

Anti-Racism Research in B.C. Government

May 15, 2024



What is the legal foundation for anti-racism research in B.C.?


- B.C. government is **committed to addressing** all forms of **racism** in **government programs and services**.
- In 2022 the **Anti-Racism Data Act** became law. It allows **public bodies** to **collect** and **use personal information**, including race and ethnicity for the **purpose** of **addressing systemic racism** in government programs and services.
- The Anti-Racism Data Act outlines a process for **consultation** and **collaboration** with **Indigenous Peoples** and provides **authority to disclose** personal information to Indigenous Governing Entities*.
- In April 2024, the **Anti-Racism Act** was introduced. It will **require public institutions** to critically **evaluate** day-to-day operations and **remove policies** and **practices** that harm Indigenous and racialized people.



* These are Indigenous entities that exercise governmental functions, and include but are not limited to an Indigenous governing body as defined in the Declaration on the Rights of Indigenous Peoples Act.

Where does the data come from?

- In 2023, BC Stats ran a **demographic survey** that collected racial and other identity information about more than **200,000 people** in a safe and centralized way.
- The survey allowed **Indigenous respondents** to **consent** to **sharing** their **information** with their respective governing entities. We've **committed not to publish statistics about Indigenous Nations** unless asked to do so by them.
- **Indigenous identity** and **race-based data standards** are currently **in development** to enable safe and uniform collection by other public bodies.
- We've heard that people in B.C. **did not want** identity information to be **collected at every** service **interaction**.
- Residents also said that a **secure platform**, an **independent body** to oversee the data, **transparency** and **culturally trained people** are needed to be in place.



BRITISH
COLUMBIA

Together we can fill gaps
in BC government services.

Take the BC Demographic Survey:
antiracism.gov.bc.ca/BCDemographicSurvey



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<https://antiracism.gov.bc.ca/what-is-the-bc-demographic-survey/>

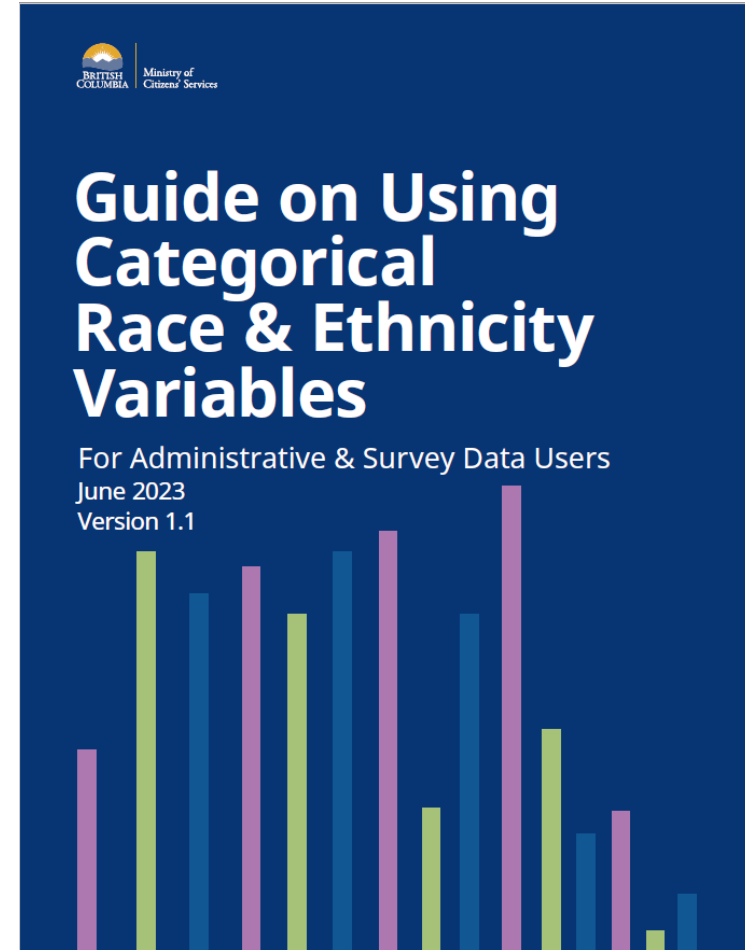
Who directs data use for research?

- In June 2023, anti-racism **research priorities** were released. These priorities **reflect what matters most to communities** impacted by systemic racism in B.C.
- They were developed by the **Anti-Racism Data Committee** and by the **Indigenous Peoples**.
- There are **10 priorities** as well as several **process commitments** for how this research is going to be conducted. This includes supporting **Indigenous data sovereignty** and a **distinctions-based** approach.
- Under the Anti-Racism Data Act, the **Director of Statistics** is **responsible for oversight** of race-based data collection, storage and use.



How are the data users supported?

- It is important to support **appropriate** and **consistent use of race and ethnicity data** through formal policy mechanisms and informally through training and resources.
- In June 2023, **we released a guide** with recommendations for use of categorical race and ethnicity data.
- Over 500 public service employees and leaders attended our **webinars** based on the guide. We are expanding it to data users outside of government.
- Users accessing the BC Demographic Survey data are **required to take online training** that introduces them to important concepts and practices in anti-racism research.



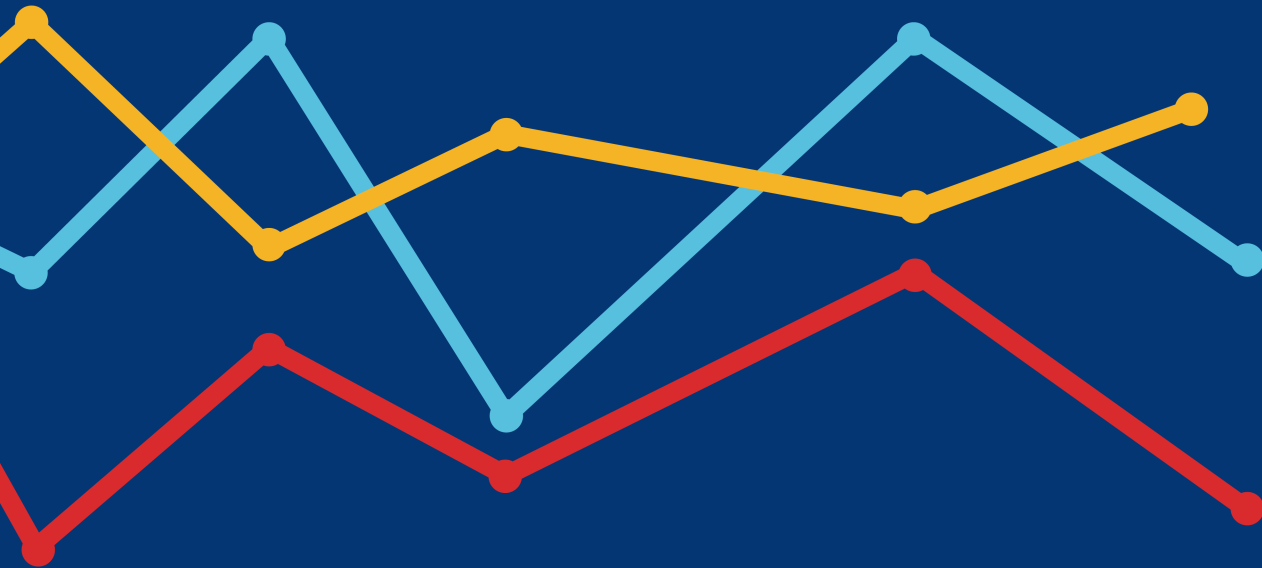
<https://antiracism.gov.bc.ca/anti-racism-statistics-insights-and-research/>

What have we learned from our first research projects?

Our first research findings will be released close to June 1st on www.antiracism.gov.bc.ca

- Due to the risk of harm to communities, teams require **diverse skill sets** and **access to training** and **support**.
- While best practices generally apply, **what’s “right” for one project may be harmful in the context of another project**.
- **Anticipate denialism** during collection and use. Education about racism and thoughtful communication are important.
- Producing **high-level statistics** on metrics or disparities **by race is a starting point**. Solutions are group- and context-specific and require research that can deliver such insights.





Thank you!

Tatiana Kim

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Projects

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**RACE,
ETHNICITY
& INDIGENOUS
IDENTITY DATA**

Let's achieve health equity together.

We are gathering race, ethnicity & Indigenous data from patients to help us understand and close existing gaps in health care access, experience and outcomes.

Race, Ethnicity and Indigenous Identity Data:

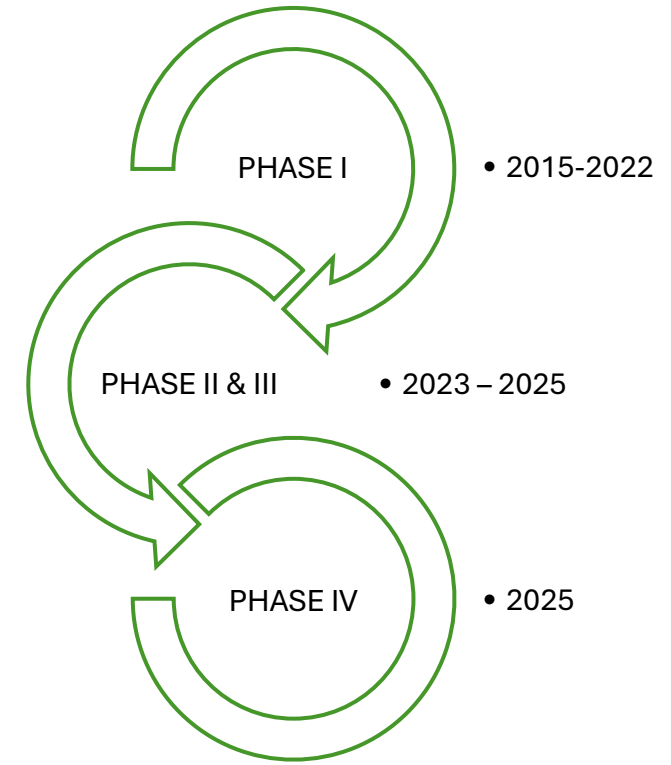
A Manitoba approach to measure the impacts of racism (not race) on health and healthcare

Nathalie Buissé, Project Manager
Centre for Healthcare Innovation

MEASURING RACISM (not RACE)

The collection and governance of REI identity data is an important tool to enable healthy systems planning and management in an effort to ensure **all** communities receive equitable care.

- Identify and address racial/ethnic disparities in health care;
- Assess the effectiveness of population health and health-care improvement interventions;
- Develop and evaluate services and programs to address health inequities, measure health systems performance or participate in quality improvement



Data collection cannot exist in the absence of these key considerations

- **Commitment to Anti-Racism**
- **Meaningful Engagement**
- **Rights-Based Data Governance**

Let's achieve health equity together.

We are gathering race, ethnicity & Indigenous data from patients to help us understand and close existing gaps in health care access, experience and outcomes.

We all have a part to play in DISRUPTING RACISM

Disrupting Racism is a deliberate act that involves learning, action and speaking up against instances of racism in any form. Our efforts to identify and confront racism will promote interactions that are thoughtful and inclusive while taking steps to create safer and respectful environments. Racism, Disrupted begins with the acknowledgment of wrongs and resulting harms and the recognition that our history is rooted in the stories of peoples facing exclusion or discrimination based on their race.

[Read the Health System's Commitment to Disrupting Racism Statement here.](#)

[Disrupting
Racism Action
Plan](#)

[Racial Climate
Survey](#)

[Learning & Improvement
Resources](#)

[Health Equity -
Closing the Gap](#)

[Indigenous
Specific Racism](#)

[Race, Ethnicity and Indigenous
Identity Data](#)



Centre for Healthcare Innovation

RACE, ETHNICITY & INDIGENOUS IDENTITY DATA

Let's achieve health equity together.

We are gathering race, ethnicity & Indigenous data from patients to help us understand and close existing gaps in health care access, experience and outcomes.

