



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



Canadian Institute
for Health Information

Institut canadien
d'information sur la santé

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For permission or information, please contact CIHI:

Canadian Institute for Health Information
495 Richmond Road, Suite 600
Ottawa, Ontario K2A 4H6
Phone: 613-241-7860
Fax: 613-241-8120
cihi.ca
copyright@cihi.ca

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Executive summary

Health systems aim to provide high-quality health care to all people regardless of their sex, gender, income, race or other socio-demographic characteristics. Disaggregating routine health care indicators can reveal inequalities across groups. Monitoring health inequalities builds our understanding of the impact of policies, programs and practices. However, in health care in Canada, there is limited collection of socio-demographic data, apart from age and sex. This is in part because of a lack of consensus on standards for collection. Data standards encourage harmonized collection and ensure high-quality and comparable data across regions, organizations and systems. The Canadian Institute for Health Information (CIHI) has supported standards for health inequality measurement through the [*Pan-Canadian Dialogue to Advance the Measurement of Equity in Health Care*](#), [*Defining Stratifiers for Measuring Health Inequality*](#) and [*Measuring Health Inequalities: A Toolkit*](#).

CIHI is proposing standards for collecting race-based and Indigenous identity data in health care that is informed by a detailed review of the research and by engagement with clinicians, researchers, organizations representing racialized groups, and representatives from governments and health systems. We continue to engage and seek feedback; several key questions for discussion are included in the [Next steps section](#).

Context

Race and ethnicity are distinct concepts:

- **Race** is a social construct used to categorize people based on perceived physical differences (e.g., skin colour, facial features). There is no scientifically accepted evidence of a biological basis for the identification and classification of discrete racial groups. Disaggregating health indicators by race can help us identify, monitor and address inequalities that potentially stem from bias and racism — systemic, interpersonal and internal.
- **Ethnicity** is a multi-dimensional concept referring to cultural group membership; it may be connected to language, religious affiliation or nationality, among other characteristics. Ethnicity data can be useful for tailoring culturally appropriate health services and understanding diversity.

First Nations, Métis and Inuit have a constitutionally recognized status that is unique. Their inherent and collective rights to self-determination include ownership and governance of their data. The collection and use of Indigenous identity data merit distinct considerations, including community engagement and, typically, data governance agreements.

Research suggests that organizations collecting race-based data should implement not only data standards but also measures to mitigate the risk of harm. These measures include facilitating informed consent; ensuring privacy, security and confidentiality; training staff to collect data; and committing to transparency and accountability for its use. Community engagement is also necessary to inform collection, analysis and reporting.

Proposed race-based and Indigenous identity data standards

CIHI's proposed race-based data standard is adapted from the [Ontario Anti-Racism Directorate's race data standards](#) and is consistent with The Upstream Lab's [recommendations on collecting data on race](#). The standard should be accompanied by a distinctions-based Indigenous identity question (at minimum), along with community engagement and/or data governance agreements.

Proposed race-based question	
We know that people of different races do not have significantly different genetics. But our race still has important consequences, including how we are treated by different individuals and institutions. Which race category best describes you? Check all that apply:	
Proposed response categories	Examples
Black	African, Afro-Caribbean, African Canadian descent
East/Southeast Asian (optional: may collect as 2 separate categories — East Asian and Southeast Asian)	Chinese, Korean, Japanese, Taiwanese descent or Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent
Indigenous (First Nations, Métis, Inuk/Inuit)*	First Nations, Métis, Inuk/Inuit descent
Latino	Latin American, Hispanic descent
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish)
South Asian	South Asian descent (e.g., East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean)
White	European descent
Another race category	Includes values not described above
Do not know	Not applicable
Prefer not to answer	Not applicable

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

Note

* It is recommended that reporting on Indigenous identity data and communities be informed through engagement with Indigenous communities in the jurisdiction of data collection. Distinctions-based approaches — that is, identifying First Nations, Inuk/Inuit and Métis communities and/or other Indigenous populations such as nations or clans — may be preferred.

