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Special issue: Engaging in culturally responsive research and programs for Black communities

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Editorial

Engaging in culturally responsive and antiracism research and programs for Black Canadian communities

Jude Mary Cénat, PhD, MSc, CPsych (1,2); Aïsha Lofters, MD (3); Josephine Etowa, RN, PhD (2,4)

Introduction

In 2021, Black people represented 4.3% of the general population in Canada.[1] Compared to other racial or ethnic groups, they experienced the fastest growth over the past 20 years, with their population doubling from 662 210 Black individuals in 2001 to 1.5 million in 2021.[1-3] Originating from 182 countries, compared to 230 birthplaces for the general population, Black communities are culturally diverse. They include individuals whose ancestors have been in Canada for centuries, such as those in Nova Scotia, as well as children and grandchildren of immigrants and recent immigrants from countries such as Jamaica, Haiti, Nigeria and Ethiopia.[1]

According to the latest census data, 4 in 10 Black Canadians were born in Canada, while more than three in four Black youth under 14 years old (77% of Black youth born in Canada out of the general population of Black youth aged under 14 years old) were also born in Canada.[1] Compared to the general population, 2021 census data show that Black communities are significantly younger.[1] Overall, 42% of Black individuals are under 25 years of age, compared to 28% in the general population. About 26% of Black people in Canada are under 15 years old, compared to 16% in the general population. Furthermore, only 6% of Black individuals are 65 years and older, compared to 18% in the general population.[1]

These data reflect the unique demographics and dynamics that influence social, economic and educational spheres. They represent a young and dynamic profile, contrasting with the aging observed in the general population. However, Black individuals, regardless of their birthplace, face various inequities that hinder both their physical and mental health, leading to limited access to healthcare services, and to their receiving lower-quality care compared to White communities.[4,5]

Understanding racial health disparities in Black communities in Canada

The physical and mental health disparities in Black communities in Canada reflect a complex combination of systemic, social, economic, educational and individual determinants that structure their experience within society.[6-8] Studies conducted over the last decade have shown that these disparities stem from five main challenges: (1) systemic and institutional racism faced by Black individuals in different areas of society, hindering their physical and mental health;[9] (2) a lack of reliable data preventing the development of evidence-based health policies for Black communities;[10] (3) insufficient training of healthcare professionals, limiting their ability to provide culturally responsive and antiracist care;[11] (4) the absence of political strategies to identify, examine and reduce racial inequalities in healthcare;[4,5,12] and (5) a lack of funding for health research on Black populations.

These inequalities are exacerbated by social determinants of health such as adversity, economic insecurity, precarious employment, income inequality and poverty, food insecurity, inadequate housing, exclusion and experience of racial discrimination, including in healthcare services.[13] Observed disparities include insufficient access to chronic disease screening (e.g. diabetes, hypertension, cancer[14]), limited disease management and self-care.

In the area of mental health, studies published since 2021 have documented the prevalence of and factors associated with depression, anxiety, posttraumatic stress disorder (PTSD), psychosomatic symptoms, alcohol and substance use, suicidal ideation and more.[15-20] They have shown that the prevalence of severe symptoms of anxiety, depression, PTSD and other disorders is significantly higher in Black communities. They also indicate that daily racial discrimination, major racial discrimination in various areas of society (e.g. healthcare, education, interactions with police), racial microaggressions and internalized racism are the main explanatory factors for poor mental health in Black populations in Canada. Furthermore, studies have shown that Black individuals have limited access to mental health care and a heightened distrust of available professionals and services.[21,22]

These inequalities have serious consequences, leading to a reduced quality of life, an increased burden on Black communities and an amplification of socioeconomic inequities. Moreover, the lack of

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evidence and representative studies on the health of Black people in Canada limits policy makers' ability to create effective policies to reduce disparities and promote health equity. This gap also reduces the ability to train students and healthcare professionals on racial issues and to provide culturally responsive and antiracist healthcare. Notably, systematic reviews conducted in recent years have shown disparities in cancer screening and care, venous thromboembolism, psychosis, mental health issues and health behaviours, including vaccine hesitancy among Black youth.[14,21,23-25]

The COVID-19 pandemic exacerbated racial health inequities and highlighted the absence of Black individuals in public health decision-making. Not only were Black people disproportionately affected in terms of infections and mortality, but they were also less likely to get vaccinated against COVID-19,[26,27] hence the need for this initiative to give voice to research documenting various health needs in Black communities by engaging them in culturally responsive and antiracist ways.

A special issue on engaging in culturally responsive research and programs for Black communities in Canada

This special issue presents five articles, including three evidence synthesis articles, one study protocol with methodological reflections about how to engage with Black youth about their mental health needs, and a qualitative research article based on an empirical evaluation of federal funding for mental health initiatives for Black people in Canada.

The first article, by Jamieson and colleagues, is a scoping review that explores the lack of data on racial health inequalities in Canada, highlighting challenges to and opportunities for improving the measurement and monitoring of health disparities among racialized populations, particularly Black Canadians.[28] Using a multistep methodology, the authors examined survey methods used in Canada and comparable countries (United States, United Kingdom, Australia and New Zealand) to identify promising practices for improving sampling strategies and data collection. The results show significant gaps in health surveys in Canada, which do not use targeted sampling strategies, such as utilizing racial or ethnic concentrations at the geographic level to increase the representation of racialized groups. In contrast, similar countries adopt these approaches to produce larger and more representative datasets. The authors recommend the adoption of targeted sampling, oversampling and predictive modelling methods in Canada to better include racialized populations. They also emphasize the importance of integrating race data into administrative databases for more effective monitoring of inequalities.

A second scoping review, by Mombo et al. examines methods of collecting, analyzing and disseminating data on the health and social determinants of Black communities in Quebec.[29] Although Black populations in Quebec represent over a quarter of Canada's Black population, little research on this population exists, including data on the impacts of the COVID-19 pandemic. This review of 43 studies highlights the challenges and strategies for data collection and analysis, focussing on the need for a better understanding of the lived realities of Black populations in Quebec. The studies cover four sectors: health, social services, education and employment.

The third article, by Yusuf et al., is a rapid review that examines culturally and structurally competent approaches to health research with Black communities in Canada's Atlantic provinces.[30] Although Black populations have resided in this region since the late 17th century, they face significant inequalities, including the highest rates of child poverty in the country. Forty-seven studies were included, highlighting the impact of racism, the importance of community engagement and the adoption of participatory research frameworks as culturally appropriate practices.

The fourth article presented in this special issue, by Salami and colleagues, explores how to engage Black youth in research, using a culturally sensitive participatory action research approach to examine their mental health needs.[31] The study involved two phases: individual interviews with 30 youths and monthly conversation cafés with 99 youths over a four-month period. Participants were recruited through community networks in Alberta, promoting youth empowerment and collaboration. The findings were shared with stakeholders, highlighting culturally relevant strategies to improve access to mental health services.

The final study, by Salami et al., examines lessons learned from the Public Health Agency of Canada's Mental Health of Black Canadians Fund, created in 2018 to address mental health inequalities among Black Canadians.[32] This analysis of annual and final reports from 15 projects, as well as interviews with representatives from nine organizations that received funding, reveals three main themes: success factors, challenges encountered and lessons learned. Success factors include honoraria and incentives, participatory action research and Black leadership. Challenges include delays in obtaining funds, the impacts of the COVID-19 pandemic and maintaining partnerships.

Conclusion

This special issue of *Health Promotion and Chronic Disease Prevention in Canada* is of vital importance in highlighting health inequalities among Black communities in Canada and offering solutions to address them. It is even more important in a changing North America, where programs related to equity, diversity, inclusion and accessibility, as well as those aimed at combating anti-Black racism, are increasingly under attack and face an uncertain future. It showcases innovative research on data collection, community engagement and culturally and structurally competent research approaches. The focus is on the need to include more perspectives from Black communities in public health decision-making, improve the training of healthcare professionals and enhance Black representation in funding organizations to better support equitable health policies. This issue represents a crucial step toward addressing current challenges and promoting health equity for racialized populations in Canada.

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Conflicts of interest

The authors declare there are no conflicts of interest.

Statement

The content and views expressed in this article are those of the authors and do not necessarily reflect those of the Government of Canada.

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Evidence synthesis

Race-based sampling, measurement and monitoring in health data: promising practices to address racial health inequities and their determinants in Black Canadians

Margaret Jamieson, PhD (1); Alexandra Blair, PhD (2); Beth Jackson, PhD (2); Arjumand Siddiqi, PhD (3)

This article has been peer reviewed.

Abstract

Introduction: Racial health inequities are explained by inequities in access to medical advice and treatment, and the physiological effects of inequities in material conditions and everyday life; however, Canadian evidence on racial health inequities is limited. This review describes promising practices in population survey methods and approaches that can strengthen sampling, measurement and monitoring of racial health inequities and determinants of health for population subgroups within Canada—particularly Black Canadians.

Methods: We employed three steps to identify promising practices in Canada's peer countries and their applicability to the Canadian context. First, we conducted a scan of websites based on prior knowledge of population-level health surveys and datasets. Second, we conducted a review of publications from 2010 to 2020 to identify any missed surveys and datasets. Third, we conducted a targeted review of Canadian population-level health surveys and data sources to identify challenges to and opportunities for implementing these promising practices.

Results: We identified 20 relevant surveys and data sources from the US, the UK, Australia and New Zealand. In several of Canada's peer countries, information on area-level racial or ethnic concentration of residents is used to conduct targeted sampling strategies, increasing the non-White sample. Our search of the available Canadian datasets found that Canadian health surveys and administrative sources do not routinely incorporate these strategies.

Conclusion: Canada could improve the measurement and monitoring of racial health inequities by applying enhanced sampling practices to collect racial data in surveys and improving procedures for administrative and other routinely collected data sources. There are also novel predictive methods being used to improve sampling of non-White groups, though further investigation of these methods is required.

Keywords: *racism, health surveys, censuses, determinants of health, health equity*

Highlights

- To date, Canadian health surveys have not routinely incorporated strategies to ensure the collection of sufficiently large and representative samples of non-White racialized groups—particularly Black Canadians.
- In several of Canada's peer countries, information on area-level racial and/or ethnic concentration of residents is used to conduct targeted sampling strategies, thereby increasing the sample of non-White groups.
- Canadian survey sampling strategies could be strengthened by incorporating targeted sampling and oversampling to produce larger and more racially representative samples for Canadian health surveys.
- Novel predictive modelling strategies to collect larger and more representative non-White samples and Canadian efforts to routinely include information on race in administrative data sources should receive particular attention.

Introduction

Over the last several decades, there have been advances in our understanding of racial health inequities in Canada. However, we still know very little about them, particularly when compared to the United States (US), where much of the evidence on racial health inequities has been produced—particularly on inequities between Black and White Americans. Research into racial health inequities in Canada has

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been hampered by several factors; notably, the lack of information on race in survey and administrative sources of health data, and insufficiently large or representative samples of non-White groups included in these sources. This review focusses on racial health inequities, a problem that sits at the nexus of three issues: health inequities,[1] anti-Black and other forms of racism[2] and concerns about the availability of insightful data about marginalized populations—particularly racialized Canadians.[3-5]

There is a well-established body of scientific evidence on racial health inequities—differences in health status across racial groups that are attributable to unjust causes.[1] This research overwhelmingly comes from the US, and demonstrates that racial health inequities have persistently impacted a wide range of health outcomes across the life course.[6,7] Compared to Whites, most non-White groups have worse health status, with the most egregious inequities occurring between Whites and Blacks.[6] The literature demonstrates that these inequities are attributable to racism, the "cultural and structural system that assigns value and grants opportunities and privileges based on race."[8,p.2] Racism is an organized system that differentially distributes social resources and opportunities based on the hierarchical ranking of racial groups, and includes the concepts of "settler colonialism,"[9] "racial capitalism"[10] and "orientalism."[8,11] These systems shape the distribution of resources, opportunities and power to favour and enable White hegemony, and have all been defined as the supporting "pillars" of White supremacy.[11,12]

The history of Black people in Canada—including historically enslaved and not enslaved Black people, and the proportionately larger group of Black immigrants who arrived following the abolition of slavery in the British Empire—is distinct from the history of Black people in the US.[13-15] Consequently, it is critical that Canada understands its own racial health inequities, rather than relying solely on evidence from other countries. Within Canada, health inequities are often most prominently documented between Whites and First Nations, Inuit and Métis people. The impact of colonialism, anti-Indigenous racism, enslavement and forced assimilation on the health of Indigenous peoples cannot be understated.[16] Forced displacement, systematic discrimination and the effects of the residential school systems are among other factors that have contributed to consistently poor health outcomes.[17]

Remarkably, we know very little about racial health inequities in key population health benchmarks, such as mortality and life expectancy. Population-level statistical evidence describing how racial health inequities vary by intersecting social positions is sparse in Canada. A major concern is that the best available population-based statistics measuring racial health inequities in Canada are still derived from very small, nonrepresentative samples of non-White groups. The ability to capture specific forms of racism, such as anti-Black racism, in Canada is limited by small samples of Black Canadians—a group representing 4.3% of the Canadian population in the 2021 census.[18] Our aim in conducting this review is to describe promising practices in population survey methods and approaches that can strengthen the measuring and monitoring of racial health inequities and determinants of health for small population subgroups within Canada—particularly Black Canadians.

Methods

We employed three key steps of data collection: (1) purposeful sampling of datasets in Canada's peer countries based on prior knowledge; (2) a scoping review of academic literature in Canada's peer countries; and (3) a website search of Canadian data sources.

Step 1: purposeful sampling of datasets based on prior knowledge

First, we conducted a scan of websites based on our prior knowledge of population-level health datasets. This "purposeful sampling"[19] strategy to produce a list of data sources was based on existing knowledge of the senior investigator of this paper (AS) gleaned from 20 years of population-level research into health inequities and the social determinants of health in the US and Canada. We restricted our search to data sources that are available in Canada's "peer" countries, which we defined as the set of countries categorized as "liberal market economies."[20,21] These countries are all longstanding, high-income democracies that receive large numbers of immigrants from around the world, and have the resources, institutions and autonomy to conduct population health surveys. Aside from Canada, this group of selected countries consists of Australia, New Zealand, the United Kingdom (UK) and the US.

After identifying our data sources, we conducted a comprehensive website scan for documentation associated with each data source. We created a spreadsheet to record information pertinent to the goals of this review, including information on the types of questions asked, the sample size, the level of subgroups that could be reported upon, and any details or concerns about the validity or reliability of reported measures (available on request from corresponding author).

Data extraction was conducted by one reviewer (MJ), with validation provided by the other authors (AB, BJ, AS), ensuring all relevant aspects of the data source were captured during extraction. We also produced short, narrative descriptions of this information for each dataset, which are available on request.

Step 2: scoping review of academic literature

Next, we conducted a systematic scoping review to capture all the population data sources among Canada's peer countries that have been used to investigate racial health inequities, and thus supplement our purposeful sampling strategy. One author (MJ) drew up preliminary drafts of search criteria, with regular validation from the other authors (AB, BJ, AS). A librarian at the University of Toronto's Gerstein Science Information Centre provided additional consultation and advice. To streamline our search process, we restricted our query to a single database. Our primary objective was to uncover any potentially missed health datasets rather than to compile a comprehensive list of all studies utilizing population-level health data. In consultation with the librarian, we concluded that conducting additional searches in other databases would be redundant. These searches were unlikely to reveal datasets beyond those already identified through our chosen database (MEDLINE) and might instead retrieve datasets not related to health, which would fall outside the scope of our investigation. The final search criteria for MEDLINE are shown in Table 1.

TABLE 1
Search strategy for systematic scoping review

Theme (in title, abstract or keywords)	Search terms
Health record or registry-based data	_((((record* or certificate* or registries or registry) adj (medical or birth or death or dental or hospital or nursing)).ab,kf,ti. OR exp Records/)_
Survey-based data	_((survey* or questionnaire* or census).ti. OR exp "Surveys and Questionnaires"/)))_
Race- or ethnic group-based data	_(exp "Ethnic Groups"/ OR exp Population Groups OR (race or races or racis* or racial or ethnic* or ethno*).ab,ti,kf. OR ((african adj3 american*) or (black adj2 (individual* or person* or people*))).ab,ti,kf.)_
MEDLINE search string: _((((record* or certificate* or registries or registry) adj (medical or birth or death or dental or hospital or nursing)).ab,kf,ti. OR exp Records/) AND ((survey* or questionnaire* or census).ti. OR exp "Surveys and Questionnaires"/))) AND (exp "Ethnic Groups"/ OR exp Population Groups OR (race or races or racis* or racial or ethnic* or ethno*).ab,ti,kf. OR ((african adj3 american*) or (black adj2 (individual* or person* or people*))).ab,ti,kf.)_	

Results were limited to English language, human research subjects and publication between 2010 and 2020. Papers went through title and abstract screening (MJ, AS), followed by full-text screening (MJ, AS) in which the following exclusion criteria were applied:

- Duplicate papers
- Full paper not available
- Not an English language publication
- Not conducted in a Canada-peer country
- Does not measure race or ethnicity, or is not chiefly focussed on race
- Data source is neither a survey nor an administrative data source (i.e. data source is a cohort study, or a non–population level registry that was not linked to a larger dataset)
- Data source described is not focussed on health
- Data source described is focussed on the delivery of clinical care
- Data source is a subnational cancer registry
- Study described sampled populations from within the described dataset sample
- Opinion piece or commentary

Some papers were excluded if they used surveys that were technically related to "health," but focussed more specifically upon healthcare or healthcare workers (as in the Nurses' Health Study), or upon diet (as in the UK's National Diet and Nutrition Survey). Covidence software[22] was used for the screening stage of the scoping review, followed by data extraction (MJ, AS) to obtain the same parameters of information as yielded in the initial website scan. The final PRISMA diagram for the scoping review is shown in Figure 1.

Because the goal of this scoping review was to glean information about available data sources in the literature, we sorted included papers into five general categories throughout the screening and extraction process:

1. Papers using large survey datasets not otherwise identified in Step 1
2. Papers using survey datasets that we had already identified in Step 1
3. Papers using survey datasets that have been linked to administrative datasets, other large surveys, census data or other data sources that are nationally representative
4. Papers using population-level cancer datasets focussing on race and ethnicity
5. Papers about survey and data linkage methods focussing on race and ethnicity

Given that the focus of this review was to learn more about the datasets themselves, there was no rigorous data extraction of these papers, and they have not been cited here (details are available upon request). Having now identified gaps in our sample of relevant surveys and datasets, we consulted available websites from data stewards to obtain the relevant information on sampling procedures and other details about the surveys and data sources.

Step 3: website search of Canadian data sources

Finally, we sought to identify the relevant sources of Canadian data, conducting a focussed search of Statistics Canada's websites, as well as the websites of data stewards in Ontario, British Columbia and Manitoba. Included data sources were limited to those that included questions (in the case of surveys) and reporting variables (in the case of the administrative data products) on health. For the surveys, we chiefly identified these first by filtering Statistics Canada's list of surveys and statistical programs by keyword,[23] then by consulting the questionnaires themselves. Although our main interest was in surveys or sources that were still being actively updated (such as the census) to inform future practice, we also included sources for which data collection had ended (such as the LSIC*). These were deemed relevant because they could still be actively used by Canadian researchers to answer health-related questions, and therefore their data collection biases could impact findings. Surveys that only contained information on activity limitations, but no other health questions, were not included.

Information on all data sources was reviewed in 2024, to capture any changes to methodologies that might have occurred since initial data collection and abstraction.

Results

Peer country datasets

In total, 20 international datasets were identified through Steps 1 and 2. In Step 1, the purposeful sampling procedure yielded the 11 surveys or administrative sources of data listed in Table 2 and described in Table 3. A comprehensive summary of the data sources is available from the authors upon request. Of these 11 data sources, nine were based in the US and two in the UK. Nine data sources were national population-based surveys (BRFSS, HRS, NHANES, NHIS, Add Health, NSAL, PRAMS, BHPS and HSE), while two sources (CDC WONDER and HIP) were based on administrative sources of data.

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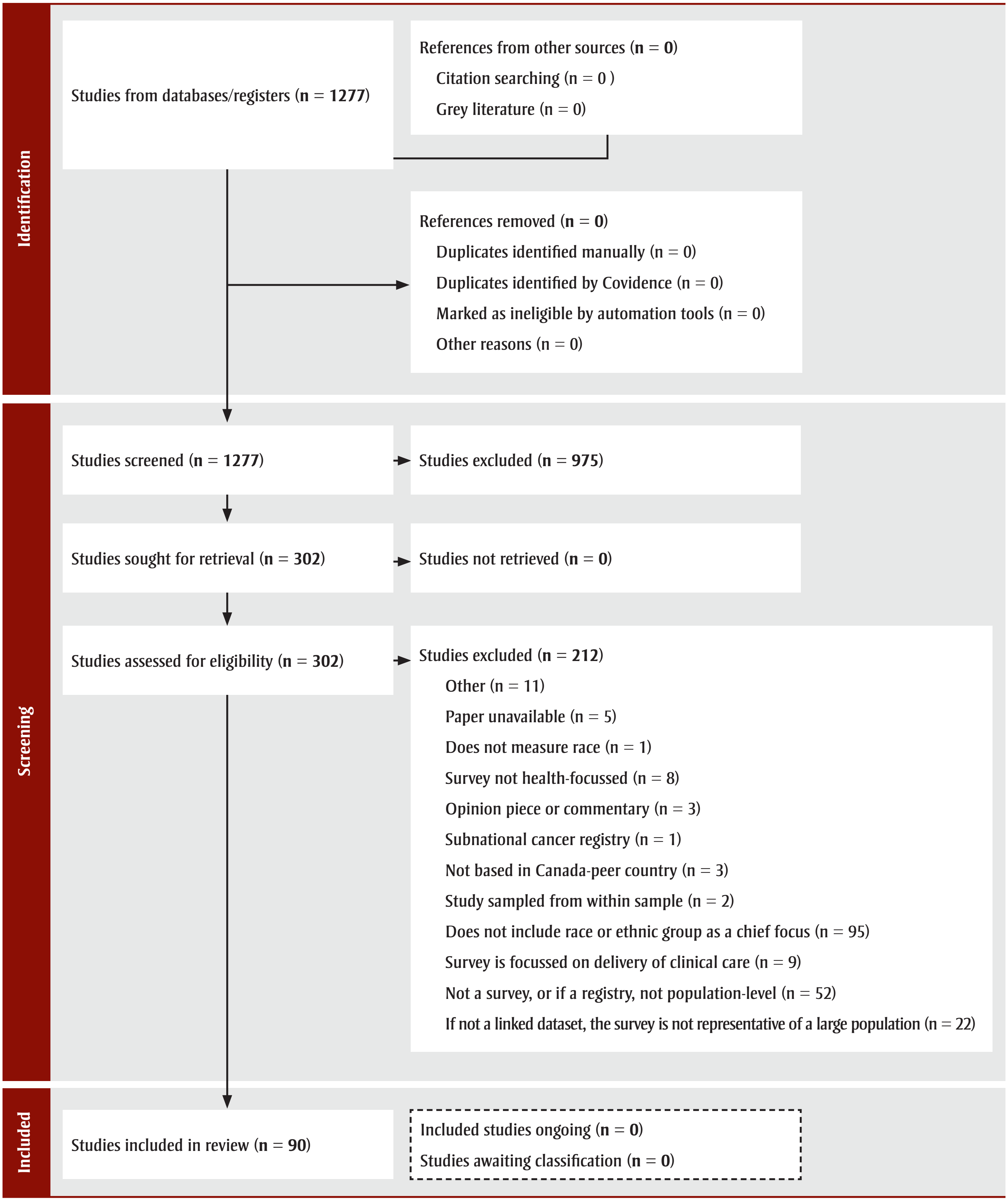
* See Table 2 for full names of surveys.

FIGURE 1
PRISMA diagram



Note: PRISMA template from Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372:n71. https://doi.org/10.1136/bmj.n71

TABLE 2
Data sources from Canada and peer countries identified in Steps 1 to 3

Peer country datasets identified in Step 1 (purposeful sampling)	
Dataset	**Country**
Behavioural Risk Factor Surveillance Survey (BRFSS)[24]	US
British Household Panel Survey (BHPS)[25]	UK
CDC WONDER[26]	US
Health and Retirement Study (HRS)[27]	US
Health Inequality Project (HIP)[28]	US
Health Survey for England (HSE)[29]	UK
The National Health and Nutrition Examination Survey (NHANES)[30]	US
The National Health Interview Survey (NHIS)[31]	US
National Longitudinal Survey of Adolescent Health (Add Health)[32]	US
National Survey of American Life (NSAL)[33]	US
Pregnancy Risk Assessment Monitoring System (PRAMS)[34]	US
Peer country datasets identified in Step 2 (systematic scoping review)	
Dataset	**Country**
California Health Interview Survey (CHIS)[35]	US
Mortality Disparities in American Communities Survey (MDAC)[36]	US
Midlife in the United States (MIDUS)[37]	US
New South Wales Population Health Surveys (NSWPHS)[38]	Australia
New York City Community Health Survey (NYCCHS)[39]	US
New Zealand Health Index and Associated Population Health Registries (NHI)[40]	New Zealand
New Zealand Health Survey (NZHS)[41]	New Zealand
Surveillance, Epidemiology and End Results (SEER)[42]	US
Understanding Society: The United Kingdom Household Longitudinal Study[43]	UK
Canadian datasets identified in Step 3 (website search)	
Dataset	**Source/repository**
Canadian Community Health Survey (CCHS)[44]	Statistics Canada
Canadian Health Measures Survey (CHMS)[45]	Statistics Canada
Canadian Health Survey on Children and Youth (CHSCY)[46]	Statistics Canada
Canadian Health Survey on Seniors (CHSS)[47]	Statistics Canada
Canadian Housing Survey (CHS)[48]	Statistics Canada
Canadian Survey on Disability (CSD)[49]	Statistics Canada
Census-linked health records[50]	Statistics Canada
Hospital Mental Health Database Metadata (HMHDB)[51]	Canadian Institute for Health Information (CIHI)
Labour Force Survey (LFS)[52]	Statistics Canada
ICES (formerly Institute for Clinical and Evaluative Sciences)[53]	ICES
Manitoba Population Research Data Repository (MPRDR)[54]	MPRDR
Longitudinal Survey of Immigrants to Canada (LSIC)[55]	Statistics Canada
National Population Health Survey (NPHS)[56]	Statistics Canada
National Longitudinal Survey of Children and Youth (NLSCY)[57]	Statistics Canada
Population Data British Columbia (PopData BC)[58]	PopData BC

Abbreviations: UK, United Kingdom; US, United States.

TABLE 3
Descriptions of health surveys and administrative data sources in Canada and Canada's peer countries[a]

Name and country/ area of dataset	Years of data availability	Target population	Sampling frame	Linkage, sampling strategy
Behavioral Risk Factor Surveillance Survey (BRFSS; US)	Information presented as of 2023 cycle, but survey dates to 1985	Adult US residents	Adults living in households, excluding vacation homes, group homes and institutions	State-specific sampling strategy based on landline and cellular telephone numbers. The landline strategy first divides each state into blocks (e.g. streets) within each state into high-density and low-density strata. This is somewhat analogous to a "probability proportional to size" method of sampling, which is the primary strategy for surveys such as NHIS and NHANES. Since 2017, 11 states have also engaged in oversampling strategies, to obtain larger samples of American Indians[b] and Alaskan Natives.[b] Each state may also have additional oversamples (by race, region and so on).
British Household Panel Survey (BHPS; UK)	Information presented as of latest wave prior to merging with Understanding Society in 2018 cycle, but survey dates to 1991	Population of the UK	Households sampled in 1991	The initial sample of 5500 households was obtained through a stratified, clustered design that drew on the Postcode Address File. Additional samples from Scotland, Wales and Northern Ireland were also added.
Health and Retirement Study (HRS; US)	Information presented as of 2020, but survey dates to 1992	Older adults in the US	Residents of the contiguous US, aged 51–61 at the collection of each wave, following through to subsequent waves; excludes institutionalized populations	Linked to US death records. HRS uses a multistage, area-level probability sample of US households. In the first stage, US geographic regions (e.g. cities, counties) are selected using probability-proportionate-to-size logic. In the second stage, area segments are sampled within these regions. Finally, housing units, and then "household financial units" within household units are selected. HRS includes oversamples of Blacks, Hispanics[b] and residents of Florida. For example, based on 1990 census data, census block groups containing more than 10% of Black-led households were located and placed in a separate stratum in the second stage of sampling. This stratum was oversampled, and thus people in this stratum had a higher probability of being selected for the sample. This strategy increased the Black sample from 10% to 18.6% of the overall HRS sample.
Midlife in the United States (MIDUS; US)	Information presented as of the latest cycle in 2014, but first survey dates to 1995/96	Americans in mid-life	All noninstitutionalized, English-speaking adults, 25–74 years of age, in the contiguous US	The baseline sample consisted of four subsamples: (1) a national random-digit dialling sample (n = 3487); (2) siblings of individuals from the national random sample (n = 950); (3) oversamples from five metropolitan areas in the US (n = 757); and (4) a national random-digit dialling sample of twin pairs (n = 1914).
National Survey of American Life (NSAL; US)	Survey conducted between 2001 and 2003	Population of Black and White persons in the US	Sampling based on a national household probability sample	Sampling was based on area-level density of African-American and Afro-Caribbean people, and Whites were selected from the same geographic areas, so that racial groups represented in the survey had similar contextual and geographic characteristics.
New Zealand Health Survey (NZHS) (New Zealand)	Information presented as of 2023/24 cycle, but survey dates to 1992/93	"Usual resident" population of New Zealand of all ages, including those who live in private dwellings	Population excluding residents of nonprivate dwellings, foreign diplomats, individuals located on islands other than the North, South and Waiheke islands	Information can be linked to other sources from the New Zealand government, asks for consent to link data. No explicit information on linkage is provided, but respondents are asked to provide their date of birth, address and name for linkage. Uses a multistage, stratified, probability-proportional-to-size sampling design, intended to sample 14 000 adults and 5000 children yearly. Uses a dual-frame approach in which respondents are selected from an area-based sample and a list-based electoral roll sample, with the aim of increasing sample sizes for Māori and other ethnic groups. NZHS uses two sampling strategies, done explicitly to increase the number of specific ethnic groups (Māori, Pacific and Asian respondents) in the sample. The first strategy uses clusters of blocks as primary sampling units, and conducts a multistage, probability-proportional-to-size method to select households. Block clusters are also differentiated by the proportion of Pacific and Asian residents, also done to increase the sample size of these groups. The second strategy uses New Zealand electoral rolls, in which Māori ethnicity is self-identified, to increase the sample of Māori. The electoral rolls are used to locate block clusters that have a higher proportion of Māori residents, and then households from these block clusters are differentially selected.

