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Frameworks that guide race and ethnicity data collection practices in health settings: A scoping review.

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Abstract

There are disparities in the health outcomes of minority populations compared with those of the majority in Canada. Unfortunately, no detailed and representative population-level data document these disparities except for Indigenous populations. This data gap is partly due to a lack of consensus on race and ethnicity data collection standards in healthcare. This scoping review identified and synthesized evidence from frameworks for collecting patient race and ethnicity information in health settings in the US and Canada.

Twenty-three articles met the inclusion criteria. The results show limited stakeholder engagement for many of the frameworks during the development process, and the data collected using most of these frameworks were not incorporated into electronic records. The frameworks originating in Canada lacked a common reference point for racial and ethnic categories, and many of them do not collect ethnicity information. These findings are crucial considerations for governments and healthcare leaders to successfully collect, manage, aggregate, and use race and ethnicity data to address health inequities in Canada.

Keywords

Summary for Lay Audience

Due to immigration, Canada is fast becoming a vast multiracial and multiethnic society, and populations other than the White majority have poorer health outcomes. Data to show the extent of these disparities is largely unavailable except for Indigenous populations. Further, data on race and ethnicity is not typically collected within Canada's health system. This gap in data availability is attributed partly to the lack of a standardized approach to data collection.

This study identified and reviewed frameworks for collecting patient race and ethnicity information in hospitals, clinics, and public health settings in the US and Canada. The findings from the review showed that, unlike the US frameworks, the Canadian ones lack a common reference point for racial and ethnic categories, and many of them do not collect ethnicity information. Further, during the development process, many of the frameworks did not engage stakeholders and those that did, involved them in limited ways.

These findings provide a basis for consolidating race and ethnicity data collection practices and evidence for advocating to Canadian governments and healthcare leaders to standardize data collection practices within the health system. Finally, information on race and ethnicity is critical for improving population health outcomes and addressing health disparities in Canada because it facilitates evidence-based decision-making for healthcare leaders.

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Chapter 1

1   INTRODUCTION

1.1   Definition of Relevant Concepts

In this study, race, ethnicity, minority population, equity, inequity, inequality, social determinants of health, cultural competence, and humility are common terms throughout the text. Table 1 below provides a definition of each term to help readers better understand the study.

Table 1: Common study terms and their definitions

Term/Concept	Definition
Minority population	Groups of people constituting less than half of the total and whose members share common characteristics of culture, religion, language, or a combination of any of these (OHCHR, 2023)
Race	A social construct that categorizes humans based on shared physical traits (Canadian Institute for Health Information et al., 2022)
Ethnicity	A concept that refers to membership in a cultural group bound together by language, religion, and beliefs (Quan et al., 2006)
Equity	The absence of unfair, avoidable, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by sex, gender, ethnicity, disability, or sexual orientation (World Health Organization, 2019)

Inequity	The presence of unfair, avoidable, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically or by sex, gender, ethnicity, disability, or sexual orientation
Inequality	The state of not being equal, especially in status, rights, and opportunities (Alkire et al., 2016)
Social determinants of health	The non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age. They also include factors that shape the conditions of daily life—for example, social policies, social norms, economic policies, development agendas, and political systems (World Health Organization, 2023)
Cultural competence	The ability to interact with people from cultures other than one's own and treat them equitably despite cultural differences (Marc, 2010)
Cultural humility	A process of egoless openness, self-awareness, and incorporating self-reflection and critique after willingly interacting with diverse individuals (Foronda et al., 2016)

1.2   Background

While many countries are pursuing achieving Universal Health Coverage (UHC) by 2030, Canada is said to have already achieved UHC (Martin et al., 2018). UHC is a condition where all those needing health services (prevention, promotion, treatment, rehabilitation, and palliative care) can access them without undue financial hardship (World Health Organization, 2010). UHC is a critical element of sustainable development

and is included in the United Nations' Sustainable Development Goals (SDGs) as target 3.8: "Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all" (United Nations, 2015).

Canada's UHC is sponsored through the Canada Health Act of 1984. The Act outlines five principles that govern the health insurance system. These principles are universality, accessibility, portability, comprehensiveness, and public administration (Health Canada, 2015). Accessibility, universality, and portability promote the right to health. Accessibility means that there are no user costs associated with publicly insured coverage; universality ensures that access conditions are uniform for all, while portability allows residents to maintain healthcare coverage when moving within the country (Martin et al., 2018). Comprehensiveness mandates that all insured health services rendered by hospitals, doctors, and dentists must be covered by the insurance plan (Health Canada, 2015). However, despite achieving UHC in Canada, health disparities exist (Public Health Agency of Canada, 2018a), and universal healthcare cannot single-handedly mitigate them (Lacey et al., 2021).

Health disparities are usually a result of prejudiced systems. It is defined as "a difference in which a disadvantaged social group systematically experiences worse health or greater health risks than the most advantaged social groups." (Braveman, 2006). Healthcare disparities are caused by discrimination in social, political, and economic opportunities and are often high among groups that have persistently been socially disadvantaged. They are characterized by poorer health outcomes for disease incidence, prevalence, morbidity, and mortality when compared with the general population's health status (Pérez-Stable et

al., 2021). The terms health disparity, health equity, and health inequity are often used interchangeably in the literature to refer to the avoidable and unjust differences in population health.

In 2011, the World Health Organization (WHO) member states, including Canada, in recognition of inequity in health, adopted a political declaration known as the Rio Political Declaration on Social Determinants of Health (World Health Organization, 2011). The declaration signified a global political resolve to apply a social determinants of health strategy to address health inequity by enhancing capacity, evidence, and action concerning the social determinants of health and health equity (World Health Organization, 2011). Prior to this, in 2008, WHO recommended that member states develop a health equity surveillance system (Commission on Social Determinants of Health, 2008). In 2018, as a response to this call to action and recognizing that a critical step to addressing health inequity is to measure, monitor, and report it, the Pan-Canadian Health Inequalities Reporting Initiative was birthed (Public Health Agency of Canada, 2018a).

The Pan-Canadian Health Inequalities Reporting Initiative is a collaboration between the Public Health Agency of Canada, the Pan-Canadian Public Health Network, Statistics Canada, the Canadian Institute for Health Information, and the First Nations Information Governance Centre (Public Health Agency of Canada, 2018a). So far, the collaborative has produced one report - *Key Health Inequalities in Canada: A National Portrait report*. The report is Canada's first pan-Canadian effort to measure and report inequities. According to the report, there are significant health disparities among Indigenous peoples, immigrants, sexual and racial minorities, and people living with functional

disabilities. It highlights the extent and distribution of health disparities in Canada and draws information from existing surveys and hospital databases. However, the social classifications considered did not include race and ethnicity beyond those of Indigenous people and consequently has been described as limited (Freemantle et al., 2015; Smylie & Firestone, 2015).

Discrimination in healthcare

Race and ethnicity data are essential for healthcare management, and without it, the system cannot track and disaggregate differences in care for minority populations to inform improvements, pursue equity (Fremont et al., 2016), and disaggregate health outcomes by population groups so that targeted efforts can be made to address inequities. Additionally, collecting and using race and ethnicity information supports clinical practice and population health research (Anwar et al., 2014; Sheikh et al., 2023). Also, its use could improve access to health services, build cultural competence (Wang et al., 2021) and encourage cultural humility to improve patients' experiences.

Collecting race and ethnicity data within healthcare is essential to address discrimination in healthcare. Historically, in multi-racial/multi-ethnic societies, minority populations have suffered discrimination in access to, quality, and delivery of healthcare services, and this has been studied extensively (Chauhan et al., 2020; Edmonds et al., 2013; Mahabir et al., 2021; Nishino et al., 2015; Okwandu et al., 2022). It is perceived that this discrimination is partly responsible for the health disparities between Indigenous and non-Indigenous people (Wylie & McConkey, 2019).

Access discrimination

Racial and ethnic bias in healthcare has been a long-standing issue in multiracial/ethnic societies. For example, the Tuskegee syphilis study conducted by the US Public Health Service in Alabama from 1932 to 1972 ensured that Black men infected with syphilis were deliberately untreated and could not access care elsewhere (US Centers for Disease Control, 2023). In the UK, a recent report on ethnic inequalities in healthcare, commissioned by the National Health Service (NHS), detailed that the treatment of people from Black ethnic groups was notably subpar, and some of the worst disparities were observed in mental healthcare. Further, compared to White patients, General Practitioners were less likely to refer patients from ethnic minorities to the Improving Access to Psychological Therapies Initiative (Kapadia et al., 2022).

Quality of care and service delivery discrimination

In Canada, Wylie and McConkey (2019) found that discrimination and poor-quality care largely discouraged Indigenous people from accessing care. Similarly, in Mahabir and colleagues' (2021) study, racialized individuals described their healthcare experience as dehumanizing, negligent, and discriminatory (Mahabir et al., 2021). The requirement of obtaining special permission to access healthcare outside of the sub-optimal services available on reserves (Gunn, 2016) where Indigenous people reside is a typical example of discrimination because it ensures that some people who require health services cannot access them when they need them.

Additional examples include studies on pain management, which found that African Americans and Hispanics in the US may not receive proper pain management compared

to their White counterparts (Badreldin et al., 2019; Guedj et al., 2021; Johnson et al., 2019; Lee et al., 2019). This difference in care could lead to undertreatment of pain, a delay in diagnosis, and a lower quality of life for these patients. Further, a quantitative study in the US by Okwandu and colleagues found that race and ethnicity were substantially related to the likelihood of having a cesarean section. Compared to White women, all other race/ethnic groups had higher cesarean odds (Okwandu et al., 2022).

Further, a quantitative study on variations in health services utilization among ethnic populations in all Canadian provinces and territories by Quan and colleagues found that minority populations used hospitals less frequently than White people and underwent cancer screening tests less often than White people (Quan et al., 2006). Shepherd et al. (2018) assert that negative experiences in health settings shape these populations' perceptions of the healthcare system (Shepherd et al., 2018), further limiting access and health service utilization.

Race and ethnicity information in Canada

Within healthcare in Canada, race and ethnicity information is mostly unavailable, and no government mandate requires healthcare institutions or agencies to collect such information (Varcoe et al., 2009). However, some agencies identify First Nations people to whom specific policies may apply (Indigenous Services Canada, 2022). Health information is mainly obtained from hospital databases and population surveys such as the Canadian Health Measures Survey, the Canadian Community Health Survey, and the Canadian Mental Health and Access to Care Survey, among many others (Canadian Institute for Health Information, 2023; Statistics Canada, 2023). However, demographic

information available in hospital databases does not include race and ethnicity because it is not typically collected within hospital records (Canadian Institute for Health Information et al., 2022).

Since COVID-19, increased efforts have been made to collect race and ethnicity data in health in Canada (Public Health Ontario, 2021; Region of Peel, 2020; Nova Scotia Fair Care Project, 2019; CAMH, 2021; CIHI, 2022a). COVID-19 negatively impacted people worldwide, but its impact was more significant among marginalized, equity-deserving, and underserved populations (Koziel et al., 2020; KFF, 2022; Office of National Statistics, 2021). Statistics Canada also holds this assertion, especially for Alberta, British Columbia, Ontario, and Quebec (Subedi et al., 2020). Although there were siloed efforts before COVID-19, most were institutional initiatives, and the frameworks for data collection vary in components and practices. Frameworks are essential because they impact the method used to collect, analyze, comprehend, and use evidence for decision-making.

1.3   Statement of problem

In Canada, health outcome disparities have been proven to exist between Indigenous and non-Indigenous populations (Public Health Agency of Canada, 2018), and the Indigenous data is argued to be fraught with misclassification errors and non-response bias (Freemantle et al., 2015; Smylie & Firestone, 2015). However, beyond this, no detailed and representative data show the health status of other minority populations, and it is challenging to access race and ethnicity data in healthcare (Thompson et al., 2021; Thorlby et al., 2011).

In addition to the challenge of accessing data, the limited collection of demographic data beyond age and sex in the healthcare system is partly due to a lack of consensus on the standards for data collection (CIHI, 2021). The variability in data availability and data collection practices could make data aggregation difficult and limit the understanding of health disparities and their extent. This poses an issue because Canada is increasingly a multi-racial/ethnic society due to its immigration policies that welcome newcomers from all over the world, and without a standardized approach to data collection, improving health outcomes for all by addressing inequity would be challenging for healthcare leaders and governments.

1.4   Review Question

What frameworks guide the collection of patient race and ethnicity information in health settings, and what can be learned about these frameworks for the Canadian healthcare setting?

1.5   Study Aim

The study aimed to identify, compare, and contrast race and ethnicity data collection frameworks in health settings.

1.6   Study Objectives

1. To identify race and ethnicity data collection frameworks in health settings.

2. To provide synthesized information to governments and healthcare leaders on how race and ethnicity data collection practices could be standardized within the Canadian health system.

1.7   Study Significance

In addition to its Indigenous people, Canada is fast becoming a vast multi-racial and multi-ethnic society due to immigration. A report of the 2021 census revealed that there are 8.3 million immigrants in Canada. Immigrants comprise about 23% of the total population (Statistics Canada, 2022), a significant proportion. Of the total immigrant population, 60% are Asians, 13% are Europeans, 12.5% are Africans, 8% are Latin American and Caribbean, 5% are Middle Eastern, 4% are Americans, and 0.4% are Australian (Statistics Canada, 2022).

The health system can no longer understate the need for a standardized approach to race and ethnicity data collection as a component of demographic health information. This study is critical because it seeks to review existing frameworks for race and ethnicity data collection and provide a basis for a standardized approach with which to advocate for data collection and facilitate data aggregation to address existing health disparities within the Canadian health system to improve the health outcomes of all residents.

Existing race and ethnicity-related healthcare research in Canada documents public opinion and patients' perspectives about the collection of race and ethnicity information in health settings (Agic et al., 2013; Kiran et al., 2019; Kirst et al., 2013; Lofters et al., 2011; Quan et al., 2006) the opinion of healthcare workers on collecting this information

(Browne et al., 2014) and racial and ethnic disparities in disease incidence (Chiu et al., 2011; d'Entremont et al., 2023; Lacey et al., 2021). Further, there is emerging evidence of race and ethnicity data collection in healthcare settings and research (Cowden et al., 2020; Lu et al., 2022; Pinto et al., 2016). Some health research studies obtained race/ethnicity information using surname algorithms (Deb et al., 2016; Shah et al., 2010); in others, patients self-identify their race and ethnicity (d'Entremont et al., 2023). In some settings, healthcare workers assign patients' race and ethnicity (Deb et al., 2023), and there are discrepancies in available racial and ethnic category classifications. These inconsistencies in how race and ethnicity information is collected necessitate this study. This scoping review is crucial because it will provide evidence for advocacy (to governments and health leaders) and the potential standardization of race and ethnicity data collection practices within the Canadian health system.

Chapter 2

2   LITERATURE REVIEW

This chapter's purpose was to identify and include publications and grey literature relevant to the topic to ensure breadth, historical perspectives, and the current state as a foundation for the subsequent scoping review (Green et al., 2006).

2.1   Literature Search Strategy for Chapter 2

The literature search commenced with the unstructured approach. In this approach, Google, Google Scholar, and the University of Western Ontario Library databases were searched for relevant articles using "Race and Ethnicity in Healthcare." A review of the relevant articles from this search led to the development of specific phrases utilized in the structured approach. The reference lists of relevant articles were also reviewed to find additional articles relevant to the study.

In the structured approach, electronic databases such as PubMed, Science Direct, and Springerlink were searched using the following terms: "Social determinants of health," "health inequity," "health inequity in Canada," "race and ethnicity data in healthcare" "minority population health," and "Indigenous health," "Canada's health system" using the phrase searching technique. Subsequently, identified articles were reviewed, and relevant ones were included. Further, during the review process, key concepts relevant to the topic were identified from the articles and used to conduct further searches. These concepts include "cultural competence" and "cultural humility."

The search was limited to articles published in English containing information relevant to the problem statement. Preference was given to research focusing on Canada and other developed countries with multiracial/ethnic populations to support peer comparisons. All identified literature was examined, and relevant ones were retrieved for inclusion in the review. Priority was given to systematic review articles and evidence from primary research, documents, and tertiary resources (textbooks). This review identified evidence on the Canadian health system, sources of health information within the health system, race and ethnicity, race and ethnicity as social determinants of health, how race and ethnicity affect health, and race and ethnicity data collection practices in Canada and contexts similar to Canada. These topics are described below.

