

SDOH Standards: Race-based and Indigenous Identity Standards

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CIHI's role in the health system

- **Comparable data and information to support health care improvement, health system performance and population health**
 - Data and indicator standards to facilitate comparability
 - Collaborative indicator development for health system accountability, performance

Meanwhile:

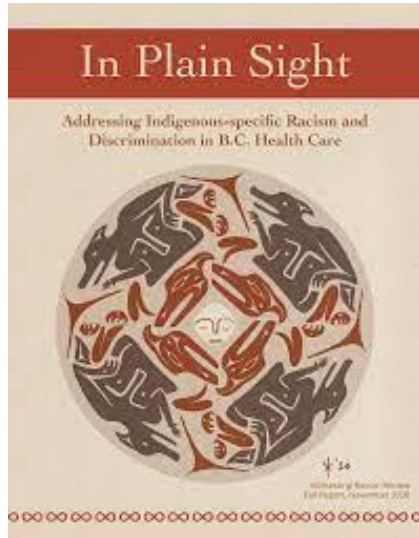
- CIHI does not have indicators related to cultural safety & systemic racism
- There is very little reporting anywhere in Canada to shed light, hold health systems accountable and drive change

Why Equity? Why Now?



- Inequities in society are not new
- COVID has exposed inequities in health and health care like never before
- George Floyd's murder and the Black Lives Matter Global Movement has allowed issues of racism into mainstream dialogue
- Joyce Echaquan's murder led to an Inquiry into Indigenous racism in BC with a call to action that includes CIHI
- Equity is a priority for CIHI's stakeholders
- Issues of equity run through other health system issues including virtual care, long term care and mental health
- The IDEA Approach (Inclusion, Diversity, Equity and Accessibility) is being built into many partnering organizations including HDRN, CIHR, Ministries of Health

Racism in health systems: awareness to action



Felt “completely safe” in hospital

Indigenous 30%, Non-Indig 64%

Always treated w/ respect & courtesy

Indigenous 28%, Non-Indig 68%

-Recommendation #9 identifies measurement role for CIHI



Protests for the experience and death of Joyce Echaquan in September 2020



People ‘dying unnecessarily’ because of racial bias in Canada’s healthcare system, researcher says – *CBC News*



Report finds ‘widespread’ anti-Indigenous racism in health system – *CTV News*



Legislation to fight anti-Indigenous racism in health care is coming – *CTV News*

Sameness is NOT Fairness



Inequality is a focus on the mere presence of a difference between two or more people/groups on a measure of health. May or may not be fair.

Inequity is an unfair or unjust difference in health. It is systemic, socially produced. Avoidable or changeable by policy or practice

Measuring Equity through Sociodemographic Variables

“It’s data about a person”

Record Level Socio Demographic Variables can include:

- Sex & gender
- Race, Ethnicity
- Indigenous identity
- Sexual orientation
- Religious affiliation
- Socioeconomic status
- Education

Area-Based Measures of Inequity can include:

- Race, Ethnicity
- Indigenous identity
- Socio economic status
- Education
- Urban vs. rural & remote

PROS AND CONS FOR BOTH

Why is Health Inequalities Measurement Important?



Unless specifically measured, inequalities in health and health care can go unnoticed by health systems even as they strive to improve care and health outcomes



Pan-Canadian Dialogue to Advance the Measurement of Equity in Health Care

Proceedings Report



Pan-Canadian Dialogue on health equity (2016)