Continued on the following page

TABLE 3 (continued)
Descriptions of health surveys and administrative data sources in Canada and Canada's peer countries[a]

Name and country/area of dataset	Years of data availability	Target population	Sampling frame	Linkage, sampling strategy
Health Survey for England (HSE; England)	Information presented as of 2022 cycle, but survey dates to 1991	Population of private households in England	Households in England, excluding institutional population	Information from some health and medical records could be added to the responses given in the survey, asks consent for this information. Survey uses name, address and date of birth to identify health records before they are linked to the anonymized survey data. Links hospital episode statistics data, mortality data, cancer registration data. Survey used a stratified random probability sample of households. 2018 survey oversampled the North East and East Midlands regions to ensure a minimum sample size of ~700 adults. In some years, the core sample is augmented to boost the number of responses from certain populations such as ethnic groups, older adults or children; however, no such boost was done to the 2022 survey. In 2004, the HSE focussed on the health of ethnic minorities, in which they obtained "boost samples" (i.e. oversamples) of several non-White racial and ethnic groups. These oversamples were based on targeting of areas in which these groups were in high proportions.
National Longitudinal Survey of Adolescent Health (Add Health; US)	Fifth wave of data collection presented (2016–2019), but earliest survey wave dates to 1994	Adolescents in the US and their parents and partners (in some waves only)	Adolescents sampled from American high schools in Grades 7–12 in 1994/95	Data for individual respondents linkable across other waves of the survey. Initial wave composed of two samples: a school sample and an in-home sample. The school sample was collected through a stratified, random sample of all high schools in the US. Stratifying variables included region, urbanicity, school size, school type (public, private, parochial), percent White, percent Black, grade span and curriculum (general, vocational, etc.). The in-home sample consisted of a core sample from each community plus some oversamples. Contains an oversample of Black individuals with at least one parent who has a college (undergraduate) degree, which ensures broad socioeconomic representation of Black people in the sample. Similarly, Add Health also includes oversamples of Asians, Cubans and Puerto Ricans to ensure their representation in the sample. The oversamples were obtained through individuals' responses on school questionnaires.
National Health Interview Survey (NHIS; adults, US)	Information presented as of 2023 cycle, but survey dates to 1957	Adults in noninstitutional households	Households in the US	Linkage done to other data sources using last 4 digits of social security number or Medicare number. Cross-sectional household interview survey, with sampling and interviewing occurring continuously throughout the year. Sample strategy is redesigned every 10 years. The total sample is subdivided into 4 separate panels, such that each panel is representative of the US population. The probability of an area being selected is not equal. Rather, areas are stratified by sociodemographic characteristics, and the probability of an individual being selected is higher in some strata than others. This methodology of "oversampling" for some characteristics ensures that the survey will have sufficient representation of these characteristics to enable robust analyses of them. Thus, until 2016, NHIS contained oversamples of several racial and ethnic groups (Blacks, Hispanics,[b] Asians were all oversampled by 2006). However, in the 2016 redesign, there are no longer oversamples of racial groups. A new sample design based on the 2020 census will be introduced in this NHIS in 2025, though details have not yet been revealed.
National Health Interview Survey (NHIS; children, US)	Information presented as of 2023 cycle, but child component of survey dates to 1997	Children under 17 y in noninstitutional households	See NHIS (adult) entry, above	See NHIS (adult) entry, above

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TABLE 3 (continued)
Descriptions of health surveys and administrative data sources in Canada and Canada's peer countries[a]

Name and country/ area of dataset	Years of data availability	Target population	Sampling frame	Linkage, sampling strategy
National Health and Nutrition Examination Survey (NHANES; US)	Information presented as of 2017–2020 cycle, but survey dates to 1971	National, noninstitutional residential population	Noninstitutionalized civilian population residing in the 50 states and the District of Columbia	Linkage using social security number provided during survey, when linkage is performed. Multiyear, stratified, clustered 4-stage sample, with sampling units and their tiers identified under "sampling unit." Oversamples are produced for several racial and ethnic groups, including Blacks, Hispanics[b] and Asians. Oversamples are also produced for all those who fall below 185% of the US poverty threshold, and for those at either end of the age distribution. These oversamples are produced by using US census data to locate areas with higher proportions of individuals with these characteristics. Nonetheless, there is some data to indicate poorer people and Black people may be more likely to be missing from the sample, and more likely to have missing data in the survey.
New South Wales Population Health Surveys (NSWPHS; Australia, NSW)	Information presented as of 2023 survey	Adults and children of NSW	Varies by survey	Random-digit dialling of both landline and mobile phone users. No further information is found about sample design for the adult survey, although the school student behaviour survey samples schools. Publicly available methodological documentation has not been updated since 2011.
California Health Interview Survey (CHIS; US, California)	Information presented as of 2023 cycle, but earliest information available as of 2001	Population of California	Sample of California addresses, with initial communication about the survey completed with a letter to the address, followed up with a phone call	Prior to 2019, CHIS used a telephone-based sampling frame. In 2019, CHIS converted to an area-based sampling frame, with households stratified by area (i.e. counties) in ways that capture larger racial and ethnic groups in California. Uses a novel predictive modelling methodology to obtain samples of smaller racial and ethnic (and other sociodemographic) subgroups that are more difficult to capture through area-based sampling. To do so, the previous year's CHIS was linked to several other sources of data, including voter registration databases and consumer databases, census planning data. Random forest models were run to predict households that had residents who are Filipino, Vietnamese and so on. Households that had residents with these characteristics were placed in a separate stratum, and residences and then individuals were randomly selected within this stratum. Additionally, in 2023 the survey introduced an oversample of numbers associated with pre-paid cell phones, which are more likely to be used by Hispanics,[b] people with lower education and lower income, and other underrepresented groups.
New York City Community Health Survey (NYCCHS; US, New York City)	Information presented as of 2020 cycle, but survey dates to 2002	Adult population of New York City, living in nongroup settings	Adults aged 18+ living in the 5 boroughs of New York City, with access to either a cell phone or landline	Stratified random sample based on neighbourhood of inhabitant (ascertained using zip codes). Ten thousand households are randomly selected from a sample of phone numbers that are stratified by neighbourhood.
Understanding Society (UK)	Information presented as of 2021–2023 cycle, but survey dates to 2009	General population aged 10+ of the UK	Households in Great Britain and Northern Ireland	Asks for consent to link responses to government records, including health records. The sampling strategy contains multiple components. The General Population Sample (approximately 26 000 households) is a clustered and stratified probability sample of households in Great Britain and a simple random sample of households in Northern Ireland. The survey also contains an ethnic minority boost sample (approximately 4000 households) selected from areas of high ethnic minority concentration in 2009–2010 where at least one member was from an ethnic minority group. An immigrant and ethnic minority boost sample (approximately 2900 households) was added in Wave 6 (2015) of the study, and it was also obtained from areas of high ethnic minority concentration in that year. Finally, a sample from the BHPS (approximately 8000 households) was added in Wave 2.

Continued on the following page

TABLE 3 (continued)
Descriptions of health surveys and administrative data sources in Canada and Canada's peer countries[a]

Name and country/ area of dataset	Years of data availability	Target population	Sampling frame	Linkage, sampling strategy
Pregnancy Risk Assessment Monitoring System (PRAMS; US)	Information presented as of 2023, but surveillance system dates to 1987	Pregnant women and new mothers	Birth certificate files from each state	Birth certificate and infant death certificate (when applicable) can be used for linkage. Some states also link to Medicaid data and other records. PRAMS samples women who have had a recent live birth, and the sampling frame is the birth certificate file of each state. Each state samples 1300–3400 women per year. Women from some groups (including Black and other racialized groups) are sampled at a higher rate to ensure their representation. The states that sample by race are Alaska, Connecticut, Florida, Iowa, Louisiana, Massachusetts, Michigan, Minnesota, Nebraska, New Jersey, New Mexico, Oregon, Texas, Washington, Wisconsin, Wyoming. Publicly available methodological documentation has not been updated since 2018.
Canadian Community Health Survey (CCHS; Canada)	Information presented as of 2024 cycle, but survey dates to 2001	Canadian population aged 12+ y	Population aged 12+, excluding persons living on reserves and other Aboriginal[b] settlements in the provinces; full-time members of the Canadian Forces; the institutionalized population, children aged 12–17 y that are living in foster care, and persons living in the Quebec health regions of Région du Nunavik and Région des Terres-Cries-de-la-Baie-James.	Data from 2019 survey were linked to tax records of the participants and all members of the participants' households. Variables used for linkage included household information (address, etc.), personal information (social insurance number, surname, age, etc.), and information about household members. The survey uses two main sampling frames: an area Canada frame, and a Canada Child Benefit (CCB) frame for the child sample. The CCHS area frame is designed to serve the Labour Force Survey (LFS). LFS first clusters areas, and the clusters are chosen based on probability proportional to size. CCHS places these clusters into health regions, so that sampling of dwellings from clusters assures representation at the health region level. Within each cluster, dwellings are chosen systematically. For the CCB frame, children are selected by simple random sample.
Canadian Health Survey on Seniors (CHSS; Canada)	Information presented as of most recent 2020 cycle, but the survey dates to 2018	Canadian population aged 65+ y	The target population is individuals aged 65+ y living in Canada's 10 provinces. Exclusions include people living on reserves and other Aboriginal[b] settlements, full-time members of the Canadian Forces, institutionalized populations and persons living in certain regions of Quebec.	Asks for permission to link the responses of the survey to the CCHS and tax data, and reminds participants that their responses may be linked by their provincial governments to other data sources. The sampling design includes selecting those aged 65 y or older who are included in the CCHS, and an oversample in all provinces except Ontario and Quebec (where no oversample was required to read sample target numbers). The oversample obtained through random selection was a sampling frame of all telephone numbers for all households with at least one occupant aged 65 y or older.
Labour Force Survey (LFS; Canada)	Information presented as of 2024 cycles, but latest re-design was implemented in 2007	Noninstitutionalized population of Canada aged 15+	Exclusions from the target population are persons living on reserves and other Aboriginal[b] settlements in the provinces, full-time members of Canadian armed forces, institutionalized populations and households in extremely remote areas with very low population density.	LFS uses a stratified, multistage design. Each province is considered a unit. Within each province, smaller geographic areas (clusters) are selected, and from each cluster, households are selected. LFS uses a rotating panel sample design so that selected households remain in the LFS sample for six consecutive months. Each month, one-sixth of the LFS sample is in their first month of the survey. One feature of the LFS sample design is that each of the six rotation groups can be used as a representative sample by itself.

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TABLE 3 (continued)
Descriptions of health surveys and administrative data sources in Canada and Canada's peer countries[a]

Name and country/ area of dataset	Years of data availability	Target population	Sampling frame	Linkage, sampling strategy
Longitudinal Survey of Immigrants to Canada (LSIC; Canada)	Information presented from first survey conducted in 2001, study later concluded in 2005	The target population consists of immigrants who: arrived in Canada in 2000/01, were aged 15 y or older at the time of landing and landed from abroad, having applied through a Canadian Mission Abroad	Individuals who applied and landed from within Canada were excluded from the survey as they may have been in Canada for considerably longer, and therefore may demonstrate different integration characteristics than those more recently arrived. Refugees claiming asylum from within Canada were also excluded from the survey.	Statistics Canada's website does not list any data linkages, although the Canadian Research Data Centre Network says the survey data has been linked to the Canadian Vital Statistics – Death Database and the Canadian Cancer Registry. The sample was made up of 12 cohorts, or, 12 independent monthly samples. The sampling frame was the administrative database of all landed immigrants to Canada that comes from Immigration, Refugee and Citizenship Canada (formerly Citizenship and Immigration Canada). The sample was first stratified by month of landing, intended province of destination and class of immigrant. The first stage of sampling involved selecting Immigrating Units (which refers to people who apply under the same visa form) within each stratum using a probability-proportional-to-size method. The second stage involved selection of one or more respondents within each Immigrating Unit. The initial sample consisted of 12 000 individuals, which declined to 7700 individuals by the third (and final) wave. Does not seem to have been any sampling by race, although there are groups that have been oversampled throughout the different waves of the survey, including (1) government sponsored refugees; (2) refugees other than government-sponsored; (3) contractor and investor immigrants (economic-business); (4) family immigrants in British Columbia; (5) overall immigrants in Alberta; and (6) economic immigrants in Quebec (economic-skilled and economic-business).
Longitudinal and International Survey of Adults (LISA; Canada)	First wave conducted 2012, latest wave in 2020	Canadians aged 15+ y. The target population excludes those living in Canada's territories, those living on reserves or other Aboriginal[b] settlements in the provinces, official representatives of foreign countries living in Canada and their families; members of religious and other communal colonies; members of the Canadian Armed Forces stationed outside of Canada; those living full-time in institutions, e.g. inmates of correctional facilities and chronic care patients living in hospitals and nursing homes; and those living in other collective dwellings.	The LISA sampling frame includes all households from the 2011 census that were not eligible for the National Household Survey, which was conducted at the same time.	Because part of LISA was integrated with part of the Programme for the International Assessment of Adult Competencies, also known as the International Study of Adults (ISA), households were stratified into ISA and non-ISA samples. Within each of these strata, households were further stratified by province and urban or nonurban status. In the stratum ineligible for ISA, the provincial and urban/nonurban stratification and the geographic clustering were identical to that described above. The selection of dwellings in this stratum, however, was done in only one phase using simple systematic sampling. Again, all members of the households in the selected dwellings became members of the LISA sample and formed the LISA-only sample. For the ISA stratum, there was further consideration of probability proportion to age (15–65 y).
National Longitudinal Survey of Children and Youth (NLSCY; Canada)	Information presented as of latest cycle in 2008/09, but survey dates to cycle 1 in 1994/95	Noninstitutionalized civilian population from Canada's 10 provinces who are aged 0 to 11 y at the time of selection into the study	Exclusions include children living on Indian[b] reserves or Crown lands, residents of institutions, full-time members of the Canadian Armed Forces and residents of some remote regions.	Ability to link is unknown, although the datasets are stored within Statistics Canada's social data linkage environment, suggesting it can be linked to other data sources. The questionnaire booklet only mentions combining data from the given survey year with data from other years, however. NLSCY consists of both longitudinal and cross-sectional samples. Each longitudinal sample is representative of the original (1994) longitudinal sample. Cross-sectional weights are provided that allow age cohorts to be considered representative of a cross-sectional population of a given age group. All NLSCY samples have been drawn from the sample of LFS respondent households (with cycle 1 also drawn from the NPHS sample).

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TABLE 3 (continued)
Descriptions of health surveys and administrative data sources in Canada and Canada's peer countries[a]

Name and country/ area of dataset	Years of data availability	Target population	Sampling frame	Linkage, sampling strategy
Canadian Health Measures Survey (CHMS; Canada)	Information presented as of 2022–2024 cycle, but survey dates to cycle 1 in 2007–2009	Population of Canada aged 3–79 y	Persons aged 3 to 79 y living in the 10 Canadian provinces. The target sample thus excludes those individuals living in the three Canadian territories, people living in institutions in Canada and those in the Canadian Armed Forces.	Data from household survey linked (with permission) to tax records. Individual clinic data linked (with permission) to provincial-level health information using personal health number. The primary sampling unit of the CHMS is the "collection site," which is a geographic unit of about a 50 km radius in urban areas and a 75 km radius in rural areas. Collection sites are stratified by region (British Columbia, Prairies, Ontario, Quebec, Atlantic), and metropolitan region (or other). Within each stratum, dwellings are stratified by age of residents, and broad age category stratification is used to select an individual within a dwelling.
National Population Health Survey (NPHS; Canada)	Information presented as of the latest cycle in 2011, but survey dates to 1994/95	Household residents of the 10 Canadian provinces in 1994/95	Excluded are persons living on Indian[b] reserves and Crown lands, residents of health institutions, full-time members of the Canadian Armed Forces and persons living in some remote areas in Ontario and Quebec.	Survey data can be linked to provincial health information using personal health number, with follow-up surveys asking if the person's health number has changed, to make sure records are kept up to date. The NPHS used the LFS as its sampling frame, with the exclusion of the sample from Quebec, which used the Santé Québec's design for the 1992/93 Enquête sociale et de santé. The LFS design is detailed elsewhere in this report. In brief, LFS sampling strategy relies on clustering geographic areas. The Quebec sample was similarly geographically clustered. In the first cycle of the NPHS (1994/95), households were randomly selected and individuals within households were selected. The initial sample contained 17 726 individuals.
Canadian Survey on Disability (CSD; Canada)	Information presented as of 2017 cycle, but survey dates to 2012, prior to which it was known as the "Participation and Activity Limitation Survey" and earlier still known as "Health and Activity Limitation Survey (Household Component)"	Canadian youth and adults who are facing long-term conditions or health-related problems	All persons aged 15+ y, and who report having difficulty "sometimes," "often" or "always" to one of the activities of daily living questions on the 2016 Census of Population long form. The long form census includes persons living in private dwellings in Canada. Persons living on First Nations reserves and in institutions are excluded.	Responses linked to census, particularly to fill in certain demographic information. Approximately one out of every four households is selected for the long form census. Respondents were stratified to assure appropriate estimation of various age groups, residence in remote versus non-remote areas and severity of disability.
Canadian Housing Survey (CHS; Canada)	Information presented as of 2022 cycle, but survey dates to first survey in 2018	Population of Canada	Population of Canada's 10 provinces and 3 territories, excluding: residents of institutions (including people living in residences for dependent seniors and people living in school residences), members of the Canadian Armed Forces living in military camps and people living on First Nations reserves.	Data linked to tax, income and immigration data by Statistics Canada, as well as potentially to other sources. The sampling frame is the Dwelling Universe File, which is stratified into 43 geographic strata, including the largest census metropolitan area in each province. Each geographic stratum is further stratified between Social and Affordable Housing (SAH) dwellings and all other dwellings. This enables oversampling of those in SAH dwellings. Within each geographic and SAH/non-SAH stratum, dwellings are sorted by predicted household income, and then a systematic random sample is taken to ensure representation of household income.
Canadian Health Survey on Children and Youth (CHSCY; Canada)	Information presented as of 2023 cycle, following the pilot in 2016, and the follow-up in 2017	Children aged 1–17 y in Canada	Children aged 1–17 y in Canada, excluding children living on First Nation reserves and other Aboriginal[b] settlements in provinces, as well as children living in foster homes and other institutionalized children.	With permission, data are linked to household-level tax records, data from other surveys, and provincial health services records (using personal health number). The sampling frame is children who received the Canada Child Benefit (CCB), which, according to 2018 population estimates, covers 98% of the Canadian population aged 1 to 17 y in Canadian provinces, and 96% of this population in the Canadian territories. The CCB file was stratified by province, with territories clustered into a single stratum. In Ontario, further stratification was done by Local Health Integration Network. The sample was then further stratified into three age groups (1–4 y, 5–11 y and 12–17 y). Within these geographic and age strata, children were randomly selected, resulting in a total sample size of 92 170 children.

Abbreviations: UK, United Kingdom; US, United States; y, years.

[a] Additional information available from the authors upon request.

[b] Terminology used in the original survey.

The scoping review (Step 2) yielded nine additional data sources from 89 papers (Figure 1). Although many papers in the scoping review identified datasets of potential interest, only nine were included for this paper. These additional sources are listed in Table 2, and described in Table 3. Of these data sources, five sources were based in the US, two were from New Zealand, one was from Australia and one was from the UK. Five sources were population-based health surveys (CHIS, MIDUS, NSWPHS, NZHS and Understanding Society), while three sources (MDAC, SEER and the NHI) were based on administrative sources of data. All sources contain questions about race or ethnicity, except for the NSWPHS, where it is somewhat unclear.

Canadian datasets

Our search of the Canadian information produced 15 data sources, listed in Table 2 and described in Table 3. All of the surveys contain questions about race or ethnicity, but the administrative data sources generally did not include this information. Table 2 lists these sources, which are described in Table 3.

Characteristics of peer country surveys

For each survey, the target population was all individuals living in households in the country (or state or city in a few cases) in which the survey was being conducted. Some surveys had target populations that excluded some regions or areas. This approach typically excludes people living in institutions, such as prisons or nursing homes, and people experiencing homelessness or precarious housing.

The sampling frame used to obtain the set of households was generally composed of administrative records containing all addresses or telephone numbers of residents in the geographic area. Addresses and telephone numbers were then generally stratified or clustered by various characteristics (including location), then randomly selecting households within each stratum or cluster and finally selecting individuals within each household. One survey (NSWPHS) contained very little information about its sampling strategy. It appeared to use a telephone-based sampling frame, and obtained its sample from random-digit dialling, but it is unclear whether any intermediate stratification steps were taken.

All US-based surveys explicitly incorporated race or ethnicity into their sampling strategy. Usually, this involved creating strata based on census estimates of the racial compositions of areas, and oversampling from strata with higher proportions of Blacks and other non-White groups. This was applied by the BRFSS, HRS, MIDUS, NHANES, NHIS and NSAL. The US Add Health surveys used indicators of the proportion of White and Black students in each school to sufficiently sample from schools with higher proportions of Black students.

An area-based sampling approach to obtain racial representation was also used by the UK's Understanding Society survey. By contrast, other UK surveys (HSE and BHPS) did not include race in their main sampling strategies. However, in some survey years, such as 2004, the HSE incorporated a "boost sample" of non-White people, which it obtained from census-based area-level information to locate places in which high proportions of people of non-White ethnicity reside.[59]

PRAMS used administrative records that contain individual-level race and/or ethnicity information as a sampling frame from which to collect an oversample of non-White racial and/or ethnic groups. PRAMS samples entirely from US birth records, which contain mother's (and sometimes father's) race and/or ethnicity. PRAMS uses the latter information to ensure a sufficient sample of Black and other racialized groups. New Zealand's NZHS also used a source of administrative data as part of its sampling frame, to ensure a sufficient sample of Māori. NZHS also uses census information to locate areas where Māori, Asian New Zealanders and other non-White ethnic groups reside, to ensure they are included in the sample.

California's CHIS is unique for having a very specific mandate to ensure that it collects ample information on the wide range of racial and/or ethnic groups that make up the population of California. Before 2019, CHIS used a telephone-based sampling frame. In 2019, CHIS converted to an area-based sampling frame, with households stratified by area in ways that capture larger racialized or ethnic groups in California. Additionally, CHIS used a novel predictive modelling methodology to obtain samples of smaller racialized or ethnic (and other sociodemographic) subgroups that are more difficult to capture through area-based sampling.

Characteristics of peer country administrative sources

The main source of administrative data in the US that can be used to measure racial and ethnic health inequities is CDC Wonder. This database is hosted by the Centers for Disease Control and Prevention, and contains approximately 11 administrative sources, including all US births and deaths. In some cases, these data are available at the individual level and contain information on individual race and/or ethnicity. In other cases, such as death records, data are available at the area level. Moreover, these county-level data can be readily linked to other data (e.g. census data), which provides county-level information on a variety of social and economic factors. The US-based HIP is a newer source of data that is not hosted by a government entity. HIP links individual-level federal tax return data, social security administrative data and death records in the US between 1999 and 2014. It provides individual-level socioeconomic and demographic characteristics of individuals who died over this period.

SEER is a US cancer registry, though not all states are included. Some SEER data have been linked to data from Medicare, which is the healthcare insurance system for adults aged 65 years and older. Despite being a census of cancer cases for participating states, analysis of racial inequities using SEER data may still suffer from statistical power considerations, due to issues related to the combination of small population sizes (Asian-Americans are given as an example in the documentation) and rare cancers.

New Zealand mandates collection of ethnicity data in its health and disability sector. Each individual who uses health or disability services has a health number, known as the National Health Index (NHI).[60] The establishment of the NHI is accompanied by information on the individual's address, gender and ethnicity. Moreover, other administrative health databases also collect ethnicity data, or can be linked to the NHI. In 2009, an algorithm effectively searched across databases to fill in ethnicity data back to 1989.

Characteristics of Canadian survey sources

Most Canadian health surveys have a target population containing all or virtually all households in Canada. Like US surveys with analogous target populations, this excludes Canadians in institutional facilities, such as prisons and nursing homes, and children living in foster care. Other excluded groups include persons living on reserves and other Indigenous settlements in the provinces; full-time members of the Canadian Armed Forces; and persons living in the Quebec health regions of Région du Nunavik and Région des Terres-Cries-de-la-Baie-James. Other groups that are excluded are persons living in Nunavut outside of the 10 largest communities. Several surveys have sampling frames of all households, with multistage, stratified sampling of these sampling frames producing geographically representative samples.

Some surveys also use administrative databases for sampling frames. The CHSCY and the child sample of the CCHS use the Canada Child Benefit database as a sampling frame, which is also stratified by geographic regions. It also incorporates age strata into its sampling strategy. The CSD samples people who reported having activities of daily living limitations on the long-form census in 2016 (for the 2017 CSD) and 2011 (for the 2012 CSD). The LSIC uses the landed immigrant registry as its sampling frame.

Characteristics of Canadian administrative data sources

Two of the administrative sources were national, while three were provincial health data holdings (British Columbia, Manitoba and Ontario). Statistics Canada has linked the long-form census (which contains information on race and ethnic origin and an extensive set of other sociodemographic and socioeconomic characteristics) to several administrative health records, including births, deaths and hospitalization information, and the Discharge Abstracts Database (DAD). The number of long-form censuses linked to administrative health records varies by health record. The long-form census samples 25% of Canadian households, with the rest receiving the short-form census (which does not query race and/or ethnicity).

At least three provinces have their own administrative data holdings. The most extensive of these appears to be Ontario's holding, named ICES. The main database in ICES is the medical billing and pharmaceutical records data for the province, containing every physician or hospital encounter, and every drug prescription for the province's population. ICES has been linked to several other data sources, though not every individual is covered. At the individual level, there are at least three sources. First, ICES has racial and/or ethnic data through its linkage with the CCHS. Second, an algorithm based on last names that aims to identify people who are South Asian- or Chinese-Ontarians was integrated in ICES. Finally, ICES has a linkage to the immigration administrative database for Ontario that contains information on country of origin, which in many cases can be used as a proxy for race and/or ethnicity. At the area level, ICES is linked to the census, and so area-level ethnic concentration is also available.

PopData BC appears to have fewer racial and/or ethnic data linkages, though again, it was difficult to assess their complete holdings. It appears that PopData also has an algorithm to identify Asian surnames. MPRDR does not appear to contain any race and/or ethnicity information. Both PopData BC and MPRDR's data holdings can be linked to the census to obtain area-level race and/or ethnicity data.

Discussion

Sample frames of surveys in Canada and its peer countries generally included the noninstitutionalized population of the country. The major concern of this strategy is that Black people are overrepresented in some institutions such as correctional institutions and in child welfare; therefore, excluding institutionalized populations may lead not only to greater exclusion of Black people, but also Indigenous and other racialized people in Canada. Black men are overrepresented in the federal prison populations, as 9% of inmates in 2020 were Black men, although they made up only 4.3% of the Canadian population in the 2021 Census.[18,61] Moreover, these populations represent individuals with important health and social experiences that are not being captured routinely, such as the differential health impacts of incarceration or the child welfare system.

US surveys generally attempt to collect sufficient samples of non-White groups in their sampling strategies. For the most part, this is done by using area-level census data to identify areas that have high proportions of households with non-White residents, then oversampling in the strata with higher proportions of non-White residents. This strategy was abandoned by the NHIS in 2016, in favour of simple geographic representation,[62] with an explanation that this new strategy might yield insufficient samples of non-White groups due to low response rates. Even if these groups were sampled in proportion to their populations, it could lead to small samples for small populations. In other words, locating and then oversampling these groups is critical to enable analysis of racial health inequities, provided that response rates can be improved.

