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Collecting Race-Based Data in Health Research: A Critical Analysis of the Ongoing Challenges and Next Steps for Canada

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Article abstract

The COVID-19 pandemic has had a global effect. The disproportionate impact on Indigenous peoples and racialized groups has brought ethical challenges to the forefront in research and clinical practice. In Canada, the *Tri-Council Policy Statement* (TCPS2), and specifically the principle of justice, emphasizes additional care for individuals “whose circumstances make them vulnerable”, including Indigenous and racialized communities. In the absence of race-based data to measure and inform health research and clinical practice, we run the risk of causing more harm and contributing to ongoing injustices. However, without an accepted framework for collecting, maintaining, and reporting race-based data in Canada, more guidance is needed on how to do this well. Importantly, a framework for collecting race-based data should build on existing guidance from Indigenous and other structurally marginalized communities, the TCPS2, recommendations from the World Health Organization, and involve relevant stakeholders. In this paper, we describe historical examples of unethical studies on Indigenous and racialized groups, discuss the challenges and potential benefits of collecting race-based data, and conclude with objectives for a pan-Canadian framework to inform how race-based data is collected, stored, and accessed in health research.

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Collecting Race-Based Data in Health Research: A Critical Analysis of the Ongoing Challenges and Next Steps for Canada

Fatima Sheikh[a], Alison E. Fox-Robichaud[b], Lisa Schwartz[a]

Résumé
La pandémie de COVID-19 a eu un effet mondial. L'impact disproportionné sur les peuples autochtones et les groupes racialisés a mis les défis éthiques au premier plan dans la recherche et la pratique clinique. Au Canada, l'Énoncé de politique des trois Conseils (EPTC2), et plus particulièrement le principe de justice, met l'accent sur les soins supplémentaires à apporter aux personnes « dont les circonstances les rendent vulnérables », notamment les communautés autochtones et racialisées. En l'absence de données fondées sur la race pour mesurer et éclairer la recherche en santé et la pratique clinique, nous courons le risque de causer plus de tort et de contribuer à des injustices continues. Toutefois, en l'absence d'un cadre accepté pour la collecte, la tenue à jour et la communication des données fondées sur la race au Canada, il est nécessaire d'obtenir davantage de conseils sur la façon de bien faire les choses. Il est important de noter qu'un cadre pour la collecte de données fondées sur la race devrait s'appuyer sur les directives existantes des communautés autochtones et d'autres communautés structurellement marginalisées, sur l'EPTC2, sur les recommandations de l'Organisation mondiale de la santé et sur la participation des intervenants concernés. Dans le présent document, nous décrivons des exemples historiques d'études non éthiques sur les Autochtones et les groupes racialisés, nous discutons des défis et des avantages potentiels de la collecte de données fondées sur la race, et nous concluons par les objectifs d'un cadre pancanadien visant à informer la façon dont les données fondées sur la race sont recueillies, stockées et accessibles dans la recherche en santé.

Mots-clés
équité en santé, diversité, inclusion, décolonisation, services de santé, déterminants sociaux de la santé, antiracisme, justice

Abstract
The COVID-19 pandemic has had a global effect. The disproportionate impact on Indigenous peoples and racialized groups has brought ethical challenges to the forefront in research and clinical practice. In Canada, the *Tri-Council Policy Statement* (TCPS2), and specifically the principle of justice, emphasizes additional care for individuals "whose circumstances make them vulnerable", including Indigenous and racialized communities. In the absence of race-based data to measure and inform health research and clinical practice, we run the risk of causing more harm and contributing to ongoing injustices. However, without an accepted framework for collecting, maintaining, and reporting race-based data in Canada, more guidance is needed on how to do this well. Importantly, a framework for collecting race-based data should build on existing guidance from Indigenous and other structurally marginalized communities, the TCPS2, recommendations from the World Health Organization, and involve relevant stakeholders. In this paper, we describe historical examples of unethical studies on Indigenous and racialized groups, discuss the challenges and potential benefits of collecting race-based data, and conclude with objectives for a pan-Canadian framework to inform how race-based data is collected, stored, and accessed in health research.

Keywords
health equity, diversity, inclusion, decolonization, health services, social determinants of health, anti-racism, justice

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INTRODUCTION

The COVID-19 pandemic has highlighted and exacerbated racial and ethnic health disparities worldwide (1,2) and has brought ethical challenges to the forefront in research and clinical practice (3,4).

