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Equitable inclusion of racialised communities in genomic research: a scoping review

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ABSTRACT

Objectives Genome Canada has committed significant resources to ensure that racialised groups are included in its initiatives; however, specific equity considerations related to engaging these communities in human genomic research continue to require deeper attention and exploration. This scoping review aims to widen the frame of analysis concerning inclusive human genomics by undertaking a synthesis that includes perspectives from genomicists, decision and policymakers, legal experts in bioethics and leaders from racialised communities.

Design We conducted a comprehensive scoping review using the Arksey and O'Malley framework to examine the equitable participation of racialised communities in human genomic research.

Eligibility criteria Our goal was to identify the barriers preventing these populations from equally participating in human genomic research. The review focused on studies from five countries: Canada, the USA, the UK, Australia and New Zealand which have similar immigration patterns and have received racialised populations from from some of the same communities around the globe. These features makes studying these particular countries germane to studying the common challenges they face in human genomics research.

Data sources Our scoping review examined both academic and grey literature, including MEDLINE, EMBASE, PsycINFO (inception to 11 June 2025), CINAHL (to 12 June 2025) and Cochrane Central Register of Controlled Trials (CENTRAL) (to 19 June 2025), as well as Google Scholar and OAISter (October, 2023).

Data extraction and synthesis Data were analysed using Braun and Clarke's thematic synthesis guidelines. These included familiarisation with the relevant texts in the selected articles, generating initial codes using an inductive approach, reviewing potential themes and finalising the themes based on the consensus of the research team.

Results The study identified key barriers and facilitators to participation in human genomic research among racialised communities. The first theme (exclusion) highlighted obstacles such as a lack of transportation, limited knowledge of genetics and distrust stemming from concerns of stigmatisation and health disparities. The second theme (diversity of positions) described varied perceptions influenced by cultural values and motivations, with preferences for transparency and autonomy in research participation. Finally, the third theme (equity in genetic research) outlined the limited use of community-based participatory models and biobanking, underscoring the need for more inclusive and equitable research practices to fully engage racialised communities.

Conclusion Future research should prioritise strategies of authentic engagement with racialised communities to enhance both inclusivity and equity in genetic, human genomic, precision medicine and precision health research.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ We conducted a comprehensive and systematic search across major academic databases as well as relevant grey literature sources.
⇒ To ensure transparency and methodological rigour, we adhered to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) guidelines.
⇒ The broad eligibility criteria outlined are designed to capture a wide range of evidence, with particular emphasis on the equitable inclusion of racialised people in human genomic research.
⇒ Excluding non-English articles may have limited the inclusion of potentially relevant studies from other language contexts.

BACKGROUND

Health disparities in the prevalence and outcomes of many conditions, such as rheumatoid arthritis, diabetes, certain cardiac events and adverse reactions to anaesthetics disproportionately affect racialised populations; these same communities experience systemic discrimination based on race or ethnicity. These disparities result from complex interactions between genetic factors, environmental conditions and social determinants of health, including access to healthcare, socioeconomic status and structural inequities.[1–4] Particularly, socioeconomic barriers to access primary care, lack of accessible information and resources required to navigate health

institutions and medical insurance, or limited primary care facilities that are proximate to racialised populations are some of the significant obstacles that impede improved health outcomes for racialised communities.[5–7] As a consequence of these kinds of persistent health disparities, conditions that disproportionately affect these communities tend to be confronted only when they escalate into a health crisis or acute care contexts.[6 8–10]

The development of proteomics, next-generation sequencing and pharmacogenetics, among other diagnostics associated with human genomics, promises individualised preventative care which potentially could better address health disparities. However, these innovations have historically relied on data from predominantly white populations that could possibly limit their effectiveness and accuracy for racialised communities. Without deliberate efforts to equitably include diverse populations in the development and validation of these technologies, they may perpetuate existing health disparities rather than address them. As genomic tools that do not genetically diversify data, human genomics may also provide less accurate results or miss important variants present in underrepresented populations.

Human genomics must contend with a chequered history of racism, exploitation and abuse by genetic researchers and the institutions with which they have been affiliated. One early human genomics project in the 1990s (the Human Genome Diversity Project) inadvertently adopted racist views of racialised communities, viewing them as 'soon-to-be-lost undiluted gene pools' which preserved humanity's genetic heritage because the ancestries of the communities targetted to be included in the study were (erroneously) thought to be 'untouched' by those of European or other populations.[11 12] Members of racialised communities were excluded from the research design process, they were not offered any guarantees of benefitting from the research results, and university institutions sponsoring the human genomics research retained full control over the biological samples and data derived from them, including the right to conduct future genetic research without first seeking additional consent.[13–17] Racialised peoples' experiences with genetic research that occurred before the introduction of human genomics are also a mixed record. In 1965, for example, the initial rollout of a sickle-cell screening programme that focused on Black Americans led to the stigmatisation of the community for the disease. As a consequence, the reproductive and marriage choices of members of the Black community were surveilled by the state and mandatory genetic testing was also introduced.[18 19] While the programme was later reformed to correct for interventions that led to the stigmatisation, experiences like this cast a shadow on the field for some racialised communities.

Without specific provisions ensuring that past experiences are not reproduced, racialised communities find themselves doubly disadvantaged concerning contemporary human genomics. Communities might be weary of participating in genetic studies, given their historical experience with the field, while they are also significantly under-represented in the databases on which possibly transformative genomics-based tools for health depend.[4 20]

Recent attempts to include racialised communities in human genomics studies in Canada demonstrate the complexity of creating an ethno-racially diverse cohort of participants in human genomics studies in Canadian settings (and perhaps beyond). Though Canada was not a participant in the Human Genome Project, its health institutions unequivocally embraced the possibilities to improve care, diagnosis and treatment offered by public health genomics, as it was called in the early 2000s, and racialised communities were integral to such a position. In 2001, public health experts, genetic researchers and policymakers attending a workshop jointly sponsored by the Canadian Institutes of Health Research (CIHR) and Genome Canada stated that Canada's universal health system afforded it rich data on 'well-defined populations' (p. 209), referring especially to racialised communities.[21] The diversity of Canada's racialised communities, whose health, social and demographic data are collected through provincially-based healthcare systems, was thought to place Canada in an advantageous starting point in the emerging field of population-based human genomics at the time, which depends on the possession of health data that is specific to distinguishable populations. The problem, however, was that the categories of ethnicity that organised such health data relied on census-based classifications that were generated as part of a colonial project to count and limit non-European populations settling in Canada.[21 22] While the policy of multiculturalism in 1982 validated ethnic diversity as a strength of Canada's growing population, the ideological and political basis of classifying racialised peoples as 'minorities' (ie, not European) remained largely intact. Employing these same census categories for racialised peoples in genomic analysis adopted the same troubled logic of how 'difference' was understood to exist within the Canadian population and thus imputed biological importance to racialised communities whose classification was politically constructed, sometimes with gross error (pp. 204–46).[21]

In 2007, Genome Canada and Genome Quebec jointly announced their support of CARTaGENE, which was in the process of creating a biobank based on the genetic data collected from populations that resided in four metropolitan areas of Québec.[23] The biobank aimed to provide insights about the influence of genetic heritage, gene-environment interactions and the study of common diseases like cancer and diabetes. The public appeal of the initiative was that it recognised, and sought to map, the diversity of genetic variations in Québec in order to identify the possible origins of complex diseases. According to its promoters, the diversity of ethnic populations who were included in the initiative enhanced the promise of the data it would generate and attested to Genome Canada and the participating researchers' commitments

to design a human genomics study that clearly included racialised communities in Québec.[24]