Canadian health surveys also mainly use area-level strategies to collect their samples, but they do not typically incorporate stratification of areas by racial and/or ethnic density of residents or conduct oversampling of non-White groups. This lack of appreciation for the importance of appropriate race-based data collection and usage is part of a wider problem in Canadian healthcare, identified in a recent report on race-based and Indigenous identity data collection.[63] Given the availability of area-level information on racial and/or ethnic density through the long-form census, it is technically feasible to add this stratification and oversampling strategy to the current simple area-level strategy. In fact, when the HSE focussed on race and/or ethnicity, it applied area-level identification and oversampling of non-White groups. Moreover, the CHSS oversampled the population of Canadians aged 65 and older by using a telephone sampling frame to locate phone numbers of households with at least one senior.

Some surveys in the US and New Zealand used administrative databases that contained information on race and/or ethnicity as sampling frames to locate non-White people. The US used this strategy for PRAMS, using birth records as the sampling frame, and New Zealand used this strategy for the NZHS, by using electoral rolls to locate Māori. In Canada, two administrative databases containing information on race and/or ethnicity are the long-form census and the landed immigrant registry (used as the sampling frame for the LSIC).[†] The long-form census contains data on race and/or ethnicity, and

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[†] "Landed immigrants" is a term used in the LSIC, which predated the establishment of the legal term "permanent resident" in 2001.[64] Both terms refer to persons who have been granted the right to permanently live in Canada, but who have not yet become Canadian citizens.[65]

the landed immigrant registry contains information on country of origin, which might be used to approximate race and/or ethnicity. However, this approach would not be appropriate for estimating the race and/or ethnicity of newcomers from countries and regions that already have high levels of immigration, such as Europe or the US.

So far in Canada, administrative records have been used as sampling frames for at least two surveys. The CSD obtains its sample from those who reported having limitations in activities of daily living on the Canadian long-form census in 2016 (for the 2017 CSD) and 2011 (for the 2012 CSD). The LSIC obtains its sample from the administrative database of all landed immigrants to Canada, provided by Immigration, Refugees and Citizenship Canada (formerly Citizenship and Immigration Canada).

An outlier in the data sources we reviewed was California's CHIS, which recently began using a novel predictive modelling methodology to obtain samples of smaller racial and/or ethnic subgroups that might not be captured through area-based sampling. The strategy used many available datasets to predict the characteristics of households with residents who belong to specific, small, non-White groups. Once located through predictive modelling, these households were placed in a separate stratum, which was then oversampled. It is unclear whether this strategy is applicable in Canada, but it is worth exploring.

Administrative sources of health data differed significantly between Canada and some of its peer countries, because other countries (US and New Zealand) tend to have race and/or ethnicity contained within the record, and so no linkage is needed to match individuals' health records to their race and/or ethnicity. New Zealand is the gold standard, where ethnicity is tied by law to a national health number and collected during various medical encounters.

By contrast, in Canada, delivery and administration of health services and their datasets is the responsibility of provincial and territorial governments, rather than the federal government,[‡] and race and/or ethnicity data for administrative health records can only be obtained through data linkages (e.g. Canadian long-form census and CCHS). There are limitations to this linkage, however. The long-form census is only administered every five years, so race and/or ethnicity data is only available every five years—meaning racial and/or ethnic information on individuals who were not eligible to complete the long-form census or who did not complete the census is missing. Since the long-form census is only administered to 25% of households, the remaining 75% are not queried about their race or ethnicity—representing a substantial data gap. Adopting pan-Canadian data collection standards is becoming more of a priority, given the important role that appropriate data collection plays in promoting equity.

Strengths and limitations

This review covered an extensive range of topics and considerations, and used in-depth methods to mitigate any omissions. We consulted not only peer-reviewed literature, but also guidance documents written by data administrators and government agencies provided for researchers using the datasets.

The scope of this study was limited to health-related data sources in a few liberal welfare states to facilitate a timely review of data collection strategies and holdings. Other countries likely have additional or unique methods for routinely collecting information on sociodemographic characteristics that could have been informative for this review. Moreover, given our focus on health datasets, we did not identify insights into the collection and aggregation of race-based data in other socio-economic surveys or datasets.

A final limitation is that, because our analysis was chiefly focussed on identifying and comparing the methods employed by surveys and datasets, we did not thoroughly explore the ramifications of these approaches in practice, specifically, the question of whether or not race-based data collection actually captures the perceptions of race that can lead to adverse experiences among racialized individuals. There is a risk that the self-identified race and/or ethnicity data collected by these sources may not be consistent with how people are perceived—a critical factor in how people are treated, and therefore an important social determinant of health status. Most peer country data sources do not contain direct questions about discrimination or racism, and so they may be missing information on this direct pathway through which the health status of racialized individuals is impacted. This issue was explored in a recent Canadian study, in which the authors recommended that an additional question to the effect of: "Are you perceived or treated as a person of colour?" be added to questionnaires to assess whether individuals were experiencing racialization and racial discrimination.[66]

Statistics Canada's General Social Survey also contains data on discrimination, but has far less information on health status, excluding it from the scope of our analysis. Research from it suggests that compared to White people, Black and Indigenous people in Canada experience routinely, and at far higher levels, being treated as not intelligent, receiving poor service in restaurants and stores, being feared by others and encountering other forms of "everyday discrimination" compared to other racial groups in Canada.[67] There is also some evidence that these experiences of discrimination are associated with chronic health conditions.[67] However, given that some forms of racism (such as structural racism) may not be as easily identified through questions like these, there have recently been calls in the literature to find ways to measure structural forms of racism, rather than "only" individual-level experiences of racism.[68,69] We are not able to adequately address these issues in this report.

Notwithstanding these limitations, we believe that the promising practices identified here can be feasibly implemented in Canada, and thereby strengthen data collection to support the study of racial and/or ethnic health inequities. Canadian health surveys should integrate targeted and oversampling strategies to ensure larger, more racially representative samples. Additionally, exploring predictive modelling techniques and incorporating race data directly into administrative sources, such as personal health card information, could enhance the representativeness and utility of health data.

[‡] The exception to this is the health services of First Nations people living on reserves, Inuit, serving members of the Canadian Armed Forces, eligible veterans, inmates in federal penitentiaries and some refugee claimants, which are delivered and administered by the federal government.

Conclusion

Canada's ability to be informed about its racial health inequities lags behind some of its peer countries, primarily the US, New Zealand and Australia, but there are promising practices to be gleaned from these countries. Canada has fairly limited collection of data on race, particularly among administrative sources of data. In the short term, we recommend continuing to expand data linkages with sources that do contain race data (e.g. the long-form census, CCHS), which will increase capacity for analysis of racial health inequities.

To facilitate high-quality research into racial health inequities, we strongly recommend encouraging these data linkages, and additionally, providing researchers with greater detail on the classification of specific racial and/or ethnic groups (while maintaining censorship over small samples). Given the prominent role that racism and discrimination play as social determinants of health, we also recommend that population-level health surveys ask respondents more questions about experiences of racism and discrimination to further this area of research. In the longer term, there must be serious conversations about implementing the routine collection and linkage of race-based data in administrative datasets, such as linking with the long-form census or the use of algorithms to identify race.

Canada's surveys currently do not have mechanisms for capturing large, representative samples of various racial groups. Based on our analysis, we found that Canadian health surveys also mainly use area-level strategies to collect their samples, but they rarely collect sufficient samples of non-White racial and/or ethnic groups. Given the availability of area-level information on racial and/or ethnic density in the census, it seems very feasible to add this stratification and oversampling strategy to the current simple area-level strategy that is being used. In the short term, we would recommend increasing these samples by revising the sampling strategy to include strata that are divided by area-level indicators of race and/or ethnicity, and to oversample from areas with higher levels of Black and other non-White groups. This will also allow for the implementation of more novel predictive modelling methodology (such as that used in the California CHIS) to improve sampling of these populations.

Although many of our data sources and approaches were discussed with a view to improving data collection and analysis of health inequities among Black Canadians, many groups can benefit from this research, including Indigenous folks and other undersampled populations in Canada. There are innovative and feasible methods, demonstrated by peer countries, that can strengthen the collection and usability of race-based data in Canada, ultimately leading to a more inclusive data infrastructure and enabling a more comprehensive understanding of health inequities and evidence-based policy solutions.

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Conflicts of interest

None of the authors has any conflicts of interest to declare.

Authors' contributions and statement

BJ, AS: conceptualization.

AS: funding acquisition.

MJ: investigation.

MJ, BJ, AS: methodology.

MJ, AB, BJ, AS: project administration.

AS: supervision.

MJ, AS: writing—original draft.

MJ, AB, BJ, AS: writing—review and editing.

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Evidence synthesis

Practices for collecting, analyzing and disseminating data on health and its social determinants among Black populations in Quebec: a scoping review

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This article has been peer reviewed.

Abstract

Introduction: The COVID-19 pandemic highlighted the deficiencies in healthcare systems both within and outside of Canada, affecting racialized populations, particularly Black communities, who face an increased risk of infection and mortality from the disease. Although Black populations in Quebec make up more than 25% of the Black population in Canada, detailed data on the impact of COVID-19 on these communities are only available at the national level. This scoping review documents the methods and issues related to the collection, analysis and dissemination of data on the health of Black populations in Quebec, and its social determinants.

Methods: We conducted a review of studies published in English and French from January 2010 to June 2024 by consulting six databases. This review exclusively comprised studies involving data collection from racialized populations, including Black populations in Quebec, and excluded Canada-wide studies involving only a subsample of Black populations in Quebec. The main keywords used were: “data on race”, “ethnic data collection”, “race data collection”, “culturally appropriate”, “health”, “survey”, “questionnaire”, “racial groups”, “racialized groups”, “Black and minority ethnic people”, “people of colour”, “migrants”, “Quebec”, “collecte de données”, “minorité”, “noir” and “ethnicité”.

Results: We selected 43 studies covering four sectors: health, social services, education and employment. We identified the main issues, methods and strategies used to recruit members of Black communities and to collect and analyze data according to ethnoracial categories while minimizing bias to better understand the sociocultural and socioeconomic context of the target populations.

Conclusion: Our review highlights the importance of collecting data on racialized groups, particularly Black communities in Quebec, to support public policies aimed at promoting health equity.

Highlights

- Although Black populations in Quebec make up more than 25% of the Black population in Canada, detailed health data for these populations in Quebec are lacking.
- We analyzed 43 studies published since 2010 that focussed on research conducted among Black populations in Quebec.
- We identified key issues, methods and strategies used to recruit members of Black communities in Quebec, and to collect and analyze data according to ethnoracial categories, while limiting bias to better understand the realities of these populations.
- The results of this scoping review could support public policies focussed on these populations to promote health equity.

Keywords: *racialized populations, ethnoracial data, health of Black populations, collection methods*

Introduction

Collecting ethnoracial data on health and its social determinants raises complex ethical issues.[1] The concept of “race” has no basis in biology (which is why we have chosen to set it in quotation marks throughout this paper), but has long been used as an excuse for discrimination. This fact in turn has led to hesitation in or misperceptions about collecting ethnoracial data in Canada, particularly in Quebec.[2-4] However, these data are crucial for measuring health inequalities and establishing informed public health policies.

For example, Statistics Canada data show that Black Canadians had the highest number of deaths due to COVID-19.[5] In Quebec, the COVID-19 mortality rate was three and a half times higher in neighbourhoods with at least 25% racialized

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populations.[5] Although the Black population in Quebec makes up more than 25% of the Black population in Canada, accurate data on the impact of COVID-19 on Black communities at the provincial level are lacking, and available only at the national level.[5,6] A report by the Direction régionale de santé publique de Montréal (the public health authority in Montréal) provides information on the COVID-19 situation in Montréal, but lacks data analysis by ethnic origin, despite the concentration of cases in the region, which has the largest Black population in the province of Quebec.[7] In contrast, Quebec researchers emphasize the importance of collecting health data based on ethnoracial background.[8]

Compared with the United States and the United Kingdom, Canada has limited experience with the systematic collection of ethnoracial health data within provincial health systems.[9] However, early initiatives have been rolled out in Eastern Canada, Ontario[10] and Nova Scotia,[11] though their implementation remains difficult and raises significant issues.[2,3]

Despite existing efforts, there is no consensus in Canada or the United States on the standards for collecting ethnoracial and sociodemographic data.[12,13] How to define the identity of racialized populations, particularly Black populations, is still under debate.[14-17] Additionally, the most relevant social determinants of health for understanding health equity issues of Black populations in Canada, and particularly in Quebec, are not clearly defined, nor is the method for obtaining these data.[18,19]

Throughout the COVID-19 pandemic, the Institut national de santé publique du Québec (INSPQ) and the regional public health authorities (particularly in Montréal) collected data by age, gender and territory or borough of residence.[7,20] These data indirectly indicate a higher number of COVID-19 cases in areas of Montréal with a greater proportion of visible minorities.[7,21] However, Quebec still lacks systematically collected health data based on ethnoracial background. The purpose of this article is to document the methods and issues involved in collecting, analyzing and disseminating data on the health of Black populations in Quebec, and its social determinants.

We conducted a scoping review to identify studies dealing exclusively with Black populations or racialized groups, including Black populations in Quebec, to analyze the methods and issues faced by researchers.

Methods

Scoping reviews "aim to map rapidly the key concepts underpinning a research area and the main sources and types of evidence available, and can be undertaken as stand-alone projects in their own right, especially where an area is complex or has not been reviewed comprehensively before."[22,p.194,23] This review was exploratory and non-exhaustive, providing an overview of the extent of research in the field of health and its social determinants as they pertain to Black populations in Quebec.[24] We applied the PRISMA-ScR approach (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) used by Tricco et al.[25]

Review of studies

The review of studies was carried out in two stages: an initial review in September 2022 and an update in June 2024. We conducted an initial literature search on studies published in English and French between January 2010 and September 2022 by consulting the PubMed, Embase, Social Care Online, Érudit, CAIRN and CINAHL databases. The main keywords used were: "data on race", "ethnic data collection", "race data collection", "culturally appropriate", "health", "survey", "questionnaire", "racial groups", "racialized groups", "Black and minority ethnic people" (which includes "African Caribbean people" and "African people"), "people of colour", "migrants", "Quebec", "*collecte de données*", "*minorité*", "*noir*", and "*ethnicité*" (Table 1). The update was carried out on 3 June 2024 on Google Scholar using the keywords "race-based data collection," "Black" and "Quebec". We consulted the first 20 pages of results. Despite the subjectiveness inherent in this search engine, past scoping reviews and systematic reviews have used it and justified its use.[26-28]

Selection of studies

The two authors (NM and KNLN) independently selected the studies using the Population, Concept and Context (PCC) method[29] based on the following criteria:

- Population: people from Black (skin colour) communities of all ages living in Quebec, regardless of whether they are Anglophone, Francophone or allophone;
- Concept: primary studies focussing exclusively on Black populations in Quebec, or on other racialized groups in Quebec including Black populations in Quebec, in the field of health and its social determinants (employment, education and access to social services); and
- Context: studies conducted between 2010 and 2024 in various settings in Quebec (schools, nonprofit organizations, hospitals, etc.) and published in English or French.

The exclusion criteria were as follows:

- studies involving Black populations in various Canadian provinces in which Black populations in Quebec formed only a subsample;
- studies including "race" or ethnicity as variables that did not involve analysis or reporting of data according to these variables;
- qualitative studies with fewer than five Black participants;
- studies dealing with Black populations in relation to feminism, racial profiling, the criminal justice system or the sociology of racism;
- studies that focussed specifically on the study of sexual diversity in Black populations; and
- reviews, opinion pieces, editorials and organization reports (grey literature).

Once the selection of studies had been completed, the two authors (NM and KNLN) met to review the list based on the previously established inclusion and exclusion criteria. Any discrepancies in the selection were resolved by consensus between the two authors. Additionally, the bibliography of the selected studies was reviewed by both authors to improve the literature search.

Data extraction

Two data extraction tables were developed and used. The following information was recorded for quantitative studies: first author, year, title, location, population, period (or study duration), purpose of

TABLE 1
Research strategy (partial list)

Database	Search terms			
PubMed	(health[Title/Abstract] OR healthcare[Title/Abstract] OR hospital*[Title/Abstract]) AND ("Ethnicity"[Majr] OR "Racial Groups"[Majr:NoExp] "Black*" OR "African*" OR "Caribbean*" OR "Afro*" OR "Person of colo?r*" OR "People of colo?r*" OR "colo?red*" OR "African*"dark-skin*" OR "ethnic minorit*") AND ("Data Collection/methods"[Majr:NoExp] OR "Data Collection/organization and administration"[Majr:NoExp] OR "Data Collection/standards"[Majr:NoExp] OR "Data Collection/statistics and numerical data"[Majr:NoExp] OR "Focus Groups"[Majr] OR "Records/methods"[Majr] OR "Records/organization and administration"[Majr] OR "Records/statistics and numerical data"[Majr] OR "Records/supply and distribution"[Majr] OR "Surveys and Questionnaires/methods"[Majr:NoExp] OR "Surveys and Questionnaires/organization and administration"[Majr:NoExp] OR "Surveys and Questionnaires/standards"[Majr:NoExp] OR "Surveys and Questionnaires/statistics and numerical data"[Majr:NoExp] OR "culturally tailored"[Majr] OR "cultural competent"[Majr] OR "culturally targeting"[Majr] OR "culturally appropriate"[Majr]) Filters: from 2010–2022			
	(("ethnicity data"[Title/Abstract] OR "race data"[Title/Abstract] OR "data on race"[Title/Abstract] OR "ethnic data"[Title/Abstract]) AND (collect[Title/Abstract] OR collection[Title/Abstract] OR collecting[Title/Abstract] OR gather*[Title/Abstract] OR monitor*[Title/Abstract] OR questionnaire*[Title/Abstract] OR survey*[Title/Abstract]) AND (health[Title/Abstract] OR healthcare[Title/Abstract] OR hospital*[Title/Abstract]) AND (Quebec)[Title/Abstract] OR (Québec)[Title/Abstract])) Filters: from 2010–2022			
CAIRN	"collecte de données" W/5 ethnique	limite=10 ans	"ethnic data" W/5 monitor*	limite=10 ans
	"collectes de données" W/5 ethnique	limite=10 ans	"ethnic data" W/5 survey*	limite =10 ans
	"collecte de données" W/5 race	limite=10 ans	"ethnic data" W/5 questionnaire*	limite=10 ans
	"collectes de données" W/5 race	limite=10 ans	"ethnicity data" W/5 collect*	limite=10 ans
	"collecte de données" W/5 minorité*	limite=10 ans	"ethnicity data" W/5 gather*	limite=10 ans
	"collecte de données" W/5 ethnicité	limite=10 ans	"ethnicity data" W/5 monitor*	limite=10 ans
	"collectes de données" W/5 ethnicité	limite=10 ans	"ethnicity data" W/5 captur*	limite=10 ans
	"collecte de données" W/5 noir*	limite=10 ans	"ethnicity data" W/5 captur*	limite=10 ans
	"collectes de données" W/5 noir*	limite=10 ans	"ethnicity data" W/5 survey*	limite=10 ans
	"collecte de données" W/5 haitien*	limite=10 ans	"ethnicity data" W/5 questionnaire*	limite=10 ans
	questionnaire* W/5 ethnique	limite=10 ans	"race data" W/5 collect*	limite=10 ans
	questionnaire* W/5 race	limite=10 ans	"race data" W/5 gather*	limite=10 ans
	questionnaire* W/5 minorite	limite=10 ans	"race data" W/5 survey*	limite=10 ans
	questionnaire* W/5 ethnicité	limite=10 ans	"race data" W/5 questionnaire*	limite=10 ans
	sondage* W/5 ethnique	limite=10 ans	"data on race" W/5 collect*	limite=10 ans
	sondage* W/5 race	limite=10 ans	"data on race" W/5 gather*	limite=10 ans
	sondage* W/5 minorite	limite=10 ans	"data on race" W/5 captur*	limite=10 ans
	sondage* W/5 ethnicite	limite=10 ans	"data on race" W/5 monitor*	limite=10 ans
	"ethnic data" W/5 collect	limite=10 ans	ethnic W/5 data W/5 monitor*	limite-10 ans
	"ethnic data" W/5 gather*	limite=10 ans	ethnicity W/5 data W/5 collec	limite-10 ans
	"ethnic data" W/5 captur*	limite=10 ans	race W/5 data W/5 collect*	limite-10 ans
			race W/5 data W/5 captur*	limite-10 ans
			race W/5 data W/5 survey*	limite-10 ans

study, data collection methods and study design, recruitment methods, variables collected, primary and secondary endpoints, types of analysis, main results, key findings and sources of funding (Table 2). The following information was added for qualitative and mixed studies: theoretical framework applied to data analysis, main topics addressed in the interviews and consent process. The data extracted from the studies have been verified by the two authors (NM and KNLN). Given the exploratory nature of this scoping review, the quality of the selected studies was not assessed.[22]

Data analysis

We analyzed the data using a thematic approach and following the main steps involved in carrying out a research project: (1) devising participant recruitment strategies; (2) determining variables of interest to the researchers; (3) deciding on data collection and analysis methods; and (4) determining the limitations and biases inherent in studies dealing with ethnoracial background (Table 3).

Results

Selection of studies

The initial literature search identified 259 articles from the six databases listed earlier. Once duplicates had been eliminated, 189 articles remained for the two authors to review (titles, abstracts) according to the process described in the PRISMA flow diagram (Figure 1). This resulted in 21 articles being selected and read in full by the authors (NM and KNLN). Eight studies were excluded on the basis that they had not been carried out in Quebec, or involved groups that fell within the exclusion criteria. Following a review of the bibliographic references of the selected articles, an additional six studies were selected. An update carried out in 2024 resulted in the selection of 24 additional articles, bringing the total to 43 studies (Figure 1).

Study characteristics

The studies selected relate to four sectors: health (n = 23), education (n = 14), social services (n = 3) and employment (n = 3), providing a cross-sectoral perspective on ethnoracial data collection on health and its social determinants (Table 2). Descriptive, empirical or experimental studies using qualitative, quantitative or mixed methodologies were selected, with the majority being quantitative (60%). Note that 12 of the selected studies focussed exclusively on Black populations in Quebec—9 on health[30-38] and 3 on education[39-41] (Table 3). The remaining studies relating to health, social services, education and employment were based on various ethnic groups living in Quebec, including Black communities (Table 3). Only 7 studies dealt with COVID-19.[50-52,56,66,67,69]

Recruitment strategies

Common recruitment methods included posters, social media, community media and participation in local events.[31,33,34,36,42-44] However, recruiting individuals from specific populations with distinct characteristics (racialized populations with precarious migratory status) is more challenging owing to the difficulty in identifying them.[44] Some authors preferred direct recruitment strategies designed to build purposeful relationships with the people contacted, such as word-of-mouth,[33] referrals from key informants within the target communities or professionals who speak the language of the people involved.[36,45-47]

Another approach involved working with community groups or students through a participatory research partnership (four studies),[31,41,44,48] or leveraging the expertise of local stakeholders (representatives of community groups, religious leaders).[35,36,38,40] These stakeholders' input was especially useful in identifying Black community members as potential study participants from a database that contained no ethnoracial information.[38]

Only a few studies (n = 7) provided details on the incentives used to boost participation or retention rates.[38,41,44,49-52] Incentives ranged from $0.50 to $20 for participation in a survey, and up to $50 for participation in an interview.[44,49-52] One study reported no financial compensation for participants after taking part in a two-hour interview.[38] In another, despite offering $50 per interview, recruiting and retaining participants proved challenging.[44] In a participatory research study in which 20 high school students were actively involved in data collection and analysis, financial compensation reached up to $500.[41] Nevertheless, 20% of the students withdrew from this study for lack of motivation or to take on other responsibilities.[41] The main reasons for students' participation in the study were: wanting to make a difference in their school, and to take on the researcher's role rather than that of the subject being observed.[41]

Participant consent

The process of obtaining consent was documented in 17 studies, with consent typically obtained before the study began, either in writing[31,34,35,38,39,42,43,47,50,52-55] or verbally.[37,40,49,54,56] In one instance, consent was implied, as individuals were asked to complete a questionnaire on a voluntary basis.[57] In another study on Haitians' beliefs about organ donation, researchers encountered difficulties with some participants, who were reluctant to sign the consent form.[36] Fearing that this would be used as consent to organ donation, these participants offered to sign a joint form involving all members of the focus group to avoid individual responsibility.[36] After the researchers clarified that the consent was limited to the study and addressed participants' concerns, the participants ultimately signed individual consent forms after the focus group.[36] In other studies, individual consent was not required, as the research involved secondary data.[58-63]

In one study examining the links between exposure to SARS-CoV-2, COVID-19-related discrimination and mental health in ethnocultural groups, researchers did not disclose the true purpose of their study, given its sensitive nature. Consequently, participants' consent was voluntary but uninformed, as the study was presented as research on COVID-19 and social distancing.[51] In another study, researchers used a testing method that involved sending fictional resumés in order to document ethnoracial discrimination in hiring.[64]

Variables of interest to researchers

The variables related to ethnicity, "race" and other social determinants of health collected in the selected studies are presented in Table 4. Ethnoracial background and immigration data encompass a range of variables and categories (Table 4). Ethnicity, whether assigned or self-reported, is defined by researchers based on biological (skin colour),[31,34,37,41,47,49-54,56-59,63,64,66,67,69,70] geographical (country of birth or origin)[30,31,33,35,36,38-40,42-48,50-53,56,61,62,64,66-69,71,72] or cultural (mother tongue, home language, religion) [30,31,34,39,46,51,61] markers (Table 4).

TABLE 2
Data extraction table

Authors (year)	Purpose of the study	Population and period	Method and funding	Main results	Findings/implications
Adeponle et al. (2012)[70]	Assess the impact of using the DSM-IV-TR cultural formulation to diagnose psychotic disorders among patients of ethnic minority[a] and immigrant backgrounds	• 323 patients from the cultural consultation service, Montréal Jewish General Hospital • 1999–2009	• Quantitative • Funding: NR	A total of 34/70 cases with a referral diagnosis of a psychotic disorder were rediagnosed as nonpsychotic, while 12/253 cases identified as nonpsychotic received a new diagnosis of a psychotic disorder. Receiving a new diagnosis of a psychotic disorder was significantly associated with being a recent immigrant (OR = 6.05), being non-Black (OR = 3.72) and having been referred by professionals other than physicians (OR = 3.23).	While the results highlight the clinical utility of the cultural formulation to improve diagnostic accuracy, the specific aspects of the cultural consultation that contribute to this outcome remain unknown.
Arcand et al. (2016)[68]	Explore the academic perseverance of permanent resident students in Montréal	• 426 university students in Montréal • 2009–2010	• Mixed • Funding: FRQ–Société et culture	Among the respondents, 40% found it difficult to establish interactions among ethnic groups. Students had difficulty establishing ties with the majority group. Most focus group participants felt that their isolation was mainly due to their difficulties in French. Some were thinking of moving to another province to find a job that matched their training.	Given the apparent inequalities in terms of intergroup relations, returning to university might be detrimental to their stated goal of rapid and successful integration into the host society, particularly the labour market. Returning to university in a migratory context might have a demoralizing effect, since the experience foreshadows the systemic barriers that these students may encounter in their efforts to enter the labour market.
Auger et al. (2012)[30]	Measure perinatal health outcomes among Haitian women and assess modifying factors in terms of severity	• 2 124 520 births in Quebec • 1982–2006	• Quantitative, retrospective • Funding: NR	Compared with Canadian-born mothers, the risk for Haitian-born mothers was 4 times higher for extreme preterm birth, 2 times higher for very preterm birth and 25% higher for moderate preterm birth.	Haitians in Quebec may be a particularly vulnerable group, as they are exposed to poor health outcomes. Additional efforts are needed to assess the health status of the Haitian community and of other minority communities to determine whether other health disparities exist.
Beauregard (2020)[64]	Analyze ethnic relations between Quebeckers in majority and minority situations in terms of access to employment	• 1569 resumés, 523 job offers in Québec City • January to July 2018	• Quantitative • Funding: NR	While female gender decreases discrimination, the analysis reveals an ethnic-gender hierarchy and significant variations among minorities. Racialized women are invited to interviews more often than their male peers.	While the ratio for the Latin American female candidate suggests a lack of discrimination against her, the indicators observed for the Arab and Black male candidates suggest that the latter experience more unequal treatment in Québec City than in Montréal.
Boatswain-Kyte et al. (2020)[58]	Examine racial inequalities related to services from the DPJ in Quebec	• 15 875 Anglophone children aged under 15 y and 4382 children aged under 17 y reported to the DPJ • 2002–2011	• Quantitative, retrospective, longitudinal • Funding: SSHRC, FRQ—Société et culture	Black children's records were reviewed, corroborated, and brought to court 5 times more often than the records of White children. Black children were also 5 times more likely than White children to be placed in foster care. The protection reports of children from other visible minorities[a] were screened in twice as often as those of White children. The inequality rate has gradually decreased over 10 years for other visible minorities[a] but has continued to rise for Black children.	By partnering with communities, child protection services can help support the infrastructure needed to build capacity, improve service coordination and strengthen the community resilience needed to improve outcomes for Black children.