SUPPORT

- Indigenous Governance Partners
- Public
- Government Leadership
- Clinical Leaders
- Health Authorities Leadership
- Staff (all levels)

EXPERTISE

- Diversity
- Community Health
- Critical Race Theory
- Human Rights
- Epidemiology
- Health Information/IT Management
- Data Analysts
- Community Engagement
- Evaluation

Manitoba's Race, Ethnicity, and Indigenous Identity Data Governance Framework

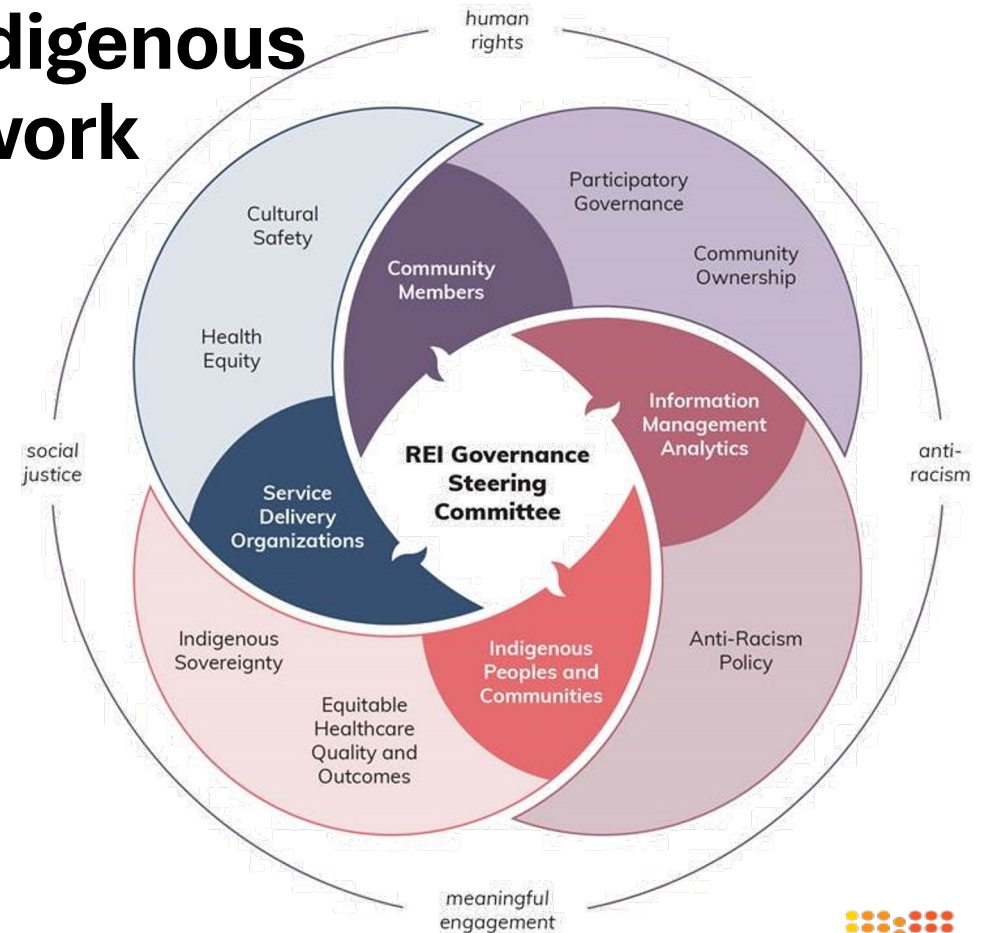
Guiding Principles

- Nation-specific data is governed by Nation-representing organizations
- Rights – Based Healthcare
- Community/Expertise Led

Purpose:

Provide oversight on how the data is used, what health indicators to prioritize

Publicly report on health indicators and engage in recommendations for health system planning and management in shared collaboration with Clinical Leads



Measuring Health Equity in Toronto Region

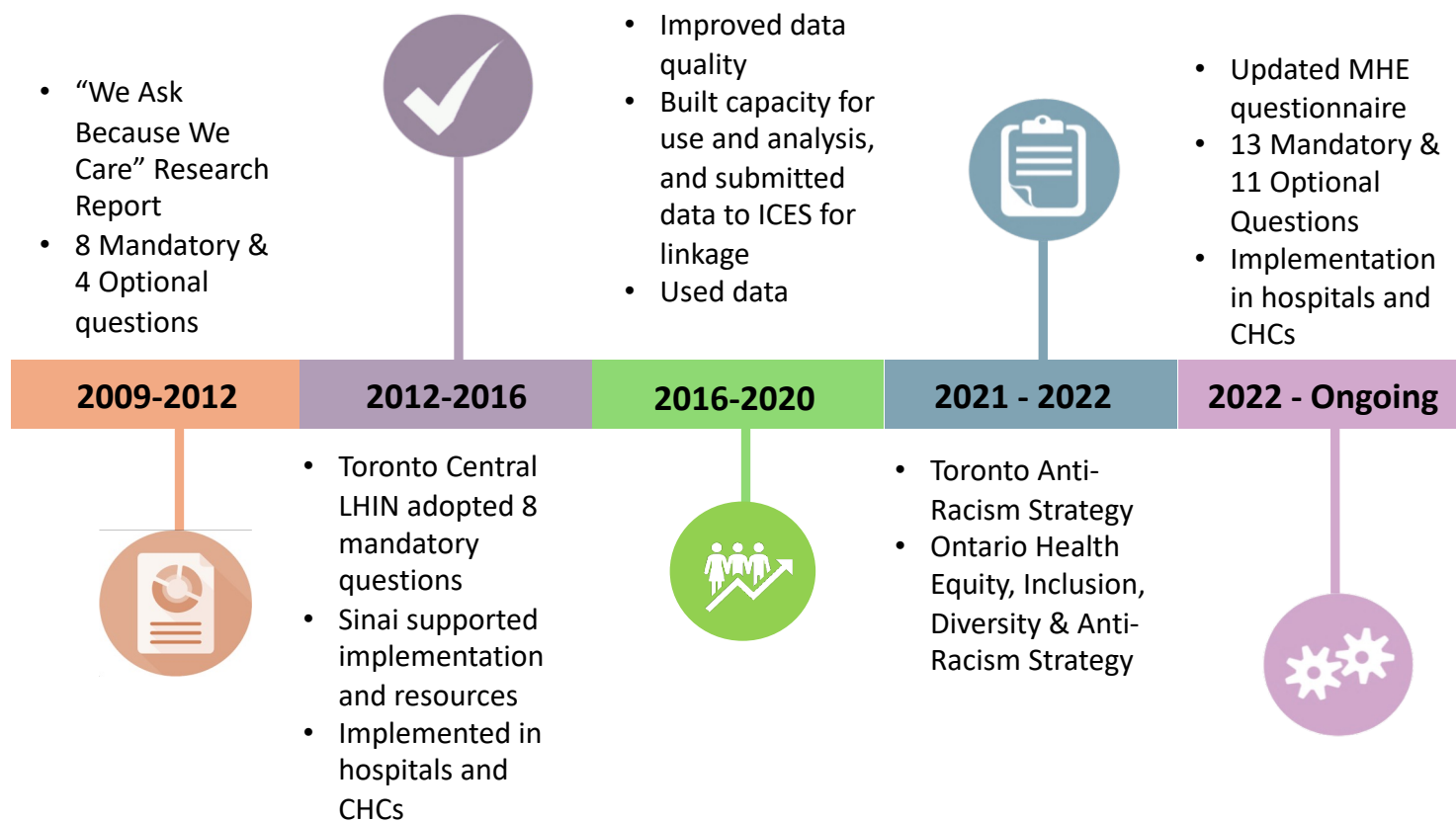
Presentation at Powering Equity: Canada's first
summit on race-based data for health

Presenter: Cynthia Damba | May 15, 2024

Measuring Health Equity (MHE) in Toronto – Our Journey

The **MHE Project** supports healthcare organizations with implementing standardized demographic data collection for adult and pediatric patients/clients

- The data is used for improving **direct patient care, program planning, quality improvement** and **system planning**
- Ultimate goal: **improving healthcare access, experience and outcomes** of patients and **removing health inequities**
- This project provides evidence-based guidance, tools, and resources for demographic data collection and use



Areas of Collection

Hospitals

Emergency departments, inpatient units (acute, rehab, complex care, mental health, palliative), specialized units, family health teams, outpatient clinics, operating rooms, medical imaging

Community Health Centres (CHCs)

At registration. New and active clients, group clients

Toronto Equity Questions

Old MHE Questions, 2013 - 2021	Updated MHE Questions, 2022
1. Preferred Language	1. Preferred Language
2a. Born in Canada b. Length of stay	2a. Born in Canada b. Length of stay
3. Racial or Ethnic Group	3. Indigenous Identity
	4. Ethnic or Cultural Background
	5. Racial Group
4. Having Disability/Chronic Illness	6a. Having Disability b. Benefit from Support
5. Gender	7. Sex at Birth
	8. Gender Identity
	9. Transgender
6. Sexual Orientation	10. Sexual Orientation
7. Family Income	11. Difficulty Paying for Basic Needs
	12. Family Income
8. People Supported by Income	13. People Supported by Income

Equity Data Collection, 2021/22

Hospitals

Patients: **~356,000**

Participation rate: **1% - 100%**

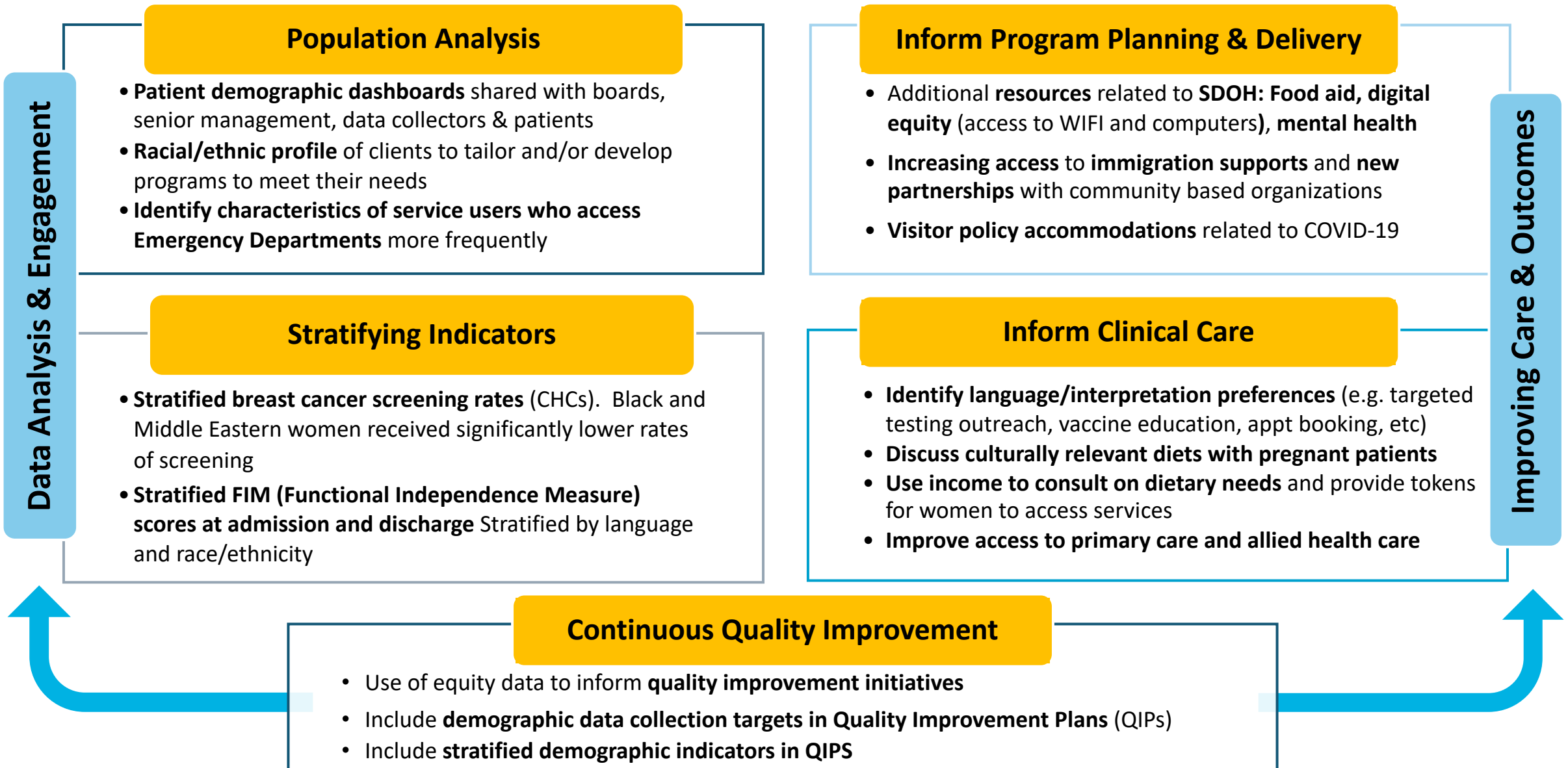
CHCs

Clients: **~46,000**

Participation rate: **56% - 94%**

Questions are never perfect, but can balance patient, provider, organizational and system needs

