BMJ Global Health

Qualitative genomic research with Indigenous peoples: a scoping review of participatory practice

Morgan Ehman [1], Nadine R Caron [2,3] Laurie Montour [4] Dean A Regier [1,5]

To cite: Ehman M, Caron NR, Montour L, *et al*. Qualitative genomic research with Indigenous peoples: a scoping review of participatory practice. *BMJ Glob Health* 2024;**9**:e015377. doi:10.1136/bmjgh-2024-015377

Handling editor Helen J Surana

► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/bmjgh-2024-015377).

Received 16 February 2024
Accepted 24 September 2024

[1]Cancer Control Research, BC Cancer Research Institute, Vancouver, BC, Canada
[2]UBC Centre for Excellence in Indigenous Health, The University of British Columbia, Vancouver, BC, Canada
[3]First Nations Health Authority Chair in Cancer and Wellness at UBC, The University of British Columbia Faculty of Medicine, Vancouver, BC, Canada
[4]Department of Medical Genetics, The University of British Columbia, Vancouver, BC, Canada
[5]School of Population and Public Health, The University of British Columbia, Vancouver, BC, Canada

Correspondence to
Dr Dean A Regier;
dregier@bccrc.ca

ABSTRACT

Introduction Indigenous peoples and perspectives are under-represented within genomic research. Qualitative methods can help redress this under-representation by informing the development of inclusive genomic resources aligned with Indigenous rights and interests. The difficult history of genomic research with Indigenous peoples requires that research be conducted responsibly and collaboratively. Research guidelines offer structuring principles, yet little guidance exists on how principles translate into practical, community-led methods. We identified the scope and nature of participatory practice described in published qualitative genomic research studies with Indigenous peoples.

Methods We performed a search of PubMed, CINAHL, Embase, Scopus and the Bibliography of Indigenous Peoples in North America. Eligible studies reported qualitative methods investigating genomics-related topics with Indigenous populations in Canada, the USA, Australia or New Zealand. Abstracted participatory practices were defined through a literature review and mapped to a published ethical genomic research framework.

Results We identified 17 articles. Published articles described a breadth of methods across a diversity of Indigenous peoples and settings. Reported practices frequently promoted Indigenous-partnered research regulation, community engagement and co-creation of research methods. The extent of participatory and community-led practice appeared to decrease as studies progressed.

Conclusion Applying non-prescriptive Indigenous genomic research guidelines to qualitative inquiry can be achieved through varied methodological approaches. Our findings affirm the adaptive nature of this process in real-world settings and identify opportunities for participatory practice and improved reporting across the research lifecycle. These findings and the breadth of characterised applied research practices are instructive for researchers seeking to develop much-needed qualitative genomic research partnerships.

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Indigenous peoples are under-represented in genomic research and resources amid historical examples of unethical genetic research using Indigenous communities' tissue and data inappropriately and without consent.
- ⇒ Researchers seeking to address this 'genomic divide' through qualitative inquiry look to research guidelines on ethical and participatory practice with Indigenous communities.
- ⇒ While valuable, research guidelines are non-prescriptive. Little published guidance exists on the practical application of research principles within the genomic research context.

WHAT THIS STUDY ADDS

- ⇒ Through a scoping review protocol, this study characterises qualitative and participatory practice among genomic research studies with Indigenous communities.
- ⇒ Study findings describe frequent and varied examples of participatory practice, and identify a particular emphasis on early relationship building and research co-development. Participatory approaches appear to decrease as studies progress, with mixed reporting around the nature and influence of community feedback.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ This review affirms participatory research with Indigenous communities as an adaptive process that affords co-creation of practice according to community-specific research priorities and preferences.
- ⇒ Study findings illustrate how qualitative approaches and research guidelines manifest in diverse, real-world settings and highlight opportunities to increase participatory and reporting practices across the research lifecycle. These results are instructive for future genomic research partnerships with Indigenous communities.

INTRODUCTION

Genomic testing can produce earlier and more accurate diagnoses and inform targeted interventions.[1] These benefits are not equitably distributed among populations.[2 3] Indigenous peoples are under-represented in genomic research and variant libraries,[2] and Indigenous patients are less likely to receive a causal diagnosis.[4] The increasing focus on genomics-informed healthcare will exacerbate health inequities between Indigenous and non-Indigenous populations unless this marginalisation is addressed.[2] Global efforts are underway to include Indigenous peoples in genomic resources.[2] For example, the Silent Genomes and Aotearoa Variome projects are developing Indigenous-specific genome reference databases for Indigenous populations in Canada and Māori and Pacific peoples in New Zealand, respectively.[5] These and other efforts embed qualitative studies to navigate acceptable resource development against the difficult history of harmful genetic research on Indigenous peoples.[4 6–8]

Qualitative research studies focus on understanding people's lived experiences, perceptions and behaviours.[9] When applied to genomic research, qualitative methods enable researchers to explore aspects such as participants' preferences and concerns toward receiving genomic testing, identify existing healthcare service gaps and barriers to access and discuss considerations for appropriate data storage and sharing. These explorations are key to aligning health research, policy and practice to real-world needs.[10] This is especially true for Indigenous communities with worldviews, knowledge systems and social structures that often differ significantly from those in Western contexts.[9] Embedding these cultural nuances is crucial to creating genome reference databases and genomic testing services that benefit Indigenous people.[5] Achieving this aim requires research practices that are both respectful and culturally appropriate.[9] Failing to do so may produce research that inadvertently undermines Indigenous sovereignty, exploits Indigenous knowledge or misrepresents participants' views.[11–13] This is particularly pertinent to qualitative genomic research studies.

Many Indigenous communities are rightfully wary of genomic research following unethical and exploitative experiences of past studies that promulgated racist and discriminatory views of Indigenous peoples.[4] Examples include using genetic traits to stereotype Indigenous populations as intrinsically unhealthy,[14] conducting experiments on community DNA samples without consent,[15] and reductively privileging genetic ancestry as the sole criterion of 'Indigeneity'.[16] Additionally, some communities attribute sacred and spiritual significance to biospecimens that will inform their appropriate collection, storage and return or disposal.[6 17] This context demands genomic research be conducted in equitable partnership with Indigenous peoples through practice grounded in community values.[3]

National and community-level guidelines for genomic research with Indigenous peoples have been established to this end.[4 18 19] Across heterogeneous regulatory and cultural environments, good practice is repeatedly affirmed as a meaningful and culturally safe partnership that privileges Indigenous research sovereignty, capacity and benefit.[3 4] However, by their nature, such guidelines are non-prescriptive,[20] owing to the highly diverse values and research needs of Indigenous peoples and communities and provide few details on qualitative practice.

Guideline principles are adapted to each research partnership according to a community-directed standard.[20 21] For example, research guidelines commonly espouse aligning data collection methods with community cultural and social values.[9] Depending on community preference, this may require purposeful and community-aided recruitment of local Elders and Knowledge Keepers,[22] or reshaping the qualitative topic guide to include salient cultural concepts.[17] Appropriately adapting guidelines is only one aspect of ethical research practice, and must occur within an overarching approach with embedded values such as respect, equity, reciprocity and beneficence.[19] Nevertheless, it is informative for prospective researchers to understand the practical and emergent scope of practice adopted by qualitative studies with Indigenous communities, particularly for the internationally relevant and historically fraught topic of genomics. However, to the authors' knowledge, there have been no reviews of qualitative genomic research with Indigenous communities.

This literature gap increases the burden on researchers and communities seeking to undertake new qualitative genomic research partnerships and challenges the timely and sustainable inclusion of Indigenous perspectives into genomic resources.[23] We address this gap through a scoping review of qualitative research and participatory practice with Indigenous peoples that investigated genomics-related topics. We selected a scoping review approach because we aimed to map the characteristics and reporting of qualitative and participatory methods applied across the literature, rather than assess study quality or rigour.[24] Participatory methods seek community involvement throughout the research lifecycle and align research aims and benefits with community-directed priorities.[25] These practices commonly underpin research with Indigenous communities and correspond with research guidelines.[26–28] We identified research principles from a framework for genomic research developed by Indigenous scholars.[5] These principles subsequently guided our characterisation and reporting of participatory practices.

