

Racism's trojan horse:

race-based data, health care, and risks to Black and racialized populations

Demands for race-based data in the health care system facilitate rather than inhibit race-medicine being practiced in Canada. Equally as important race-based data are not inherently compatible with 'equity,' and self-determination, and are unlikely to align with authentic efforts to end structural anti-Black racism. This is large part due to the interests involved. Data collection involves opportunities for both profit and recognition at different scales. For example, electronic medical record companies sell data personal health data that belongs to the patient on the open market; insurance companies may use algorithms derived from race-based data to hike rates, or deny claims; while police departments in Canada have used health care data both for surveillance purposes, and seemingly for their own personal amusement.

Patients and research subjects, on the other hand, are rarely made aware of the profitability of their own data and motivations this may fuel. In addition, patients aren't made aware of the privacy concerns that are emerging as a result of a confluence of factors including: the rise of Artificial Intelligence (AI); the commodification of health care data; the use of health care data as a tool of surveillance; and, the exceptionally weak privacy protections currently in place in Canada. Finally, while race is a social construct, health care and public health often default to racist and long-discredited tropes that link race to biology or "behaviour," and position Black populations as inherently "vulnerable" or as vectors of disease. Race-based data has the potential to reify these tropes, as has already been seen in the context of COVID-19 research.

Importantly, researchers, health care administrators and organizations responsible for collecting, storing or analyzing race-based data may not be aware of some or all of these factors. For example, some researchers working in the space of race-based data may not be fluent in recent changes to health data privacy legislation in Ontario. As another example, health care administrators may not be immersed in the implications of both AI and data

interoperability for patient privacy. Still others may not have investigated the implications of public-private partnerships in health care research. Even so, researchers, physicians, clinics and hospitals continue to sign contracts with insurance, pharmaceutical data and software companies to lease access private patient information without patient knowledge or consent and [patients do not support the practice as it stands](#). While health care decision-makers may not be aware of all the implications of these contracts, they are responsible for the ethical, privacy, and legal consequences.

Given the risks to patients and communities, we encourage NDRI to err on the side of caution. In particular, we advise NDRI to refrain from collecting, linking or transferring [race-based data](#) within DRI until updated regulations and laws are in place to address the specific risks at the intersection of race-based data, anti-Black racism and race medicine. This will decrease NDRI likelihood of losing credibility at the outset and risking both future public relations issues and legal action.

Right now, NDRI has the opportunity to follow the lead of the national data justice and civil liberties lawyers, critical data scientists, bioinformaticists and critical code anti-Black racism experts monitoring the national situation. In addition, NDRI would be well advised to align its approach with [well-informed data justice expertise](#).

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