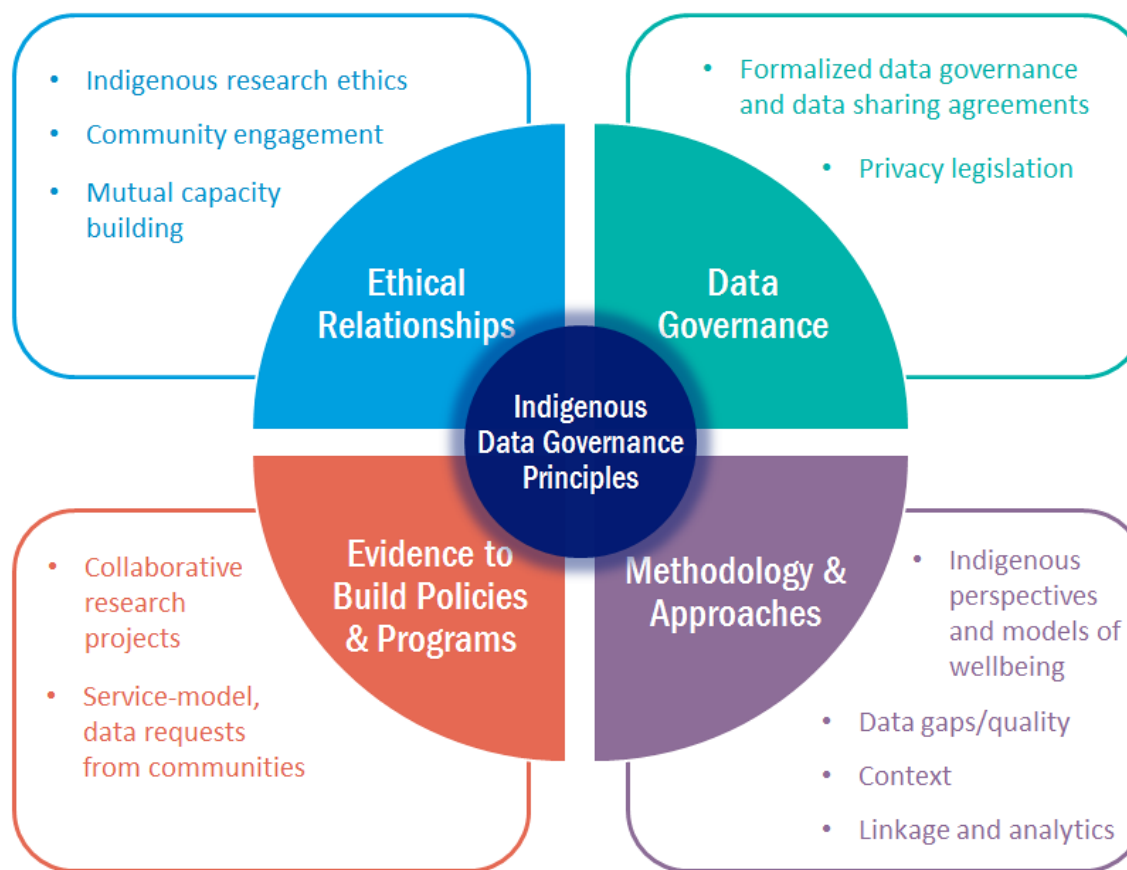
Urban Indigenous

- Aboriginal Health Access Centres
- Indigenous Primary Health Care Council

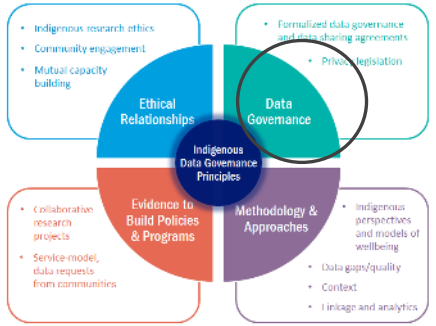
