



# Collecting data on race during the COVID-19 pandemic to identify inequities

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*The [Upstream Lab](#) is a research team focused on addressing the social determinants of health. These are the daily living conditions and social processes that shape who is healthy and who is not. We incubate novel interventions in collaboration with patients, health providers, community organizations and policymakers. We rigorously evaluate these interventions, using a variety of methods, and share our findings widely. We train health professionals and students to go “upstream”. The Upstream Lab is based in [MAP/Centre for Urban Health Solutions](#), within the [Li Ka Shing Knowledge Institute](#) at [Unity Health Toronto](#).*

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## **COVID-19 outcomes are associated with race**

Early evidence from several jurisdictions in the United States indicate that **racialized populations experience disproportionately higher rates of negative outcomes related to COVID-19 infection than non-racialized individuals**. In Louisiana, [media](#) reported on April 6, 2020 that more than 70% of the people who had died so far from COVID-19 were Black, but only represent a third of the state's population. On the same day in Chicago, Illinois, the Mayor [announced](#) that 70% of those who died due to COVID-19 were Black, though again they only represented approximately one third of the city's population. Similar overrepresentation of Black people in either positive tests or deaths due to COVID-19 have been found in Michigan, Connecticut, North Carolina and South Carolina, as [reported](#) by the New York Times on April 7, 2020. On April 8, 2020, the CDC [reported](#) on data from a project called COVID-NET that includes 14 states. From 1,482 patients hospitalized due to COVID-19, 33% were Black, even though they only represent 18% of the COVID-NET catchment population. The authors concluded, "black populations might be disproportionately affected by COVID-19".

Based on what is known about the COVID-19 virus, including how it is transmitted between individuals and who is more likely to require hospitalization and/or ICU admission, as well as characteristics associated with death, it is likely that Black people are experiencing worse outcomes related to **a combination of biological and social causes stemming from compounding effects of historical and present-day anti-Black racism**.

Dr. Anthony Fauci, Director of the US National Institute of Allergy and Infectious diseases [suggested](#) that "underlying medical conditions, [including] diabetes, hypertension, obesity, [and] asthma" make it more likely that African Americans will be admitted to the ICU or die from the disease. Others, such as Dr. Rashawn Ray, a fellow at the Brookings Institution and a professor at the University of Maryland, [suggests](#) the **disparity seen is due to deeper structural issues**. These include: [testing at lower rates](#) for COVID-19 than other racial groups; living in neighbourhoods that lack adequate access to health care (and hence people rely more on public transit, where infection spreads readily) and also have higher exposures to pollution; working in jobs that have lower pay and do not permit working from home, physical distancing, or paid sick days; criminalization that limits the use of face masks when in stores; and racial discrimination in health care. Much remains unknown about the causal link between COVID-19, race and other social determinants of health. Data that is disaggregated by race is a starting point to developing and implementing solutions that reduce health inequities.

## **Lack of data on race in Canada during COVID-19 pandemic**

**In Canada, many health care institutions do not routinely collect data on race** or other key sociodemographic variables, beyond age and sex. This issue has been noted for many years by institutions, such as [CIHI](#), [epidemiologists](#) and [public health academics](#). Research that has used available data on race in Canada (e.g. specific research projects, surveys, data linked from the Census) has consistently documented that racial disparities in [access to health care](#) and overall [health outcomes](#) exist. In Canada, preventable negative health outcomes are disproportionately seen in [Indigenous](#) and [Black](#) patients.

During the COVID-19 pandemic, community leaders have urged that data on race be collected. As Angela Robertson, executive director of the Parkdale Queen West Community Health Centre in Toronto stated in an [article](#) published on April 8, 2020, “We in Canada have been glacial in our movement in the collection of race-based data in our health-care system. As a result we will not be able to identify the disproportional access challenges, deaths, illnesses that Black communities will experience as a result of COVID-19... My fear is that the real health impact on [the] Black community will be hidden.”