Sources

Ontario Anti-Racism Directorate. [Data Standards for the Identification and Monitoring of Systemic Racism](#). 2018.

The Upstream Lab. [Screening for Poverty And Related social determinants and intervening to improve Knowledge of and links to resources \(SPARK\)](#). Accessed May 29, 2020.

Next steps

To advance equity in health care, Canada's health systems need to be able to recognize and respond to health inequalities experienced by racialized groups. Feedback from ongoing engagement, including responses to discussion questions, will inform a pan-Canadian standard.

We want to hear from you

If you are interested in sharing your feedback, please email cphi@cihi.ca.

Introduction

Canada's racial and ethnic diversity continues to increase each year, and Indigenous peoples in Canada are the fastest-growing population in the country.^{1–3} In light of these changing demographics, there is a growing interest in collecting race-based, ethnicity and Indigenous health data to understand patient diversity and monitor inequalities.^{4–7} Awareness of and interest in reporting racial health inequalities has accelerated with emerging international evidence that racialized communities have experienced disproportionate morbidity and mortality associated with COVID-19.^{8–10} Although race-based data has seldom been part of Canadian information systems to date, many health stakeholders are committed to implementing race-based data collection and reporting.^{8, 10–13} A pan-Canadian data standard ensures that high-quality race-based data is consistently collected, analyzed and reported, thus improving our ability to monitor and compare health care access, quality and outcomes.

Purpose

This document proposes standards for collecting race-based and Indigenous identity data in health care in Canada, with considerations for ethnicity. The proposed standards were informed by extensive literature reviews, an environmental scan and several years of engagement with researchers, clinicians, organizations representing racialized groups, Indigenous organizations, and representatives of governments and health systems. The Canadian Institute for Health Information (CIHI) continues to seek feedback to identify best practices and implementation approaches across practice settings and jurisdictions. Questions to spark continued feedback and engagement are listed in the [Next steps section](#).

The intended audience of this document includes

- Individuals, researchers, health organizations and governments collecting or interested in using race-based, ethnic and/or Indigenous identity data to identify and reduce inequalities in health care access, quality and outcomes; and
- Communities who can draw on lived experience and understanding to inform preferred questions and response categories for data collection, strategies to mitigate risk and considerations for analysis and reporting of data.

A glossary of key concepts and relevant terminology is in [Appendix A](#).

Context

Distinguishing race and ethnicity

The terms “race” and “ethnicity” are often used interchangeably or as a single, conflated construct — “race/ethnicity.”^{14–16} Race and ethnicity are commonly used in health research as proxies for one another and/or to identify health inequalities stemming from other closely related concepts, such as immigration, culture or language.^{17–20} However, race and ethnicity are distinct social constructs, and the measurement and reporting of racial and ethnic health inequalities should reflect these differences.^{20–22}

Organizations interested in monitoring and addressing inequalities that may stem from racism and bias can consider collecting race-based data. However, if the interest is in tailoring services or initiatives to improve care (e.g., anticipating language service needs), then ethnicity-related concepts (e.g., language) may be more relevant. It may also be useful to collect race-based and ethnicity data on providers, to understand the diversity of the workforce. Collecting and using both race-based and ethnicity data together can support the responsiveness of health care systems to the diverse needs of patients.

What is race?

Race is a social construct that is politically, historically and socially informed. It is contextually dependent and there is no universal measure for it.^{23, 24} Commonly recognized racialized groups vary around the world and often over time within regions.^{3, 25–28} People are generally classified into racialized groups based on perceived physical differences such as skin colour and facial features. However, there is no scientifically accepted evidence of a biological basis for the identification and classification of discrete racial groups.^{29, 30}

Race is a social construct, not a biological attribute

Genetics research has shown that people are about 99.9% genetically similar and that there is more genetic similarity across socially constructed racialized groups than within them.^{31, 32} Research has shown that disease risk — often associated with race — is in fact driven by geographic origin and environmental selection pressures.³³ For example, sickle cell anemia is commonly thought of as a condition that affects Black populations.³⁴ However, it is not being Black that puts a person at risk of the disease, but whether their ancestry is from a malaria-endemic region of the world.³⁵ Consequently, multiple populations — including some West African, Middle Eastern, Mediterranean and Asian populations — are at increased risk of sickle cell anemia.³⁶

