A Systematized Review of Anti-Racism Data Legislation for Healthcare

by

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Abstract

Background. Health disparities among racialized individuals and the general population have persisted throughout time. In response to global events highlighting these inequities, there have been increasing calls to collect race, ethnicity and Indigenous (REI) identity data to foster health equity. As part of this data collection, it is pivotal for organizations to ensure proper governance of this data to mitigate the potential for harm towards racialized communities. One way to safeguard this data is through the implementation of anti-racism data legislation for race-based data collected in the healthcare sector. **Aim.** The purpose of this study was to explore the current landscape of anti-racism data legislation for healthcare by answering the following research question: What is the justification for enacting anti-racism data legislation for race-based data collected in healthcare environments? **Methods.** A systematized review was conducted as it allows academic literature to be reviewed with minimal resources, while maintaining key elements of a systematic review. **Results.** After removing duplicates, 7625 articles underwent title and abstract screening, of which 18 articles were reviewed in full, resulting in the inclusion of one article. **Implications.** This study highlights the ongoing need for research centered on the benefits and challenges of implementing anti-racism data legislation for race-based data collection within healthcare, and can serve as a pilot for a larger systematic review.

Keywords: anti-racism, race-based data collection, healthcare reform, legislation

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Lastly, I want to thank myself for never giving up on my goal of becoming a Physician Assistant, for persevering through a rigorous program and giving myself grace throughout this journey.

Dedication

For those who champion social justice and anti-racism.

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Introduction

Throughout Canada, health disparities have persisted between racialized individuals and the general population. Specifically, gaps in health and health care quality among Indigenous Peoples and racialized communities stemming from the legacy of colonialism have been well documented throughout time (Katz et al., 2019;Lavoie et al., 2010; McCallum & Perry, 2018). For instance, the incidence of active tuberculosis (TB) (per 100,000) among non-Indigenous Canadian born individuals in 2021 was 0.2, while rates among Inuit, First Nations and Métis were 135.1, 161 and 2.1 respectively (Public Health Agency of Canada [PHAC], 2018; PHAC, 2023). Likewise, literature has demonstrated that Black Canadians "account for 30% of HIV prevalence and 15% of new HIV infection" (Odhiambo et al., 2023, p.7), despite making up less than 3% of the population (Odhiambo et al., 2023). These disparities were further magnified in Manitoba during the COVID-19 pandemic whereby self-identified Black, Indigenous and People of Colour (BIPOC) Manitobans had higher rates of testing positive for COVID-19 compared to non-BIPOC Manitobans (Manitoba Health, 2021). Due to the ongoing gaps in health and health care outcomes between racialized Canadians and the general population, increasing calls to collect self-identified race, ethnicity and Indigenous (REI) identity data for health equity enhancing purposes reverberated across the nation (Ahmed et al., 2021; Datta et al., 2021).

In response to calls to collect race-based identity data in healthcare, jurisdictions across Canada commenced the collection of this sociodemographic data via various avenues. In Ontario, the Toronto Local Health Integration Network (LHIN) and Sinai Health system began collecting language and REI identifiers through the *Measuring Health Equity Initiative*, while Nova Scotia implemented the collection of race-based data through the provincial health card renewal process via the *Fair Care Project* (Government of Nova Scotia, 2022; Sinai Health

System, 2017). In the prairies, Manitoba implemented the collection of self-identified REI identity data at the point of patient registration within healthcare facilities province-wide (Shared Health, 2023). Carrying out the collection, analysis and reporting of race-based identity data in healthcare is a complex process requiring interdisciplinary expertise and collaboration to execute system-level changes such as adapting existing infrastructure and developing new policies and procedures to safeguard data misuse that may disenfranchise and/or cause harm to racialized communities (Etowa et al., 2021; Lion et al., 2022; Mathur et al., 2022; Ponce et al., 2023). However, these policies and procedures are at-risk of being disregarded due to their reliance on transient leadership across healthcare organizations who may not uphold those directives overtime. To circumvent this issue, anti-racism data legislation may be an additional avenue to legally ensure that REI identity data collected in healthcare environments is used to enhance health equity while mitigating harm towards racialized communities.

Purpose and Research Questions

To date, seldom literature has explored current use of anti-racism data legislation within healthcare sectors and to the authors knowledge there has yet to be a study identifying anti-racism data legislation for race-based data collected within healthcare. For these reasons, the purpose of the proposed project is to conduct a systematized review to explore the current landscape of anti-racism data legislation for healthcare. This project will achieve this purpose by addressing the following research question: What is the justification for enacting anti-racism data legislation for race-based data collected in healthcare environments?