### **Previous experience with collecting data on race in Canadian health settings**

Community Health Centres (CHCs) across Canada have collected data on race and other key sociodemographic variables for many years, related to their [long history](#) of addressing the social determinants of health. Beginning in 2010, with the support of the Toronto Central Local Health Integration Network (TC-LHIN), a project called [“We Ask Because We Care”](#) resulted in 8 core demographic questions – including one on race/ethnicity – for use in health settings. These questions were pilot tested in 4 institutions: St. Michael’s Hospital, Mount Sinai Hospital, CAMH and Toronto Public Health. A similar [pilot](#) with 5 CHCs was conducted in 2014, and CHCs across Ontario soon began to align their data collection to use these questions. The TC-LHIN mandated hospitals to collect this data, and supported a team to develop [resources](#) for implementation. In a [2019 report](#), this team noted that hospitals and CHCs had started using collected data to identify racial and other socioeconomic inequities in health service utilization.

#### *Question related to race on the TC-LHIN “We Ask Because We care” [tool](#)*

<b>3. Which of the following best describes your racial or ethnic group? Check ONE only</b>	
<input type="checkbox"/> 1. Asian - East (e.g. Chinese, Japanese, Korean)	<input type="checkbox"/> 11. Latin American (e.g. Argentinean, Chilean, Salvadoran)
<input type="checkbox"/> 2. Asian - South (e.g. Indian, Pakistani, Sri Lankan)	<input type="checkbox"/> 12. Metis
<input type="checkbox"/> 3. Asian - South East (e.g. Malaysian, Filipino, Vietnamese)	<input type="checkbox"/> 13. Middle Eastern (e.g. Egyptian, Iranian, Lebanese)
<input type="checkbox"/> 4. Black - African (e.g. Ghanaian, Kenyan, Somali)	<input type="checkbox"/> 14. White - European (e.g. English, Italian, Portuguese, Russian)
<input type="checkbox"/> 5. Black - Caribbean (e.g. Barbadian, Jamaican)	<input type="checkbox"/> 15. White - North American (e.g. Canadian, American)
<input type="checkbox"/> 6. Black - North American (e.g. Canadian, American)	<input type="checkbox"/> 16. Mixed heritage (e.g. Black - African & White – North American) Please specify: _____
<input type="checkbox"/> 7. First Nations	<input type="checkbox"/> 17. Other(s): Please specify: _____
<input type="checkbox"/> 8. Indian - Caribbean (e.g. Guyanese with origins in India)	
<input type="checkbox"/> 9. Indigenous/Aboriginal - <i>not included elsewhere</i>	<input type="checkbox"/> 88. Prefer not to answer
<input type="checkbox"/> 10. Inuit	<input type="checkbox"/> 99. Do not know

The Upstream Lab has conducted research on the “We Ask Because We Care” questions in primary care settings:

- In a pilot at St. Michael’s Hospital, which involved a convenience sample of 407 individuals approached in the Family Health Team waiting room, **400 (98%) provided a valid answer to the question about race** (i.e. did not choose “Do not know”, “Prefer not to answer” or skipped the question).<sup>1</sup>

<sup>1</sup> Pinto AD et al. Building a foundation to reduce health inequities: routine collection of sociodemographic data in primary care. JABFM 2016; 29: 348-355. <https://www.jabfm.org/content/jabfp/29/3/348.full.pdf>

- In a subsequent research study funded by the TC-LHIN, data from 15,221 patients who were offered the survey between Dec 2013-Mar 2016 in the St. Michael's Hospital Family Health Team was analyzed. 14,247 (94%) completed at least one question on the survey, and of these **92% answered the question about race**. Only 2% indicated "Prefer not to answer", 0.5% indicated "Do not know" and 5.7% skipped the question.<sup>2</sup> This data has been used to identify inequities in cancer screening rates, although the **large number of options led to the variable being dichotomized** into "White" and "Other ethnicity".<sup>3</sup>
- A qualitative study also conducted at the St. Michael's Hospital Family Health Team, found that **patients did not report significant discomfort** answering a question about race and ethnicity. However, some patients found the question difficult to interpret, given that the question combined race, ethnicity and geographic location, and people of mixed heritage found it challenging to select an option.<sup>4</sup>

In 2018, the Upstream Lab with colleagues and patient partners from five provinces (Ontario, Saskatchewan, Manitoba, Nova Scotia, Newfoundland and Labrador) was awarded a grant from CIHR to work on a Canadian tool for collecting sociodemographic data in primary care settings. Called the [SPARK Study](#), a revised set of questions has been developed, building on those used in "We Ask Because We care". The question related to race was changed to focused on race (not both race and ethnicity) and used the response options created by the [Ontario Anti-Racism Directorate](#).