Rationale for collecting race-based data in Canada's health systems

The primary purpose of measuring race-based health inequalities is to identify, monitor and address inequities that potentially stem from bias and racism — including at systemic, interpersonal and internal levels (see [Appendix B](#)).³⁷ These levels of racism all have well-documented consequences on health care access, quality and outcomes that can influence the health and well-being of populations.^{38–49} Racism influences multiple opportunities across the lifespan, such as education, employment, housing and treatment by a variety of public services, including police, education, child welfare and health care.⁵⁰ Because of the subtle, often unintentional nature of bias, health care providers can be unaware of the impact their practices and actions have on patient care.^{51, 52} Standardized race-based data can help uncover health care inequalities and identify opportunities for health care quality improvement.

There are also potential harms that are important to consider, to inform the decision to responsibly collect race-based data. Some argue that measuring race should be avoided since biological races do not exist and continued use of the term “race” risks perpetuating racism.^{52–56} Furthermore, patients may have concerns around potential harms from the use of race-based, ethnicity and Indigenous identity data, such as reinforcing stereotypes and the risk of actually receiving worse care.^{57–59} Asking questions about race or ethnicity may cause feelings of anxiety, fear or anger.^{55, 60} In response to these concerns, others argue that failing to measure race serves to support and protect existing racial hierarchies, hides differences and exempts people from engaging in discourse around the topic of racism.^{53, 56}

Strategies to mitigate the risk of harm include establishing a clear purpose for collecting and using race-based data; providing rigorous training for staff who collect the data; ensuring informed consent, as well as the privacy, security and confidentiality of the data; and engaging communities.^{57, 61, 62} Some health care organizations also recommend that organizations and governments that collect or use race-based data commit to being transparent and accountable about its use.^{8, 63}

What is ethnicity?

Ethnicity is a multi-dimensional social construct that refers to a sense of group belonging based on shared characteristics such as geographic origins, cultural traditions, language and/or religion.^{64, 65} An individual's association with a particular ethnic group can be influenced by a number of factors, including knowledge of their family background, number of generations that have lived in a country, time since immigration and socio-political context.^{14, 21, 54, 64–66} Ethnicity information can be collected using a variety of concepts and approaches.

Rationale for ethnicity data in Canada's health systems

An ethnic group question (e.g., “To which ethnic or cultural groups did your ancestors belong?”) provides information about the diversity of a population served^{67–69} and may be informative as a population indicator. However, it has limited utility as a stratifier for routine performance measurement and reporting. For instance, the large number of response options (some collection approaches include more than 90 categories^{70, 71}) can result in issues of small population sizes.⁷² Additionally, an ethnic group variable cannot reveal important differences within ethnic groups that could be useful for tailoring care and identifying barriers.⁷³

Ethnicity-related concepts (e.g., language, religion, immigration) may be more useful as equity stratifiers, and these variables can help tailor programming and services to specific cultural groups. For example, health care organizations have used language data to provide linguistically appropriate materials and interpretation services.^{62, 68, 74, 75} Information on religion may be important so health care providers can provide care that meets patients' personal needs and improves their hospital experience (e.g., receiving blood, space for prayer, smudging).^{76, 77}

Indigenous peoples in the context of race and ethnicity

It is common to see categories such as First Nations, Inuit and Métis within race-based or ethnicity data collection standards.^{78–82} There may be some commonalities between these concepts, such as experiences of racism and cultural belonging; however, First Nations, Inuit and Métis are constitutionally recognized sovereign nations with inherent rights to self-determination.^{83, 84} Although the term “Indigenous peoples in Canada” often refers to First Nations, Inuit and Métis peoples, these categories may not reflect the preferred community or nation-specific labels.^{85, 86}