How Hospitals and CHCs are Using the Equity Data

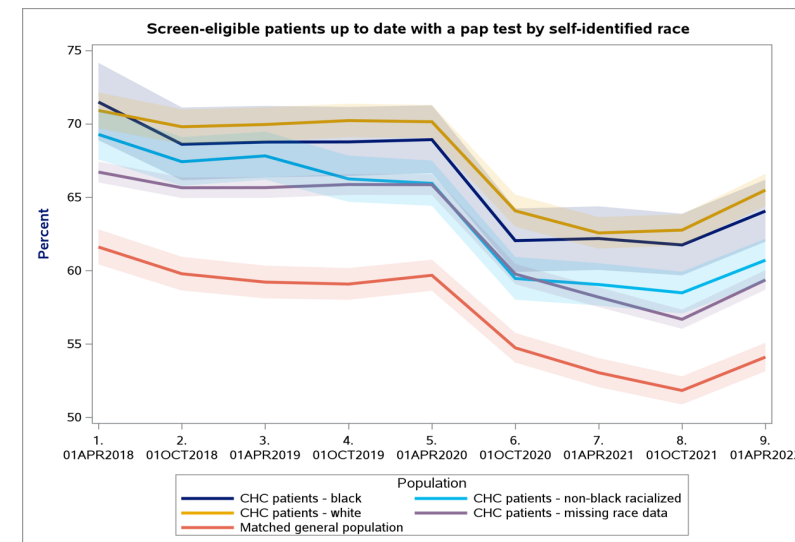
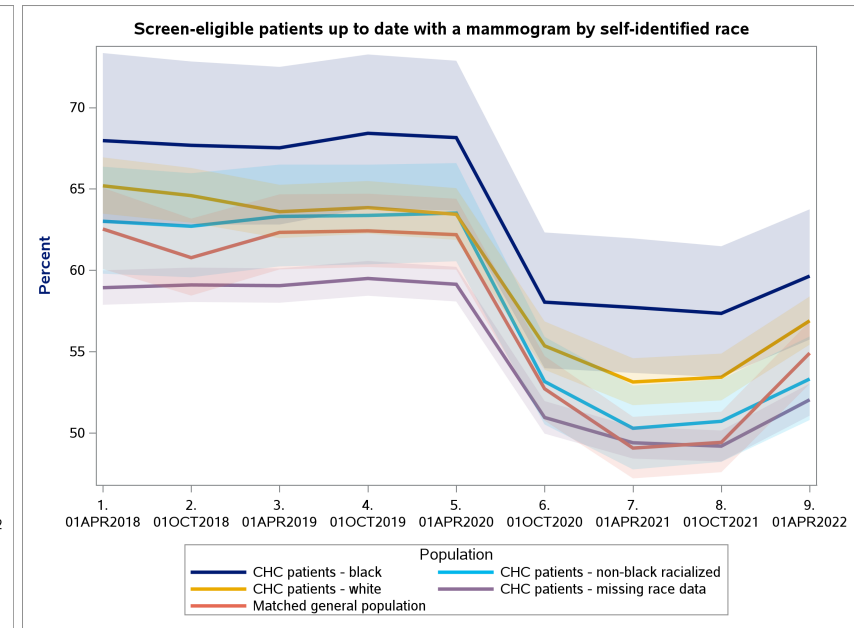
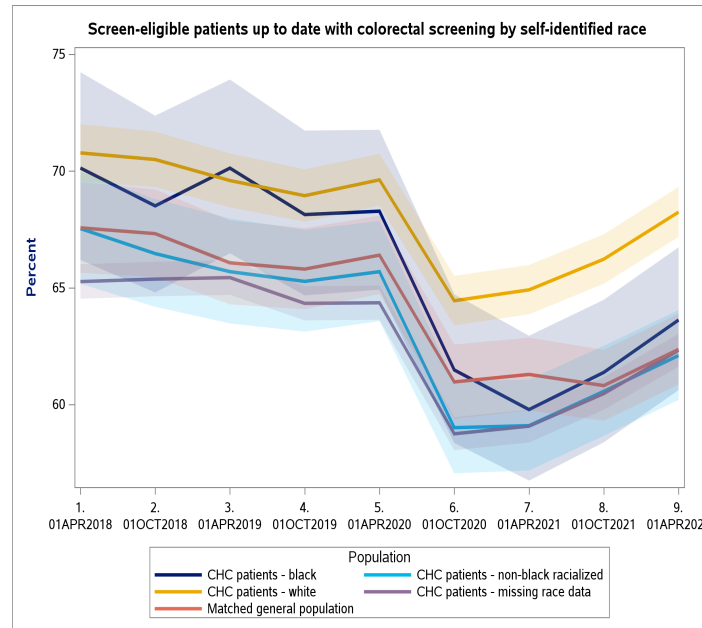


Use of MHE Data for Cancer Screening in CHCs

- ICES AHRQ request using CHC equity linked data compared differences in cancer screening rates for CHC clients to a community control group of non-CHC clients, 2018 - 2022
- *Colorectal*: Higher screening among Black and White groups
- *Breast*: Higher mammograms among Blacks
- *Cervical*: Higher screening of CHC clients, irrespective of racial group

Use of results:

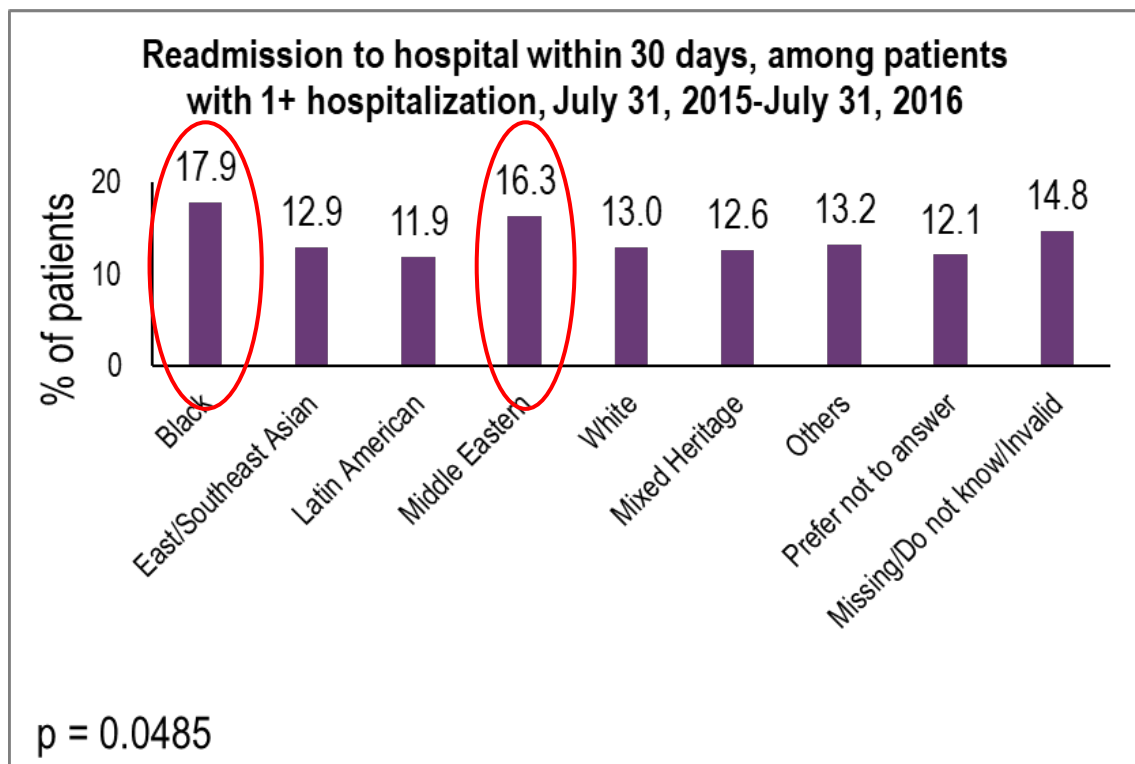
- CHCs - Direct patient care, program planning
- System planning – Improve care pathways in Black Health Plan, Cancer Plan 6 and High Priority Communities



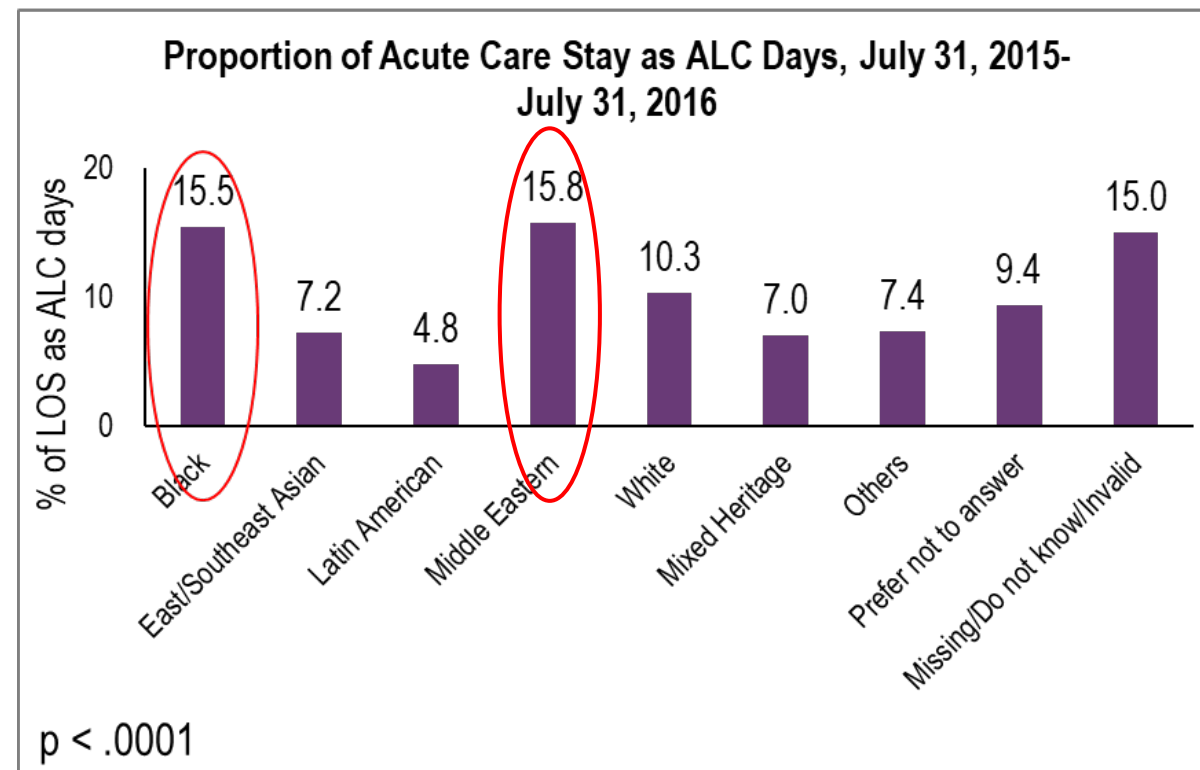
Use of MHE Data for System Planning

Health Disparities (readmissions and ALC days) by Race/Ethnic Group

Black patients had the highest rate of readmissions (17.9%)



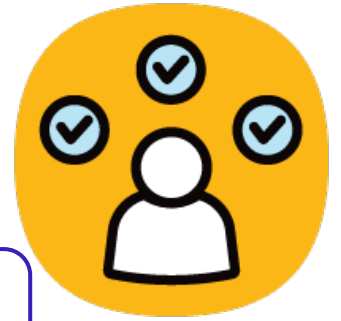
Black patients had the second highest proportion of ALC days (15.5%)



Study results informed the establishment of the Black Health Plan Table

Data Source: ICES AHRQ Project 2016 0900 839 000

Lessons Learned from Equity Data Collection



- Implementing changes can be more challenging than introducing new practices
- Competing priorities

Organizational Cultural Change Leadership



- Equal Care ≠ Equitable Care
- Build a respectful and inclusive environment

Health Equity Vision



- Staff resources and training on collecting and using the data for service planning and quality improvement initiatives
- Address staff discomfort

Adequate Resourcing & Training



- Framework to guide collection, management, analysis, and use of data
- OCAP, EGAP
- Meaningful engagement of community

Data Governance



- Standardize data entry practices to improve quality
- Modify IT systems for data extraction
- Identify data reporting goals and embed in early planning

Data Entry, IT & Quality, Reporting



- Collection in high volume areas or from some populations

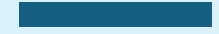
Challenging Populations & Areas



- Use results to improve outcomes
- Monitor and evaluate progress towards desired outcomes
- Share results with community

Improve Outcomes





APPENDIX 1

The Core Survey Questions

Updated Pre-Amble



We Ask Because We Care

We would like to ask you some questions to help us better understand our patients/clients. Your answers will help us provide you with the best care possible, and help improve programs and services for everyone.

Why are you collecting this information?

These questions will help us to better understand our patients/clients and help us provide better care and services. Some questions may feel very personal or private; we are asking these questions because sometimes people have been treated differently because of who they are as a person. Being treated differently like this is discrimination and can affect our health.

Do I have to answer all the questions?

No. You can choose to answer these questions or not. You can stop answering the questions at any time, or ask us to remove your answers at any time. We will provide you with care whether you answer the questions or not.

Updated Pre-Amble, continued



Who will see this information?

Only people involved directly in your care will see your answers. It will be protected like all of your other health information. We will also take your answers and remove your name from them and combine them with the answers of all the other people we serve. Those combined answers may be used by us, as well as by researchers, to provide better care and services.

How long will this take?

It will take six to eight minutes to complete all 13 questions.

Do you agree to answer the questions?