Methods

A systematized review was selected for this project as it allows a review of literature to be conducted with minimal resources while still retaining key elements of a systematic review

(Grant & Booth, 2009). As such, this systematized review aims to identify academic literature centered on anti-racism data legislation for healthcare in academic literature to outline the current landscape of this field, as well as identify existing anti-racism data legislation for healthcare discussed in included articles.

Protocol and Registration

A protocol informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocol (PRISMA-P) Checklist was developed a priori, and revised by the primary author's mentor in consultation with a health sciences librarian and law librarian (PRISMA-P Group et al., 2015).

Eligibility Criteria

Academic literature was searched in consultation with a health sciences and law librarian respectively. All literature published from inception to December 31, 2024 was reviewed. Literature was included if it was: written in English, described anti-racism legislation, policy or commitments, healthcare and race-based data collection. Literature centered on sectors outside of healthcare (e.g., education, judicial, military, employment), only found in conference proceedings or in abstract were excluded.

Information Sources

Databases searched for academic literature included Scopus and Hein Online, while consolidated statutes, regulations, and bills discussed in included articles were retrieved from website sources available through Google and government websites.

Search

The literature search was developed by the primary author in collaboration with a health sciences librarian (see Appendix). The search for consolidated statutes, regulations and bills was tailored based on descriptors included within the article of interest.

Selection of Sources of Evidence

The primary author completed title and abstract screening of articles using the inclusion/exclusion study checklist followed by a full text review. Legislation was also reviewed by the primary author. Covidence was utilized to organize the review process and references were managed using a reference management software.

Data Charting Process

A data charting form was developed in Excel by the primary author and mentor to identify pertinent information to be extracted from included articles and legislative documents.

Data Items

The following characteristics of included articles were captured: first author, year of publication, title, country of origin, study design, justification for race-based data collection, sustainability (one-time project, implemented across healthcare system), race-based and Indigenous identity data standards, point of data collection, data quality (ask completion rates, ask completion rates before and after enacted legislation, decline rates), data governance (standards, policies, procedures), and supportive measures (staff training, public education). Data items captured from included legal documents included: title of document, applicable jurisdiction, type of legal document, year of enactment, and key points.

Synthesis of Results

Separate tables were used to summarize data arising from the academic search and the search of legislation (see Table 1 and Table 2).

Results

The academic literature search yielded 7696 results, of which 2052 were identified via Scopus and 5644 were identified through Hein Online. After removing 71 duplicates, 7625 articles underwent title and abstract screening. Following this stage, 18 articles were reviewed in full, resulting in the inclusion of one article (see Figure 1). The included article was based in the United States and centered on the impact of the state of Massachusetts mandating the collection of race, ethnicity and language (REL) data in hospitals statewide from the perspective of hospital executives (see Table 1). The regulation that mandated REL data collection in Massachusetts hospitals and discussed in the included article is summarized in Table 2.