Continued on the following page

TABLE 2 (continued)
Data extraction table

Authors (year)	Purpose of the study	Population and period	Method and funding	Main results	Findings/implications
Boatswain-Kyte et al. (2022)[59]	Examine the results of reunifications of Black children following placement in out-of-home care	• 1395 children received services from Quebec's DPJ • 2002–2011	• Quantitative, retrospective, longitudinal • Funding: SSHRC, FRQ—Société et culture	Black children spend longer periods of time in out-of-home placement and are less likely to experience family reunification compared with other children. Poorer reunification outcomes for Black children are associated with placement instability, the age of the child and reasons for child welfare involvement.	Racial disparities in reunification vary depending on a combination of factors that are unique to the child, their family and the DPJ, as well as the family's external factors. When younger children are reported, being Black significantly reduces the likelihood of reunification. Thus, being Black only leads to inequalities in the presence of other factors.
Boudarbat et al. (2010)[65]	Establish the professional profile of immigrants to Quebec	• 1875 economic immigrants admitted to Quebec • 1997–2000	• Quantitative • Funding: NR	There is a strong correlation between country of origin and the extent to which employment matches expectations for both men and women. Men from Eastern Europe, Africa (including the Maghreb region) and Western Asia are the least likely to be satisfied with their jobs. Among African women, there is a very strong tendency to occupy positions that fall short of their expectations.	The public policy implications of these results relate to the following: (1) the issue of resources dedicated to recruiting and providing information to immigrants in their country of origin; (2) the efforts that the host community must make to help them enter the job market; (3) the need to adjust the selection grid to increase the chances of success of newcomers.
Brousseau et al. (2021)[69]	Explore factors associated with SARS-CoV-2 seroprevalence in healthcare workers during the first wave of the pandemic	• 2056 healthcare workers from 10 Quebec hospitals • July to September 2020	• Quantitative, cross-sectional, prospective • Funding: MSSS	Of the 2056 healthcare workers, 11.7% were seropositive for SARS-CoV-2. The incidence of seropositivity was significantly higher among Black individuals and Latin Americans than White individuals, with an increased risk of 41%. The most exposed workers (support staff) had an increased risk of at least 30%.	The healthcare workers who were the most directly and most frequently in contact with patients were the most affected by COVID-19. Being Black or Latin American was associated with seropositivity. The high risk of SARS-CoV-2 infection among healthcare workers requires making vaccination among this category of workers a priority.
Carazo et al. (2022)[54]	Measure the prevalence of psychological distress among Quebec healthcare workers, whether or not they were infected with SARS-CoV-2	• 4068 patients + 4152 controls • 2020–2021	• Quantitative • Funding: MSSS	The prevalence of high work-related psychological distress was 42%. It was associated with risk factors such as work-life balance, value conflicts and high psychological demands but not associated with SARS-CoV-2 infection. COVID patients were more often men, older, identified as Black, and worked more often as patient healthcare assistants and in long-term care facilities.	Primary prevention measures targeting psychosocial risk factors are needed to reduce mental health risks for healthcare workers.
Collins et al. (2018)[39]	Study the postsecondary pathways of Montréal youth of Haitian origin	• 11 Quebec students of Haitian origin • Period: NR	• Qualitative • Funding: NR	The students' pathways were marked by various financial, institutional and social barriers. They had negative experiences with guidance counsellors during the transition to postsecondary education level. Perceived racism and discrimination emerged as themes in the young people's discourses.	The study provides complex insights on some aspects that may be hidden in studies that traditionally group Haitians into broader categories, such as "Caribbean," "Black" or "immigrant."

Continued on the following page

TABLE 2 (continued)
Data extraction table

Authors (year)	Purpose of the study	Population and period	Method and funding	Main results	Findings/implications
Dagher et al. (2024)[66]	Describe the experience of access to care and access to interpreters during admission to four Montréal hospitals	• 1104 hospitalized patients who tested positive for SARS-CoV-2 • March to June 2020	• Quantitative • Funding: Gilead, the Jewish General Hospital Foundation	There were 36% of immigrants with a language barrier who did not have access to an interpreter during hospitalization. Prior to admission, 14/41 of allophone immigrants had difficulty accessing COVID-19 information in their first language. Among non-White allophone immigrants, 9/27 had difficulty accessing COVID-19 services.	A large proportion of patients had difficulty accessing COVID-19 information and services, which may have increased exposure to SARS-CoV-2 and hospitalizations. After hospitalization, a large proportion of them did not have access to interpreters. Providing information and care in the first language of these communities is important for promoting health equity.
Darwish et al. (2022)[56]	Describe the characteristics of healthcare workers admitted to hospital with COVID-19 and associated risk factors for ICU admission and death	• 150 healthcare workers admitted to four Montréal hospitals between 1 March and 30 June, 2020	• Quantitative, retrospective • Funding: MSSS	Migrants made up 68% of hospitalized workers, with sociodemographic characteristics that were similar to those of Canadian-born workers. Immigrants were more likely to be personal support workers than their Canadian-born colleagues and more likely to be Black. Over 1/3 of workers had not received COVID-19-specific infection control training and over 50% did not always have access to personal protective equipment.	The results of this study are similar to those of a survey conducted by the INSPQ between May 2020 and May 2021, in which personal support workers and foreign-born or Black healthcare workers were 2.2 times, 1.3 times and 2.5 times more likely, respectively, to test positive for SARS-CoV-2 than other healthcare workers. These health disparities are unexplained.
Debrosse et al. (2024)[49]	Explore the links between neighbourhood experiences, the ethnic/ideal alignment of identities and well-being in youths	• 179 young people who were members of racialized groups living in the east end of Montréal • Period: NR	• Quantitative • Funding: FRQ	Youths' neighbourhoods predict the extent to which they perceive that opportunities are accessible to them. Youths who reported more opportunities for people similar to them in their neighbourhood tended to report higher alignment between their racial/ethnic and ideal future identities and higher flourishing.	The findings highlight the connection between neighbourhood factors—such as cues about whether similar people are welcomed, valued and have access to opportunities—and the identities and well-being of Black and Indigenous youths and youths of other racialized groups.
Dufour et al. (2015)[60]	Study the relationships between neighbourhood characteristics and rates of immigrant children reported to child protective services	• 8263 children reported to the DPJ from 505 census areas • 2009–2010	• Quantitative, retrospective • Funding: CIHR, Centre Jeunesse de Montréal	Black children living in Montréal neighbourhoods where there are low education levels, a higher rate of lone-parent families, low population density and a small number of Black children are more likely to be reported to the DPJ.	Analyzing the distribution of reporting rates without considering ethnocultural background underestimates important observable differences. This shows that services need to be adapted to the realities specific to each neighbourhood and ethnocultural group.
Fang et al. (2023)[31]	Study the relationship between discrimination and disparities in healthcare accessibility	• 531 Black people living in Quebec • April 2021	• Quantitative • Funding: CIHR, SSHRC	Black Anglophone participants experienced more discrimination, had fewer healthcare providers, had less access to COVID-19 information during the pandemic and were more dissatisfied with the healthcare system than their Francophone peers.	Discrimination based on racialized identity and language is pervasive in healthcare, reinforcing greater dissatisfaction in this regard, which establishes the intersecting effects of multiple forms of discrimination as unique stressors with detrimental impacts on health.

Continued on the following page

TABLE 2 (continued)
Data extraction table

Authors (year)	Purpose of the study	Population and period	Method and funding	Main results	Findings/implications
Frounfelker et al. (2022)[50]	Study the link between social distancing due to COVID-19 and mental health	• 3183 people living in Quebec • June 2020	• Quantitative • Funding: MUHC Foundation and McGill University	Five classes of individuals were identified based on the perceived aspects of social distancing related to COVID-19: "Low Impact," "Freedom/Flexibility," "Safety," "Family/Home" and "Hardships." People in the "Hardships" class (more often from racialized groups and unemployed) were more likely to report a significant impact of COVID-19 on their mental health (OR = 2.09).	The analysis identified a subgroup of individuals (the "Hardships" class) who presented a higher risk of mental health problems than the rest of the population and who could be prioritized for awareness and intervention efforts. The "Low Impact" class suggests that, for healthcare workers, normalizing an abnormal crisis can be a successful coping strategy.
Gomez Cardona (2012)[32]	Explore the testimonies of children affected by gastrointestinal disorders and those of their mothers	• 5 Haitian families from Montréal • 2008–2009	• Qualitative • Funding: FRQ—Santé	Six therapeutic dynamics were highlighted: (1) multiple care (illness of unknown origin); (2) nutrition and the mother's central role (gas-related illnesses); (3) contagion and withdrawal into the family (illnesses of microbial origin); (4) social suffering; (5) medical/religious approach (prayers and maintaining ties with the community); (6) no medical consultation.	The results confirm that Haitian families' low attendance at the gastroenterology clinic could be due to the following: (1) their ability to treat their children's stomach aches using means other than biomedicine; and (2) the fact that stomach aches are seen as a problem that does not require a medical opinion. Mistrust of healthcare services is due to negative experiences.
Kamanzi et al. (2018)[62]	Study the postsecondary pathways of Quebec youth from immigrant backgrounds	• 20 387 students, including 5334 with at least one first generation immigrant parent. • 1994–2004; 2002–2012	• Quantitative • Funding: NR	The rate of access to postsecondary education is higher among youth from East Asia (80%), the Maghreb region and the Middle East (74%), but lower among those from Latin America and the Caribbean (58%). Their access pathway is generally linear.	Despite significant differences in postsecondary education access, pathway morphology tends to be similar between immigrants when educational background in high school is accounted for: the commonality is a linear pathway to university specifically.
Kamanzi (2021)[61]	Explore the factors for academic resilience among young people of African and Caribbean origin	• 8415 Montréal students, including 574 who were originally from the Caribbean or sub-Saharan Africa • 2003–2013	• Quantitative, longitudinal, retrospective • Funding: NR	Students of African and Caribbean origin attend college at a rate that is comparable to that of their peers of European-Canadian origin. Black students enrolled in college are less likely to graduate by age 22. In addition, university is less accessible to them.	Some Black Quebec students manage to overcome barriers despite the fact that they are more exposed to precarious living conditions. The author calls on public authorities to place greater emphasis on improving learning conditions and supporting success.
Kanouté et al. (2014)[45]	Explore academic issues and the use of community resources by Haitian families	• 31 parent-student pairs • 7 community workers • 10 teachers, principals • Period: NR	• Qualitative • Funding: SSHRC	The data intersects the views of students, parents and school/community stakeholders on students' resilience factors and the specific family realities that need to be considered to better support families. Parents and workers highlighted the effects of the migration journey on parenting and the intertwined relationship between the family's migration journey and the child's academic plans.	A better understanding of the links between the family's migration journey and the student's academic plans would better support students from an immigration background and anticipate various pitfalls likely to hinder the school/family relationship and the parents' involvement with the school. Schools would benefit from working with community groups that have expertise in supporting immigrants.

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TABLE 2 (continued)
Data extraction table

Authors (year)	Purpose of the study	Population and period	Method and funding	Main results	Findings/implications
Kanouté et al. (2016)[71]	Explore the academic experience of students from immigrant backgrounds	• 32 immigrant elementary school students • 2010	• Qualitative • Funding: NR	The students shared their views on the variations in their identity, their relationship with learning, their academic plans and their use of spaces and resources in their neighbourhood.	An intercultural perspective at school should include the student's social/educational experience, acknowledge the student in their identities and achievements, instill a certain heterocentric approach in the interpretation of the program, support living in harmony, manage daily school life in an inclusive way and develop a partnership with families and the community.
Kanouté et al. (2020)[46]	Examine the educational persistence of permanent resident students	• 1077 students enrolled in six higher education institutions in Quebec • Period: NR	• Mixed • Funding: NR	Students are worried about building a comfortable home in a new society. This comfort is tied to the financial resources available and the caregivers' responsibility for their children. Students found it difficult to create the optimal conditions to support their family needs and balance family, studies and work.	It would be important to document the challenges relating to the transition to the workplace, social integration, balancing family/studies/work, decoding university culture and practices, and the perception of discriminatory practices.
Lafortune et al. (2020)[40]	Examine Haitian students' relationship with their college-level studies in Montréal	• 34 students • 11 teachers • 8 other professionals • 2017–2018	• Qualitative • Funding: NR	The college experience: [translation] "We were abandoned in the wilderness, it was a cold plunge, I hit a wall, I was fed up" (p. 23). Participants were unanimous in emphasizing the individual factors in college success (motivation, vocational choice, work habits). The student experience was affected by immigration status and minority status.	The authors reiterate the importance of shared values, such as the principle of nondiscrimination. They suggest continuing to raise awareness among stakeholders about the impact of systemic factors that contribute to the marginalization and exclusion of certain minority groups. CEGEPs share responsibility for ensuring equality of opportunity and the inclusion of all students.
Lafortune et al. (2024)[48]	Examine the practices and activities that promote French language proficiency among immigrant youth in Montréal	• 21 elementary and high school students attending a summer educational camp • 6 workers • July to August 2021	• Qualitative, participatory research • Funding: SSHRC, UQAM	Young people and guardians reported improvements in language skills (vocabulary, oral fluency, improved reading skills, etc.). The camp gave young people with limited social networks an opportunity to expand their circle of friends.	The educational camp experience highlighted the levers for efficient community/family/school collaboration. It consolidated school/community collaboration, which allowed the partnership to be maintained for future camps and for the creation of new joint projects.
Leduc et al. (2021)[57]	Study barriers faced by Black students in entering medical school in Quebec	• 4283 candidates for the Doctor of Medicine program in Quebec • 2019–2020	• Quantitative, cross-sectional, prospective • Funding: NR	The proportion of Black students in the applicant pool for medical school in 2020 is estimated to be 4.5%. It is estimated that Black students represented 1.8% of applicants invited to admission interviews and 1.2% of admitted students in Quebec in 2019. Although no direct comparisons can be made, it seems that Black applicants are disproportionately rejected compared with non-Black students.	Two barriers are noted: (1) a significant proportion of students from Black communities in Quebec may not consider medicine as a career and do not apply to medical school; and (2) when Black students apply to medical school, their applications seem to be disproportionately rejected before the interview compared with non-Black students. A longitudinal study is needed to monitor progress and determine the factors that contribute to this progress.

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TABLE 2 (continued)
Data extraction table

Authors (year)	Purpose of the study	Population and period	Method and funding	Main results	Findings/implications
Livingstone et al. (2014)[41]	Identify actions to reduce the dropout rate among Black students	• 20 Black students from four Montréal high schools • 2009–2010	• Qualitative, participatory action research • Funding: NR	According to the students, their academic success was influenced by multiple and interrelated factors, including family, peers, school and neighbourhood. In their view, schools should offer more support to Black students by fostering a better school climate and introducing multicultural curricula and innovative pedagogies.	The authors recommended that participatory action research with youth be introduced in schools as a tool for enhancing school success in the long term. Young people's insight and idealism shows that dropping out of school is not as an unsolvable issue as it might seem.
Magnan et al. (2017)[43]	Explore immigrant children's relationship to education and their postsecondary choices	• 60 students from immigrant backgrounds • Period: NR	• Qualitative • Funding: NR	Young people from the Caribbean, sub-Saharan Africa and Latin America are more likely to follow the paths that coincide with the following approaches: [translation] "elitist/laissez-faire, laissez-faire/laissez-faire and cocoon/laissez-faire."	Two issues deserve more attention: How can the school system's resources be used to facilitate young people's freedom of choice and how can they be better equipped? How can we better support families in their understanding of the school system and the job market?
Magnan et al. (2017)[42]	Understand the experience of immigrant youth in their choice of CEGEP program	• 60 students from immigrant backgrounds • Period: NR	• Qualitative • Funding: NR	An analysis of testimonies from immigrant youth shows that the family plays a determining role in the choice of postsecondary programs. Compared with youth from other countries, youth from sub-Saharan Africa, the Caribbean and Latin America perceived facing more constraints (familial, economic and academic) when choosing their programs.	Youth from Asia, Eastern Europe, the Maghreb region and the Middle East are more likely to follow an academic path in line with the [translation] "elitist/supportive approach." Youth from the Caribbean, sub-Saharan Africa and Latin America are more likely to follow a path in line with the [translation] "elitist/laissez-faire approach." This can be explained in part by the fact that Black families are more likely to belong to low or middle social classes.
Magnan et al. (2023)[72]	Study the factors that shape the academic pathways of Black students in Quebec	• 12 Black students of African or Caribbean origin • Period: NR	• Qualitative • Funding: Citizen's forum on Black representation in health sciences	Most students first enroll in a program other than their desired one to ensure their financial security or to improve their grades for a limited-enrollment program. Medicine and pharmacy studies remain a dream for most of the participants.	Students face a seemingly unfair admissions system for highly selective programs (medicine and health sciences). These results shed light on possible changes to admissions policies for certain programs.
Ménard et al. (2020)[63]	Measure the rate of pregnancy complications in a multicultural group of women	• 1387 pregnant women • 2013–2015	• Quantitative • Funding: Canadian Foundation for Dietetic Research	The risk of anemia was higher in Black women than in White women (aOR = 1.74). Black women were at higher risk of preterm birth (aOR = 1.79). Immigrant women had an increased risk of anemia compared to Canadian-born women (aOR = 1.85).	Nutritional interventions need to be targeted toward prevention of adverse pregnancy outcomes, prioritization of higher-risk groups and adaptation of the community organization's program to a multiethnic, low-income population.
Miconi et al. (2021)[51]	Investigate the association between risk of exposure to SARS-CoV-2 and mental health in ethnocultural groups	• 3273 Quebec residents • June 2020	• Quantitative • Funding: McGill University	Exposure to the virus, COVID-19-related discrimination and stigma were associated with poorer mental health. Black participants who were exposed and discriminated against reported greater mental distress.	Interventions that take into account race and culture and that consider factors such as discrimination and historical and racial trauma are needed.

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TABLE 2 (continued)
Data extraction table

Authors (year)	Purpose of the study	Population and period	Method and funding	Main results	Findings/implications
Miconi et al. (2021)[52]	Examine the extent of experiences of discrimination related to COVID-19	• 3273 Quebec residents • June 2020	• Quantitative • Funding: McGill University	COVID-19-related discrimination was reported by 16.6% of participants. Non-White participants, younger participants and healthcare workers were more likely to experience discrimination. Participants of East Asian descent and essential workers were more likely to report discrimination because of their ethnicity and occupation.	Health communication actions informed by a social pedagogy approach should target public beliefs related to the association of COVID-19 with ethnicity, age and occupation to minimize pandemic-related discrimination.
Noubicier et al. (2013)[33]	Study the meaning of aging among older Black women living in Montréal	• 7 women from 3 sub-Saharan African countries • Period: NR	• Qualitative • Funding: Centre for Research and Expertise in Social Gerontology	For these women, aging is inevitable. They see this period of their lives as a privilege, placing great importance on intergenerational relationships, faith and social involvement.	Social policies should take gender and ethnicity into account.
Nweze et al. (2023)[34]	Analyze the impact of racial and linguistic discrimination on mental health	• 531 Black Quebeckers • April 2021	• Quantitative • Funding: Health Canada and SSHRC	English-speaking participants experienced more discrimination and reported more barriers to accessing mental health care. They also had poorer mental health than their French-speaking counterparts.	The study justifies a mechanism by which language affects mental health by exposing Black Quebeckers to more discrimination and thus higher barriers to care.
Paquette et al. (2019)[35]	Study the impact of ASD on the quality of life of mothers of Haitian origin living in Montréal	• 12 mothers of Haitian origin of boys aged 5 to 18 with ASD • Period: NR	• Mixed, prospective • Funding: NR	Mothers anchored their strategies for controlling ASD in their religious faith. Their quality of life was considered to be average and their coping strategies were primarily focussed on problem-solving or seeking social support. They did not confide in strangers or professionals.	Family members are the first people consulted when a physical or mental illness appears. This is why it is so important that interventions consider the subjects' culture and choices. It is vital to develop expertise in intervening with families who have a child with ASD and on using an ethnopsychiatric approach.
Passos-Castilho et al. (2022)[67]	Identify factors associated with ICU admission and hospital mortality among COVID-19 patients	• 1104 patients hospitalized in Montréal who tested positive for SARS-CoV-2 • March to August 2020	• Quantitative, retrospective • Funding: Gilead, the Jewish General Hospital Foundation	Immigrants are more likely to be admitted to intensive care. This risk is higher among Caribbean Black individuals than White individuals. The risk of hospital mortality is higher among Canadian-born individuals than among immigrants, and higher among Caribbean Black individuals (but not Africans) than White individuals.	The data highlight the disproportionate impact of COVID-19 on foreign-born communities, the significant heterogeneity of COVID-19-related outcomes within ethnic groups and between countries, and the significant gaps in understanding the individual impacts of the social determinants of health and their interactions.
Salamanca (2018)[44]	Examine the role of temporary employment agencies in Montréal in exploiting immigrant labour	• 42 immigrant workers and members of immigrant workers' rights groups • Period: NR	• Qualitative, longitudinal, participatory research • Funding: NR	Nurses and attendants with valid immigration status who work through an agency are underpaid compared with workers with similar degrees and levels of education. Agency workers in the health sector, the majority of whom are Black, believe they are underpaid.	Workers with precarious immigration status experience long-term hardship, making them a vulnerable labour pool when they work for poorly regulated employment agencies. As a result, the likelihood of experiencing the effects of systemic racism is greater.

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TABLE 2 (continued)
Data extraction table

Authors (year)	Purpose of the study	Population and period	Method and funding	Main results	Findings/implications
Sherry et al. (2013)[36]	Understand the attitudes and beliefs of the Haitian adult population regarding organ donation	• 24 Haitians • 2008–2009	• Qualitative • Funding: Newton Foundation, MUHC Foundation	Participants recommended that Haitian health professionals and leaders use community media to spread messages about organ donation and to spark debate within families. People over 45 were more reluctant. Some of them had never heard about this issue and showed an interest in it.	The use of bilingual French/Creole Haitian moderators facilitated discussions during the study. Some of the reluctance to participate was overcome by addressing participants' questions and concerns. The authors plan to share the study's results with Haitian community groups, ethnocultural consultants and the Haitian media.
Spence et al. (2014)[55]	Study the effect of age at time of circumcision and race on prostate cancer risk	• 1590 cases • 1618 matched controls • Montréal • 2005–2009	• Quantitative • Funding: Canadian Cancer Society, Cancer Research Society, FRQ—Santé	Circumcision proved protective among men who were circumcised at age 36 and over (OR = 0.55). The strongest protective effect of circumcision was recorded in Black men (OR = 0.40; $p = 0.02$).	There is an inverse relationship between prostate cancer risk and circumcision performed at age 36 y and over. The protective effect appears only among Black men, the group most at risk of prostate cancer.
St-Louis et al. (2014)[37]	Study antigens in red blood cells from Black donors living in Quebec	• 1476 Black donors • Quebec • 2009–2012	• Quantitative • Funding: Héma-Québec	Genotyping results predicted the presence of rare phenotypes.	Black donors, with or without a rare phenotype, are precious to the patient cohort depending on blood transfusions and to Héma-Québec.
Tran et al. (2013)[38]	Examine the factors leading to increased blood donation in Montréal's Black communities	• 33 participants, including 27 Black participants • 2009–2010	• Qualitative • Funding: Héma-Québec	The participation of groups interested in bettering the lives of those affected by sickle cell anemia combined with the fact that leaders felt more comfortable donating to someone close to the community suggests that promoting blood donation from this angle would be well received.	Pointing out that phenotyped blood can be set aside for patients with sickle cell anemia is an argument for encouraging members of the Black community to donate blood. Since 2010, donors have been able to specify their ethnoracial background.
van der Ven et al. (2012)[53]	Study first-episode psychotic symptoms by ethnic background	• 301 patients with psychosis • 2003–2010	• Quantitative, prospective • Funding: CIHR	Compared with the reference group (Euro-Canadians), the African/Afro-Caribbean group had a higher level of negative symptoms and general psychopathology scores. Ethnic groups did not differ on positive symptom scores.	Particular attention should be paid to targeting negative symptoms and improving cooperation and engagement among certain patients from racialized groups during the initial phase of psychosis.
Weiler et al. (2022)[47]	Assess vitamin D levels and modifiable factors	• 1035 mother-child dyads • Montréal • 2016–2019	• Quantitative, cross-sectional • Funding: CIHR	Thirty-five percent of mothers gave their consent. Most newborns had adequate vitamin D levels. However, non-White groups, particularly Black newborns, had a higher risk of deficiency (5.5 times higher).	Most newborns had adequate vitamin D levels, but 1/5 were vitamin D deficient, with differences between population groups.

Abbreviations: aOR, adjusted odds ratio; ASD, autism spectrum disorder; CEGEP, collège d'enseignement général et professionnel (general and professional teaching college in Quebec); CIHR, Canadian Institutes of Health Research; DPJ, Direction de la protection de la jeunesse (Quebec's child/youth protection services); DSM-IV-TR, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision; FRQ, Fonds de recherche du Québec (Quebec's research fund); ICU, intensive care unit; INSPQ, Institut national de santé publique du Québec (Quebec's public health institute); MSSS: Ministère de la Santé et des Services sociaux (Quebec's department of health and social services); MUHC, McGill University Health Centre; NR, not reported; OR, odds ratio; SSHRC, Social Sciences and Humanities Research Council; UQAM, Université du Québec à Montréal; y, years.

[a] Terminology used in original study.

