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

Supplementary Report

Canadian Institute
for Health Information

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Updated March 2022 — This supplementary report was originally released July 24, 2020, as a discussion document to support engagement with a variety of stakeholders. It has been updated to reflect the revised standards in CIHI's *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada* (2022), which also includes information on the standards development process and considerations for implementation.

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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 population 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*.

In 2020, CIHI published proposed standards for collecting race-based and Indigenous identity data in health care. The standards were 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. After the release, CIHI gathered feedback from a wide range of stakeholders and partners, and in 2022, published updated standards and recommendations in *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada*.

This supplementary report includes important context and considerations for implementing the new standards.

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.

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 identity 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 summarizes the rationale for and process of developing race-based and Indigenous identity standards. The standards development process was 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. CIHI continues to seek feedback to identify best practices and implementation approaches across practice settings and jurisdictions.

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](#).

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 some disease risks often associated with race are 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.

Standard for race-based data collection

A consistent 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]

CIHI's standard for collecting and reporting on racialized group data, updated in 2022, is available in *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada*. This standard is an adaptation of the Government of Ontario's Anti-Racism Directorate (ARD) race data standards, which were developed to identify, monitor and eliminate systemic racism in the public sector as part of the Government of Ontario's anti-racism strategy.[121] CIHI's standard is consistent with the Upstream Lab's Screening for poverty and related social determinants and intervening to improve knowledge of and links to resources (SPARK) study.[120] CIHI's approach has several strengths:

- It 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 Indigenous identity standards. 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]

Indigenous identity

"Indigenous" is included as its own category in the 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. 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 has included a distinctions-based Indigenous identity standard with response categories for First Nations, Inuit and Métis identity in *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada.*

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.

Appendices

Appendix A: Glossary

The table below presents a list of key terms and concepts used in this document, as well as their definitions. It is provided to clarify the language, 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, religion, geographic origin, nationality, cultural traditions, ancestry and migration history, among others.[23]
health equity	The absence of unjust, avoidable differences in health care access, quality, experience 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 in ways that create and maintain power differentials within social hierarchies. There is no scientifically supported biological basis for discrete racial groups.[23, 136]

Concept	Definition
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]
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	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 — internalized, interpersonal and systemic.
	internalized racism: The acceptance by a marginalized racialized group of negative messages concerning their abilities and worth.[37]
	interpersonal racism: Racism that occurs when an individual experiences discriminatory behaviour from others.[37]
	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]
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
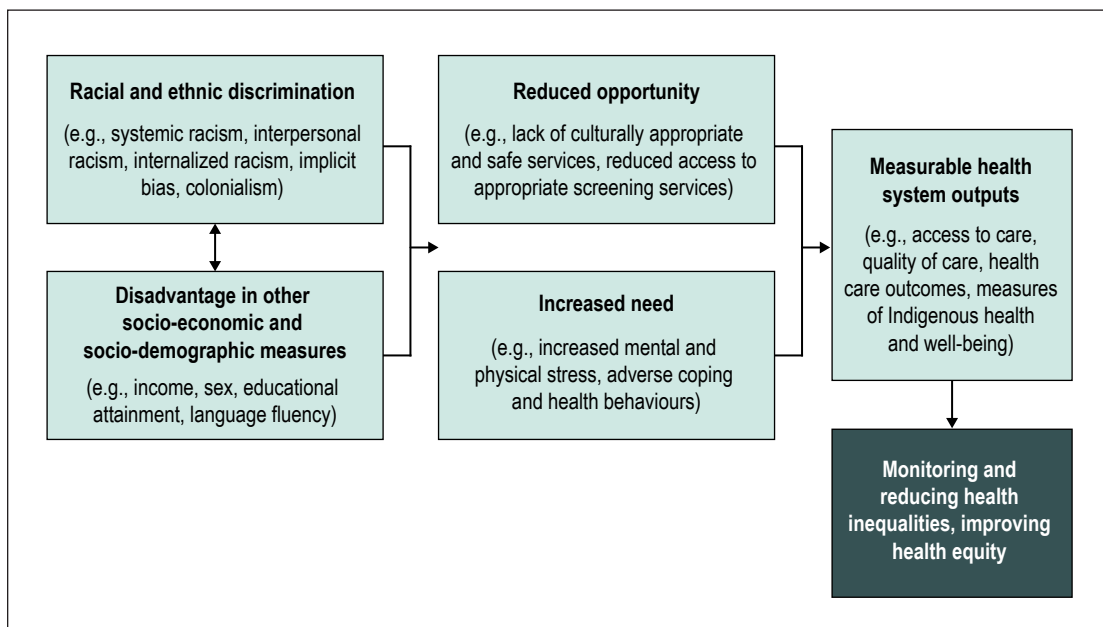
Note
Interpersonal racism, systemic racism and internalized racism are adapted from Camara Phyllis-Jones' theoretical framework for understanding racism.[37]