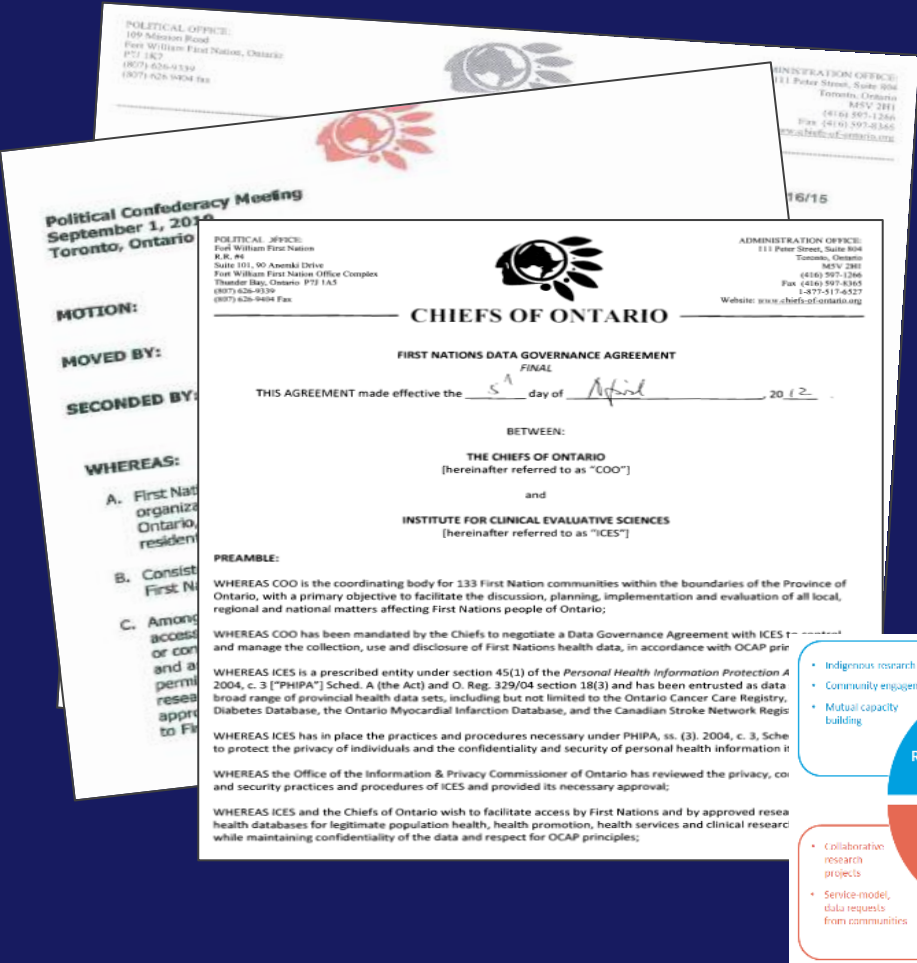
Inuit

- 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



Data Governance

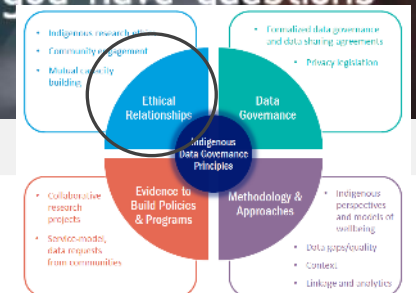
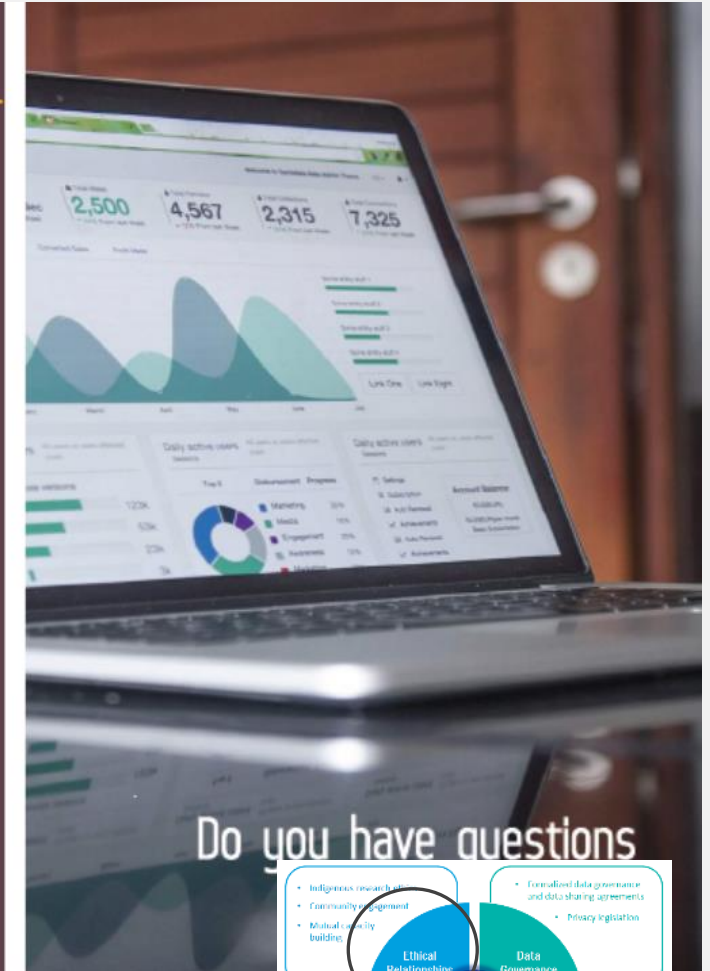