<b>We now 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:</b>	
<input type="checkbox"/> Black	<input type="checkbox"/> South Asian
<input type="checkbox"/> East/Southeast Asian	<input type="checkbox"/> Latino
<input type="checkbox"/> Indigenous (First Nations, Metis, Inuit)	<input type="checkbox"/> Middle Eastern
<input type="checkbox"/> White	<input type="checkbox"/> Do not know
<input type="checkbox"/> Another race category: _____	<input type="checkbox"/> Prefer not to answer

The new questions were tested in a pilot study in Toronto and Kingston. In three clinics (two academic Family Health Teams, and a suburban Family Health Organization), 827 patients answered at least one question. Preliminary findings from this study include that **717 (87%) answered the question on race**, 4% indicated "Prefer not to answer", 3% indicated "Do not know" and 6% skipped the question. At the time of writing, further analysis is required to examine associations between other variables (e.g. income, educational attainment) and choosing not to respond to the question on race. Planning is underway for a study to evaluate the psychometric properties of the SPARK Tool, including this question about race, and a separate study to better understand implementation in diverse clinical settings.

<sup>2</sup> Pinto AD et al. Evaluating robust sociodemographic data collection within a primary care setting: Final Report and Recommendations. Report to TC-LHIN. Oct 10, 2017

<sup>3</sup> Lofters A et al. Using self-reported data on the social determinants of health in primary care to identify cancer screening disparities: opportunities and challenges. BMC Family Practice 2017: 8. <https://bmcfampract.biomedcentral.com/articles/10.1186/s12875-017-0599-z>

<sup>4</sup> Kiran T et al. Patient perspectives on routinely being asked about their race and ethnicity. CFP 2019; 65: e363-e369. <https://www.cfp.ca/content/cfp/65/8/e363.full.pdf>

**A crucial issue that has emerged through the SPARK study is that community engagement is of critical importance.** Many communities, particularly Indigenous and Black communities, have a long history of negative experiences with data collection efforts by government officials, health organizations and academics. Some concerns include that individuals who answer a question about race in the context of seeking health care may have justifiable concerns that they will be discriminated against, given [systemic racism](#) in health settings. Individuals may also have concerns about who will have access to the data and with whom it will be shared. Finally, without community engagement there is a risk that members of affected communities will not be part of analyzing the data, helping “tell the story” of the findings, nor part of developing solutions to address the inequities uncovered. Community engagement is important for **building trust, gathering high quality data, and holding organizations accountable to act based on the data.** The 2017 United Nations [Report of the Working Group of Experts on People of African Descent](#) emphasized a need for strategies aimed at addressing anti-Black racism to "include consultation with members and representatives of communities that are most adversely impacted by systemic racism, including Indigenous and Black communities."

### **Recommendations on collecting data on race during COVID-19**

1. During the COVID-19 pandemic all jurisdictions in Canada should rapidly move to routinely collect data on race and a small number of other key social determinants that are anticipated to impact on outcomes or could shape the public health response. These could include income, housing status, health insurance status, and type of employment.
2. Canadian jurisdictions should use the same questions to allow comparison across the country. The Public Health Agency of Canada with the Canadian Institute for Health Information (CIHI) could coordinate this effort. The set of recommended questions could be implemented quickly in standard procedures at COVID Assessment Centres, on lab requisitions for COVID-19 tests, as part of hospital discharge data submitted to CIHI, and in data that local public health collects as they follow-up on suspected and probable cases and through contact tracing.
3. Asking about race remains uncommon in Canadian health care settings. It is important that the question is prefaced, as stated above, so that patients are aware of why this question is being asked and to avoid reinforcing the false idea that genetic differences exist between people of different racial identities.
4. All organizations and governments that collect this data should commit to transparency in its use, and to engage with local leaders and representatives – particularly from the Indigenous and Black communities – on the questions used, how to train staff to administer the questions, the appropriate way to collect, store and use this data, and to help generate rapid community-based interventions to reduce inequities.