2.2   Canada's Health System

The Canadian healthcare system is publicly funded, and roles and responsibilities are divided between federal, provincial, and territorial governments. The federal government bears policy responsibilities for setting and ensuring the administration of policies under the Canada Health Act. It also assumes financial and service delivery responsibility for providing primary healthcare and supplementary services to First Nations people living on reserves, members of the armed forces and veterans, inmates, and refugees (Government of Canada, 2022). The provincial and territorial governments are responsible for delivering health and other social services, healthcare planning and funding, health insurance administration, health promotion and public health initiatives, and negotiation of fee schedules with health professionals. (Government of Canada, 2022).

The health system operates in accordance with the Canada Health Act of 1984 (Martin et al., 2018). The primary objective of the Act is to protect, promote, and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers (Canada Health Act, 1985) in line with the universal health coverage (UHC) concept. Further, within the Act, the federal government makes financial contributions to provinces and territories that meet the following conditions under the Canada Health Transfer:

- Health plans must be administered and operated on a non-profit basis by a public authority.

- Plans must cover all insured health services provided by hospitals, physicians, or dentists (for surgical and dental procedures that require a hospital setting).

- All insured residents must be entitled to the insured health services on uniform terms and conditions.

- Insured residents moving from one province or territory to another or temporarily absent from their home province or territory or Canada must continue to be covered for insured health services (within certain conditions).

- Plans must not impede reasonable access to insured health services.

The system is decentralized to each of the provinces and territories. It covers a specific set of services through health insurance, combining public and private funding. Through this healthcare system, Canada is said to have achieved universal healthcare (Martin et al., 2018). However, Indigenous and minority populations experience health inequities (Browne, 2017; Chauhan et al., 2020; Mahabir et al., 2021). For example, in hard-to-reach First Nation reserves and other Indigenous communities, health centers are usually

understaffed and underfunded (Nelson & Wilson, 2018). The centers have limited open hours, and the equipment required for treatment in Indigenous communities is said to be inadequate (Nguyen et al., 2020a). Further, people on reserves require permission to access care outside the reserve. This means that residents on reserves have limited access to care and are marginalized because they do not have access to care when they need it. The extent of healthcare disparity among minority populations other than Indigenous people remains unknown due to data availability gaps.

2.3   Sources of Health Information within the Health System

The Canadian Institute for Health Information (CIHI) provides data to Health Canada for decision-making in actionable and comparable forms to improve healthcare. (Canadian Institute for Health Information, 2023a). CIHI collects data on hospital care, specialized care, community care, pharmaceuticals, patient experience, the health workforce, specifically the regulated health professions, and health spending (Canadian Institute for Health Information, 2023b). Some of these data are obtained directly from healthcare facilities, the health/regional authority, or the Ministry of Health responsible for the facilities' jurisdiction in almost all provinces. The only exception to this in some instances is Quebec. CIHI receives some health data types for healthcare facilities in Quebec from the Ministry of Health and Social Services (Canadian Institute for Health Information, 2023b).

Most of the healthcare information in Canada is generated at the hospital level, and data collection methods within hospitals vary (Canadian Institute for Health Information, 2023b). However, population surveys such as the Canadian Health Measures Survey, the

Canadian Community Health Survey, and the Canadian Mental Health and Access to Care Survey, among others, are additional sources of health information (Canadian Institute for Health Information, 2023; Statistics Canada, 2023).

At the hospital level, some information is obtained from electronic medical and health records (EMR & EHR). EMR and EHR are computerized systems that store medical information (Heart et al., 2017). The EMR is considered an internal system within practices, whereas the EHR is an inter-organizational one where patient information is accessible across providers (Heart et al., 2017). EMRs and EHRs collect and store data on medical history, patient consultation reports, laboratory reports, diagnostic imaging reports, medication information, and patient demographics. However, race and ethnicity data are not collected as part of patient demographic information (Canadian Institute for Health Information et al., 2022; Blair et al., 2021; Velmurugiah et al., 2022). This presents a gap in healthcare management because it limits the ability of the system to identify inequities and track and disaggregate health outcomes for population groups to inform interventions for health improvement.

2.4   Race and Ethnicity

Race and ethnicity are crucial social stratifications that have permeated health. In the 18th and 19th centuries, European scientists classified human populations based on physical attributes such as skin color, facial features, and hair color. This classification led to the social development of the idea of race (Hudson, 1996), and it was used to justify the suppression, exploitation, and colonization of non-Europeans (Hudson, 1996).

Although race was previously perceived in Western medicine as a biological characteristic connected to innate differences in health outcomes (Fine et al., 2005), some geneticists have proven that race is not based on biology but is misattributed to it. Several studies have concluded that race is not a biological or genetic categorization (Collins et al., 2003; National Human Genome Research Institute, 2003; Templeton, 2013). While there are marked physical variations among human populations, these variations are said to be more a function of natural selection and adaptation to various settings than the product of clear genetic distinctions between racial groups (Tishkoff & Kidd, 2004). Genetic research has also shown that genetic variation is often more significant within racial groups than between groups (Pearce et al., 2004). However, to this day, race continues to be contentious in healthcare.

Anthropologists believe that race is a social construct and that interbreeding among different species whenever they come into contact propagated the sharing of genetic materials, which has maintained all of humankind as a single species (American Anthropological Association, 1998). This position agrees with the opinion that human variation is continuous, and there is no clear designation of where a race ends and another begins (Audrey Smedley, 1998; Goodman, 2000).

Nevertheless, there are two leading schools of thought regarding race in healthcare. One school argues that race helps identify health disparities and develop targeted interventions. The other argues that it is a flawed and imprecise concept that can perpetuate harmful stereotypes and biases (Citrin & Modell, 2014; Goodman, 2000; Reich, 2018). Racialization is "the extension of racial meaning to a previously racially unclassified relationship, social practice, or group" (Omi & Howard, 2014, p.111). It can

be conceptualized as othering to place oneself within existing social structures and to offer cues that direct our interactions with other people and groups (Omi & Howard, 2014). Racialization benefits White people and harms Indigenous and other racialized populations (National Collaborating Centre for Determinants of Health, 2017). This research work is in line with the former school of thought that believes that race is useful for improving health inequity and, consequently, health outcomes because race, a social construct that is a social determinant of health, greatly affects the minority population's access to healthcare, utilization of health services and the quality of care that they receive (Nelson & Wilson, 2018; Quan, Fong, et al., 2006; Thorlby et al., 2011). In minority populations, discrimination in healthcare based on race has led to mortalities, reduced quality of life, and life expectancy.

Race and ethnicity are often used together and interchangeably. However, they have distinct meanings. Race is a social construct often used to categorize people based on differences in physical attributes such as skin color and hair type (Canadian Institute for Health Information et al., 2022). Further, an individual's race has been described as of two types: reflected and self-expressed (Veenstra, 2011). Reflected racial identity is the racial identity that individuals think other people generally see them as, while self-expressed racial identity is what an individual professes to be (Veenstra, 2011). These racial identity types have been found to be a mismatch for many self-expressed Black and South Asian people. It also corresponds with a high risk of poor health outcomes, especially for people who self-express as White (Veenstra, 2011).

On the other hand, ethnicity is a concept that refers to membership in a cultural group bound together by language, religion, and beliefs (Quan et al., 2006). For example,

Vietnamese, Chinese, Korean, and Cambodian peoples can be seen as Asian. But they represent different ethnic groups. Cornell and Hartmann (2007) define an ethnic group as "a collectivity within a larger society having a real or putative common ancestry, memories of a shared historical past, and a cultural focus on one or more symbolic elements defined as the epitome of their peoplehood" (p. 19). Further, ethnicity refers to clusters of people sharing common cultural characteristics like religion, language, customs, and nationality that distinguish them from others (Smedley & Smedley, 2005). These definitions show that an individual's race is not necessarily the same as their ethnicity. For example, a person who identifies as Black could be Arab. Therefore, recognizing and accounting for these differences within healthcare is critical for improving health outcomes by addressing disparities.

Ethnicity impacts people's beliefs: In some cultures, it is established that wellness and illness of the body are related to the mind. For example, some Indigenous cultures believe in the interconnectedness of all aspects of life, including the mental, physical, spiritual, and emotional, as depicted by the Indigenous Medicine Wheel (Orr et al., 2023). Illness is frequently understood to be the outcome of an imbalance or disharmony in this interrelated system, and healing entails addressing all these parts. The mind and body are not viewed as separate in these cultures, unlike in Western medicine (Marc, 2010), and these perceptions are useful for equitable healthcare planning and delivery (Green et al., 2021).

Canada's population is becoming increasingly diverse. A report of the 2021 census revealed that immigrants make up a significant part of the population (23%), and the majority are from Asia, Africa, Latin America, the Caribbean, and the Middle East

(Statistics Canada, 2022). This indicates that a significant percentage of the population is of a racial and possibly ethnic minority; therefore, collecting race and ethnicity data in the health system is pertinent to ensuring and improving positive health outcomes for all. Further, according to the 2023-2025 immigration level plan, the government will welcome about 1,450,000 permanent residents (Government of Canada, 2022). Based on previous statistics, most of these individuals are minorities in Canada. Therefore, race and ethnicity data collection standards must be reviewed, defined, and standardized to facilitate data availability and ensure health equity for all.

2.5   Race and Ethnicity as Social Determinants of Health

Race and ethnicity are social determinants of health. The World Health Organization defines social determinants of health as the non-medical factors that impact an individual's health outcomes (World Health Organization, 2023). These factors include income, education, housing, food security, access to health services, gender, physical environment, culture, and race/racism (Canada Public Health Services, 2023; World Health Organization, 2023).

Racism in healthcare has been shown to exist (Mahabir et al., 2021; Weerasinghe, 2012; Wylie & McConkey, 2019a). It can be experienced individually (Paradies et al., 2015). It could also be interpersonal or structural (Paradies et al., 2015). Structural racism is "the macro-level systems, social forces, institutions, ideologies, and processes that interact with one another to generate and reinforce inequities among racial and ethnic groups" (Powell, 2008 in Gee & Ford, 2011). Therefore, structural racism could be perceived as central and at society's core. Gee and Ford (2011) liken structural racism to the unseen

portion of an iceberg and assert that it is more dangerous than that which is seen and difficult to eliminate (Gee & Ford, 2011). An example of structural racism in today's world is the racial profiling of Black men in the US and Canada by the criminal justice system, which reflects discriminatory policing and sentencing patterns (Braveman et al., 2022; McKay, 2021). In healthcare, racial profiling of Indigenous people led to the death of Joyce Echaquan, who allegedly received too much morphine, to which she was allergic, causing her to die of pain in the hospital (CBC News, 2020)

The prominent difficulty with accessing race and ethnicity data within the health system in a racially and ethnically diverse population such as Canada is akin to structural racism. Figure 1 below is a common framework of the social determinants of health developed by Solar & Irwin (2010) and adopted by the WHO (World Health Organization, 2019). It shows the different types of social determinants of health and their relationship. This framework has since been used in various health systems, including Canada's.
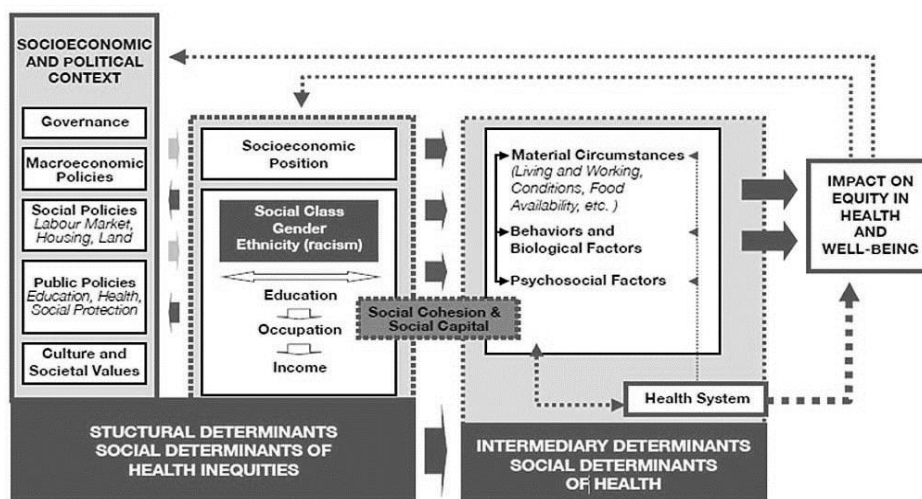
Figure 1: A conceptual framework for action on the social determinants of health

Within the framework, ethnicity and race interact with living and working conditions, psychosocial factors and behaviors, and biological factors to impact health and well-being because they affect social cohesion and social capital. The impact could be negative or positive depending on structural determinants such as governance, economic, social, and public policies. To fully realize the right to health, disparities in health and living conditions must be identified and eliminated (World Health Organization, 2019), and without the data, it could be impossible for governments and institutions to do so. Further, to address inequity through system efforts, there is a need to standardize data collection tools and practices to ensure the possibility of data aggregation on a larger scale. However, identifying existing frameworks that guide data collection in healthcare is the first step.

The inadequacy of data disaggregated by race and ethnicity in the health system puts patients from minority populations at a disadvantage, putting them at risk of experiencing inequity in health care because, without this information, health service delivery and practice decisions could be inadequately informed, thereby maintaining or even widening any existing health disparities. This is evidenced in systematic reviews and meta-analysis studies that have shown that there is a relationship between racism and health outcomes (Paradies et al., 2015; Pascoe & Richman, 2009). The established relationship between racism and health outcomes further underscores the significance of examining how race and ethnicity data are collected in healthcare settings to address racial inequities in Canadian healthcare.

2.6   How Race and Ethnicity Affect Health

Race and ethnicity can affect access to health services, utilization of health services, and the quality of care obtained by minority populations. Quality of care is often used as a metric in health service delivery. It encompasses effectiveness, safety, and people-centeredness in healthcare delivery. It may be assessed through an equity lens with the expectation that care provided does not vary in quality due to ethnicity, gender, geographic location, and other socio-economic status (WHO, 2022).

Additionally, epidemiological and genetic research have demonstrated the hereditary nature of some health issues specific to certain populations. Examples are thalassemia and sickle cell anemia, which are prevalent in North African people (Anwar et al., 2014). Mass migration of people from this part of the world has the potential to redefine disease endemicity in other parts of the world where this disease was previously non-existent. So, unless race and ethnicity information are deliberately collected in a way that ensures comparison across the board, the health system may not be able to work towards meeting the population's health needs.

In access to healthcare, differences in access to health services and health outcomes relative to race and ethnicity have been studied extensively in developed countries (Boghossian et al., 2019; Edmonds et al., 2013; Kapadia et al., 2022; Nishino et al., 2015; Okwandu et al., 2022). Most of the findings from these studies show that Indigenous, Black, Asian, and Hispanic people have poorer access to health care and are less likely to access it than White people.

Several studies have also established variability in the quality of care minority populations receive (Chauhan et al., 2020; Higginbottom et al., 2016; Mahabir et al., 2021). Research on patient safety suggests that patients from minority groups are at higher risk of patient safety events such as treatment complications, adverse drug events, dosing errors, and hospital-acquired infections than the broader population (Chauhan et al., 2020). This emphasizes how crucial it is to collect racial and ethnic data for inequity surveillance to ensure that receiving high-quality healthcare is not a privilege enjoyed exclusively by the White population.

The impact of ethnicity on health service access and utilization is exemplified in a descriptive study on race and ethnicity in pediatric obsessive-compulsive disorder (OCD). The study found that Asian youth reported significantly later ages of OCD symptom onset, clinical diagnosis, and treatment than Caucasian youth and were considerably less likely to participate in OCD-specific treatment despite similar clinician recommendation rates (Wang et al., 2021). Further, in a quantitative study on variations in health services utilization among ethnic populations in all Canadian provinces and territories, Quan and his colleagues found that minority populations used hospitals less frequently than White people and underwent cancer screening tests less often than White people (Quan, Fong, et al., 2006).