Ethical Relationships

- 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?



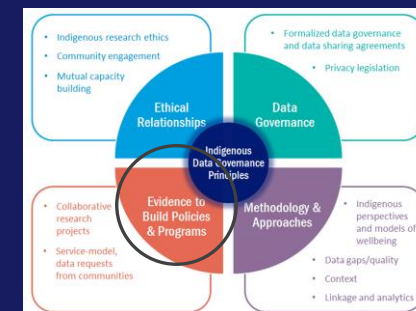
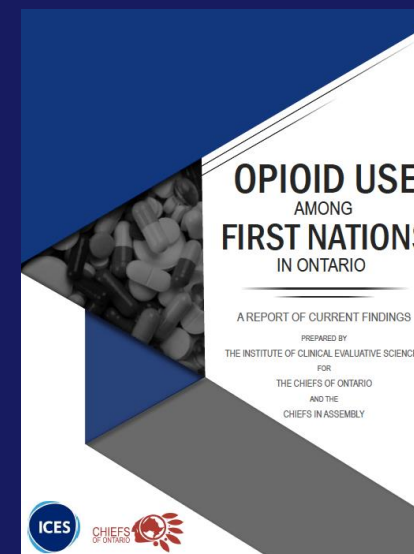
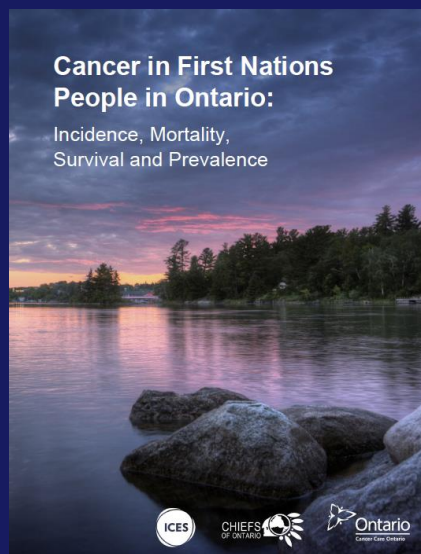
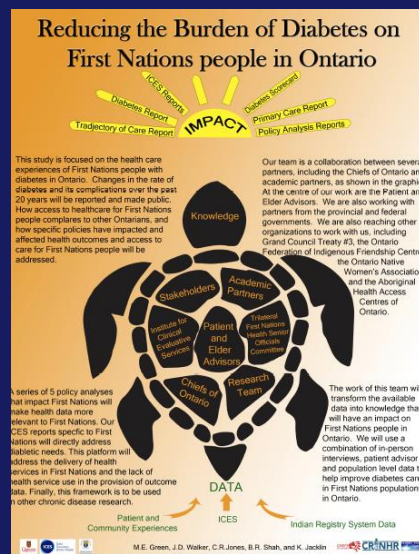
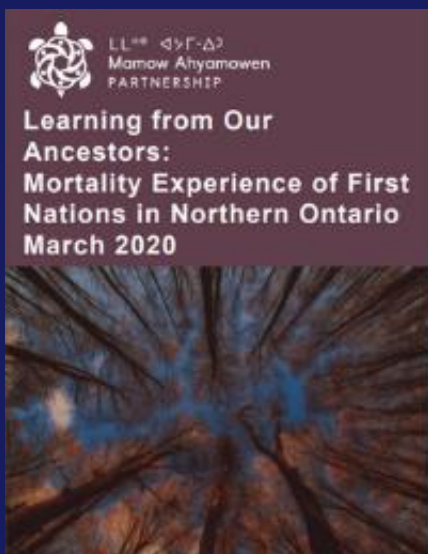


