

**Canada needs a national strategy for disaggregated race-based data  
to ensure equitable decision-making in health**

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## **Problem and Urgency of Action**

Racial health inequities at the population level are not well documented or reported in Canada. The lack of access to and reporting of disaggregated race-based data does not allow for evidence linking race to health outcomes to reveal sub-population health inequities. This is a problem for key stakeholders, including disproportionately affected communities, health equity researchers, interventionists, healthcare providers, advocates, and policy makers attempting to reduce health disparities among at risk sub-populations. There are targeted studies that have revealed health inequities for Indigenous, Black and racialized communities resulting from structural and systemic racism (1,2). Issues of discrimination, negligent communication, professional misconduct (implicit bias), feeling dehumanized as a patient, and unequal access to health services; these create mistrust, dissuading health seeking and leading to negative health outcomes (1,3–6). Unfortunately, without race-based data, evidence at the population health level is not feasible.

Due to the COVID-19 crisis, immediate action is necessary to ensure efficient healthcare and social services response. This includes targeting vaccine strategies and culturally sensitive access to healthcare and social services for vulnerable and marginalized populations. Currently, Canadian public institutions do not report disaggregated race-based data. A comprehensive, representative, standardized national approach to collection and publication of disaggregate race-based data is essential for intersectional analysis that can identify sub-populations' health inequalities and associated social determinants of health factors (i.e. racism, gender, income, precarious employment) (7,8).

## **Issues in Disaggregated Race-Based Data Reporting and Access – *What's not working***

Current health data collection methods by Statistics Canada (SC) include race-based data (Supplement 1), however, the reporting is at an aggregated level (9–11). Health Canada and SC currently use the term “visible minority” in reports; this is an aggregate level designation for persons other than Indigenous peoples, who are non-Caucasian in race or non-white in colour (12). Consequently, diverse groups with distinct experiences from one another are reported at this high-level category which is not helpful when looking at national averages regarding health outcomes. Evidence regarding differential impacts of social determinants of health on vulnerable minority groups is limited which results in required policies and programs being hindered or missed (10). Access to SC micro data by researchers,

health policy analysts and interventionists for their work is onerous even with SC's robust data security (13). Even though provincial and regional entities are collecting disaggregated race-based data because of COVID-19, it is not standardized or comparable nationally for informing decisions to help protect the most vulnerable subgroups who continue to face systemic racism and barriers to healthcare.

### **Historical Perspective - *What are key challenges with collecting race-based data?***

Despite the clear link between structural racism and other determinants of health leading to health inequities among several sub-populations, several reasons exist for why governments do not collect and report race-based data. There is fear of perpetuating existing stigmatization, discrimination, injustice, stereotypes and ethnic profiling by entities in positions of power (i.e., health care providers, police) if not properly analyzed, explained or used (10,14,15). The current reality of patient care for Indigenous, Black and People of Colour (IBPOC) in Canada is one of mistrust and neglect; a history of slavery of Black people and colonization of Indigenous populations have led to disproportionate health outcomes (1,16). Decisions about healthcare programming and policies (i.e. screening, health provision, medications) are predominantly based on research with white populations and do not necessarily translate to diverse racial groups (17). Additionally, there is fear of health data privacy issues due to the electronic health and medical records repurposed without consent (15).

### **Current Status - *How has COVID-19 revealed the need for race-based data?***

At the onset of the pandemic, racial minorities and immigrants in Canada were excluded from the list of populations vulnerable to COVID-19 as response concentrated on the elderly and immunocompromised (18). Concurrently, the US and UK were reporting Black and immigrant communities being disproportionately affected by COVID-19 based on national race-based data (8,19). Throughout Canada, several regions realized the need for race-based data to tackle the pandemic. The City of Toronto, Ottawa Public Health, Ontario, Manitoba and Quebec continue to collect and report their own race-based data to inform interventions and strategies that prioritize or target vulnerable sub-groups during the pandemic in their provinces, regions, cities or communities (20). This variation in data collection and reporting (i.e., non-standardized) is leading to non-comparable results and inadequate evidence to inform health care decisions and strategies beyond local contexts. A

standardized data collection strategy beginning at the local level can be rolled up to a population health level to provide clear and comparable evidence of population health outcomes.