We acknowledge that this review blends the research experiences and expectations of a wide diversity of Indigenous peoples, each comprised of unique cultures and histories. Our intention is not to assimilate these distinct populations into a pan-Indigenous amalgam, but rather to highlight participatory practices used with Indigenous peoples with related experiences of colonialism and exploitative research.

METHODS

This review was undertaken by a team of Indigenous and non-Indigenous researchers. ME is a Canadian settler of British and Norwegian ancestry. NRC is Anishnawbe from Sagamok First Nation. LM is Kanien'kehá:ka from the Mohawk Nation of Kahnawake. DAR is a Canadian settler of Prussian and British ancestry. The research team has significant experience conducting scoping reviews, applying qualitative methods and partnering with Indigenous communities in research. Team members additionally completed the S̲an'yas Anti-racism Indigenous Cultural Safety Training Program[29] and The Fundamentals of OCAP course from the First Nations Information Governance Centre,[30] describing the importance of First Nations ownership, control, access and possession of First Nations data. Indigenous team members were involved at each stage of this review.

We conducted a scoping review according to the protocol outlined by Arksey and O'Malley,[24] with reporting aligned to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) extension for scoping reviews guidelines.[31] Included articles applied qualitative research methods to examine genetics-related or genomics-related topics with Indigenous participants. Eligible qualitative methods included any approach to collecting oral data,[9] including structured or unstructured interviews,[32] focus groups and Indigenous methodologies such as sharing circles[33] and yarning.[34] Genetics-related or genomics-related topics included, but were not limited to, biobanking, pharmacogenomics, genetic research practices and genomic testing services. We included primary research with Indigenous participants and articles written in English. No date restrictions were imposed. To manage heterogeneity and cross-study comparison, we restricted this review to research conducted in Canada, the USA, Australia or New Zealand. Indigenous peoples in these countries have experienced similar harmful histories of colonisation and genetic and genomic research that require intentional consideration. These countries have each developed national guidelines for research with Indigenous peoples, and Indigenous scholars and policy advocates within these countries are leading comparable, though culturally district, initiatives promoting Indigenous sovereignty and governance models in research.[4] We excluded articles that did not comprehensively report study methods or align with the conceptual framework of this review (eg, mailed-out surveys or qualitative investigations of participants' experience living with a genetic disease). We also excluded studies that primarily included health professionals as participants (eg, key informant interviews with clinicians or other researchers), as preliminary review identified that these studies often excluded details around community engagement.

Search strategy

We developed a search strategy in February 2022 based on existing literature and consultation with the X̲wi7x̲wa Library at the University of British Columbia (UBC), the Indigenous branch of the academic library (https://xwi7xwa.library.ubc.ca/). The X̲wi7x̲wa Library provided guidance on potential Indigenous research databases and journals to hand search. We searched PubMed, CINAHL, Embase, Scopus and the Bibliography of Indigenous Peoples in North America and reviewed the reference lists of eligible studies (table 1). The search strategy was re-executed in October 2023. Search results were exported to Microsoft Excel for review and selection.

Study selection

One primary reviewer (ME) selected studies for inclusion in three phases. First, titles and abstracts were reviewed for relevance and inclusion. Second, potentially eligible articles were reviewed in full. Finally, the primary reviewer examined the reference list of each included article to affirm the capture rate of the search strategy. Studies that remained potentially eligible following full-text review were discussed with a second reviewer (LM) until a consensus was reached.

Data abstraction

Data abstraction was performed independently by two reviewers (ME and LM). Reviewers met to reach a consensus following independent abstraction. Abstracted information included general and qualitative characteristics and participatory practices. Literature review informed the development of the initial data abstraction form. A set of potentially relevant participatory practices were preliminarily identified through a review of guidelines for Indigenous research and community-engaged research.[18 19 26 27 35 36] The form was jointly developed by the reviewers across a subset of five studies, evolving as patterns of participatory practice emerged. The final set of participatory practices was defined and organised according to a framework for enhancing ethical genomic research with Indigenous communities published by Claw *et al*.[19]

Abstracted data were compiled in Excel for reviewer discussion and coding. Data were first coded as a general characteristic or participatory practice. General characteristics included author name, date, study location, research topic, study population of focus, number of study participants, as well as approaches to recruitment and qualitative data collection and analysis. Participatory practices were coded to a corresponding research principle outlined in Claw *et al*.[19] This process aimed to connect related practices, delineate inter-principle boundaries and create a broadly chronological reporting structure.

Defining participatory practices according to genomic research principles

Claw *et al*[19] describe six principles to enhance genomic research with Indigenous communities. We selected this framework due to its genomic focus, its grounding in participatory approaches and its applicability across diverse research settings and populations. By adapting this framework, we sought to provide a theoretical underpinning to our review, structure its reporting and ensure we included participatory practices relevant both to the genomic research context and Indigenous peoples.

Following a review of research guidelines to identify the scope of participatory practice, we used the Claw *et*

Table 1 Search strategy applied to PubMed in October 2023, without date restriction

Category	Concept	Search terms
Methods	Qualitative research methods	(Qualitative Research(MeSH) OR qualitative method*(Title/Abstract) OR qualitative study(Title/Abstract) OR qualitative data(Title/Abstract) OR qualitative evidence(Title/Abstract) OR focus group*(Title/Abstract) OR talking circle*(Title/Abstract) OR sharing circle*(Title/Abstract) OR discussion group*(Title/Abstract) OR deliberation*(Title/Abstract) OR interview*(Title/Abstract) OR yarn*(Title/Abstract) OR semi-structured(Title/Abstract) OR thematic analysis(Title/Abstract) OR grounded theory(Title/Abstract) OR conversation analysis(Title/Abstract) OR phenomenology(Title/Abstract) OR ethnography(Title/Abstract))
		AND
Population	Indigenous peoples	(Indigenous Peoples(MeSH) OR Aborigin*(Title/Abstract) OR Indigenous*(Title/Abstract) OR Torres Strait Islander*(Title/Abstract) OR Maori(Title/Abstract) OR First Nation*(Title/Abstract) OR First People*(Title/Abstract) OR Métis(Title/Abstract) OR Inuit(Title/Abstract) OR Alaska Native*(Title/Abstract) OR Native American*(Title/Abstract) OR American Indian*(Title/Abstract) OR Native Hawai*(Title/Abstract) OR Pacific Island*(Title/Abstract) OR Tribal(Title/Abstract) OR Tribe*(Title/Abstract))
		AND
Research topic	Genetics-related or genomics-related topics	(Genomics(MeSH) OR Genetic Research(MeSH) OR Genetic Testing(MeSH) OR Pharmacogenetics(MeSH) OR Genetic Services(MeSH) OR Biological Specimen Banks(MeSH) OR Human Genetics(MeSH) OR genetic research*(Title/Abstract) OR genetic test*(Title/Abstract) OR genetic material*(Title/Abstract) OR genetic service*(Title/Abstract) OR clinical genetic*(Title/Abstract) OR genomic*(Title/Abstract) OR pharmacogen*(Title/Abstract) OR biobank*(Title/Abstract) OR bio bank*(Title/Abstract) OR biospecimen*(Title/Abstract) OR biological sample*(Title/Abstract))

al[19] framework to finalise the set of practices eligible for abstraction. We translated each principle into one or more conceptually aligned participatory practices indicative of whether this principle was applied in the reviewed study (table 2). For example, Principle 1: understand Indigenous sovereignty and research regulation was translated into whether the article reported a community-guided review process. This was an iterative process. The final set of participatory practices evolved as we identified which practices could feasibly be abstracted. A diagram of the research principles and corresponding participatory practices is available in the supplementary materials

Table 2 Research principles and corresponding participatory practices abstracted through article review

Research principle (Claw *et al*)	Abstracted practice
1. Understand Indigenous sovereignty and research regulation	► Community-guided research review process by participating Indigenous community. – Involvement of an Indigenous-governed research institution or community-institutional partnership.
2. Engage and collaborate with the community	► Community-engaged research approach. – Community-based participatory research approach. ► Community engagement approach.
3. Build cultural safety	► Community-comprised advisory group. ► Community or culturally adapted approaches to data collection.
4. Improve transparency of research practices	► Community-led or community-guided research question. ► Community involvement in developing research materials. ► Community participation in data analysis. – Member checking process.
5. Build research capacity	► Community members hired into research roles.
6. Disseminate findings in a community-accessible format	► Findings returned to community. – Data ownership conferred to community.