Appendix C: 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]

References

1.   Statistics Canada. Number and proportion of visible minority population in Canada, 1981 to 2036. Accessed May 29, 2020.

2.   Statistics Canada. Immigration and ethnocultural diversity: Key results from the 2016 Census. *The Daily*. 2017.

3.   Statistics Canada. Aboriginal peoples in Canada: Key results from the 2016 Census. *The Daily*. 2017.

4.   Colour of Poverty – Colour of Change. *Proposed Framework for a New Anti-Racism Strategy for Canada*. 2019.

5.   Human Rights & Health Equity Office; Sinai Health System. *Guide to Demographic Data Collection in Health-Care Settings*. 2017.

6.   Canadian Public Health Association. *Racism and Public Health*. 2018.

7.   Canadian Partnership Against Cancer. *Canadian Strategy for Cancer Control, 2019–2029*. 2019.

8.   Pinto AD, Hapsari A. *Collecting Data on Race During the COVID-19 Pandemic to Identify Inequities*. 2020.

9.   Barr C, et al. Ethnic minorities dying of COVID-19 at higher rate, analysis shows. *The Guardian*. April 22, 2020.

10.   Nasser S. Early signs suggest race matters when it comes to COVID-19. So why isn't Canada collecting race-based data?. *CBC News*. April 17, 2020.

11.   Lindsay B. B.C. "actively discussing" collecting race-based data on COVID-19. *CBC News*. April 23, 2020.

12.   CBC News. Toronto will start tracking race-based COVID-19 data, even if province won't. April 22, 2020.

13.   CBC News. Councillor calls for race-based data on COVID-19. April 27, 2020.

14.   Stevens G, et al. Measuring race and ethnicity in the censuses of Australia, Canada, and the United States: Parallels and paradoxes. *Canadian Studies in Population*. Spring/Summer 2015.

15. Hunt LM, Megyesi MS. The ambiguous meanings of the racial/ethnic categories routinely used in human genetics research. *Social Science and Medicine*. January 2008.

16. Afshari R, Bhopal RS. Ethnicity has overtaken race in medical science: MEDLINE-based comparison of trends in the USA and the rest of the world, 1965–2005. *International Journal of Epidemiology*. December 2010.

17. Jones CP. Invited commentary: "Race," racism, and the practice of epidemiology. *American Journal of Epidemiology*. August 2001.

18. Manly JJ, Echemendia RJ. Race-specific norms: Using the model of hypertension to understand issues of race, culture, and education in neuropsychology. *Archives of Clinical Neuropsychology*. March 2007.

19. Kaplan J, Bennett T. Use of race and ethnicity in biomedical publication. *JAMA*. May 2003.

20. Veenstra G. Mismatched racial identities, colourism, and health in Toronto and Vancouver. *Social Science and Medicine*. October 2011.

21. Ford CL, Harawa NT. A new conceptualization of ethnicity for social epidemiologic and health equity research. *Social Science and Medicine*. July 2010.