TABLE 3
Main characteristics of studies selected for the scoping review

Characteristic	Number of studies n (%)
Sector	
Health	23 (53.5)
Education	14 (32.5)
Social services	3 (7.0)
Employment	3 (7.0)
Year of publication	
2010–2019	22 (51.0)
2020–2024	21 (49.0)
Methods	
Quantitative	26 (60.5)
Qualitative	14 (32.5)
Mixed	3 (7.0)
Study focussed exclusively on Black populations	
Health	9 (21)
Education	3 (7)
Social services	0 (0)
Employment	0 (0)

Various ethnoracial classification systems were used, including those from Statistics Canada[53] and the Canadian Institute for Health Information,[47] with some systems adapted to the specific characteristics of the studies in which they were used.[38,42,43,46,49,51,52,56,58,59,62,64-67]

Immigration data were self-reported in 60% (26/43) of the studies (Table 4),[31-35,40,42-46,48,49,51-53,56,58,60-63,65,66,68,70] with migratory status and generation status (first, second generation, etc.) being the most commonly used variables (24 studies). Socioeconomic status was generally defined in a consistent manner, with level of education, income and employment status being the most frequently used variables (Table 4),[31-34,36,42,43,45-47,49-55,58,59,61-63,66-69,71,72] alongside the Material and Social Deprivation Index.[59,66,67]

Quantitative data collection

Primary data collection was carried out using questionnaires either distributed online[31,34,46,48,50-52,54,68,69] or given in person,[35,37,47,70] as well as by consulting medical records[51-53,55,56,66,67] and supplementing demographic information with telephone or in-person interviews.[46,55,56,66-68] In other studies, ethnicity was assigned by a third party based on the language spoken and the country of birth of the individual and their mother or both parents.[30,53,59]

Data of interest were also extracted from various centralized databases, including those maintained by Statistics Canada,[58-61] the Quebec Register of Civil Status[30] and other Quebec public agencies (departments, youth centres, etc.),[59-62,65,67] with cross-referencing of multiple datasets allowing for the inclusion of missing information on ethnoracial background or socioeconomic status.[58-61]

Qualitative data collection

Data were primarily collected through individual interviews,[32,33,38-40,44-46,71,72] with occasional use of focus groups.[36,41,46,48,68] Some interviews were conducted in familiar environments (home, school, community centres) to ensure that participants felt comfortable sharing their experiences.[35,38-40,71] In one study, culturally appropriate food was offered during focus groups as a sign of respect.[36] In this study, the participants, all from the Haitian community, were grouped by age to facilitate discussion and avoid any shyness that younger participants might feel in relation to their elders because of cultural codes.[36] Another researcher facilitated informative workshops during which participants could share their experiences of discrimination, creating a safe space for open dialogue and knowledge-sharing.[44]

To build trust between researchers and participants, other strategies included collecting data through professionals from the same community, with an immigrant background, who spoke the same language, or in the presence of a cultural mediator.[33,36,38,40,42,43,70] Some authors found that cultural proximity enhanced engagement, as it sparked participants' interest in the subject matter.[36] However, some participants were hesitant to have their interviews recorded,[40] and researchers in some studies faced challenges in maintaining appropriate professional distance with participants, as cultural proximity sometimes blurred the boundaries of the study's objectives.[33]

Quantitative analysis methods

In some studies, researchers used descriptive statistics to document discrimination or coping strategies in response to health issues.[35,54,57,64,68] Many other researchers carried out quantitative analyses using a contextualized, intersectional approach. Multivariate or regression analyses were used to compare results with a reference group, controlling for as many variables as possible.[30,47,50,53,55,56,58,60,61,63,67,69,70] These analyses also measured the influence of ethnicity on different variables, calculated proportional risk over time (Cox analysis) and examined the geographic distribution of variables in relation to ethnicity.[30,51,59,60] Note that the reference group varied across studies, and participants could be designated as "White Canadians" or "Euro-Canadians,"[30,47,51,53,56,61,67,69] "Whites,"[50,55,58,63] "Canadian-born"[56,63,67] or "Blacks."[60,70]

One study used the Latent Class Analysis statistical method to identify nonapparent homogeneous subgroups within a heterogeneous population.[50] Longitudinal surveys were used to track changes in variables or phenomena over time,[30,61,64] allowing for the identification of trends reflecting the impact of multiple waves of immigration from populations with varying sociodemographic profiles.[30]

Qualitative analysis methods

In three studies, an intersectional approach was used to address complex notions such as the inequalities experienced by Haitian students[40] and Black African older adult women,[33] or the discrimination and racism

FIGURE 1
PRISMA[25] flow diagram

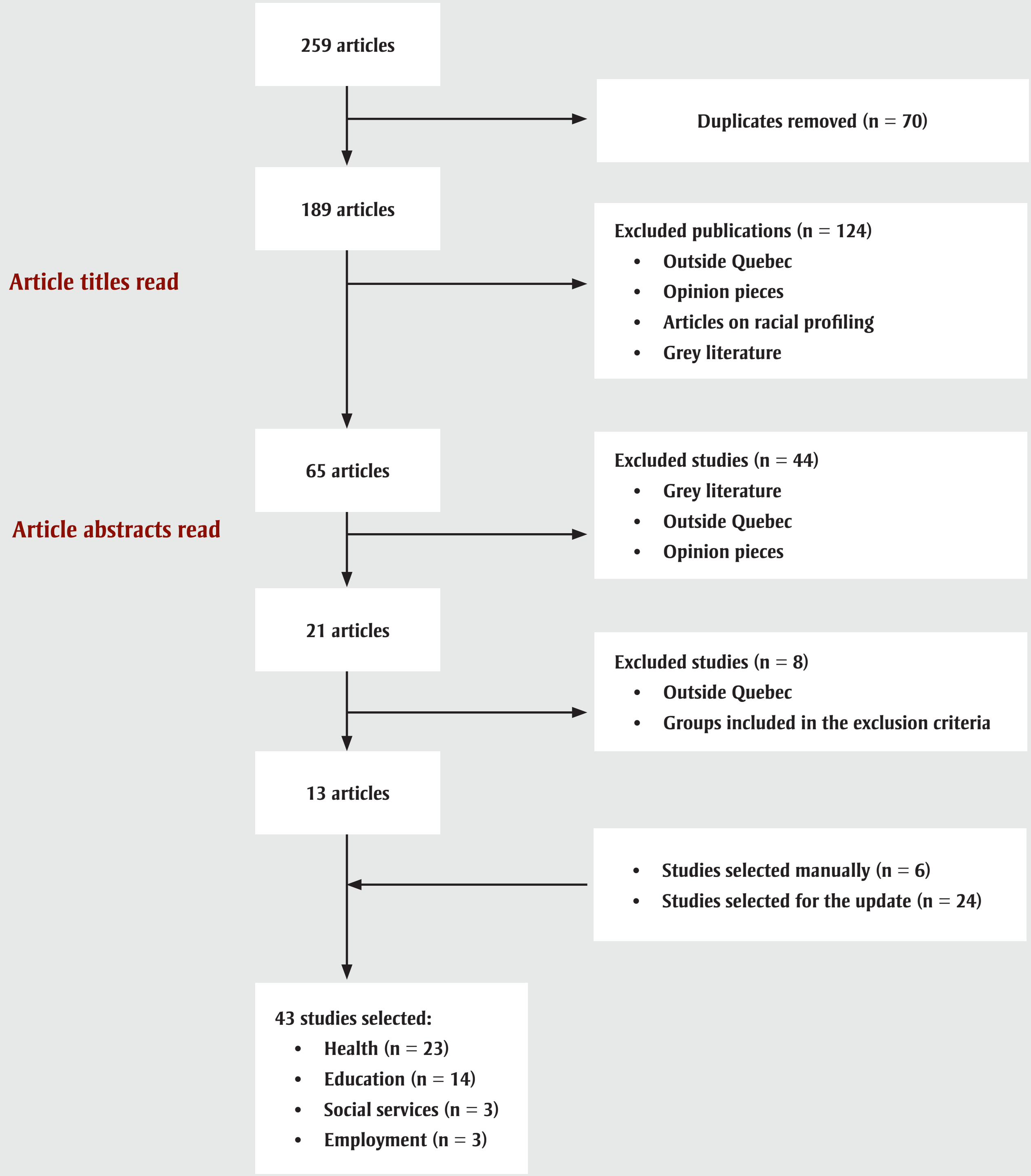

TABLE 4
Variables related to ethnicity and social determinants of health identified in selected studies

Author (sample size)	Age, gender, sex	Ethnoracial background	Immigration	Socioeconomic status	Additional information
Health					
Adeponle et al. (2012)[70] (N = 323)	Age Sex	"Race" or ethnicity (White, Black, Asian, other)	Migration status Length of stay	n/a	Mental health clinical data
Auger et al. (2012)[30] (N = 31 868)	Age Female	Haitian community Country of birth (Haiti, other Caribbean islands, other countries, Canada)[a] Mother tongue and language spoken at home (English, French, Creole)	n/a	n/a	Perinatal health data
Brousseau et al. (2021)[69] (N = 2056)	Age Sex	"Race" or ethnicity (White, Black, Hispanic[b])	n/a	n/a	COVID-19 clinical data
Carazo et al. (2022)[54] (N = 8220)	Age Sex	"Race" or ethnicity (White, Black, other)	n/a	Type of employment	COVID-19 clinical data and psychological distress
Dagher et al. (2024)[66] (N = 1104)	Age Sex	Country of birth Ethnicity (White, Black, Asian, Latino,[b] Middle Eastern/North African, mixed, other)	Migration status	Material and Social Deprivation Index	Language skills (English, French) Availability of interpreters Comorbidity score
Darwish et al. (2022)[56] (N = 150)	Age Sex	Country of origin Ethnicity (White, Black, Asian, Latino,[b] Middle Eastern/North African, mixed, other)	Migration status	n/a	Intensive care admission, in-hospital mortality Length of hospital stay
Debrosse et al. (2024)[49] (N = 179)	Age Sex	"Race" (Black, non-Black people of colour[b]) Ethnicity (Afro, African descent, Caribbean; Latino,[b] Hispanic,[b] Peruvian or Maya; Arab, Lebanese or Middle Eastern; Algerian, Kabyle, Maghrebin; Indigenous)		Median family income Unemployment rate	Neighbourhood characteristics Social identity Future aspirations Well-being (having basic needs met)
Fang et al. (2023)[31] (N = 531)	Age Gender	Black communities in Quebec Language spoken Country of birth (participants, parents)	Generational status	Employment status Family income	Mental and physical health Access to healthcare Experiences of discrimination
Frounfelker et al. (2022)[50] (N = 3183)	Age Gender	"Race" or ethnicity (White, East Asian, South Asian, Southeast Asian, Black, Arab, other)	n/a	Family status Income Type of employment	Mental health data Positive and negative effects of social distancing
Gomez Cardona (2012)[32] (N = 5)	Age Female	Haitian community	Migration status Generational status Length of stay	Socioeconomic status Family status	Strategies for coping with stomach aches
Ménard et al. (2020)[63] (N = 1387)	Age Female	"Race" (White, Black, Asian)	Migration status Country of origin Length of stay	Level of education Family status Income	Clinical data (pregnancy, nutritional intake)

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TABLE 4 (continued)
Variables related to ethnicity and social determinants of health identified in selected studies

Author (sample size)	Age, gender, sex	Ethnoracial background	Immigration	Socioeconomic status	Additional information
Miconi et al. (2021)[51] (N = 3273)	Age Gender	“Race” or ethnicity (White, East Asian, South Asian, Southeast Asian, Black, Arab, other) Mother tongue, religion	Generational status	Level of education Income Employment status	COVID-19 and mental health clinical data
Miconi et al. (2021)[52] (N = 3273)	Age Gender	“Race” or ethnicity (White, East Asian, South Asian, Southeast Asian, Black, Arab, other)	Generational status	Level of education Employment status	Exposure to COVID-19 Perceived discrimination related to COVID-19
Noubicier et al. (2013)[33] (N = 7)	Age Female	Ethnicity (sub-Saharan African)	Migration path	Socioeconomic status	Perceptions of successful aging
Nweze et al. (2023)[34] (N = 531)	Age Gender	Black Spoken language	Generational status	Employment status Family income	Mental and physical health Experiences of discrimination Access to mental health care
Paquette et al. (2019)[35] (N = 12)	Female Age of child	Haitian community	Migration status Generational status	n/a	Quality of life and ASD
Passos-Castilho et al. (2022)[67] (N = 1104)	Age of mother Sex of child	“Race” or ethnicity (White, Black [Caribbean, sub-Saharan African], Asian, Latino,[b] North African/Middle Eastern, mixed, other) Country of birth	n/a	Material and Social Deprivation Index	COVID-19 clinical data Perceived discrimination
Sherry et al. (2013)[36] (N = 24)	Age	Haitian community	n/a	Level of education	Social role or position Past experiences Beliefs about organ donation
Spence et al. (2014)[55] (N = 3208)	Age Male	“Race” (White, Black, Asian, other)	n/a	Level of education	Clinical data (circumcision, prostate cancer screening)
St-Louis et al. (2014)[37] (N = 1476)	n/a	Black	n/a	n/a	Genotypes
Tran et al. (2013)[38] (N = 33)	Age Sex	Ethnicity (African, Haitian, other Caribbean)	n/a	n/a	Beliefs and attitudes about blood donation
van der Ven et al. (2012)[53] (N = 301)	Age of mother	Statistics Canada categories (2006)[a] Country of birth	Migration status Generational status Migration path (previous countries of residence)	Level of education	Mental health clinical data
Weiler et al. (2022)[47] (N = 1035 pairs)	Age Female	Ethnicity according to CIHI (White, Black, East Asian, South Asian, Southeast Asian, Latino/a,[b] Middle Eastern, other/mixed) Country of birth	n/a	Level of education Income	Lifestyle habits Vitamin D levels

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TABLE 4 (continued)
Variables related to ethnicity and social determinants of health identified in selected studies

Author (sample size)	Age, gender, sex	Ethnoracial background	Immigration	Socioeconomic status	Additional information
Social services					
Boatswain-Kyte et al. (2020)[58] (N = 15 875)	Age (child, mother)	White, Black, other visible minorities,[b] unidentified	Migration status	Level of education Income Employment status Family status	Reporting, placement, legal decision Rate of inequality
Boatswain-Kyte et al. (2022)[59] (N = 1395)	Age at placement Sex	White, Black, other visible minorities,[b] unidentified	n/a	Socioeconomic Disadvantage Index	Type of abuse Type of placement Number of breakdowns resulting from out-of-home placement
Dufour et al. (2015)[60] (N = 8263)	Age	"Race" or ethnicity (Black, other visible minorities,[b] visible nonminorities[b])	n/a	Level of education Income Family status Family size	Relocation Population density
Education					
Arcand et al. (2016)[68] (N = 426)	Age	Country of origin	Migration status Length of stay	Employment status	Network and involvement with associations Perceived degree of loneliness and exclusion
Collins et al. (2018)[39] (N = 11)	Age Sex	Haitian (parents) Born in Quebec (students) Mother tongue	n/a	n/a	Family experiences Elementary and high school experiences CEGEP experiences Linguistic, cultural and geographic identity Postsecondary endeavours Employment
Kamanzi et al. (2018)[62] (N = 20 387)	Gender	Region of birth (parents)	Generational status	Level of education (parents) Family income	Postsecondary education pathways
Kamanzi (2021)[61] (N = 8415)	Gender	African/Caribbean, Euro-Canadian Mother tongue	Generational status	Income	Type of school Educational delay
Kanouté et al. (2014)[45] (N = 48)	Age Sex	Country of origin (parents)	Migration path	Economic profile (disadvantaged)	Day-to-day schooling Parental supervision Use of neighbourhood resources Social integration of families

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TABLE 4 (continued)
Variables related to ethnicity and social determinants of health identified in selected studies

Author (sample size)	Age, gender, sex	Ethnoracial background	Immigration	Socioeconomic status	Additional information
Kanouté et al. (2016)[71] (N = 32 parent-child pairs)	Age Sex	Country of origin (parents)	Migration status Generational status	Economic profile (disadvantaged)	Ethnocultural identity Relationship with school Follow-up and school project Neighbourhood life
Kanouté et al. (2020)[46] (N = 1077)	Age Gender	Region of birth Mother tongue	Migration status Length of stay Premigration context	Family situation Employment status Financial resources	Institutional life experience Learning and training experience General living conditions in Quebec
Lafortune et al. (2020)[40] (N = 53)	Age Sex	Haitian community	Migration status	n/a	Social and family support Academic achievement
Lafortune et al. (2024)[48] (N = 27)	Age Sex	Country of origin	Migration status Length of stay	n/a	Sociocultural integration Progress in French Commitment and interest
Leduc et al. (2021)[57] (N = 4283)	n/a	"Race" (White, Black)	n/a	n/a	Admission to medical school
Livingstone et al. (2014)[41] (N = 20)	Age	"Race" (Black)	n/a	n/a	Equity/diversity School climate Curriculum Academic support Extracurricular activities
Magnan et al. (2017)[43] (N = 60)	Age Sex	Region of origin (parents)	Generational status	Financial support from parents School capital (parents)	Education pathways (four types defined)
Magnan et al. (2017)[42] (N = 60)	Age	Region of origin (parents)	Generational status	Financial support from parents School capital (parents)	Choice of postsecondary studies Family constraints Academic constraints
Magnan et al. (2023)[72] (N = 12)	Age Gender	Ethnicity: country of origin (father, mother)	Generational status	Level of education (father, mother)	Education pathway
Employment					
Beauregard (2020)[64] (N = 1569)	Sex	"Race" or ethnicity (Arab, Latin American, Black) Majority/minority status	n/a	n/a	Invitation for an interview

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TABLE 4 (continued)
Variables related to ethnicity and social determinants of health identified in selected studies

Author (sample size)	Age, gender, sex	Ethnoracial background	Immigration	Socioeconomic status	Additional information
Boudarbat et al. (2010)[65] (N = 1875)	Age Sex	Region of origin	Generational status Migration status	Level of education Employment status Salary	Job matching aspirations
Salamanca (2018)[44] (N = 42)	Gender Age	Country of origin	Migration status Work permit	Employment sector	Violations of labour legislation Interethnic relations in the workplace

Abbreviations: ASD, autism spectrum disorder; CEGEP, Collège d'enseignement général et professionnel (general and professional teaching college in Quebec); CIHI, Canadian Institute for Health Information; n/a, not available.

[a] Categories assigned by a third party.

[b] Terminology used in original study.

experienced by temporary migrants.[44] These issues were analyzed from an intersectional perspective, taking into account identity markers such as skin colour, ethnic origin (minority/majority status), social origin (migratory and socioeconomic status) and gender.[33,40,44]

An anthropological approach was used in another study on the experience of Haitian mothers in dealing with their children's illness.[32] Life stories were also used to illustrate individual educational trajectories.[42,43,72] Four studies used inductive thematic analysis to examine the data.[35,36,38,46]

Discussion

The purpose of this scoping review was to analyze the methods used to collect, analyze and disseminate health, education, social services and employment data regarding Black populations in Quebec. This review enabled us to present a comprehensive corpus of data illustrating the fields of interests of Quebec researchers, the challenges in recruiting and retaining participants from Black communities in Quebec, and the quantitative and qualitative methods of analysis used.

Few studies have examined disaggregated health data based on ethnoracial background in Quebec. Most studies included in this scoping review are cross-sectional in nature, with the exception of a few longitudinal surveys[30,58,59,61] conducted on secondary datasets. These longitudinal surveys allow for analyses on large samples covering the entire population targeted by the research, thereby reducing selection bias.

Several factors can influence the accuracy and relevance of conclusions drawn from studies on health issues affecting Black populations in Quebec. Biases may be introduced at various stages, from data collection to dissemination of results, posing significant methodological challenges.

Recruiting members of Black communities remains a significant challenge in qualitative studies, whereas quantitative studies rarely report this issue. However, this does not imply that researchers have not encountered such a challenge. Soliciting participation from members of Black communities requires a greater investment of time compared with other ethnocultural groups, particularly White people of European descent.[36]

The reluctance of Black communities to participate in research is rooted in historical events in which members were exploited under the guise of science. Notable examples include the Tuskegee Syphilis Experiment in the United States (1932–1972) and the illegal blood trade in Haiti during the 1970s. Additionally, in the 1980s, the Haitian community was improperly associated with HIV by the Canadian Red Cross.[73,74]

These historical precedents have fostered distrust of public and health authorities among Black populations in Quebec and Canada.[74-76] To address this, it is crucial to keep participants well informed about research objectives and results. However, the true purpose of a study can sometimes be difficult to disclose due to its nature.[51,64] These cases, though exceptions, are governed by the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (articles 3.7A and 10.3).[77] More attention must be paid to research dissemination practices in Quebec. Only a few studies have identified effective knowledge transfer strategies.[36,41,48] Providing feedback to participants and the broader community can help mitigate feelings of exploitation and encourage greater participation in future research projects.[36]

Recruitment challenges can lead to selection bias, which is difficult to correct. For instance, an online survey with a low response rate (37%)[51,52] and a sample predominantly composed of college- or university-educated participants may not be representative of the broader population. Therefore, the results of the study are not applicable to populations with a lower level of education.[51,52] Similar logic can be applied to the language spoken, since the studies were conducted solely in English or French, which excludes allophones. Additionally, attrition bias, which involves certain participants dropping out selectively, is a common issue in research.[36,41,44,47] This bias can be estimated by comparing the characteristics of participants who remained in the study with those who left.[47]

The attribution of ethnicity is another significant issue. Analysis of the studies in this review indicates that self-identification is the standard practice, compared with third-party identification. However, this method is not exempt from potential biases (nonresponses, willingness to self-identify with the majority group), which may be difficult to measure.[64]

Missing information on ethnoracial background or socioeconomic status can be supplemented by cross-referencing the data from the census or the Quebec Register of Civil Status, which contain details such as the mother's country of birth, language spoken at home or mother tongue.[30,58,61] Missing data can be inferred from individuals' country of birth and language spoken.[56,67] However, according to our analysis, this imputation method is not error-free if the data are not cross-referenced with migration status and generation status.

The characteristics that define ethnicity are not fixed; they are often poorly defined and depend on the classification systems used.[16,17] Ethnicity is a flexible concept. While it differs from "race," nationality, religion and migratory status, it can include aspects of these concepts.[78,79]

Some researchers have tried to account for this fluidity by differentiating, within the same ethnoracial group, between individuals who speak French or English at home and those who speak their mother tongue.[30] This enables a more detailed analysis, highlighting the complex realities that define a given group that is neither monolithic nor static. Moreover, at the individual level, there is sometimes a discrepancy between how a person is perceived by society and how they define themselves on an ethnocultural level, a meaning that can shift with time and life circumstances. Some researchers suggest defining "race" not as a biological phenotype, but as a complex social phenomenon, or classifying populations according to socioenvironmental variables rather than "race."[26]

Our study shows that researchers prefer one-on-one interviews over focus groups for collecting qualitative data. In focus groups, the size, composition and internal dynamics of the group, as well as the topics addressed, can greatly influence what participants say and disclose, compared with the more confidential atmosphere of one-on-one interviews.[80] Some studies show that people are more inclined to discuss sensitive topics in one-on-one interviews than in groups,[81-83] while others find the opposite.[80,84] This raises confidentiality concerns, as participants in focus groups get to know each other, increasing the risk of unintentional disclosure of sensitive information. The risk is particularly critical in small, tightly knit communities.

At the analytical level, descriptive analyses carried out using an intersectional approach enable the generation of hypotheses about the processes underlying observed phenomena. Correlation studies on relevant quantitative data can test these hypotheses and measure the interaction between several variables, requiring granular data on target populations. When such data are unavailable, researchers use the Material and Social Deprivation Index[7,59,66,67] to identify trends. However, the ability to establish causal links remains limited.[26] The common practice of documenting ethnoracial differences in health without adequately explaining their basis presents a number of risks. It limits primary prevention initiatives and reinforces the idea of biological determinism linked to "race."[26,85]

Additionally, processing data on individuals of mixed ethnic origin poses challenges.[47,56,66,67] How can these data provide us with more information, and what further analysis can be carried out? Additionally, creating broad ethnoracial categories (Black, White, Asian, Latin American, etc.) for comparisons introduces significant heterogeneity.[47,51-53,56,57,60,67,69] Therefore, the results of these studies must be interpreted carefully. Analyses based on non-standardized ethnoracial categorization risk leading to erroneous conclusions that overlook nuances that have gone unnoticed as a result of classification bias.[26,79] This could jeopardize the ability to provide culturally appropriate healthcare and services.[4,85]

Strengths and limitations

This scoping review sheds light on cross-sectoral practices (health, social services, education, employment) in the collection, analysis and dissemination of ethnoracial data relating to health and its social determinants among Black populations in Quebec. To our knowledge, this is the first scoping review to be carried out on this topic in Quebec. It analyzes the experiences of these populations, considering the intersections of ethnoracial background, age, gender and language. It also reflects the interest of researchers, physicians and other health and community professionals in issues affecting racialized populations, including Black populations in Quebec.

However, this scoping review has several limitations. It does not take into account the grey literature in Quebec on the topic. This was explored in another component of our research, which, in addition to the scoping review, included the analysis of case studies describing best practices in Quebec for culturally adapted approaches, as well as a qualitative study on the experiences and needs of researchers whose work focusses on Black populations in Quebec. Furthermore, since our review only includes studies conducted in Quebec, the results are not generally applicable to all Black populations in Canada, particularly due to Quebec's migratory history.

Additionally, our literature search strategy focussed on specific fields (health, education, employment and social services), which means other potentially relevant studies may have been omitted. While there may be other methods of collecting, analyzing and disseminating health data based on ethnoracial background, their omission from this study does not invalidate the scope of our work. This study is intended to be exploratory. It provides an overview of the diversity of theoretical and methodological approaches used in Quebec to collect, analyze and disseminate ethnoracial data on health and its social determinants, and associated issues.

Future directions

Systematic health data collection initiatives among Black populations are still uncommon in Quebec. However, the COVID-19 pandemic has sparked growing interest among health authorities and researchers in health data based on ethnoracial background. The number of studies recorded since the start of the pandemic (in 2020) is equivalent to the number recorded between 2010 and 2019 (Table 3). A reflection on best practices governing the collection, protection and use of health data concerning Black populations is necessary in Quebec, in order to better equip researchers. Additionally, a qualitative study of these populations would provide a more in-depth understanding of their needs and the challenges they face.

The COVID-19 pandemic highlighted the glaring health inequities affecting Black populations in Quebec. The lack of data on the health of these populations hinders the development and implementation of public health policies. Initiatives to collect health data from Black populations in Ontario,[10] Nova Scotia[11] and, more recently, Manitoba,[86] are a step in the right direction. These efforts are fostering a dynamic that could revive the political debate on this issue in Quebec.

Finally, note that 58% (25/43) of the studies presented in this scoping review were funded in part by the researchers' respective institutions, or reported no funding at all (Table 2). Promoting research on the health of Black populations should be a priority in order to better address the challenges of inequity faced by these communities. To achieve this, increased funding is needed for this field of research.

Conclusion

The purpose of this scoping review was to document the methods and issues involved in collecting data on health and its social determinants for Black populations in Quebec. This review has enabled us to analyze current practices in Quebec using a cross-sectoral approach, with studies covering health, social services, education and employment. It also highlights the importance of collecting granular data on racialized groups, particularly on Black populations in Quebec, to support public policies designed for these populations and to promote health equity.

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Conflicts of interest

The authors declare that there are no conflicts of interest in relation to this work.

Authors' contributions and statement

NM, KNLN: conceptualization, data curation, formal analysis.

NM: writing—original draft.

NM, KNLN: writing—review and editing.

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Evidence synthesis

Culturally and structurally competent approaches to health research with Black communities in Atlantic Canada: a rapid review

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Abstract

Introduction: Anti-Black racism is deeply entrenched in Canadian institutions and has deleterious impacts on Black populations. Black populations have resided in the Atlantic region since the late 17th century. Despite longstanding histories, Atlantic Black populations face significant inequities, including the highest rates of child poverty among Black children across Canada. Community consultations in Atlantic Canada have highlighted a desire to bring attention to these health inequities. The purpose of this review was to identify existing literature pertaining to Black health research in Atlantic Canada and highlight culturally appropriate practices.

Methods: The search strategy was developed with a librarian and focussed on health research pertaining to Black populations in the Atlantic provinces of Canada, covering eight databases. All articles were imported into Covidence for screening, with independent reviewers assessing titles, abstracts and full texts.

Results: Forty-seven studies met the inclusion criteria. Findings demonstrated the pervasiveness and impact of racism, the importance of community engagement as a key cultural consideration and the adoption of participatory action research frameworks as culturally appropriate.

Conclusion: This review revealed opportunities for improving Black health research in Canada's Atlantic provinces. Future research warrants attention to this region and the use of culturally and structurally appropriate research approaches and methods. Recommendations include improved education on Black history and a training module within existing ethical guidelines for culturally and structurally competent research with Black communities.

Keywords: *Black Canadians, racism, health inequity, cultural competency, Atlantic Canada*

Highlights

- Atlantic Black populations face significant health inequities, and there is a need to identify and to develop culturally appropriate practices to help address these inequities.
- The rapid review identified 47 studies on Black health in Atlantic Canada.
- The findings underscore a significant gap in culturally and structurally competent Black health research in Atlantic Canada.
- A culturally and structurally competent research base begins with all researchers completing at least one module on ethical research with Black populations.

Introduction

The systematic inequities facing Black people have persisted since Canada's colonization, but police brutality, global anti-racism protests and a pandemic that disproportionately affected Black communities have brought anti-Black racism into prominence.[1-4] Anti-Black racism in Canada is defined as "policies and practices rooted in Canadian institutions, such as education, health care and justice, that mirror and reinforce beliefs, attitudes, prejudice, stereotyping and/or discrimination towards people of Black-African descent."[5] The legacy of colonialism, the Trans-Atlantic slave and historic segregation have created a social ecosystem that disproportionately disadvantages Black Canadians. This has manifested in disproportionately high rates of poverty in Black families,[6] limited access to education[7,8] and inequitable access to healthcare for Black Canadians, resulting in significant health

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and social disparities.[9,10] Despite growing recognition of the magnitude and pervasive nature of anti-Black racism and the health inequalities it has created, comprehensive, empirical research reporting on the health outcomes of Black Canadians remains limited.

Eurocentric research institutions have a long and problematic history of perpetrating harm and excluding racialized populations from research, policy and practice. The legacy of misappropriated findings, experimentation and the morbid maltreatment of Black bodies and communities (e.g. the Tuskegee Syphilis Study) have had lasting, intergenerational impacts.[11] Studies have found that people of African descent are more likely than age-, education- and gender-matched White people to believe that research findings will be used to reinforce negative stereotypes[12] or that the research itself will expose them to unnecessary risks.[13,14] Contemporary research and research methodologies are often exclusionary and continue to include majority White, English-speaking, affluent participants.[13,15] Investigators themselves have been known to assume that people of African descent will not consider participating in research, and do not put in the time or effort to make studies inclusive and safe.[16,17] The problematic categorization of participants by race or ethnicity without context has contributed to the perpetuation of negative stereotypes about certain racial groups.[18] Many standardized measures, interventions and assessments have been designed using majority-White participants and may not be appropriate to use with Black or other racialized people.

Canada has a growing and diverse Black population. As of 2021, over 1.5 million Black people were residing in Canada, comprising 4.3% of the national population.[19] This number is set to double by 2041, with new immigrants and refugees arriving from Africa and the Caribbean annually.[20] Despite Canada's multicultural identity, discrimination against Black people is deeply entrenched and normalized in Canadian institutions, policies and practices, and is often not noticed by non-Black folk.[21] In fact it has been reported that anti-Black structural racism was present in most of Canada's core institutions (e.g. health, criminal-legal, education), with ongoing negative impacts causing further marginalization for Black communities.[21] Stigma and discriminatory maltreatment are experienced by Black Canadians in intersecting ways across individual, institutional and systemic dimensions. This shapes access to social and economic resources that promote health and wellness (e.g. food, housing, education and employment) contributing to chronic stress, with devastating implications for Black people's physical and mental health. The Public Health Agency of Canada has found significant gaps in the lifespan of Black men and women: White, university-educated men had life expectancies 14.2 years higher than those of Black men without a high school education; and White, university-educated women had life expectancies 10.3 years higher than those of Black women without a high school education.[9,22] Black Canadians were significantly more likely than White Canadians to report diabetes and hypertension.[23,24]

Atlantic Canada is a geographic region of Canada that comprises four provinces: New Brunswick (NB), Nova Scotia (NS), Prince Edward Island (PE) and Newfoundland and Labrador (NL). Atlantic Canada is home to a historic Black community known as the African Nova Scotians (ANS) or indigenous African Nova Scotians.[25] This distinct population has a unique history, with an ancestral lineage dating back to the late 17th century. After that time, thousands of formerly enslaved Black Loyalists arrived in Nova Scotia in 1783, followed by the Jamaican Maroons and other Caribbean immigrants in the 19th and 20th centuries.[26] In contrast to other regions, these historic Black populations have predominately resided in Atlantic Canada for over four hundred years and have a history and culture specific to the region. This review uses the term "Black" as a collective term for all people of African descent, but recognizes the greater discussion that needs to continue regarding culturally appropriate identifiers.[27]

Though ANS have resisted extensive racial and colonial violence, centuries of maltreatment have contributed to intergenerational trauma, health inequalities and barriers to healthcare access that remain today.[1,28] For example, the Atlantic provinces have reported the highest rates of child poverty among Black children in the country (40% in NS, 41% in NL, 37% in NB and 33% in PE), compared to the non-Black national average of 17%.[29] Moreover, Black men in Nova Scotia are six times more likely to experience street checks by police than their White counterparts. Additionally, anti-Black racism in the Nova Scotian education system has affected African Nova Scotian children aged as young as 18 months.[7,30,31]

Community consultations with ANS and other Black communities in Atlantic Canada have highlighted a desire to bring attention to the health inequities facing their communities. Yet, they also report mismanagement of Black health data and the over-researching of their communities. This is consistent with existing evidence documenting how the researchers and health practitioners have caused undue harm to Black communities through insensitive, inappropriate and unethical research.[11,14,32] Common examples of repeated and ongoing harm in research include reporting research results in a manner that reinforces negative stereotypes, failing to consult with communities consistently and meaningfully and conducting research that does not align with community needs. While the renewed awareness of anti-Black racism is welcomed, novel research conducted with Black communities must be conducted in a way that promotes their best interests and safety.