**Political Will and Government Priorities- *Is there a policy window to make this happen?***

The pandemic has revealed an opportunity for action regarding a national strategy for disaggregated race-based data, creating a policy window (21,22). *Political Stream* – Health Canada currently has the support of ten Provincial and Territorial (P/T) Ministers of Health (MOH) and the Parliamentary Black Caucus regarding a national strategy for disaggregated race-based data (23,24). *Problem Stream* - Preliminary and pilot initiatives in Canada and lessons learned from international contexts (i.e. UK and US) have revealed that race-based health inequalities for IBPOC during COVID-19 (7,8). *Policy Stream* – Key stakeholders and advocacy groups<sup>1</sup> have been calling for action regarding disaggregated data for many years, outside of the pandemic context. Disaggregated data may reveal inadequate government policies affecting marginalized subgroups and negatively impacting the current political power image (14). Additionally, the recent speech from the throne declares that “this is the moment to stand up for diversity and inclusion...fighting systemic racism, sexism, discrimination, misconduct, and abuse, including in our core institutions, will remain a key priority...continue to invest in the empowerment of Black and racialized Canadians and Indigenous Peoples.” (25; p.19). To do this, we must be accountable by measuring health outcomes of sub-populations to ensure they are receiving culturally informed care and have equitable access to services.

**Recommendations - *How can we move forward?***

The Canadian Federal Government should consider a Federal Framework for Standardized Disaggregated Race-Based Health Data Collection & Reporting which requires Provincial and Territorial (P/Ts) Health Ministries to report annually on evidence of progress regarding health equity goals (i.e., health outcomes and experiences across health care sectors). Health Canada should:

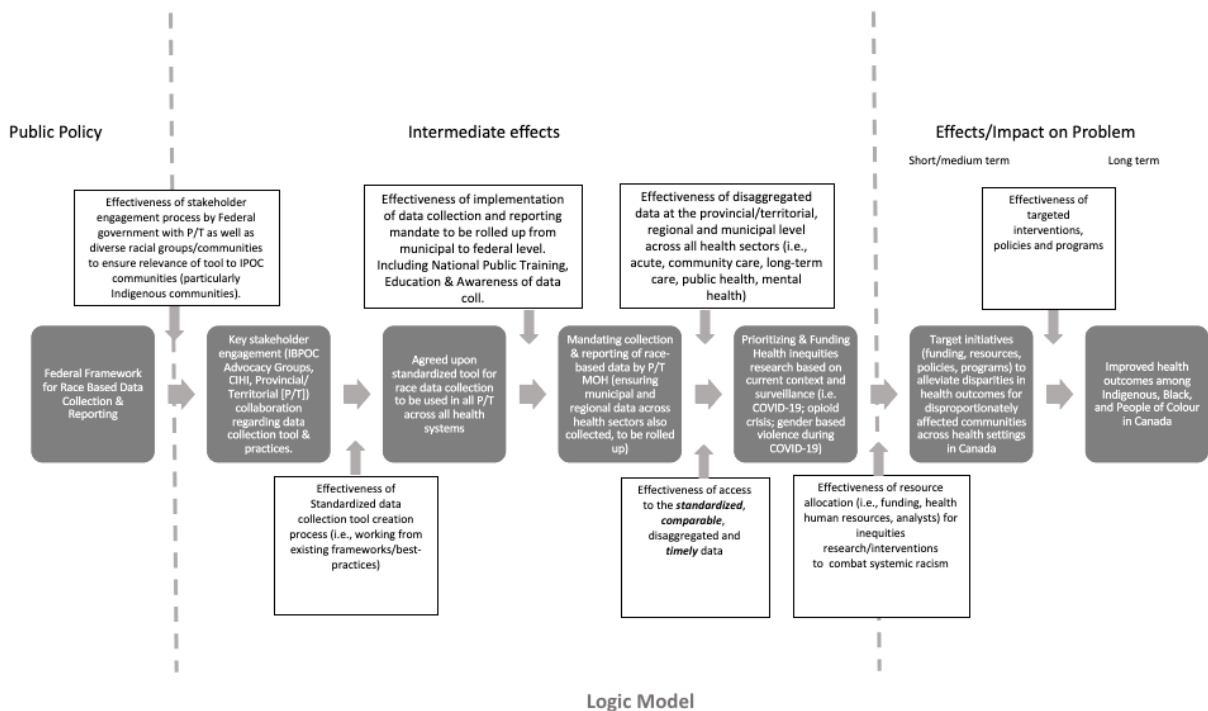
- Require standardized data collection & reporting tool used by all P/Ts - Recommend working with SC and adopting CIHI’s *Proposed Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada* which maps on to SC’s categories (Supplement 1) (11,26).