Research principles are adapted from the Claw *et al*[19] framework for ethical genomic research with Indigenous communities.

(online supplemental figure 1). We also renamed some principles to recognise our broader review of research with Indigenous peoples and evolving terminology.[37] Review and abstraction were limited to the information reported in the article text. Reviewers recorded practices as 'Not reported' either when it was explicitly not performed or when it was simply unclear. We describe our conceptual definition for each principle and participatory practice(s) below.

Principle 1: understand Indigenous sovereignty and research regulation

The United Nations Declaration on the Rights of Indigenous Peoples recognises the inherent human rights of Indigenous peoples.[38] This is not contingent on formal recognition as Indigenous nations or delegated authority by other governments and includes the right to self-determination in research.[38 39] University Research Ethics Boards (REBs) ethical protocols often do not consider the breadth of research concerns relevant to Indigenous peoples.[18] Community research review entities may take several forms, ranging from a local research governance council to an REB representing a coalition of Indigenous communities. Communities without a formal review entity may dictate an appropriate alternative, for example, community leadership or an ad hoc review council.[18]

Abstracted participatory practice(s): Articles were reviewed for reference to a community-guided research review process and whether research emerged from an Indigenous-governed institution or community-institutional partnership.

Principle 2: engage and collaborate with the Indigenous community

Community-engaged research (CEnR) encompasses the continuum of engagement-based and participatory action research approaches that seek to improve community well-being and motivate social change through active community involvement.[40] Community-based participatory research (CBPR) is a higher-order example of CEnR, incorporating community participation to a degree considered best practice for research with Indigenous communities.[28]

Abstracted participatory practice(s): Articles were reviewed for reference to a CEnR-aligned or CBPR approach and reporting on community engagement.

Principle 3: build cultural safety

Cultural safety describes one's ability to respect cultural diversity, communicate effectively across different cultures and worldviews and be critically conscious of personal and systemic biases that impede health equity.[19 37] Discussions with community partners rooted in honesty, humility and mutual reciprocity then bolster cultural understanding.[41] A form of community advisory council often serves as the community conduit for this dialogue, with community preference dictating appropriate format and membership.[42]

Abstracted participatory practice(s): Articles were reviewed for reference to a community-comprised research advisory group, as well as examples of community-specific adaptations to data collection.

Principle 4: improve transparency of research practices

Transparent research includes open and ongoing discussion—a community-defined and community-specific standard—between partners and begins with agreement on research aims and anticipated benefits.[19 43] Continued engagement throughout data analysis ensures researchers' interpretations are reached transparently and grounded within community and cultural context.[28 35] Member checking, in which participants or community groups review preliminary findings, is an additional step often used to check the accuracy and appropriateness of researchers' interpretations.[44]

Abstracted participatory practice(s): Articles were reviewed for a description of how community priorities guided the identification of research questions and or development of research materials. Articles were also reviewed for descriptions of community involvement during data analysis, including reference to a member checking process.

Principle 5: build research capacity

Research capacity enables communities to take on autonomous and active roles in research partnerships.[19] Hiring local community members into research roles builds research capacity and promotes reciprocity. Community researchers can be trained in skills such as research methods, interviewing participants and project planning and in turn share their experience and knowledge with the research team.[45]

Abstracted participatory practice(s): Articles were reviewed for description of local community members hired and trained to assist with research activities. To delineate from Principle 3, studies in which community members acted solely in advisory roles were excluded. Authors' Indigenous identity or community membership was not abstracted.

Principle 6: disseminate findings in a community-accessible format

Indigenous communities have the right to access, engage with and benefit from the knowledge that they helped create.[39] Community-accessible dissemination holds researchers accountable to their partnership commitments and empowers communities to use research findings to advocate for political, policy or social change.[36]

Abstracted participatory practice(s): Articles were reviewed for descriptions of how research findings were returned to participants or participating communities, as well as references to community data ownership.

RESULTS

The search strategy yielded 291 articles. After removing duplicate records and title and abstract screening, 48

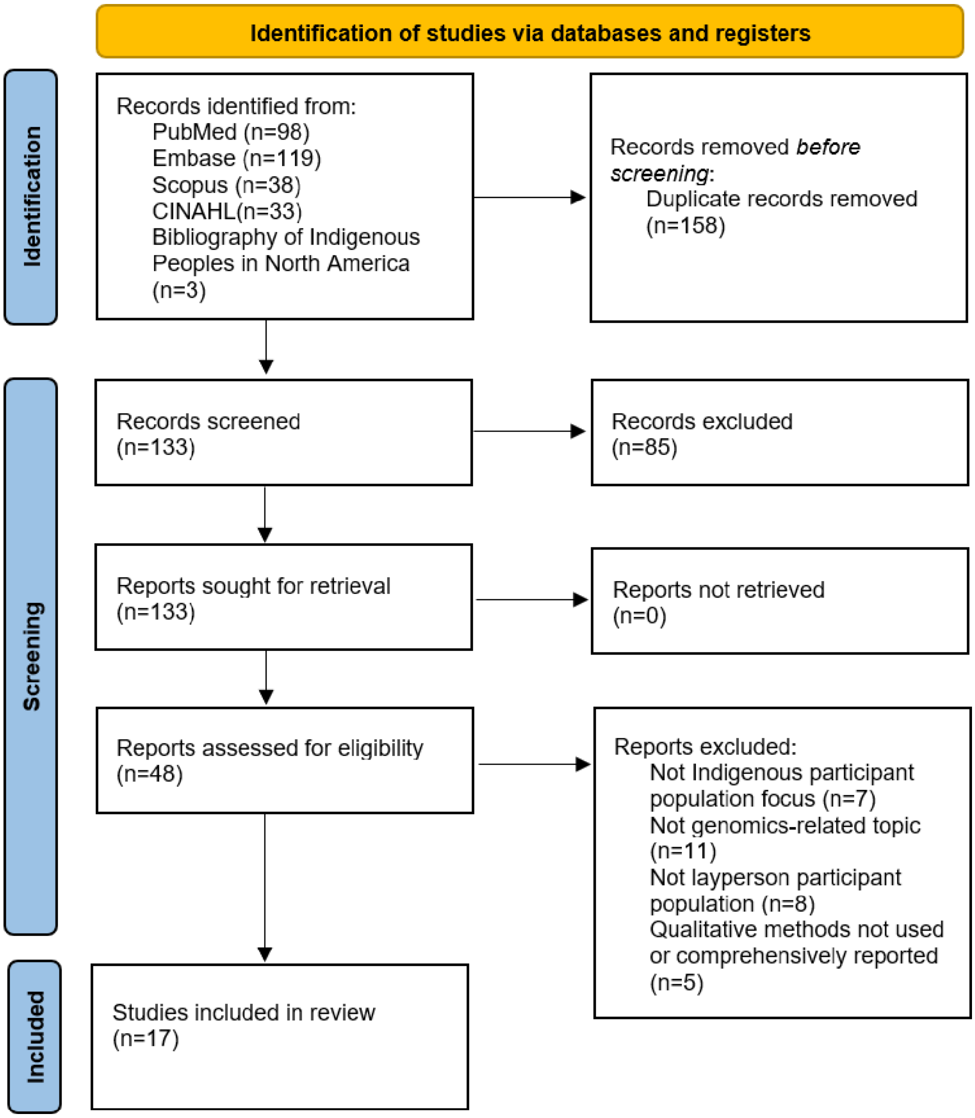

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analysis flow diagram.

studies were identified as eligible for full-text review. Full-text review narrowed to 17 remaining articles. Exclusions included: non-Indigenous participant population focus (n=7); non-genomics-related focus (n=11); non-layperson study population (n=8); or non-qualitative or non-comprehensive methodology (n=5). The remaining articles underwent abstraction and characterisation. Figure 1 presents the PRISMA[46] search flow diagram from identification to final inclusion.