- Ontario Ministry of Health (MOH) **funding program** to produce research evidence that informs planning, policy and program development that will benefit the Ontario health system
- Dedicated resources for **Indigenous partners**:
 - Individual communities
 - Groups of communities
 - PTOs
 - First 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

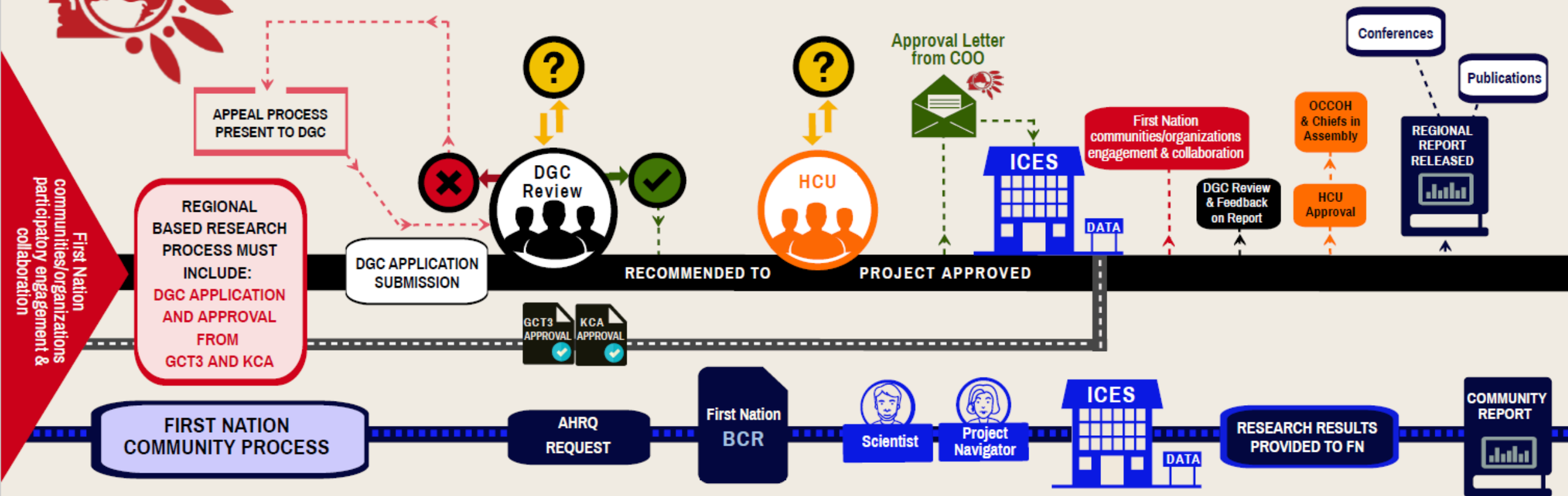
**Applied Health Research
Questions (AHRQ)**

Access to Evidence to Build Policies and Program

- Collaborative Research projects
- Data request from communities



CHIEFS OF ONTARIO's HEALTH RESEARCH ROAD MAP



LEGEND

ACRONYMS

AHRQ - Applied Health Research Question
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)

RESEARCHER PROCESS:

ONTARIO FIRST NATIONS (OFN)
REGIONAL BASED RESEARCH

*****REGIONAL BASED RESEARCH PROCESS MUST INCLUDE:
DGC APPLICATION AND APPROVAL FROM GCT3 AND KCA**

RESEARCHER PROCESS:

GCT3 & KCA APPROVAL REQUIRED

OFN COMMUNITY PROCESS:

FN COMMUNITY BASED RESEARCH



DECLINED



QUESTIONS OR REVISIONS REQUIRED



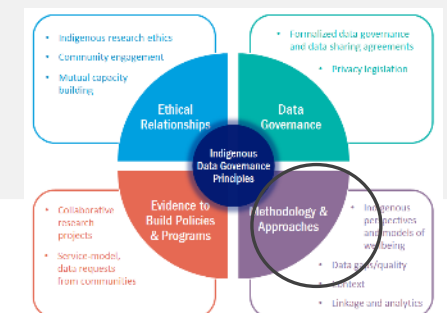
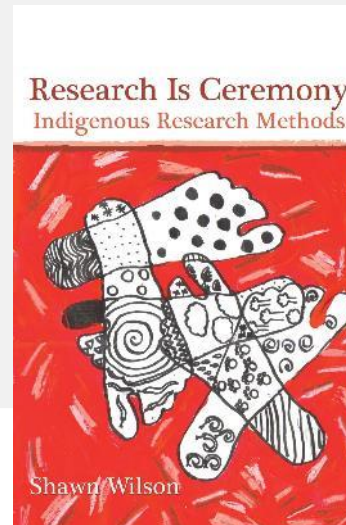
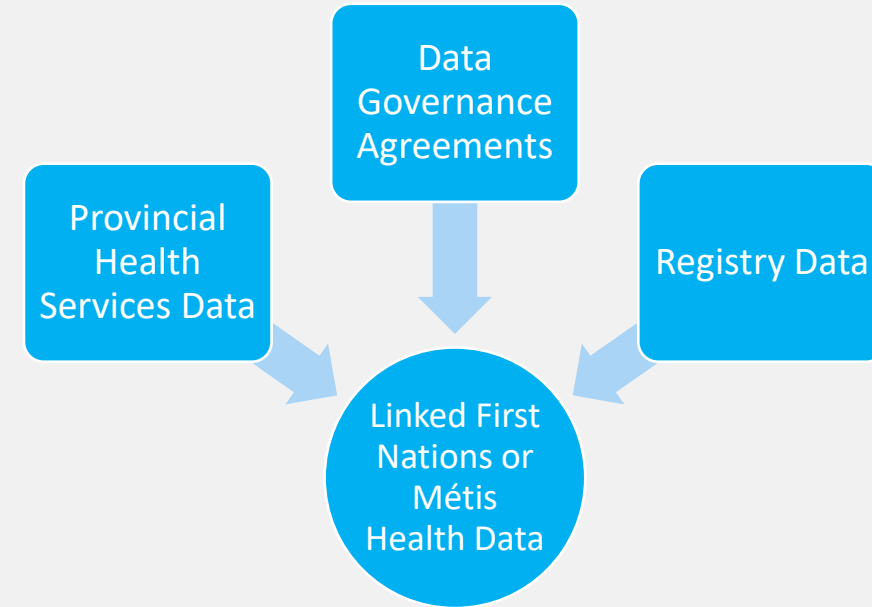
DGC RECOMMENDATION OR HCU APPROVAL

Methodology & Approaches

○ Linkage & Analytics

⊘ Context

⊘ Data Gaps/ quality





How are Indigenous Peoples Identified in ICES Data?

Indigenous Data at ICES



Self-identifiers

- Self-identifiers in data holdings at ICES.

*Data we receive from non-Indigenous organization that has Indigenous data embedded.