Despite CARTaGENE's public profile as an inclusive undertaking, the study of presumed homogeneity among white Québequers dominated the broader field of human genomics research in the province at the time and thus competed with the multiculturalist valence of the initiative.[25] Among human genomics researchers in Québec at the time, Québequers of French origin were believed to be genetically unique because they were descendants of approximately 8500 French settlers who arrived in Canada between the 17th and 18th centuries, who remained isolated from other populations, and who reproduced prolifically.[26] (The perceived genetic homogeneity of a given population has been thought to be germane to discovering disease-associated genetic variations for which lucrative diagnostic tests and therapeutics can be developed.) Perhaps ironically then, among some researchers in the wider field of human genomics in Québec in which CARTaGENE was introduced, the presence of racialised communities in Québec—particularly their intermarriage with French Québequers—was seen to be a diluting threat to discovering future diagnostics and therapeutics through human genomics studies of the assumed genetic uniqueness of French Québequers.[25 26]

From a different vantage point, potential participants in CARTaGENE from ethnic and racialised communities were apprehensive about the kinds of conclusions the initiative would generate. A study that formed part of a community engagement component of CARTaGENE reported that a subset of focus group participants, comprising members of ethnic, linguistic or cultural communities, had misgivings that CARTaGENE would classify individuals in a manner that inadvertently promoted racist or exclusionary research in human genomics.[27] Despite the intentions of the designers of CARTaGENE who sought to include racialised communities and other ethnic or linguistic groups as part of the study population, the legacies of scientific racism in (pregenomic) genetic research countered perceptions of the initiative's professed inclusive orientation. Probably most important, the hesitancy to participate in CARTaGENE by racialised and other ethnic communities revealed that the terms of participant inclusion in CARTaGENE were perceived to be vague and therefore risky for these community members.

Initiatives involving human genomics research announced more recently articulate robust commitments to equity, inclusion and diversity. The CIHR's Institute of Genetics Strategic Plan 2022–2027 recognises the need to accurately represent the diversity of the Canadian population in genomic databases because the genomes of persons of European descent comprise a majority of sequenced genomes so far. The Institute's Strategic Plan strives to overcome this bias by oversampling 'minority groups' in order to obtain an accurate reference genome without which these groups are unlikely to reap the health benefits that have been introduced by advances in genomics. According to the Plan, such genomic data would also advance clinical trials for inherited disease by clarifying which genetic variations are associated with disease occurrence in underrepresented populations. Additionally, it is possible that obtaining diverse genetic information for the Canadian population may reduce the incidence of adverse side effects to pharmaceutical therapies, which is a known experience among some racialised communities also.[1 28] Echoing the strategy articulated in the Institute of Genetics' strategic plan, Genome Canada's Canadian Precision Health Initiative (announced in 2024) aims to build a public genomic database containing 100 000 human genomes and strives to oversample underrepresented groups (in which racialised communities are included) as a way to meet its inclusion objectives. The Initiative views the inclusion of genomes of underrepresented groups as a way to provide all Canadians access to the benefits of innovations in precision health while also modelling the practice of collecting genomic data that is representative of the Canadian population.[29 30]

Announced in 2023, the CIHR-funded Pan-Canadian Genome Library (PCGL) aims to facilitate the sharing of locally held genomic and health data nationally. Through its Equity, Diversity and Inclusion (EDI) Working Group, the PGCL works with marginalised communities to ensure genomic data that is collected in its datasets are diverse compared with Canadian demographic data, to engage with communities to co-create research frameworks that reflect their needs, build capacity among researchers and promote EDI best practices, and facilitate knowledge-sharing about the importance of EDI in genomics.[31 32]

All three of these important initiatives are unequivocal in their commitment to include racialised communities and they identify multiple strategies to include these groups in the research they support in Canada (ie, oversampling and monitoring the degree to which data collection captures the genomes of marginalised communities). Indeed, these initiatives are part of a new global wave of genomics research that strives to correct the poor historical legacy of the field of genetics as it concerns either excluding or exploiting racialised peoples in genetic-based studies.[9 33–37] Nevertheless, the terms of such forms of inclusion remain either ill-fitting for racialised communities in Canada and undefined in regards to the strategies that are adopted to equitably include them. Both the Institute of Genetics strategic plan and Canadian Precision Health Initiative pair their inclusion efforts with the crucial goal of supporting Indigenous rights, particularly by maintaining data sovereignty for Canada's First Nations. As currently defined, achieving data sovereignty aligns with a diversity of historical and cultural contexts of Indigenous communities specifically, and less so for racialised communities and their cultural, sociotechnical and institutional-legal contexts.[2 38–40] Though Indigenous and racialised communities in Canada encounter some parallel challenges regarding health disparities and achieving more equitable and culturally safe health services, there are also significant historical, socioeconomic, institutional-legal and cultural differences between

them. For example, in recent times, some Indigenous communities have worked to acquire political autonomy in countries like Canada, which rightly enables them to define the terms of their participation in genomic studies through data governance frameworks.[38–40] However, most racialised communities do not possess such forms of institutional autonomy and typically fall under provincial or territorial health authorities and governments. Furthermore, the cultural approaches to health and healing differ substantially between these two sets of communities, and indeed within them, in ways that require distinct approaches. The following composite representations are suggested to offer an example of the problem: Indigenous healing traditions are often deeply connected to lands, ceremonies and oral knowledge systems that are community-specific and driven by understandings of sovereignty (among other things). In contrast, many racialised communities draw from established global medical traditions such as Ayurveda, Traditional Chinese Medicine or forms of medical practice associated with Islam (like Unani), among other examples, that have standardised texts, formal training systems and can be practiced across diverse geographical locations. As such, the institutional and sociocultural contexts, as well as the experiences, of racialised communities as they pertain to human genomics in Canada are only beginning to be understood, as are the model practices of equitably including them in genomic science. Stated another way, identifying strategies for equitable inclusion in human genomics becomes occluded when the needs, ethics and histories of Indigenous and racialised peoples are conflated with each other.[30]

Objectives

Efforts to fill the gaps in existing human genome-wide association studies have been undertaken by investigators to create 'a reference that is more complete and more representative', which might include racialised populations whose ancestries originate in the global south and north.[37 39 40] The ultimate goal is to identify markers that existing genomic-based catalogues do not already document. If and how such forms of research in genomics can navigate the issue of equity for racialised communities is a significant gap in the study of creating a genuinely inclusive field of human genomics. While Genome Canada and the Canadian Institutes of Health have committed significant resources to ensure that racialised groups are included in its initiatives generally, its undertakings do not address the unique equity challenges involved in including racialised communities in human genomic research specifically. This study will widen the frame of analysis concerning inclusive human genomics by undertaking a synthesis that includes perspectives from geneticists, decision and policymakers, legal experts in bioethics and—most important—leaders from racialised communities. Conceptualised in this way, our scoping review addresses the problem of creating inclusive genomic projects that also define equitable terms for the participation of racialised communities. Reporting on current research and practices on this issue from countries which are in a comparable stage, or slightly ahead, of Canada in terms of their adoption of human genomics (ie, New Zealand, the UK, the USA and Australia) will help identify how to create equitable policies for racialised communities in the creation of inclusive human genomics by a range of cross-sectoral actors including academic, public, private and non-profit organisations. The five countries—Canada, the USA, the UK, Australia and New Zealand—were selected due to their similar immigration patterns and the presence of comparable racialised populations from around the globe. This makes them well-suited for our examination of the challenges they share in promoting inclusive human genomics research. Insights generated from our review will identify the institutional commitments and practices that can inform the creation of policies ensuring inclusive and equitable human genomics for racialised peoples.

