

# Collecting race-based data during pandemic may fuel dangerous prejudices

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Credit: AI-generated image (disclaimer)

Brian Sinclair wheeled himself into a Winnipeg emergency room in September 2008 seeking assistance with his catheter bag. He had a bladder infection, but instead of receiving treatment, remained in the waiting room for 34 hours until his body—now lifeless—finally received medical attention.



Sinclair was an Indigenous man who hospital staff believed was there "to watch TV," appeared "intoxicated" and was simply "sleeping it off." He was arguably triaged within what scholars of Indigenous histories Mary Jane Logan McCallum and Adele Perry call a "highly racialized" healthcare system.

Sinclair's case shows how <u>stereotypes of indigeneity in Canada</u> can influence patient care with fatal consequences. More broadly, this adds to trends of <u>cumulative disadvantage</u>, where negative circumstances that affected population groups in the past continue to affect the same groups today.

Is there a risk that the COVID-19 pandemic will fuel such trends in Canada, especially against the backdrop of the country's racialized past? As a sociologist, my answer to this question is yes.

As a researcher affiliated with the <u>Surveillance Studies Centre</u>, I am also concerned with how racially sorted patients are surveilled, often with negative consequences. Therefore, as a privacy and ethics officer evaluating <u>health data</u> for Ontario's <u>Pandemic Threat Response</u> (<u>PANTHR</u>), I caution the Ministry of Health and its partners against the use of <u>race</u>- and ethnicity-based health data in dealing with COVID-19.

## Collecting race data for good medicine?

Canada's attention to race during the first 100 years of immigration policy shaped aspirations of a settler colonial "White Canada Forever." Unsurprisingly, historical racial inequalities shape Canadian experiences in health care.

Dr. Kwame McKenzie of Toronto's <u>Wellesley Institute</u> believes that <u>race-based data is essential for "good medicine."</u> And many additional doctors and scholars believe that collecting race data might improve



understandings of the social determinants of health.

However, when race data is collected to understand the social determinants of health, it could inadvertently <u>legitimate biological</u> <u>understandings of race</u>. This is an essentialist position that necessarily ties the racial attributes and behaviors of one person to another.

Further, when race data is used in these circumstances, it creates more scope to arrive at racist responses to a pandemic than it does to address social vulnerabilities like the poor work conditions of minority populations in essential services.

# Linking race and health

Alberta's Chief Medical Officer of Health, Dr. Deena Hinshaw, acknowledges that systematic racism disadvantages certain populations. However, Hinshaw has not yet committed to collecting such data. Initially, her Ontario counterpart, Dr. David Williams, said the province would focus on age and chronic illness "regardless of race, ethnic or other backgrounds." Ontario now says it will collect race-based data during the pandemic.

Williams' revised position certainly eases tensions with a coalition of Black health leaders that has called for attention to race.

Endorsed by 192 organizations and 1,612 individuals, the coalition wrote an <u>open letter</u> to Ontario Premier Doug Ford and other provincial officials. It argues for "the collection and use of socio-demographic and race-based data in health and social services ... as it relates to COVID-19."

But the use of race data may be problematic because links between health conditions and race have been connected to discriminatory



outcomes in the past.

### **Race-based medical practice**

Diseases like Tay-Sachs and sickle cell anemia <u>have discursively been</u> <u>described as a "Jewish disease" and "Black disease" respectively at least since the early 1900s</u>, even though these associations with races <u>can lead to inaccuracies</u> in terms of who is deemed high risk. Moreover, racializing these diseases reinforced discriminatory notions of race that were tied to other policies of racial oppression, such as <u>anti-immigrationism</u>.

Because <u>race data are routinely associated with medical conditions and treatment</u>, many medical doctors turn to race as <u>illness inducing</u>, instead of examining an individual's symptoms, individual patient history or family history.

Racial categories are therefore deemed scientific, despite their unscientific construction.

# **Racializing COVID-19**

If race-based data collection is to be attached to COVID-19 in Ontario, then attention should be given to what happens when medical conditions are associated with one's race.

What happens when a disease is racialized? One example of the racializing of COVID-19 are the many <u>cases of anti-Asian racism across</u> <u>North America</u> ignited by <u>xenophobic hysteria</u>.

Another example comes from China where a McDonald's franchise in Guangzhou <u>allegedly posted a sign</u> in April reading, "We've been informed that from now on Black people are not allowed to enter the



restaurant" because of "rumors" that coronavirus was spreading among African people.

If surveillance is the <u>attention to human attributes and behaviors</u> so that people can be "<u>socially sorted</u>" and potentially treated differently, then the systematic collection of race data is also a form of surveillance.

When rumors like those in the McDonald's example are connected to reports generated through <u>racial surveillance by leading health agencies</u> that monitor COVID-19 by race (like the U.S. Centers for Disease Control and Prevention), then the racial dimensions of the virus can further fuel xenophobia.

Therefore, a call for <u>increased racial surveillance potentially fuels racism</u>

## Measuring race, fuelling racism

Health scholars have raised concerns about "... how anti-Black racism, anti-Indigenous racism and other forms of intersectional violence will impact the health of our communities during this crisis."

In the <u>open letter</u> from the coalition of Black health leaders to Ontario's political leaders, a case is made for collecting race data because, "<u>We cannot address what we cannot measure</u>." But can race be measured?

What determines the boundary between one race and another, especially if self-identification means that race is a subjective term, not a medically objective one?

Prejudicial inferences from race-based data are of significant concern. It is these prejudices, contributing to historical trends of racism, that we are reminded of when recalling Brian Sinclair's tragic death in a



## Winnipeg ER.

It is these prejudices that are fuelled by collecting race data for health care, especially when coupled with public hysteria during a pandemic.

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