In the Public Health Agency of Canada's 2018 report on crucial health inequalities, life expectancy and health-adjusted life expectancy were consistently lower in areas populated with First Nations, Inuit, and Métis people (Canada Public Health Agency, 2018). However, there is no information on other minority ethnic groups in Canada. Further, some Indigenous researchers argue that the categorization of Indigenous peoples

into First Nations, Métis, and Inuit is inadequate and ignores a vast amount of cultural variation (Nelson & Wilson, 2018). To address inequities wholistically in Canada, the health outcomes of racial and ethnic populations other than the majority must be accounted for, and to account for this, race and ethnicity information should be collected in health settings in a standardized format.

Weerasinghe (2012) found that visible minority immigrant women in Nova Scotia faced racism in healthcare settings, which affects their access to healthcare and the quality of care that they receive (Weerasinghe, 2012). Also, Mahabir and colleagues found unequal medical care through negligent communication, professional misconduct, and unequal access to health and health services when they interacted with minority populations on their experiences with racism in Toronto's healthcare system (Mahabir et al., 2021). In Alberta, Higginbottom and colleagues (2016) found that migrant women faced structural barriers, such as discrimination, lack of informed consent, and immediate discharge, among others, in maternity care (Higginbottom et al., 2016). All these experiences affect an individual's care-seeking behavior and ultimately affect their health outcomes.

The most recent perspective on how race and ethnicity affect health is from COVID-19. COVID-19 statistics showed that racial and ethnic minorities were disproportionately affected in multi-racial/ethnic societies such as England and the US (KFF, 2022; Office of National Statistics, 2021). In England, all ethnic minority groups other than the Chinese had high death rates in males and females (Office of National Statistics, 2021). In the US, Black, Hispanic, American Indian, and Alaska Native (AIAN), and Asian, Native Hawaiian, and Other Pacific Islander (NHOPI) people experienced higher rates of

COVID-19 cases and even deaths than White people when data are adjusted to account for differences in age by race and ethnicity (KFF, 2022).

According to Statistics Canada, the results are similar in Canada, especially in Alberta, British Columbia, Ontario, and Quebec (Subedi et al., 2020). However, this evidence was derived using neighborhood diversity as proxy data (Subedi et al., 2020). Further, results from a study by Statistics Canada on COVID-19 mortality among the racialized population found that the mortality rate was nine times higher for racialized populations in comparison to the non-racialized and non-Indigenous populations (Gupta & Aitken, 2022). These results were produced from the Canadian Census Health and Environment Cohorts (CanCHECs) datasets by linking census respondents to the Canadian Vital Statistics Death Database (Subedi et al., 2020), not race and ethnicity data collected in healthcare settings. Nevertheless, these findings reflect health disparities influenced by socioeconomic variables like housing, income, employment, and education. Minority populations are more likely to face poorer living and working situations like lower salaries, crowded housing, unstable jobs, and limited access to health services, all of which could increase their susceptibility to COVID-19 (Public Health Agency of Canada, 2021).

The inadequacy of race and ethnicity information means that disease prevalence and mortality may be inadequately accounted for, thus underestimating the necessary action needed to address health inequity. For example, in Ontario, a Canadian province with the highest number of racialized individuals (Statistics Canada, 2023), some of the COVID-19 data collected lacked person-level race and ethnicity data. Although on June 26, 2020, race-based data were asked to be reported within Ontario's case and contact management

systems, 43% of all reported cases between June 2020 and April 2021 did not include data on race and were therefore excluded (Ontario Health, 2022). Forty-three percent is a significant figure, and even more so regarding lives. Without a doubt, the availability of person-level race and ethnicity data in the heat of the pandemic would have facilitated the analysis of COVID-19 impact and promoted evidence-based corresponding action, barring proxies.

Further, according to the Canadian Institute for Health Information, the limited collection of demographic data beyond age and sex in the healthcare system is partly due to a lack of consensus on the standards for data collection (CIHI, 2021). Considering these, this study, through the synthesis of evidence on data collection frameworks, will provide evidence on what exists, which could serve as a basis for how to move forward on consensus building for standardization. The standardized collection and subsequent use of race and ethnicity information is crucial in medicine and public health because both concepts are related to the social determinants of health and have implications for healthcare access, health service utilization, and the quality of care obtained in healthcare settings, especially for minority populations.

The race and ethnicity of the patient and the healthcare provider's cultural competence work in tandem to affect health. This functions such that the provider's cultural competence could positively impact known personal barriers to healthcare access, such as cultural beliefs and even communication for racialized people (Truong et al., 2014). Cultural competence is the ability to interact with people from cultures other than one's own and treat them equitably despite cultural differences (Marc, 2010). Accounting for this difference, for example, would require healthcare workers who understand what

illness and wellness mean to people from different cultures within different contexts to promote equitable access to care.

Beyond cultural competence, cultural humility - a process of egoless openness, self-awareness, and incorporating self-reflection and critique after willingly interacting with diverse individuals is being advocated in healthcare to recognize the discrimination experienced by minority populations based on race and ethnicity (Foronda et al., 2016). Cultural humility entails a power-balancing act whereby those of higher power must attempt to be humble (Foronda et al., 2016). Both cultural competency and humility are valuable skills for interactions in healthcare settings. They could facilitate the collection of race and ethnicity data.

2.7   Race and Ethnicity Data Collection Practices in Contexts Similar to Canada

In the US and the UK, race/ethnicity data is reported in healthcare. In the US, data on race/ethnicity is collected from patients during clinic visits and hospitalizations and grouped as follows: Asian, Black, Hawaiian, multiracial, American Indian/Alaska Native, Pacific Islander, Hispanic, Unknown/Other, and White categories (Okwandu et al., 2022). The data collected are used for research, hospital-based quality improvement, and monitoring health outcomes. The collection and use of ethnicity data in the US have progressed with the introduction of cultural competence in medicine. It has also been promoted by the Department of Health and Human Services (Marc, 2010; US Centers for Disease Control, 2019). Techniques such as interpreter services, health worker recruitment and retention policies, training, health promotion, and administrative and organizational accommodation have been employed to decrease racial and ethnic

disparities by monitoring ethnic inequalities within the health system (Marc, 2010; US Centers for Disease Control, 2019).

In the UK, data on patient ethnicity diversity is collected in General Practice (GP) electronic systems and hospital episode statistics. The data is used for local and national monitoring reporting for effective commissioning, monitoring of health outcomes, and addressing health inequalities (National Health Service, 2022). There are standard diversity categories used within the UK health system. Some systems use the 2001 and 2011 categories. However, these categories cover White, Asian, Black, Chinese, Arab, Gypsy, African, Caribbean ethnicities, and Other drawn from the periodic census (Pineda-Moncusí et al., 2022; UK Government, 2022).

2.8 Some efforts made to collect Race and Ethnicity data within the Canadian health system

In Canada, no specific laws or policies mandate reporting race and ethnicity data in healthcare (Blair et al., 2021). As such, health authorities, provinces, and health facilities often do not request this information from patients/clients. Within private practice, these data are also not commonly collected. The importance of population-specific considerations in healthcare planning, delivery, and monitoring cannot be overemphasized, and there is a demonstrated and recognized need for collecting these data (Allen et al., 2021; Ontario Health, 2022; Thompson et al., 2021; Yousif, 2021). An example is the use of self-reported race data collected by the Center for Addiction and Mental Health (CAMH). CAMH found that Black patients were restrained 44% more than White ones and 22% more than all patients. In recognition of this inequity and

others, CAMH resolved to develop an anti-Black racism strategy to address the issues (Yousif, 2021).

Health organizations and provincial governments have recognized the overwhelming need to collect information on race and ethnicity in Canada in recent years. They have begun considering and developing projects and tools to address racial disparities in healthcare and, in some cases, implement race and ethnicity data collection. Collecting race and ethnicity data in healthcare would be an action towards reconciliation. This is because the data will support deliberate efforts to close the gap in health outcomes between Indigenous and non-Indigenous communities, as requested by the Truth and Reconciliation Committee. Call to action 19 states:

> "We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities and to publish annual progress reports and assess long-term trends. Such efforts would focus on indicators such as infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services." (Truth and Reconciliation Commission of Canada, 2015, p.322).

Therefore, synthesizing evidence on frameworks employed so far to provide a way forward for charting the future is crucial to ensure data collection and reporting uniformity.

In 2016, the Mental Health Commission of Canada (MHCC) identified the urgent need to develop mental health services to meet the needs of immigrant, refugee, ethnocultural, and racialized (IRER) populations living in Canada. Stakeholders told the MHCC they needed evidence of what was working nationwide to provide better services and support for IRER populations. This birthed "The Case for Diversity" project. The project has identified policies, programs, treatments, and supports capable of effectively addressing disparities in mental health service delivery in Canada (McKenzie et al., 2016).

The Department of Health and Wellness Nova Scotia is collecting race-based data through the "Race-based data in Healthcare: Fair Care Project" using a standard for self-identification proposed by the Canadian Institute for Health Information. The province collects the data voluntarily from people when they renew their health cards, register a birth, or go online whenever they want to share this information. Although the data collected does not include ethnicity, it is a good step in the right direction (Government of Nova Scotia, 2022).

The Canadian Institute for Health Information has supported the development of standards for health inequality measurement by creating a tool kit. They have also developed a Pan-Canadian Primary Health Care EMR Minimum Data Set for Performance Measurement, and the standard includes race as a core data element and ethnicity as a supplementary one (Canadian Institute for Health Information, 2022). Further, the institute has developed a document for developing race-based and Indigenous identity standards in consultation with relevant stakeholders such as clinicians, Indigenous organizations, organizations representing racialized groups, government representatives, and researchers (Canadian Institute for Health Information et al., 2022).

Pursuing equity in healthcare in a multi-racial/cultural society like Canada requires collecting and using accurate information on similarities and differences in health status and healthcare utilization disaggregated by characteristics such as race and ethnicity in a standardized format that supports aggregation. Some studies document the importance of race and ethnicity considerations in healthcare in Canada and the potential benefits and possible harm (Gunn, 2016; Pinto et al., 2023; Varcoe et al., 2009; Wylie & McConkey, 2019). However, the benefits are far-reaching, and reviewing current frameworks for collecting this information in healthcare settings is a crucial step and a gap that this study attempts to fill.

Chapter 3

3   METHODOLOGIES

3.1   Introduction

This research study employed a scoping review methodology guided by Arksey and O'Malley's Scoping Review framework (2005) with guidance from an updated version by Levac and colleagues (Levac et al., 2010) and the Preferred Reporting Items for Systematic Reviews and Meta-analyses Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). A scoping review is a method used to identify topical knowledge gaps, the application of concepts and terminology, research priorities, and knowledge for decision-making (Peters et al., 2021; Tricco et al., 2016). It is also used to determine the essential attributes associated with a concept (Munn et al., 2018).

The selection of a scoping review, a distinctive evidence synthesis method, as the preferred method, was driven by the research question's unique requirements. The research question was: *What frameworks guide the collection of patient race and ethnicity information in healthcare, and what can be learned about these frameworks for the Canadian healthcare setting?* This question is broad and requires the identification of the available frameworks and a determination of the key components of the framework. This method not only allows for a comprehensive description of the components of the standards that guide the collection of patient race and ethnicity information in health settings but also plays a crucial role in analyzing existing frameworks, thereby providing valuable insights for future practice (Peters et al., 2021).

Further, a scoping review was employed because the study does not aim to make any conclusions, unlike systematic reviews, which aim to use explicit methodical techniques to reduce bias to produce more trustworthy results from which judgments and conclusions can be reached (Higgins et al., 2023). This research aims to identify, compare, and contrast existing race and ethnicity data collection frameworks in health settings; therefore, a systematic review was inappropriate. Scoping reviews are ideal for identifying the evidence available on a topic and the associated critical components (Tricco et al., 2016). Thus, a scoping review supports the aim of this research.

A scoping review was suited for the study because the research question is broad (Tricco et al., 2018). Its output targets government users, policymakers, and other knowledge users who may not have the time, skill, or means to synthesize evidence independently and where multiple study designs might apply (Tricco et al., 2016; Arksey & O'Malley, 2005). Additionally, scoping reviews are appropriate for complex knowledge areas or areas not previously thoroughly examined (Mays, Roberts, & Popay, 2001, p. 194 in Arkey & O'Malley, 2005). To the best of the researcher's knowledge, the study topic has yet to be explored comprehensively, and no other completed reviews of the topic have been identified. In this study, a framework is defined as "a set of assumptions, concepts, values, and practices" (Binder et al., 2013, p. 2).

3.2   Researcher Positionality

To demonstrate reflexivity, the researcher must clearly state their positionality, reflecting on their material and social location in the world and how it relates to the study (Finlay, 2005, p.537). I come to the study as an "insider" and an "outsider." As an outsider, I have limited experience and interactions with multiracial health systems. I have lived in

Canada for less than two years, worked within the health system for about eight months, and had three patient-provider encounters with physicians at two walk-in clinics.

As a member of a visible minority group (African) in Canada, I bring a unique perspective to the study. This insider position, i.e., my identity as a racialized person, my awareness of the social determinants of health that affect populations, and my role as a student researcher in health information science, placed me in a good position to research the topic. However, I do not view myself as an expert but as a knowledge facilitator. Acknowledging my identity and role and how both may influence the research process, I employed reflexivity to examine my biases, especially as a person from a minority population, and how this influenced reporting (Bukamal, 2022). This transparency in my positionality is crucial for the trustworthiness of the research.

My interest in the research topic is not purely academic but also personal. It was borne out of dismay, which stemmed from the lack of evidence for why the Canadian health system did not typically collect patient race and ethnicity information. Although I found that efforts had been made to advance race and ethnicity data collection practices, they appeared fragmented, experiencing inertia and constraints. This personal connection to the topic fuels my determination to contribute to the understanding and improvement of race and ethnicity data collection in health settings.

3.3   Methods

This study adhered to the five-stage process of conducting scoping reviews described by Arksey and O'Malley (2005) in their scoping review framework utilizing recommendations from an updated version by Levac and colleagues (Levac et al., 2010).

The framework guided data collection, data analysis, and data collation through the following five stages:

- Stage 1: Identifying the research question

- Stage 2: Identifying relevant studies

- Stage 3: Study selection

- Stage 4: Charting the data

- Stage 5: Collating, summarizing, and reporting the results

3.3.1 Stage 1: Identifying the research question

The research question was identified in this stage to guide the review process. The study's research question is: *What frameworks guide the collection of patient race and ethnicity information in healthcare, and what can be learned about these frameworks for the Canadian healthcare setting?* This review question is in tandem with the study's aim, and the rationale for the study hinged on a lack of detailed and representative health data for minority populations and the lack of demographic information beyond age and sex, attributed to a lack of consensus on the standards for data collection (CIHI, 2021). Further, this review question was decided because of its relevance to the ongoing interest of governments and health institutions in addressing inequity in healthcare since COVID-19 (Abdi et al., 2021; Government of Nova Scotia, 2022; Ottawa Public Health, 2020; Shared Health Manitoba, 2020).

The review question is broad, and the decision to maintain a broad approach is in line with Arksey and O'Malley's (2005) recommendation that scoping reviews should ensure

a broad review question that can cover a wide range that could impact the second stage (Arksey & O'Malley, 2005).

3.3.2   Stage 2: Identifying relevant studies

This stage began with a consultation with a health sciences librarian to identify and develop a search strategy that includes keywords and concept terms. A preliminary literature search was conducted, and the search terms were further defined to ensure a robust search. The preliminary search helped determine whether a scoping review on the topic had been conducted, whether there was enough information to support a scoping review, and the breadth of the review question (Mak & Thomas, 2022). The keywords employed were generated in line with study-related concepts identified during the preliminary search. Table 2 below provides details of the concepts and keywords mapped to each.

Table 2: Keywords and concepts employed for electronic search

S/N	Concept	Keywords
1.	Health information	- Demographic data - Sociodemographic information - Framework - Standards - Health record - Data quality - Health system - Hospital
2.	Data collection	- Survey - Question - Script - Questionnaire - Poll - Self-report - Health record

3.	Equity	- Race - Ethnicity - Minority - Indigenous

According to Arksey and O'Malley (2005), the goal of a scoping review is to be as detailed as possible in finding reviews and published and unpublished primary studies that can answer the research question. The concept and keyword mapping were completed to facilitate subsequent comprehensive electronic database and reference list searching. These words and concepts were identified in the literature and during the preliminary search. During the initial exploration, the librarian advised on relevant databases to search relative to the topic and how to conduct the searches using the keywords and concepts.