METHODS

A comprehensive systematic scoping review

We have conducted a systematic scoping review of the literature to synthesise evidence from the current literature on equitable inclusion of racialised communities in research on human genomics in Canada, the USA, the UK, Australia and New Zealand. To ensure rigour, our systematic scoping review followed the methodological framework described by Arksey and O'Malley.[41] The stages include identification of the research question, identifying relevant studies, study selection, charting the data and collating, summarising and reporting results. This framework was chosen because it is well-suited to address broad research questions and mapping key concepts in complex and underexplored areas. This approach also supports the inclusion of a wide range of study designs, making it appropriate for synthesising diverse evidence. The reporting of this review has followed the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) extension for Scoping Reviews checklist for ensuring transparency and rigour.[42]

Identifying research questions

We propose to conduct a comprehensive knowledge synthesis on this issue with the following research questions:

1. What are the knowledge strengths and gaps related to equity and inclusion of racialised communities in human genomics?
2. What existing barriers prevent racialised communities from participating in human genomics in an equitable manner?
3. What promising policies, models and practices are recommended to equitably include racialised communities in human genomics?

Identifying relevant studies

This phase of the scoping review focuses on developing search strategies and identifying databases to conduct a

Table 1 Academic and grey literature databases to search

Literature	Database type	Database name
Academic	Health and wellness	MEDLINE EMBASE CINAHL PsycINFO Cochrane Central Register of Controlled Trials (CENTRAL)
Grey		Google Scholar OAISter

comprehensive search as well as specifying inclusion and exclusion criteria for selecting relevant studies.

Systematic search

We conducted a comprehensive systematic search—initial and updated—across five major databases: MEDLINE, EMBASE, PsycINFO (inception to 11 June 2025), CINAHL (to 12 June 2025) and Cochrane Central Register of Controlled Trials (CENTRAL) (to 19 June 2025) (see table 1, online supplemental file 1). We have also employed the Google Scholar search engine to identify relevant academic articles. We developed our search strategy following the scoping review methodology of Arksey and O'Malley.[41] We have included our whole search string in box 1. We also searched grey literature using resources like OAISter to gain a thorough understanding of human genomic research beyond peer-reviewed publications.

To ensure relevance to our research objectives, we developed the search string by identifying key concepts from our research questions (ie, equity, racialised communities and human genomics) and selecting appropriate controlled vocabulary (eg, MeSH (Medical Subject Headings) terms) and free-text terms for each concept. The search strategy was iteratively refined through pilot searches in MEDLINE and reviewed by a librarian with expertise in systematic searching. We also held group discussions during and after the pilot search to evaluate the effectiveness and coverage of the terms. Additionally, we used seed papers and manually explored the literature to identify relevant terminology, which further informed and expanded our search terms. Terms were adapted for each database to account for differences in indexing and structure.

Although we did not register or publish our scoping review protocol, a detailed internal protocol was developed before commencing the screening phase. No major changes were made to the initial search strategy after title/abstract screening and data extraction began; however, minor refinements to search terms and database-specific syntax were made during the pilot search phase to optimise coverage. These modifications were discussed and agreed on by the research team before final implementation.

Box 1 Search strategy and search terms

Search terms for genomics:
Genomics [(MeSH]) OR "Genomic Medicine" [Keyword; MeSH] OR Human Genomics [(Keyword]) OR "Precision Medicine" [MeSH; Keyword] 'Genome-Wide Association Study" [Keyword; MeSH] OR Proteomics [MeSH; Keyword] OR Transcriptomics [Keyword; MeSH] OR Lipidomics [Keyword; MeSH] OR Metabolomics [Keyword; MeSH] OR Phenomics [Keyword; MeSH] OR Genetics [Keyword; MeSH] OR Epigenomics [Keyword; MeSH] OR 'Functional Genomics" Keyword; [(MeSH]) OR "Comparative Genomic Hybridization" [Keyword; MeSH] OR "Genomic Instability" [Keyword; MeSH] OR "Genomic Imprinting" [Keyword; MeSH] OR "Genomic Library" [Keyword; MeSH] OR "Genomic, Human" [Keyword; MeSH] OR "Gene Expression Profiling" [(MeSH]) OR Omics [(Keyword]) OR Meta-Genomics [(Keyword]) OR Metagenomics [(MeSH]) OR "Genetic Analysis" [(Keyword]) OR Epigenomics [(Keyword]) OR "Genomic Data" [(Keyword]) OR "Genomic Sequencing" [(Keyword]) OR "Genomic Structure" [(Keyword]) OR "Genomic Variation" [(Keyword]) OR "Genomic Research [(Keyword]) OR Bioinformatics [(Keyword])
Search terms for immigrant/Refugee/Ethnic minorities/ Racialized communities:
Undocumented Immigrants" [(MeSH]) or Emigrants [Keyword; MeSH] or Emigration and Immigration [(MeSH]) or newcomer* [(Keyword]) or refugees [(MeSH]) or refugee* [(Keyword]) or alien* [(Keyword]) or foreigner* [(Keyword]) or foreign worker* [(Keyword]) or Transients and Migrants [(MeSH]) or transient* [(Keyword]) or Migrant Workers [(MeSH]) or Migrant Farm Workers [(MeSH]) or migrant* [(Keyword]) or asylum [(Keyword]) or asylum seeker* [(Keyword]) or humanitarian [(keyword]) or displaced person [(Keyword]) or displaced population [(Keyword]) or war population [(Keyword]) or forced migration [(Keyword]) or refugee camp* [Keyword; MeSH] or ethnic groups [(Keyword]) or "Minority Groups" [(MeSH]) or Ethnicity [(MeSH]) or Minority Groups [(MeSH]) or Minority Health [(MeSH]) or Racial Groups [(MeSH]) or Race Factors [(MeSH]) or ethnic minorit* [(Keyword]) or racial minorit* [(Keyword]) or visible minorit* [(Keyword]) or national minorit* [(Keyword]) or Racial Identity [(MeSH]) or mixed race* [(Keyword]) or multiracial person [(keyword]) or minority communit* [(Keyword]) or marginalized group* [Keyword; MeSH] or marginalized communit* [(Keyword]) or marginalized people [(Keyword]) or marginalized population* [(Keyword]) or marginalised group* [(Keyword]) or marginalised communit* [(Keyword]) or marginalised people [(Keyword]) or marginalised population* [(Keyword]) or people of colo?r [(Keyword]) or BME [(Keyword]) or BIPOC [(Keyword]) or BAME [(keyword]) or immigrant* [(Keyword])
Search terms for health equity:
"Health Equity" [Keyword; MeSH] OR "Health Status Disparities" [(MeSH]) OR "Healthcare Disparities" [Keyword; MeSH] OR "Socioeconomic factors" [Keyword; MeSH] OR "Social Justice" [(MeSH]) OR "Vulnerable Populations" [Keyword; MeSH] OR "Cultural Diversity' [Keyword; MeSH] OR "Racism" [(MeSH]) OR "Social Class" [(MeSH]) OR "Social Discrimination" [(MeSH]) OR "Prejudice" [(MeSH]) OR "Disparit*" [(Keyword]) OR "Social Determinants of Health" [(Keyword]) OR "Health adj3 Equity" [(Keyword]) OR "Health adj3 Disparit*" [(Keyword]) OR "Equity adj3 Inclusion" [(Keyword]) OR "Ethnic Disparit*" [(Keyword]) OR "Racial Disparit*" [(Keyword]) OR Equit* [(Keyword]) OR Inequit* [(Keyword]) OR Inclusion [(Keyword]) OR Exclusion [(Keyword]) OR Discrimination [(Keyword]) OR Marginalization [(Keyword]) OR Bias [(Keyword]) OR "Equitable Polic*" [(Keyword]) OR "Social Equality [(Keyword]) OR "Equal Opportunit*" [(Keyword]) OR Equality [(Keyword]) OR Fairness [(Keyword])
MeSH, Medical Subject Headings.