Study characteristics

Most studies (n=12, 71%) were conducted with Indigenous communities in the USA,[8,17,47–56] primarily Alaska. Three studies (18%) originated from Australia,[7,57,58] and two (12%) from Canada.[22,59] No eligible studies were identified from New Zealand. A diversity of Indigenous peoples participated (table 3). Two studies (12%) sought perspectives from community leadership specifically,[22,54] and one study solely involved community Elders.[58]

The storage of biospecimens in biobanks and their use for genetic research was the most common topic (n=9, 53%).[7,8,17,22,47,50,52,54,55] Three studies (18%) elicited perspectives on genetic research without referencing biobanking,[48,49,56] and one article probed participants' views on incorporating their genomic data into public variant libraries.[59] Topics investigated across the remaining articles included local understandings of genetics and heredity,[53] pharmacogenetics[51] and access to clinical genetics services.[57,58]

Study recruitment was conducted by the research team in the majority of articles (n=9, 53%).[7,48,50,51,53,54,56,57,59] Approaches included a community presentation,[53] recruitment tables in a tribal primary care centre,[48] mail-out invites[57] and community flyers.[51,56,59] Research team recruitment was often enabled by prior researcher-community familiarity, such as longstanding research relationships[22,53,54] or community-based[7] or community-embedded researchers.[50] Eight articles (47%) reported recruitment assisted by community partners or affiliated organisations.[8,17,22,47,49,52,55,58] Three studies that recruited across multiple communities used a mixed, two-stage

Table 3 Characteristics of the 17 qualitative genomic studies with Indigenous populations

Author, year	Location	Topic	Population of focus (n)*	Recruitment	Data collection method(s)	Data analysis approach
Johnson *et al*,[49] 2009	USA; Oklahoma	Genetic research	Native Americans (48) and African Americans (25)	Community-facilitated	Focus groups	Content analysis
Hiratsuka *et al*,[8] 2012	USA; Alaska	Biobanking research	Alaska Natives (178)	Mixed; community-facilitated and research team	Focus groups	Not specified
West *et al*,[53] 2013	USA; Alaska	Genetics and heredity	Yup'ik Eskimos (26)	Research team	Focus group, semi-structured interviews and participant observation	Modified grounded theory
Shaw *et al*,[51] 2013	USA; Alaska	Pharmacogenetics	Alaska Natives (32)	Research team	Focus groups	Thematic analysis
Sahota,[50] 2014	USA; Southwestern USA	Biobanking and genetic research	Native Americans (53)	Research team	Semi-structured interviews and participant observation	Thematic analysis
Kwan *et al*,[17] 2014	USA; California	Biobanking research	Pacific Islanders (60)	Community-facilitated	Semi-structured interviews	Not specified
Taualii *et al*,[52] 2014	USA; Hawai'i	Biobanking research	Native Hawaiians (92)	Community-facilitated	Focus groups	Not specified
Abadie and Heaney,[47] 2015	USA; Minnesota	Biobanking research	Native Americans (16)	Community-facilitated	Semi-structured interviews	Not specified
Trinidad *et al*,[56] 2015	USA; Alaska	Genetic research	Yup'ik Alaska Natives (60)	Research team	Focus groups	Content analysis
Morgan *et al*,[59] 2019	Canada; British Columbia	Genomic data banking	Indigenous Canadians (30)	Research team	Focus groups	Thematic framework approach
Gonzalez *et al*,[58] 2019	Australia; New South Wales	Clinical genetics service	Aboriginal Elders (9) and health researchers† (7)	Community-facilitated	Semi-structured interviews, focus group and field notes	Thematic analysis
Hiratsuka *et al*,[48] 2020	USA; Alaska	Genetic research	American Indian and Alaska Natives (19)	Research team	Public deliberation	Cross-comparison content review
Reedy *et al*,[55] 2020	USA; Oklahoma	Biobanking and genetic research	Tribal citizens within Chickasaw Nation (16)	Community-facilitated	Public deliberation	Not specified
Dalach *et al*,[57] 2021	Australia	Clinical genetics service	Aboriginal and Torres Strait Islander people (63)	Research team	Semi-structured interviews	Thematic analysis
Hermes *et al*,[7] 2021	Australia	Biobanking research	Aboriginal people (42)	Research team	Semi-structured interviews	Thematic analysis

Continued

Table 3 Continued

Author, year	Location	Topic	Population of focus (n)*	Recruitment	Data collection method(s)	Data analysis approach
Blacksher *et al*,[54] 2022	USA; Alaska	Biobanking and precision medicine research	American Indian and Alaska Native Tribal leaders (10)	Research team	Public deliberation	Not specified
Caron *et al*,[22] 2023	Canada; British Columbia	Biobank development and genomic research	First Nations community members (46) and key informants‡ (32)	Mixed; community-facilitated and research team	Focus groups and semi-structured interviews	Interpretative phenomenological analysis

*The original terminology used to characterise each study population has been retained.
†Health researchers included Indigenous and non-Indigenous social science and genetics researchers working with Indigenous communities in Australia.
‡Key informants include elected Chiefs of northern BC First Nations, health directors, First Nations Council members or community health centre staff.

recruitment approach in which researchers identified potential communities followed by community staff conducting within-community recruitment.[8 22 55] Several studies described how community partners provided a necessary role in guiding recruitment of diverse and hard-to-reach participants.[17 22 55 58]

10 studies (59%) reported research team members having significant experience in qualitative research methods or receiving research training.[7 17 47 48 51 52 54–57] Data collection primarily included focus groups (n=9, 53%)[8 22 49 51–53 56 58 59] and semi-structured interviews (n=7, 53%).[7 17 22 47 50 53 57] Two articles (12%) incorporated both.[22 53] Three studies (18%) used public deliberation,[48 54 55] a large group-based discussion format. Two ethnographic studies (12%) complemented primary data collection with participant observation.[50 53] A variety of approaches to qualitative analysis were reported, including content analysis (n=3, 18%),[48 49 56] thematic analysis (n=6, 35%),[7 50 51 57–59] modified grounded theory (n=1, 6%)[53] and interpretative phenomenological analysis (n=1, 6%).[22]

Participatory practice

Table 4 summarises reporting of participatory practice. Practices are organised according to Claw *et al*[19] research framework principles to enhance genomic research with Indigenous communities. Principles include: (1) Indigenous sovereignty and research regulation, (2) community engagement and collaboration, (3) cultural safety, (4) research transparency, (5) community research capacity and (6) community-accessible dissemination.

Principle 1: understand Indigenous sovereignty and research regulation

Community-guided research review

14 articles (82%) reported community research review approval,[7 8 17 22 48 50–58] primarily through Indigenous community-partnered REBs. The majority of research (n=11, 65%) was conducted by Indigenous-governed research institutions or institutional partnerships. For example, several studies[8 48 51 54–56] involved researchers at the Southcentral Foundation, a tribally owned and operated non-profit healthcare organisation.[60] Non-REB, community-level review entities included tribal health organisations[8] and community governing councils.[22 50 53 54] Abadie and Heaney[47] described how unsuccessful attempts to obtain tribal approval to interview community Elders prompted the authors to work with Native Americans living off-reserve because tribal approvals were not required.