The keywords and concepts outlined in Table 2 were used to systematically search electronic databases that could contain valuable publications that can answer the research question. The electronic databases searched included Medline (Ovid), Scopus, and Web of Science. These four databases are multidisciplinary sources and provide a helpful combination of sources for health and social sciences (Heath et al., 2022), both of which are relevant areas to the topic. To conduct the search, a combination of keywords, concepts, and Boolean operators were employed to improve search sensitivity and ensure that all relevant publications were pulled.

The electronic search for this study began in March 2024 and ended in May 2024. All electronic databases were accessed through the University of Western Ontario library. All search strategies employed are presented in Appendix A. The reference list of all relevant

publications was also searched. This process, called citation chaining, was completed to identify additional relevant publications (Pawliuk et al., 2021).

Grey literature from government websites, healthcare organizations, and health information organizations pertinent to the research topic were included (e.g., Black groups and Indigenous health authorities). The literature referencing their work on race and ethnicity data collection and a Google search informed the decision to include these organizations' resources. These websites include the Canadian Institute for Health Information, the Centre for Addiction and Mental Health (CAMH), McKenzie Health, Wellesley Institute, the Indigenous Health Authority, The Black Health Equity Group, the Nova Scotia Government, and the Government of Manitoba. Search terms used included "race-based data," "race and ethnicity," and "demographic information."

3.3.3   Stage 3: Study selection

Predetermined study eligibility criteria were applied in this stage of the study (Arksey & O'Malley, 2005). These criteria included the type of study, study setting, and publication language. Eligibility criteria definitions include: i) primary studies, ii) review articles, iii) healthcare setting-related publications, iv) publications that include frameworks or other recommendations on race and ethnicity data collection, and v) publications in the English language. Therefore, primary studies and review articles that collected race and/or ethnicity information in a healthcare setting and published in English were selected and included in the study.

Electronic databases were searched from inception. No publication year limit was applied deliberately to support the capture of relevant publications in their entirety because the

year of publication had no bearing on the scope of the review question. Further, the year limit was not applied to allow the comparison of collection standards by time periods to observe differences there have been, if any. While no geographical limitation was applied during the search, it was anticipated that articles would come from the US, UK, Canada, and New Zealand.

Covidence, a screening and data management software for systematic reviews (Covidence, 2024), was used to organize and screen all publications identified in Stage 2. The researcher and Sherrif Ibrahim (SI), who served as a second reviewer to demonstrate rigor and enhance study reliability, completed the publication screening independently. The screening process commenced with removing duplicates among the publications identified, followed by title and abstract screening to remove irrelevant publications. Finally, the full-text screening relied on the established inclusion criteria to ensure publication relevance and inclusion data extraction. Based on the study eligibility criteria, the researcher and SI documented the reason (s) for full-text exclusion in Covidence. All screening discrepancies were discussed and resolved. The PRISMA flow diagram, which provides a visual depiction of the flow of publications through the various stages of the review process, is documented in Chapter Three.

3.3.4   Stage 4: Charting the data

This stage can also be referred to as the data extraction stage. The researcher completed data extraction using a structured data charting table (the data extraction tool) developed in Excel with input from the thesis advisory committee to extract relevant information systematically. The tool was developed to facilitate standardized comparison across all publications included in the study and enhance study utility (Arksey & O'Malley, 2005).

The tool was recorded on Covidence and used therein. It contained information about the article's characteristics, framework attributes, framework components, and framework transferability. Article characteristics were included per recommendations from Arkey and O'Malley (2005) and Tricco and colleagues (Tricco et al., 2018). The researcher deemed all other components essential to extract to answer the research question (Levac et al., 2010). The choice of Covidence for data extraction is due to its ease of use and data management capability (Elamin et al., 2009).

The following information was extracted from articles and grey literature using the data extraction tool:

1. Characteristics of the articles included:
   a. Title of the article
   b. Type of article (review or primary)
   c. Name of framework/standard
   d. Author(s)
   e. Year of publication
2. Context of the article
   a. Framework has been applied (yes/no)
   b. Application type (pilot/full implementation)
   c. Race and ethnicity is defined (yes/no)
3. Attributes of the framework:
   a. Rationale for framework development
   b. Theoretical influence
   c. Stakeholders engaged in development: (yes/no)
   d. Country of application
   e. Type of health setting
   f. Level of application (micro/mezzo/ macro)
   Micro: Departmental within a health setting or setting-wide use
   Mezzo: community level

Macro: region, state-wide, or country-level

4. Description of components:
   a. Tool type (paper-based/electronic)
   b. Tool administration (self-administered/administered)
   c. Question type (short answer/multiple choice/open-ended/closed-ended)
   d. Ability to select multiple options (yes/no/not applicable)
   e. Response type (mandatory/voluntary)
   f. Race categories (where listed or referenced)
   g. Ethnicity categories (where listed or referenced)
   h. Point of data collection
   i. Data collected is integrated into EMR/EHR (yes/no/not stated/not applicable)
5. Transferability
   a. Framework is transferable according to the author(s) (yes/no/not stated)

Attributes of the framework were selected for extraction because 3 a and b could promote knowledge of the theories pertaining to health inequity. Further, 3 a, b, d, and e could influence how data is collected. 3 c could provide insight into the framework development process, and 3 d and f could provide additional insight into the components. All this information is also useful for making standardization recommendations.

The researcher conducted a pilot extraction of one article, and the thesis advisory committee reviewed the extraction and provided feedback. The feedback provided was then used to refine the data extraction tool, and subsequently, extraction was completed for all screened articles included in the review. A sample of the data extraction tool can be found in Appendix B.

3.3.5   Stage 5: Collating, summarizing, and reporting the results

The data extracted were analyzed and presented quantitatively as descriptive aggregates and qualitatively through short descriptions (Levac et al., 2010). However, the findings are highlighted where there are significant differences between the findings from grey literature and published articles. Levac and colleagues (2010) opine that this stage should be undertaken in three separate steps as follows: i) analysis, ii) results reporting, and iii) consideration of study findings relative to the purpose of the study (Levac et al., 2010). Although Arksey and O'Malley's (2005) framework includes an optional stage that involves consultation with practitioners and end-users to enhance the utility of the study results, this stage was not completed because of time constraints.

3.3.5.1   Analysis

Characteristics of the included publications, such as type and year of publication, and framework attributes, such as stakeholder engagement in its development, application level, response type, question type, tool administration, and country of application, were summarized descriptively by counts and percentages. At the same time, all other information extracted was categorized into characteristics, context, attributes, description of components, and transferability. These were eventually grouped into *processes* and *practices* for the discussion.

The decision to categorize data was influenced by the review question and existing literature that establishes various data collection processes and practices even within the Canadian health system—the context in which the researcher hopes the results of this study will support advocacy for standardized race and ethnicity data collection. Further, the categorization will enhance visibility into the multiple processes and practices that

exist, providing evidence simultaneously for how to collect race and ethnicity information in health settings and a need for standardization.

3.3.5.2   Results Reporting

Study results were reported according to the PRISMA Extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). Details include a PRISMA flow diagram that details the number of sources of evidence screened and the number of publications accessed for eligibility and included in the review. Also reported are extracted data and their citations, descriptions of the findings, and a summary of the data as they pertain to the review question and study objectives (Tricco et al., 2018; Levac et al., 2010).

3.3.5.3   Consideration of study findings relative to the purpose of the study

As suggested by Tricco and colleagues (2018), significant findings will be summarized in connection with the review question, study objectives, and relevance to knowledge users. The summary will include an overview of concepts, themes, and evidence types (Tricco et al., 2018). Further, considering study findings relative to the study purpose will strengthen its validity and implication for policy and practice (Levac et al., 2010).

3.4   Rigor

As Lincoln and Guba (1985) established, credibility, dependability, confirmability, and transferability are the operational techniques that support research trustworthiness. Credibility in this study was established through a thesis advisory committee, including a second reviewer during article screening and the researcher's positionality statement (Shenton, 2004).

The thesis advisory committee comprised experienced researchers and subject matter experts who acted as sounding boards and provided research advice. The researcher held meetings with members of the thesis advisory committee at all stages of the research process. In these meetings, we discussed research approaches and their potential flaws, ideas, concepts, and interpretations. The meetings facilitated deep thought on the research methods, the rationale for the data points extracted, the design of the data extraction form, and the correct use of race-related terms and terminologies. It also checked the researcher's potential biases while reporting study results. A second reviewer independently screened the articles included in the review to improve the study's credibility. The researcher's positionality explicitly stated in this chapter also supported credibility because it details my social location in the study and how I relate to it.

This study's findings are dependable because the research process is in-depth and can be repeated to achieve similar results (Lincoln & Guba, 1985). Regarding confirmability, an audit trail and triangulation are suggested (Shenton, 2004). For this study, a review management software, Covidence, was employed for data management. This enhanced the study's confirmability by leaving evidence that can be referenced and audited. Further, the study's findings were triangulated with existing literature that supports or contradicts them. For transferability, background information that establishes a knowledge gap that this study attempted to fill was provided in chapters one and two (Shenton, 2004).

3.5   Ethical Considerations

Unlike studies involving human subjects, this study did not require ethical approval for its conduct because the information used is publicly available.

Chapter 4

4   RESULTS

This study aimed to identify, synthesize, compare, and contrast race and ethnicity data collection frameworks in health settings. This chapter presents the study results guided by the PRISMA Extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). It begins with a presentation of the results of the literature search. Subsequently, the findings of this scoping review are presented under four main headings: the characteristics of the articles included in the review, the context of the articles, the attributes of the frameworks identified, and a description of their components.

4.1   Results of the Literature Search

The keywords and concepts in Table 1 in the previous chapter were used to systematically search the following electronic databases: Medline (Ovid), Scopus, and Web of Science. The comprehensive database search resulted in 591 publications. References from citation searching and grey literature yielded 16 articles: five from citation searching and 11 from grey literature. The five articles identified through citation searching were included at the title and abstract screening stage. At the same time, the 11 grey literature documents were uploaded straight to full text screening because they met the study eligibility criteria.

After removing 93 duplicates using Covidence, the researcher and the second reviewer screened the titles and abstracts of 503 articles. This led to the initial exclusion of 480 articles and the selection of twenty-three articles for a full text review. After reading the twenty-three articles' full text, twelve met the study eligibility criteria. They were

included in this scoping review in addition to the eleven grey literature articles. During

the full text review process, eleven articles were excluded due to the study type and the

lack of description of the data collection framework in the publication. This scoping

review included twenty-three articles in total. The PRISMA flow diagram (Figure 2)

below provides details of the search and selection process.
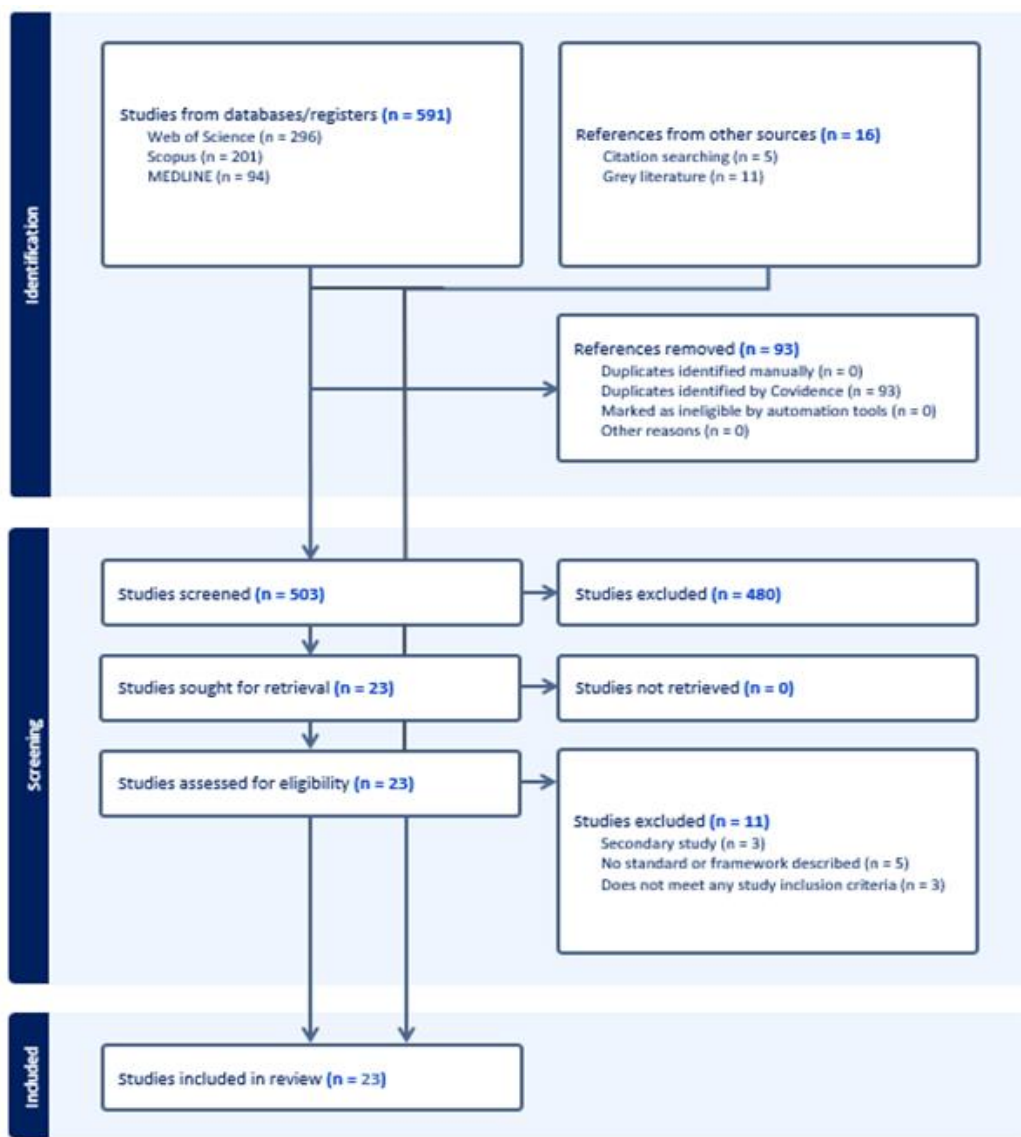
Five studies from the citation searching were included in the studies screened, while 11 grey literature articles went straight to studies included. 480 studies were excluded at the abstract screening stage.

Figure 2: A PRISMA flow diagram for a scoping review of the frameworks that guide race and ethnicity data collection in health settings

4.2   Characteristics of the Publications Included

Table 3 below provides an overview of the articles included in the review, detailing the authors, publication year, article titles, and publication type. The article ID presented in Table 3 will be used in this section and subsequent sections and sub-sections within this chapter.