Table 2 Population, Concept and Context Framework

Element	Description
Population	Racialised minorities, including immigrants, refugees, asylum seekers, undocumented individuals, migrant workers.
Concept	Equitable inclusion and participation in human genomics research.
Context	Research in Canada, the USA, the UK, Australia and New Zealand; research published in English, across all study designs.

Inclusion and exclusion criteria

We used the Population–Concept–Context framework recommended for scoping reviews to guide the development of our inclusion and exclusion criteria (see table 2). The population includes racialised minorities; the concept focuses on equitable inclusion in genomics research; and the context is limited to research settings in Canada, the USA, the UK, Australia and New Zealand. This study included all journal articles on human genomic research in Canada, the USA, the UK, Australia and New Zealand. Primary research on the equitable involvement of racialised immigrant/refugee groups in human genomics research was included. No restrictions were put on the study design. We included studies in the English language only. Studies focusing exclusively on Indigenous populations were excluded, as our review focused specifically on racialised non-Indigenous communities. This distinction was made given the unique political and governance contexts of Indigenous communities, as noted in the Introduction.

Racialised minorities refer to groups perceived as socially different from the majority based on characteristics such as skin colour, origin, language or religion, and who experience disadvantage due to processes of racialisation. We use this term in our study, rather than 'racial minorities' or 'ethnic minorities', because it highlights that race is a social construct shaped by context and power relations, rather than a fixed biological or cultural fact.[43 44] This term emphasises how categorisation and marginalisation are context-dependent and can shift across time and place. In this study, 'racialized minorities' include immigrants, refugees, asylum seekers, undocumented and displaced persons, foreign and migrant workers and other historically and structurally marginalised groups. Our search strategy reflected this diversity by using a comprehensive set of keywords and indexing terms such as 'ethnic minorities', 'visible minorities', 'people of color', 'BIPOC', 'BAME', 'migrant workers', 'minority groups', 'marginalized communities', 'racial identity' and 'immigrants', among others (see box 1).

Study selection

A two-stage screening approach (title-abstract and full-text) based on predetermined inclusion and exclusion criteria was used in this study. All articles have been entered into Covidence for screening and duplication removal after the systematic searches were finished. Independent reviewers assessed the articles, and disagreements were resolved through discussions led by a third reviewer to reach a consensus. The PRISMA flow diagram was used to visualise the screening procedure applied to articles from academic sources and grey literature (figure 1).[45]

Charting the data

Data extraction for selected articles was conducted in duplicate by two trained reviewers, working independently to ensure accuracy and minimise bias. Each reviewer recorded information on the study location, objectives, sample characteristics (eg, age, gender), study design, settings and methodologies. We also extracted data on barriers and facilitators to equitable participation in genomics research among racialised communities. Any discrepancies between reviewers were resolved through discussion, with input from a third team member when necessary to reach consensus. This approach ensured the reliability and consistency of the extracted data.

Collating, summarising and reporting results

To understand the reported barriers and facilitators to equitable participation in human genomic research, we conducted a thematic analysis following the guidelines by Braun and Clarke.[46] Following familiarisation with the relevant texts in the selected articles and generating initial codes using an inductive approach, we identified and reviewed potential themes. Two members of the research team independently coded a subset of articles and generated initial codes. These were then compared and discussed in group meetings to ensure consistency in coding. Themes were developed through an iterative process involving multiple team discussions, where overlapping or ambiguous codes were grouped, refined or separated. We held regular meetings to review emerging themes, resolve discrepancies and ensure alignment with our research objectives. Consensus on final themes was reached through group deliberation, and all team members reviewed and approved the final thematic framework to ensure analytical rigour and trustworthiness. The themes have been finalised and reported following discussion with the team.

We conducted a full-text thematic analysis of all 24 included studies to ensure that themes were drawn not only from the results sections but also from introductions, methods, discussions and contextual framing. This approach aligns with Braun and Clarke's (2006) reflexive thematic analysis method, which supports both semantic and latent theme identification across diverse qualitative data.

Our interdisciplinary team includes members from health equity, sociology, law, molecular biology, the history of medicine and the medical humanities, many of whom identify as racialised, immigrant or from other equity-deserving communities. Our positionalities informed our