- Yes
- No
- I prefer not to answer any of these questions, at this time

Updated Measuring Health Equity Questions

1. What language do you feel most comfortable speaking in with your provider? (check all that apply)				
<input type="checkbox"/> English* (Canadian Official Language) <input type="checkbox"/> French* (Canadian Official Language) <input type="checkbox"/> Albanian <input type="checkbox"/> Amharic <input type="checkbox"/> Arabic <input type="checkbox"/> ASL (American Sign Language) <input type="checkbox"/> Bengali <input type="checkbox"/> Bulgarian	<input type="checkbox"/> Burmese <input type="checkbox"/> Georgian <input type="checkbox"/> Greek <input type="checkbox"/> Cantonese <input type="checkbox"/> Czech <input type="checkbox"/> Dari <input type="checkbox"/> Farsi <input type="checkbox"/> Gujarati	<input type="checkbox"/> Hausa <input type="checkbox"/> Hebrew <input type="checkbox"/> Hindi <input type="checkbox"/> Hungarian <input type="checkbox"/> Italian <input type="checkbox"/> Karen <input type="checkbox"/> Korean <input type="checkbox"/> Mandarin <input type="checkbox"/> Nepali	<input type="checkbox"/> Pashto <input type="checkbox"/> Polish <input type="checkbox"/> Portuguese <input type="checkbox"/> Punjabi <input type="checkbox"/> Rohingya <input type="checkbox"/> Romanian <input type="checkbox"/> Russian <input type="checkbox"/> Serbian <input type="checkbox"/> Slovak <input type="checkbox"/> Somali <input type="checkbox"/> Spanish <input type="checkbox"/> Swahili <input type="checkbox"/> Turkish <input type="checkbox"/> Twi <input type="checkbox"/> Ukrainian <input type="checkbox"/> Tagalog <input type="checkbox"/> Tamil <input type="checkbox"/> Thai	<input type="checkbox"/> Tibetan <input type="checkbox"/> Tigrinya <input type="checkbox"/> Taishanese/Toishanese <input type="checkbox"/> Urdu <input type="checkbox"/> Vietnamese <input type="checkbox"/> Another language (please specify):____ <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
2. (a) Were you born in Canada?		2.(b) If no, when did you arrive?		
<input type="checkbox"/> Yes <input type="checkbox"/> Do not know <input type="checkbox"/> No <input type="checkbox"/> Prefer not to answer		<input type="checkbox"/> Less than 5 years ago <input type="checkbox"/> 5 to 9 years ago	<input type="checkbox"/> 10 years ago, or more <input type="checkbox"/> Do not know	<input type="checkbox"/> Prefer not to answer
3. Do you identify as First Nations, Métis and/or Inuk/Inuit? (check all that apply). This question is about how you identify yourself (e.g. includes status or non-status)				
<input type="checkbox"/> Yes, First Nations <input type="checkbox"/> Yes, Inuk/Inuit <input type="checkbox"/> Yes, Métis		<input type="checkbox"/> No <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer		

Updated Measuring Health Equity Questions

<p>4. What is your ethnic or cultural background? For example: Canadian, Chinese, East Indian, English, Filipino, French, German, Irish, Italian, Jamaican, Jewish, Polish, Portuguese, Scottish, etc</p> <p><input type="checkbox"/> Please specify _____</p> <p><input type="checkbox"/> Do not know</p> <p><input type="checkbox"/> Prefer not to answer</p>				
<p>5. Which of the following best describes your racial group? (check all that apply, for example If you are multi-racial or mixed race)</p>				
<p><input type="checkbox"/> Middle Eastern, Arab or West Asian (e.g., Afghan, Egyptian, Iranian, Lebanese, Persian, Turkish, Kurdish, etc.)</p> <p><input type="checkbox"/> Black (e.g., African, Afro-Canadian, Afro-Caribbean, Afro-Egyptian etc.)</p> <p><input type="checkbox"/> East Asian (e.g., Chinese, Korean, Japanese, Taiwanese, etc.)</p> <p><input type="checkbox"/> Latin American (Hispanic or Latin American descent)</p> <p><input type="checkbox"/> South Asian (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan, etc.)</p>		<p><input type="checkbox"/> Southeast Asian (e.g., Filipino, Vietnamese, Cambodian, Thai, Indonesian, etc.)</p> <p><input type="checkbox"/> White (e.g., European descent)</p> <p><input type="checkbox"/> Another race/ethnic group (please specify): _____</p> <p><input type="checkbox"/> Not Applicable (e.g. Identified as Indigenous in question #3)</p> <p><input type="checkbox"/> Do not know</p> <p><input type="checkbox"/> Prefer not to answer</p>		
<p>6.(a) Do you identify as a person with a disability?</p>		<p>6.(b) Could you benefit from support related to any of the following? (check all that apply)</p>		
<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> If you wish, please specify _____</p> <p><input type="checkbox"/> No</p>	<p><input type="checkbox"/> Do not know</p> <p><input type="checkbox"/> Prefer not to answer</p>	<p><input type="checkbox"/> Alzheimer's Disease/Dementia</p> <p><input type="checkbox"/> Autism Spectrum Disorder</p> <p><input type="checkbox"/> Chronic Illness (e.g. sickle cell, diabetes etc.)</p> <p><input type="checkbox"/> Cognitive Disability</p>	<p><input type="checkbox"/> Developmental Disability</p> <p><input type="checkbox"/> Drug or Alcohol Dependence</p> <p><input type="checkbox"/> Learning Disability</p> <p><input type="checkbox"/> Mental Illness</p> <p><input type="checkbox"/> Physical Disability</p>	<p><input type="checkbox"/> Sensory Disability (e.g., low vision, blindness, deafness, hard of hearing etc.)</p> <p><input type="checkbox"/> Other (please specify) _____</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> Do not know</p> <p><input type="checkbox"/> Prefer not to answer</p>
<p>7. What was your sex assigned at birth? (check one)</p>				
<input type="checkbox"/> Male	<input type="checkbox"/> Female	<input type="checkbox"/> Intersex	<input type="checkbox"/> Do not know	<input type="checkbox"/> Prefer not to answer

Updated Measuring Health Equity Questions

8. What is your gender identity? (check all that apply)				
<input type="checkbox"/> Genderfluid or genderqueer	<input type="checkbox"/> Two- Spirit	<input type="checkbox"/> Questioning or unsure	<input type="checkbox"/> Do not know	
<input type="checkbox"/> Man	<input type="checkbox"/> Woman	<input type="checkbox"/> Another gender identity (please specify) _____	<input type="checkbox"/> Prefer not to answer	
<input type="checkbox"/> Nonbinary				
9. Do you identify as transgender? Transgender is an umbrella term used to describe people whose gender identity or gender expression differs from the sex they were assigned at birth.				
<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Do not know	<input type="checkbox"/> Prefer not to answer	
10. Which category(ies) best describe your sexual orientation? (check all that apply)				
<input type="checkbox"/> Asexual	<input type="checkbox"/> Pansexual	<input type="checkbox"/> Straight/Heterosexual	<input type="checkbox"/> Prefer not to answer	
<input type="checkbox"/> Bisexual	<input type="checkbox"/> Queer	<input type="checkbox"/> Two-spirit		
<input type="checkbox"/> Demisexual	<input type="checkbox"/> Questioning or unsure	<input type="checkbox"/> Another sexual orientation (please specify) _____		
<input type="checkbox"/> Gay	<input type="checkbox"/> Same-gender loving	<input type="checkbox"/> Do not know		
<input type="checkbox"/> Lesbian				
11. Do you currently have difficulty paying for basic needs?				
<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Not applicable, I do not have to pay for basic needs	<input type="checkbox"/> Do not know	<input type="checkbox"/> Prefer not to answer
12. What was your total family income before taxes last year?				
<input type="checkbox"/> \$0 - \$19,999	<input type="checkbox"/> \$40,000 - \$59,999	<input type="checkbox"/> \$80,000 - \$119,999	<input type="checkbox"/> \$150,000 or more	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> \$20,000 - \$39,999	<input type="checkbox"/> \$60,000 - \$79,999	<input type="checkbox"/> \$120,000 - \$149,999	<input type="checkbox"/> Do not know	
13. How many people does this income support?				
<input type="checkbox"/> _____ persons	<input type="checkbox"/> Do not know	<input type="checkbox"/> Prefer not to answer		

Optional Survey Questions

Updated Measuring Health Equity Questions



Please note:

The optional questions that follow in the next slides are not part of the core data set and are not mandatory.

These questions are from the original Toronto Central LHIN Measuring Health Equity additional questions and SPARK Study and have been made available for HSPs to use based on their needs and demographic data collection goals.

Updated Measuring Health Equity Questions

1. What is your current level of education?

- | | |
|--|---|
| <input type="checkbox"/> No formal schooling | <input type="checkbox"/> College, CEGEP or other non-university certificate or diploma (or ongoing) |
| <input type="checkbox"/> Grade school (grade 1-8) | <input type="checkbox"/> Undergraduate degree or some university |
| <input type="checkbox"/> Some high school, but did not graduate | <input type="checkbox"/> Postgraduate degree or professional designation (e.g., Master's, PhD, MD) |
| <input type="checkbox"/> High school or high school equivalency certificate (grade 9-12) | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Completed Registered Apprenticeship or other trades certificate or diploma (or ongoing) | <input type="checkbox"/> Prefer not to answer |

2. Please respond to the following statements:

(a) "Within the past 12 months, we worried whether our food would run out before we could buy or get more"

- Often True
- Sometimes True
- Never True
- Do not know
- Prefer not to answer

(b) "Within the past 12 months, the food we bought just didn't last and we could not buy or get more."

- Often True
- Sometimes True
- Never True
- Do not know
- Prefer not to answer

Updated Measuring Health Equity Questions

3. In the past 12 months, were you unable to get medicine or medical supplies, or did you do anything to make them last longer because of the cost?			
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable, I did not have to get any medicine or medical supplies in the past 12 months		<input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer	
4. (a) What is your current housing situation?			
<input type="checkbox"/> A place you or your family owns <input type="checkbox"/> A place you or your family rents <input type="checkbox"/> Social housing, Subsidized housing or Rent -geared -to -income <input type="checkbox"/> Supportive housing or Group Home	<input type="checkbox"/> Long -term care facility <input type="checkbox"/> Correctional facility <input type="checkbox"/> Staying in someone else’s place because you have no alternative <input type="checkbox"/> Experiencing homelessness (e.g., shelter, living in a public place or vehicle)		<input type="checkbox"/> Other (Specify) _____ <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
(b) Who do you live with? Select all that apply :			
<input type="checkbox"/> Parent(s) or Guardian(s) <input type="checkbox"/> Spouse or Partner <input type="checkbox"/> Child(ren)	<input type="checkbox"/> Grandparent(s) <input type="checkbox"/> Sibling(s) <input type="checkbox"/> Other family	<input type="checkbox"/> Friends or Roommates <input type="checkbox"/> Paid caregiver or attendant <input type="checkbox"/> Alone	<input type="checkbox"/> Other (Specify) _____ <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
(c) In the past 12 months, was there a time when you were not able to pay the mortgage or rent on time?			
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable, I did not have to pay rent or mortgage		<input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer	
5. In the past 12 months, has lack of transportation kept you from medical appointments, meetings, work , or from getting things needed for daily living? Select all that apply:			
<input type="checkbox"/> Yes, it has kept me from medical appointments or getting medicines <input type="checkbox"/> Yes, it has kept me from non - medical meetings, appointments, work, or getting things that I need <input type="checkbox"/> No		<input type="checkbox"/> Not applicable, I did not need transportation for these activities in the past 12 months <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer	

Updated Measuring Health Equity Questions

6. Do you currently have consistent access to a phone or the internet?

- | | |
|---|---|
| <input type="checkbox"/> Yes, phone only | <input type="checkbox"/> No |
| <input type="checkbox"/> Yes, internet only | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Yes, both | <input type="checkbox"/> Prefer not to answer |

7. In the past 12 months, did you miss making a payment on any utility bills (e.g., electric, gas/oil, water) because of cost?

- | | |
|--|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Not applicable, I did not have to pay utility bills in the past 12 months or utilities already included in rent | |

8. (a) Do you feel you have people who you can open up to or confide in?

- | | |
|--|---|
| <input type="checkbox"/> Yes, I always or sometimes have someone | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> No, I don't have anyone | <input type="checkbox"/> Prefer not to answer |

(b) Do you have people to rely on if you needed help?

- | | |
|--|---|
| <input type="checkbox"/> Yes, I always or sometimes have someone | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> No, I don't have anyone | <input type="checkbox"/> Prefer not to answer |

9. (a) Are you currently employed (this includes self-employed, full-time, part-time or other)?

- | | |
|------------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to answer |

(b) Are you currently looking for work?

- | | |
|------------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to answer |

Updated Measuring Health Equity Questions

(c) Is your main job temporary or part-time (e.g., casual, contract, freelance, short-term, seasonal)?

- | | |
|------------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to answer |

(d) Do you feel that your current employment could be negatively affected if you raised concerns about your work (e.g., health, safety, rights)?

- | | |
|------------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to answer |

(e) In the past 12 months, did your income change a lot from month to month?