22. Griffith D. An intersectional approach to men's health. *Journal of Men's Health*. June 2012.

23. Balestra C, Fleischer L. *Diversity Statistics in the OECD: How Do OECD Countries Collect Data on Ethnic, Racial and Indigenous Identity?*. 2018.

24. United Nations. Ethnocultural characteristics. Accessed May 29, 2020.

25. White PM; Statistics Canada. *Testing 1991 Census Ethnic Ancestry, Ethnic Identity and Race Questions: Results of Two Surveys*. 1988.

26. Statistics Canada. Visible minority of person. Accessed May 29, 2020.

27. Boxhill W; Statistics Canada. *Making the Tough Choices in Using Census Data to Count Visible Minorities in Canada*. December 1990.

28. Schwartzman LF. Does money whiten? Intergenerational changes in racial classification in Brazil. *American Sociological Review*. December 2007.

29. Cooper RS, et al. Race and genomics. *The New England Journal of Medicine*. March 2003.

30. Diez Roux AV. Conceptual approaches to the study of health disparities. *Annual Review of Public Health*. April 2012.

31. Zubaran C. Human nomenclature: From race to racism. *World Health & Population*. 2009.

32. Bamshad M, et al. Deconstructing the relationship between genetics and race. *Nature Reviews: Genetics*. August 2004.

33. Jorde L, Wooding S. Genetic variation, classification and "race". *Nature Genetics*. October 2004.

34. Bediako SM, Moffitt KR. Race and social attitudes about sickle cell disease. *Ethnicity & Health*. August 2011.

35. Williams DR, et al. The concept of race and health status in America. *Public Health Reports*. 1994.

36. Piel FB, et al. Global distribution of the sickle cell gene and geographical confirmation of the malaria hypothesis. *Nature Communications*. November 2010.

37. Jones CP. Levels of racism: A theoretic framework and a gardener's tale. *American Journal of Public Health*. August 2000.

38. Krieger N. Methods for the scientific study of discrimination and health: An ecosocial approach. *American Journal of Public Health*. May 2012.

39. Feagin J, Bennefield Z. Systemic racism and U.S. health care. *Social Science and Medicine*. February 2014.

40. Williams DR, Mohammed SA. Racism and health I: Pathways and scientific evidence. *The American Behavioral Scientist*. August 2013.

41. Williams DR, Mohammed SA. Discrimination and racial disparities in health: Evidence and needed research. *Journal of Behavioral Medicine*. February 2009.

42. Bailey ZD, et al. Structural racism and health inequities in the USA: Evidence and interventions. *The Lancet*. April 2017.

43. Paradies Y, et al. Racism as a determinant of health: A systematic review and meta-analysis. *PLOS One*. September 2015.

44. Kwate NOA, Meyer IH. On sticks and stones and broken bones: Stereotypes and African American health. *Du Bois Review: Social Science Research on Race*. Spring 2011.

45. Aronson J, et al. Unhealthy interactions: The role of stereotype threat in health disparities. *American Journal of Public Health*. January 2013.

46. Shavers VL, et al. The state of research on racial/ethnic discrimination in the receipt of health care. *American Journal of Public Health*. May 2012.

47. Cooper LA, et al. The associations of clinicians' implicit attitudes about race with medical visit communication and patient ratings of interpersonal care. *American Journal of Public Health*. May 2012.

48. Sabin JA, Greenwald AG. The influence of implicit bias on treatment recommendations for 4 common pediatric conditions: Pain, urinary tract infection, attention deficit hyperactivity disorder, and asthma. *American Journal of Public Health*. May 2012.

49. Loppie S, Reading C, de Leeuw S. *Indigenous Experiences With Racism and Its Impacts*. 2014.

50. Williams DR, Cooper LA. Reducing racial inequities in health: Using what we already know to take action. *International Journal of Environmental Research and Public Health*. February 2019.