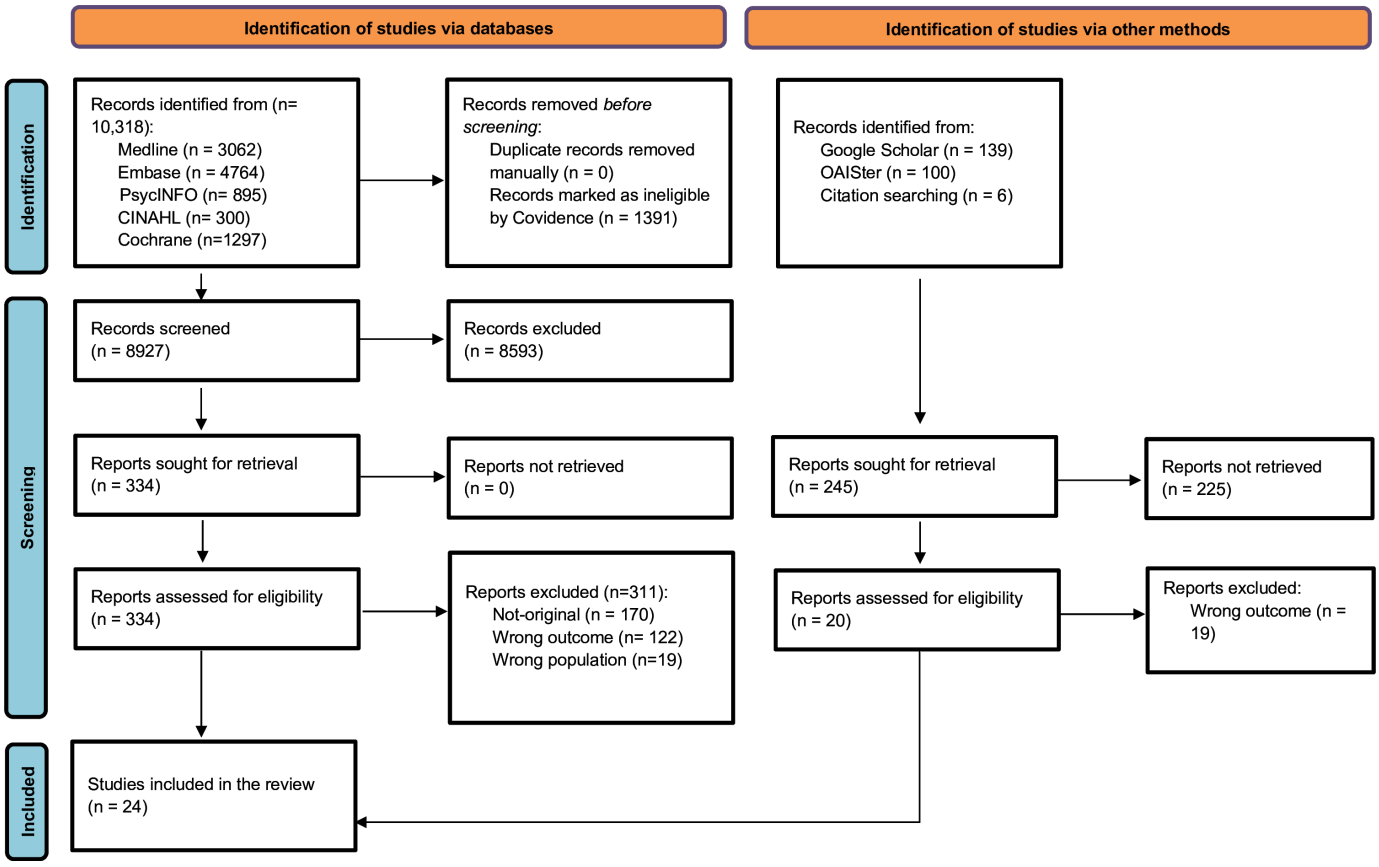

Figure 1 Flow diagram of the search and selection process for the systematic scoping review. Source: Adapted from diagram for systematic review.[45]

approach to theme development, particularly in recognising structural and institutional dimensions of equity that may be underexplored in the literature. We acknowledge that our perspectives may shape theme interpretation; to enhance rigour, all codes and themes were developed through an iterative process involving independent coding, collaborative dialogue and consensus-building across the team.

Patient and public involvement

This review did not include patients or public stakeholders, such as leaders from racialised communities, during the review process. However, several members of the research team self-identify as members of racialised communities. Their lived experiences and community knowledge informed the design, analysis and interpretation of findings, which helped to partially mitigate the lack of external stakeholder involvement.

RESULTS

Our search of academic databases initially identified 10318 articles. After removing 1391 duplicates, we started the first stage of screening with 8927 records. Following the first stage of title and abstract screening, 8593 papers were excluded, and 334 articles proceeded to full-text screening. After full-text screening, 311 articles were excluded, and 24 articles were selected for the final analysis and synthesis. The most common reasons for exclusion at the full-text stage included the absence of focus on racialised communities, lack of relevance to human genomics or not addressing equity or inclusion in any meaningful way. In our search for grey literature through Google Scholar and OAIster as well as citation search, 245 potentially eligible sources were found. However, only one study met the eligibility criteria when screened using the same inclusion criteria, and the rest were excluded primarily due to a lack of relevance to the research questions or insufficient information on equity-focused genomic research involving racialised communities. These resulted in a total of 24 studies included in the final evidence synthesis.

Study characteristics

The study characteristics are presented in the online supplemental file 2. The majority of the studies were conducted in the USA (n=22), followed by Canada (n=2). Studies encompassed a range of research types, most commonly taking up a qualitative method (n=14), followed by quantitative (n=4) and mixed-methods (n=6). Also, most studies used a cross-sectional research design (n=19), followed by a cohort (n=3) and an audit of a randomised controlled study (n=1). The studies were conducted in diverse settings, including only urban or urban-hospital or hospital settings (n=14), followed

Table 3 Summary of the study characteristics

Characteristics	Category	Number of studies (out of 24)	Percentage (%)
Study type	Qualitative	14	58.33
	Quantitative	4	16.67
	Mixed methods	6	25
Study design	Cross-sectional	19	79.17
	Cohort	3	12.5
	Audit of a randomised controlled study	1	4.17
Study setting	Urban or hospital-based	14	58.33
	Community-based	6	25
	Multisite or national consortium	3	12.5
Population	Black (including African American and African Immigrants)	17	70.83
	Other racialised minorities (Latino/Hispanic, Asian, Hmong, Pacific Islander, Multinational)	7	29.17

by urban, community-based (n=6). The study participants varied in gender distribution, with the majority involving both male and female participants (9 studies), followed by predominantly female (n=9), studies encompassing male, female and non-binary genders (n=1), and one study focusing on newborns (n=1). The study participants reported a range in mean age, with the lowest recorded at 30.3 years old and the highest at 61.3 years old. Racial and ethnic representation across the studies was diverse. Some studies focused exclusively on African American or Black participants, while others included individuals identifying as Latino/Hispanic and Asian. Additional studies engaged African immigrants and primarily Spanish-speaking Hispanic/Latino populations. Furthermore, studies involving genomics researchers included participants who self-identified as Chinese, Greek, Haitian, Indo-Pakistani, Italian, Jewish and Moroccan.

Overall, 58.33% of studies were qualitative, 79.17% used a cross-sectional design and 58.33% were conducted in urban or hospital settings. Around 70.83% of the studies focused on Black populations, including African American participants and African immigrants. Additionally, 29.17% of studies included other racialised communities such as Latino/Hispanic, Asian, Hmong and Pacific Islander communities (see table 3).

Theme 1: exclusion

Our scoping review identified multiple dimensions through which racialised communities are excluded from participation in genetic and human genomics research, as discussed in 11 of the included studies. These include obstacles that are outside the control of potential participants, such as a lack of transportation to access research facilities or clinics where these forms of research might be undertaken.[47 48] Being knowledgeable, or having access to learn, about fundamental principles in genetics and human genomics is also a source of exclusion.[48–53] Barriers to participation in genetic or human genomics research that we identified in our review include unwillingness by a potential participant's own primary health professional to engage in these domains of research, which can thus discourage participation on behalf of their racialised patient(s).[54 55] Furthermore, our review revealed that when the fundamentals of human genomics research are understood by a potential racialised participant, they can still be sceptical or there can exist a lack of clarity about how these domains of research can effectively address health barriers that they might experience.[50 54 56]

Similarly, our review found that black patients with cancer were significantly under-represented in clinical trials and were less likely to receive precision oncology treatments, including tumour genomic testing.[57] These exclusions were linked to systemic barriers such as financial constraints, limited awareness, inadequate provider communication and deep-seated mistrust of the medical system. Additionally, some participants reported that their oncologists never mentioned clinical trial options, reinforcing structural exclusion from research participation.

Theme 2: diversity of positions on medical and human genomics research among racialised communities

In nine of the included studies, potential participants articulated various forms of distrust in genetic and human genomics research.[58–64] The research we reviewed indicates that members of racialised communities possess general knowledge of genetics, including concepts of ancestry and heredity, even if fundamental principles of human genomics might not be well understood by a potential racialised participant.[57 60 64] Because of the chequered history of genetic research involving racialised communities, the studies we analysed indicate that members of racialised communities may be concerned with risks of stigmatisation, that is, of being associated as a group with a specific disease or condition which can consequently adversely affect employment, housing, insurance and civil liberties.[58 60–64] In our review, we find that such concerns extend to perceptions that stigmatisation of a community might also result in the promotion of one race over another, or in its most dire of scenarios, be used to justify genocide.