Principle 2: engage and collaborate with the Indigenous community

Community-engaged research approaches

CEnR approaches were prevalent (n=16, 94%),[7 8 17 22 48–59] and nine articles (53%) specifically referenced CBPR.[8 17 49–54 59] Hermes *et al*[7] reported a 3-year relationship and trust-building process with

Table 4 Reporting of community involvement and participatory practices, categorised by research principle

	Principle 1	Principle 2	Principle 3	Principle 4			Principle 5	Principle 6
Author, year	**Research review**	**Community-engaged research approach**	**Advisory council**	**Research question**	**Research materials**	**Data analysis**	**Hired local community members**	**Findings returned**
Johnson *et al*,[49] 2009	NR	Y; CBPR	Y	Y	Y	Y; MC	Y	NR
Hiratsuka *et al*,[8] 2012	Y; IGIP	Y; CBPR	Y	Y	Y	MC	Y	Y
West *et al*,[53] 2013	Y; IGIP	Y; CBPR	Y	Y	NR	MC	Y	Y
Shaw *et al*,[51] 2013	Y; IGIP	Y; CBPR	Y	Y	NR	NR	NR	NR
Sahota,[50] 2014	Y	Y; CBPR	Y	Y	Y	NR	NR	Y
Kwan *et al*,[17] 2014	Y; IGIP	Y; CBPR	Y	Y	Y	Y	Y	Y
Tauali'i *et al*,[52] 2014	Y; IGIP	Y; CBPR	Y	Y	Y	NR	Y	NR
Abadie and Heaney,[47] 2015	NR	NR	NR	NR	NR	NR	NR	NR
Trinidad *et al*,[56] 2015	Y; IGIP	Y	Y	Y	Y	Y	Y	NR
Morgan *et al*,[59] 2018	NR	Y; CBPR	NR	NR	NR	MC	NR	Y; DO
Gonzalez *et al*,[58] 2019	Y	Y	Y	Y	Y	MC	NR	NR
Hiratsuka *et al*,[48] 2020	Y; IGIP	Y	Y	Y	Y	MC	NR	Y; DO
Reedy *et al*,[55] 2020	Y; IGIP	Y	Y	Y	Y	NR	Y	NR
Dalach *et al*,[57] 2021	Y	Y	Y	NR	Y	Y; MC	Y	NR
Hermes *et al*,[7] 2021	Y; IGIP	Y	Y	Y	Y	Y; MC	NR	Y
Blacksher *et al*,[54] 2022	Y; IGIP	Y; CBPR	Y	Y	Y	MC	NR	Y
Caron *et al*,[22] 2023	Y; IGIP	Y	Y	Y	Y	NR	Y	Y

Participatory practices are organised according to adapted Claw *et al*[19] principles for ethical genomic research with Indigenous communities; Principle 1, understand Indigenous sovereignty and research regulation; Principle 2, engage and collaborate with the community; Principle 3, build cultural safety; Principle 4, improve transparency of research practices; Principle 5, build research capacity; Principle 6, disseminate findings in a community-accessible format.

CBPR, community-based participatory Research; DO, data ownership; IGIP, Indigenous-Governed Institution or Partnership; MC, member checking; NR, not reported or unclear; Y, yes.

community leaders and members. West *et al*[53] noted that authors spent years building community relationships and research collaborations prior to the introduction of the lead student researcher. Two studies (12%) described an ethnographic approach: Sahota[50] was embedded and engaged in community functions and tribal council meetings, whereas a cultural guide facilitated the research team's entrance into communities in Johnson *et al*.[49] Four studies (24%) held community information sessions to describe the research and build rapport.[22 53 54 58]

Articles also described engagement challenges. Hiratsuka *et al*[8] noted that 14 out of 25 Alaskan health organisations provided research approval after 18 months of outreach. Reasons for declining included a lack of tribal research approval process and scheduling challenges. Abadie and Heaney[47] explained that tribal administration rejected their research engagement request due to its genetics focus. Morgan *et al*[59] stated that planned engagement with community leaders was cancelled due to funder-imposed time constraints and seasonal travel concerns.

Principle 3: build cultural safety

Community advisory council

15 articles reported community advisory councils (88%),[7 8 17 22 48–58] spanning study-specific advisory councils,[49 57] community advisors[52] or existing community-based groups.[7 48 50] Dalach *et al*[57] collaborated with two advisory groups: a Project Reference Group of policymakers and academic and clinical experts, and an End-User Group, comprised of Aboriginal women who had accessed or worked in community health services. Trinidad *et al*[56] similarly established a Community Planning Group of Yupi'ik community members to guide the development of research methods, as well as a Ciuliat ('leaders' in Yup'ik) group of urban-living Yup'ik professionals and academics to act as bicultural liaisons between the Community Planning Group and research team. Gonzalez *et al*[58] described how an Aboriginal Elders group acted as both community advisors, aiding the creation of a culturally relevant topic guide and participants in an Elders-specific focus group.

Community-adapted data collection

Articles reported diverse discussion settings, including participant homes,[50 53] tribal health centres,[50 51] community agencies[52] and local churches.[49] Some participants preferred to be interviewed in pairs.[7 53] Gonzalez *et al*[58] held a focus group 'yarn' with an Aboriginal Elders group, an informal discussion held at the Elders' meeting place. The Elders group did not provide permission to record this discussion, so qualitative data collection and analysis relied on researcher field notes. Morgan *et al*[59] described focus group sharing circles in which an Elder facilitated discussion with a talking stick. The Elder opened the circle with a traditional greeting and prayer, introductions and sharing of food. Elders opened and closed research meetings in two other articles (12%).[22 54] Caron *et al*[22] also offered participants culturally relevant gifts, in addition to their honoraria. Blacksher *et al*[54] described community 'site-dialogues' as a form of culturally appropriate adaptation. Rather than sending out written pre-deliberation briefing materials, researchers travelled to each community to discuss the research with participants. These dialogues served as an opportunity for participants to learn about the research, ask questions and build trust with the researchers.

Age stratification appeared in four Alaska-based studies.[8 51 53 56] Hiratsuka *et al*[8] explained that community advisors identified that younger community members may feel reticent in front of community Elders. Therefore, focus groups were stratified by participant age, under and over the age of 40. West *et al*[53] aligned data collection and setting with cohort preferences. Younger participants were interviewed in English in a school office to ensure privacy, while Elders were interviewed in Yup'ik in their homes with their families. The opportunity to build rapport and familiarity in this informal setting offset concerns around confidentiality. Alternatively, during the public deliberation, Blacksher *et al*[54] stratified small group discussions on data governance by geographical region due to the relevance of region-specific governance and sovereignty issues.

Principle 4: improve transparency of research practices

Research question

14 articles (82%) referenced community involvement during research question development.[7 8 17 22 48–56 58] In several studies, research questions emerged from established community-researcher partnerships or as community-identified priorities. For example, a tribally managed biobank seeking to understand how Alaska Natives view the collection and use of biological samples,[8] or community needs assessments identifying genetic research as a salient issue.[49 52]

Sahota[50] conversely described a researcher-identified question that was then approved through community dialogue. The author proposed an ethnographic study to the tribal council, aiming to understand how tribal members have been impacted by their community's long history as research subjects. The council agreed these perspectives would be valuable and could be used to develop community-guided research regulations. Gonzalez *et al*[58] redesigned the research question following consultation with a community partner, shifting the focus toward promoting community well-being and including more direct community engagement. By contrast, Morgan *et al*[59] noted their research received criticism because the research question was initially identified by non-Indigenous medical genetics professionals and lacked engagement with Indigenous leaders external to the team.

Research materials

13 articles (73%) referenced community feedback on research materials.[7 8 17 22 48–50 52 54–58] Feedback primarily

centred on the qualitative topic guide. Hiratsuka *et al*[8] reported a 7-month co-development process, beginning with the research plan and extending to piloting the focus group discussion guide. In another case, 'community-based and placed' members of the research team internally consulted on discussion scenarios.[48]

The nature of community feedback was commonly unstated, though some examples were provided. Sahota[50] added a question on interviewees' self-identification as a 'traditional person' after pilot interviews. Kwan *et al*[17] incorporated a question regarding the cultural significance of biospecimen donations following community partners' advisement. In Caron *et al*,[22] community advisors recommended against including a quiz as part of the pre-focus and post-focus group self-rated biobanking knowledge assessment exercises. Including a quantitative assessment of knowledge was determined to be inappropriate within the historical context of harmful research on First Nations peoples and risked to undermine researcher-participant trust.