In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality

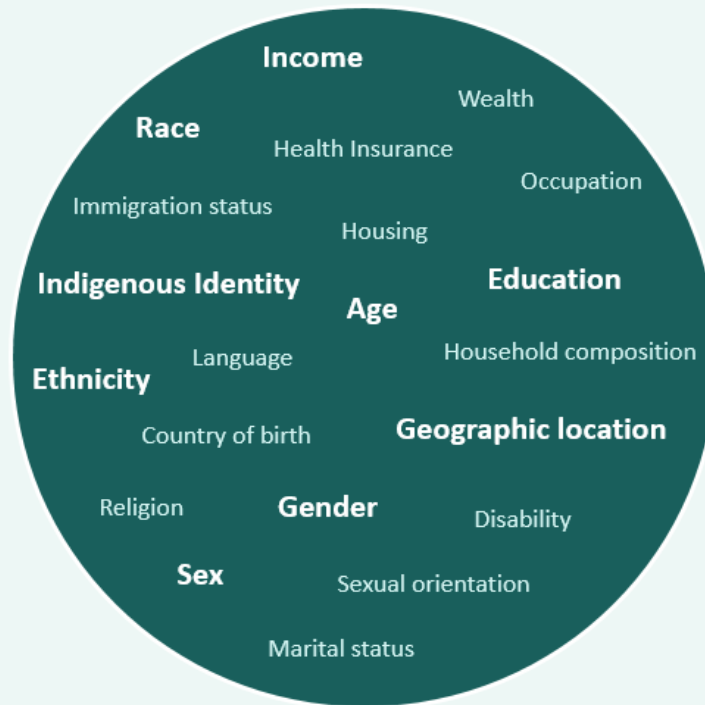
A Focus on Age, Sex, Gender, Income, Education and Geographic Location

April 2018



Defining Stratifiers for Measuring Health Inequality (2018)

Prioritizing Data Needs for Assessing Health Equity



Why do we need race-based data?



- Calls for race-based and Indigenous identity data grew louder during COVID
- Strong need for disaggregated data
- Pan-Canadian standards help ensure high-quality racial and Indigenous data is collected, analyzed and reported using a harmonized approach
- Researchers, P/T stakeholders and advocacy groups look to CIHI as a trusted source of data standards for health care systems

Race-based data landscape

- Ontario Anti-Racism Directorate Race Data Standard (ARDS) is currently used in the Education and Justice sectors
- Upstream Lab's SPARK study is testing a modified ARDS in primary care settings across Canada with success
- B.C. introduced anti-racism legislation codeveloped with Indigenous Peoples with the goal of dismantling systemic racism and discrimination
- Researchers, P/T stakeholders and advocacy groups are looking to CIHI as a trusted source of data standards for health care systems





Proposed Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada

Discussion document —

Proposed Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada

Released July 24, 2020

Re-branded as Supplementary Report March 17, 2022

[Race-based and Indigenous identity data | CIHI](#)

Race and Ethnicity are Distinct Concepts

Race

Social construct used to categorize people based on perceived physical differences

Ethnicity

Multi-dimensional concept referring to cultural group membership

Indigenous health strategy: Guiding principles



- Inherent rights to self-determination includes Indigenous data sovereignty, irrespective of where data is held
- Cultural safety and humility, and meaningful and respectful engagement are essential
- Recognizes the distinct histories, interests, needs and priorities
- Indigenous-led partnerships and processes guide our work

Indigenous identity

Indigenous groups are often considered alongside racial and ethnic categories in existing data collection systems

Indigenous identity data and measurement should be determined and supported by engagement with Indigenous communities

First Nations, Inuit and Métis have inherent and collective rights to self-determination, including ownership and governance of their data

CIHI's engagement and feedback gathering

CIHI engaged with stakeholders and partners to identify:

- Support/concerns for proposed standards, building towards consensus
- Preferred approaches for collection, reporting, and analysis
- Considerations for Indigenous populations and Indigenous identity data

Key stakeholders and partners:

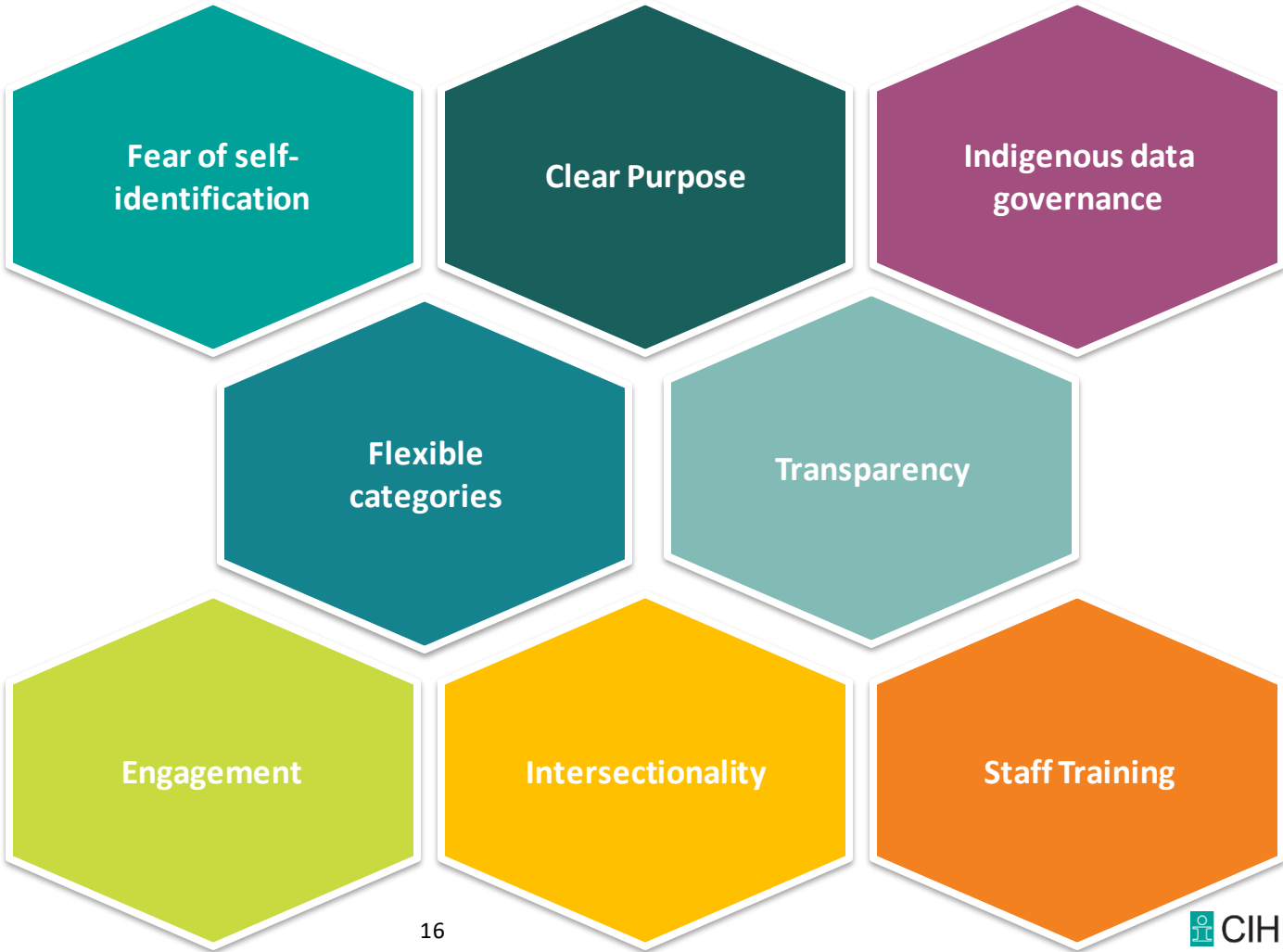
Federal and P/T governments

Health system stakeholders (clinicians, data custodians, public health units), health researchers

Organizations representing racialized groups and communities

Indigenous groups and organizations

What we heard



Guidance on Race-based and Indigenous Identity Data

- CIHI released [guidance](#) and standards on racialized group and Indigenous identity for voluntary adoption by health systems
- These standards include 2 data collection items: a distinctions-based measure for Indigenous identity and a race-based data element.
- Community engagement, data governance agreements and processes for safe collection and use are essential for implementation.