51. Hoffman KM, Trawalter S, Axt JR, Oliver MN. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. *Proceedings of the National Academy of Sciences*. April 2016.

52. Mazzocco P. *The Dangers of Not Speaking About Race: A Summary of Research Affirming the Merits of a Color-Conscious Approach to Racial Communication and Equity*. 2006.

53. Simon P. The choice of ignorance: The debate on ethnic and racial statistics in France. *French Politics, Culture & Society*. Spring 2008.

54. Statistics Canada, United States Department of Commerce. *Challenges of Measuring an Ethnic World: Science, Politics and Reality: Proceedings of the Joint Canada–United States Conference on the Measurement of Ethnicity, April 1–3, 1992*. 1993.

55. Varcoe C, Browne AJ, Wong S, Smye VL. Harms and benefits: Collecting ethnicity data in a clinical context. *Social Science and Medicine*. May 2009.

56. Bonilla-Silva E. The structure of racism in color-blind, "post-racial" America. *American Behavioral Scientist*. May 2015.

57. Hasnain-Wynia R, Baker DW. Obtaining data on patient race, ethnicity, and primary language in health care organizations: Current challenges and proposed solutions. *Health Services Research*. August 2006.

58. Baker DW, et al. Patients' attitudes toward health care providers collecting information about their race and ethnicity. *Journal of General Internal Medicine*. October 2005.

59. Hasnain-Wynia R, Pierce D, Pittman MA. *Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals*. 2004.

60. Browne AJ, Varcoe CM, Wong ST, Smye VL, Khan KB. Can ethnicity data collected at an organizational level be useful in addressing health and healthcare inequities?. *Ethnicity & Health*. 2014.

61. Pinto AD, Bloch G. Framework for building primary care capacity to address the social determinants of health. *Canadian Family Physician*. November 2017.

62. Sinai Health System. *Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres*. 2017.

63. Robertson A, et al. Black health leaders respond to CMOH. Accessed June 2, 2020.

64. Bhopal R. Glossary of terms relating to ethnicity and race: For reflection and debate. *Journal of Epidemiology and Community Health*. June 2004.

65. United Nations. *Principles and Recommendations for Population and Housing Censuses*. 2017.

66. Senior PA, Bhopal R. Ethnicity as a variable in epidemiological research. *BMJ*. July 1994.

67. Statistics Canada. Canadian Community Health Survey — Annual component (CCHS) — 2020. Accessed May 29, 2020.

68. Institute of Medicine. *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. 2009.

69. Statistics Canada. Ethnic and cultural origins of Canadians: Portrait of a rich heritage. Accessed May 29, 2020.

70. ICES. Data Dictionary: Library: PCAS — Variable: ETHNIC1. Accessed May 29, 2020.

71. Rapid Risk Factor Surveillance System. Sociodemographics — Ethnicity. 2019.

72. Statistics Canada. Ethnic origin of person. Accessed May 29, 2020.

73. Weinick RM, Jacobs EA, Stone LC, Ortega AN, Burstin H. Hispanic healthcare disparities: Challenging the myth of a monolithic Hispanic population. *Medical Care*. April 2004.

74. Massachusetts General Hospital. *Annual Report on Equity in Health Care Quality, 2018–2019*. 2019.

75. Sultana A, Aery A, Kumar N, Laher N. *Language Interpretation Services in Health Care Settings in the GTA*. 2018.

76. Alberta Health Services. *Health Care and Religious Beliefs*. 2015.

77. John Ehman. Religious diversity: Practical points for health care providers. Accessed May 29, 2020.

78. Canadian Institute for Health Information. *Canadian Patient Experiences Survey — Inpatient Care*. 2019.

79. Interior Health. *Mental Health and Addiction Outpatient Experience Survey*. 2017.

80. Ontario Health Study. *Baseline 2 Questionnaire*. 2013.

81. Canadian Partnership Against Cancer. *Inventory of Profiles: Existing Patient Identification Systems With Ethnocultural Identifiers Specific to First Nations, Inuit, and Métis Peoples in Canada*. 2012.