Health inequities experienced by Indigenous peoples are rooted in colonialism and racism.^{87–90} Addressing these inequities requires that Indigenous self-determination is recognized and affirmed by all areas of society, including the health sector.^{91, 92} First Nations, Inuit and Métis communities need culturally accepted and relevant health data to inform programs and services, monitor community strength and wellness, and address health inequalities.^{93–97} However, there is a long history of using data that is collected from Indigenous communities to further colonization.^{98–100}

Conventional approaches to data and analysis often do not adequately consider Indigenous perspectives on health and wellness and community priorities, and data collection systems sometimes lack appropriate Indigenous identifiers (e.g., they do not use a distinctions-based approach).^{87, 101, 102} For health data to become a source of empowerment, communities should be involved in conceptualizing, implementing, collecting, analyzing, reporting and disseminating their data.^{95, 99, 103, 104} This is, in part, illustrated through principles of Indigenous data sovereignty (e.g., First Nations principles of Ownership, Control, Access and Possession [OCAP®]).⁹⁹ Engagement with Indigenous communities and data governance agreements can establish how these principles will be met.¹⁰⁵

In addition to engaging with communities and preparing data governance agreements, health care organizations can implement practices to build trust and mitigate the risk of harm; for example, they can create an Indigenous advisory committee, build relationships with Indigenous Knowledge Keepers and Elders, hire Indigenous staff and health care providers, and design and develop a culturally safe environment for patients and staff (e.g., through a declaration of commitment, mandatory ongoing training for staff, creation of culturally reflective spaces).^{106–109}

Data in action: Improving health care and community outcomes using race-based data in the United States

The standardized collection of race-based, ethnicity and language data is common across hospitals in the United States.^{110–112} Mounting evidence that minority patients receive lower-quality care than White patients has spurred health care organizations to identify how they can use race-based, ethnicity and language data to improve quality of care.¹¹³

Since 2005, Massachusetts General Hospital (MGH) has been publicly reporting race-, ethnicity- and language-stratified results for measures of processes of care, outcomes and patient experience in annual reports.^{74, 114} For example, MGH found a higher rate of Caesarean section deliveries among Black women compared with White women, even after adjusting for factors such as age and obesity. The hospital initiated a campaign in 2016 to increase provider awareness of inequities in outcomes and care, including staff training on unconscious bias. Disparities in C-sections continued into 2018; however, the difference was no longer statistically significant. The hospital continues to work with its obstetrics department to understand variations and temporal trends.⁷⁴ MGH also used patient experience surveys to inform opportunities to improve communication and care coordination for Asian populations.

To reduce health inequities, action must also occur outside the health sector to promote upstream change.¹¹⁵ For example, cities across the United States are using intersectoral partnerships to address racial health inequalities and promote population health through initiatives in housing, education and the economy.^{116, 117}

Key message: When race-based data is collected, it should be used to inform actions to reduce inequities.

Proposed standard for race-based data collection

A standard approach is important to ensure harmonized collection, measurement and reporting of racial health inequalities. If data collection and use are respectful and appropriate, race-based data can serve as a basis for evidence-informed policy and be a powerful tool to promote health equity.^{118, 119}

For organizations interested in collecting race-based data and/or reporting racial health inequalities, CIHI is proposing a standard that is an adaptation of the Government of Ontario's Anti-Racism Directorate (ARD) race data standards, which was developed to identify, monitor and eliminate systemic racism in the public sector as part of its Anti-Racism Strategy.¹²¹ The proposed standard is consistent with The Upstream Lab's SPARK study (Screening for Poverty And Related social determinants and intervening to improve Knowledge of and links to resources),¹²⁰ with the modification that it be accompanied by a distinctions-based Indigenous identity question. This standard has several strengths:

- It better delineates the concepts of race and ethnicity. The ARD developed race categories in a way that avoids mixing race and ethnic origin by using commonly recognized race categories (e.g., East Asian) rather than specific ethnic origin categories (e.g., Korean).¹²¹
- It also enables recognition of multi-racial identities. Research indicates that specific multi-racial populations may experience health inequalities differently than individuals who identify as belonging to a single racialized group.^{122, 123} This emphasizes the need to permit multiple responses so health inequalities can be reported using mixed categories (e.g., Black–White).
- The unique racialized group categories in the ARD's standard map to Statistics Canada's Population Group and Aboriginal Group standards (see [Appendix C](#)). The mapping can be used to compare or assess outcomes from practice settings/jurisdictions with the outcomes from a population-based reference group (i.e., for benchmarking).¹²¹
- Early evidence suggests that respondents may be comfortable with the response categories. Preliminary SPARK study results from 827 patients indicate that 87% were willing to self-identify their racial group, which supports other research that many patients are comfortable disclosing this type of information.^{8, 124}

Proposed approach for Indigenous identity

"Indigenous" is included as its own category in the proposed race-based data standard; this is designed to collect information about how Indigenous peoples may be racialized by society. However, consistent with the Government of Ontario's ARD as well as calls for data by Indigenous scholars and organizations,^{121, 125–127} CIHI also proposes that Indigenous identity be collected independently to allow for flexibility in the way Indigenous peoples choose to self-identify, which may be tied to an individual's clan, community, nationhood or language family.¹²¹ The question and response categories for Indigenous identity should be decided in collaboration with Indigenous groups in the jurisdiction where data is being collected and respect fundamental principles of Indigenous data sovereignty (e.g., OCAP®, Inuit Qaujimajatuqangit).^{95, 99} Data governance agreements with appropriate

Indigenous authorities are typically required to establish how these principles are being met.¹⁰⁵ At minimum, we recommend considering a distinctions-based approach that includes response categories for First Nations, Inuit and Métis identity. CIHI is continuing to engage with First Nations, Inuit and Métis organizations to refine this proposed approach and consider other standards of importance and relevance (e.g., questions about Indigenous ancestry, Métis citizenship).

Table Proposed race-based and Indigenous identity data collection standards

Proposed race-based question	
We know that people of different races do not have significantly different genetics. But our race still has important consequences, including how we are treated by different individuals and institutions. Which race category best describes you? Check all that apply:	
Proposed response categories	Examples
Black	African, Afro-Caribbean, African Canadian descent
East/Southeast Asian (optional: may collect as 2 separate categories — East Asian and Southeast Asian)	Chinese, Korean, Japanese, Taiwanese descent or Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent
Indigenous (First Nations, Métis, Inuk/Inuit)*	First Nations, Métis, Inuk/Inuit descent
Latino	Latin American, Hispanic descent
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish)
South Asian	South Asian descent (e.g., East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean)
White	European descent
Another race category	Includes values not described above
Do not know	Not applicable
Prefer not to answer	Not applicable

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

Note

* It is recommended that reporting on Indigenous identity data and communities be informed through engagement with Indigenous communities in the jurisdiction of data collection. Distinctions-based approaches — that is, identifying First Nations, Inuk/Inuit and Métis communities and/or other Indigenous populations such as nations or clans — may be preferred.

Sources

Ontario Anti-Racism Directorate. [Data Standards for the Identification and Monitoring of Systemic Racism](#). 2018.

The Upstream Lab. [Screening for Poverty And Related social determinants and intervening to improve Knowledge of and links to resources \(SPARK\)](#). Accessed May 29, 2020

Community engagement: A key consideration

Recognizing socio-political history and the use/misuse of race-based, ethnicity and Indigenous data in the past, working and engaging with communities to mitigate risks at all levels (collection, analysis, reporting) is essential, as illustrated through the following examples:

Data collection: Engagement is critical, for example, in identifying appropriate categories that reflect patient identities. For example, the Black Experience Project noted that although about half of respondents self-identified as “Black,” the other half used terms such as “African” or specified regions or countries in Africa or the Caribbean.¹²⁸ Additional granularity of racialized groups could be collected using a complementary ethnicity question. This highlights the need to understand how groups perceive themselves in order to develop appropriate data collection approaches. Engagement with racialized and ethnic groups helps establish community support, encourages participation and increases the likelihood of high-quality data collection.