Data analysis

Five articles (29%) described community involvement in the design or process of preliminary data analysis.[7 17 49 56 57] These included the development of the coding framework[57] and ongoing meetings with the advisory council.[49] Kwan *et al*[17] and Trinidad *et al*[56] reported actively involving community partners to ensure meaningful interpretation of results. Hermes *et al*[7] described how the Aboriginal qualitative interviewer acted as a participant in a structured follow-up discussion with research team members. In addition to speaking about her cultural experiences and knowledge, she explained and clarified the participants' perspectives.

Nine articles (53%) included a member checking process.[7 8 48 49 53 54 57–59] Where reported, member checking was conducted by mail[48 49 54] or in person.[8 53 59] Johnson *et al*[49] described a 'data checking' process in which participants rated their agreement with researchers' interpretations. West *et al*[53] held member-check interviews with a community leader and community member research assistants. Morgan *et al*[59] held follow-up focus groups with participants to review a video describing genomic testing alongside participants' quotes and views for use as a community-accessible study output. Two articles (12%) noted that participants had the opportunity to review their transcript.[50 53] Sahota[50] additionally afforded interviewees the option to edit their transcript. In Gonzalez *et al*,[58] because the focus group was not audio recorded, the research team provided participants a synopsis of researchers' field notes for approval prior to data analysis.

Two studies (12%) reported member checking outcomes.[48 59] In Morgan *et al*,[59] participants suggested the video include a better explanation of current genomic reference databases. Similarly, Hiratsuka *et al*[48] noted that participants described the initial summary report of study findings as too complex.

Principle 5: build Indigenous research capacity

Hired local community members

Nine articles (53%) referenced hiring local community members.[8 17 22 49 52 53 55–57] Kwan *et al*[17] employed community partners across multiple community sites to conduct interviews and assist with data collection. Interviewers participated in a 1-day qualitative interview training session, and the research team created a complementary online training guide. Dalach *et al*[57] recruited local Aboriginal women as interviewers and provided training on interview techniques and supporting distressed participants. Hiratsuka *et al*[8] identified community-specific liaisons to facilitate within-community recruitment. Caron *et al*[22] described local community engagement coordinators purposefully recruiting participants who could be a 'voice' for the community.

Principle 6: dissemination of findings in a community-accessible format

Findings and data returned to communities

Nine articles (53%) described disseminating study findings to participants or communities.[7 8 17 22 48 50 53 54 59] Forms of return included community presentations,[8 17 53] newsletters,[7 8] a summary report[22 48 54] and a co-created summary video.[59] Kwan *et al*[17] described community partners presenting a poster at a national conference. Two studies (12%) shared a draft version of the manuscript for review prior to journal submission.[48 50]

Explicit statements of community data ownership appeared in two articles (12%).[48 59] Morgan *et al*[59] stated the final video deliverable was the equal property of study participants and researchers. Participants quoted in the video signed a second consent to approve their language and indicate if they would like to be identified. Hiratsuka *et al*[48] included a data availability statement recognising tribal sovereign authority and data ownership. Suggestive of community control of data, if not ownership, two articles (12%) described seeking community approval prior to publication.[8 53] Dalach *et al*[57] referenced privileging Aboriginal and Torres Strait Islander perspectives in the governance and analytical approach of the research, though study data governance was not specifically described. Similarly, Caron *et al*[22] stated that the First Nations principles of OCAP[30] guided study ethics and protocols.

DISCUSSION

This scoping review characterises the nature and reporting of qualitative and participatory practice in genomic research with Indigenous communities. Examples of participatory practices facilitating community research review, community engagement and culturally safe and community-guided research development were frequently reported across diverse settings. Articles included fewer practices as studies progressed; collaborative data analysis, hiring local community members and community-accessible dissemination were less common, suggesting opportunities for increased engagement or reporting across the research lifecycle. The diversity of participatory approaches identified across this review underscores the adaptive nature of community-partnered research. Our study adds to the emerging literature reviewing participatory approaches among health research with Indigenous peoples. Previous reviews have characterised research among Inuit communities,[61] Indigenous children,[62] Indigenous communities in Atlantic Canada,[63] American Indian and Alaska Native peoples[26] and articles on primary healthcare use by Indigenous peoples.[64] This is the first study examining qualitative genomic research.

Community-guided research review is foundational to participatory research with Indigenous peoples,[19] affording research sovereignty and relationship building.[39 40] In some cases, for example, among urban-living individuals,[26] it can be difficult to define 'community' or identify a representative review entity.[41] The three included articles that did not report a community review process involved urban-living participants. The absence of a clear review entity may contribute to fewer studies with urban-living Indigenous people, highlighting how a prescriptive conceptualisation of research guidelines can marginalise populations that are judged too challenging to work with.[26] Community-partnered research must be inclusive and thus adaptive to ensure under-represented populations are not further marginalised.[65]

Community engagement enables participatory research practice, and CEnR-aligned approaches were prevalent among the included studies. This is reflected among other reviews of research with Indigenous peoples,[26 62] though reviews also identify common examples of articles purporting CEnR or CBPR approaches without clear descriptions of how engagement occurred.[62 63] CEnR principles alone also do not meet the breadth of historical, cultural or political considerations inherent to research with Indigenous communities.[26] Culturally safe research requires an understanding of the historical and ongoing colonisation experienced by Indigenous peoples and supports the preservation and integration of Indigenous culture and knowledge.[35 37] Responsibility for cultural safety rests foremost on researchers. Prior to engagement, researchers should learn about local and historical community context, pursue cultural safety training and reflect on how cultural safety informs both researcher-participant interactions and overarching research processes.[35 37] Community partners may then guide the development of culturally safe research methods.[41] Safely integrating culture into research improves its rigour, increases participation rates and enhances translational outcomes for community partners.[43]

Participatory research development is inherently a transparent process in which community strengths, knowledge and capacities shape research questions, materials and methods.[35 45] The majority of reviewed articles reported community-collaborated research questions, a finding that diverges from some other reviews of Indigenous health research studies.[62] Early discussion of anticipated research benefits is particularly relevant for genomic research that often does not realise immediate health benefits.[19] By contrast, participatory data analysis was less common. Community feedback was primarily elicited through post-analysis member checking. Previous reviews of health research conducted through group-based qualitative methods with Indigenous children[62] and among Indigenous communities in Atlantic Canada[63] similarly identified few examples of community-involved data analysis. Qualitative data analysis can be a time-consuming and laborious process, especially when collaboratively adapting Western analytical approaches to Indigenous ways of knowing.[66] Little attention is often paid to participatory co-analysis processes, but applications have been described across several settings and research populations.[67–69] Researchers are encouraged to explore collaborative opportunities with community partners that ameliorate the burdens of analysis while ensuring its cultural congruence.[9]

We found mixed reporting on community-accessible dissemination and the nature of community feedback. Dissemination is a documented challenge for community-partnered research projects generally,[70] and reviews of health research with Indigenous peoples identify insufficient reporting on both data governance and knowledge translation.[63 64 71] In notable contrast, a review of participatory action research with Inuit societies found all studies reported Inuit participation in knowledge transfer.[61] Codifying principles of Indigenous data governance at the project outset can resolve dissemination-related tensions by enabling community access and ownership throughout the data lifecycle.[4] In several included studies, it was unclear if or how community feedback tangibly informed the research. Previous reviews of Indigenous-partnered and community-partnered research studies have similarly highlighted varied degrees of reporting transparency around community involvement across all study aspects.[26 63 64 72] Reporting the influence of community feedback holds researchers accountable and ensures community partners' time and knowledge are not solicited as simply a 'checkbox' step.[9]

This review should be interpreted in light of its limitations. Characterisation of participatory practices relied on author interpretation and mapping to an existing research framework. Dependence on abstracted article text meant we were unable to include research characteristics or activities that were not explicitly reported, for example, research dissemination or translational efforts that often occur post-publication. This additionally limited the depth of some practices. For example, though increasing the representation and visibility of Indigenous researchers is a key facilitator and outcome of building research capacity, we deemed it inappropriate to assess authors' Indigenous identity. Further, studies were restricted to English-language articles that were conducted in Canada, the USA, Australia or New Zealand. This decision was informed by our intention to provide a clear and structured overview of participatory practices that seek to align with research guidelines and considerations toward Indigenous self-determination in research that exist in response to shared histories of colonialism and exploitative research, such as the Claw *et al*[19] framework. Studies with Indigenous peoples in other countries may identify alternative research priorities.[73–75] This review is not an exhaustive account of the participatory or qualitative approaches relevant to genomic research studies with Indigenous populations globally. As well, the ethical framework structuring this review focused on Indigenous groups in the USA. While broad and adaptable, this framework may not be appropriate for all Indigenous communities or research projects.