In Canada, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2)* is used to govern research involving humans. One of its key tenets is the principle of justice – the obligation to treat people fairly, equitably, and in a way that does not create or reinforce inequities (5). In health research, this guidance emphasizes additional care for individuals "whose circumstances may make them vulnerable", such as members of racial minority groups (5). The ongoing health inequities faced by these groups are a form of structural racism (3), defined as racial discrimination through the reinforcement of inequitable systems (6), which have detrimental effects on the health and well-being of these communities.

Although the National Institute of Health (NIH) has adopted standards for collecting, maintaining, and reporting race and ethnicity data in the United States of America (USA) (7), there is no similar expectation in Canada. Even with established ethical standards, health research often fails to address structural inequities, influenced by race and ethnicity, which have led to health disparities among Indigenous and racialized groups. To ensure that health research and administered care are equitable, there is a need to understand, challenge, and restructure the collection and use of race-based data.

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The purpose of this paper is to 1) identify how historical cases of exploitation highlight the challenges and importance of the way in which we collect race-based data; 2) explain why race-based data in health research needs to be collected, in a particular way; and 3) provide objectives for the development of a Canadian framework for collecting race-based data.

Key Points

- The COVID-19 pandemic has highlighted and exacerbated pre-existing racial and ethnic health disparities.
- Health research in Canada lacks a standard framework for collecting race-based data, a gap that needs to be addressed.
- Historical mistreatment of Indigenous and racialized groups, ongoing mistrust of healthcare institutions, concerns about reinforcing existing inequities, and data privacy issues can impede the collection of race-based data.
- The development of a Canadian framework needs to be co-designed with relevant stakeholders, including members of Indigenous and racialized groups.

Definitions

In this paper, we understand *justice* to be the obligation to treat people fairly, equitably, and in a way that does not create or reinforce inequities, based on a core principle of the TCPS2. We draw on the TCPS2 because it is the standard of ethical research practice in Canada, and as such, is a "benchmark for the ethical conduct of research involving humans." (8) We acknowledge a plurality of views on justice and explore it here through a lens of health equity. We draw on the WHO statement on *health equity*, as an approach to justice, understood as the "absence of unfair, avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by other dimensions of inequality." (9) This understanding of health equity includes consideration of social determinants of health, structural injustice, and how these can impact health, and health access. With regard to race and ethnicity, understood as two distinct social constructs, we refer to guidance from the Canadian Institute for Health Information (CIHI) (10) and the National Collaborating Centre for Determinants of Health (11). Here, race is conceptualized as "a social construct used to judge and categorize people based on perceived differences in physical appearance in ways that create and maintain power differentials within social hierarchies." Ethnicity is described as a shared culture, or community belonging, on the basis of socio-demographic variables, including language, religion, and cultural traditions.

WHAT ARE THE CHALLENGES OF COLLECTING RACE- AND ETHNICITY-BASED DATA IN HEALTH RESEARCH?

Historically, racial, and ethnic minoritized groups, specifically African-origin people and Indigenous groups, have been exploited as subjects of unethical studies, creating a persistent environment of distrust (12). Systematic collection of race-based data could reinforce existing inequities by conforming to deficit orientations, biases, and preconceived notions. Among the many examples of this, the Tuskegee Syphilis Study in the US and nutrition studies conducted on Canadian Indigenous people demonstrate how racist beliefs perpetuated existing inequities among vulnerable groups.

The Tuskegee Syphilis Study (1932-1972) was designed to determine the natural course of untreated, latent syphilis among 400 infected and 200 uninfected African American men (13). In 1950, penicillin was identified as the preferred treatment for syphilis and became widely available; however, treatment was withheld from this cohort. When the study ended, at least 28 participants had died from untreated syphilis, the risks of which had been identified. Following public criticism due to significant media attention, the study was determined to be unjustified and informed consent had not been obtained; the US National Archives showed that men were falsely led to believe that they were receiving free medical care for a serious disease. Racist beliefs and attitudes toward African American men resulted in an unethical 40-year-long study in which a communicable disease was left untreated, and participants were exposed to avoidable risks and harm (13).

Although this study took place in the US, racism in healthcare is neither unique to the USA nor limited to anti-Black racism.