Table 3: An overview of the articles included and their characteristics

Article ID	Author and publication year	Title	Publication type
1.	Abdi et al. (2021)	Provincial implementation supports for socio-demographic data collection during COVID-19 in Ontario's public health system	Primary
2.	Baker at al. (2006)	A System for Rapidly and Accurately Collecting Patients' Race and Ethnicity	Primary
3.	Bhalla et al. (2012)	Standardizing Race, Ethnicity, and Preferred Language Data Collection in Hospital Information Systems: Results and Implications for Healthcare Delivery and Policy	Primary
4.	Cornrick et al. (2023)	Centering patient perspectives to achieve injury-related health equity in trauma care systems: Improving trauma registry data	Primary
5.	Hussain et al. (2024)	Leveraging Ethnic Backgrounds to Improve Collection of Race, Ethnicity, and Language Data	Primary
6.	Montoya-Barthelemy et al. (2021)	Using advanced racial and ethnic identity demographics to improve surveillance of work-related conditions in an occupational clinic setting	Primary

Article ID	Author and publication year	Title	Publication type
7.	Palaniappan et al. (2009)	Collecting Patient Race/Ethnicity and Primary Language Data in Ambulatory Care Settings: A Case Study in Methodology	Primary
8.	Pinto et al. (2016)	Building a Foundation to Reduce Health Inequities: Routine Collection of Sociodemographic Data in Primary Care	Primary
9.	Straus et al. (2023)	Evaluating Demographic Data to Improve Confidence in Equity Analytics in a Children's Hospital	Primary
10.	Webstar & Sampangi (2013)	Report on data improvement project on patient ethnicity and race (dipper): pilot design and proposed voluntary standard	Primary
11.	Webstar & Sampangi (2017)	Did We Have an Impact? Changes in Racial and Ethnic Composition of Patient Populations Following Implementation of a Pilot Program	Primary
12.	Wilson et al. (2013)	Implementing Institute of Medicine Recommendations on Collection of Patient Race, Ethnicity, and Language Data in a Community Health Centre	Primary
13.	Bierer (2021)	Achieving diversity, inclusion and equity in clinical research. Toolkit	Guidance document
14.	Canadian Institute for Health Information (2022)	Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada	Guidance document
15.	Health Research and Educational Trust (2013)	Reducing health care disparities: Collection and use of race, ethnicity, and language data	Guidance document

Article ID	Author and publication year	Title	Publication type
16.	Imbeah et al. (2021)	A Roadmap for Race, Ethnicity, and Language Data Collection and Use in Connecticut	Guidance document
17.	Ottawa Public Health (2020)	Report: COVID-19 and Racial Identity in Ottawa	Report
18.	Pinto & Haspari (2020)	Collecting data on race during the COVID-19 pandemic to identify inequities	Report
19.	Agic et al. (2013)	We ask because we care. The Tri-Hospital + TPH Health Equity Data Collection Research Project: Final Report 2013	Report
20.	Shared Health Manitoba (2020)	Racial/Ethnic/Indigenous Identity: Collection of Identifiers	Guidance document
21.	Sinai Health System (2017)	Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres	Report
22.	Winnipeg Regional Health Authority (2012)	Framework for Action: Cultural proficiency & diversity	Guidance document
23.	Wynia et al. (2011)	Collecting and using race, ethnicity and language data in ambulatory settings: a white paper with recommendations from the Commission to End Health Care Disparities	Guidance document

The articles included in this review were mainly original research papers (n =12) (1, 2, 3,

4, 5, 6, 7, 8, 9, 10, 11, 12), with the remaining being grey literature (n =11) (13, 14, 15,

16, 17, 18, 19, 20, 21, 22, 23). The original research papers were all primary articles (n =12) (1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12), while the grey literature included guidance documents (n =7) (13, 14, 15, 16, 20, 22, 23) and reports (n = 4) (17, 18, 19, 21). The majority of the articles were published before the COVID-19 pandemic (n = 12) (2, 3, 7, 8, 10, 11, 12, 15, 19, 21, 22, 23), many after it (n = 8) (1, 4, 5, 6, 9, 13, 14, 16) and few (n = 3) during the pandemic (17, 18, 20).

4.3   Context of the publications included

The publication contexts described here include the framework application status, the country of application, the type of application, the type of setting in which the framework was applied, and the application level. In this review, the application levels are described as micro, mezzo, or macro. Micro includes the application of the framework in a department within a health setting or setting-wide use. Mezzo depicts a community-level application that includes a community of practice, while macro refers to a region, state-wide, or country-level application of the framework. Results for these are described in the sub-sections below and individual summaries in Table 3.

4.3.1   Framework application status and country of application (n = 23)

All articles included in this review originated from the US and Canada. Most of the publications (n = 14, 61%) originated from the US (2, 3, 4, 5, 6, 7, 9, 10, 11, 12, 13, 15, 16, 23), while the rest (n = 9, 39%) were from Canada (1, 8, 14, 17, 18, 19, 20, 21, 22). The majority (n = 18) of the frameworks produced in the articles have been applied (1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 17, 18, 19, 20, 21, 22) while for five (n = 5), the application status is unknown because they are recommendations (13, 14, 15, 16, 23).   Of the

eighteen frameworks that have been applied, eight (n = 8) were applied in Canada (1, 8, 17, 18, 19, 20, 21, 22), and ten (n = 10) were applied in the US (2, 3, 4, 5, 6, 7, 9, 10, 11, 12). Each of these eighteen frameworks was applied in the country it originated from.

4.3.2   Framework application type and level (n = 18)

Eighteen of the frameworks (n = 18) have been applied. Most of them (43%, n =10, 43%) were implemented as pilots (2, 4, 7, 8, 9, 10, 11, 18, 19, 22), eight (3n = 8, 35%) were fully implemented (1, 3, 5, 6, 12, 17, 20, 21), and the application status for five (n = 5, 22%) were unknown (13, 14, 15, 16, 23). Notably, all five with unknown status were recommendation frameworks from the grey literature. Many of the frameworks (n = 10, 56%) were applied on a micro level (2, 3, 4, 5, 7, 8, 9, 12, 18, 22), while some others (n = 7, 38%) were applied on a mezzo level (6, 10, 11, 17, 19, 20, 21). Only one (n = 1, 6%) of the frameworks was applied on a macro level (1). Of the five with unknown status for application, the application level for one (n = 1) (14) is recommended as macro.

4.3.3   Framework application setting (n = 23)

The frameworks were applied or recommended for application within five distinct health settings. These settings are hospitals (n = 12, 52%) (2, 3, 5, 9, 10, 11, 14, 15, 16, 19, 21, 22), clinics (n = 3, 13%) (6, 8, 18), health centers (n = 2, 9%) (12, 21), ambulatory care (n = 2, 9%) (7, 23), public health (n = 3, 13%) (1, 17, 20), clinical trial (n = 1, 4%) (13) and a trauma center (n = 1) (4). Hospitals are the most common setting (n =12, 52%), which could be because of the prevalence of research in this setting. Notably, the three frameworks applied in the public health setting were from Canada and were applied in Canada. The clinical trial and trauma center framework originated in the US and was also applied there.

Table 4: A summary of the context of the articles included

Author & Year of publication	Framework has been applied	Country of application	Application type	Type of health setting	Level of application
Abdi et al. (2021)	Yes	Canada	Full implementation	Public health	Macro
Baker et al. (2006)	Yes	USA	Pilot	Hospital	Micro
Bhalla et al. (2012)	Yes	USA	Full implementation	Hospital	Micro
Cornrick et al. (2023)	Yes	USA	Pilot	Trauma Center	Micro
Hussain et al. (2024)	Yes	USA	Full implementation	Hospital	Micro
Montoya-Barthelemy et al. (2021)	Yes	USA	Full implementation	Occupational health clinic	Mezzo
Palaniappan et al. (2009)	Yes	USA	Pilot	Ambulatory care	Micro
Pinto et al. (2016)	Yes	Canada	Pilot	Clinic	Micro
Straus et al. (2023)	Yes	USA	Pilot	Hospital	Micro

Author & Year of publication	Framework has been applied	Country of application	Application type	Type of health setting	Level of application
Webstar & Sampangi (2013)	Yes	USA	Pilot	Hospital	Mezzo
Webstar & Sampangi (2017)	Yes	USA	Pilot	Hospital	Mezzo
Wilson et al. (2013)	Yes	USA	Full implementation	Health center	Micro
Bierer (2021)	Not stated	USA	Recommendation	Clinical trial	Micro
Canadian Institute for Health Information (2022)	Not stated	Canada	Recommendation	Hospital	Macro
Health Research and Educational Trust (2013)	Not stated	USA	Recommendation	Hospital	Mezzo
Imbeah et al. (2021)	Not stated	USA	Recommendation	Hospital	Micro
Ottawa Public Health (2020)	Yes	Canada	Full implementation	Public health	Mezzo
Pinto & Haspari (2020)	Yes	Canada	Pilot	Clinic	Micro
Agic et al. (2013)	Yes	Canada	Pilot	Hospital	Mezzo
Shared Health Manitoba	Yes	Canada	Full implementation	Public health	Mezzo

Author & Year of publication	Framework has been applied	Country of application	Application type	Type of health setting	Level of application
(2020)					
Sinai Health System (2017)	Yes	Canada	Full implementation	Hospital & Community Health Center	Mezzo
Winnipeg Regional Health Authority (2012)	Yes	Canada	Pilot	Hospital	Micro
Wynia et al. (2011)	Not stated	USA	Recommendation	Ambulatory care	Micro

4.4   Attributes of the Frameworks

Five attributes of the frameworks included in the review are described here. These attributes include the authors' rationale for developing the frameworks, a theoretical influence on the work, stakeholder engagement in the framework development process, the stakeholders engaged, and integration of the data collected into electronic medical or health records. Table 4 presents a breakdown of these findings.

4.4.1   Rationale, Theoretical Influences, and Definitions (n = 23)

All authors (n = 23) provided a rationale for developing the framework. Ten distinct rationales were identified and are presented here in order of commonality. Many authors' rationale for developing a framework is to collect data to address health disparity (n = 7,

30%) (1, 4, 6, 7, 11, 18, 19). Some others developed their frameworks in response to data concerns. For a few (n = 4, 17%), the concern pertained to race, ethnicity, and language data availability and quality concerns (5, 10, 12, 23), while for some others, it was to support standardized data collection (n = 3, 13%) (13, 14, 16). Further, three frameworks were developed to collect data that would improve care (n = 3, 13%) (3, 15, 22) and another two (n = 2, 9%) because leaders, physicians, and staff were interested in the data collection (8, 20).

Other frameworks were developed to assess the feasibility of collecting race and ethnicity information from patients using their preferred terms (n = 1, 4%) (2), to accurately track and validate equity metrics (n = 1, 4%) (9), to collect data for community engagement during COVID-19 (n = 1, 4%) (17) and finally because the population had become diverse (n = 1, 4%) (21).

None of the authors explicitly stated a theoretical influence on their work, but from the various rationales provided, many were influenced by social justice. Social justice involves identifying disparities and developing suitable, culturally safe, and significant remedies to address them (Lewis, 2012).

Further, the review found that nearly all (n = 21, 91%) of the authors did not provide a definition for race and ethnicity in their publications; only two authors (n = 2, 9%) did (2, 14). Bhalla et al (2012) define race as: *"a sociocultural concept wherein groups of people sharing certain physical characteristics are treated differently based on stereotypical thinking, discriminatory institutions and social structures, a shared worldview, and social myths,"* and ethnicity as: "*a concept referring to a shared culture and way of life,*

especially as reflected in language, folkways, religious and other institutional forms,

material culture such as clothing and food, and cultural products such as music,

literature and art."

CIHI (2022) defines race 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" and ethnicity as "*a multi-dimensional*

concept referring to community belonging and a shared cultural group membership. It is

related to socio-demographic characteristics, including language, religion, geographic

origin, nationality, cultural traditions, ancestry, and migration history, among others."

4.4.2   Stakeholder Engagement (n = 23)

The authors underwent different framework development processes. A few (n =6, 26%)

involved stakeholders (4, 8, 10, 11, 14, 19), while most (n =17, 74%) did not. Stakeholder

consultations and involvement are critical to support implementation success. The types

of stakeholders engaged during the framework development processes included patients

(n =1, 4%) (4), physicians (n = 2, 9%) (8, 19), hospital staff (n = 4, 17%) (8, 19, 10, 11),

federal, provincial and territorial governments (n = 1, 4%) (14), individuals and groups

representing racialized and Indigenous communities (n = 1, 4%) (14) and subject matter

experts (n =1, 4%) (14). Further, of the six (n = 6, 4%) authors whose work engaged

stakeholders, three (n = 3, 13%) originated from the US (4, 10, 11), and the other three

were from Canada (8, 14, 19). Noteworthy is that the Tri-Hospital + TPH framework is

referenced in two (n = 2) articles by different authors (8, 19).

4.4.3 Data integration with Electronic Medical Records/Electronic Health Records (EMR/EHR) (n = 18)

In the US and Canada, electronic medical/health records are a standard data management facility in health settings. Of the frameworks that have been piloted or fully implemented (n =18), most (n = 12, 67%) were not linked to an EMR/EHR, while few (n = 6, 33%) were linked (8, 9, 12, 16, 22, 23). Further, three (n =3) of the six that were linked to electronic records have been piloted (8, 9, 22), two (n = 2) are recommendations (16, 23), and one (n =1) has been implemented fully (12).

Table 5: Attributes of the frameworks included

Author & Publication year	Rationale	Theoretical influence	Stakeholder engagement	Type of stakeholders engaged	Data collected is integrated with EMR/EHR
Abdi et al. (2021)	COVID-19 incidence and disproportionate impact on marginalized communities	Not stated	No	N/A	No
Baker et al. (2006)	To assess the feasibility of collecting race/ethnicity data from patients using their own preferred racial/ethnic terms.	Not stated	No	N/A	No
Bhalla et al. (2012)	To improve cardiovascular care for African Americans and Latinos and sharing relevant lessons with healthcare providers and policymakers.	Not stated	No	N/A	No

Author & Publication year	Rationale	Theoretical influence	Stakeholder engagement	Type of stakeholders engaged	Data collected is integrated with EMR/EHR
Cornrick et al. (2023)	Researchers' inability to identify and address disparities in injury and outcomes for patients who experience traumatic injury	Not stated	Yes	Patients	No
Hussain et al. (2024)	Upstream incapacity to collect high-quality and accurate race, ethnicity, and language (REaL) data	Not stated	No	N/A	No
Montoya-Barthelemy et al. (2021)	A large Hmong and Somali populations and an existing data gap in occupational health disparities in Minneapolis	Not stated	No	N/A	No
Palaniappan et al. (2009)	Race, ethnicity and language-based health disparities in the Palo Alto Medical Foundation catchment area	Not stated	No	N/A	No

Author & Publication year	Rationale	Theoretical influence	Stakeholder engagement	Type of stakeholders engaged	Data collected is integrated with EMR/EHR
Pinto et al. (2016)	Physicians and staff expression of interest in the routine collection of socio-demographic data	Not stated	Yes	Staff and physicians at participating organizations (CAMH, Mt. Sinai Hospital, St Michaels Hospital, and Toronto Public Health)	Yes
Straus et al. (2023)	To accurately track and validate equity metrics at Akron Children's Hospital	Not stated	No	N/A	Yes
Webstar & Sampangi, (2013)	The standard was developed in response to race and ethnicity data concerns.	Not stated	Yes	Hospital staff from patient registration, Cancer registration, Health information management, Hospital	No

Author & Publication year	Rationale	Theoretical influence	Stakeholder engagement	Type of stakeholders engaged	Data collected is integrated with EMR/EHR
				administration, Partners in cancer control, and staff from the Rhode Island Department of Health (RIDH)	
Webstar & Sampangi (2017)	The need for high-quality data to eliminate health disparities in cancer prevention and control	Not stated	Yes	Hospital staff from patient registration, Cancer registration, Health information management, Hospital administration, Partners in cancer control, and staff from the RIDH	No

Author & Publication year	Rationale	Theoretical influence	Stakeholder engagement	Type of stakeholders engaged	Data collected is integrated with EMR/EHR
Wilson et al. (2013)	To maximize data collection rates; to obtain self-reported data from patients	Not stated	No	N/A	Yes
Bierer (2021)	The lack of uniformity in data collection limiting the ability to capture results that represent diverse populations	Not stated	No	N/A	N/A
Canadian Institute for Health Information (2022)	To support harmonized, high-quality data collection and to help identify and address health inequities related to racism.	Not stated	Yes	Individuals and groups who represent racialized and Indigenous communities, subject matter experts, research organizations, and federal, provincial and territorial government	No

Author & Publication year	Rationale	Theoretical influence	Stakeholder engagement	Type of stakeholders engaged	Data collected is integrated with EMR/EHR
Health Research and Educational Trust (2013)	To eliminate inequities in healthcare by improving the quality of care, reducing the cost of care, and to meet regulatory and accreditation standards.	Not stated	No	N/A	N/A
Imbeah et al. (2021)	Lack of a standardized way for healthcare systems and clinics to collect, report, and use REL data in Connecticut	Not stated	No	N/A	Yes
Ottawa Public Health (2020)	To use data to engage community groups and provide additional information and supports where needed	Not stated	No	N/A	No
Pinto & Haspari (2020)	In Canada, preventable negative health outcomes are disproportionately	Not stated	No	N/A	No

Author & Publication year	Rationale	Theoretical influence	Stakeholder engagement	Type of stakeholders engaged	Data collected is integrated with EMR/EHR
	seen in Indigenous and Black patients. During the COVID-19				
Agic et al. (2013)	Massive changes in Toronto's demography over the last three decades and a decline in the physical and mental health status of recent immigrants	Not stated	Yes	Staff and physicians at participating organizations (CAMH, Mt. Sinai Hospital, St Michaels Hospital, and Toronto Public Health)	No
Shared Health Manitoba (2020)	Leaders are broadly recognizing the need for reporting on the impacts of COVID-19 by race, ethnicity, and indigeneity (REI).	Not stated	No	N/A	No

Author & Publication year	Rationale	Theoretical influence	Stakeholder engagement	Type of stakeholders engaged	Data collected is integrated with EMR/EHR
Sinai Health System, (2017)	The Toronto Central LHIN serves a population of 1.3 million (2015 estimates). It has the most diverse patient/client population in Ontario	Not stated	No	N/A	No
Winnipeg Regional Health Authority (2012)	The absence of language and ethnicity data impedes service planning and delivery of healthcare	Not stated	No	N/A	Yes
Wynia et al. (2011	Poor collection of basic demographic information from patients and even worse in ambulatory settings	Not stated	No	N/A	Yes

4.5   Description of the components of the frameworks

Data were extracted from eight components of the frameworks. These components are i) the data collection tool type, ii) the tool administration, iii) the type of questions the tool asks, iv) the ability to select multiple responses within the race category, v) the type of response, vi) the race and ethnicity categories used, vii) the data collection point and viii) the inclusion of a data collection script to support the data collection process. Components i-v are presented together in the data collection tools format. All components described are presented in Table 5.