Figure 1

Flowchart

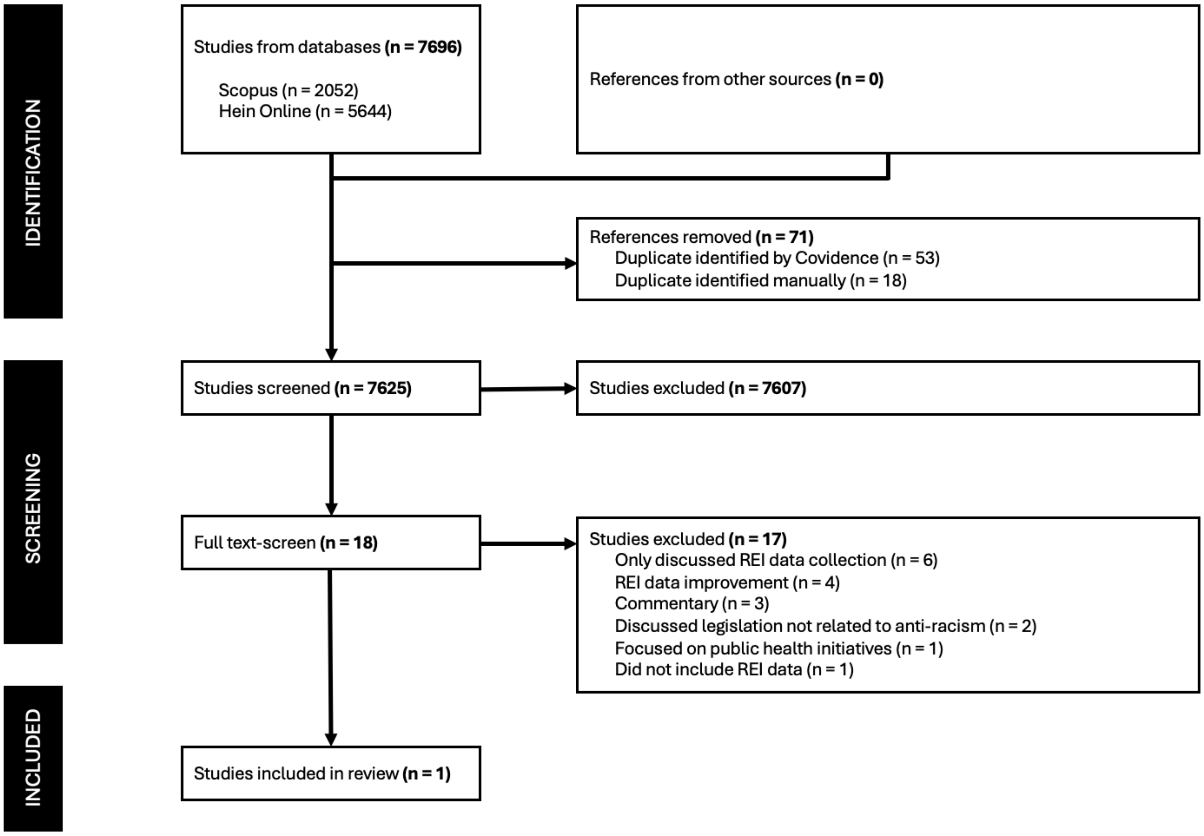

Table 1

Included Article

First Author	Jorgensen, Selena
Year of Publication	2010
Title	Responses of Massachusetts hospitals to a state mandate to collect race, ethnicity and language data from patients: a qualitative study
Country of Origin	United States
Study Design	Qualitative (semi-structured interviews)
Justification for Race-Based Data Collection	To standardize data collection in hospitals across the state of Massachusetts
Sustainability	Statewide implementation
Race-Based and Indigenous Identity Data Standards	1) Are you Hispanic/Latino/Spanish? -Yes -No 2) What is your ethnicity? -African -African American -Asian -Asian Indian -Brazilian -Cambodian -Cape Verdean -Caribbean Island -Central American -Chinese -Columbian -Dominican -Eastern European -European -Filipino -Guatemalan -Haitian -Honduran -Japanese -Korean -Laotian -Mexican, Mexican American, Chicano -Middle Eastern -Portuguese -Puerto Rican -Russian -Salvadoran

	-South American (not otherwise specified) -Vietnamese -Other Ethnicity -Unknown/not specified 3) What is your race? -American Indian/Alaska Native -Asian -Black/African American -Native Hawaiian or other Pacific Islander -White -Other Race -Unknown/not specified
Point of Data Collection	Patient registration
Data Quality	Data Collection and Use Prior to the State Mandate Executives reported inconsistent data collection prior to the implementation of the state regulation. Sites collecting REL data prior to regulation implementation also highlighted this data was not always used to foster health equity. Data Collection and Use Post-Implementation of State Regulation Hospital sites expressed having challenges with small sample sizes within specific reported ethnicities, which resulted in collating ethnicities in order to perform data analyses.
Data Governance	Hospital executives expressed wanting more specific guidance on how to use REL data sets to foster health equity and/or provide specific outcome measures to track and report on moving forward. There was no mention of Indigenous or community data governance in the article.
Supportive Measurements	Staff training materials

Table 2.

Included legal document

Title of Document	**Applicable Jurisdiction**	**Type of Legal Document**	**Year of Enactment**	**Key Points**
114.1 CMR 17.00: Requirement for the submission of hospital case mix and charge data	State of Massachusetts	Regulation	2006	Collected data is to be used for but not limited to the development of public health policy and research centered on public health. Hospitals are required to submit reports of required data to the Division of Health Care Finance and Policy Hospitals and Clinics on a quarterly basis. Failure to comply with these requirements may result in penalties (e.g., fines, funding cuts).