CONCLUSION

Sustainably addressing the under-representation of Indigenous peoples in genomic research and resources demands collaborative and responsible research practice. This review is for researchers aiming to meet this need. Our findings describe the scope of participatory practice among qualitative genomic research with Indigenous communities through applied examples of how research principles manifest in real-world settings. Participatory approaches promoting community research regulation and co-development were frequently and diversely reported, though opportunities exist for increased collaboration across the research lifecycle and reporting on community feedback. This is particularly relevant to partnerships with Indigenous communities, whose rights to self-determination have been ignored or violated by past genomic research projects. This trust can only be rebuilt through appropriate and accountable research practice grounded in community voices and values. In this way, applying participatory practice and rigorous reporting standards to qualitative genomic research with Indigenous peoples may help close the genomic divide.

Acknowledgements The authors wish to thank Dr Laura Arbour for her valuable feedback on the development and reporting of this research.

Contributors Conceptualisation: ME, NRC, LM and DAR. Methodology: ME, NRC, LM and DAR. Data curation: ME and LM. Formal analysis: ME and LM. Writing—original draft: ME, NRC, LM and DAR. Writing—review and editing: ME, NRC, LM and DAR. Guarantor: DAR.

Funding This research was conducted as part of the Silent Genomes project and supported by Genome British Columbia/Genome Canada (G02696).

Disclaimer The funders of this study has no role in its design or the content of this article.

Competing interests DAR has received travel funding from Illumina; his institution has received research funding for a project from Roche. ME, NRC and LM have no conflicts of interest to disclose.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval Ethical approval was not sought because this was a secondary analysis of published data. No human or animal participants were involved in this review.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplementary information. The published article includes all data generated or analysed during this study.

ORCID iD

Morgan Ehman http://orcid.org/0000-0002-0343-7115

REFERENCES

1 Clark MM, Stark Z, Farnaes L, *et al*. Meta-analysis of the diagnostic and clinical utility of genome and exome sequencing and chromosomal microarray in children with suspected genetic diseases. *NPJ Genom Med* 2018;3:16.
2 D'Angelo CS, Hermes A, McMaster CR, *et al*. Barriers and Considerations for Diagnosing Rare Diseases in Indigenous Populations. *Front Pediatr* 2020;8:579924.
3 Hudson M, Garrison NA, Sterling R, *et al*. Rights, interests and expectations: Indigenous perspectives on unrestricted access to genomic data. *Nat Rev Genet* 2020;21:377–84.
4 Garrison NA, Hudson M, Ballantyne LL, *et al*. Genomic Research Through an Indigenous Lens: Understanding the Expectations. *Annu Rev Genomics Hum Genet* 2019;20:495–517.
5 Caron NR, Chongo M, Hudson M, *et al*. Indigenous Genomic Databases: Pragmatic Considerations and Cultural Contexts. *Front Public Health* 2020;8:111.
6 Beaton A, Hudson M, Milne M, *et al*. Engaging Māori in biobanking and genomic research: a model for biobanks to guide culturally informed governance, operational, and community engagement activities. *Genet Med* 2017;19:345–51.
7 Hermes A, Wiersma M, Kerridge I, *et al*. Beyond platitudes: a qualitative study of Australian Aboriginal people's perspectives on biobanking. *Intern Med J* 2021;51:1426–32.
8 Hiratsuka V, Brown J, Dillard D. Views of biobanking research among Alaska native people: the role of community context. *Prog Community Health Partnersh* 2012;6:131–9.
9 Wright A, Wahoush O, Ballantyne M, *et al*. Qualitative Health Research Involving Indigenous Peoples: Culturally Appropriate Data Collection Methods. *TQR* 2016;21:2230–45.
10 Sallee MW, Flood JT. Using Qualitative Research to Bridge Research, Policy, and Practice. *Theory Pract* 2012;51:137–44.
11 Hyett SL, Gabel C, Marjerrison S, *et al*. Deficit-Based Indigenous Health Research and the Stereotyping of Indigenous Peoples. *Can J Bioeth Rev Can Bioéthique* 2019;2:102–9.
12 Hyett S, Marjerrison S, Gabel C. Improving health research among Indigenous Peoples in Canada. *CMAJ* 2018;190:E616–21.
13 Browne AJ. Discourses influencing nurses' perceptions of First Nations patients. *Can J Nurs Res* 2005;37:62–87.
14 Nelkin D. A brief history of the political work of genetics. *Jurimetrics* 2002;42:121–32.
15 Garrison NA. Genomic Justice for Native Americans: Impact of the Havasupai Case on Genetic Research. *Sci Technol Human Values* 2013;38:201–23.
16 TallBear K. Genomic articulations of indigeneity. *Soc Stud Sci* 2013;43:509–33.
17 Kwan PP, Briand G, Lee C, *et al*. Use of a community-based participatory research approach to assess knowledge, attitudes, and beliefs on biospecimen research among Pacific Islanders. *Health Promot Pract* 2014;15:422–30.
18 Hayward A, Sjoblom E, Sinclair S, *et al*. A New Era of Indigenous Research: Community-based Indigenous Research Ethics Protocols in Canada. *J Empir Res Hum Res Ethics* 2021;16:403–17.