4.5.1   The Format of the Data Collection Tools (n = 23)

Data collection within the frameworks was either paper-based, electronic, or both. The most common method was electronic (n = 9, 39%) (2, 3, 5, 8, 9, 10, 11, 13, 22). Of the nine, seven (n = 7) originated from the USA (2, 3, 5, 9, 10, 11, 13), and two (n = 2) from Canada (8, 22). The authors preferred this method for reasons such as eliminating the need for data entry, ease of use, and data reconciliation and aggregation. For the frameworks applying or recommending paper-based data collection (n = 7, 30%) (1, 4, 6, 7, 12, 20, 23), most of them (n = 5) originated from the US (4, 6, 7, 12, 23), while the others originated from Canada (n = 2) (1, 20). No specific reasons were provided for the authors' choice of paper-based data collection.

Three articles (n = 3, 13%) employed paper-based and electronic data collection (15, 16, 19). Two of the three originated in the US (n = 2), and both articles are recommended frameworks (15, 16). The third (n = 1) originated from Canada (19) and was piloted in

three settings. In each setting, the decision on how to collect the data was based on preference; one of the settings collected data electronically, while the other two used the paper-based method. Four authors (n = 4, 17%) did not state or recommend a format for the data collection (14, 17, 18, 21).

Most of the data collection tools (n = 17, 74%) contained multiple-choice questions for race and ethnicity (1, 2, 4, 5, 6, 7, 9, 12, 13, 14, 15, 16, 17, 19, 20, 21, 23) while four (n = 4, 17%) contained only open-ended questions (3, 8, 10, 11) and for two (n = 2, 9%) the questions were not included (18, 22). Various cadres of staff within the health setting administered all the data collection tools with open-ended questions. It is worth mentioning that many (n = 10) of the data collection tools contained both multiple-choice and open-ended questions (2, 5, 6, 7, 12, 14, 15, 16, 21, 23). A combination of both types of questions is facilitated by an "Other" category that allows respondents to document a racial identity not included in the categories listed for race.

For most tools, it was voluntary to provide one's information by responding to the questions in the data collection tool t (n = 20, 87%) of the articles (1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 13, 14, 17, 18, 19, 20, 21, 22, 23). Therefore, patients were not mandated to respond or participate in data collection. However, three articles (n = 3, 13%) do not provide any information on this (12, 15, 16).

4.5.2   How Race and Ethnicity Data Were Collected

The data collection tool administration was described in twenty articles (n = 20), while four (n = 4) articles were silent on the subject. The data collection tools were either administered, self-administered, or both. Most of the articles (n = 11, 55%) stated that the

tool was/should be administered to patients (1, 2, 3, 4, 5, 9, 10, 11, 17, 20, 22), five (n = 5, 25%) stated that it was/should be self-administered by patients (6, 7, 8, 12, 15) and four (n = 4, 20%) stated that administration was/could be both (13, 16, 19, 23). Of the eleven that were administered, nine (n =9, 47%) authors specifically stated what cadre of staff administered the tool (1, 2, 3, 5, 13, 16, 17, 19, 23).

Seven different staff cadres were mentioned in the hospital and public health settings. In the hospital setting, registration staff (n = 4) (3, 5, 16, 23), medical assistants (n = 1) (16), volunteers (n = 1) (19), research staff (n = 1) (19), trained students (n = 1) (19), healthcare providers (n = 1), and a research assistant (n =1) (19) administered the tools. In public health settings, the data collection tools were administered by a nurse (n =1) (17) and a case manager (n =1) (1). Three (n = 3, 16%) articles did not describe tool administration, while eight (n = 8, 42%) did not state what staff cadre collects the information.

In eleven articles (n = 11), respondents could choose multiple options from a list of categories for race (1, 2, 6, 7, 9, 11, 12, 13, 14, 16, 23). In six articles (n = 6), respondents could choose only one option (3, 4, 5, 19, 20, 21), and in another six (n = 6), this information was not provided. Few data collection tools (n = 5) allowed respondents to identify as multiracial (2, 3, 8, 19, 21). Two of the five articles originated from the US (2, 3), while the other three were from Canada (8, 19, 21).

Data was collected at various points within the settings. The authors mention seven distinct points, which include registration (3, 4, 5, 9, 11, 12, 21, 23), front desk (7), discharge area (2), waiting room (8, 19), examination room (7), admissions (19, 21),

programs (21), via phone in a follow-up call post-COVID-19 positive diagnosis (17) and

Outpatient programs (19). The most common point for data collection was at registration

(n = 8).

4.5.3   Race and Ethnicity Categories in the Frameworks (n = 19)

This review identified nineteen (n = 19, 83%) unique frameworks (1, 2, 3, 4, 5, 6, 7, 9,

10, 11, 12, 13, 14, 17, 18, 19, 20, 21, 23). Uniqueness here is defined by the race and/or

ethnicity categories referenced or produced by the author(s). In addition to the definition

of uniqueness, publication year was employed as a tiebreaker where more than one author

referenced or produced the same race and/or ethnicity categories. Two frameworks (n =

2) list the same race and ethnicity categories as Wynia et al. (2011) (15, 16), while (n = 1)

(8) use the same race categories as Agic et al. (2013) and one (n = 1) (22) does not list the

race and ethnicity categories. Only the unique frameworks are described here in this sub-

section.

Most of the unique frameworks (n = 12, 63%) originated from the US (2, 3, 4, 5, 6, 7, 9,

10, 11,12, 13, 23), while the others (n = 7, 37%) were from Canada (1, 14, 17, 18, 19, 20,

21).   Frameworks originating from the US referenced either the US Office of

Management and Budget (OMB) race and/or ethnicity categories tied to the census or the

Institute of Medicine (IOM), which suggest collecting granular ethnicity information by

generating a list of locally relevant granular ethnicities in addition to the census

categories established. There are variations in each framework, but the differences are not

marked. Most of them include one or two additional categories or the expansion of an

existing category. For example, the White race category can be split into White (North

American) and White (European).

Three (n = 3) of the seven frameworks originating from Canada developed/adopted their race categories with reference to the Toronto District School Board census survey (18, 19, 21). Race categories for Indigenous identity included in one framework (n = 1) (14) are comparable to those of Statistics Canada and the Canadian Community Health Survey. The other three (n = 3) do not reference any sources (1, 17, 20).

Only eight (n = 8, 42%) frameworks included ethnicity categories (3, 5, 6, 11, 13, 15, 16, 23). All eight frameworks originated from the US and reference the OMB/census ethnicity categories. One (n= 1) of the articles referenced the CDC/HL7 Ethnicity Code set and Massachusetts super set, in addition to the OMB ethnicity categories (5). Notably, one article (n = 1) does not list ethnic categories; instead, it allows patients to provide free text responses, which are then mapped to the census ancestry list and a hospital program database (7). None of the Canadian frameworks provide or reference ethnic categories. Within some frameworks (n =6), there are no clear distinctions between race and ethnicity categories, such that ethnic groups are listed within the racial categories (4, 6, 7, 10, 12, 20).

4.5.4   Inclusion of a Data Collection Script (n = 23)

Only nine authors included a data collection script (n = 9, 39%) (1, 2, 3, 4, 5, 7, 14, 16, 20, 23). Two frameworks with a data collection script (n = 2) incorporated it as a preamble within the data collection tool and not as a stand-alone addition (7, 14). Data collection scripts were developed and included to help the data collector articulate the reason for data collection, what the data will be used for, and, in some cases, answer patient pre-empted questions. All other authors not referenced here (n = 14, 61%) did not include a data collection script.

Table 6: Details of the components of the frameworks included in the review

Author & publication year	Tool format	Tool administration	Question type	Ability to select multiple options	Response type	Race categories	Ethnicity categories	Data collection point	Data collection script included
Abdi et al. (2021)	Paper-based	Administered	Multiple choice	Yes	Voluntary	1. Black 2. East/Southeast Asian 3. Latino 4. Middle Eastern 5. South Asian 6. White 7. Another race category 8. Prefer not to answer	Not collected		Yes
Baker et al. (2006)	Electronic	Administered	Open-ended Multiple choice	Yes	Voluntary	1. Non-Hispanic White 2. Non-Hispanic Black 3. Hispanic White 4. Asian 5. Native American or Alaska Native 6. Native Hawaiian or Pacific Islander 7. Multiracial 8. Other		Discharge area	Yes

| Bhalla et al. (2012) | Electronic | Administered | Open-ended | No | Voluntary | 1. American Indian/Alaskan Native; 2. Asian; 3. Black/African American 4. Native Hawaiian/Pacific Islander 5. White 6. Multiracial subcategories: a. multiracial: Asian/Black African American, b. multiracial: Asian/White, c. multiracial: Black African American/White, d. multiracial: other combination, 7. Declined 8. Patient unavailable | 1. Hispanic or Latino 2. Not Hispanic or Latino 3. declined 4. patient unavailable | Registration | Yes |

| Cornrick et al. (2023) | Paper-based | Administered | Multiple choice | No | Voluntary | 1. American Indian or Alaskan Native   a. Alaska Native   b. American Indian/Native American   c. Canadian Inuit, Metit or First Nation   d. Other 2. Asian   a. Asian Indian   b. Cambodian   c. Chinese   d. Fillipin(x)   e. Hmong   f. Japanese   g. Korean   d. Laotian   f. South Asian   g. Other 3. Black   a. African American   b. African (Black)   c. Afro Caribbean   d. Other 4. Hispanic or Latin(x) | | Registration | Yes |

| | | | | | | a. Central American
   b. Mexican
   c. South American
   d. Indigenous Mexican, Central American, or South American
   e. Hispanic or Latin(x)
   f. Other
5. Middle Eastern or North African
   a. Middle Eastern
   b. North African
   c. Other
6. Native Hawaiian or Pacific Islander
   a. Guamanian or Chamorro
   b. Micronesian
   c. Native Hawaiian
   d. Samoan
   e. Tongan
   f. Other
7. White
   a. Western European | | | |

						b. Eastern European
						    c. Northern European
						    d. Southern European
						    e. Other
						7. Other
						    a. Don't know
						    b. Decline
						    c. Other			

| Hussain et al. (2024) | Electronic | Administered | Open-ended Multiple choice | No | Voluntary | 1. Asian
2. Black or African American
3. Native Hawaiian
4. Other Pacific Islander
5. White
6. American Indian or Alaska Native
7. Blank
8. Other | i) 2000 Census
ii) CDC/HL7 Ethnicity Code set and
iii) Massachusetts super set | Registration | Yes |

| Montoya-Barthelemy et al. (2021) | Paper-based | Self-administered | Multiple choice Open-ended | Yes | Voluntary | 1. White 2. American Indian/Alaskan Native 3. Asian a. Chinese b. Hmong c. Indian d. Laotian e. Thai f. Vietnamese g. Other Asian background 4. Black, African or African American a. African American b. Black c. Ethiopian d. Liberian e. Nigerian f. Somali g. Other Black/African background 5. Hispanic, Latino or Latina a. Mexican d. Puerto Rican c. Other Hispanic/Latino | Hispanic, Latino or Latina a. Mexican b. Puerto Rican c. Other Hispanic/Latino background | | No |

						background			
						6. Native Hawaiian/Other Pacific Islander			
						7. Other background not listed above			

Palaniappan et al. (2009)	Paper-based	Self-administered	Multiple choice Open-ended	Yes	Voluntary	1. White/Caucasian 2. Black/African American 3. American Indian/Alaska Native 4. Asian Indian 5. Chinese 6. Filipino 7. Japanese 8. Korean 9. Vietnamese 10. Other Asian 11. Native Hawaiian 12. Guamanian or Chamorro 13. Samoan 14. Other Pacific Islander 15. Cuban 16. Puerto Rican 17. Mexican, Mexican American, Chicano 18. Other Spanish/Hispanic or Latino 19. I prefer not to answer	Free text response matched to: i) Census Ancestry List and ii) The Surveillance, Epidemiology and End Results (SEER) Program	Front desk and Examination room	Yes

Pinto et al. (2016)	Electronic	Self-administered	Open-ended		Voluntary	Trihospital + TPH categories		Waiting room	No
Straus et al. (2023)	Electronic	Administered	Multiple choice	Yes	Voluntary	1. African American/Black 2. American Indian and Alaska Native 3. Asian 4. Native Hawaiian and Other Pacific Islander 5. Patient refused 6. Unknown 7. White or Caucasian		Registration	No

Webstar & Sampangi (2013)	Electronic	Administered	Open-ended		Voluntary	1. White (*including English, French, French Canadian, German, Irish, Italian, Polish, Scottish, and Swedish*) 2. Black or African American 3. American Indian or Alaska Native 4. Native Hawaiian *or Other Pacific Islander (NHOPI)* 5. Asian Indian 6. Chinese 7. Cambodian 8. Vietnamese 9. Other Asian 10. Unavailable 11. Declined/Refuse to answer 12. Other			No

Webstar & Sampangi (2017)	Electronic	Administered	Open-ended	Yes	Voluntary	1. White 2. Black 3. Asian 4. Native Hawaiian/ or Pacific Islander 5. American Indian/ or Alaska Native 6. White and Black 7. White and Asian 8. White and American Indian 9. White and some other race 10. Black and some other race 11. Other 12. Unknown	1. Hispanic 2. Non-Hispanic 3. Unknown	Registration	No
Wilson et al. (2013)	Paper-based	Self-administered	Multiple choice Open-ended	Yes		1. Hispanic/Latino 2. Native Hawaiian 3. Asian 4. Black/African American 5. White 6. Other Pacific Islander 7. American Indian/Alaska Native 8. Some other race		Registration	No

| Bierer (2021) | Electronic | Self-administered Administered | Multiple choice | Yes | Voluntary | 1. American Indian or Alaskan Native
    a. Alaska Native
    b. American Indian
    c. Caribbean Indian
    d. Central American Indian
    e. Greenland Inuit
    f. Nupiat Inuit
    g. Siberian Eskimo
    h. South American Indian
    i. Yupik Eskimo
2. Asian
    a. Asian American
    b. Asian Indian
    c. Bangladesh
    d. Bhutanese, Burmese
    e. Malagasy
    f. Malaysian
    g. Maldivian
    h. Mongolian
    i. Nepalese
    j. Cambodian
    k. Chinese | 1. Hispanic or Latino
a. Central American
b. Cuban
c. Cuban American
d. Latin American
f. Mexican
g. Mexican American
f. South American
g. Spanish
2. Not Hispanic or Latino
3. Not reported | | No |

					l. Filipino m. Hmong n. Indonesian o. Iwo Jiman p. Japanese q. Korean r. Laotian s. Okinawn t. Pakistani u. Singaporean v. Sri Lankan w. Taiwanese x. Thai y. Vietnamese 3. Black or African American a. African b. African American c. African Caribbean d. Bahamian e. Barbadian f. Black Central American g. Black South American h. Botswanan i. Dominica Islander j. Dominican			

					k. Ethiopian
					l. Haitian
					m. Jamaican
					n. Liberian
					o. Malagasy
					p. Namibian
					q. Nigerian
					r. Trinidadian
					s. West Indian
					t. Zairean
					4. Native Hawaiian or Other Pacific Islander
					   a. Melanesian
					   b. Micronesian
					   c. Polynesian
					   d. Indigenous Mexican, Central American, or South American
					   e. Hispanic or Latin(x)
					   f. Other
					5. White
					   a. Arab
					   b. Eastern European
					   c. European
					   d. Mediterranean
					   f. Middle Eastern			

						g. North American
						  h. Northern European
						  i. Russian
						  j. Western European
						  k. White Caribbean
						  l. White Central American
						  m. White South American
						6. Other
						  a. Unknown
						  b. Not reported			