Geographic identifiers

- Postal code or residence codes in community



Registries

- Indian Register System
- Métis Citizenship Registry



Indigenous-Specific Datasets

- Indigenous surveys
- Data from Indigenous healthcare providers

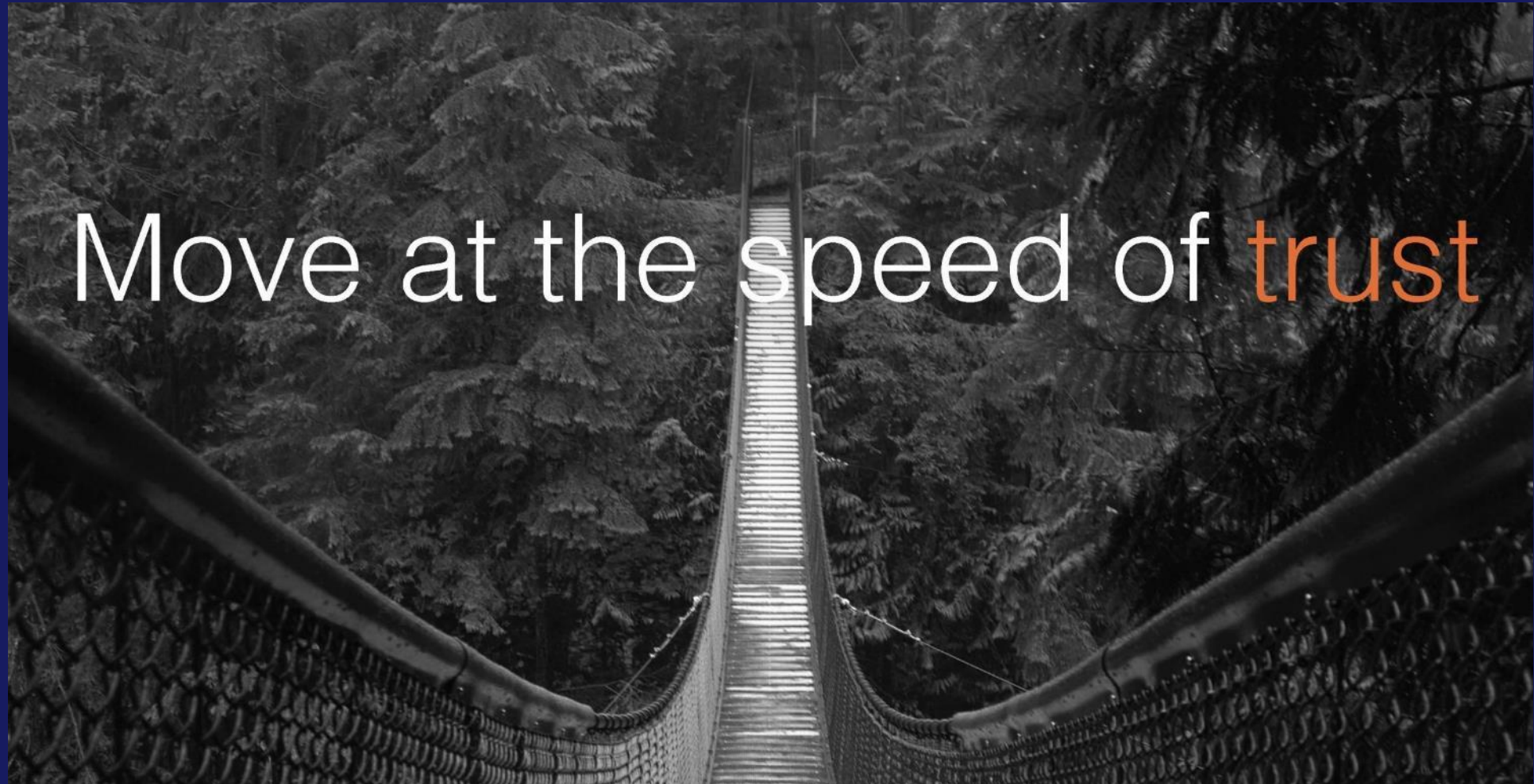



Next steps

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 titled the 'Northern and Rural Algorithm Validation initiative'

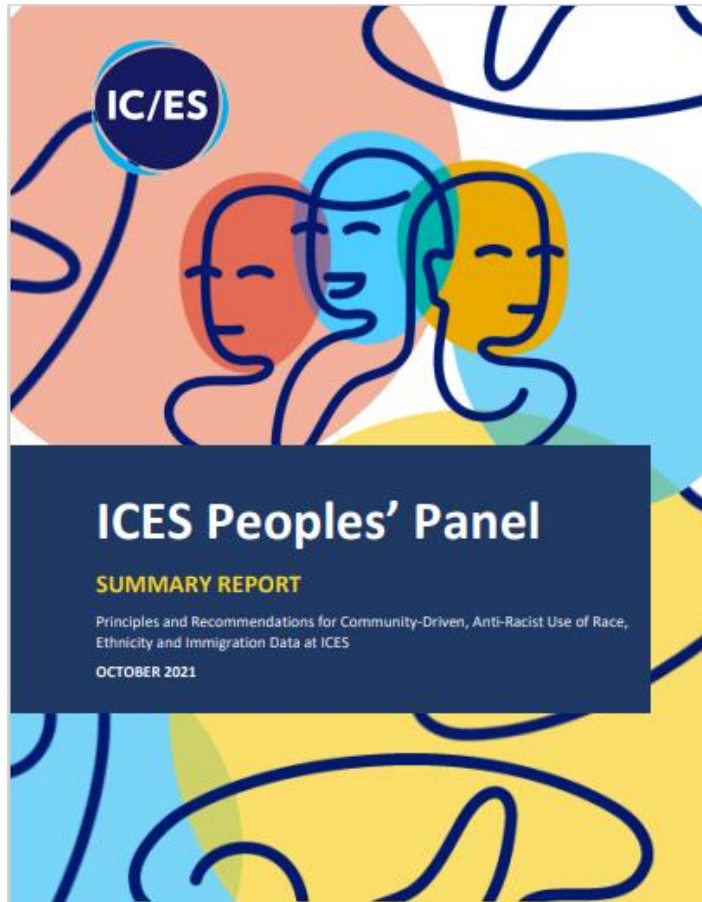
Relationships as the foundation of research