Guidance on the Use of Standards
for Race-Based and Indigenous
Identity Data Collection and
Health Reporting in Canada



CIHI's Indigenous identity data standard

Table 1.1 Indigenous identity data standard

Indigenous identity question*
Do you identify as First Nations, Inuk/Inuit and/or Métis?
Response categories (select all that apply)
Yes, First Nations
Yes, Inuk/Inuit
Yes, Métis
No
Do not know
Prefer not to answer

Note

*The implementation of the Indigenous identity data standard should include data governance agreements, engagement with appropriate Indigenous authorities, and processes related to culturally safe data collection.

- Distinctions-based
- Minimum standard
- Optional additional details

CIHI's Indigenous identity data standard compared to Statistics Canada's Population Group & Indigenous data standard categories

Table A1 Comparison of CIHI's Indigenous identity data standard with Statistics Canada's census and Canadian Community Health Survey questions

CIHI's standard	Statistics Canada's 2021 Census	Statistics Canada's 2016 Census	Statistics Canada's 2021 Canadian Community Health Survey*
Question			
<p>Do you identify as First Nations, Inuk/ Inuit and/or Métis? Select all that apply.</p>	<p>Is this person First Nations, Métis or Inuk (Inuit)?</p> <p>Note: First Nations (North American Indian) includes Status and Non-Status Indians.</p> <p>If "Yes", mark "x" the circle(s) that best describe(s) this person now.</p>	<p>Is this person an Aboriginal person, that is, First Nations (North American Indian), Métis or Inuk (Inuit)?</p> <p>Note: First Nations (North American Indian) includes Status and Non-Status Indians.</p> <p>If "Yes", mark the circle(s) that best describe(s) this person now.</p>	<p>Are you an Aboriginal person, that is, First Nations, Métis or Inuk (Inuit)? First Nations includes Status and Non-Status Indians.</p> <p><i>[and follow-up question]</i></p> <p>Are you First Nations, Métis or Inuk (Inuit)?</p>
Response categories			
Yes, First Nations	Yes, First Nations (North American Indian)	Yes, First Nations (North American Indian)	First Nations (North American Indian)
Yes, Inuk/Inuit	Yes, Inuk (Inuit)	Yes, Inuk (Inuit)	Inuk (Inuit)
Yes, Métis	Yes, Métis	Yes, Métis	Métis
No	No, not First Nations, Métis or Inuk (Inuit)	No, not an Aboriginal person.	No
Do not know	Not applicable	Not applicable	DK
Prefer not to answer	Not applicable	Not applicable	RF

Note

* The Indigenous identity categories presented include a combination of 2 questions within the Canadian Community Health Survey.

Note: Indigenous identity should be collected through a separate distinctions-based question under both approaches.

Indigenous Identity-Optional Additional Details

Minimum Standard (CIHI)

Indigenous Identity Question*
Do you identify as First Nations, Inuk/Inuit and/or Métis?
Response categories (select all that apply)
Yes, First Nations
Yes, Inuk/Inuit
Yes, Métis
No
Do not know
Prefer not to answer

Option to provide more detail

First Nations
Status Non-status
On reserve Off reserve
Is this person a member of a First Nation or Indian band? If "Yes", which First Nation or Indian band?
Inuk/Inuit
Are you enrolled under, or a beneficiary of, an Inuit land claims agreement?
Yes -- Specify agreement: (open-text)
No
Métis
Are you a registered member of a Métis organization or Settlement?
Yes -- Specify organization or Settlement: (open-text)
No

CIHI's race-based data standard

Question: In our society, people are often described by their race or racial background. These are not based in science, but our race may influence the way we are treated by individuals and institutions, and this may affect our health. **Which category(ies) best describes you? Check all that apply:†**