19 Claw KG, Anderson MZ, Begay RL, *et al*. A framework for enhancing ethical genomic research with Indigenous communities. *Nat Commun* 2018;9:2957.
20 Morton Ninomiya ME, Pollock NJ. Reconciling community-based Indigenous research and academic practices: Knowing principles is not always enough. *Soc Sci Med* 2017;172:28–36.
21 Lavallée LF. Practical Application of an Indigenous Research Framework and Two Qualitative Indigenous Research Methods: Sharing Circles and Anishnaabe Symbol-Based Reflection. *Int J Qual Methods* 2009;8:21–40.
22 Caron NR, Adam W, Anderson K, *et al*. Partnering with First Nations in Northern British Columbia Canada to Reduce Inequity in Access to Genomic Research. *Int J Environ Res Public Health* 2023;20:5783.
23 Blanchard JW, Tallbull G, Wolpert C, *et al*. Barriers and Strategies Related to Qualitative Research on Genetic Ancestry Testing in Indigenous Communities. *J Empir Res Hum Res Ethics* 2017;12:169–79.
24 Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8:19–32.
25 Key KD, Furr-Holden D, Lewis EY, *et al*. The Continuum of Community Engagement in Research: A Roadmap for Understanding and Assessing Progress. *Prog Community Health Partnersh* 2019;13:427–34.
26 Beans JA, Saunkeah B, Woodbury RB, *et al*. Community Protections in American Indian and Alaska Native Participatory Research—A Scoping Review. *Soc Sci (Basel)* 2019;8:127.
27 Fisher PA, Ball TJ. Tribal participatory research: mechanisms of a collaborative model. *Am J Community Psychol* 2003;32:207–16.
28 Rasmus SM. Indigenizing CBPR: evaluation of a community-based and participatory research process implementation of the Elluam Tungiinun (towards wellness) program in Alaska. *Am J Community Psychol* 2014;54:170–9.
29 Provincial Health Services Authority. San'yas anti-racism Indigenous cultural safety training program. 2024 Available: https://sanyas.ca
30 First Nations Information Governance Centre. The First Nations Principles of OCAP. 2023. Available: https://fnigc.ca/ocap-training [Accessed 10 Oct 2023].
31 Tricco AC, Lillie E, Zarin W, *et al*. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med* 2018;169:467–73.
32 Jamshed S. Qualitative research method-interviewing and observation. *J Basic Clin Pharm* 2014;5:87–8.
33 Rothe JP, Ozegovic D, Carroll LJ. Innovation in qualitative interviews: "Sharing Circles" in a First Nations community. *Inj Prev* 2009;15:334–40.
34 Kennedy M, Maddox R, Booth K, *et al*. Decolonising qualitative research with respectful, reciprocal, and responsible research practice: a narrative review of the application of Yarning method in qualitative Aboriginal and Torres Strait Islander health research. *Int J Equity Health* 2022;21:134.
35 Lin CY, Loyola-Sanchez A, Boyling E, *et al*. Community engagement approaches for Indigenous health research: recommendations based on an integrative review. *BMJ Open* 2020;10:e039736.
36 Huria T, Palmer SC, Pitama S, *et al*. Consolidated criteria for strengthening reporting of health research involving indigenous peoples: the CONSIDER statement. *BMC Med Res Methodol* 2019;19:173.
37 Curtis E, Jones R, Tipene-Leach D, *et al*. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *Int J Equity Health* 2019;18:174.
38 United Nations. United Nations Declaration on the Rights of Indigenous Peoples (a/res/61/295). 2007.
39 Schnarch B. Ownership, control, access, and possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities. *Int J Indig Health* 2004;1:80–95.
40 Oetzel JG, Villegas M, Zenone H, *et al*. Enhancing stewardship of community-engaged research through governance. *Am J Public Health* 2015;105:1161–7.
41 Tobias JK, Richmond CAM, Luginaah I. Community-based participatory research (CBPR) with indigenous communities: producing respectful and reciprocal research. *J Empir Res Hum Res Ethics* 2013;8:129–40.
42 Yuan NP, Mayer BM, Joshweseoma L, *et al*. Development of Guidelines to Improve the Effectiveness of Community Advisory Boards in Health Research. *Prog Community Health Partnersh* 2020;14:259–69.
43 Minkler M. Community-based research partnerships: challenges and opportunities. *J Urban Health* 2005;82:ii3–12.
44 Tracy SJ. Qualitative Quality: Eight "Big-Tent" Criteria for Excellent Qualitative Research. *Qual Inq* 2010;16:837–51.
45 Kyoon-Achan G, Lavoie J, Avery Kinew K, *et al*. Innovating for Transformation in First Nations Health Using Community-Based Participatory Research. *Qual Health Res* 2018;28:1036–49.
46 Page MJ, McKenzie JE, Bossuyt PM, *et al*. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:71.
47 Abadie R, Heaney K. "We can wipe an entire culture": fears and promises of DNA biobanking among Native Americans. *Dialect Anthropol* 2015;39:305–20.
48 Hiratsuka VY, Beans JA, Blanchard JW, *et al*. An Alaska Native community's views on genetic research, testing, and return of results: Results from a public deliberation. *PLoS One* 2020;15:e0229540.
49 Johnson VA, Edwards KA, Sherman SL, *et al*. Decisions to participate in fragile X and other genomics-related research. *Nat Am & Afr Am voices J Cult Divers* 2009;16:127–35.
50 Sahota PC. Body Fragmentation: Native American Community Members' Views on Specimen Disposition in Biomedical/Genetics Research. *AJOB Empir Bioeth* 2014;5:19–30.
51 Shaw JL, Robinson R, Starks H, *et al*. Risk, reward, and the double-edged sword: perspectives on pharmacogenetic research and clinical testing among Alaska Native people. *Am J Public Health* 2013;103:2220–5.
52 Taualii M, Davis EL, Braun KL, *et al*. Native Hawaiian views on biobanking. *J Cancer Educ* 2014;29:570–6.
53 West KM, Hopkins SE, Hopper KJ, *et al*. Found in translation: Decoding local understandings of genetics and heredity in a Yup'ik Eskimo community. *Public Underst Sci* 2013;22:80–90.
54 Blacksher E, Trinidad SB, Woodbury RB, *et al*. Tribal Deliberations about Precision Medicine Research: Addressing Diversity and Inequity in Democratic Deliberation Design and Evaluation. *J Empir Res Hum Res Ethics* 2022;17:304–16.
55 Reedy J, Blanchard JW, Lund J, *et al*. Deliberations About Genomic Research and Biobanks With Citizens of the Chickasaw Nation. *Front Genet* 2020;11:466.
56 Trinidad SB, Ludman EJ, Hopkins S, *et al*. Community dissemination and genetic research: moving beyond results reporting. *Am J Med Genet* 2015;167:1542–50.
57 Dalach P, Savarirayan R, Baynam G, *et al*. This is my boy's health! Talk straight to me!" perspectives on accessible and culturally safe care among Aboriginal and Torres Strait Islander patients of clinical genetics services. *Int J Equity Health* 2021;20:103.
58 Gonzalez T, Harris R, Williams R, *et al*. Exploring the barriers preventing Indigenous Australians from accessing cancer genetic counseling. *J Genet Couns* 2020;29:542–52.
59 Morgan J, Coe RR, Lesueur R, *et al*. Indigenous peoples and genomics: starting a conversation. *J Genet Couns* 2019;28:407–18.
60 Hiratsuka VY, Beans JA, Robinson RF, *et al*. Self-determination in health research: an Alaska Native example of tribal ownership and research regulation. *Int J Environ Res Public Health* 2017;14.
61 Hervé C, Laneuville P, Lapointe L. Participatory action research with Inuit societies: A scoping review. *Polar Rec* 2023;59:e22.
62 Hunt SC, Young NL. Blending Indigenous Sharing Circle and Western Focus Group Methodologies for the Study of Indigenous Children's Health: A Systematic Review. *Int J Qual Methods* 2021;20:160940692110151.
63 Murphy K, Branje K, White T, *et al*. Are we walking the talk of participatory Indigenous health research? A scoping review of the literature in Atlantic Canada. *PLoS One* 2021;16:e0255265.
64 Hiyare-Hewage A, Sinka V, Grande ED, *et al*. The cultural safety of research reports on primary healthcare use by Indigenous Peoples: a systematic review. *BMC Health Serv Res* 2024;24:873.
65 McCracken J. Ethics as Obligation: Reconciling Diverging Research Practices With Marginalized Communities. *Int J Qual Methods* 2020;19:160940692096433.
66 Simonds VW, Christopher S. Adapting Western research methods to Indigenous ways of knowing. *Am J Public Health* 2013;103:2185–92.
67 Brewer KM, Harwood MLN, McCann CM, *et al*. The Use of Interpretive Description Within Kaupapa Māori Research. *Qual Health Res* 2014;24:1287–97.
68 Clarke CL, Wilkinson H, Watson J, *et al*. A Seat Around the Table: Participatory Data Analysis With People Living With Dementia. *Qual Health Res* 2018;28:1421–33.
69 Flicker S, Nixon SA. The DEPICT model for participatory qualitative health promotion research analysis piloted in Canada, Zambia and South Africa. *Health Promot Int* 2014;30:616–24.
70 Chen PG, Diaz N, Lucas G, *et al*. Dissemination of results in community-based participatory research. *Am J Prev Med* 2010;39:372–8.

71 Morton Ninomiya ME, Maddox R, Brascoupé S, *et al*. Knowledge translation approaches and practices in Indigenous health research: A systematic review. *Social Science & Medicine* 2022;301:114898.
72 Dadich A, Moore L, Eapen V. What does it mean to conduct participatory research with Indigenous peoples? A lexical review. *BMC Public Health* 2019;19:1388.
73 Ogunrin O, Gabbay M, Woolfall K, *et al*. Community engagement in genomic research: Proposing a strategic model for effective participation of indigenous communities. *Dev World Bioeth* 2022;22:189–202.
74 Taiwo RO, Ipadeola J, Yusuf T, *et al*. Qualitative study of comprehension of heritability in genomics studies among the Yoruba in Nigeria. *BMC Med Ethics* 2020;21:124.
75 Ortiz-Prado E, Simbaña-Rivera K, Gómez-Barreno L, *et al*. Potential research ethics violations against an indigenous tribe in Ecuador: a mixed methods approach. *BMC Med Ethics* 2020;21:100.