The purpose of this review was to identify existing literature pertaining to culturally and structurally competent Black health research in Atlantic Canada. The objectives of this rapid review were twofold: (1) to identify and document available literature pertaining to Black health in Atlantic Canada; and (2) to describe the research topics, methodologies, methods and reporting techniques employed in studies that examined Black health in Atlantic Canada. The findings of this review will be useful for informing future research with Black communities in and beyond Atlantic Canada. The concept of culturally and structurally competent research was recommended to us by a Black health community organization. The term combines the familiarity of cultural competence (i.e. sensitivity and responsiveness to racial, ethnic, gender-based and sociodemographic differences and preferences) with the less familiar structural competence (i.e. sensitivity and responsiveness to the impact of forces at the societal, policy, socioeconomic and individual levels).[33] Thus, culturally and structurally competent research is sensitive to both Africentric ways of knowing and the macrosystems that influence Black populations.

Methods

A rapid review was conducted to develop timely and culturally adept synthesis of the current state of research on Black health in Atlantic Canada. This review was conducted in accordance with guidelines outlined by Tricco et al.[34] The search strategy was developed in collaboration with a health science librarian at Dalhousie University. The search was conducted in July 2022 and was performed in eight databases: MEDLINE, Embase, CINAHL, Cochrane, PsycInfo, Scopus, Sociological Abstracts and Social Services Abstracts (full search strategy available on request from authors). The criteria for inclusion followed the mnemonic PCC—representing the population, concept and context.

Eligibility criteria

Population

While ANS constitute a significant portion of Black people in Atlantic Canada, this review included studies with participants of African descent. Search terms included Black, Black-Indigenous, African Nova Scotian, Black Scotian, African descent, Black descent, African. Studies that included multiple populations in Atlantic Canada alongside an analysis of Black populations were included; however, only the sub-analysis of Black Canadians in the Atlantic region was considered.

Concept

The concept under study was health as it relates to Black communities in Atlantic Canada. The World Health Organization's definition of health is "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity."[35] The review includes social determinants of health, referring to the range of personal, social, economic and environmental factors that influence population health, such as socioeconomic status, racism, working conditions, physical environments and access to healthcare.[36]

Context

This review considered studies that explored the health of people of African ancestry in the four provinces of Atlantic Canada (New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland and Labrador). The total population of the Atlantic region is 2.41 million.[37]

Types of sources

This rapid review considered studies that utilized a variety of research designs, encompassing both qualitative and quantitative data. These included experimental and quasi-experimental study designs, analytical observational studies, descriptive observational study designs, phenomenology, grounded theory, ethnography, and participatory action research. Commentary, opinion and perspective articles were also included in an effort to capture a breadth of research and varying ways of disseminating research. Evidence synthesis articles were not included but reference chaining was used to identify articles for inclusion.

Screening, study selection and extraction

All articles were imported into Covidence (Veritas Health Innovation, Melbourne, AU), an online evidence synthesis tool, and were assessed in detail against the inclusion criteria by two independent reviewers. Any disagreements that arose between the reviewers at each stage of the selection process were resolved through discussion or with a third reviewer. The data extraction process was carried out in Covidence. For consensus purposes, two independent researchers extracted the data. The data extraction tool contained fields for purpose and objectives, location of study, population, health dimension, research design, theoretical framework used, data collection and analysis methods, key findings, community engagement techniques, cultural considerations and recommendations.

Results

Three thousand, seven hundred and fourteen (3714) articles were retrieved, and 1169 duplicates removed. Two thousand, five-hundred and forty-five (2545) titles and abstracts were screened by two independent reviewers for assessment against the inclusion criteria. A total of 169 full text articles were reviewed. The results of the search are presented in a Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Reviews (PRISMA-ScR) flow diagram (Figure 1).[34]

This rapid review included a total of 47 studies. Two of the studies were published prior to the year 2000, 27 were published between 2000 and 2014 and 18 were published from 2015 onward. Of the studies that met the inclusion criteria, almost all were from Nova Scotia (n = 44).[25,38-80] Only one study from each of New Brunswick,[81] Prince Edward Island[82] and Newfoundland and Labrador[83] met the inclusion criteria.

Findings are presented in three sections that cluster the stages of the research cycle. The first section, "Designing and implementing research with Black populations," outlines frequently used approaches and theoretical models, and common features of the target populations, recruitment and data collection and analysis. The second section, "Findings and recommendations of the available research," describes common findings and recommendations of included studies. Finally, section three, "Considerations outside of Eurocentric approaches to research," highlights the importance of considering culture and community engagement in research with Black populations. Each section provides a narrative synthesis of extracted data.

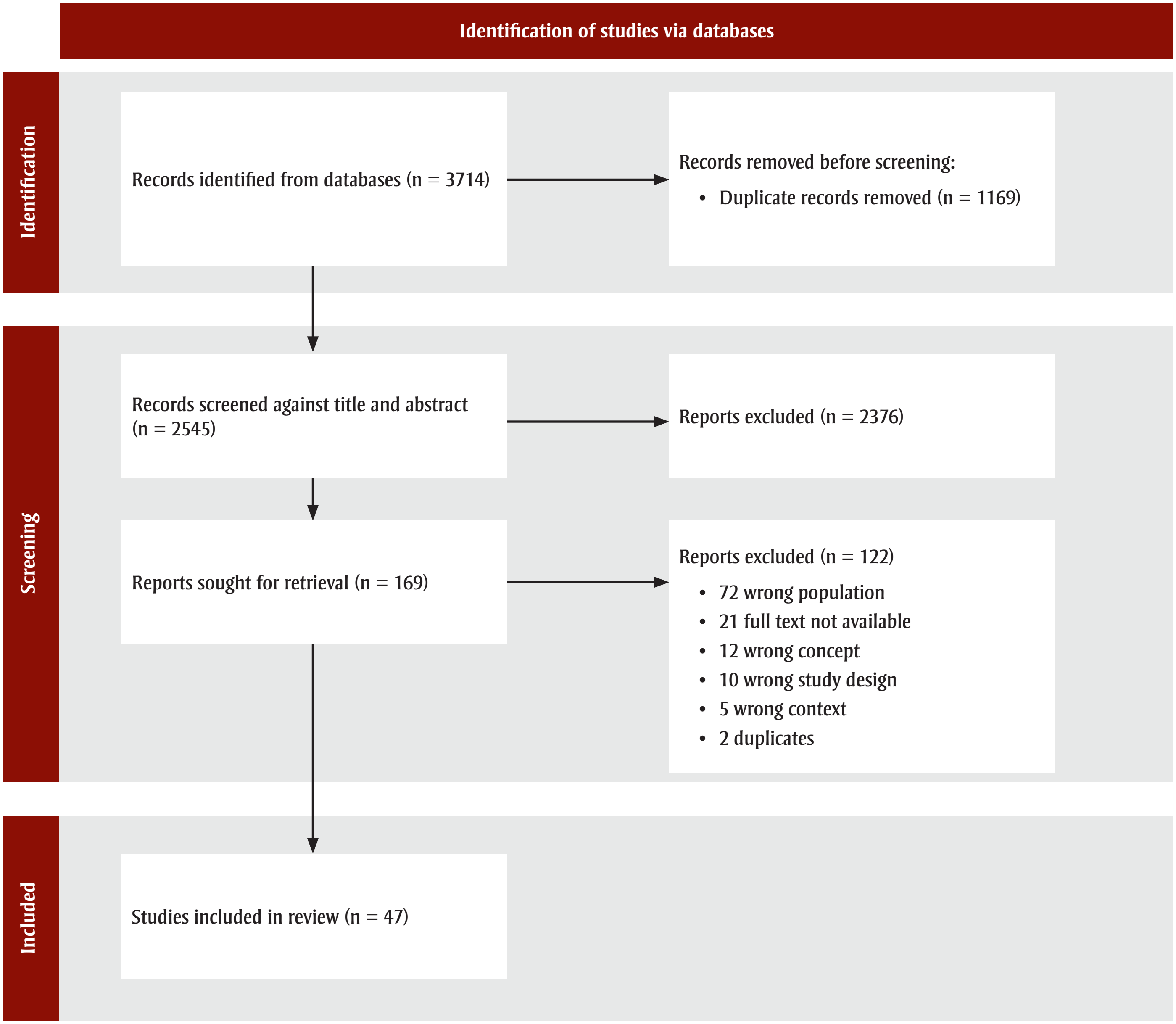
Designing and implementing research with Black populations

Included studies focussed on varying areas of health and included mental health,[40,45,49,55,58,78,80,82] sexual and reproductive health,[43,46,54,56,57,59,65,71] racism,[39,41,47,52,68,69,71,81] food security[42,66,67,79] and palliative care.[62,75,77] Table 1 provides an overview of research approach; research design; theory, frameworks or models; recruitment and sampling; data collection; and data analysis. Research approaches designated as "other" in Table 1 include articles that do not fall under the traditional qualitative-quantitative dichotomy—for example, viewpoint articles, perspective articles and opinion articles.

Target populations

Varying terminology was used to describe Black populations in Atlantic Canada—for example, ANS,[38,40,41,77] Black[48,66,81] and African Canadian.[75] Several included studies focussed on multiple populations (e.g. Black populations and Punjabi British Columbians, White Canadians, Southeast Asian immigrants, etc.).[59,66,67,72,78] Studies sampled diverse Black populations at the intersections of gender, age, socioeconomic status, ability and immigration status. While some studies focussed on Black communities,[70,73] most focussed on subpopulations such as middle-aged women,[39,40,49,55] school-aged youth[45,78] and nurses.[48,52] No studies

FIGURE 1
PRISMA[34] chart outlining the stages of the rapid review process and number of sources retrieved and selected for each stage



focussed on children, and four focussed on youth.[45,64,78,81] Three studies focussed on parents or family entities.[46,75,83] With respect to gender, 13 studies focussed solely on women,[39-41,44,48,50,51,53-55,59,71,72] while no studies solely focussed on men, and one study included, but did not focus on, gender-diverse individuals.[25]

Findings and recommendations of the available research

Key findings

The key outcomes and results from included studies had varying implications for Black health and associated research. The pervasiveness and impact of experiencing racism was threaded through the findings of several studies.[39,41,48,51,71,81] For example, racism impacted engagement in education,[81] had a distinct influence on occupation[39] and directly impacted health.[51] Several studies explored conceptualizations of health and health concerns. A core focus of such studies was developing an understanding of the social determinants of health that impact Black Canadians.[46,51,80] For example, Etowa and colleagues highlighted key determinants of health for rural Black Nova Scotian women and their families (e.g. racism, poverty, unemployment, access to health services and caregiving roles).[51] One study explored definitions of health.[53] Other studies found key health outcomes for Black Canadians, including higher likelihood of living in a food-insecure household[79] and higher morbidity levels associated with treated disease.[60]

Culture was woven through the findings of several studies. One study noted the importance of meals to ANS as a source of pride and identity.[42] Culture-based spirituality was also noted as a strong influence on African Canadians in Halifax.[77] Spirituality and religion were used as key coping mechanisms to deal with racism, as

TABLE 1
Characteristics of included studies

Author(s) Year	Research approach	Research design	Theory, framework or model	Recruitment Sampling	Data collection	Data analysis
Adjei et al.[83] 2018	Qualitative	Multifaceted research design	Critical race study	Existing networks Purposive	Semistructured interviews (one-on-one and focus group)	Qualitative analysis
Aziz et al.[82] 2022	Mixed methods	Cross-sectional study	NA	Local media (newspapers and radio) and community networks (notice boards and social networks) Representative	Surveys (with qualitative, open-ended questions)	Statistical analysis (independent sample *t* tests, ANOVA, compared mean scores), content analysis
Baker et al.[81] 2001	Qualitative	Constructivist research design	NA	Board members of multicultural associations assisted recruitment Purposive and snowball	Interviews (one-on-one)	Constant comparative analysis
Beagan and Etowa[39] 2009	Mixed methods	NA	Everyday racism	Word of mouth Nonrepresentative purposive and snowball	Surveys and semistructured interviews	Thematic analysis, statistical analysis
Beagan and Etowa[40] 2011	Qualitative	Narrative research	NA	Word of mouth Purposive and snowball	In-depth, semistructured interviews	Thematic analysis
Beagan et al.[41] 2012	Mixed methods	Exploratory design	NA	Word of mouth Purposive and snowball	Interviews and surveys	Thematic analysis, statistical analysis
Beagan and Chapman[42] 2012	Qualitative	NA	NA	Advertisements and word of mouth Purposive and snowball	Semistructured, one-on-one interviews and observation	Thematic analysis
Beals and Wilson[25] 2020	Qualitative	Arts based and community-based research	Intersectional Black feminist decolonizing perspectives and identity theory	Through “Proclaiming Our Roots” project Convenience	Workshops, semistructured interviews	Thematic analysis
Bernard et al.[77] 2014	Mixed methods	Naturalistic inquiry and cross-sectional secondary data analysis	NA	Purposive	Secondary data analysis (survey data) of data from Racism, Violence, and Hate Study and interviews (one-on-one and focus group)	Thematic analysis
Bernard[38] 2020	Other	NA	Practice Principles based on Africentric theory	NA	NA	NA
Bhawra et al.[79] 2021	Quantitative	Quasiexperimental (prospective cohort study)	NA	Face-to-face intercept sampling method stratified by region and type of location	Surveys	Statistical analysis (descriptive, multinomial logistic regression)
Crooks[43] 2018	Qualitative	Case study	NA	NA	NA	NA
Davidson et al.[44] 2001	Qualitative	Cross-sectional	NA	Database of provincial telephone numbers, systematic sampling procedures from a list of randomly selected Nova Scotian households in the database	Surveys	Statistical analysis (descriptive statistics, one-way ANOVAs, Pearson chi-square tests)

Continued on the following page

TABLE 1 (continued)
Characteristics of included studies

Author(s) Year	Research approach	Research design	Theory, framework or model	Recruitment Sampling	Data collection	Data analysis
Davis[45] 1964	Quantitative	Cross-sectional	NA	Students were drawn from Grades 7, 8 and 9 to correspond as closely as possible in educational level to Karon's school children Purposive	Standardized tests	Statistical analysis
Davis et al.[46] 2013	Qualitative	NA	Critical race theory	Phase 2: flyers, word of mouth and community networks Purposive	Interviews (one-on-one and focus groups)	Thematic analysis
Delisle and Sweeney[47] 2018	Other	NA	NA	NA	NA	NA
Etowa[48] 2005	Qualitative	Grounded theory	NA	Community organizations and existing networks Purposive convenience, theoretical and snowball sampling	Interviews (informal), observation, field notes and group meetings	Constant comparative method
Etowa et al.[49] 2007	Mixed methods	Participatory action research and interpretive phenomenology	Interpretive phenomenology paradigm (Africentric paradigm)	Purposive sampling	Interviews (one-on-one and focus groups), community workshops and survey	Thematic analysis and statistical analysis (descriptive)
Etowa et al.[50] 2007	Qualitative	Participatory action research	NA	Community networks Purposive, theoretical and snowball sampling	Interviews (one-on-one)	NA
Etowa et al. [51] 2007	Mixed methods	Participatory action research	NA	Existing networks of community facilitators and community networks Purposive and snowball sampling	Interviews (one-on-one and focus groups) and surveys	Thematic analysis
Etowa et al.[52] 2009	Qualitative	Grounded theory	NA	Theoretical sampling	Interviews (one-on-one and focus groups), interview observations and field notes	Constant comparative method
Etowa et al. [53] 2012	Other	NA	Participatory action research	NA	Surveys	Statistical analysis and thematic analysis
Etowa[54] 2012	Qualitative	Feminist participatory action research	NA	NA	Interviews (one-on-one and focus groups)	Thematic analysis
Etowa et al.[55] 2017	Mixed methods	NA	NA	Purposive, snowball sampling	Surveys, interviews (one-on-one and focus groups) and community workshops	Qualitative and quantitative analysis
Evans et al.[56] 2005	Qualitative	Participatory action research	NA	Community networks (organizations and leaders)	Interviews (focus groups)	Thematic analysis
Gahagan et al.[57] 2011	Mixed methods	NA	NA	Flyers, existing networks (community and healthcare services contacts)	HIV surveillance data and interviews (in-depth, semistructured, one-on-one)	Thematic analysis and statistical analysis (descriptive)
Jean-Pierre[58] 2021	Qualitative	Cross-sectional	Cultural trauma	Word-of-mouth, email, posters Snowball sampling/ respondent-driven sampling	Interviews (one-on-one and focus groups)	Thematic analysis

Continued on the following page

TABLE 1 (continued)
Characteristics of included studies

Author(s) Year	Research approach	Research design	Theory, framework or model	Recruitment Sampling	Data collection	Data analysis
Johnston et al.[59] 2003	Quantitative	Cohort study	NA	Mailing letters Sample derived from a provincial database	Data registry	Statistical analysis (two dimensional cross-tabulations and chi-square tests, logistic regression)
Kisely et al.[60] 2008	Quantitative	Retrospective cohort study	NA	NA	Administrative databases	Statistical analysis (incidence rates, descriptive statistics)
LeBrasseur[74] 2022	Mixed methods	Participatory action research	NA	Existing networks (to form advisory committee)	Survey (digitally map-based)	Literature review, descriptive analysis
Maddalena[61] 2005	Qualitative	Case study, reflexive ethnography	Feminist ethics	Mail survey Purposive sample	Interviews, surveys and document review	Discourse analysis, thematic analysis, reflexive ethnography and ethnography
Maddalena[76] 2010	Qualitative	Case study	NA	Purposeful sampling	Interviews (one-on-one, in-depth)	Discourse analysis, thematic analysis, reflexive ethnography and ethnography
Maddalena et al.[75] 2010	Qualitative	Case study	NA	Purposeful sampling	Interviews (one-on-one)	Thematic analysis and discourse analysis
Maddalena et al.[62] 2013	Qualitative	NA	Naturalistic inquiry and participatory action research	Through local community church Purposeful and snowball sampling	Interviews (focus groups)	Thematic and discourse analysis
Nourpanah[63] 2019	Qualitative	Ethnography	NA	NA	Interviews (ethnographic)	Narrative analysis
Nyika[64] 2022	Qualitative	Photovoice	Critical race theory–social constructivism framework	Invitations through school staff (principals, vice principals and support staff) Purposeful	Photovoice and interviews (one-on-one and focus groups)	Thematic analysis
Paynter et al.[65] 2022	Qualitative	NA	Community-based research	Email to past doula training participants	Semistructured interviews	Thematic analysis
Ristovski-Slijepcevic et al.[67] 2008	Qualitative	NA	NA	Community based organizations, community contacts and public notices	Interviews, observations	Thematic analysis
Ristovski-Slijepcevic et al.[66] 2010	Qualitative	NA	NA	Community-based organizations and public notices Purposive and snowball sampling	Part of a family-oriented food study (described elsewhere), interviews, shopping trip, participant observation	Critical discourse analysis
Taylor[80] 2022	Qualitative	Grounded theory	Straussian grounded theory	Social media, community organization email lists Purposeful and snowball sampling	Interviews	The data were analyzed using techniques specific to Straussian grounded theory
Wade[78] 1973	Quantitative	Cross-sectional	Maslow's Theory of Needs	Existing network, letter to school Random sampling	Standardized tests and surveys	Theoretical analysis

Continued on the following page

TABLE 1 (continued)
Characteristics of included studies

Author(s) Year	Research approach	Research design	Theory, framework or model	Recruitment Sampling	Data collection	Data analysis
Waldron[68] 2015	Other	NA	NA	NA	Workshops	NA
Waldron[69] 2018	Other	NA	NA	NA	NA	NA
Waldron[70] 2018	Other	NA	NA	NA	NA	Sociospatial analysis
Watson[71] 2009	Qualitative	Ethnography	Interdisciplinary, problem-oriented approach	Direct requests at educational classes	Observations and interviews (one-on-one)	Thematic analysis
Weerasinghe[72] 2012	Qualitative	NA	Cultural health capital framework	Contact information obtained from community organizations	Surveys, interviews and discussions	Theory-driven coding and inductive coding
Wong et al.[73] 2005	Other	NA	NA	Project assistants were used for recruitment, existing networks	Interviews (focus groups) and surveys	NA

Abbreviations: ANOVA, analysis of variance; HIV, human immunodeficiency virus; NA, not applicable.

Note: "Other" refers to articles that do not fall under the traditional qualitative–quantitative dichotomy—for example, viewpoint articles, perspective articles and opinion articles.

well as means of advocating for social justice.[41] Furthermore, a lack of access to culturally appropriate, sensitive and safe services and education was highlighted.[58,61,76]

Recommendations

Many studies offered valuable future directions for Black health data. The recommendations broadly fit into five categories: (1) recognizing the pervasive and real impact of racism on Black populations; (2) developing and providing education and cultural competence and safety training; (3) building partnerships with community prior to project start; (4) recognizing the importance of community-based approaches; and (5) developing a stronger research foundation.

Research conducted with Black populations is fundamentally flawed if the research team does not recognize the impacts and pervasive nature of racism. Etowa and colleagues state that it is important that "research in this area be undertaken with the recognition that race interacts with numerous other variables and experiences to determine the health of Canadian Black women and their families."[51,p.72] The interactions between race and other variables and experiences denote the pervasive impact of racism on everyday lives of Black people.

Developing and providing education and cultural competence and safety training was the second most common recommendation. One study recommended ongoing education training for faculty and staff in nursing programs due to a lack of diversity and social inclusion training.[48] Another study suggested the need for cultural competence and safety training within curricula for childbirth educators and healthcare providers.[54] Jean-Pierre adopted a systems-level recommendation aimed at integrating culturally relevant and sustaining pedagogy within Nova Scotia's education system.[58] Furthermore, she provides an explanation of how such integration would benefit Black learners:

> Implementing culturally relevant and sustaining pedagogy across Nova Scotia may foster equitable learning environments for Black learners by providing fluency in their cultural heritage, fulfilling the long-awaited democratic promise of integrated public schools, and representing a form of civic repair where we redress the legacy of anti-Black racism in education.[58,p.1167-8]

Several other studies recommended cultural and structurally appropriate and competent training be implemented within healthcare and health education. Educational recommendations were mostly made for childbirth settings and professionals,[54,65,71] followed by nurses.[48]

Partnership and community were at the heart of culturally and structurally competent research throughout this review. This is reflected in the studies that recommended building community partnerships prior to commencing research.[51,54,62,68,69,73] Etowa and colleagues suggested that embedding community partnerships as an explicit goal can help research teams fully understand health issues and achieve improved health outcomes for Black populations.[51] Another study added that partnerships foster mutual respect between healthcare providers or organizations and community that, in turn, empowers communities to find their voices.[54] While partnerships were a core focus of recommendations to improve Black health research, one study recommended exploring mechanisms of developing partnerships to ensure effective engagement.[62]

Considerations outside of Eurocentric approaches to research

Community engagement

Community engagement (CE) is a process of working collaboratively with populations or groups that share specific characteristics to positively impact the health and well-being of that population.[84] CE operates on a spectrum from minimal involvement to community-led initiatives. CE as a spectrum was reflected in the conceptualizations expressed in the included studies in this review. For example, three studies discussed having appropriate population representation on the research team,[42,55,75] while others discussed community involvement in varying ways, including having community members assist in recruitment,[48] connecting with community organizations,[67] creating community advisory committees[46,73,74] and encouraging community leads and/or involvement throughout the entire research process.[51,54,56,75]

Articles often included community engagement but did not discuss the importance of the process. For example, Beagan and Etowa acknowledge the presence of "close-knit local communities"[40,p.287] and developed an African Nova Scotian research team, but do not touch on the reasons for adopting this method of community engagement. Further, Davis and colleagues hired an advisory committee of community members, but again, do not discuss the importance of the process of engaging community members in the research process.[46] Wong and colleagues touch on a "failure to identify leaders in each of the participant communities to act as cultural representatives"[73,p.12] as part of the reason for difficulty with recruitment and response rates.

Cultural considerations

Connecting with community arose as a key cultural consideration, and the importance of working collaboratively with community is discussed in the community engagement section above. Other key considerations were selecting appropriate theoretical frameworks[50,51,58,68,69,74,75] and engaging members of the Black population throughout the research cycle.[42,52,53,62,72,75] The theoretical frameworks adopted by included studies are outlined in Table 1. It is important to note that certain frameworks were discussed as culturally relevant and appropriate. Specifically, participatory action frameworks were frequently discussed as appropriate and relevant.[50,51,68,69,74] Other frameworks that were included, discussed and identified as culturally considerate were cultural trauma[58] and storytelling.[75]

Discussion

This rapid review was conducted as part of a national inquiry across three key regions in Canada (the Prairies, Quebec and the Atlantic region). The purpose of this review was to develop an understanding of the research cycle in the field of Black health in the Atlantic provinces of Canada. Specifically, key issues, opportunities and promising practices were identified to further improve the state of Black health research across the region. The results of our study suggest a dearth of literature in the Atlantic region, but also key areas for consideration to ensure that research is conducted with Black Canadians in a manner that is safe, culturally appropriate and beneficial to the community.

The lack of available literature (only 47 studies) poses a serious concern to ensuring culturally and structurally appropriate research. Trends in number of publications by year indicate that the turn of the millennium sparked an increased interest in Black health. However, the International Decade for People of African Descent—declared by the United Nations to extend from 2015 to 2024—did not result in a further, noticeable increase in interest in and generation of Black health data.[85] Because of the prevalence of anti-Black racism and systemic injustice, a broader foundation for this research area should be available.

A recent scoping review of participatory research methods in Indigenous health research supports this notion.[86] The study identified 211 articles for inclusion. Given the similarities in proportion of the population that Indigenous and Black individuals represent, and similarities in scope between the two reviews, one might expect a greater availability of research on Black health. The sparsity of available evidence may, in part, be due to the lack of mandatory race-based data collection in Canada,[87] community fatigue from exploitative research projects or a lack of culturally and structurally appropriate and ethical training for researchers and practitioners.[48,54,58]

Central to contributing to a broader foundation for Black health research in Atlantic Canada is ensuring that the design, development and execution of research is premised on cultural considerations. Our findings suggest that community engagement is an integral consideration for conducting research with Black populations and may improve project outcomes. Husbands and colleagues found that through engaging Black churches in an intervention (Black PRAISE) to promote critical awareness of HIV, congregants' knowledge of HIV increased.[88] In addition to the importance of community leaders discussed by Wong and colleagues,[73] Black PRAISE may indicate the how crucial context is in the process of community engagement with Black populations. Integrating community engagement techniques into research has the potential to ensure culturally and structurally competent research is undertaken with Black populations in Atlantic Canada.

While community-based and participatory action research were frequently adopted, the importance of community extends beyond the adoption of a model or framework. Data governance frameworks exist that help to explain the centrality of community in Black health data. For example, the Engagement, Governance, Access and Protection (EGAP) Framework, out of Ontario, outlines engagement as the first of four core principles for data governance.[89] Engagement is not only a process of listening but rather ensuring the project hinges on what is meaningful to communities. This review highlights the many meaningful ways community can be engaged, from the creation of community advisory committees to the inclusion of Black researchers at the beginning of the project. Given the geographic spread and diversity of Black populations in Canada, there is a need for a framework that extends beyond Ontario and that represents the collective data ownership, governance and accessibility rights of all Black Canadians.

This review highlighted the many recommendations arising from the limited Black health research conducted in the Atlantic region of Canada. In order to develop an evidence base that informs action to address health inequities, there is a fundamental need for greater education and consideration of the histories and contributions of Black populations to the region. Currently, the Tri-Council Policy Statement "Ethical Conduct for Research Involving Humans (TCPS 2)" does not offer a module for conducting research with Black Canadians.[90] We recommend, to ensure and support the implementation of cultural and structural competence and safety training into services, that the federal funding agencies develop an appropriate module, created by Black communities and researchers, that will form the ethical groundwork for all research involving Black participants in Canada.