Discussion

This systematized review identified one article discussing the impact of regulation in Massachusetts mandating the collection of REL data across hospitals statewide (Jorgensen et al., 2010). This regulation came to fruition in 2006, when hospitals were instructed to develop a plan to subsequently commence data collection by July of 2007 (Massachusetts Division of Health Care Finance and Policy, 114.1 CMR 17.00, 2006; Welnick et al., 2007). As part of this regulation and by way of following the gold standard, acute care hospitals began collecting self-identified "race and ethnicity data from all patients with an inpatient hospitalization, and observation unit stay, or an emergency department visit" (Welnick et al., 2007, p.1293) (Moorthie et al., 2022). The selected data standards consisted of three questions that asked patients if they identified as Hispanic/Latino/Spanish, and what ethnicity and race they identified with, respectively. The options within each question were chosen to reflect the diversity among residents of Massachusetts, and this reasoning has also been used in other countries who collect race-based data in hospital settings (Knox et al., 2020). As a result of representing the diversity of its residents, the options within each category for patients to self-identify with exceeded those offered and set forth by the Office of Management and Budget (OMB) (Dorsey et al., 2014).

The OMB is responsible for setting minimum standards for race and ethnicity data collected at the federal level, and as of 2024 these categories include American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Middle Eastern or North African, Native Hawaiian or Pacific Islander, and White (Office of Management and Budget, 2024). While this current iteration differs from the standards in place at the time Massachusetts implemented regulation, the state initially selected their categories with the ability to be rolled up into the minimum federal standards set by the OMB and that principle remains true at present. It is also important to note that at the time of regulation implementation, the state of Massachusetts was in the process of healthcare reform that required all residents to have some degree of health insurance or be subjected to a fine enforced through state income tax (Kolstad & Kowalski, 2012; Steinbrook, 2006). Markedly and following this reform, the rate of uninsured adult residents in Massachusetts declined by approximately 16% and access to care increased due to the decrease in financial barriers (Graves & Swartz, 2012; Weissman & Bigby, 2009).

It is understood that the philosophy behind healthcare reform in Massachusetts centered on working towards societal equity through collaborative efforts (Weissman & Bigby, 2009). Further to this, literature describing the impact of the regulation mandating the collection of REL data attributes its implementation to the state's desire to track health disparities and foster health equity among Massachusettsans; however, some hospital executives interviewed in the included article expressed wanting more guidance from the state as to how REL data can and should be used (Jorgensen et al., 2010; Welnick et al., 2007). For instance, one participant representing a large teaching hospital stated:

> I'm not a clinician and I'm not an IT person, so…how does just collecting race and ethnicity help me with the next step? I think there are some steps missing in between that would be helpful… Some hospitals know what they're doing more on that and others may not, so maybe having some consistent things to tell us to be looking for, I think would be helpful (Jorgensen et al., 2010, p.356).

On the contrary, other hospital executives described various ways they have used REL data since the mandate which included, but is not limited to tailoring interpreter services based on patient populations, tracking health disparities related to breast cancer and type two diabetes, as well as developing targeted patient outreach initiatives (Jorgensen et al., 2010). This discrepancy between hospitals highlights the importance of governing bodies detailing proper data governance of race-based data collected in health care alongside anti-racism data legislation to mitigate data misuse that may lead to harm inflicted upon racialized individuals and communities.

In Canada, few jurisdictions have implemented a form of anti-racism data legislation and/or collect race-based data in healthcare facilities. Most notably, the province of British

Columbia (BC) enacted the Anti-Racism Data Act (ARDA) under the direction of the "BC Human Rights Commissioner, First Nations and Métis leadership, and racialized communities." (Anaduaka et al., 2024, p.580). The ARDA was developed with an understanding that disaggregated race-based data can be used to dismantle systemic racism, while remaining cognizant of the importance of safeguarding this type of data against misuse (Anti-Racism Data Act, 2022; British Columbia's Office of the Human Rights Commissioner 2020). Due to the historical impact of colonization and ongoing social injustices, members of racialized communities may be distrustful towards governing bodies collecting race-based data (British Columbia's Office of the Human Rights Commissioner 2020). In recognition of this mistrust, British Columbia's Office of the Human Rights Commissioner made it a point to work with community members when laying the groundwork for the development of the ARDA. Community engagement is a key aspect when implementing race-based data collection that is often overlooked, yet necessary to set the foundation for data governance rooted in anti-racism and social justice, which can then be reinforced through legislation. Since the enactment of the ARDA in 2022, BC has made strides in collecting race-based data to monitor inequities in government services, although it has yet to collect this data within a healthcare environment (British Columbia, 2024). The collection of race-based data in healthcare has taken place across Canada to various extents, however Manitoba was the first province to systematically collect REI data at the point of patient registration in hospitals province-wide (Abdi et al., 2021; Government of Nova Scotia, 2022; Sinai Health System, 2017; Shared Health, 2023).