Analysis: It is good practice to involve communities in setting priorities for analysis and supporting interpretation and co-development of solutions. An example is selecting a reference category when comparing the inequalities experienced by different groups. In practice, the reference category often ends up being the group with the most ideal or desirable outcome on the measure of interest. Although the “White” category is often used as the reference, it should not be assumed that this is appropriate in all circumstances. Engagement with racialized communities is encouraged to identify an appropriate reference category.¹²¹ Other analytical issues that would benefit from community engagement include how to handle mixed-identity groupings, missing data and small numbers.

Reporting: Identifying the causes of inequalities (e.g., due to immigration, racism, language barriers, cultural preferences) is not always straightforward; it is important to be cautious about making inferences. Leveraging qualitative data can further support interpretation and co-development of solutions. For example, eliciting feedback from the community can help identify whether racial and ethnic health inequalities may be stemming from racism or other causes, such as a language barrier or low familiarity with Canada’s health care systems.

Next steps

CIHI is gathering feedback regarding the collection, analysis and reporting of race-based, ethnic and Indigenous identity data, including responses to the following questions:

1. How applicable and appropriate are the proposed race-based question and response categories (shown in the table) for racialized populations in your province, territory or jurisdiction?
2. How should standards for the collection of First Nations, Inuit and Métis data in health information systems be designed to best serve the needs of their respective communities?
3. How appropriate is it to include a category for “Indigenous” in the racialized group standard, if it is accompanied by a distinctions-based Indigenous identity question?
4. What successes and challenges have you had using ethnicity and/or ethnicity-related concepts (e.g., immigration status, country/place of birth, religion, language) to measure health inequalities?
5. What data collection methods (e.g., point of care, health card registration) are preferred?
6. How are you currently collecting and/or using race-based and ethnicity data in health care?
7. How are you using race-based and/or ethnicity data to inform actions to reduce inequalities?
8. If you are collecting or using race-based or ethnicity data, what strategies are you implementing to mitigate the risk of harm?
9. What other considerations are important for collection, analysis and reporting of race-based data?

We want to hear from you

If you are interested in sharing your feedback, please email cphi@cihi.ca.

Appendix A: Glossary

Below is a summary of key terms and concepts used in this document. They aim to provide clarification, avoid the conflation of concepts and distinguish them from colloquial language and understandings, where applicable.