Strengths and limitations

A notable strength of this study is the rigorous search strategy adopted. The collaboration with a university librarian ensured the search strategy was comprehensive and accurate and captured all applicable and available information on the topic. Another strength is the use of a broad definition of health, enabling the capture of culturally and structurally appropriate and ethical Black health research that specific definitions might overlook.

This study also has potential limitations. Critical appraisal of literature may be of benefit to assess the trustworthiness of the study findings. Given the importance of community engagement in conducting research with Black populations, a search of grey literature might have identified key community-level data collection initiatives that exist outside the realm of published literature.

Conclusion

Findings from this study suggest there is a need for dedicated resources (e.g. a TCPS 2 chapter on ethical conduct in research with Black populations, and regional ethics frameworks for Black populations similar to the EGAP framework) to improve the state of Black health research in Atlantic Canada. There is a paucity of Black health data in the region, particularly for subpopulations including men, children and Black populations in NB, PE and NL. To maximize research participation and outcomes, particular attention should be paid to community engagement throughout the stages of the research process. A nationwide data collection and governance framework would provide an opportunity to improve the state of Black health data in the Atlantic region.

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Conflicts of interest

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Authors’ contributions and statement

JY, ESC, KJ, BB, CS: data curation.

JY, ESC, KJ, BB, CS: formal analysis.

BHH: funding acquisition.

ESC, KJ, BHH: methodology.

JY, BHH: project administration.

JY, CS: visualization.

JY, ESC, KJ, BB, BHH: writing—original draft.

JY, BHH: writing—review and editing.

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Study protocol

Methodological reflections from a research project on the mental health of Black youth

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Summary

The aim of this study was to provide an illustrative example of how researchers can effectively engage Black youth using a culturally responsive, participatory action research (PAR) approach. We aimed to examine the mental health needs of Black youth and identify culturally relevant strategies to increase access to and uptake of mental health services. The study took a PAR approach to foster maximum inclusion of youth in the research process. We collected data in two phases: (1) individual interviews with 30 youths; and (2) monthly conversation cafés over a four-month period with 99 youth participants. We recruited youth participants through the Africa Centre Youth Empowerment Group in Alberta, at a soccer tournament hosted by Africa Centre and through affiliated social networks, and established a youth advisory group that met quarterly and assisted with data collection, data analysis and dissemination. We shared our findings at a community engagement session for stakeholders. The study provided space for youth to share their experiences and to imagine solutions to their mental health difficulties; it also allowed us to conduct research that carefully integrated the perspectives of those most affected by the study's policy and practice recommendations. This project is an important case example that demonstrates promising practices and accessible methods across the data collection cycle, as well as the key ingredients and mechanisms that support culturally responsive practice.

Keywords: *methodology and research, mental health, adolescent health, Black youths, participatory*

Highlights

- This study examined the mental health needs of Black youth in Alberta.
- The study undertook a youth empowerment model situated within a postcolonial feminist paradigm to understand the mental health experiences and needs of Black youth.
- Researchers identified culturally relevant and effective approaches to improving access to and uptake of mental health services while capitalizing on the agency of this population.

Introduction

Participatory research with youth is a transformative approach that positions youth as active co-researchers, enhancing their inclusion, empowerment and equitable decision-making throughout the research process.[1,2] However, despite its potential, there has been limited research examining how to effectively conduct culturally responsive research with Black populations, particularly African, Black and Caribbean youth in Canada and around the world.[3,4] This gap is evident in the scarcity of studies that prioritize culturally appropriate methods and address the unique social, structural and systemic barriers these youth face, including racism, discrimination and marginalization.[5,6] As noted by Bailey et al., researchers often encounter difficulties in building trust with Black communities, exacerbating challenges in fostering meaningful engagement and generating impactful findings that resonate with the community.[7]

A culturally responsive and equitable approach to youth research requires thoughtful incorporation of practices that address power imbalances and the historical mistrust between Black communities and researchers.[4] For example, collaborating with community gatekeepers, employing inclusive data collection strategies and ensuring Black leadership within research teams are critical to enhancing research acceptability and fostering local ownership of outcomes.[8] Moreover, while this project focussed on African, Black and Caribbean youth, all participants self-identified as Black. Therefore, the term "Black youth" will be used interchangeably with "African, Black and Caribbean youth" to reflect participants' self-identifications.

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This paper offers an illustrative example of youth-led participatory action research (PAR) that successfully engaged Black youths in Alberta, Canada, to explore and address their mental health needs. Drawing on a postcolonial feminist empowerment model, this study integrated culturally responsive practices such as involving youth co-leadership, creating supportive research environments and ensuring the inclusion of diverse voices within the research process.[4,9] By emphasizing the engagement of Black youth as co-researchers, the project not only promoted inclusivity but also fostered valuable insights into culturally appropriate and impactful research practices.

These strategies are essential for researchers looking to ethically and meaningfully engage with Black youth populations.[7] Studies suggest that African, Black and Caribbean populations, including youth, may experience higher rates of mental health problems compared to the general Canadian population.[10-12]

Despite this evidence, we are unaware of any Canadian study prior to the conceptualization of this research in 2017 that has provided a basis for action that could inform the efforts of African, Black and Caribbean youth to improve their mental health outcomes. Indeed, we conducted interviews with 57 African immigrant parents, community leaders, service providers and policy makers on parenting and mental health promotion practices; these individuals collectively expressed a strong need for research that will provide useful interventions to promote the mental health of African immigrant children and youth.[13-15]

Furthermore, our preliminary consultations with youths called for collective action among African, Black and Caribbean immigrant youth while acknowledging the vital influences of race and colonialism on their experiences. Thus, our study focussed on diverse generation (first, second, third, etc.) immigrant youths as well as those who migrated through various streams (immigrants, refugees and international students). While we recognize the heterogeneity of this group (i.e. African, Black and Caribbean youth, as well as refugees, immigrants and international students), we are also following the lead of youths consulted prior to our study. During our consultations, the youths emphasized the importance of focussing on the collective identity of African, Black and Caribbean youth rather than focussing on African, Black or Caribbean communities in isolation. Our definition of our population was thus informed by our consultations; we nonetheless maintained space for the analysis of subgroups.

Overall, our project aimed to improve the mental health outcomes of African, Black and Caribbean youth in Alberta. This paper is an important case example that demonstrates promising practices and accessible methods across the data collection cycle, as well as the key ingredients and mechanisms that support culturally responsive practice.

Purpose and research questions

The aim of this paper was to provide an illustrative example of how researchers can effectively engage African, Black and Caribbean youth in Canada using a PAR approach. By leveraging postcolonial feminist theory, the paper offers insights into culturally responsive and ethical research practices that promote meaningful collaboration and empowerment of Black youth as co-researchers, addressing systemic barriers such as racism and marginalization in the research process. From the outset, the PAR approach was employed to co-develop the project's research questions in partnership with Black youth. Through early consultations with Black youths (described later in this article), the research questions were collaboratively crafted and subsequently refined to ensure alignment with funder priorities. The final research questions guiding this study were as follows:

- What are the mental health needs of African, Black and Caribbean youth in Alberta?
- What are the barriers to access to and use of mental health services for African, Black and Caribbean youth in Alberta?
- What are culturally relevant and effective approaches to increasing access to and uptake of mental health supports by African, Black and Caribbean youth in Alberta?
- What potential exists to mobilize African, Black and Caribbean youth to improve mental health outcomes and/or to build resilience and capitalize on their agency?

The outcomes of the project, addressing these questions, have been documented and shared in multiple peer-reviewed journal articles.[3,8]

Methods

Ethics approval

This project received approval from the University of Alberta Research Ethics Board 1, # Pro00079877.

Theoretical framework—postcolonial feminist empowerment model

We used a youth empowerment model situated within a postcolonial feminist paradigm to understand the mental health experiences and needs of African, Black and Caribbean youth. The postcolonial feminist paradigm is a critical framework that draws on the intersections of postcolonial theory and feminist thought to examine how colonial histories, power structures and imperialist legacies continue to shape gender, race and class inequalities, particularly for marginalized groups in formerly colonized societies.[16] It recognizes that colonialism did not only impose political and economic domination but also cultural and social hierarchies that persist today.[16]

Within this framework, gender is not an isolated factor but is deeply intertwined with race, class and other social categories, making it essential to address the unique experiences of marginalized populations,[17] such as African, Black and Caribbean youth in Canada. Postcolonial feminism critiques traditional Western feminist frameworks for universalizing women's experiences and ignoring the diverse struggles faced by women in the Global South. It rejects the notion of a singular "Third World Woman" as a monolithic subject of oppression, emphasizing instead the importance of understanding local contexts and the various forms of resistance employed by marginalized groups.[18] In this way, the postcolonial feminist paradigm offers a more nuanced understanding of the unique social and structural barriers faced by Black youth, particularly the ways in which racism, systemic marginalization and colonial legacies intersect to affect their mental health and well-being.[4,16]

This paradigm is particularly well-suited for this study because it aligns with the PAR methodology, which seeks to challenge traditional power dynamics by actively involving youth as co-researchers. By positioning Black youth as experts of their own experiences, the postcolonial feminist approach not only acknowledges the historical and systemic oppressions they face but also values their agency in addressing these issues.[19] This framework supports the ethical engagement of marginalized communities and fosters the development of culturally responsive and community-driven solutions to the mental health challenges these youth encounter. Therefore, the postcolonial feminist paradigm provides a robust theoretical lens to critically explore the intersections of race, gender and colonial history, making it the ideal model to address the research questions posed in this study.

Empowerment is defined as gaining control of one's life through active participation, with an emphasis on creating and building awareness of and engagement with one's environment.[20] This empowerment model guides youth empowerment processes and outcomes in research by creating safe and supportive spaces, ensuring meaningful participation, equalizing power dynamics between adults and youth, providing opportunities for personal and community development and encouraging critical reflection on broader processes and structures that shape their lives.[21] These five dimensions guided the research design to ensure adherence to participatory and community-driven principles.

By creating a safe and supportive environment and encouraging meaningful participation, we acknowledged the different histories and impacts of social, economic and political marginalization experienced by African, Black and Caribbean communities.[5,6] Providing spaces for critical reflection and community engagement allowed youths to understand the forces that influence their lives, articulate their experiences and recognize their capacity for creating change.[22] By using an empowerment model, we made explicit our commitment to providing a space for youths to use their voices and to simultaneously recognize their strengths and capacity for resilience as well as the oppressive structures and narratives that hinder agency.

Youth-led participatory action research

PAR is a power-equalizing, collaborative research approach that sees community members as partners in the research process and experts on the issues of concern in their lives.[23,24] This methodology is based on principles of shared leadership, collaborative decision-making and researcher–community trust building with the end aim of creating sustainable, action-oriented research outcomes. PAR approaches that genuinely incorporate youth as equitable decision-makers and collaborators throughout the research process are rare, despite ample evidence of the positive outcomes.[1] We see youth-led PAR as a valuable approach that allows for increased youth empowerment and sociopolitical engagement and will lead to improved understanding of the mental health needs of youth in ways that can inform policy and community health initiatives.[2,9,25] We engaged in youth-led PAR with African, Black and Caribbean youths to better understand their experiences with mental health, their perceived mental health needs, barriers to meeting these needs and culturally appropriate strategies to improve access to and uptake of mental health services.

Consultation with youths

Before this project began, the first author and principal investigator (BS) was a member of Africa Centre, a major service provider for Africans in Alberta. During one of the board meetings, she became aware that the youths had no resources to address issues that were of concern to them. She thus arranged to meet with the youth leader and subsequently with eight African, Black and Caribbean youths of the Africa Centre Youth Engagement Group (YEG). The youths identified a crucial need to improve mental health outcomes within the community and, with the mentorship of the principal investigator (PI), who is herself a young African immigrant, devised a plan of action to address mental health concerns.

First, they identified a need for data to inform future programs and strategies around mental health. Second, they opted for participatory research methodology as a viable strategy to enhance mental health outcomes. Third, they stressed the need to shed light on issues of discrimination rooted in colonial histories that mediate their experience; they also wanted an intersectional approach to this postcolonial perspective in exploring their mental health concerns. Fourth, the youths wanted to involve African, Black and Caribbean youth, emphasizing their collective, racialized identity.

Furthermore, with the help of the PI, the youths developed a five-year plan and an Alberta-wide strategy to improve their mental health, the first step of which was to actively participate in the application for a grant to collect data on African, Black and Caribbean youth mental health. The youth leader was a co-investigator on the grant proposal and was involved in its development.

Youth advisory committee

Upon receiving the funding, the PI communicated with the youth group. However, the PI went on a one-year maternity leave, during which time the project was suspended and the leadership of the youth group changed. Upon the PI's return, a meeting was arranged with the new leadership and advertised to recruit advisory committee members. Ten youths indicated interest in being on the advisory committee and attended the first meeting. Advisory committee members were all female or nonbinary, reflecting the composition of the YEG's Black youth empowerment group ("The Come Up").

Advisory committee members met three times throughout the research process. Sub-teams of members met with the PI and one of the two PhD student research assistants (DA) assigned to the project an additional six times. The youths also met with each other additional times and maintained a WhatsApp group for communication among themselves. This was interpreted as a strategy for them to negotiate power relations with the PI who, although Black, was older (late thirties).

The role of the advisory committee members included advising on data collection procedures, on delivery of conversation cafés and interviews and on knowledge translation and dissemination. Before the initial meeting, we presented the youths with our ethics documents and our preliminary interview guide. The youths commented on and made recommendations for the interview guide, including adding questions on preferences for healthcare provider (as it relates to race concordant health service provision). Youths also emphasized their desire to be actively involved in the project, especially in the collection and analysis of data.

We thus hired youths (at approximately $20/h) who were interested in actively being involved as research assistants (seven youths). Advisory committee members who were not research assistants (three youths) were also paid an honorarium totalling an equivalent amount. The advisory committee members who were hired as research assistants took more active roles in interviewing participants, organizing and leading conversation cafés, developing the initial conversation café guide, facilitating participant recruitment, analyzing data and co-authoring reports and publications.

We infused a number of strategies to build the capacity of these youths. Prior to data collection, all research personnel received four hours of training on qualitative research and completed a research ethics training module. Research assistants involved in data analysis completed one day of training on the use of NVivo qualitative data analysis software and individual mentorship by a PhD student and research coordinator skilled in the use of NVivo. Throughout the research process, the research assistants received close mentorship from two PhD student research coordinators and the PI. They also met with the project lead to discuss their plans before each conversation café.

Data collection and analysis

Data collection and analysis occurred between August 2019 and February 2020 in two phases: Phase 1 involved interviews with African, Black and Caribbean youths, while Phase 2 involved conversation cafés with youths.

Phase 1: interviews

We conducted 30 individual interviews with youths to obtain an in-depth understanding of their mental health experiences. Upon obtaining ethics approval, we recruited youths through the Africa Centre YEG, which is the Africa Centre's youth collective and represents diverse African and Afro-Caribbean communities. We also recruited youths through the personal networks of our research assistants and advisory committee members. During our recruitment, we determined that males were underrepresented in our sample, likely due to the all-female, nonbinary composition of our advisory committee. To increase the gender diversity in our sample, we attended the All Africa Soccer Tournament and Festival (hosted by Africa Centre in Edmonton, Alberta) to recruit more male participants. All study participants were of African, Black or Caribbean heritage, aged between 16 and 30 and fluent in English. We strived for maximum variation sampling by recruiting participants with diverse immigration backgrounds, genders, countries of origin and religious backgrounds.

Individual interviews lasted around one hour, were audio-recorded (to be later transcribed verbatim by an experienced transcriptionist) and were conducted in person at a location that was comfortable for participants. The interviews were all one-on-one interviews, except for one participant with significant mental health challenges who brought his sister to the interview for support. Individual interviews included a sociodemographic questionnaire and semistructured interview questions centred on personal mental health experiences, perceptions around available support systems, perceived barriers to mental health, culturally appropriate and effective strategies to improve access to and uptake of mental health services, and implications for research, policy and practice.

The interviews were conducted by the youth research assistants or one of the PhD students, who wrote reflexive notes at the end of each interview. The reflexive notes summarized the interview, identified any information that might not be obvious in interview audio recording (such as nonverbal cues) and discussed how their positionality may have affected the interview process. Participants received $10 for transportation and a $25 honorarium for participating in the study.

Phase 2: conversation cafés

Conversation cafés effectively fostered youth engagement and dialogue because youths could take the lead in identifying issues of concern to them and in explaining the impact these issues have on their lives. Conducted monthly over four months, these three-hour conversation cafés constituted a crucial data source for our study. Each café included 30 to 50 youths. Each conversation café began with a 30-minute meal and social time for youths, followed by a guest speaker who provided a 30-minute presentation related to mental health. The meal was often African or Caribbean and always bought from a Black vendor. We ensured vegetarian options were available and that all meals were halal.

Guest speakers were chosen based on the results of previous interviews and on the advice of the youth advisory committee members. Upon reflecting on the data from Phase 1, youth research assistants and advisory committee members met to determine conversation café topics. The first conversation café was on mental health promotion. The youth research assistants wanted to focus on mental health promotion, as it was the beginning of the semester. The speaker was a Black PhD-prepared therapist and community leader. The second conversation café focussed on intergenerational relations. The session was led by a Black associate professor of counselling psychology. Following up on the presentation, the youth research assistants asked participants questions to spark conversations related to intergenerational relations (as detailed below).

The third conversation café focussed on intersectionality and mental health to address the needs of Black 2SLGBTQI+ populations. The conversation café had a panel presentation by a Black 2SLGBTQI+ activist and leader, a non-Black 2SLGBTQI+ therapist and a Black female community leader who was also a social worker. The fourth conversation café focussed on mental health policy and practice. The PI gave a brief presentation. The youths then led small-group discussions on policy implications. The research assistants also asked the youths to think through what an ideal mental health clinic should look like (these data were later used to support an application for the creation of a mental health clinic).

Youths had around 1.5 hours for focus groups in breakout sessions with a semistructured interview guide. The interview guides were developed by the youth research assistants and shared with the PI prior to the study. The interview guide reflected the perspective of youths on their lived experiences. We had planned to audio-record the sessions, but the youths strongly advised against this; therefore, we instead took notes during the sessions. Upon completion of the breakout sessions, the youths reconvened in a bigger session for 30 minutes to report back and discuss strategies for action; detailed reflexive field notes were also collected during this portion. Youths received $10 for transportation-related costs.

The following are examples of conversation café questions on intergenerational relationships and mental health:

- Your parents are a few of many immigrants who have escaped civil war, persecution and other traumatic events. You notice signs of PTSD in one of your parents and whenever you try to hint at it, they are in denial. How would you approach them about this? How would you wish they would respond?
- You decide that you do not want to attend university, but wish to pursue a different career (art, music, entrepreneurship). How do you think your parents will react? How comfortable are you sharing this with your parents?
- Your child comes home from school and tells you that they wish they had lighter skin. How would you respond to your child and why do you think they might feel this way?
- You approach your parents and try to explain to them that you are depressed. They tell you that you have food, clothes and a house to live in and have no reason to be depressed. How does this make you feel and why do you think they respond this way?
- It has been two years since you and your family immigrated to Canada. Before leaving to attend a cultural event, your child tells you they do not want to go because they do not claim your culture/ethnicity anymore. Where might your child's feelings rise from? How do you respond?
- You are worried that your sibling may be contemplating suicide and, when you tell your parents, they tell you they are probably just experiencing stress and to pray for them. How do you respond to this?

Data management

Data were stored on a secured, internal shared drive at the University of Alberta Faculty of Nursing. Only the seven research assistants, two PhD student research coordinators and PI had access to the shared drive and the data. A central concern was issues related to confidentiality, especially given the small community in which we work. Thus, we developed our drive in such a way that the youth research assistants only had access to data from the interviews they conducted (usually 3–8 interviews per youth). The two PhD students (both of whom were Black males) and the PI had access to all data. However, at the data analysis stage, the youth research assistants indicated interest in analyzing the data themselves. Thus, we provided two youth research assistants with access to all data. The two youths trained in the use of NVivo data analysis software were mentored by a senior PhD student who has experience providing training in data analysis to graduate and undergraduate students. On the first two days, the youths analyzed the data in the presence of the graduate student to help with any challenges that arose.

Data analysis

Thematic data analysis was used to identify relevant patterns and themes emerging from the data. Thematic analysis allowed us to identify and analyze patterns of data while situating these patterns within the broader context of their occurrence.[26] First, the research assistants and PI read the interview transcripts multiple times and developed a preliminary coding tree. Two youth research assistants then coded the data. These codes were expanded and condensed based on emerging data. The codes were then translated into themes. The themes were compared and contextualized with the notes from cafés and field notes prior to writing the results of the study. Thus, the steps in data analysis included familiarizing ourselves with the data, generating initial codes, searching for themes, reviewing and refining themes, defining and naming themes and writing the report.[26]

The use of a postcolonial feminist empowerment model supported the focus on strengths and resilience, while acknowledging the broader sociocultural, economic and political influences that serve to limit youths' potential for agency. As the study progressed, advisory committee members and youth research assistants encouraged the incorporation of an intersectional lens. Thus, we incorporated an intersectional lens including the delivery of a workshop focussed on intersectionality and considering the intersecting influences on our data. We invited our advisory committee of youths to engage in data analysis by commenting on emerging data patterns, offering additional insights and identifying final relevant themes. The first final product of the youth-led participatory action research was a report co-written by youths and presented to Africa Centre leadership. Before dissemination, we provided participants of both the interviews and conversation cafés with the data for feedback.[27]

Quality and ethics

Quality in PAR is defined as ensuring the principles of empowerment, local knowledge development and social action are safeguarded in all aspects of the research process.[23,24] In our study, all research personnel, including the transcriptionist and research assistants, signed a confidentiality agreement. The use of a youth empowerment model grounded in postcolonial feminist theory to guide the PAR allowed us to safeguard research quality by ensuring the research questions were useful to the community, the research findings were grounded in the community's experiences and the final outcome supported sustainable changes in the community through knowledge dissemination. Furthermore, we incorporated reflexive memos regarding our positioning in the research process over time and consulted with youths regarding their perceptions on inclusion and participation.[28] Including youths in the analysis phase and writing of the final documents allowed for greater transparency, ownership and legitimacy of findings within the community, and was also crucial for assuring rigor in PAR.[28]

Discussing past experiences of mental health challenges can pose an emotional risk to participants. As noted by Morse et al.,[29] those who have not had the time to process or resolve a crisis or who have experienced psychic trauma may be highly emotional, and participants may not be aware of upsetting memories until they start discussing them. Hence, ethically important moments may occur during the research.[30] Research assistants were sensitive to the psychological and emotional needs of the research participants. We offered to stop interviews if participants became emotional. We provided participants in interviews and conversation cafés with a list of resources. Participants were also given an opportunity to debrief at the end of the interviews and conversation cafés to ensure their emotional well-being and referral to appropriate services.

Results

Our interviews and conversation cafés with Black youths provided rich knowledge at a time when there was a scarcity of information on the mental health of Black youth. Racism and intergenerational gaps in families were the two priority factors identified as contributing to the mental health challenges of Black youth.[8] Additional factors identified by Black youths include academic stress, microaggression, stigma, financial stress and previous traumatic events. The experience of Black youths illustrated the intersectionality of race, income and other factors. Youths also identified that spirituality, peer support and sense of community contributed positively to their mental health. Youth co-researchers were keen on asking questions about access to culturally appropriate healthcare for Black youth.[3] Participants identified the need for culturally responsive and safe service provision from both Black and non-Black service providers. Additional barriers to access to services included cost of services and stigma. Mental health services are often located in geographic areas that are not culturally accessible to Black people. These barriers inspired the youths to advocate for the creation of an ideal mental health clinic for Black youth.

Knowledge mobilization

We were committed to facilitating a multidirectional flow of knowledge between the research community and knowledge users, including policy makers, decision-makers, community partners, service providers and immigrants. Youths were active participants in the dissemination process. The youths produced a report that was disseminated to diverse stakeholders.[31] We also held a stakeholder engagement session that was attended by approximately 80 stakeholders including youths, community leaders and members of the Public Health Agency of Canada. The stakeholder event was led by and delivered by the youths.

In addition, the results of this work were shared by the PI with the Prime Minister of Canada. The results were also shared with the Executive Director of Africa Centre, who used them in collaboration with the Alberta Black Therapists Network to create the first mental health clinic for Black Canadians in Western Canada. The results have also been published in two peer-reviewed papers,[3,8] and several presentations have been made. In our reports, we referred to our participants as "Black youths," given that all those in our study self-identified as such.

Conclusion

Our project provided useful knowledge on the mental health of Black youth and informed policy and practice. A strength of this project is that while PAR approaches do not always engage communities from beginning to end, in this case, youths were involved in every aspect of the study and had a strong sense of project ownership. Our prior engagement in the field, consultation with youths and positionality as Black researchers (and two non-Black researchers with strength in participatory research) helped advance the research process. Power relations along the lines of class and age were key challenges that we addressed during the research process. Meetings between one of the PhD student research assistants (BD) and the youths prior to meeting with the research team helped address this challenge.

As we engaged in the participatory approach, we expected time to be a challenge. However, we were able to collect our data in a period of six months. A challenge we found upon completion of our data collection was that youths who attended multiple cafés often did not complete consent and demographic forms each time they attended. Thus, we had more individuals attend our sessions than the number we recorded. We also had to reconcile gaps between our academic and community priorities. We ensured we did not submit any data for publication prior to submitting a report to our communities. We tackled issues of confidentiality and data security by ensuring youths only had access to the data they collected unless they were engaged in data analysis and needed access to all data.

Our participant demographics were reflective of youths in the community. Our research assistant demographics (although predominantly female) were also reflective of our participants. Future studies should further examine how to increase gender diversity in research with Black youth.

All of these efforts produced tangible and meaningful results. We recruited more participants than we had initially proposed for our conversation cafés, built the capacity of youths (many of whom are now graduate students or working in professional jobs) and gathered useful data that changed policy and practice.

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Conflicts of interest

We have no conflicts of interests to disclose, and no financial interest or benefit has arisen from the direct applications of this research.

Authors' contributions and statement

BS: conceptualization.

BS, JS: funding acquisition.

BS, JS, BD, DA: investigation.

BS, JS, BD, DA: methodology.

BD, DA: project administration.

BS: supervision.

BS, AM: writing—original draft.

DA, JS, BD: writing—review and editing.

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Original qualitative research

An analysis of the Mental Health of Black Canadians Fund: facilitators of success, challenges and recommendations

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This article has been peer reviewed.

Abstract

Introduction: In 2018, in an effort to address the mental health inequities experienced by Black Canadians, the Government of Canada announced a CAD 10 million investment to establish the Public Health Agency of Canada's Promoting Health Equity: Mental Health of Black Canadians Fund (MHBC). The aim of this study was to examine and document the lessons learned from the MHBC, including successes and challenges.

Methods: Researchers conducted document analysis of 15 participating projects from 14 organizations' annual and final reports. Researchers then conducted interviews with representatives from nine of these organizations. An embedded case study design was used in the data collection and data analysis that included content analysis of annual and final reports, as well as thematic analysis of individual interviews.

Results: Analysis of the data from annual and final reports and interviews illuminated three main themes: facilitators of successes; challenges; and lessons learned and recommendations for funders. Facilitators included honorariums and incentives, participatory action research design and Black leadership. Challenges included delays (for obtaining ethics approval and program implementation); impacts of the COVID-19 pandemic; and difficulties maintaining partnerships. Finally, the lessons learned and recommendations that emerged for funders were that there is a need for longer term and more flexible funding, more Black representation and leadership within funding organizations and greater support of antiracist practices among mainstream service providers.

Conclusion: The findings of this study present the challenges and opportunities in supporting work aimed at improving the mental health and well-being of Black people in Canada.

Keywords: *mental health, Black Canadians, service provision, funding, health equity*

Highlights

- Facilitators of success among participating organizations included honorariums and incentives, participatory action research design and Black leadership.
- Challenges included delays (for obtaining ethics approval and program implementation), impacts of the COVID-19 pandemic and difficulties maintaining partnerships.
- Recommendations that emerged were that funders should provide longer term and more flexible funding, that more Black representation and leadership is needed within funding organizations and that there should be greater support of antiracist practices among mainstream service providers.

Introduction

Black Canadians experience mental health care inequities in Canada. Poorer health outcomes may be attributed to inequities in social determinants of health, including income disparities and racial discrimination.[1] Racialized mental health inequities in Canada have more recently gained attention from service providers and policy makers. Mental health inequities have been connected to pervasive systemic racism,[2] corresponding inequities related to housing, income inequities[3] and racialized barriers to mental health care and promotion services.[4] Lack of representation in mainstream healthcare and a systemic absence of mental health care for Black Canadians has left many without supports.