Our analysis reveals that a diversity of personal and cultural values, as well as norms, influence positions that racialised persons might take regarding genetic and/or human genomics research. A portion of the literature that

we examined comprised studies that surveyed members of racialised communities on their views about genetic and/or human genomics research. Such surveys indicate that disease is often viewed by members of racialised communities as a private affair, one that is not typically shared beyond a primary health professional. As such, respondents ascribing to such a private view of disease were also not inclined to support participation in genetic or human genomics research.[58] The studies we interpreted indicate that participation in genetic research by pregnant women or children is generally supported provided, according to the respondents, the research is medically safe and that it maintains the woman's decision-making autonomy.[65] Particularly as it concerns the participation of children in genetic or human genomic research, racialised respondents emphasised that researchers ought to take into consideration and mitigate the vulnerability of participating children.[65]

Diverse factors seem to underlie motivation to participate in genetic or human genomic research. Our review suggests that racialised community members who are active in their respective healthcare systems, often facilitating alliances between themselves and their primary health professional, may motivate patients to participate in genetic or human genomic research.[49 66] The studies we investigated highlight that such relationships within healthcare systems are vital to members of the racialised community because they tend to be viewed as forms of empowerment. Additionally, our review finds that the manner in which participants are recruited and retained in studies influences their full participation in genetic or human genomic research.[65 67 68] The degree to which researchers and research staff comprehensively plan how information about a study will be conveyed and how progress and findings will be reported to participants is central to consistent participation in a genetic or human genomic study.[58 68] This may include addressing issues like the relevance of a study to their health priorities and the possible side effects or unforeseen outcomes of participation.[61 62 65 69]

Our review also yielded the insight that participation in genetic and human genomic research by members of racialised communities might be influenced in significant manners by the degree to which researchers disclose if biological samples will be biobanked (ie, stored for future research) and how the genetic data generated from a study will be used after a study is concluded.[58 59] In all, the extant literature suggests that transparent disclosure of biomedical and health knowledge to potential participants plays an important role in governing the participation of members of racialised communities in genetic or human genomic research.

According to the research that we reviewed, members of racialised communities may hold personal beliefs about the body that may not be commensurate with biomedical epistemologies that are foundational to genetic and human genomic data and knowledge.[58] Similarly, members of these communities may embrace forms of medical reasoning and treatment for specific conditions that conflict with biomedical interventions typically recommended for the same conditions. Our review indicates that because colonisation of Asia, Africa and the Americas introduced epistemologies of biomedicine to communities in the global South as early as the 18th century, racialised individuals have comprehensive experiences with biomedical knowledge and its associated practices that usually predate migration, resettlement and/or the occurrence of a specific illness. Our analysis reveals that members of racialised communities, therefore, are not untouched by the logics and forms of intervention that constitute biomedicine. Instead, our review underscores the manners in which genetic and human genomic-*compete* with forms of reasoning and knowledge from other systems of medicine that might predate the introduction of biomedicine to these communities, or those that have emerged by blending historically existing ('traditional') and biomedical insights together thus forming their own hybrid systems of medicine that are regarded as meaningful by members of racialised communities.

Our review found that genomic scientists conducting research in the field of pharmacogenomics in Canada identify various unforeseen consequences of including racialised communities in pharmacogenomic studies, some of which are particularly relevant to the diverse racialised communities that make up the Canadian population, the context of immigration, and universal healthcare access in Canada. Pharmacogenomic research employs genomic tools to study variability in drug efficacy and safety based on inter-individual or population-to-population comparisons. Including racialised communities in genomic research like pharmacogenomic studies necessarily involves considering possibilities that race is used as a classificatory category in the genomic study of drug efficacy, but also—as our review finds—in associating a particular condition with a specific racialised group(s). The possible adverse consequences of such associations are especially important for human genomics research in Canada because racialised immigrants increasingly contribute to the Canadian population. Our review finds that genomics researchers in the greater Montreal area perceive risks of *genetic reductionism* in studies that seek to correlate drug effects with specific racial populations.[69] Genomicists who were interviewed in the study by Égalite and their coauthors[69] acknowledge that pharmacogenomic studies that seek to correlate genetic variations associated with drug metabolisation (or the lack of it) with categories of racial communities potentially offer patients targeted drug interventions for rare diseases more prevalent in certain populations. At the same time, however, this same cohort of genomic scientists also viewed race as a flawed surrogate for complex environmental and genetic factors that mediate drug effectiveness. Other concerning forms of potential reductionism identified in our analysis also include reducing humans to their genetic code or the conflation of a particular race with a drug which

several genomic scientists conducting genomic research in the Canadian context did not view as an example of productive science. We find that this specific cohort of genomicists conducting research in Canada did not want to see the development of the field of pharmacogenomics in Canada reproduce past experiences in the USA. One well-known case is the drug BiDil that was associated in the 2000s with Black American men often for reasons thought to be 'innate' to the community.

Our review also identified concerns among genomicists regarding the misuse of genomic data and research results, especially in the context of Canadian public health institutions and immigration policies. Specifically, the potential misuse of research results by insurers, employers and government to associate a condition with a specific community. Such correlations risk excluding a specific community from immigration selection if the Canadian government seeks to not burden the existing universal healthcare system(s) based on a strategy that excludes a racialised community thought to be susceptible to a particular condition.[69] Given the small relative size of racialised communities in Canada, our review found that there is a concern among a cohort of genomic scientists in Canada that pharmacogenomic studies which associate a condition with a specific racialised community might contribute to a situation in which there is little incentive to develop a drug therapy for it because the beneficiary population is too small. The culture of information sharing in Canada is especially developed in terms of publicising research relevant to public health often through national news organisations. Our review finds that some genomic scientists conducting pharmacogenomic research in Canada caution that sharing the findings from a pharmacogenomic study involving race in the national Canadian media context could introduce various kinds of bias which would harm or stigmatise a racialised community identified in the research. Genomic scientists working in this particular Canadian setting felt that a better understanding of understanding of genetics and pharmacogenomics by the public had to be achieved first before the findings of pharmacogenomic studies involving race were publicly shared.

Theme 3: few genetic research studies embrace robust practices that promote equity

This theme is addressed in seven of the included studies. Our review finds that only a small number of genetic or human genomic studies fully adopted a community-based participatory model in which researchers actively included members of racialised communities in the research process. Though few in number, our analysis reveals the importance of community based participatory research (CBPR) approaches in the design of genetic and human genomic research because these models, when fully undertaken, are typically able to engage community members in ways that are comprehensive (which we describe below).[57 70 71] These studies in particular are effective in understanding and incorporating a diversity of views on genetic and human genomic research into the design of a specific study.[51 57] Such views may include aligning the goals of a genetic or human genomic study with addressing the community's health priorities and addressing its members' possible concerns about providing biological samples, for example.[59 65 71] Our analysis suggests that such dimensions of CBPR studies typically are successful in securing the participation of racialised community members and, as a consequence, they can publish findings (with informed consent from community members) on genetic variation within specific racialised communities.[70] These studies indicate that such findings are indispensable to the identification of disease-associated markers with which researchers and/or a primary health professional can explore, with the consent of patients, possible preventative forms of care or lifestyle changes.