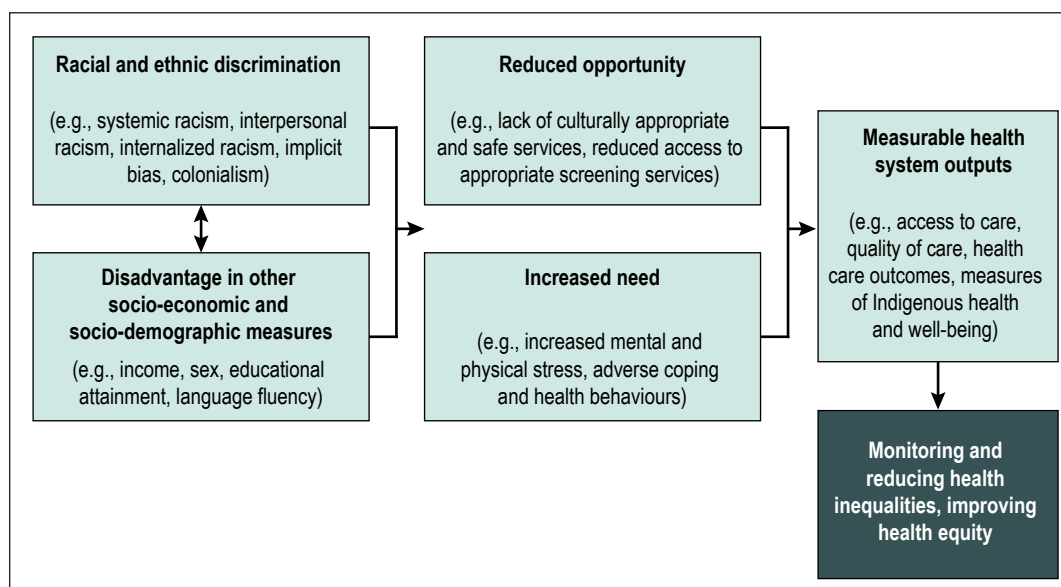
Concept	Definition
colonialism	Colonization is not only a process of taking political control over Indigenous lands, but also a system designed to maintain power and influence (e.g., imposition of colonial institutions of education, health care and law). ¹²⁹
culture	The overt and subtle value systems, traditions and beliefs that influence our decisions and actions. ¹³⁰
distinctions-based	An approach that aims to avoid conflating the Indigenous peoples within Canada, and instead recognizes First Nations, Inuit and Métis as separate groups, each with their own diverse cultures, traditions, communities and histories. A distinctions-based approach ensures that the unique rights, interests and circumstances of each of these groups are acknowledged, affirmed and implemented. ¹³¹
equity stratifier	A characteristic such as a demographic, social, economic, racial or geographic descriptor that can identify population subgroups for the purpose of measuring differences in health and health care that may be considered unfair or unjust. ¹³²
ethnicity	A multi-dimensional concept referring to community belonging and a shared cultural group membership. It is related to socio-demographic characteristics including language, religious affiliation, nationality, traditions, ancestry and migration history, among others. ²³
health equity	The absence of unjust, avoidable differences in health care access, quality or outcomes. ¹³²
health inequality	Differences in health between individuals, groups or communities. Measuring health inequalities is a first step toward identifying and reducing health inequities. ^{132, 133}
implicit bias	Unconscious thoughts, attitudes or reactions that precipitate unintentional discriminatory behaviour. ¹³⁴
Indigenous data sovereignty	The collective and individual rights of Indigenous peoples to the self-governance and management of data from and about their communities, lands and individuals. ^{99, 125, 135}
race (or racial group)	A social construct used to judge and categorize people based on perceived differences in physical appearance to create and maintain power differentials within social hierarchies. There is no scientifically supported biological basis for discrete racial groups. ^{23, 136}
racialization	The process by which people are judged and categorized into races primarily using differences in physical appearance. In this process, societies construct races as “real,” different and unequal in ways that pertain to economic, political and social life. ¹²¹

Concept	Definition
racialized group	A social construct describing groups that have racial meanings associated with them that affect their economic, political and social life. This term is sometimes preferred over “race” because it acknowledges the process of racialization. ^{23, 121, 136}
racism	<p>Includes thoughts or actions that establish or reinforce the superiority or dominance of one racialized group over another.¹²¹ Racism exists on a spectrum and acts on multiple levels — systemic, interpersonal and internalized.</p> <p>internalized racism: The acceptance by a marginalized racialized group of negative messages concerning their abilities and worth.³⁷</p> <p>interpersonal racism: Racism that occurs when an individual experiences discriminatory behaviour from others.³⁷</p> <p>systemic racism: Racism that occurs at societal and organizational levels, giving rise to the other forms of racism.^{37, 137} It is often pervasive and subtle, and not always intentional. It is embedded in societal and institutional policies, regulations, legislation and ideologies that perpetuate racial disadvantage.^{137, 138}</p>
self-determination	A principle that concerns a person's or nation's right to determine and have control over their own future, political status, culture, economy and independence. ^{139, 140}
social construct	An idea that has been created and accepted by the people in a society and that is not an intrinsic property of a person or thing. ¹⁴¹

Appendix B: Factors influencing racial health inequalities

Figure B1 summarizes how health inequalities may be impacted by racism and discrimination as well as other social determinants of health. Race contributes to health inequalities both independently and in compounding ways with other socio-demographic characteristics (e.g., income, gender);¹⁴² racial health inequalities often persist between racialized groups even after adjusting for these socio-demographic factors.^{65, 143} Because of the close association between race and the other social determinants of health, it can be difficult to know whether observed inequalities are due to racism or other associated factors (e.g., income, immigration, language proficiency). Consequently, intersectional analysis (or disaggregation by 2 or more stratifiers) is encouraged to explore the causes of inequalities. Data collection initiatives in health care settings often promote the collection of several socio-demographic measures, including race, which can help identify the relative contribution of these factors to better inform quality improvement.^{10, 119, 120}