Canadian Institute for Health Information (2022)			Multiple choice Open-ended	Yes	Voluntary	1. Black (African, African Canadian, Afro-Caribbean descent) 2. East Asian (Chinese, Japanese, Korean, Taiwanese descent) 3. Indigenous (First Nations, Inuk/Inuit, Métis descent) 4. Latin American (Hispanic or Latin American descent) 5. Middle Eastern: Arab, Persian, 6. West Asian descent (e.g., Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish) 7. South Asian: South Asian descent (e.g., Bangladeshi, Indian, 8. Indo-Caribbean, Pakistani, Sri Lankan) 9. Southeast Asian (Cambodian,			Yes

						Filipino, Indonesian, Thai, Vietnamese, or other Southeast Asian descent) 10. White (European descent) 11. Another race category *Optional — please specify: [open text]* 12. Do not know 13. Prefer not to answer Indigenous Identity 1. Yes, First Nations 2. Yes, Inuk/Inuit 3. Yes, Métis 4. No 5. Do not know 6. Prefer not to answer			

Health Research and Educational Trust (2013)	Paper-based Electronic	Self-administered (with support from registration staff)	Multiple choice Open-ended			1. Black or African American 2. White 3. Asian 4. American Indian or Alaska Native 5. Native Hawaiian or Other Pacific Islander 6. Some other race OMB race categories	1. Hispanic or Latino 2. Not Hispanic or Latino 3. Granular ethnicity: • Locally relevant choices from a national standard list of approximately 540 categories with CDC/HL7 codes • Other, please specify:__		No

| Imbeah et al. (2021) | Paper-based Electronic | Self-administered Administered | Multiple choice Open-ended | Yes | | 1. Black or African American 2. White 3. Asian 4. American Indian or Alaska Native 5. Native Hawaiian or Other Pacific Islander 6. Some other race | 1. Hispanic or Latino 2. Not Hispanic or Latino 3. Granular ethnicity: • Locally relevant choices from a national standard list of approximately 540 categories with CDC/HL7 codes • Other, please specify:__ | | Yes |

| Ottawa Public Health (2020) | | Administered | Multiple choice | | Voluntary | 1. Asian (East) – e.g. Chinese, Japanese, Korean, Taiwanese, etc. 2. Asian (South) – e.g. East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean, etc. 3. Asian (South East) – e.g. Cambodian, Indonesian, Filipino, Thai, Vietnamese 4. Black – e.g. African, Afro-Caribbean, African-Canadian 5. Indigenous - First Nations, Métis, Inuit Aboriginal identity 6. Latino – e.g. Latin American, Hispanic, Argentinian, Chilean, etc. 7. Middle Eastern – | | Follow-up post COVID-19 positive diagnosis | No |

					e.g. Arab, Persian, West Asian descent, Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish, etc. 8. White - e.g. European, English, Italian, Portuguese, Russian			

Pinto & Haspari (2020)					Voluntary	1. Black 2. East/Southeast Asian 3. Indigenous (First Nations, Metis, Inuit) 4. White 5. Sout Asian 6. Latino 7. Middle Eastern 8. Another race/category_____ _____ 9. Do not know 10. Prefer not to answer			No

| Agic et al. (2013) | Paper-based Electronic | Self-administered Administered (with support from volunteers, students, research staff, and healthcare providers) | Multiple-choice | No | Voluntary | 1. Asian - East (e.g., Chinese, Japanese, Korean) 2. Asian - South (e.g., Indian, Pakistani, Sri Lankan) m Métis 3. Asian - South East (e.g., Malaysian, Filipino, Vietnamese) 4. Black - African (e.g., Ghanaian, Kenyan, Somali) 5. Black - Caribbean (e.g., Barbadian, Jamaican) 6. Black - North American (e.g., Canadian, American) 7. First Nations 8. Indian - Caribbean (e.g., Guyanese with origins in India) 9. Indigenous/Aboriginal not included | | Bedside Waiting room Outpatient programs | No |

| | | | | | | elsewhere
10. Inuit
11. Latin American (e.g., Argentinean, Chilean, Slvadorian)
12. Metis
13. Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
14. White - European (e.g., English, Italian, Portuguese, Russian)
15. White - North American (e.g., Canadian, American)
16. Mixed heritage (e.g., Black-African and White-North American)
17. (Please specify)
_____
_____
_
18. Other (Please specify)
_____
_____ | | | |

						19. Prefer not to answer 20. Do not know			

Shared Health Manitoba (2020)	Paper-based	Administered	Multiple choice	No	Voluntary	1. African 2. Black 3. Chinese 4. Filipino 5. Latin American 6. North American Indigenous- that is, First Nations, Metis or Inuit 7. South Asian 8. Southeast Asian 9. White 10. Other			Yes

| Sinai Health System (2017) | | | Multiple-choice Open-ended | No | Voluntary | 1. Asian - East (e.g., Chinese, Japanese, Korean) 2. Asian - South (e.g., Indian, Pakistani, Sri Lankan) m Métis 3. Asian - South East (e.g., Malaysian, Filipino, Vietnamese) 4. Black - African (e.g., Ghanaian, Kenyan, Somali) 5. Black - Caribbean (e.g., Barbadian, Jamaican) 6. Black - North American (e.g., Canadian, American) 7. First Nations 8. Indian - Caribbean (e.g., Guyanese with origins in India) 9. Indigenous/Aboriginal not included | | Admission Registration Programs | No |

						elsewhere 10. Inuit 11. Latin American (e.g., Argentinean, Chilean, Slvadorian) 12. Metis 13. Middle Eastern (e.g., Egyptian, Iranian, Lebanese) 14. White - European (e.g., English, Italian, Portuguese, Russian) 15. White - North American (e.g., Canadian, American) 16. Mixed heritage (e.g., Black-African and White-North American) (Please specify) _____ _____ _ 17. Other (Please specify) _____ _____			

						— 18. Prefer not to answer 19. Do not know 20. Other (Please specify) _____ 21.Indigenous/Aboriginal not included elsewhere 22. Prefer not to answer			

Winnipeg Regional Health Authority (2012)	Electronic	Administered			Voluntary				No
Wynia et al. (2011)	Paper-based	Administered Self-administered	Multiple choice Open-ended	Yes	Voluntary	1. Black or African American 2. White 3. Asian 4. American Indian or Alaska Native 5. Native Hawaiian or Other Pacific Islander 6. Some other race	OMB Hispanic Ethnicity: 1. Hispanic or Latino 2. Not Hispanic or Latino 3. Granular ethnicity: • Locally relevant choices from a national standard list of approximately 540 categories with CDC/HL7 codes 4. Other, please specify:__	Registration	Yes

4.6   Summary

This chapter detailed the study findings. The findings were presented quantitatively as descriptive aggregates and qualitatively through short descriptions highlighting relevant details. Twenty-three frameworks were identified, but only nineteen of them were unique. The components of the data collection tools and the methods for data collection in the frameworks identified varied. Frameworks originating from the US used the US OMB race and ethnic categories as a standard reference point, while the Canadian frameworks did not have a standard reference point. Further, none of the Canadian frameworks distinctly include ethnic categories in the data collection tools. The next chapter will discuss these findings, make recommendations, and conclude the thesis.

Chapter 5

5   DISCUSSION & CONCLUSION

This scoping review identified evidence from published research and grey literature on race and ethnicity data collection frameworks in health settings. Twenty-three frameworks were identified, all of which originated from the US and Canada. The review's aim was to identify, compare, and contrast race and ethnicity data collection frameworks in health settings. Given the existing health disparities for minority populations (Public Health Agency of Canada, 2018), addressing the race and ethnicity data collection gaps in Canada is not only important but paramount. With an already diverse population and further plans to increase diversity through immigration, the health system's inability to track health inequity effectively impedes health equity.

In this review, evidence concerning attributes of existing frameworks, components of the frameworks, and how these components are applied were identified. The evidence shows that there are many unique frameworks for data collection in health settings. However, stakeholders were not engaged in the development process for many. Further, data can be collected at various points in a patient's care continuum by various staff cadres. However, data collection at registration was the most common. Few frameworks integrate race and ethnicity data collected into electronic medical records, and unlike the US frameworks, the Canadian frameworks lack a common reference point for race and ethnicity categories.

 The study's findings led to observations discussed below about i) processes (stakeholder engagement, types of stakeholders engaged, and data integration into EMR/EHR) and ii)

practices (who administers the data collection tools, where it is administered, and race and ethnicity categories in the tools). The processes can be described as steps to developing and implementing a data collection framework, while practices would be the application of the frameworks' components.

5.1   Processes

Stakeholder engagement

Analysis of the articles revealed that stakeholder engagement was uncommon during the development of many of the frameworks. Engaging relevant stakeholders in developing race and ethnicity data collection frameworks is crucial because their unique knowledge and perspectives can significantly enhance the utility of a framework. Through knowledge co-production, stakeholders from clinical, community, policy, and academic settings can be integrated into the framework development process (Nguyen et al., 2020a).

Co-production could empower these stakeholders, particularly those who will use the framework and those who would benefit from the data collected (Kothari et al., 2022). However, it is no easy task, given the resource requirements, lack of incentives for participation, and differing stakeholders' priorities (Gagliardi et al., 2016). Also, engagement must be meaningful to avoid tokenism (Kothari et al., 2020). Further, whether the intention for implementation is on a micro or macro level, stakeholder input could be a critical success factor. This is because knowledge is of various types-traditional that stems from research, tacit in the form of experience, pattern recognition, and even mindlines (Greenhalgh & Sietsewieringa, 2011), and stakeholders come with

different and possibly multiple knowledge types that could enrich the framework development process and eventual output. Stakeholders could collaborate to determine the types of questions asked, methods for implementation, race and ethnicity classifications, and desired outputs (Voorberg et al., 2014) and essentially on all aspects of the framework development.

Stakeholder engagement took place at various stages of the framework development process. It occured before implementation (Conrick et al., 2023), at the planning stage (Pinto et al., 2016; Webster & Sampangi, 2013), and during the development process (Canadian Institute for Health Information, 2022). When it occurred, the engagement style with stakeholders was consultative, primarily seeking input, feedback, and advice on patients' level of comfort with the questions and who should collect the data. (Canadian Institute for Health Information, 2022; Conrick et al., 2023; Pinto et al., 2016; Webster & Sampangi, 2013).

Other than a consultative approach, stakeholder engagement could be informing, supporting, involving, or collaborating (Amirav et al., 2017). A collaborative approach that involves equal partnership among stakeholders would be a more effective choice when developing a framework for race and ethnicity data collection. This approach could foster a sense of ownership and center the voices of those who matter (Fowler-Woods, 2022). For example, in Canada, some Indigenous scholars have expressed dissatisfaction with the existing racial classifications of First Nations, Inuit, and Metis because they do not account for heterogeneity within these groups (Nelson & Wilson, 2018). Collaborating with representatives of this population group throughout the development process could provide the required insight into their identity and contribute to an

understanding of their heterogeneity and how they prefer to be grouped. However, there are debates on the issue of representation in partnered research. These debates range from its failings, such as the selection of socially advantaged people whose voices do not represent the group's interests (Church et al., 2002; Martin, 2008), to how it is approached (tokenistic), knowledge-type tension (expert vs. lay) (Chinn & Pelletier, 2020) and the issue of power (Turnhout et al., 2019). Notwithstanding, stakeholders should be engaged in collaborative ways that contribute to the shared goal of developing and implementing a data collection framework.

Types of stakeholders engaged

Some framework authors engaged stakeholders such as patients from racially and ethnically diverse populations, staff and physicians, hospital leadership, health information management staff, registration assistants, local health departments, subject matter experts, governments, and individuals and groups representing minority and Indigenous populations. While these stakeholders are relevant and can support the success of implementation through their input, how much power they have during engagement also matters as much as how they are engaged. Power is always present in human interactions. In co-production, its imbalance has been identified as a collaboration barrier (Sibley et al., 2022). Some factors associated with power tensions include knowledge-type hierarchies, project funding authority, and control, and differing perceptions of outputs (Cooke et al., 2002). Deliberately addressing these at all stages of the collaboration process through power sharing, thinking of the partnership as an equal one with shared expertise, and creating a shared goal that translates into an acceptable

output for all stakeholders contributes to successful engagement (Kothari et al., 2002; Sibley et al., 2022; Nguyen et al., 2020).

Registration assistants were the most frequently involved stakeholder group in the development of frameworks for collecting race and ethnicity data at patient registration in hospital settings. This is logical, as incorporating feedback from personnel whose workflows will be directly impacted by the data collection process is crucial for successful implementation. A pertinent example of the importance of engaging such stakeholders is seen in electronic health records (EHRs). When EHR designs do not align with doctors' workflows, it often leads to usability issues and burnout. (Tutty et al., 2019). So, careful consideration should be given to who should be engaged in the process and how they should be engaged.

A common challenge in stakeholder engagement is the lack of incentives for collaboration (Audia et al., 2021). To address this, stakeholder-specific collaboration incentives can be pre-identified to facilitate engagement. For instance, an academic subject matter expert might be motivated to collaborate on developing a data collection framework due to the growing emphasis on co-production in research funders' agendas (Visman et al., 2018). By identifying and incorporating what incentivizes each stakeholder into the collaboration process, the likelihood of successful collaboration can be significantly enhanced.

Where minority groups have documented how they wish for their information to be collected, managed, and used, those should be respected. Examples of these exist in Canada, and they are The First Nations' Principles of Ownership Control Access and

Possession (OCAP) and The Engagement Governance Access and Protection framework for Black communities (EGAP) (The Black Health Equity Working Group, 2021). However, this may be challenging because of existing federal or provincial health data management laws that are often perceived as superior to these. Therefore, there is a need to examine the group-stated principles in tandem with the extant health data management laws to identify overlaps and contradictions so that the preferred principles can be respected without breaking the law. However, this is a potentially tense position, especially with OCAP, because Indigenous people have a right to self-determination.

Designing and implementing a framework of this kind impacts the setting and the patients. Setting impact could be staff burnout, while patient impact could be their decision to stop seeking care within that setting because of the sensitivity of the information sought from them. Therefore, patient engagement should be deliberate through communication using posters, banners, and mail before the framework is implemented, while potential staff burnout should also be addressed.

Race and ethnicity data integration into EMR/EHR

An EMR is considered an internal system within clinical practices, whereas the EHR is an inter-organizational one where patient information is accessible across providers. (Heart et al., 2016). Only a few frameworks integrated the data collected into an existing EMR. In one, a patient portal was redesigned so that patients could provide and edit their race and ethnicity information on the portal. In another, the hospital EMR had to be modified to accommodate the information collected on race and ethnicity.

Much of the health information in the Canadian health system is electronically managed, so it is plausible for data to be integrated with patients' records. Nevertheless, collecting race and ethnicity data outside of an EMR will help identify disparities and improve the quality of care. However, accessing the information and painting a setting-wide picture could be problematic because of data management-associated difficulties such as data fragmentation, data quality, and increased physical labor for staff (Boothe et al., 2020). Also, the data should be integrated into electronic medical records to protect patient privacy and confidentiality, as guided by several laws in Canada to protect personal health information. These laws include the eHealth Act, the Freedom of Information and Protection of Privacy Act, and the Personal Information Privacy Act (PHIPPA) (Boothe et al., 2020).