Response category	Examples
Black	African, African Canadian, Afro-Caribbean descent
East Asian	Chinese, Japanese, Korean, Taiwanese descent
Indigenous (First Nations, Inuk/Inuit, Métis)‡	First Nations, Inuk/Inuit, Métis descent
Latin American	Hispanic or Latin American descent
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish)
South Asian	South Asian descent (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan)
Southeast Asian	Cambodian, Filipino, Indonesian, Thai, Vietnamese, or other Southeast Asian descent
White	European descent
Another race category <i>Optional — please specify: [open text]</i>	Includes values not described above
Do not know	Not applicable
Prefer not to answer	Not applicable

Notes

* The collection of race-based and Indigenous data should involve community engagement to mitigate the risk of harm to individuals and communities, and to ensure the safe and appropriate use of the data.

† Individuals who identify as mixed race can select all categories that apply.

‡ Distinctions-based approaches — that is, separately identifying First Nations, Inuit and Métis Peoples — may be preferred.

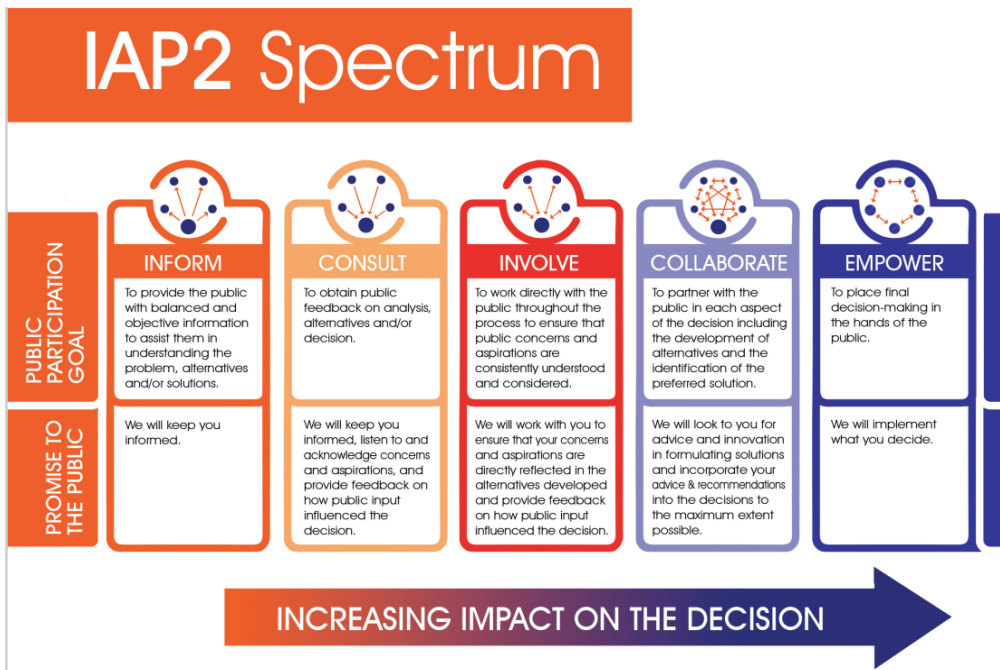
Sources

Government of Ontario Anti-Racism Directorate. [Data Standards for the Identification and Monitoring of Systemic Racism](#). Updated November 2021.

Upstream Lab. [Screening for poverty and related social determinants and intervening to improve knowledge of and links to resources \(SPARK\) study](#). Accessed January 27, 2020.

