

Race-Based Data Collection and Health Reporting

Summary

There is heightened awareness of and interest in collecting information to better understand the spread of COVID-19 and the impact of the pandemic, particularly within racialized communities.

The lack of data on race in Canada makes it difficult to monitor racial health inequalities. To help harmonize and facilitate collection of high-quality data, the Canadian Institute for Health Information (CIHI) is proposing an interim race data collection standard based on work that has been ongoing for a number of years, including engagement with researchers, clinicians, organizations representing racialized communities, and federal, provincial and territorial governments. It is intended for use by any jurisdiction or organization that decides to collect this type of data.

Supporting health inequality measurement

Health inequality monitoring involves looking beyond national or provincial/territorial averages to understand differences in health and health care across population subgroups. 2 types of data need to come together for health inequality monitoring: data about health and health care, and data about patient demographics (i.e., social determinants of health). Monitoring health inequalities builds our understanding of the impact of health outcomes, policies, programs and practices on population subgroups.

In 2016, CIHI hosted a pan-Canadian [dialogue](#) of health system stakeholders in an effort to understand and harmonize health inequality information needs. The group identified a priority list of socio-demographic data for use in stratifying health care indicators. In 2018, CIHI released the report from the first phase of this work, [In Pursuit of Health Equity: Defining Stratifiers for Measuring Health Inequality](#), which provides standard definitions for age, sex, gender, income, education and geographic location. This report is a key resource supported by CIHI's [Measuring Health Inequalities: A Toolkit](#).



Interim race standard

Based on a detailed review of the research and consultations over the last few years, and in response to the current interest in data on race and COVID-19, we are proposing the interim race standard found in the appendix. It is consistent with The Upstream Lab's [recommendations on collecting data on race](#). The interim race standard should be accompanied by a distinctions-based Indigenous identity question, along with community engagement and/or data governance agreements. This approach is adapted from the [Ontario Anti-Racism Directorate's race data standards](#) published in 2018.

CIHI's work on measuring racial inequalities

To date, CIHI has engaged with a wide variety of stakeholders, completed an evidence review and conducted an environmental scan of racial and ethnic group standards within Canada and abroad. Pan-Canadian standards can help ensure that high-quality racial and ethnic data is collected, analyzed and reported using a harmonized approach. In addition to data standards, measures are needed to enhance cultural safety, facilitate consent and appropriate use, support the staff who are collecting the data and implement data quality assessments. It is also important to ensure ongoing dialogue with communities to support collection and interpretation.

Key findings from our work to date include the following:

- Despite a growing interest in and demand for racial and ethnic data, it is not routinely collected or collected in a standard way in Canadian health administrative databases.
- Race and ethnicity are distinct concepts that are often conflated:
 - **Race** is a social construct used to categorize people based on perceived physical differences (e.g., skin colour, facial features).
 - **Ethnicity** is a multi-dimensional concept referring to membership in a cultural group; it is often connected to socio-demographic characteristics including language, religious affiliation, nationality, cultural traditions and migration history, among others.
- Data on race is needed to monitor health inequalities that may stem from racism, bias and discrimination. Ethnicity, as a broad construct, may be more useful to tailor culturally appropriate health services and to understand patient diversity.
- Community engagement is necessary to inform data collection, analysis and reporting needs. Engagement can also encourage participation, reduce risk of harm and facilitate the co-development of solutions to address inequalities.
- **Indigenous groups** are often considered alongside racial and ethnic categories in existing data collection systems. However, First Nations, Inuit and Métis have inherent and collective rights to self-determination, including ownership and governance of their data. Both the collection of Indigenous data and the measurement of health inequalities among Indigenous groups warrant distinct consideration and must include engagement with Indigenous communities and data governance agreements.

Next steps

In the coming months, CIHI will release a broader discussion document that provides greater detail on measuring racial health inequalities in Canada, with more detailed considerations for ethnicity and Indigenous identity. CIHI continues to be open to feedback as we learn from projects where race-based data collection has been implemented.

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

Appendix: Interim race standard

Proposed approach: SPARK study (Screening for Poverty And Related social determinants and intervening to improve Knowledge of and links to resources) adapted from the Ontario Anti-Racism Directorate’s race data standards (2018)

Table 1 Proposed racial group question and response categories

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:	
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, Inuk/Inuit, Métis)*	First Nations, Inuk/Inuit, Métis 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

Notes

* It is recommended that reporting about Indigenous data and communities be informed through collaboration 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.

Statistics Canada is reviewing its ethnocultural data standards.

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 April 17, 2020.

Indigenous is included as its own category in the race standard above, which was designed to collect information about how Indigenous people may be racialized by society. It is recommended that Indigenous identity be collected independently from race to allow for flexibility in the way Indigenous people choose to self-identify, which may be tied to an individual’s clan, community, nationhood or language family. 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 appropriate data governance respecting Indigenous data sovereignty and self-determination must be in place. At minimum, we recommend considering the following:

Table 2 Proposed Indigenous identity question and response options

Do you identify as First Nations, Inuk/Inuit and/or Métis?	If yes, select all that apply:
<ul style="list-style-type: none"> • Yes • No • Prefer not to answer 	<ul style="list-style-type: none"> • First Nations • Inuk/Inuit • Métis



For data-specific information:

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