Informing new approaches for race-related data governance

ICES Peoples' Panel



Peoples' Panel Recommendation:

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.*

Level of agreement:

63%

of respondents
STRONGLY agree with this
recommendation

n=42

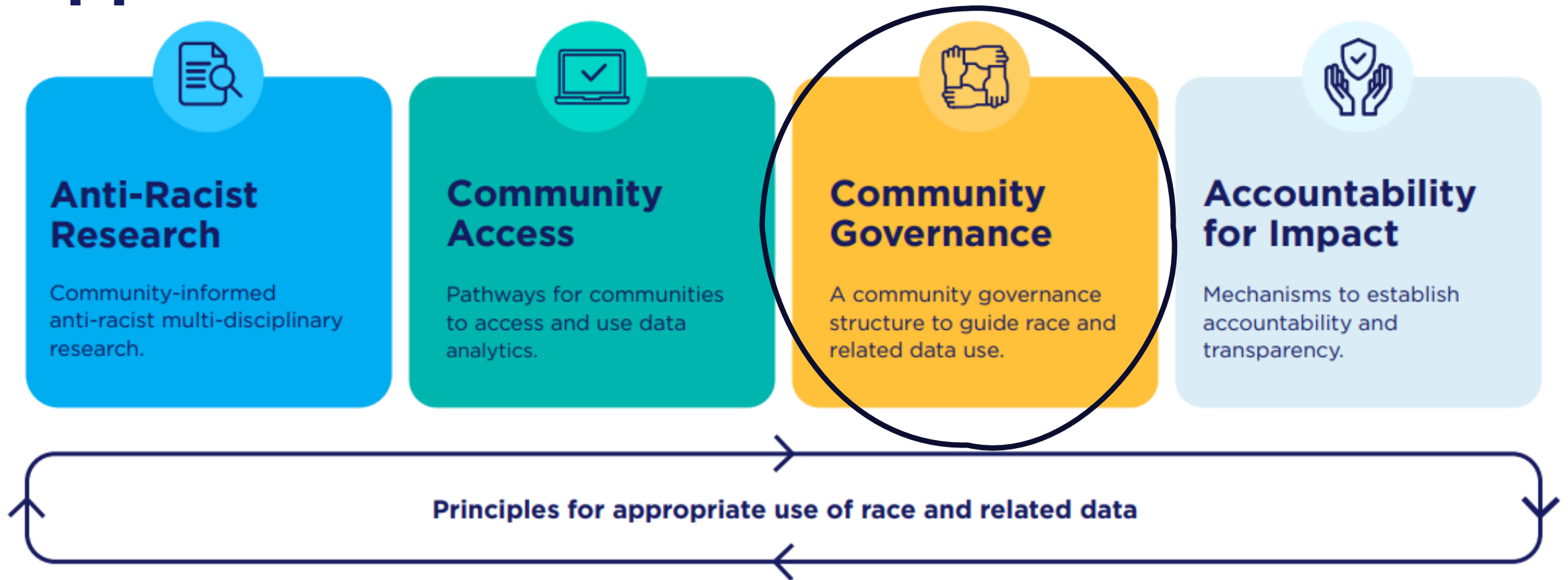
Level of importance:

4.4/5

Is the average level of IMPORTANCE
respondents give to this
recommendation

n=42

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



www.ices.on.ca/health-equity-at-ices/

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



What types of projects should engage community and when?

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

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

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?



What could this process look like in action?

Existing ICES process

Scientist has project idea & starts initiation process

ICES reviews submitted privacy paperwork

Project approval and project begins

Data analysis
Data interpretation
Dissemination & Publication

Project closure

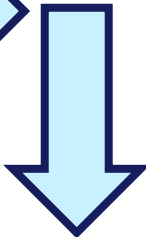


Addition of community data governance

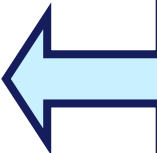


Community co-developed criteria with required action(s)

Our team is looped in if project uses IRCC data



Our staff communicate required action(s) to ICES Project Teams



Community advisory table meets to oversee progress



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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