Commentary

Considerations for collecting data on race and Indigenous identity during health card renewal across Canadian jurisdictions

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In Canada, Indigenous and racialized patients have been shown to have worse access to health care, receive poorer care and have worse outcomes than White people.[1] A recent concept-mapping study found that Indigenous and racialized patients often feel belittled by clinicians and report that their symptoms are not taken seriously.[2] In health care, racism faced by Indigenous and Black patients has been extensively documented in key reports and postmortem investigations.[3] Although race is a social construct that uses perceived physical differences to create and maintain power differentials and the existence of discrete racial groups has not been shown to have any biological basis, perceived race influences how people are treated by individuals and institutions. Having data on race available for analysis can facilitate the measurement of racial inequities in health care, help to hold organizations and governments accountable for addressing these inequities and monitor progress. We discuss health card renewal as a potentially efficient and effective way of collecting race and Indigenous identity data in Canada and highlight the key preconditions to the collection, governance and use of such data that would facilitate positive action on racism in health care in Canada.

How could race and Indigenous identity data be used for good in Canada? A few Canadian health organizations have used self-reported data on race and Indigenous identity to identify and address inequities. For example, the Centre for Addiction and Mental Health in Toronto found that Black patients were restrained 44% more often than White patients, and cited this statistic in the justification for a broad antiracism plan.[4] Earlier in the COVID-19 pandemic, public health programs in Ontario and Manitoba used data on race and Indigenous identity to inform their respective rollouts of SARS-CoV-2 vaccine. Disaggregated data can support accountability to treaty rights to health care, the United Nations Declaration on the Rights of Indigenous Peoples, and the calls to action of the Truth and Reconciliation Commission of Canada.

Key points

- Canada's health care systems do not routinely collect self-reported race and Indigenous identity data and often lack a standardized and consistent approach to data collection that would permit comparisons between organizations or jurisdictions.

- Collecting racial and Indigenous identity data is necessary for measuring health inequities related to racism, holding organizations accountable and tracking progress; however, collecting such data could cause harm if done inappropriately.

- Near-universal race and Indigenous identity data could be collected efficiently at health card application and renewal across Canadian jurisdictions, which would likely be more efficient and effective than data collection at other touchpoints.

- Essential preconditions to collection of data on race and Indigenous identity include Indigenous data governance and sovereignty, engagement and governance by racialized communities, recognition of the potential for and mitigation of the misuse of data, and transparency, accountability and a commitment to act on inequities.

Existing research suggests that many patients are open to answering questions about race that are posed within health care organizations they trust and where the rationale for data collection is explained.[5] However, data collection by individual health organizations is inefficient and often results in patients being asked to self-report race or identity numerous times, including when it is inappropriate (e.g., when a patient is in pain, in the emergency department). Organizations that do collect such data often request the information from a small fraction of patients and may find the process difficult to sustain. Linking organization-collected race data to other demographic data can be difficult and costly. Moreover, data collected by individual organizations with unclear data-retention practices could be used in a way that harms individuals and communities.

Collecting data on race and Indigenous identity during the health card application or renewal process — an approach currently undertaken in Nunavut and the Northwest Territories and being implemented in Nova Scotia — would be efficient and nearly universal, with patients being asked for their data only once or every few years. We suggest that this approach should be the norm across Canada, with the caveat that potential harms be considered, anticipated and addressed. We suggest the following steps.

First, individuals should be asked about their race and Indigenous identity in a culturally responsive and safe manner, with a clear explanation that this is voluntary, why the data are being collected, and what protections are in place to prevent misuse.

Second, data should not be interpreted or presented in a manner that reinforces racism and discrimination. For example, data on race collected earlier in the COVID-19 pandemic identified higher rates of COVID-19 among South Asian communities in the Greater Toronto Area, and media reports blamed social gatherings happening during festivals such as Diwali. This misinterpretation of data — and the conflation of race with ethnic practices and customs — ignored systemic factors such as precarious work in warehouses, crowded and insufficient transit, a lack of testing, and the lack of affordable housing.[6]

Third, data on race and Indigenous identity should not be used to make biased decisions or incorrectly employ race correction in clinical algorithms, by individual clinicians or by automated algorithms. To mitigate against individual and organizational bias, we would suggest not making data on race or Indigenous identity visible on health cards, and ensuring that individuals and teams who have access to the data have received appropriate antiracism training. However, tackling biases at the level of individual and organizational behaviour is without simple solutions.

Fourth, Canadian laws on data provide some protection to individuals, but not necessarily to communities. For example, in Canada, data on Indigenous communities have been sold to researchers and other entities who have potentially used the data without appropriate context and without abiding by principles of Indigenous data governance and sovereignty. Preventing the sale of health data — even if it is de-identified at the individual level but could still be used to draw conclusions about whole communities without their involvement — is essential.[7] These concerns necessitate legislated requirements, not simply recommendations.

Fifth, Indigenous and racialized communities must be supported to lead and direct the process of data collection, analysis and dissemination, in a way that recognizes communities are not homogenous in their goals. Preconditions for data collection on race and Indigenous identity at health card renewal include adhering to the First Nations' principles of Ownership, Control, Access and Possession (OCAP),[8] the Manitoba Métis Federation principles of Ownership, Control, Access and Stewardship (OCAS),[9] and the Inuit Qaujimajatuqangit (IQ) principles to guide the use of knowledge to improve Inuit community wellness.[10] Key frameworks now exist to guide community engagement, including the Collective Benefit, Authority to Control, Responsibility and Ethics (CARE) Principles for Indigenous Data Governance,[11] and Ontario's Black Health Equity Working Group data governance framework (EGAP)[12] (Appendix 1, www.cmaj.ca/lookup/doi/10.1503/cmaj.221587/tab-related-content). Implementing data governance can build on the lessons learned from existing partnerships between First Nations, Métis and Inuit organizations and Black communities, and key data holders such as ICES and the Manitoba Centre for Health Policy.

In summary, racism in Canada's health care systems continues to lead to injustice, but data that would assist in tracking progress and ensuring accountability are lacking or inadequate. Near-universal race and Indigenous identity data could be collected efficiently at health card application and renewal across Canadian jurisdictions. Essential preconditions for data collection during health card renewal include Indigenous data governance and sovereignty, engagement and governance by racialized communities, recognition of the potential for and mitigation of the misuse of data, and the importance of transparency, accountability and a commitment to act on inequities.

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