- | | |
|------------------------------|---|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> No | <input type="checkbox"/> Prefer not to answer |

10. What is your religious or spiritual affiliation? Select all that apply:

- | | | | | |
|---|---|--|---|---|
| <input type="checkbox"/> Agnosticism | <input type="checkbox"/> Christian Orthodox | <input type="checkbox"/> Jainism | <input type="checkbox"/> Rastafarianism | <input type="checkbox"/> Zoroastrianism |
| <input type="checkbox"/> Animism or Shamanism | <input type="checkbox"/> Christian, not included elsewhere on this list | <input type="checkbox"/> Judaism | <input type="checkbox"/> Roman Catholic | <input type="checkbox"/> Other (Specify) _____ |
| <input type="checkbox"/> Atheism | <input type="checkbox"/> Confucianism | <input type="checkbox"/> Native Spirituality | <input type="checkbox"/> Sikhism | <input type="checkbox"/> Not Applicable, I do not have a religious or spiritual affiliation |
| <input type="checkbox"/> Baha' I Faith | <input type="checkbox"/> Hinduism | <input type="checkbox"/> Pagan | <input type="checkbox"/> Spiritual | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Buddhism | <input type="checkbox"/> Islam | <input type="checkbox"/> Protestant | <input type="checkbox"/> Unitarianism | <input type="checkbox"/> Prefer not to answer |

11. In what language would you prefer to read healthcare information? Check one only.

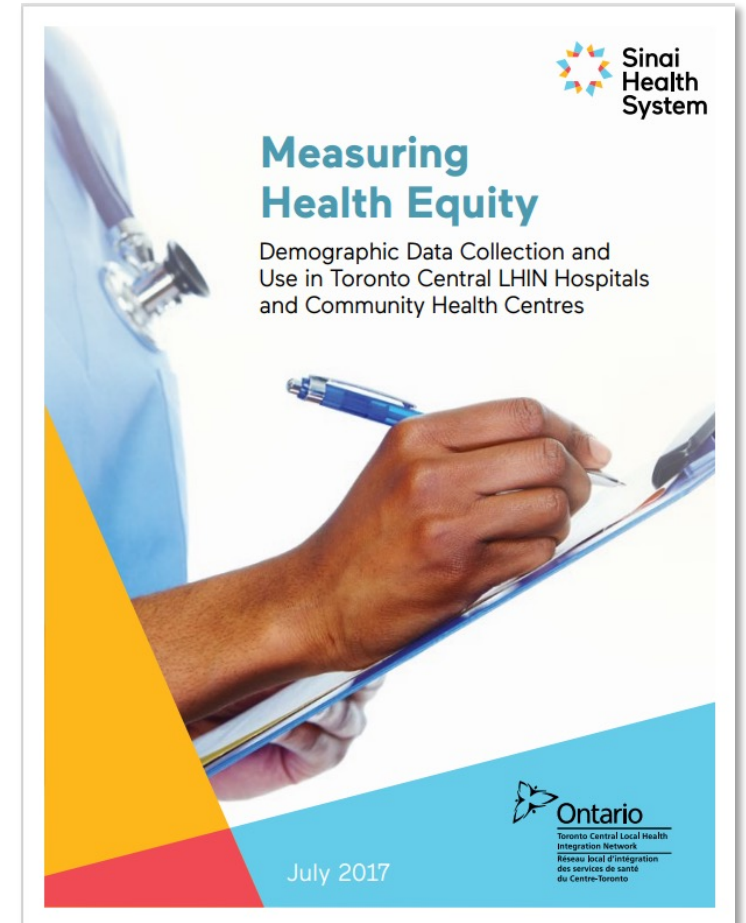
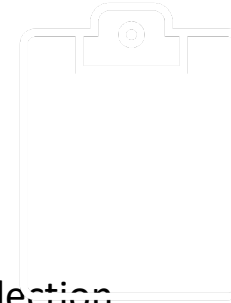
- | | | | | | | |
|----------------------------------|--|------------------------------------|-------------------------------------|----------------------------------|------------------------------------|---|
| <input type="checkbox"/> English | <input type="checkbox"/> Chinese (Simplified) | <input type="checkbox"/> Hindi | <input type="checkbox"/> Nepali | <input type="checkbox"/> Serbian | <input type="checkbox"/> Tamil | <input type="checkbox"/> Urdu |
| <input type="checkbox"/> French | <input type="checkbox"/> Chinese (Traditional) | <input type="checkbox"/> Hungarian | <input type="checkbox"/> Polish | <input type="checkbox"/> Slovak | <input type="checkbox"/> Tigrinya | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Amharic | <input type="checkbox"/> Czech | <input type="checkbox"/> Italian | <input type="checkbox"/> Portuguese | <input type="checkbox"/> Somali | <input type="checkbox"/> Turkish | <input type="checkbox"/> Other (please specify) _____ |
| <input type="checkbox"/> Arabic | <input type="checkbox"/> Dari | <input type="checkbox"/> Karen | <input type="checkbox"/> Punjabi | <input type="checkbox"/> Spanish | <input type="checkbox"/> Twi | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Bengali | <input type="checkbox"/> Farsi | <input type="checkbox"/> Korean | <input type="checkbox"/> Russian | <input type="checkbox"/> Tagalog | <input type="checkbox"/> Ukrainian | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Braille | <input type="checkbox"/> Greek | | | | | |

Appendix 2– MHE Resources

Toronto Region Legacy MHE Resources

Sharepoint Site and Equity Website

- Demographic Questionnaires
 - Adult Hospital, Paediatric hospitals, Adult CHC,
 - Translated into 13 languages
- Implementation Guide
 - Guide to planning and implementing demographic data collection
- Patient facing resources
 - Patient information form and Brochures
- Training materials
 - Slide deck and script outlining definition, rationale, and examples of demographic questions
- Reporting materials
 - Indicator Technical Specifications documents and reporting templates



[Measuring Health Equity - Demographic Data Collection \(torontohealthequity.ca\)](https://torontohealthequity.ca)

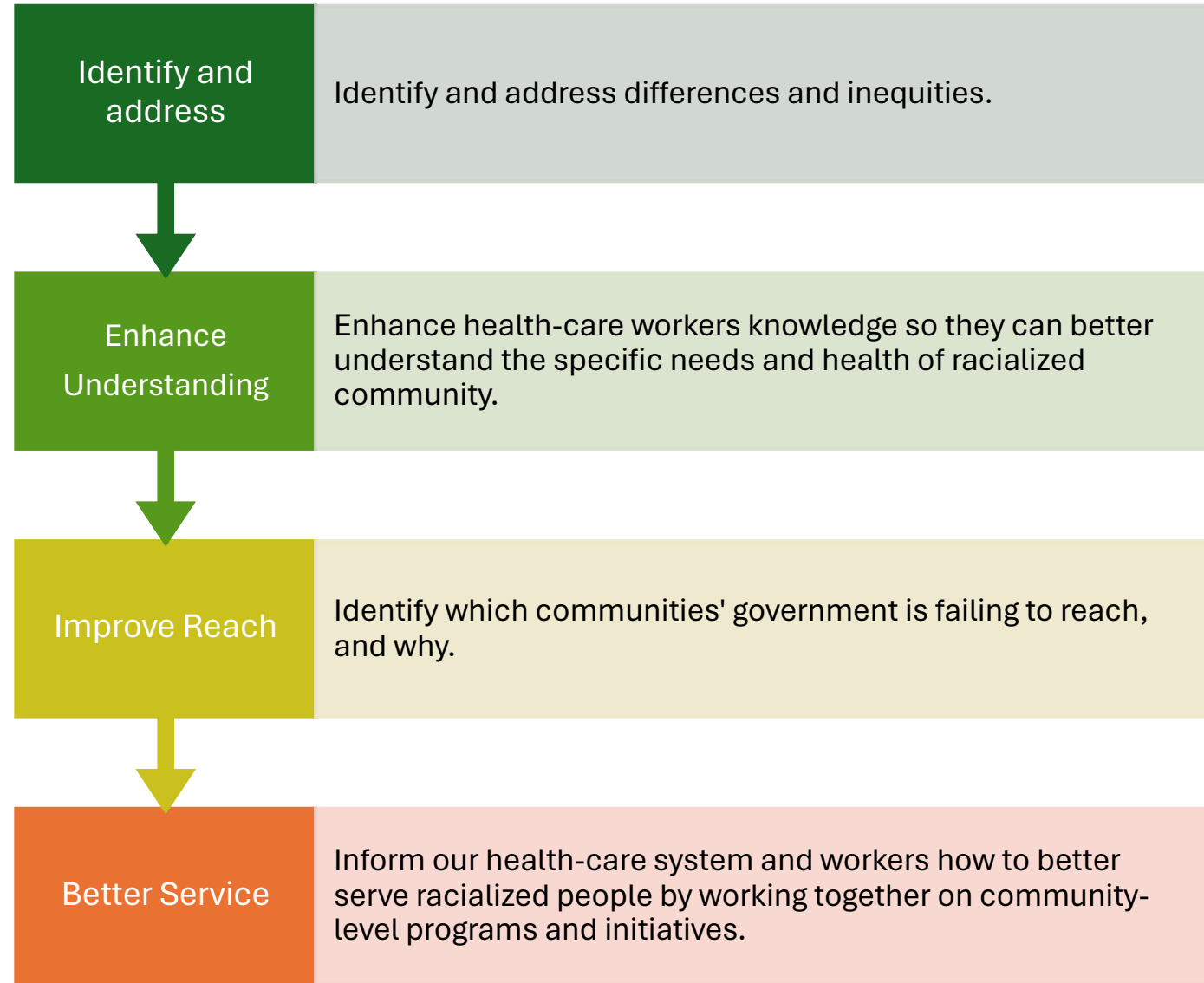
FAIR CARE

*Nova Scotia's Race-Based &
Linguistic Identity (RBLI) Initiative*

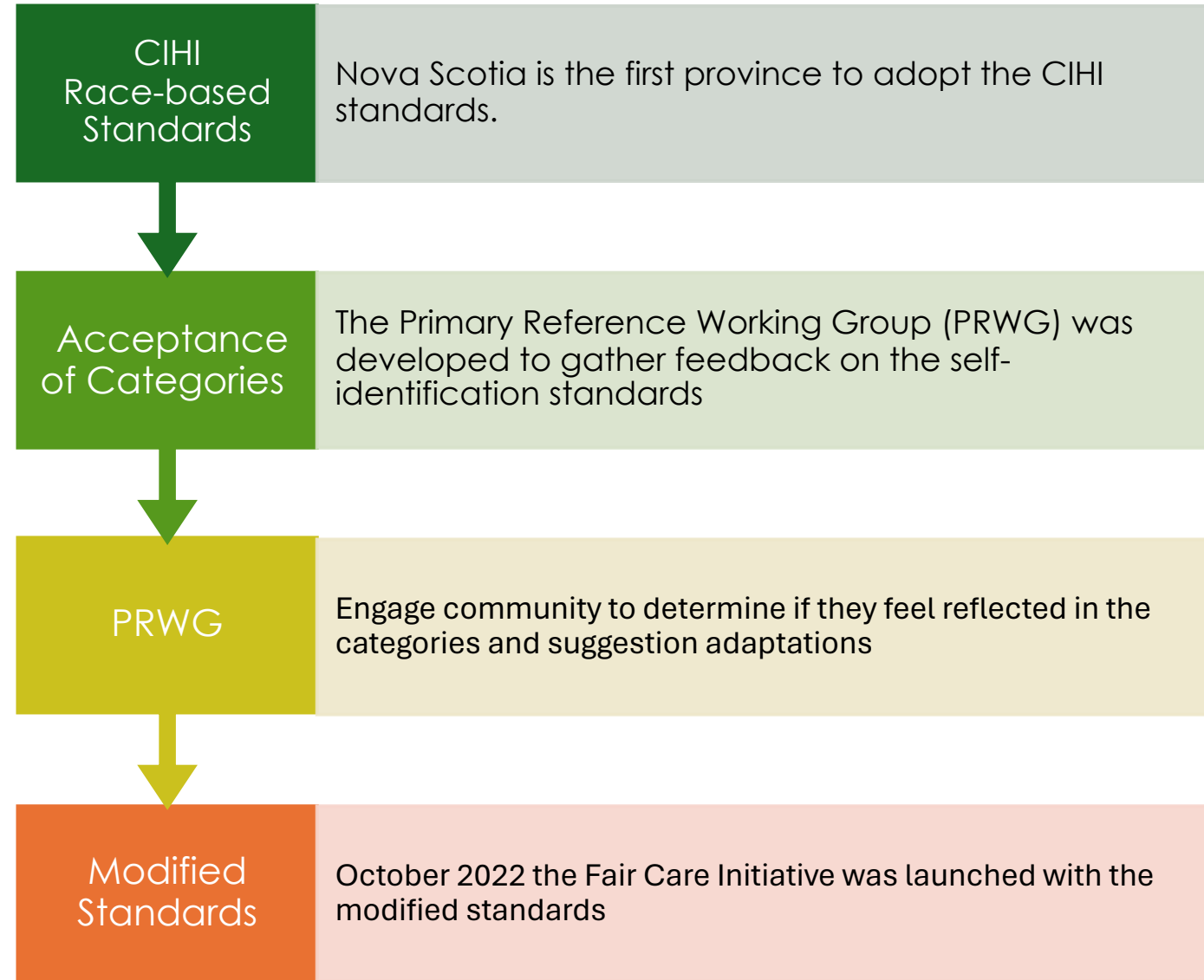


NOVA SCOTIA

How will collecting race-based identity data help?



What race-based & linguistic identities should be used?