In contrast to BC, the province of Manitoba implemented REI data collection on May 11, 2023 prior to having any anti-racism data legislation for healthcare (Shared Health, 2023). Initial groundwork for this systematic collection began in 2007 when language and ethnicity questions were integrated into the patient registration system at a tertiary care hospital in the city of Winnipeg, though this collection was halted following the results of an evaluation (Fowler-Woods, 2023). A second attempt to collect this data was also made in 2013 prior to the successful integration of REI indicators within the provincial electronic patient record in 2023 (Fowler-Woods, 2023). One of the contributing factors to the successful implementation of this data collection was the integration of community engagement throughout the development of this initiative. More specifically, community members were sought out to be members of the REI data governance steering committee (Shared Health, n.d.a) whose mandate is "to apply rights-based governance principles to the collection and use of the disaggregated REI data to maximize the potential for benefits and minimize the risks for harms, as well as ensure data governance allows for improved health reporting and health planning for equity enhancing purposes" (Shared Health, n.d.a, p.1). However, it is important to note that despite the role of the REI data governance steering committee, maintaining Indigenous sovereignty is of the utmost importance and in accord, First Nations data collected through this initiative is governed by "the Health Information Governance Committee, the Chiefs mandated committee" (Shared Health, n.d.b., p.1), while data specific to individuals self-identifying as Métis and Inuit are to be governed by the appropriate body (Shared Health, n.d.b.). Since its development, the REI data governance steering committee has been diligently working to identify health outcomes to report on by REI indicators that meet the needs of community and the healthcare system, but ongoing strides to develop anti-racism data legislation are still needed in Manitoba. As exemplified by Massachusetts and British Columbia, different avenues can be taken to dismantle systemic racism in healthcare through the collection of race-based data, however it is pivotal for jurisdictions looking to implement some form of anti-racism data legislation to do so while working with community, specifically Indigenous Peoples and racialized communities to ensure the legacy of colonialism is not perpetuated through the absence of their voices.

Limitations

This study is not without limitations. First off, while a systematized review was purposefully selected due to its feasibility, this method also introduced bias as there was only one reviewer to screen titles and abstracts, review full texts and complete data extraction. In addition to this, only two databases were searched to identify articles pertaining to the topic of interest. Finally, the regulation from Massachusetts discussed in the included article and in this paper was repealed and replaced to account for a transfer of power from the Division of Health Care Finance and Policy to the Massachusetts Executive Office of Health and Human Services (Commonwealth of Massachusetts Executive Office of Health and Human Services, 2016). The regulation that replaced *114.1 CMR 17.*00 is *957.8.03(3)* and is not discussed in this study (Center for Health Information and Analysis, 2016).

Conclusion

The collection of race-based data in healthcare is considered one avenue that can be taken to dismantle systemic racism that has persisted and been brought to the forefront due to global events such as the COVID-19 pandemic (Anaduaka et al., 2024; British Columbia's Office of the Human Rights Commissioner 2020). Being able to identify and monitor health disparities through disaggregated REI data is a necessary first step when working towards health equity, and ensuring this data is governed to maximize benefit and minimize harm for racialized communities while upholding Indigenous sovereignty is key. Implementing anti-racism data legislation offers a unique opportunity to safeguard REI data for healthcare and examples from

Massachusetts, British Columbia and Manitoba highlight the complexity that accompanies undertaking this meaningful work.

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Appendix

Scopus

1 (disaggregated OR “race-based” OR racial OR ethnic OR ethnicity) W/2 data

2 legislat* OR law OR (statue OR “consolidated statute” OR “annual statute”) OR regulation OR act OR bill OR code

3 (healthcare OR “health care”) AND ((public OR community OR system OR service) W/2 health) AND ((medical OR clinical OR patient OR primary OR acute OR tertiary OR “long-term”) W/2 care)

4 1 AND 2 AND 3

HeinOnline

((disaggregated OR “race-based” OR racial OR ethnic OR ethnicity) W/2 data) AND ((legislat* OR law OR (statue OR "consolidated statute" OR "annual statute") OR regulation OR act OR bill OR code)) AND ((healthcare OR “health care”) AND ((public OR community OR system OR service) W/2 health) AND ((medical OR clinical OR patient OR primary OR acute OR tertiary OR “long-term”) W/2 care))