EHR adoption across Canada is highly variable across provinces, with Ontario still in its infancy and Alberta much advanced (Boothe et al., 2020). However, hospitals, clinics, and health units should aim for systems that support data sharing without compromising confidentiality. Also, beyond data management and accessibility, race and ethnicity information provided by patients should be one-time and accessible to every patient's circle of care across settings, as this kind of information is unlikely to change. However, this can only be achievable through the interoperability of health record systems at provincial and national levels.

5.2   Practices

Administration of data collection tools

The articles noted that registration staff, medical assistants, research assistants, nurses, volunteers, and student researchers can administer data collection tools. It can also be self-administrated with or without support for completion provided to the respondent. Whichever method is decided, the pros and cons should be thoroughly examined to ensure data completeness. Some advantages of self-administered questionnaires are that respondents can see the questions and they have privacy when responding. Its disadvantages include poor data quality, literacy bias, and low response rates. However, prenotification may be used to address low response rates (de Leeuw, 2008; Islam et al., 2010). Administered questionnaires are advantageous because the interviewer may be able to convince reluctant patients to respond and provide guidance and additional explanations for completion. On the cons, the presence of an interviewer may negatively impact the response provided because of the sensitive nature of the questions being asked (de Leeuw, 2008).

Although providing this type of information is usually voluntary, ensuring that respondents receive adequate information about why the data is collected and what it will be used for is critical, mainly because of the distrust in the health system by minority populations that have experienced discrimination in the type and quality of care that they receive. Failure to inform patients of this could lead to decreased health service utilization, thereby limiting access to health services and further widening disparity gaps that the data collection attempts to close. It is advised that the decision on how the data collection tool will be administered should be contextualized and consider the health

settings' staff strength, the format of the tool (paper-based or electronic), and the catchment population of the setting to determine whether language would be a barrier to receiving responses and where it is, translation of the tool into the most common languages or the use of an interpreter is advised.

As evidenced in this review, data can be collected during patient registration, in the examination room, in a waiting room, at discharge, and during outpatient programs. One framework supported data collection over the phone during COVID-19. The decision on where to collect data would depend on factors such as who would collect the data, staffing, and patient flow. However, data collection should be private, easy, and convenient.

Eventually, because concerted efforts and investments are being made to move records from paper-based to electronic in Canadian health settings, patients should be able to provide race and ethnicity information through a patient portal linked to their hospital records. Nevertheless, the option to respond outside the use of technology to accommodate patients who may be unfamiliar with technology or even unwilling to engage in its use should continually be made available to prevent bias.

Data aggregation

Data aggregation cannot be discussed without referencing the racial and ethnic categories characteristic of the frameworks identified. All US frameworks reference the US OMB race and ethnicity categories. Some frameworks collect granular ethnicity information by identifying racial and ethnic groups common to the locality. The race and ethnicity categories are listed so that patients can identify themselves with one or more on the list.

Palaniappan and colleagues' (2009) framework allowed patients to write their ethnic affiliation, which was then matched to categories in the census ancestry list. Further, in US frameworks, granular ethnic categories are listed in such a way that they can be rolled up into the OMB's two broad categories of Hispanic and non-Hispanic. The inclusion of granular ethnic categories was suggested by the Institute of Medicine in 2008 (Hussain et al., 2024) and has since become a prominent feature of race and ethnicity data collection frameworks in health settings in the US.

Unlike the US frameworks, which had OMB categories as a central reference point for race and ethnicity, the Canadian frameworks did not have a common reference point. Race categories from Statistics Canada and the Toronto District School Board were referenced in a few frameworks, while many others had no reference point. Also, some frameworks combine racial and ethnic identities and refer to them as race categories. This finding agrees with CIHI (2022) that there is a lack of consensus on the standards for data collection. Further, it is evidence that there is a need to agree on standard categories that will act as a reference point to support data aggregation.

Providing patients with categories based on ethnic groups local to the setting's catchment population (granular categories) is a good practice that Canadian health settings could adopt. Granular categories could promote data accuracy and reflect inclusivity because they allow patients to identify their ethnic affiliation within a relevant list easily(US Agency for Healthcare Research and Quality, 2009) and could account for group heterogeneity that is otherwise missed. Further, it would allow healthcare institutions to collect information specific to the locality where they are located to better understand and serve the local populace (US Agency for Healthcare Research and Quality, 2009).

However, there are disadvantages. Coding responses could be laborious (US Agency for Healthcare Research and Quality, 2009), data could be lost during aggregation (Wang et al., 2020), and there could be increased fear of harm and data privacy and confidentiality concerns owing to data granularity (Utah Department of Health and Human Services, 2022). Establishing a reference point that granular categories common to a locality can be rolled into is critical for data aggregation, system-level decision-making, and comparisons. This should be decided upon with relevant stakeholders.

There is a fundamental difference between race and ethnicity (van den Berghe, 1978), and this information is useful individually for providing care to minority populations. However, many authors in this review do not define race and ethnicity. The lack of definition could reflect how the authors understood both concepts and may also explain why race and ethnicity categories were not distinguished in some frameworks or collected in many others. This is erroneous, and the definition of these concepts should guide how they are thought of, determined, and applied within any framework.

Race is often associated with physical attributes, while ethnicity is related to cultural factors such as language and nationality. Within race, there is also the issue of reflected racial identity vs. the self-expressed one. The conflation of both terms could mask significant differences, e.g., group heterogeneity and cultural beliefs, which are important for framework design, data collection, analysis, and use. Further, precise definitions could improve the knowledge of cultural identities, which could contribute to the success of healthcare quality improvement initiatives.

Some authors have written about the difference between both concepts, reflected and self-expressed racial and ethnic identities (Stevens, 2015) and how they affect health and well-being (Veenstra, 2011), and the need to standardize associated terminologies to avoid misuse (Lewis et al., 2023). Others argue that they are poor markers for the differences in cultural and structural characteristics responsible for health inequity, and the focus should be on scientific evidence (Braun et al., 2007) and that racialization is essentially power-driven (Veenstra, 2009). Nonetheless, both concepts have been implicated in health inequity and should be addressed to promote equity in health service delivery and used to dismantle biased social structures to improve health outcomes.

It is unclear why race and ethnicity data collection in healthcare has not progressed beyond its current state, where efforts are siloed. However, it is worthwhile to ponder whether it has anything to do with the widespread belief that Canada is not a racist country (Gulliver, 2018) even though residents report racist experiences within healthcare (Mahabir et al., 2021; Higgingbottom et al., 2016; Weerasinghe, 2012).

Canada's history of collecting race and ethnicity information relied on perceived identity for visible minorities (Stevens et al., 2015). Before 1996, Statistics Canada deduced racial identities for minorities by combining answers to language and origin questions. In 1996, the census began collecting information on visible minorities because responses to the ethnic/cultural questions typically asked had become unreliable in identifying the visible minority population (Stevens et al., 2015). Canada spent more than a decade neglecting the need to capture race-based information directly through the census and has done the same in healthcare amid the growing numbers of immigrants from diverse racial and ethnic backgrounds. Unfortunately, ignoring the need to collect race and ethnicity

information in healthcare cannot undo health disparities or improve the poor health outcomes of minority populations entrenched in racism in healthcare. Informal conversations with health information management professionals and provincial health staff suggest that some provincial governments are willing to move toward collecting this information. However, the question is when, how, and how soon?

The primary reason for advocating the collection of race and ethnicity data within health settings is not just to gather information, but to analyze and utilize it for making decisions that enhance health equity. Additionally, data collection should be standardized to allow for the aggregation of data from the micro to the macro level. Without these practices, universal health coverage in an inequitable healthcare system serves little purpose.

Collecting race and ethnicity information is vital for any health system genuinely interested in fostering health equity. In Canada, it could be perceived as an act toward reconciliation by Indigenous people based on Call to Action 19 of the Truth and Reconciliation Report because the data will help to address health disparities between Indigenous and non-Indigenous people through the design of targeted culturally sensitive health programs to promote health services access and utilization. However, without a standardized approach to collection, efforts will remain siloed, and the data will continually be fragmented.

5.3   Recommendations from the review

The recommendations for standardizing race and ethnicity data collection within Canadian health settings are anchored in the Tri-Council Policy Statement 2 (TCPS 2) framework. This framework, which guides the ethical conduct of human research,

considers three fundamental principles: autonomy, protection from harm, and fair and equitable treatment (TCPS 2, 2022). These principles align with those of healthcare ethics: autonomy, beneficence, non-maleficence, and justice (Varkey, 2021) and form a basis for the recommendations. For each principle, associated recommendations have been made. Table 6 below presents the recommendations by principle.

Table 7: Recommendations from the review by TCPS 2 principles

S/N	TCPS 2 Principles	Ethical Considerations	Recommendations
1.	Respect for persons	Autonomy	1. Collaborative stakeholder engagement 2. Respect for minority populations' preference for data management 3. Voluntary and informed data collection
2.	Concern for welfare	Protection from harm	4. Careful determination of who should collect the data 5. A private, safe, and convenient location and mode of data collection should be predetermined 6. Data should be integrated with EMR to ensure data privacy and confidentiality and avoid fragmentation
3.	Justice	Fair and equitable treatment	7. Engagement of all populations during framework development and before implementation 8. Development of "exhaustive" options for race and ethnicity categories 9. Data collected should be used for quality improvement and to address health inequities

Race and ethnicity data collection can begin by engaging relevant stakeholders to develop or adapt an existing framework collaboratively. The goal should be to standardize data collection practices, ensuring that racial and ethnic classifications can be aggregated to a

national scale to facilitate decision-making for improved health outcomes for all and close the existing gaps in health equity in Canada.

To effectively collect race and ethnicity information from patients, training clinical and administrative staff in healthcare settings on cultural competence and cultural humility is of utmost importance. This training will equip them with the required skills to engage with patients from diverse backgrounds and help to build trust between patients and healthcare providers. Although frontline healthcare workers in Canada receive this training as part of their medical education, other staff in patient-facing roles do not. So, this would be beneficial to them.

5.4   Study Limitations and Strengths

Firstly, only frameworks from the US and Canada were included in the review. The review did not identify frameworks from the UK, an equally multicultural and racially diverse country where race and ethnicity information is collected in health settings. Although the search strategy incorporated relevant keywords and concepts, its inability to capture UK frameworks could mean that there are limited publications from the UK on the subject, or none of them are published in any of the journals indexed by the databases searched, thus limiting the comprehensiveness of the findings.

Secondly, excluding articles not written in English may have led to the omission of insightful information from non-English publications. Thirdly, the review's sole reliance on frameworks published online may have potentially led to missed information available offline.

Despite its limitations, the study successfully synthesized existing frameworks for race and ethnicity data collection in health settings and highlighted areas for future research. The method employed allowed for the inclusion of both primary research articles and grey literature, enhancing the study's richness (Peters et al., 2021). Additionally, the study integrated perspectives from a range of knowledge bases, including genetics and sociology. Finally, the study offered recommendations based on the TCPS2 principles for developing a race and ethnicity data collection framework tailored to Canadian health settings.

5.5   Conclusion and Future Research

This review of the frameworks guiding race and ethnicity data collection in health settings exposes significant gaps in existing data collection practices in Canada. It offers valuable insights for healthcare leaders to standardize these practices across the Canadian health system. The findings serve as a call to action for all health system stakeholders to pursue health equity actively. Future research is needed to evaluate fully implemented frameworks, providing a clearer understanding of their successes and failures. This will strengthen the evidence base for standardized data collection and support equity-oriented decision-making.

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Appendices

Appendices A: Search terms and databases searched

Database	Search terms	Search date
Web of Science	1. health equity (All Fields) AND data collection (All Fields) AND health system (All Fields) AND race (All Fields) 2. health system (All Fields) AND demographic data (All Fields) AND race (All Fields) AND hospital (All Fields) AND data collection (All Fields) 3. health system (All Fields) AND demographic data (All Fields) AND race (All Fields) AND standard (All Fields) AND data collection (All Fields) 4. health system (All Fields) AND demographic data (All Fields) AND ethnicity (All Fields) AND survey (All Fields) AND data collection (All Fields)	17th April, 2024
MEDLINE (Ovid)	1. data collection.tw,kf. AND Health system.tw,kf. AND race.tw,kf 2. data collection AND health System AND demographic data 3. data collection.tw,kf. AND questionnaire.tw,kf. AND race.tw,kf	26th March, 2024
Scopus	1. (TITLE-ABS-KEY (data AND collection) AND TITLE-ABS-KEY (race) AND TITLE-ABS-KEY (health AND system)) AND TITLE-ABS-KEY (hospital) AND (LIMIT-TO (SUBJAREA , "MEDI") OR LIMIT-TO (SUBJAREA , "SOCI") OR LIMIT-TO (SUBJAREA , "HEAL") OR LIMIT-TO (SUBJAREA , "NURS") OR LIMIT-TO (SUBJAREA , "PSYC")) AND (LIMIT-TO (EXACTKEYWORD , "Article")) 2. (TITLE-ABS-KEY (data AND collection) AND TITLE-ABS-KEY (questionnaire) AND TITLE-ABS-KEY (race) AND TITLE-ABS-KEY (health AND system)) AND (LIMIT-TO (SUBJAREA , "MULT") OR LIMIT-TO (SUBJAREA , "PSYC") OR LIMIT-TO (SUBJAREA , "NURS") OR LIMIT-TO (SUBJAREA , "HEAL") OR LIMIT-TO (SUBJAREA , "SOCI") OR LIMIT-TO (SUBJAREA , "MEDI")) AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re")) 3. (TITLE-ABS-KEY (data AND collection) AND TITLE-ABS-KEY (framework) AND TITLE-ABS-KEY (	18th April 2024

| | ethnicity) AND TITLE-ABS-KEY (questionnaire) AND TITLE-ABS-KEY (health AND system)) AND (LIMIT-TO (SUBJAREA , "MULT") OR LIMIT-TO (SUBJAREA , "PSYC") OR LIMIT-TO (SUBJAREA , "NURS") OR LIMIT-TO (SUBJAREA , "HEAL") OR LIMIT-TO (SUBJAREA , "SOCI") OR LIMIT-TO (SUBJAREA , "MEDI")) | |

Appendices B: Data extraction form

S/N	Extraction domain	Question	Guidance
1.	Characteristics of the articles	What is the title of the article	
2.		What year was it published?	
3.		What type of article is it?	Primary/Grey (*guidance document, report*)
4.	Context of the articles	Has the framework been applied?	Yes/No
5.		Where was it applied?	Country name
6.		Status of application	Full implementation/pilot/recommended
7.		Application setting	Hospital/Clinic/Public Health/Other
8.		What is the level of application?	Micro/Mezzo/Macro
9.	Attributes of the framework	What was the rationale for developing the framework?	As stated by the author(s)
10.		What theory influenced the development?	As stated by the author(s)
11.		Were stakeholders engaged during the development?	Yes/No
12.		What type of stakeholders were engaged	List the stakeholders
13.		Was the data collected integrated into an electronic record?	Yes/No
14.	Components of the framework	In what format is the data collection tool?	Paper-based/Electronic
15.		How is the tool used?	Administered /Self-administer it

16.		What type of questions does the tool ask?	Multiple-choice/Open-ended/Closed-ended
17.		Can the respondent select multiple choices?	Yes/No/Not applicable
18.		What is the data collection participation type?	Voluntary/Mandatory
19.		Race categories	List them out
20.		Ethnicity categories	List them out
21.		Where was the data collected?	List them out
22.		Did the framework include a data collection script	Yes/No

Curriculum Vitae

Name: Oluwabambi Tinuoye

Post-secondary Bowen University
Education and   Iwo, Osun State, Nigeria
Degrees: 2006-2010 Bachelor of Science, Microbiology

University of Surrey
Guildford, Surrey, England
2011-2013 Master of Science, Public Health

The University of Western Ontario
London, Ontario, Canada
2022-2024 Master of Health Information Science

Related Work   Research Assistant
Experience   School of Health Studies, Faculty of Health Science
Western University, London, Ontario
2023-Present

Summer Student
London Health Sciences Center
2023-2023

Teaching Assistant
Western University, London, Ontario
2023-2023

Senior Health Information Systems Advisor
Abt Global
2021-2022

Associate (Health Systems)
Health Strategy & Delivery Foundation
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Senior Analyst (Health Systems)
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