82. Shared Health Manitoba. *COVID-19 Script for Racial, Ethnic, Indigenous Identity: Collection of Identifiers*. 2020.

83. United Nations. *United Nations Declaration on the Rights of Indigenous Peoples*. 2008.

84. Government of Canada. *Constitution Act, 1982*. Accessed May 29, 2020.

85. Voyageur C, Calliou B. Various shades of red: Diversity within Canada's Indigenous community. *The London Journal of Canadian Studies*. 2000.

86. Frideres J. *Aboriginal Identity in the Canadian Context*. 2008.

87. Smylie J, Firestone M. Back to the basics: Identifying and addressing underlying challenges in achieving high quality and relevant health statistics for Indigenous populations in Canada. *Statistical Journal of the International Association for Official Statistics*. 2015.

88. Mowbray M. *Social Determinants and Indigenous Health: The International Experience and Its Policy Implications*. 2007.

89. National Collaborating Centre for Aboriginal Health. *Social Determinants of Health: Understanding Racism*. 2013.

90. Adelson N. The embodiment of inequity: Health disparities in Aboriginal Canada. *Canadian Journal of Public Health*. March 2005.

91. Canadian Council on Social Determinants of Health. *Roots of Resilience: Overcoming Inequities in Aboriginal Communities*. 2013.

92. Royal Commission on Aboriginal Peoples. *Report of the Royal Commission on Aboriginal Peoples*. 1996.

93. Trevethan S. *Strengthening the Availability of First Nations Data*. 2019.

94. First Nations Health Authority. *Health and Wellness Planning: A Toolkit for BC First Nations*. 2019.

95. Inuit Tapiriit Kanatami. *National Inuit Strategy on Research: Implementation Plan*. 2018.

96. Geddes B. *Measuring Wellness: An Indicator Development Guide for First Nations*. 2015.

97. Métis Nation British Columbia. *Métis Community Health Indicators Capacity and Need*. No date.

98. Mosby I. Administering colonial science: Nutrition research and human biomedical experimentation in Aboriginal communities and residential schools, 1942–1952. *Social History*. 2013.

99. First Nations Information Governance Centre. *Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance*. 2014.

100. McBride K. *Data Resources and Challenges for First Nations Communities: Document Review and Position Paper*. No date.

101. Lux M. Perfect subjects: Race, tuberculosis, and the Qu'Appelle BCG vaccine trial. *Canadian Bulletin of Medical History*. 1998.

102. Métis Centre of the National Aboriginal Health Organization. *Paucity of Métis-Specific Health and Well-Being Data and Information: Underlying Factors*. 2011.

103. Métis Centre of the National Aboriginal Health Organization. *Principles of Ethical Métis Research*. No date.

104. United Nations. Data collection and disaggregation for Indigenous peoples. Accessed May 29, 2020.

105. Walker J, Lovett R, Kukutai T, Jones C, Henry D. Indigenous health data and the path to healing. *The Lancet*. 2017.

106. Greenwood M, Lindsay N, King J, Loewen D. Ethical spaces and places: Indigenous cultural safety in British Columbia health care. *AlterNative: An International Journal of Indigenous Peoples*. 2017.

107. Allen L, Hatala A, Ijaz S, Courchene D, Bushie B. Indigenous-led health care partnerships in Canada. *CMAJ*. 2020.

108. Nickerson M. *Cultural Safety and Humility: Case Study Report*. 2019.

109. Henderson R, Montesanti S, Crowshoe L, Leduc C. Advancing Indigenous primary health care policy in Alberta, Canada. *Health Policy*. 2018.

110. Agency for Healthcare Research and Quality. Chapter 3: Defining categorization needs for race and ethnicity data. In: Ulmer C, McFadden B, Nerenz DR, eds. *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. 2009.

111. Regenstein M, Sickler D. *Race, Ethnicity, and Language of Patients: Hospital Practices Regarding Collection of Information to Address Disparities in Health Care*. 2006.