In Canada, Indigenous communities continue to be affected by inequities in healthcare, and many examples demonstrate exploitative practices in research involving Indigenous populations. Nutrition experiments implemented in residential schools (1942-1952) are a striking example (14). Prior to these studies, there had been reports that Indigenous children were severely malnourished. Rather than addressing the structural causes of malnutrition, 300 malnourished children were recruited into a study and received supplements, while the rest remained deprived of adequate amounts of food and nutrients. The levels of malnutrition observed at Norway House and neighbouring communities were described as a "tragedy but also an unprecedented research opportunity." (14) Ultimately, racist attitudes towards Indigenous communities and the emphasis on experienced deficits rather than structural causes of malnutrition facilitated the exploitation and practice of unethical studies.

Unfortunately, the cases of racial discrimination faced by Indigenous communities and the harmful implications within health systems continue and demonstrate how vulnerable groups can be exploited by racist attitudes and practices (15,16). Without a clear reason for why race-based data are being collected and how they will be used, collecting these data in the context of past and present structural inequities can cause further harm and distrust of health systems. The suspicion and fear generated

by the Tuskegee Syphilis Study in the US and the ramifications of the nutrition experiments in Canada are still evident today and require appropriate consideration (12).

In describing these examples of unethical studies, we highlight the challenges of collecting race-based data and emphasize the importance of the ways in which we could ethically collect race-based data.

WHY SHOULD RACE-BASED DATA BE COLLECTED IN HEALTH RESEARCH?

Implementing the Nuremberg Code (1948), the Declaration of Helsinki (1964), and the adoption of the TCPS (1998) helped prevent unethical research; however, there remain ongoing concerns. Discussions of race and ethnicity can be rooted in a deficit perspective where the narrative is negative, focused on deficiencies, and can be disempowering (17); nevertheless, it can also be problematic not to address race and ethnicity in health research as though these social constructs have no implication at all on the social determinants of health (SDH). More guidance is needed to do this well.

The underrepresentation of minoritized groups in health research is well established (18-20). The reasons for this lack of representation are not singular; they can be attributed to distrust of health research, lack of opportunity, and structural barriers. In some cases, it is due to misguided attempts to protect vulnerable groups by excluding them from the risks of health research, although it is understood that exclusion can also reinforce existing harms and inequities. Failure to collect race and ethnicity data in research prevents disparity measures and limits the available evidence to inform patient-centred care, thus reducing the quality and relevance of care provided to racialized groups (19). In contrast, the inclusion of race-based data in both interventional and observational studies can inform quality improvement initiatives, increase the applicability of evidence to Indigenous and racialized groups, and can be used to address knowledge gaps specific to structurally marginalized populations.

Collecting race-based data along with other demographic information would, we argue, promote an intersectional approach to health research and the development of targeted programs, policies, and institutions. This added dimension would clarify the structural determinants of health, taking into account the context in which people experience poor health, as well as the systems and policies that impact their experiences and create structures that marginalize (21).

Moving away from an approach that categorizes people as vulnerable and assumes that all members of a particular group have the same experience, this research paradigm would provide a more representative analysis in which multiple factors and the intersection of a person's experience are considered. Importantly, this approach accounts for intersectional identities, for example, of race, ethnicity, and gender, that can lead to multiple, and overlapping forms of discrimination, disadvantage, and oppression (22). The concept of vulnerability and the challenges faced by Indigenous and racialized groups are complex and layered; this requires us to better understand, challenge, and re-think the use of race-based data in health research (23). Early identification of factors contributing to the inequities faced by these groups can foster discussion on ways to avoid or minimize the impacts in clinical practice and through policy development.

From a practical standpoint, the availability of accurate race-based data, reported by the individual, can be used to serve multiple purposes: 1) promote the implementation of specific cultural training for staff; 2) prepare the resources needed to provide appropriate care to populations experiencing racism in the healthcare system (i.e., interpreters, patient information materials, and resources); and 3) help inform upstream policies and practices that minimize the effects of racism (24).

From 1981 to 2001, Canada experienced a marked increase in individuals who identify as a visible minority; and the Indigenous population has increased by 42.5%, since 2006, four times faster than the rest of the Canadian population (25,26). Given the increased proportion of minoritized populations and the disproportionate impacts of SDH on these groups, it is reasonable to expect that increasingly racialized communities will face negative health effects in the absence of culturally specific and sensitive care. Collecting race-based data will facilitate an intersectional approach to research in which multiple realities and their intersection are considered alongside biological factors to provide evidence-based and patient-centred care (27). Although race-based data should be collected to address disparities and inform programs, policies, and institutions, consideration of how these data are collected, accessed, and stored, is imperative. The discussion around race-based data collection should not be centred on whether to collect, but on how to collect race-based data to address the challenges highlighted by past and present examples of unethical studies.