In 2018, the Government of Canada announced a CAD 10 million investment to the Public Health Agency of Canada to establish the Promoting Health Equity: Mental Health of Black Canadians Fund (MHBC). The MHBC delivered a grants and contributions program to provide support to community-based projects to develop culturally focussed mental health programs in Black communities across Canada over a five-year period from 2018 to 2023, and was later extended to 2024. The organizations funded through this program promoted mental wellness through mentorship and community-based interventions. The

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program features three key pillars: investing in community, strengthening data and evidence, and mobilizing knowledge. Key principles include a focus on anti-Black racism, leadership by Black Canadians, evidence-based research and programming, a social determinants of health approach to program delivery, a health equity lens, cultural competence and safety, and emphasis on partnerships and collaboration.[5]

The MHBC supports community-led projects focussed on promoting the mental health of Black Canadians through two funding streams. The Incubator Stream provided short-term funding to support capacity-building activities that help community and university organizations design, develop, implement and evaluate projects that promote mental health and address its determinants for Black Canadians. The Implementation Stream provided multiyear funding to support the implementation and evaluation of community-based projects that promote mental health and address its determinants for Black Canadians.[5]

The aim of this work was to examine and document the lessons learned from the Public Health Agency of Canada's (PHAC) Mental Health of Black Canadians Fund. Our intent is to inform future policy and program development in the areas of health equity and mental health for diverse Black communities in Canada. The study was guided by the following questions:

1. What have funded organizations reported as successes, facilitators and challenges of the PHAC Mental Health of Black Canadians Fund?
2. What are the perspectives of funded organizations, working group members and PHAC on the successes, challenges, lessons and opportunities for further refinement of the approaches used throughout the PHAC Mental Health of Black Canadians Fund?

Methods

Ethics approval

Ethics approval was obtained from the University of Alberta Research Ethics Board 1 (Pro00130072).

Data collection

We sought to analyze the MHBC through two stages of data collection. First, researchers conducted document analysis of 15 participating projects from 14 participating organizations' annual and final reports. Of the 15 projects, nine representatives agreed to participate in interviews. In the second stage, researchers conducted interviews with representatives from these nine organizations. All organizations involved in the MHBC program were invited to participate. The nine that did were representative of the larger group of funded organizations and included community and university organizations and provided geographic representation.

Study design and analysis

Researchers used an embedded case study design that used content analysis of annual and final reports as well as thematic analysis of individual interviews. An embedded case study design involves a researcher considering each aspect of a larger case.[6] Therefore, researchers explored each organization in isolation before comparing all interviews and analysis of reporting documents, to understand the broader impacts of the MHBC.

Document review and analysis

As a first stage in gauging organizations' experiences with the MHBC, researchers reviewed annual reports of 15 participating projects from 14 organizations' that received funding through the implementation stream of the MHBC. Six of these organizations (organizations 001 through 006) provided annual reports for three years (2019/20, 2020/21 and 2021/22). Two organizations (007, 008) provided annual reports for 2019/20 and 2020/21. The other seven organizations (009–015) provided one-year reporting, all for the year 2021 to 2022. Three organizations also provided final reports (001, 007, 008).

To consider each report and the entirety of the reporting provided, researchers used content analysis to map each organization's reporting. Items on reporting grids included "Please describe some key highlights or achievements of the project during the reporting period (e.g. innovations, new partnerships, etc.)" and "Please describe any difficulties or challenges that your project encountered during this reporting period, how these were addressed and the lessons learned (e.g. reaching priority populations, governance issues, recruiting or working with partners, administrative barriers, etc.). Report contents included information about key successes, challenges, facilitators of success and recommendations for funders.

Information on each topic was captured and tracked as its own individual code (for example: "Organization 001 - key successes - Honorariums and incentives). We then compiled all, for example, honorarium and incentives codes together, to track how many organizations focussed on each topic and what themes arose. This technique required researchers to analyze messages, meanings and themes within and across a set of documents (the 14 organizations' annual and final reports).[7] Looking at the entirety of this information, we found themes across facilitators of success, challenges and recommendations for future funding.

Interviews

At the second stage of data collection, the project's Principal Investigator (BS) conducted individual interviews with nine representatives from organizations that received funding through the MHBC (002, 004, 005, 007, 008, 010, 012, 013, 015). The researchers provided a letter of invitation to staff of the Public Health Agency of Canada, which was distributed to representatives of each of the funded organizations. Interested participants contacted researchers to complete interviews. Prior to interviews, all participants completed the informed consent process. Interviews took approximately one hour and were conducted over Zoom. They were audio-recorded and transcribed verbatim. Interviews used a semistructured interview guide.

Data analysis

Data collection and data analysis occurred concurrently. After the data were transcribed, the researchers familiarized themselves with the data through repeated reading of text and listening to the audio recording. These data were thematically analyzed.[8] Two members of the research team (BS and MT) developed preliminary codes, after which they met to review and agree on a coding framework. The key topics in the annual and final reports (key successes, challenges and facilitators of successes) were used as preliminary major codes, with subcodes under these codes. A member of the team then coded the data using NVivo qualitative software version 14 (Lumivero LLC., Denver, CO, US). The codes were revised, collapsed and expanded based on emerging data. Codes were refined and translated into themes as data was further analyzed and interviews were considered alongside one another.

Throughout the process, we wrote memos and notes to record our emerging awareness, including connections between themes and codes. This allowed us to further define, describe and name the themes. Data from interviews were then compared to data from annual and final reporting, and researchers identified where themes overlapped. The themes and our report were shared with all members of the team for feedback.

Results

Analysis of the results from annual and final reports and interviews illuminated three main themes: facilitators of success; challenges; and lessons learned and recommendations for funders. Within these themes, subthemes offered insight into specific factors that shaped organizations' experiences during their funding period. A summary of these findings is presented in Table 1.

TABLE 1
Summary of facilitators of success, challenges and recommendations for funding, Mental Health of Black Canadians Fund, 2018 to 2024

Themes	Examples	Implications for funding and policy
Facilitators of success	Honorariums and incentives	Despite the importance of honorariums in encouraging participation in programming and health interventions, a lack of support was reported. Participants identified barriers from the funder in providing honorariums to participants.
	PAR research design	PAR design allowed organizations to better respond to changing community needs during program delivery. Funder support of PAR design was a benefit of the MHBC, especially during the pandemic.
	Black leadership	Support of Black leadership and diversity in racial, gender and sexuality representation enabled organizations to tailor program design and recruitment to their client populations and embed Afrocentric principles throughout programming.
Challenges	Delays	Delays were related to pandemic interruptions and long waits to obtain ethics approvals. PHAC's Research Ethics Board helped process one organization's ethics submission when university delays were too long. This shows potential for funders to assist organizations experiencing delays at this stage of research.
	Impacts of the COVID-19 pandemic	Service interruptions, the move to online programming and the need to redesign programming delayed service provision to populations already feeling pandemic impacts particularly starkly. Funders may offer greater support during future crises.
	Structural violence and community-specific challenges	Systemic racism, including over-policing, lack of affordable housing, homophobia and systems of gender oppression shaped the mental health needs of organization's client populations. Some organizations suggested funders do not understand these issues, and emphasized the need for funding flexibility.
	Maintaining partnerships	Staff turnover led to breakdown of relationships and vision shifts that impacted networking and partnerships between organizations. Thus, there is a need for long-term stability within organizations for successful collaboration.
Lessons learned and recommendations for funders	Longer term and more flexible funding	Challenges associated with creating spaces for Black people where none had previously existed demand longer term and flexible funding.
	Black representation and leadership	A lack of Black representation among funders meant that even those who approached the issues with sensitivity and competency often needed aspects explained to them because they were not Black. Perceptions of being micromanaged were largely shaped by organizations' sizes. Smaller organizations tended to relay appreciation for PHAC support. Conversely, larger, more established organizations were more critical of being managed.
	Antiracist practices among mainstream providers	Removing barriers to Black people's access to mainstream healthcare providers should go hand in hand with ensuring Black people do not face barriers to other aspects of mental health supports. There is a need for funders to better support Black organizations.

Abbreviations: MHBC, Mental Health of Black Canadians Fund; PAR, participatory action research; PHAC, Public Health Agency of Canada.

Facilitators of success

Honorariums and incentives

The most reported facilitator of success across both annual reporting and interview data was having the organizations provide honorariums and incentives to encourage participants to attend various activities offered by projects. Eleven organizations reported either in their annual reporting or their interviews that this was a key factor that aided their success (001, 002, 003, 004, 005, 006, 007, 008, 009, 010, 012).

Incentives usually took the form of gift cards or financial compensation, but also included certificates for program completion and access to free services. Honorariums were especially necessary to encourage participation in virtual programming, as in-person events were able to provide food, which some organizations advised was enough of an incentive to encourage participation:

> We had to look for different ways to do that [provide meals during online programming], and really, you know, making sure that folks were eating

> properly, so giving them gift cards so they could buy their own food, and then also giving them meaningful, not tokenistic honorariums. A lot of the youths were, you know, folks who were struggling financially, whether they're in school or, you know, working—working survivor jobs or, you know, in households that, you know, weren't meeting the median income. So, folks needed to be properly compensated [005].

In this interview, we heard how the move to online events, coupled with economic impacts of the pandemic, meant that it was even more important to provide gift cards so people could eat. However, despite the importance of honorariums in their work, some organizations perceived a lack of support from funders related to honorariums. Two organizations (005, 007) explained there were long delays in receiving reimbursement from PHAC.

Participatory action research design

Another key facilitator of success was the use of participatory action research (PAR) design. This topic was discussed by six organizations during interviews. Organizations 004, 005 and 007 all explicitly discussed the use of PAR in their programming and research. Some cited the importance of peer-led programming (002, 004), an advisory committee (004, 013), the use of ambassadors to connect to community (012) and the importance of community stakeholder involvement (010) in their design. Additionally, organizations 006, 007 and 011 all included benefits of PAR approaches in their annual reports. PAR approaches enabled them to respond to community needs and achieve better research data.

> It's a peer-led project, and so really having them invested in the work from the beginning. I think while—as I said earlier that, you know, we actually had to do a complete shift of the model we were using, and the workshops that we were going to use in community, and so when we actually had to develop our own workshops, I think while in the beginning, you know, that was a lot of work, because we essentially had to start over, but it actually worked to our benefit, because the peers were that much more invested in the work, you know, and in terms of the great outcomes that is beneficial for community [004].

As this interviewee explains, PAR was especially beneficial when organizations were forced to pivot at the onset of the pandemic. Organizations engaged in PAR were already embedded in the communities they served so were best positioned to understand and respond to changing needs.

The use of the PAR approach also meant an initiative focussed more on knowledge mobilization. For example, the TAIBU Community Health Centre in Toronto and PHAC co-developed the Amandla Olwazi Project, which included knowledge products and a knowledge hub to mobilize knowledge on mental health of Black Canadians. The initiative has also held conferences to support knowledge mobilization. Further information is available online.

Black leadership

Four organizations (002, 007, 012, 014) cited in their annual reporting having a diverse and Black-led team as a key facilitator in their success. During interviews, organizations 002, 007, 010 and 012 discussed the importance of having Black leadership, and that diversity in racial, gender and sexuality representation in programming was important to program design and recruitment of participants. Embedding Afrocentric values and principles throughout project design was also shared as an important element that itself comes from having Black people in positions of leadership and decision-making within organizations (013).

> I think from an organizational perspective, the work that we've been doing so far around framing programs with and embedding them within an Afrocentric values and principles has also been very, very helpful, because it speaks to all members of the funded project people. It brings us into a space where, you know, that unifying kind of a, you know, brainstorming and discussions, and everybody can identify with those principles, so I think that has also been very helpful [013].

This participant explained during the interview that the program has grounded itself in questions around the meaning of knowledge in the African context, as well as how knowledge is gathered, who participates and how it is disseminated. In another case, organization 007 explained how programming drew on poetry practices from the Democratic Republic of the Congo. These practices enabled healing through writing about family, lineage and place.

Challenges

Delays

The most reported challenge across reporting was delays with program implementation. Delays were reported as a key challenge by 11 organizations in their reporting (001, 002, 003, 004, 005, 007, 008, 010, 011, 012 and 014). Four of these organizations expanded on this topic during their interviews (002, 003, 013, 014). These delays were mainly related to obtaining research ethics approval in order to collect data from project participants. Organization 005 eventually applied through PHAC's Research Ethics Board process when they were unable to obtain approval from a university.

In several cases, organizations were forced to delay program launch or data collection because they could not obtain ethics approval in time for planned start dates. For example, organization 001 had to push all Year 1 activities into Year 2. Organizations 003 and 012 were able to begin programming and service provision, but data collection had to wait until the following year.

> By the time we actually get the approval [for a funding carryover request], like two months or three months has passed, right? And so, let's say it was a five-month window, if that two months has passed by the time we actually get an approval, I'm not going to act on those projects, because what if it's not approved, right? And so, then it kind of limits the amount of time I have to actually get the activities done, so it kind of puts a stress or strain in that regard [004].

This interview showed that, in this case, and in others (002, 003, 013, 014), delays in approvals to requested changes to the initial terms of the funding agreements (e.g. time period, funding amount), as well as delays in finalizing evaluation plans and funding agreements with PHAC, pushed back program activities.

Impacts of the COVID-19 pandemic

A total of 10 organizations reported various COVID-19 pandemic impacts on their projects in their annual reports (001, 002, 003, 004, 005, 006, 007, 008, 009, 011). With the exception of organizations 009 and 011, organizations that reported key challenges related to the pandemic were all operating in 2019/20—the year of the onset of the pandemic and initial public health guidelines. Challenges included the need to shift programming from in-person to online, and issues related to ethics and funding. Several organizations were forced to apply for ethics amendments to move activities online, which delayed program launch dates. Some also had to submit budget change requests to PHAC to either move Year 1 funding to Year 2 or to spend money initially earmarked for space, travel, food and so on, to honorariums for online participants.

Additionally, during interviews, eight organizations (002, 004, 005, 007, 008, 010, 012, 013) explained that impacts of the COVID-19 pandemic were a key challenge. These impacts included service interruptions, the move to online programming, redesign of programming in some cases and the fact that most organizations were serving populations that felt the pandemic particularly harshly. Pre-existing income inequities including lack of affordable housing and food insecurity became even more significant to service provision and program planning. During their interview, one organization said:

> People lost their ability to even pay their rent. You know, because they didn't have an income. Food insecurity. You know, so one of the things we had to do was we were able to, you know, we gave—you know, in our budget for the program, we had put refreshments, because that's always an incentive as well, to come. But instead of refreshments, we gave people food vouchers, and food cards to buy groceries and buy food, and that was really important [007].

Additionally, organizations that served Black populations facing intersecting oppressions, for example queer Black youth, had to contend with impacts unique to their communities. For example, one organization (012) saw clients who already faced pressure to mask their faces suffer increased mental health effects of social isolation during lockdowns.

Structural violence and community-specific challenges

Five organizations (004, 005, 007, 010, 013) explained broader systemic violence and inequities were a challenge in their work during interviews. Examples of such inequities are the over-representation of Black people in the criminal justice system and parallel under-representation of Black people in restorative justice programs, a lack of affordable housing, low income and systemic racism, homophobia and systems of gender oppression. In interviews, several organizations (004, 007, 010, 013) discussed how the murder of George Floyd increased mental health needs among their client populations.

> Then the George Floyd murder happened that was, you know, sort of visible to the whole world … and I think what I noticed was, there was a bit of even more anger among this group, simply because they said, "We've been saying this for so long, and no one listened to us. We've been talking about the fact that we are brutalized every—you know, by police. We're afraid to go out of our house, because, you know, we'll just get stopped because we're Black, walking while Black." Because, you know, this is a community where people are just walking on the street or waiting for a bus. They're not necessarily driving. But it—and they're younger folks. So, it made them angry, and they discussed it. They had the opportunity to discuss it in the group [007].

Acute anger and fear about police brutality following George Floyd's murder was an important example of the demand to address community needs as they arise. This representative went on to suggest that funders may not understand issues organizations and their client populations are dealing with and therefore may be unable or unwilling to offer necessary flexibility.

Maintaining partnerships

Maintaining partnerships during the pandemic was cited as a key challenge by four organizations. Organizations 001, 004, 007, 010 mentioned losing partnerships in their reporting. Such breakdown was often due to staff turnover within their partner organization, leading to the interruption of relationships and project momentum. Organizations 001 and 010 reported how staff changes at partner organizations led to vision shifts and meant organizations started to pursue divergent goals.

For example, organization 001 reported the loss of partnership and participant attendance due to their partnership with an organization that provided gender and sexuality inclusion training. In this case, inclusive programming and their partnership with a gender and sexuality inclusive organization led to the dissolution of other partnerships or prevented potential partnerships from forming. While those LGBTQ organizations that participated in interviews did not report similar problems, one representative did explain how queerness and transness is often invisibilized or deprioritized in work supporting Black client populations. Thus, they contended that collaborations to support Black LGBTQ clients can take a long time to form.

Lessons learned and recommendations for funders

Longer term and more flexible funding

A key recommendation for funders was to provide longer term and more flexible funding (002, 004, 012, 015), and to provide infrastructure and core funding (008). As one participant explained during the interview:

> We're trying to create spaces that like almost maybe for like at least 350 years haven't existed here, and so to think about time in that way, it's like yeah, maybe we should be looking at five to seven years of funding, right? Because we're trying to work at—we're trying to work in opposition to these 350 years where Black spaces definitely couldn't exist. Black people couldn't even be, right? That's part of why our mental health suffers. It's like so I think for me, I'm always thinking about time, how to like slow down, and to be so intentional [012].

The magnitude of such a challenge may demand long-term and sustained funding. Additionally, some organizations explained that, although capacity increased during the funding period, it receded back to pre-funding levels once their MHBC project funding ended. Funders can also consider the larger context within which Black organizations are operating in across Canada. For instance, two representatives explained how funding scarcity creates competition between organizations engaged in similar work (005, 010). Thus, there is a need for funders to provide increased financial support to Black organizations. Doing so may help support better collaboration and partnership between these organizations.

Participating organizations also advised that administrative work could be better organized. Financial and impact objective reporting could be made clearer and easier to complete, as bureaucracy is a barrier to program success (005, 010, 015). Additionally, an organization suggested PHAC use its reputation to facilitate partnerships with institutions that are unlikely to meet with organizations (such as school boards) without this connection (002). Brokering partnerships may offer a way to support organizations after funding relationships end.

Black representation and leadership

A lack of Black representation among funders meant that even those who approached the issues with sensitivity and competency often needed aspects explained to them because they were not Black. Additionally, funder expectations around data collection sometimes didn't match organizations' practices (005). Also, more dedicated funding of antiracist, third-party evaluation is needed (002). These challenges created the perception among some organizations that funders do not really understand the issues facing these organizations and the communities they serve (002, 005). Additionally, project requests to PHAC for non-White, third-party evaluators were not met at times. A lack of Black evaluators combined with the fact that the main evaluator contact for the organization was White was also a challenge.

> You know, we do data collection, and we do it in our way…. You know, the—this particular project is part of a very, very rigorous, as you probably know, evaluation process, and so we have an evaluator who is deeply embedded in the work to ensure that, you know, the project is in fact doing the work that it said it would do. And I think that that's a positive because it gives credibility to this work. But, you know, there's also wonderment about other non-Black or nonracialized organizations, and do they go through the same rigor in terms of the evaluation process that we're going through [005].

Here, the interview participant discussed how, although a high degree of communication between PHAC and the organization was beneficial at times, there was also the perception that funders were micromanaging the organization because it was a Black organization. Perceptions of being micromanaged were largely shaped by organizations' sizes. Smaller organizations tended to relay appreciation for PHAC support. Conversely, larger, more established organizations felt they were being over-managed.

Antiracist and antioppressive practices among mainstream service providers

Finally, interview participants advised funders to support work aimed at decreasing anti-Black racism. Removing barriers to Black people's access to mainstream healthcare providers should go hand in hand with ensuring Black people do not face barriers to other aspects of mental health supports, such as housing (008). Along with this, funders need to better acknowledge anti-Black racism and anti-Blackness and generate disaggregated race-based data to allow for a better understanding of the link between anti-Black structural racism and social determinants of health (010, 013, 015). PHAC and other funders could consider the larger funding context within which Black organizations are operating in Canada as well, as funding scarcity creates competition between organizations engaged in similar work. Thus, there is a need for funders to better support Black organizations. Doing so may help improve collaboration and partnership between these organizations (010).

> So because there are a lot of people who are working in healthcare, so PHAC really needs to look also at ways to try to make sure that individuals who haven't had any experience even growing up with Black Canadians, they need to understand more about the culture and cultures of individuals who are non-White Canadians, and we really need to see people who are—funding being provided to Black-led organizations, to have them to be a part of that, part of getting individuals to be a little bit more familiar with their needs [008].

In this interview, we learned that increasing antiracist practices across health institutions, both public health and healthcare systems, is the best way to ensure Black people do not face barriers to other aspects of mental health supports across the social determinants of health and mental health, for instance, housing, income, employment, education and so on.

Discussion

Despite the fact that participants reported more challenges than facilitators of success, the majority described their participation in the program as a benefit. Our findings suggest the MHBC was largely successful in supporting capacity building among organizations that received funding, despite continued room to improve the program. Facilitators of organizations' successes included the ability to provide honorariums and incentives to participants, the incorporation of PAR design during project conceptualization and data collection and the centralization of Black leadership in program delivery.

These results support many prior findings that have asserted the benefits of incentives to encourage community participation in health interventions.[9,10] However, the significance of honorariums has also generated ethical debates. Some have cautioned against the use of monetary incentives to encourage participation (see, for example Head's concern that incentives motivated participants to agree to interviews even if they contributed nothing "useful" to the research[11]). Others have called on researchers to establish upfront rules surrounding incentives in community-based research.[12] Neither perspective here seems to engage participants as equal and valuable co-creators of research with diverse needs. Instead, our study shows the need for reciprocal relationships between providers, researchers and community members, as well as the need to value efforts of participants.

Bottom-up approaches, such as PAR, to data collection, knowledge mobilization and service provision need not demand rigid rules around incentives and honorariums, nor be concerned with whether or not the value researchers can extract from participants is worth the cost. Instead, participants in our study explained they need the ability to pivot and adapt incentives to meet the needs of the client populations and communities they serve.

Our conclusions surrounding incentives should be considered alongside our findings advocating the benefits of PAR design in supporting community-based research and service provision and funding targeting such work. A recent article noted the challenges of PAR, including risks of power inequities between researchers and participants.[13] Failure to offer relevant, materially significant and flexible incentives may undermine PAR efforts.

A third facilitator of success, Black leadership, enabled organizations to ground their programming in antiracist and culturally relevant principles of service provision, data collection and knowledge mobilization. This leadership enabled the incorporation of Afrocentric practices such as lineage poetry in programming. The need for representation and diverse leadership across healthcare has recently gained increased traction.[14,15] We add to these calls for greater support of Black leadership in community-based mental health programming and research alongside the need for increased representation within funder organizations.

Key challenges included delays (both related to and separate from the onset of the COVID-19 pandemic) as well as impacts of pandemic lockdowns, structural violence and community-specific challenges, and difficulties maintaining partnerships. Delays were most often tied to obtaining ethics approval but also sometimes occurred when organizations applied for funding amendment requests or sought to finalize evaluation plans and funding agreements with PHAC. Other studies have found research with marginalized communities often faces similar ethics approval delays due to lack of representation within institutional review boards (IRBs), ideological assumptions surrounding vulnerability and divergent understandings of risk between researchers, participants and IRB boards.[16,17] IRBs have also been critiqued for institutionalizing “colonial unknowing” by separating risk from structural context.[18] Future funding may seek to interrogate the increased onus placed on research with Black communities. It may also make these processes more streamlined, and lower barriers.

Pandemic impacts demanded that organizations adapt by moving services online, changing honorariums and incentives and shifting service provision to address new mental health challenges. Our findings largely support prior work around pandemic interruptions and the potential to learn from flexible funding and service delivery during crises.[19] They also highlight the significance of inequities in the social determinants of health by showing how inequities such as poverty, racial discrimination and homophobia interwove to shape the experiences and needs of organizations’ client populations. However, it is also important to consider how flexibility is necessary outside of global crises. As we learned from organization 012, programming is often being created in spaces where none had previously existed for Black Canadians. There has been a lack of representation in mental health care and a systemic lack of care for this population. In fact, the absence of an informed, antiracist and culturally responsive approach to mental health care for Black Canadians led to the development and implementation of the MHBC.

Mainstream service provision and medical research began considering the connections between systemic racism and health more strongly following the murder of George Floyd by Minneapolis police.[20] Some studies have linked experiences with racial discrimination as a key factor contributing to mental health problems.[21] Others have focussed on ways systemic racism within healthcare (including provider prejudice) prevent many racialized people from accessing services.[22] Our findings should refocus funders’ attention on the ways that the over-representation of Black people in the criminal justice system and parallel under-representation of Black people in restorative justice programs, a lack of affordable housing, low income, and systemic racism, homophobia and systems of gender are all key determinants of mental health.

The MHBC emphasized the importance of partnerships and collaboration. Here, the initiative may need to offer organizations greater support. Maintaining partnerships during the pandemic was cited as a key challenge by four organizations and others explained they had difficulty forming or maintaining partnerships due to lack of reputation, divergent vision and staff turnover. This may be a gap that future funders can consider supporting in nonmonetary ways. For example, funders who have established reputations, such as PHAC, may broker these reputations to facilitate meetings between organizations and potential partners.

Considering these facilitators of success and the challenges faced, there are important lessons to be learned, and ways in which funders can improve funding support moving forward. First, longer term and more flexible funding may help build capacity in permanent ways. Second, by considering the context within which many Black organizations are operating, funders may better understand how historical and current funding scarcity pits organizations against one another and is not conducive to partnership and collaboration. Though Black leadership was an important factor in organization successes, a lack of Black representation among funder staff was a challenge for several organizations. We heard that divergent expectations around data collection and a lack of Black third-party evaluators made some organizations feel as though they were being micromanaged in ways non-Black organizations might not be. Third, participants advised that funders should support work that increases antiracist competencies among mainstream service providers.

Strengths and limitations

Strengths of this study include a two-stage process whereby researchers first conducted a content analysis of annual and final reporting provided by organizations that had received funding through the MHBC. This allowed us to refine our interview guide and gather greater information about key findings from these documents. However, the study was limited by the fact that some organizations did not provide annual reports from all years, and only three organizations had final reports available at the time of the study. Further, representatives from only 9 out of the total 14 organizations agreed to interviews (one organization had two participants from two different projects). Despite these limitations, interview analysis did reach data saturation and we believe we gained a holistic view of the implementation of the MHBC.

Conclusion

The MHBC offered multiyear funding to organizations to develop Black-focussed mental health programs in Black communities across Canada. This study used an embedded case study research design to explore the experiences of organizations that received this funding. We found that organizational success was facilitated by providing honorariums and incentives, by organizing programming through PAR design and through Black leadership. Challenges faced by organizations through this period included delays, impacts of the COVID-19 pandemic, structural violence and community-specific challenges, and difficulties maintaining partnerships.

Funders can better support the provision of participant honorariums and incentives, continue to support PAR design and other tools that enable organizations to respond to shifting community needs, continue to support Black leadership and diversity in program management, assist organizations experiencing delays with obtaining ethics approvals, offer greater assistance during crises such as we experienced during the onset of the COVID-19 pandemic, better consider issues related to systemic racism and structural violence, offer longer term stability within organizations through long-term and flexible funding and seek greater Black representation among funding agencies.

In addressing barriers, a critical race theory intersectional analysis can be helpful.[23-25] A critical race theory intersectional analysis shifts from the individual cultural competency frame to addressing structural issues, and refutes two liberalist claims about the law or policies: (1) that it is colour blind and (2) that colour blindness is superior to race consciousness. Keeping central a critical race theory intersectional competency analysis for Black people will steer the conversation into challenging the anti-Black racism, cisnormative and Eurocentric mentality endemic in social services.

Black LGBTQ and nonbinary people find themselves at the intersection of multiple and compounding forms discriminations, such as anti-Blackness and anti-LGBTQ sentiments. There is, therefore, a need for funders to be intentional about improving research, healthcare delivery, laws and policies that address the intersectional issues for Black LGBTQ persons, as well as those who are nonbinary, seniors, those experiencing homelessness, persons with disabilities, and the incarcerated as we explore the intersections of race and sexual orientation for Black communities.[26-29] Black communities research in all fields warrants and deserves complexity. Refusing to recognize these intersectional complexities and the heterogeneity of Black people only denies us our humanity.

There are deeply engrained, cisgender, compulsory, heteronormative assumptions that there are only two sexes (male and female) and only two corresponding genders (man and woman); that to be cisgender is the only “natural and normal” gender modality; and that deviations from the status quo are rare, exceptional and aberrant.[28] Along with this, funders need to better acknowledge anti-Black racism and anti-Blackness and generate disaggregated race-based data to allow for a better understanding of the link between anti-Black structural racism and social determinants of health. Collaborating with and co-producing knowledge with Black communities in a project of liberation can further advance mental health outcomes.

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Conflicts of interest

Dr. Ifrah Abdillahi was an employee of the Public Health Agency of Canada at the time of this research. She supported conceptualization and participant recruitment for the project but had no access to confidential information.

Authors’ contributions and statement

BS: conceptualization, data curation, funding acquisition, methodology, project administration, supervision, validation, writing—original draft, writing—review and editing.

MT: formal analysis, methodology, validation, writing—original draft.

IA: conceptualization, data curation, funding acquisition, project administration, resources, writing—review and editing.

WC: conceptualization, funding acquisition, methodology, writing—review and editing.

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Other PHAC publications

Researchers from the Public Health Agency of Canada also contribute to work published in other journals and books. Look for the following articles published in 2024 and 2025:

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