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<sup>1</sup> National Advocacy/Research Organizations representing IBPOC, including but not limited to: Colour of Poverty – Colour of Change, National Collaborating Centre for Aboriginal Health, First Nations Health Authority, Inuit Tapiriit Kanatami, Métis Centre of the National Aboriginal Health Organization, Canadian Public Health Association

- Ensure specific considerations are taken regarding Indigenous identity data including community engagement & data governance agreements for culturally appropriate implementation (11).
- Ensure intensive engagement with key stakeholders (P/T MOHs, IBPOC communities, Statistics Canada) during analysis, interpretation, and reporting.
- Require P/Ts to ensure proper training for data collection across all health sectors to alleviate unintended effects of anxiety, anger, fear, and mistrust by vulnerable/marginalized sub-groups.
- Secure/increase funding and seek opportunities to leverage existing funding<sup>2</sup> for research, initiatives, interventions that prioritize disproportionately affected communities (27).
- Require P/Ts to annually report on actions taken to eliminate health inequities and promote equity goals across all health sectors, by incorporating a racial equity impact lens (26).
- Mandate a robust and secure data collection system (i.e., privacy, anonymity) in place by all P/Ts.

The following logic model outlines the impact of implementing a Federal Framework for Race-based Disaggregated Data to improve health outcomes among Indigenous, Black, and racialized communities in Canada.



Federal Framework for Race Based Data Collection & Reporting requiring all provincial and territorial government to collect and analyze racially disaggregated data (using the same framework to be rolled up nationally but can be disaggregated and used regionally) on health outcomes and experiences across the health care system.

<sup>2</sup> Building a Foundation for Change: Canada's Anti-Racism Strategy 2019-2022

## Conclusion

Racial health inequities at the population level are not well documented or reported in Canada. The lack of access to and reporting of disaggregated race-based data does not allow for evidence linking race to health outcomes to reveal sub-population health inequities. The current COVID-19 situation has exacerbated health inequities among Indigenous, Black and People of Colour (IBPOC). The problem of the pandemic, along with raised voices from IBPOC advocates as well as the political will, have opened a policy window to a national Federal strategy for standardized, disaggregated health data on race and indigeneity in Canada. IBPOC communities contend with a history of colonization and continued discrimination that has led to disproportionate health outcomes. Although key actors/advocates in health and research have been calling for race-based data for years, COVID-19 has emphasized the need given the disproportionate effect on Indigenous, Black, immigrant and refugee communities. Statistics Canada (SC) collects but does not report/provide access to race-based micro-data. Although some cities and provinces are collecting race-based data, the variation in collection/reporting (i.e., non-standardized) is non-comparable and inadequate to inform health care decisions and strategies at the national level, beyond the local contexts. Thus, a comprehensive, representative, standardized national approach to health surveillance is essential for intersectional analysis to identify vulnerable populations.

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## Supplement 1

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

# 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.

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#### Proposed standard

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

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