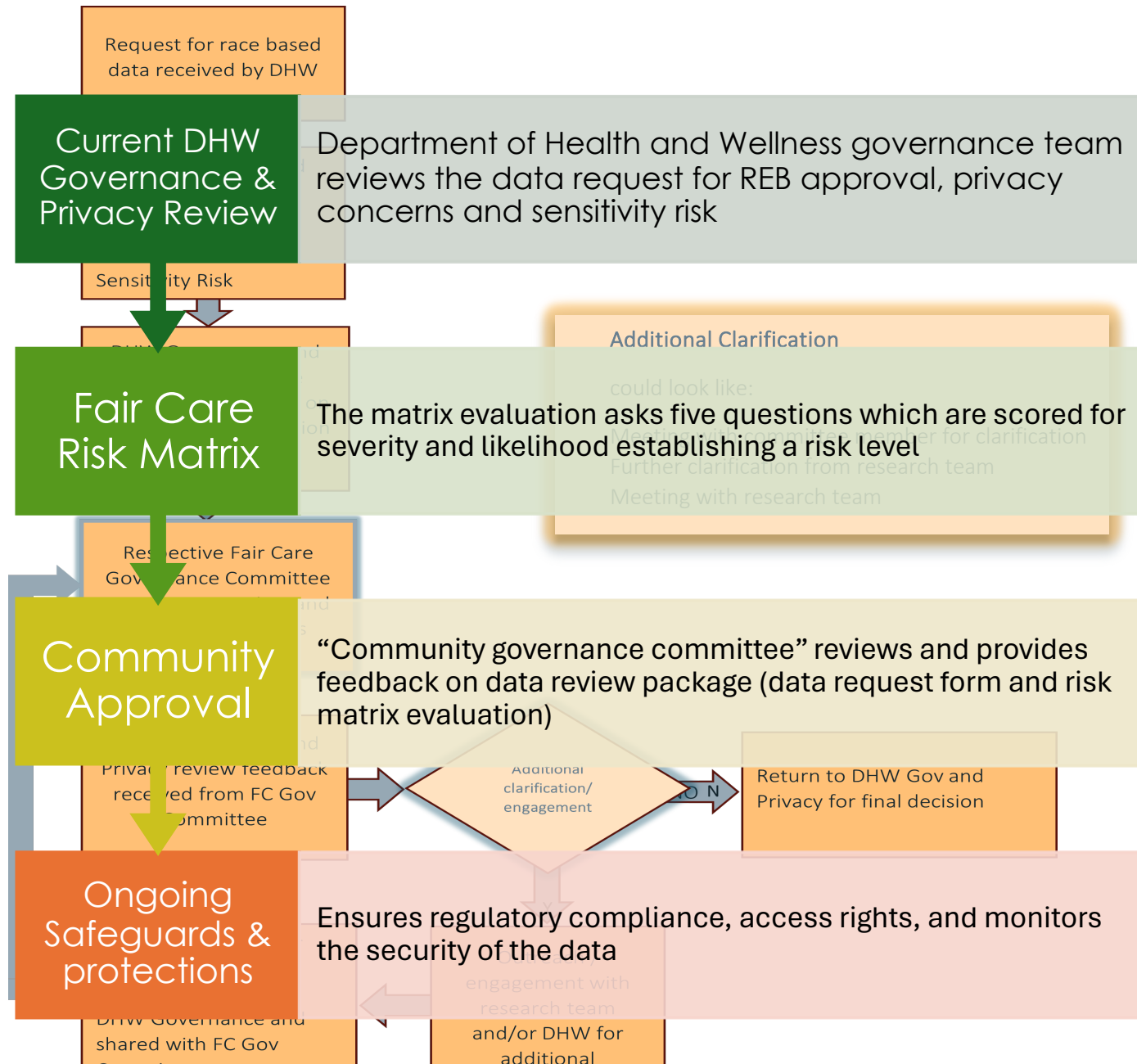


Which category best describes you? Select all that apply by completely filling in the circle:

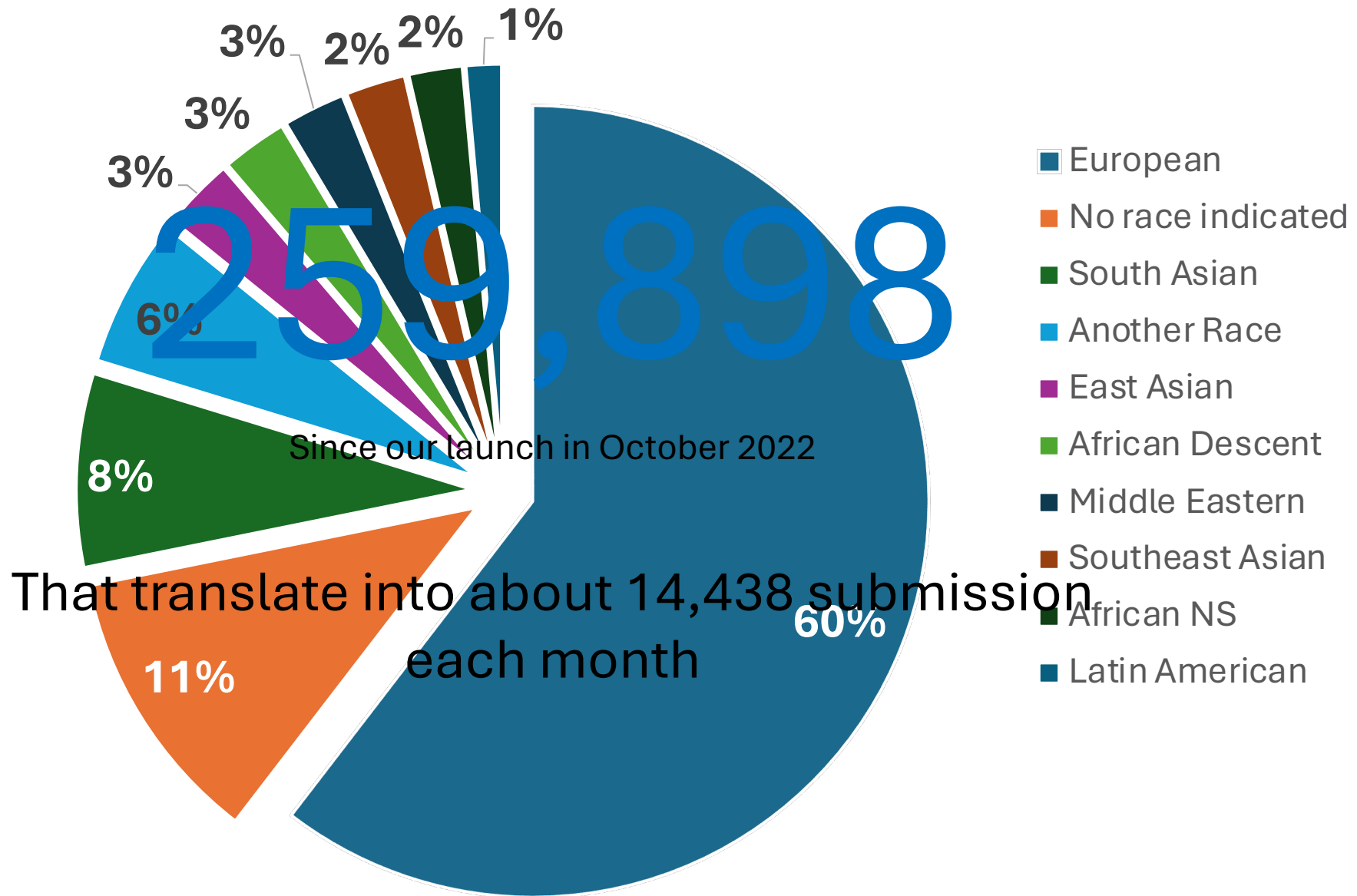
NS Modified Standard: Which category best describes you?

- | <u>Race categories</u> | <u>Examples</u> |
|---|--|
| <input type="radio"/> Indigenous | First Nations, Inuk/Inuit, Métis
Mi'kmaq not included due to the existence of the Mi'kmaq Client Linkage Registry |
| <input type="radio"/> African Nova Scotian | African descent with a Nova Scotian heritage |
| <input type="radio"/> African Descent | African Canadian, African American, Caribbean/Afro-Caribbean, other African descent |
| <input type="radio"/> Latin American | Mexican, Central American, South American, and Caribbean descent |
| <input type="radio"/> Middle Eastern | Egyptian, Iranian, Lebanese, Turkish, Kurdish, other Middle Eastern descent |
| <input type="radio"/> East Asian | Chinese, Korean, Japanese, Taiwanese, other East Asian descent |
| <input type="radio"/> Southeast Asian | Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent |
| <input type="radio"/> South Asian | Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean, other South Asian descent |
| <input type="radio"/> European Descent | British, French, Scottish, Irish, German, other European descent |
| <input type="radio"/> Another race category | Includes categories not described above |
| <input type="radio"/> Prefer not to answer | |

What is the data governance for Fair Care data collection?




Where is Fair Care's race-based data today?



As February 2024 Total records received : ~234,000

THANK YOU!





ESDC's Data Strategy: *Putting data into action by enabling **the right insights at the right time.***

Ima Okonny

Assistant Deputy Minister and Chief Data Officer

Employment and Social Development Canada

May 15, 2024

Powering Equity: Canada's first summit on race-based data for health



- ❑ **Discuss Employment and Social Development Canada's work to enhance data-driven strategies through an equity lens.**
- ❑ **Discuss potential opportunities to collaborate.**

The need for the right insights at the right time

Building data and analytics capabilities to provide **timely, granular disaggregated data:**

- ✓ To improve our **understanding of the populations we serve** and the services they receive
- ✓ To support **design and implementation** of a range of short and long-term interventions for clients including those most at-risk
- ✓ To enable **responsible innovation to generate relevant insights.**
- ✓ To **report on results** and **monitor the impacts** of policy, programs and services.
- ✓ To support increased take-up and **reduced barriers for at-risk populations.**

What it Takes From Data to Insight

ESDC Data Strategy Vision

ESDC will drive toward better services and outcomes for all Canadians by empowering departmental employees to treat data as a shared, protected enterprise asset, grounded in a culture of data stewardship and collaboration.

LEGEND

Service Area

Workstream

Functional Grouping

Foundational Data Infrastructure	Data Governance and Trust			Data Culture and Literacy			Data Innovation	
Infrastructure Development	Process & Policy	Data Management	Risk Mitigation	Strategic Alignment	Business Relationship Management	Talent & Capacity Building	Business Optimization	Analytics for Decision Making
Enterprise Data Architecture	Accountability Framework	Data Integration, Curation & Quality	Impact Assessment	Resource Planning Assessment	Stakeholder Partnerships	Upskilling & Reskilling	Advanced Methods	Design & Development
Enterprise Data Engineering	Stewardship	Secure Access	Privacy, Legal & Ethics	Awareness & Engagement	Data Sharing	Data Literacy	Artificial Intelligence	Reporting & Analytics Visualization
Analytical Platforms & Tools	Guidance & Standards	Inventory of Data Holdings	Vendor & Tool Assessment	Community of Practice	Advisory	Hiring & Retention	Intelligent Automation	Provisioning & Dissemination

COMMUNICATION - MONITORING - ISSUE MANAGEMENT - REPORTING

Foundational Data Infrastructure: Architectural design, tools and infrastructure support to enable data strategy implementation

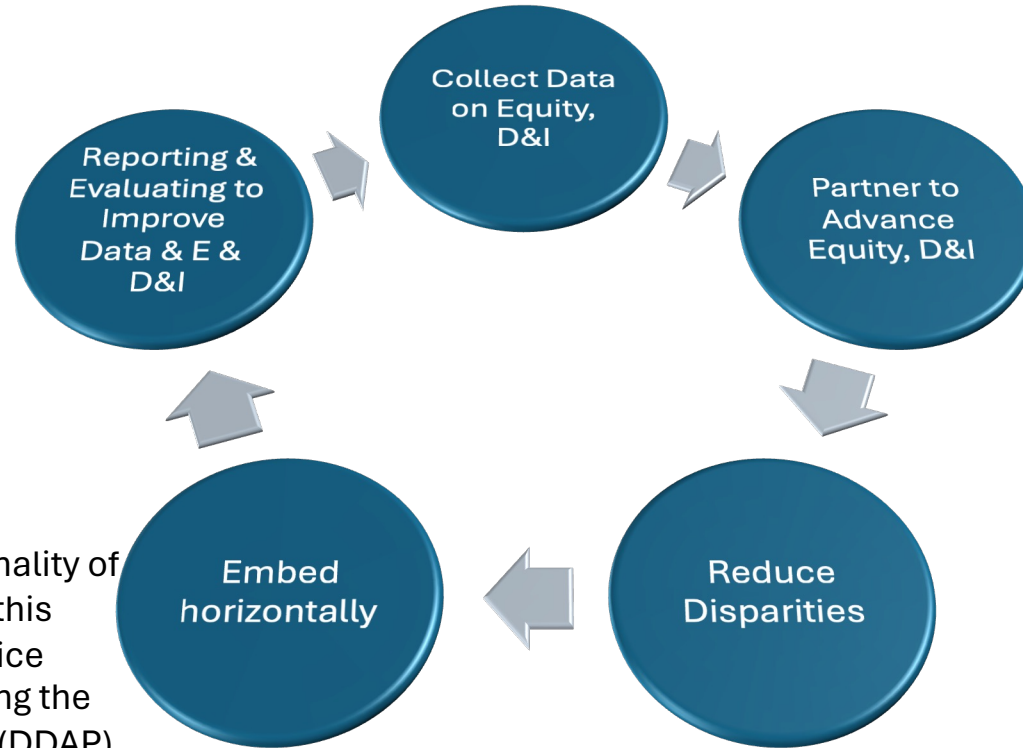
Data Governance and Trust: Foundations for sustainable data management

Data Culture and Literacy: Empowering our employees and executives to better understand and use data

Data Innovation: Advice, methods and data science and analytics capacity to drive innovation and decisions with data

Enhancing the evidence base to enable fuller insights

Manage and rectify data gaps, establish a comprehensive interdepartmental inventory of EDI data, and in turn, derive valuable insights from this data.



Strategically plan for intersectionality of EDI data with raw data, aligning this information with policy and service delivery objectives, and leveraging the Disaggregated Data Action Plan (DDAP).

From EEA/EEA2023, continue to collect information, and build a comprehensive interdepartmental inventory of EDI and EE data, embed our work in our horizontally.

We partner with IRCC, CRA, ISC & CIRNAC, CMHC, StatCan, ECCC, TBS, HC, Justice Canada, and other stakeholders. For example, Interdepartmental Data Strategy with StatCan.

Identify disparities in data and methodologies, internally and in collaboration with stakeholders.

Deeper insights for action - Examples



- **Leveraging administrative data sources** provided key insights **to identify and help overcome the barriers** that prevent potential beneficiaries from applying for the benefits to which they are entitled.
- **Partnering with Statistics Canada** and leveraging Statistics Canada's data holdings and ESDC's program data allowed for **fuller insight into workers**, and analysis by demographic characteristics and main industry of employment which **enable timely policy intervention**.