HOW CAN CANADA APPLY AN EQUITY-BASED APPROACH TO COLLECTING RACE-BASED DATA IN HEALTH RESEARCH?

If the collection of race and ethnicity data is integrated into regular research practices, a tailored decision-making process will be necessary to reduce the potential for misunderstanding and distrust (22). This introduces additional hurdles regarding what these categories should be, who should report this information, and the practical implications related to soliciting this information.

In the US, the NIH specifies two ethnic categories – Hispanic/Latino and non-Hispanic/Latino – and five racial categories, including American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian, and White (7). Although the

terms Hispanic, Asian, Latino, and Black have been used in the US, the Latino/Hispanic category collapses differences among populations who have diverse historical experiences of oppression. Collecting race and ethnicity-based data with a limited set of choices can alienate participants and further contribute to the stigmatization and marginalization of groups, especially when these categories do not reflect their perceptions. To avoid reinforcing existing disparities, it is necessary to critically assess current practices for collecting race-based data and to engage racial and cultural communities to inform a Canadian framework.

In addition to determining which categories should be included, if any, we need to consider how and by whom the information should be collected. Self-identified race and ethnicity are different from the categories included in hospital databases and inconsistent with their self-reported identities (28). Incorrect collection of information jeopardizes the validity of the study and runs the risk of profiling participants, thereby doing more harm than good. This highlights the need for self-reported data (with the evident limitations) and challenges the notion of traditional and overly broad categories.

To avoid contributing to ongoing racial discrimination based on deficit orientations, and the significant harms associated with both, the development of a Canadian framework must be co-designed with relevant stakeholders (29). This implies meaningful and transversal participation of Indigenous and racialized groups, and members of the healthcare and research teams, to inform how race-based data should be collected, stored, and accessed. Importantly, this framework should build on existing guidance from Indigenous communities, including the First Nations Ownership, Control, Access, and Possession (OCAP) principles (30), and TCPS2 on research involving First Nations communities (31); consider recent clinical standards, developed by CIHI, on collecting race-based and Indigenous identity data (10) and; align with recommendations from the World Health Organization on a human rights approach to data collection (29). Building on these guidelines, and other emerging guidelines (32), will help ensure that the processes for collecting race-based data in health research are community-informed and controlled.

Decisions about which individuals, groups, and communities to include in research bring to the forefront issues of fair and equitable treatment. The TCPS2 principle of justice upholds that “inclusiveness in research and fair distribution of benefits and burdens should be an important consideration.” (33) Collecting race-based data in ways that are community-informed and controlled will help ensure that guidance, protocols (34), and principles (30) from racialized and Indigenous communities are used to inform the collection of race-based data.

We argue that race and ethnicity data need to be collected to ensure that health research and administered care are equitable. Based on our analysis, the objectives of a Canadian framework to support the collection of race-based data should aim to:

1. Reduce disparities in accessing care and health outcomes in groups affected by racism and structural inequities;
2. Address the concerns faced by Indigenous and racialized groups and ensure an equal distribution of research benefits, as perceived by structurally marginalized communities;
3. Appropriately quantify and describe health inequities to guide patient-oriented and community-informed research, clinical practice, and active measures to support health equity, and eliminate race-correction practices that reinforce inequities (35);
4. Co-create governance structures to guide race-based data collection, use, and ownership.

CONCLUSIONS

Health research is designed to inform clinical practice and policies. A critical evaluation of how race and ethnicity are currently handled in health research in Canada is urgently needed. Although other SDHs are important, race and ethnicity are necessary to understand the social, cultural, and economic context in which healthcare occurs. Otherwise, clinical and policy decisions will not consider the effects of structural racism, leading to narrowly informed evidence-based decisions (36). There are ongoing challenges associated with identifying vulnerable populations for inclusion in research while also minimizing harm and preventing further injustices. However, unjust exclusion and the lack of race-based data to monitor progress, reinforce the need for this information to be collected in the first place. We concluded by arguing for a set of objectives to inform the development of a framework for collecting race-based data. Building on the OCAP principles and TCPS2 and seeking guidance from Indigenous and racialized groups to establish safe practices for data collection will help reduce hesitancy and support race-based data collection. Although what is suggested here are small first steps, the collection of race-based data can contribute to ongoing efforts by Indigenous and other marginalized communities to address the impacts of structural racism and promote health equity in Canada.

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