Community Engagement

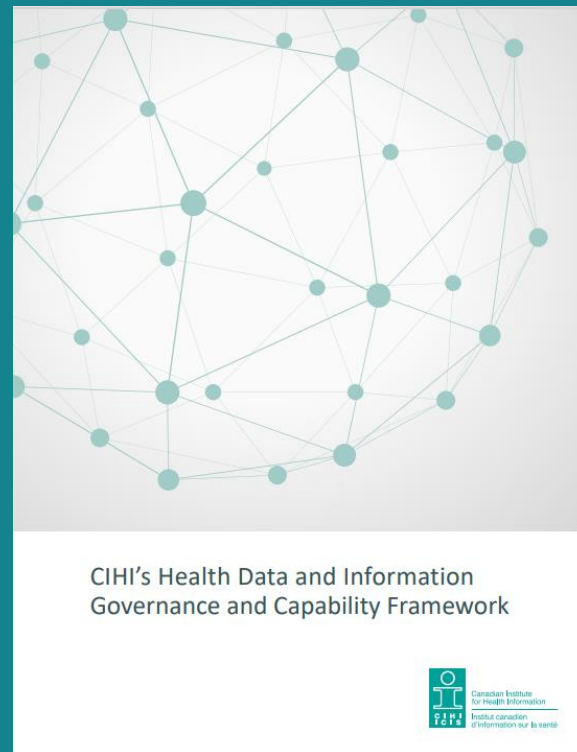
IAP2 Spectrum



- Best practice and foundational to the respectful collection and appropriate use of race-based and Indigenous identity data in health care
- Prerequisite for establishing data governance agreements with Indigenous Peoples and governments
- Community members (that is, people with lived experience and local knowledge) can provide valuable input

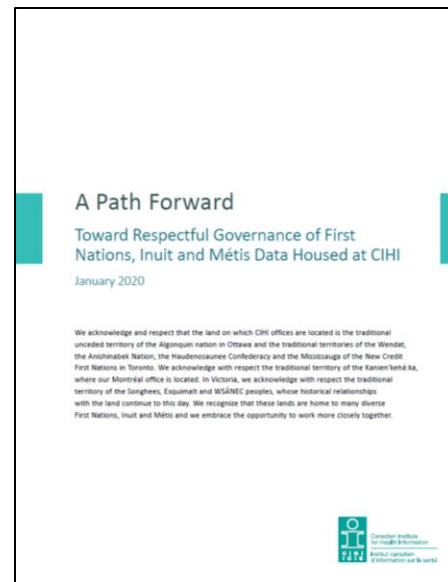
Data Governance

- Strong data and information governance ensures that data is timely, trusted and accurate
- Data and information governance mechanisms should be reviewed and revised, as needed, with special focus and consideration given to the impact on Indigenous Peoples and racialized groups, and on the collection of their data
- Indigenous data sovereignty principles



Governance of Indigenous data at CIHI

- August 2020 [CIHI policy](#) on Indigenous-identifiable data reflects principles of Indigenous data sovereignty, including OCAP.
- Based on what we heard... to help ensure data is used in appropriate and safe ways.
- Other policies and procedures updated to align. Staff training and support provided.
- As a federal not-for-profit, records held by CIHI are not subject to *Access to Information* legislation



Policy at a Glance

Indigenous identifiable data
only released with approval
from appropriate Indigenous
authorities



Safe Data Collection

Providing staff training and clear information to patients about the data collection process can facilitate culturally safe data collection

These practices reduce the risk of harm and improve the quality of collected data

Staff Training and Support for Patients

- Staff script for data collection
- Answers to frequently asked questions
- Resources on topics such as implicit bias

Clear Purpose

- Transparency with why data is collected
- Explain risks/benefits
- Provide choice to patients to share information

Mitigate Risks to Privacy

- Implement processes and create infrastructure to ensure data, privacy, confidentiality, and security



Measuring Health Inequalities: A Toolkit

- Tailored to analysts and researchers with varying knowledge and skill sets
- Consists of guidelines and resources organized in 3 phases:



Update
coming
June 9!

<https://www.cihi.ca/en/measuring-health-inequalities-a-toolkit>