Of the small number of genetic or human genomic studies involving the participation of racialised community members that were included in our sample, very few engaged (or addressed) biobanking of biological samples and future use of genetic data generated from research.[58 59] We found that there is a significant gap in understanding how to introduce biological and data governance models in genetic or human genomic research that includes members of the racialised community participating in a genomic study. A lack of equitable data governance practices have long been the locus of past abuses particularly when researchers engaged in the continued use of biological and genetic samples without the knowledge of the participating community. This issue is even more pressing given the ease with which genomic data can be stored and reanalysed long after the conclusion of a study. While this review strove to include the findings of legal experts, which would have been particularly illuminating on the issue of designing models for data governance, our search and screening process did not yield studies that included legal perspectives. Our analysis suggests that the incorporation of such models is essential to the co-creation of equitable terms for the inclusion of racialised peoples in genetic or human genomic research, particularly because they rely on fostering long-term and trusting relationships between researchers and community members.

DISCUSSION

Our review foregrounds the complex ways members of racialised communities strongly distrust human genetics research.[15 58–64 72] The reasons for this are historical and stem from known experiences of exploitation of racialised people who participated in genetic research in the distant and recent past by biomedical researchers and/or institutions. As Égalite *et al*[69] underscore, genomic scientists conducting research in the field of pharmacogenomics in Canada demonstrate a sophisticated understanding of this history of genetic research and echo similar concerns about the use of race in their research. Also playing a role are perceptions that advances in genetics, particularly

genomics and the increased importance of health data (including genomic data), sharpen inequalities between racialised peoples and biomedical researchers and organisations.[54 58] As Buseh *et al* reported, members of African communities who were surveyed perceived researchers and entrepreneurs reaping prestige and personal gain from genetic and human genomic research, while the former gained little.[58] This observation suggests that media representations of genetic and human genomic research and its broader power relationships to community and societal welfare generally may play a role in fuelling such perceptions. Genomic scientists in Canada extend this observation by identifying the pitfalls of sharing the findings of pharmacogenomic studies involving race through the media without further public education on human genomics and pharmacogenomics. Previous research on the media (in Australia) also suggests that media representations of genetic research may seem to inform community members about this field of knowledge, but it also may do so with errors, which additionally skew understandings of human genomics.[72]

Distrust of genetics and human genomic research also involves unauthorised or unintended use of genetic data, and its storage, which could adversely affect members of racialised peoples in ideological terms, that is, by classifying communities and thus imputing their value and importance, to affecting their material realities in employment, housing, safety and welfare, as well as legal rights.[25 54 58–60] Genomic scientists in Canada additionally identify potential adverse consequences of the use of findings from pharmacogenomic studies involving race in immigration selection as well.[69]

Distrust of genetics and human genomic research appeared to be mitigated by the degree to which researchers engaged in *authentic engagement* with the participating racialised community.[70] Three studies demonstrated the importance of researchers comprehensively engaging with community members as a means to conduct genetic or human genomic research inclusively.[68 70 71] As reported in the studies we reviewed, and other similar studies involving racialised communities, efforts to translate patient-facing materials, vetting published or presentation information for appropriate and accessible language by multilingual medical staff iteratively with a translator significantly impacted recruitment of racialised community members in genetics and human genomic research (we refer to this as *comprehensive translation*).[53 68] As the findings of Kraft *et al*[71] suggest, not only does comprehensive translation facilitate understanding, it also conveys the researchers' respect for community members, which plays a significant role in recruiting and retaining racialised participants in genetic and human genomic research.

In studies conducted previously in Australia, Uebergang *et al* further outlined that translation alone, however comprehensive and well-intentioned, may not provide a full solution because translators themselves have requested additional training in order to understand the concepts they are asked to translate often into languages that do not have similar terms.[72] Further complicating the dependence on translation, the participation of subjects in genetic studies can be frustrated by the fact that much more information about genetics is available in English compared with other languages, which can rely on adaptations and summaries of genetic knowledge. Both Uebergang *et al* and Saleh *et al* further illustrate that comprehensive approaches to translation can often be ineffective when the structure of decision-making within families asked to participate in studies does not afford the person affected by a condition to make their own health decisions.[72 73]

Replicating the findings of Port *et al* in New Zealand, Culhane-Pera *et al* additional interventions exemplify what Hendricks-Sturrup called 'authentic engagement' by explicitly employing CBPR methods, which involved members of the Hmong community in St. Paul (Minnesota) from the inception and design of the study and through its milestones (p. 245).[47 70 74] These included the formation of community-run review boards ('Hmong Genomics Board'), which monitored the progress of the study, discussed the meaning of findings and deliberated on continued participation.[70] The model adopted by Culhane-Pera *et al*[70], in which a board comprised of community members was involved through multiple phases of the study, also foregrounds the potential of incorporating biobanking of genetic data collected through the study that could be co-governed by researchers and community members through the established review boards discussed in Canadian contexts also.[39] Though Culhane-Pera *et al*[70] demonstrated their awareness of data sharing as an ethical issue in CBPR, data sharing was not explicitly part of the study. Nevertheless, the substantive efforts of all participants to design and enact CBPR exemplified what researchers view as an area in which a significant shift to promote equitable benefit sharing between researchers and participating communities can be undertaken and mitigating barriers to access data generated from the study or unauthorised data sharing.[75 76] It involves researchers and community members jointly devising and overseeing data collection and its future use, drawing the two parties into a long-term relationship, building possibilities for continued knowledge exchange and, ultimately, trust.[77] Review boards and the relationships they foster create a routinised data management approach that researchers identify as being indispensable to addressing privacy concerns that can impede participation from underrepresented groups like racialised peoples.[58 62 78–82] While many of these models have been developed in genomics research involving Indigenous communities, Culhane-Pera *et al*[70] provide a trust-generating model adapted for the institutional realities of racialised communities who might not participate in genomics research under the auspices of autonomous self-government as do some Indigenous communities.[38 40 83]

From a different angle concerning 'community', Ewing *et al* survey of African American cancer survivors illustrates

that respondents were less likely to provide a biosample if it was not clear that participation in genetic research would benefit future generations.[59 65 84] Articulated in terms of social networks within a healthcare system, which we view as speaking to the importance of 'community' within the healthcare system, three studies confirmed that the degree to which a respondent's primary health professional, or the degree of involvement of their healthcare network, can facilitate participation in genetic or human genomic research.[47 61] Such social connections appear to facilitate participation in genetics and human genomic research because they are viewed as 'alliances' (p.806).[66]

Authentic engagement appears to facilitate recruitment and retention of participants because it creates an opening for members of racialised communities to articulate positions on genetic and human genomic research in reference to their cultural values and alternative views of health and wellness. As the findings of Buseh *et al*[58] suggest, their sample of black immigrants embraced different views of the body and disease which compete with biomedical assumptions and knowledge. Despite suggesting that community understandings of health and biomedical ones might be incommensurable, the respondents participating in this study held that genuine engagement with the community, its beliefs and values, still holds potential for participation if awareness about the benefits of genetic or human genomic research for the entire community is raised.[58] Previous studies underscore how researchers and community members may hold strong and incommensurable beliefs about marriage, reproduction and consanguinity. For example, Saleh *et al*, as well as Shaw *et al*, found that community members may not identify interconsanguine marriages or partnerships to researchers, choosing to keep these a secret for fear of judgement and because they are known or accepted within their own group but appear to be at odds with the values of those outside of the community.[73 85]

In light of the importance of authentic engagement, barriers frustrate the creation of trust when there is a trust deficit or genetics and human genomic research is an unknown area. As three studies we reviewed demonstrate, participating members of racialised communities placed significant weight on researchers' efforts to include, translate and facilitate an ongoing dialogue about genetic or human genomic research with community members.[54 70 71] Probably requiring more research, genetic researchers' inattentiveness to challenges in terms of transportation and proximity, inadequate linguistic and knowledge translation, as well as the general framing of how genetic or human genomic research is relevant to racialised communities, is perceived to be more than mere communication oversights on behalf of researchers.[54 59] Such failures to reach racialised peoples and speak on a linguistic register that resonates among them may be construed as a lack of respect for the community and its ways of knowing and living.