Figure B1 Factors influencing racial health inequalities



Note

Interpersonal racism, systemic racism and internalized racism are adapted from Camara Phyllis-Jones' theoretical framework for understanding racism.³⁷

Appendix C: Mapping CIHI's proposed standards to Statistics Canada's Population Group and Aboriginal Group standards

The following table maps CIHI's proposed standards to Statistics Canada's Population Group and Aboriginal Group standards. The proposed standards are adapted from the Ontario ARD's race data standards and The Upstream Lab's SPARK study (Screening for Poverty And Related social determinants and intervening to improve Knowledge of and links to resources).

CIHI's proposed race-based and Indigenous identity data standards		Statistics Canada's Population Group and Aboriginal Group standards
Proposed response categories	Examples	Response categories
Black	African, Afro-Caribbean, African Canadian descent	Black
East/Southeast Asian (optional: may collect as 2 separate categories — East Asian and Southeast Asian)	Chinese, Korean, Japanese, Taiwanese descent or Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent	Chinese, Japanese, Korean, Filipino and Southeast Asian
Indigenous (First Nations, Métis, Inuk/Inuit)*	First Nations, Métis, Inuk/Inuit descent	Aboriginal† (First Nations, Inuit and Métis)
Latino	Latin American, Hispanic descent	Latin American
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish)	Arab, West Asian
South Asian	South Asian descent (e.g., East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean)	South Asian
White	European descent	White
Another race category	Includes values not described above	Other — specify
Do not know	Not applicable	Don't know
Prefer not to answer	Not applicable	Refused

Notes

* It is recommended that reporting on Indigenous identity data and communities be informed through engagement with Indigenous communities in the jurisdiction of data collection. Distinctions-based approaches — that is, identifying First Nations, Inuk/Inuit and Métis communities and/or other Indigenous populations such as nations or clans — may be preferred. The distinctions-based categories (First Nations, Métis, Inuk/Inuit) are collected in a separate Indigenous identity question.

† The distinctions-based categories (First Nations, Inuit and Métis) are collected in the separate Aboriginal Group question.

Statistics Canada is in the process of reviewing its ethno-cultural data standards.

Sources

Proposed standard

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Appendix D: Text alternative for figure

Figure B1: Factors influencing racial health inequalities

The figure illustrates how racial and ethnic discrimination — including systemic racism, interpersonal racism, internalized racism, implicit bias and colonialism — influence and are influenced by disadvantage in other socio-economic and socio-demographic domains, such as income, educational attainment, sex and language fluency. These factors influence opportunity across the lifespan to achieve good health and well-being, including lack of culturally safe services and appropriate health care services (e.g., screening services, referrals). Racism, discrimination and socio-economic disadvantage also lead to increased need for health care to manage their adverse consequences on health, such as increased mental and physical stress, and adverse coping mechanisms and health behaviours such as smoking. These effects have consequences for health and health care, and can be identified and measured within the health care system, such as by looking at measures of health care access, quality and outcomes stratified by race. Measures of Indigenous health and well-being can also be helpful for characterizing relevant measures of health specific to Indigenous communities. Identifying racial and ethnic health inequalities can thus be used as evidence for monitoring health care, implementing quality improvement initiatives and improving health equity.

Note

Interpersonal racism, systemic racism and internalized racism are adapted from Camara Phyllis-Jones' theoretical framework for understanding racism.³⁷

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CIHI Ottawa

495 Richmond Road
Suite 600
Ottawa, Ont.
K2A 4H6
613-241-7860

CIHI Toronto

4110 Yonge Street
Suite 300
Toronto, Ont.
M2P 2B7
416-481-2002

CIHI Victoria

880 Douglas Street
Suite 600
Victoria, B.C.
V8W 2B7
250-220-4100

CIHI Montréal

1010 Sherbrooke Street West
Suite 602
Montréal, Que.
H3A 2R7
514-842-2226

cihi.ca

23198-1020