Considerations

Developing, maintaining and growing trust:

Proactive steps to ensure the purpose of sharing fits with the intended use.

Ongoing impact assessment and risk mitigation strategies – to ensure proper storage and use of information.

- Risk assessment and mitigation - Privacy, legal, cyber, reputational, ethical, security
- Organizational Data literacy programs, Data and information policies and guidance.

Leverage expertise from a cross-section of industries, community groups, as well as academia, government and the not-for-profit sector.

- Continuously work on opportunities to strengthen, maintain and build trust.
- Include a peer review process.

Ongoing transparency – Indigenous data sovereignty, Communication, *explainability*, co-creation, engagement, diversity, equity and inclusion.



Thank you !

Any questions, comments or suggestion?

IMA OKONNY, Chief Data Officer
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CHIEF
DATA
OFFICE

Race-based and Indigenous identity data standards

Evasha Rasasakaram, Senior Analyst
Population Health

Canadian Institute for Health Information

May 15, 2024

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



June 2016



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



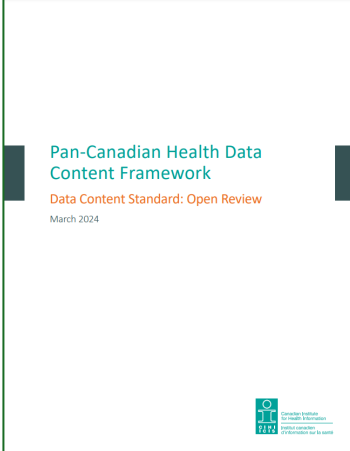
March 2022

Racialized Group Equity Stratifier added to Measuring Inequalities: A Toolkit


June 2022

Shared Health Priorities Navigation and Early Intervention survey-based indicators started collecting race-based data

Fall 2022




Pan-Canadian Health Data Content Framework
Data Content Standard: Open Review
March 2024



March 2024

July 2020

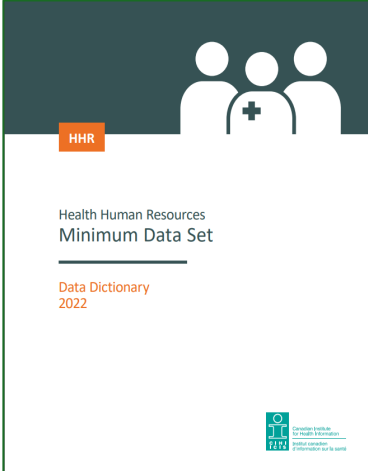


Proposed Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada


April 2022

Racialized Group and Indigenous Identity data elements added to the DAD and NACRS data submission record layout for FY 2022-2023

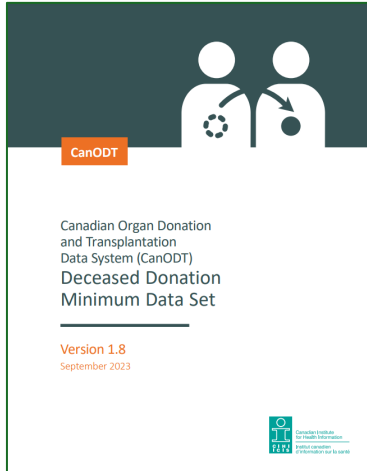
Sept. 2022




HHR
Health Human Resources Minimum Data Set
Data Dictionary 2022



Sept. 2023



CanODT
Canadian Organ Donation and Transplantation Data System (CanODT) Deceased Donation Minimum Data Set
Version 1.8
September 2023



Spring 2024

Race added to upcoming Commonwealth Fund survey

Minimum data standards

Race-based data standard

Table 2 Race-based question and responses*

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.

Indigenous identity data standard

Table 1 Indigenous identity question and responses*

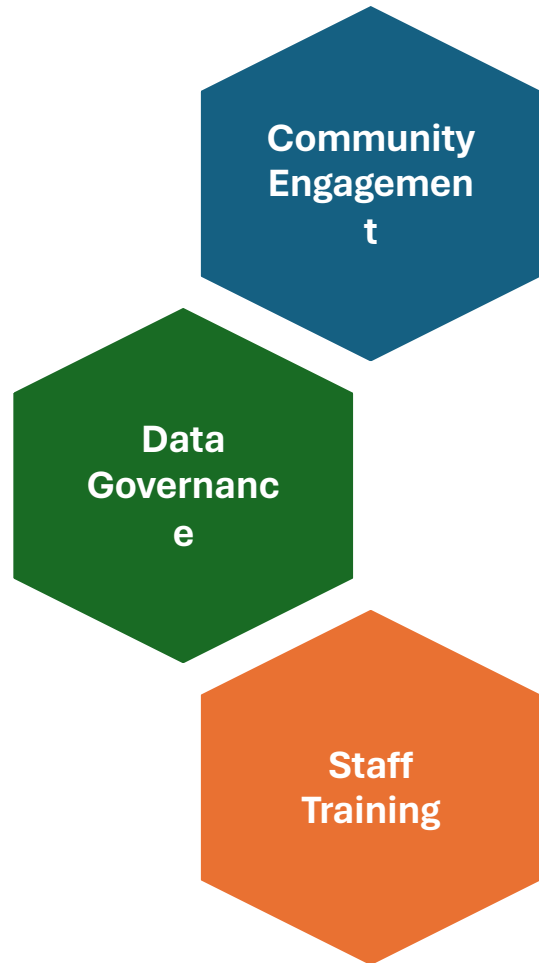
Question: Do you identify as First Nations, Inuk/Inuit and/or Métis?

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 Indigenous groups, and processes related to culturally safe and appropriate data collection.

Community engagement, data governance agreements and processes for safe collection and use are essential for implementation



- Best practice and foundational to the respectful collection and appropriate use of data
- Prerequisite for establishing data governance agreements with Indigenous Peoples and governments
- Strong data and information governance ensures that data is timely, trusted and accurate
- Indigenous data sovereignty principles
- Providing staff training and clear information to patients can facilitate culturally safe data collection
- Reduces the risk of harm and improves the quality of collected data

Continuous learning journey



- **Not a "one size fits all" approach**
- **Need for the flexibility depending on the mode of data collection**
 - Concerns about the preamble being too long
 - Change order of response categories
 - Move Indigenous identity and race-based question to the end of the sociodemographic data section
- **Data collection responses may not always align with current data system infrastructures**
 - E.g., multiple response options can only be coded as a single multiracial group

CIHI's Ongoing Support and Collaboration



Data Standards

- Implement standards across health care systems
- E.g., Pan-Canadian Health Data Content Framework



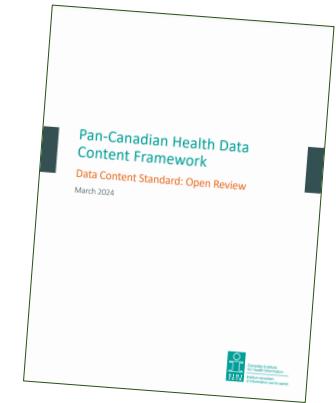
Capacity Building

- Support stakeholders with race-based data collection
- E.g., BC Provincial Health Services Authority capacity-building webinar



Tools

- Support race-based data analysis and reporting
- E.g., Measuring Health Inequalities: A Toolkit



PHSA research leaders release joint statement to encourage engagement with more diverse research participants

October 10, 2023

In July 2023, six research leaders signed a joint statement endorsing the collection of race-, ethnicity-based and Indigenous Identity data in PHSA-led research.



Six leaders representing PHSA's research institutes have signed a joint statement - the first of its kind at the organization.





Canadian Institute for Health Information
Better data. Better decisions. Healthier Canadians.

How to cite this document:

Canadian Institute for Health Information. *Race-based and Indigenous identity data standards*. Ottawa, ON: CIHI; 2024.

 @cihi_icis

populationhealth@cihi.ca

cihi.ca



**Using Race-Based Data to Design a Black Communities-Focused
Communications and Empowerment Strategy for COVID-19 and Vaccine
Uptake**

Powering Equity Summit, May 15 2024

Presented by:

Kataisee Richardson, The Federal Anti-Racism Secretariat,
Interdepartmental, Intergovernmental and International Affairs Team

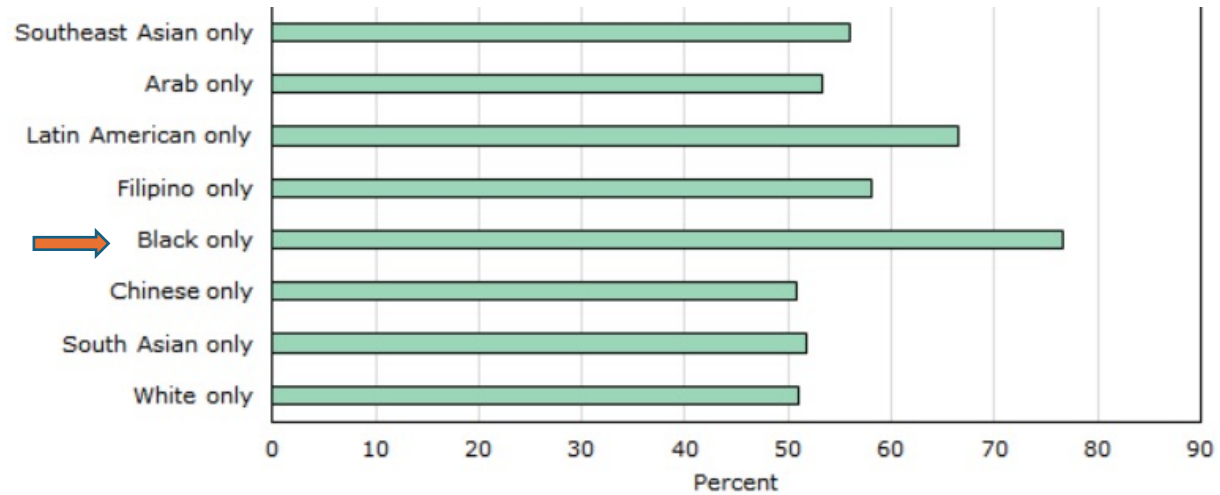
Outline

- The Genesis of the Initiative
- The Barriers to Vaccine Uptake
- The Strategy
- The Outcomes and Implications



The Genesis of the Initiative

Proportion of people in Canada not very likely to get a vaccine, Sept 2020



Note: "Not very likely" includes response categories indicating "somewhat likely," "somewhat unlikely," "very unlikely," and "don't know."
Source: Canadian Community Health Survey, September 2020 Provisional Data.

To advance impactful solutions, in April 2021, the Federal Anti-Racism Secretariat approached the Privy Council Office and the Public Health Agency of Canada with a strategy to address systemic anti-Black racism in healthcare and increase vaccine uptake within Black communities.

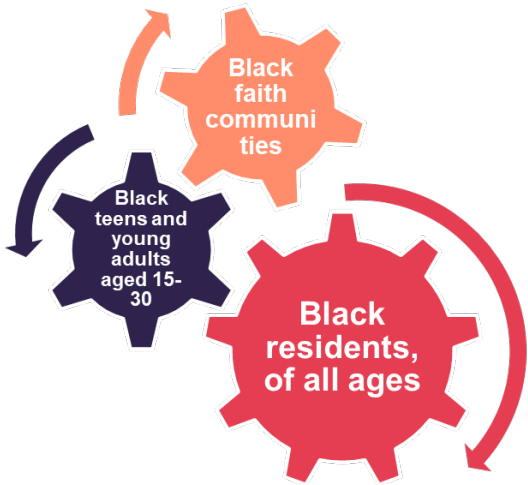
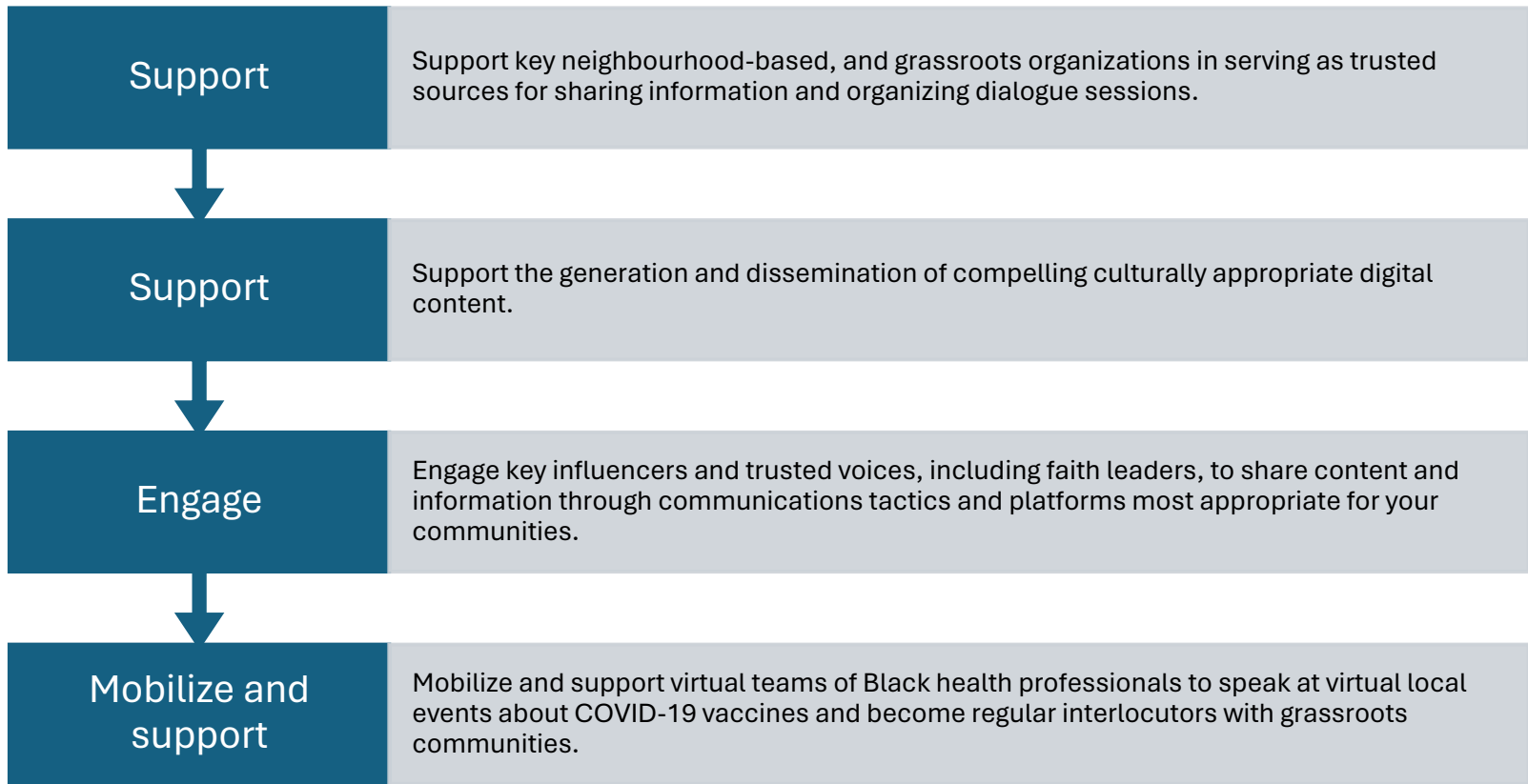