Our scoping review has several strengths. One notable strength is the comprehensive search strategy, which includes both academic databases and grey literature to ensure a broad and diverse range of sources. Also, our review advances a nuanced discussion that bridgesg technical aspects of genomic research (like biobanking and CBPR approaches) to its relationship to issues of inclusion, equity and historical experiences with medicine and genetics. Another key strength is the composition of our research team, which includes multidisciplinary researchers from medical humanities, health equity, law, sociology and molecular biology, who contributed to every step of the review process—from search and screening to data analysis and manuscript writing. We adopted a collaborative approach to ensure that a wide array of perspectives was incorporated throughout the review study. Additionally, our team reflects the diversity of the community to which we belong. Our team comprises researchers from who are different in the broadest sense: it includes academics from different disciplines and visible minority communities, genders and immigration statuses. Our backgrounds informed and motivated us to ask questions about identifying more equitable methods in genomic research involving racialised communities.

Limitations

Nevertheless, this scoping review has certain limitations. Human genomics and equity in research are complex and multifaceted subjects that can be interpreted and studied through diverse disciplinary lenses. While our review aimed to incorporate insights from multiple fields, it may not have captured all relevant factors influencing the participation of racialised communities in human genomics research. Additionally, given that it is a scoping review, we did not formally assess the methodological quality of the included studies, which may affect the consistency and credibility of the findings. Another important limitation concerns the specificity of the search strategy. Although we developed comprehensive search strings that include indexing terms and keywords for different databases, certain studies using context-specific terminologies—such as 'CALD' (culturally and linguistically diverse) in Australian research to describe racial/ethnic minority populations, which are not included in equivalent indexing terms in databases—may not have been captured. Finally, the review did not include engagement with stakeholders such as leaders from racialised communities during the review process, which may limit the contextualisation and interpretation of the results; however, having multiple members of this research team who are from racialised communities may mitigate that limitation to a certain extent.

Recommendations

We recommend that more systematic adoption of strategies that promote authentic engagement, which, based on our review, would enable equitable research in future genetic and human genomic research in Canada

involving racialised communities; we extend such a recommendation to future precision medicine and precision health studies also given their strong methodological reliance on human genomic tools. Of course, it a fully informed community articulates a desire, or receptiveness, to participate in genetic, human genomic, precision medicine or precision health research as vital to equitable and inclusive scholarship in these interrelated domains of research. So far, CBPR approaches represent some of the most effective protocols and trust-building strategies to comprehensively engage community members in genetic and human genomic research when consistently used as a method to design a study. We recommend the adoption of CBPR methodologies, comprehensively, in future genetic, human genomic, precision medicine and precision health studies. However, CBPR is not without limitations. It can be resource-intensive and time-intensive, often requiring long-term relationship building, ongoing community involvement and adequate funding to support equitable collaboration.[86] Moreover, implementing CBPR on a larger scale or across diverse geographical regions can pose logistical and coordination challenges. Future efforts should prioritise institutional support, capacity-building and flexible implementation strategies to address these barriers and ensure the scalability and sustainability of CBPR approaches.

Future genetic, human genomic, precision medicine or precision health research ought to aim to authentically engage with racialised community members to mitigate structural injustices and promote more equitable forms of research, versus forms of consultation that are minimally compliant with informed consent protocols. The existing evidence suggests that adoption of these elements of community engagement would productively contribute to overcoming existing barriers, especially those concerning language and knowledge about genetics or human genomics, and to enable equitable and inclusive participation in genetic, human genomic, precision medicine or precision health research. To be effective, such strategies presumably include the co-creation of a plan by which information and findings are disseminated to community members, an agreed-upon mode(s) by which community-defined recommendations are implemented after the study concludes (for interventions, treatment, etc). This can be achieved by working with community advisory boards to co-develop accessible materials (eg, reports, infographics) and by applying frameworks like the Knowledge-to-Action (KTA) model to guide implementation of findings into local programmes or services. Finally, we suggest that future research in these domains make every effort to secure the consistent participation of physicians who serve community members considering participation in a study. This can be achieved by engaging physicians early in the study design phase, integrating culturally tailored educational materials into clinical workflows and establishing formal partnerships with healthcare networks and community clinics. Potential barriers such as time constraints, lack of incentives and limited awareness of genomics research among physicians should be proactively addressed through capacity-building initiatives, streamlined referral processes and policy-level support.

As the recently emerged field(s) of human genomic, precision medicine and precision health continue to evolve and mature, we take the view that they would be made more equitable if medical education augmented and made more comprehensive its training of the medical profession, as well as that for scientific and medical professionals, in the constellation of issues associated with inclusivity and equity. While we acknowledge that many medical curricula have come to include modules that address inclusivity, we recommend that medical education augment the presence of issues of inclusion within medical education and more comprehensively explore problems and practices of equity. Specifically, we suggest that learning modules in colonial histories of science and medicine, intersectional technoscience and bioethics scholarship, and postcolonial science studies could be better integrated throughout the curriculum.[4 5 7–9 11 12 16 18 19 33–35 38–40 87 88] We are beginning to see more robust criteria for inclusivity integrated into scientific reviews; this can be further expanded in ways that would be significant if the relevant learning modules were included in strategic and related areas of the curriculum (not as a standalone course or module).

CONCLUSION

This scoping review synthesised evidence on the barriers and facilitators shaping the equitable inclusion of racialised communities in genetic, human genomic, precision medicine and precision health research. We identified key challenges, including systemic mistrust rooted in historical exploitation, insufficient culturally relevant genetic literacy and limited infrastructure supporting the participation of racialised communities. At the same time, we highlighted actionable strategies such as CBPR, culturally grounded and multilingual communication, and the involvement of trusted healthcare providers, all of which can enhance engagement and participation when thoughtfully implemented.

The findings point to practical steps that can inform current research practices and policy frameworks. For example, co-creating dissemination and implementation plans with racialised communities, integrating equity-focused frameworks and ensuring transparency in data governance and biobanking can help build trust and improve long-term engagement. These approaches can be embedded into ethics review processes, institutional protocols and funding criteria to ensure that equity is not only aspirational but operationalised across the lifecycle of genomic research projects.

Future research should move beyond general calls for inclusivity and instead define what equitable inclusion looks like in practice for racialised communities. This includes engaging communities as co-creators in

study design, addressing context-specific barriers and establishing metrics to evaluate the quality of participation and benefit-sharing. For example, studies in this review demonstrated how CBPR, when paired with community advisory boards and culturally tailored consent materials, resulted in higher participation and greater trust.[70] Frameworks such as the KTA model and the Equity-Oriented Healthcare framework may guide researchers in translating these strategies into practice by emphasising relational accountability, reflexivity and shared decision-making. We also recommend integrating training on colonial histories, intersectional bioethics and community-engaged methods into scientific and medical education to equip future researchers with the tools to foster ethical and equitable genomics research.

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