112. Health Research & Educational Trust. *Reducing Health Care Disparities: Collection and Use of Race, Ethnicity and Language Data*. 2013.

113. Smedley BD, Stith AY, Nelson AR, eds.; Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. 2003.

114. Massachusetts General Hospital. *Annual Report on Equity in Health Care Quality, 2018–2019*. 2019.

115. Kingston, Frontenac and Lennox & Addington Public Health. *Health Inequities Series*. 2019.

116. Robert Wood Johnson Foundation. Broward County's "destination": Health equity. Accessed May 29, 2020.

117. Robert Wood Johnson Foundation. In Kansas City, health becomes the driving force. Accessed May 29, 2020.

118. Ontario Human Rights Commission. *Policy and Guidelines on Racism and Racial Discrimination*. 2009.

119. European Network Against Racism. *Measure, Plan, Act: How Data Collection Can Support Racial Equality*. 2014.

120. 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.

121. Anti-Racism Directorate. *Data Standards for the Identification and Monitoring of Systemic Racism*. 2018.

122. Veenstra G. Black, White, Black and White: Mixed race and health in Canada. *Ethnicity & Health*. 2017.

123. Bratter JL, Gorman BK. Does multiracial matter? A study of racial disparities in self-rated health. *Demography*. 2011.

124. Kiran T, Sandhu P, Aratangy T, Devotta K, Lofters A, Pinto AD. Patient perspectives on routinely being asked about their race and ethnicity. *Canadian Family Physician*. 2019.

125. Smylie J. *Achieving Strength Through Numbers: First Nations, Inuit, and Métis Health Information*. 2010.

126. Smylie J, Anderson M. Understanding the health of Indigenous peoples in Canada: Key methodological and conceptual challenges. *CMAJ*. 2006.

127. Barrera J. First Nations COVID-19 cases undercounted, says AFN national chief. *CBC News*. May 8, 2020.

128. Black Experience Project. *The Black Experience Project in the GTA: Overview Report*. 2017.

129. Czyzewski K. Colonialism as a broader social determinant of health. *International Indigenous Policy Journal*. 2011.

130. Ontario Human Rights Commission. *Teaching Human Rights in Ontario: A Guide for Ontario Schools*. 2013.

131. Department of Justice Canada. *Principles: Respecting the Government of Canada's Relationship With Indigenous Peoples*. 2018.

132. Canadian Institute for Health Information. *In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality — A Focus on Age, Sex, Gender, Income, Education and Geographic Location*. 2018.

133. National Collaborating Centre for Determinants of Health. *English Glossary of Essential Health Equity Terms*. 2015.

134. Narayan MC. Addressing implicit bias in nursing. *American Journal of Nursing*. 2019.

135. University of Manitoba. *Framework for Research Engagement With First Nation, Metis, and Inuit Peoples*. No date.

136. National Collaborating Centre for Determinants of Health. *Let's Talk: Racism and Health Equity*. 2017.

137. McKenzie K. Rethinking the definition of institutional racism [Wellesley Institute's Building Healthy Communities blog]. May 30, 2017.

138. Ontario Human Rights Commission. Racial discrimination, race and racism (fact sheet). Accessed June 3, 2020.

139. United Nations. *Charter of the United Nations*. 1945.

140. Moeke-Pickering TM. Decolonisation as a Social Change Framework and Its Impact on the Development of Indigenous-Based Curricula for Helping Professionals in Mainstream Tertiary Education Organisations [PhD thesis, University of Waikato, New Zealand]. 2010.

141. Merriam-Webster. Definition of social construct. Accessed May 29, 2019.

142. Penner AM, Saperstein A. Engendering racial perceptions: An intersectional analysis of how social status shapes race. *Gender & Society*. 2013.

143. Williams DR, Lawrence JA, Davis BA. Racism and health: Evidence and needed research. *Annual Review of Public Health*. 2018