The Barriers to Vaccine Uptake

- 1. Historical mistrust:** Historical instances of mistreatment and unethical experimentation on Black communities by medical institutions.
- 2. Systemic racism in healthcare:** Black communities often face inequities in access to healthcare and experience systemic racism within the healthcare system.
- 3. Lack of culturally competent healthcare:** Healthcare systems may not always adequately address the specific needs and concerns of Black communities, leading to a lack of confidence in the healthcare system and its recommendations, including vaccination.
- 4. Misinformation and conspiracy theories:** Black communities were deliberately targeted by misinformation and conspiracy theories about vaccines through social media, word of mouth, or other sources.



The Strategy

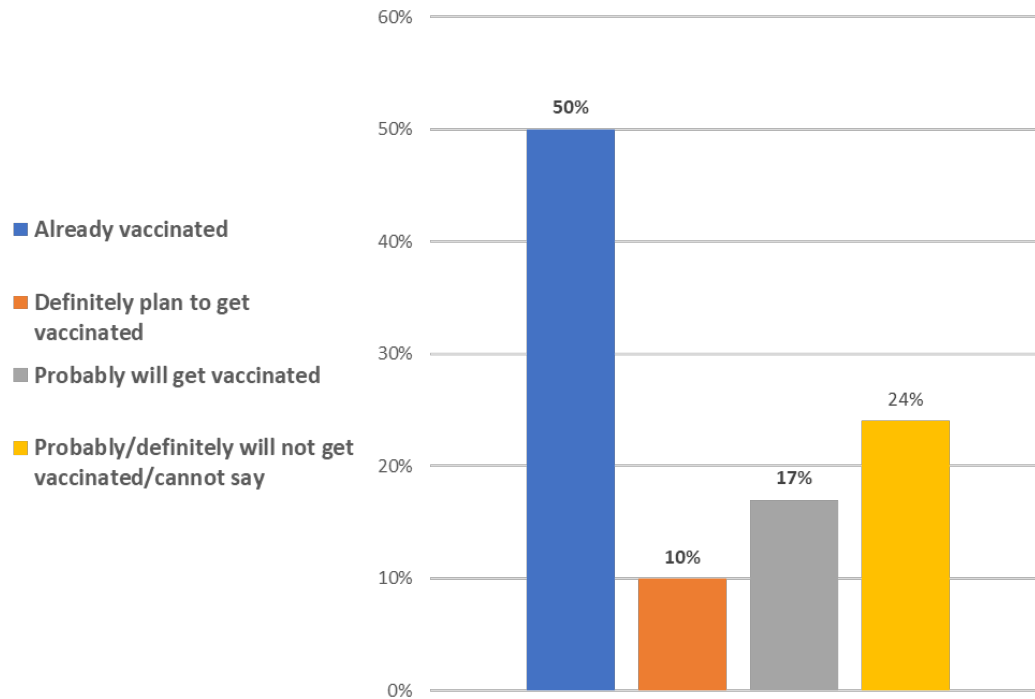


Carried out in partnership with *Black Health Alliance*, *Black Opportunity Funding*, *Federation of Black Canadians*, *Edmonton Community Foundation* and *Foundation For Black Communities*



Significant change in perspectives and in vaccine uptake.

Vaccination rate and intentions- Black Communities 2021



Outcome:

One year later the Environics Institute reported a 100% attitudinal and behavioral shift in Black communities related to taking the vaccine.

Source: Environics Institute, [Race Relations in Canada 2021: A survey of Canadian public opinion and experience](#)



Implications

Having timely access to race-based data was critical for:

- making the case to federal departments for the need for remedial plans that would take into account the lived and living experiences of Black communities and enable them to have equitable access to and trust in quality and culturally relevant healthcare, credible information and vaccines, related to COVID-19; and
- determining whether or not the identified initiatives were effective in closing the racial gap.



Towards health equity in Canada: Data for diverse population groups

Josée Bégin, Assistant Chief Statistician
Social, Health and Labour Statistics Field Statistics
Canada
Statistics Canada

May 15, 2024



Presentation Overview

National Statistical Standards
and the collection &
dissimination of ethnocultural
data

Disaggregated Data Action
Plan

Health statistics outcomes for
racialized populations in
Canada

Population Health Framework



has many concepts to capture the ethnocultural diversity of population and most of these concepts have established standards

Statistics Canada has a number of standard measures, including those to measure diverse groups, including, but not limited to:

- Gender
- Sex at birth
- Ethnic or cultural origin
- Indigenous identity
- Indigenous group
- **Visible minority / Population group**
- Immigrant status
- Sexual orientation



Current standard population group question

Is this person:

- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan)
- Chinese
- Black
- Filipino
- Arab
- Latin American
- Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai)
- West Asian (e.g., Iranian, Afghan)
- Korean
- Japanese
- Other group—specify

Disaggregated Data Action Plan (DDAP) & enhancing health statistics

Statistics Canada's approved standards should be used for disaggregation across all platforms

Data and analyses should be disaggregated at the lowest level

Analysis should focus on intersectionality as opposed to binary interactions

Data should be available at the lowest level of geography possible

Health Statistics & DDAP in Action

- Health surveys - racialized groups are taken into account at the data collection, analysis and dissemination stage
- Oversampling
- Data integration
- Census – testing new questions

Population Health Framework at Statistics Canada

Determinants of health

- Social, economic and environment factors: e.g., childhood experiences, income, employment, education, culture, access to health services, healthy behaviours, biology and genetics, racism)

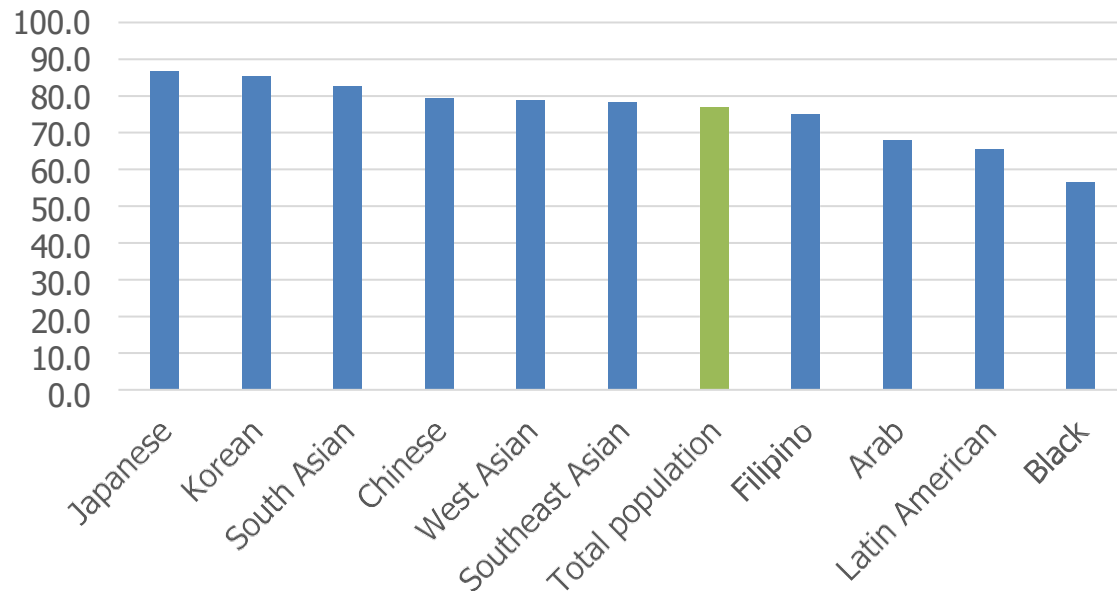
Health status/outcomes of diverse groups

- E.g., Measures of health: life expectancy, infant mortality, suicide mortality, mental illness hospitalization, self-rated mental health, self-rated health, physical activity, functional health status, fruit and vegetable consumption

Keeping a pulse on health inequity in Canada through StatCan surveys

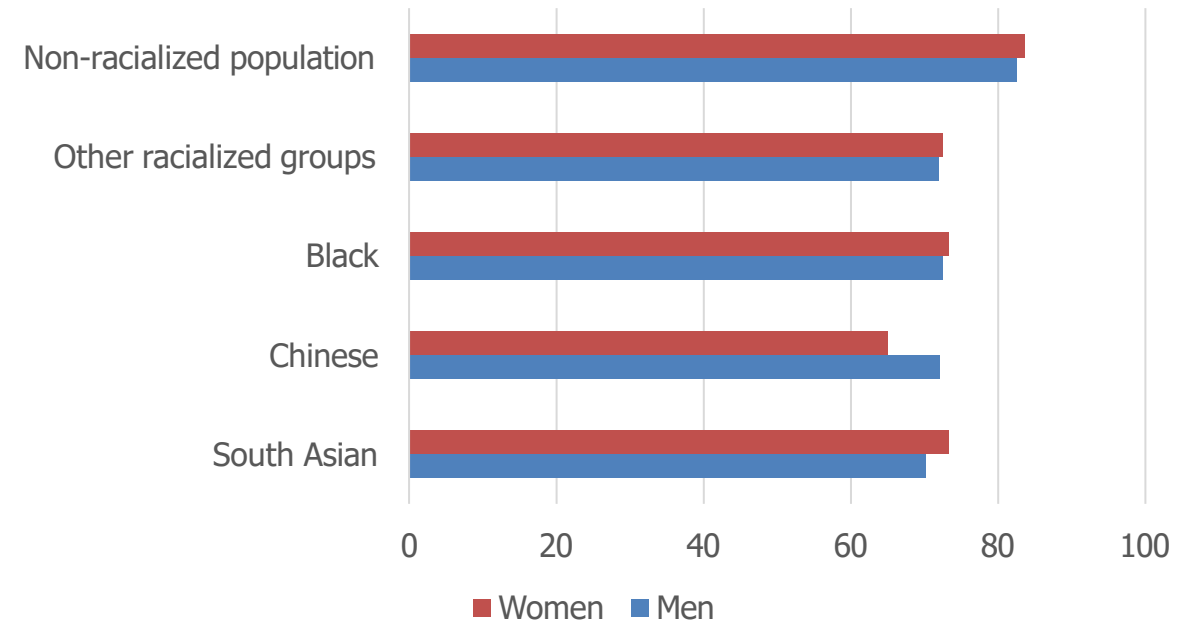
Insights into health inequity provided through StatCan surveys (during and after the pandemic):

Percentage of Canadians who were very or somewhat willing to receive the COVID-19 vaccine, by population groups, Canada excluding the territories



[Source: COVID-19 vaccine willingness among Canadian population groups](#)

Percentage of men and women aged 12 and over covered by any drug insurance plan, Canada excluding the territories, 2015, 2016 and 2019



[Source: Exploring gaps in prescription drug insurance coverage among men and women in Canada using an intersectional lens \(statcan.gc.ca\)](#)

Looking ahead



National Standards & Race-based Data

Rigorous testing of ethnocultural concepts and promotion of National Standards



Partnerships & Engagement

Greater engagement & partnerships



Relevant Health Statistics

Continued collection of health statistics informing health equity policies



Innovation

Use innovative methods and approaches

Useful links

- [Gender, Diversity and Inclusion Statistics Hub \(GDIS Hub\)](#)

- [What is DDAP and why it matters to you](#)

- [Disaggregated Data Action Plan Accomplishments 2019-2022](#)

- [2023: Building on a solid foundation](#)

- [Updated disaggregated data standards](#)

- [Consultative engagement on the visible minority concept](#)

[Insights on Canadian Society](#)

- [StatCan COVID-19: Data to Insights for a better Canada](#)

[Health Reports](#)



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Statistics Canada— Your National Statistical Agency



Delivering insight through data for a better Canada