Ramkumar *et al. International Journal for Equity in Health* (2025) 24:90
https://doi.org/10.1186/s12939-025-02458-7

International Journal for Equity
in Health

RESEARCH **Open Access**

Priorities and expectations of researchers, funders, patients and the public regarding equity in medical research and funding: results from the PERSPECT qualitative study

Raksha Ramkumar[1], William R. Betzner[1], Nora Cristall[1], Bogna A. Drozdowska[1], Joachim Fladt[2], Tanaporn Jaroenngarmsamer[3], Rosalie McDonough[2], Mayank Goyal[1,2,4] and Aravind Ganesh[1*]

Abstract

Background Considerations of equity in funding and conduct of medical research are receiving greater attention. However, perspectives of diverse stakeholder groups on this topic are poorly characterized. Our study aimed to further understand broad stakeholder perspectives and priorities regarding inequities in medical research and funding, including implications for international collaborations with low-and middle-income countries (LMICs).

Methods Participants were recruited through purposive and snowball sampling. We employed a qualitative descriptive methodology embedded in an interpretive grounded theory framework. This approach involved in-depth, semi-structured interviews with researchers, funders, patients, and members of the public. Participants were asked to discuss their perspectives on the current state of equity in medical research and funding. Collected data were analyzed using constant comparison, open-coding, and theme identification to generate a substantive theory.

Results We conducted 41 interviews involving 11 researchers, 10 funders, 10 patients, and 10 members of the public. Participants perceived several inequities within research participation, funding opportunities, topic prioritization, and lack of international collaborations inclusive of LMICs. Potential strategies to address these inequities were also identified. Through participants' perspectives, we developed a central theory that addressing inequities in medical research and funding can promote collaborative spaces and produce greater research impact for society, regardless of demographics, socioeconomic status, and geographical residence. While we gained diverse perspectives from four distinct stakeholder groups, our primary limitation was that participants in our study were predominantly from Canada and the United States.

Conclusions Participants perceived various inequities in the funding and conduct of medical research. Our findings were primarily captured from participants living in Canada and the United States. However, we were able to gain insights of challenges and potential solutions through their diverse perspectives, and we are optimistic that sustaining

*Correspondence:
Aravind Ganesh
aganesh@ucalgary.ca

Full list of author information is available at the end of the article

efforts to mitigate medical research and funding inequities will help accelerate and broaden the societal impact of medical research within and across countries, including in LMICs.

Keywords Equity, Medical research, Funding, Collaboration, Perspectives, Patients, Public, Qualitative

Background

Equity in medical research is a continuously growing area of importance. With equity, diversity, and inclusion being prominent principles in modern workforces and communities, these principles also apply to medicine and healthcare, where representation of various races, ethnicities, genders, and health issues is essential [1, 2]. Failing to integrate such principles can lead to harmful and regressive consequences, especially in marginalized communities and regions with greater socioeconomic deprivation [3]. These consequences include disparities in health outcomes as well as disconnection from and mistrust of medical research and academia [3, 4]. It is also important to recognize that inequities in medical research exist in both high-income countries (HICs) and low-and middle-income countries (LMICs) [5]. Inequities in LMICs are exacerbated by factors such as resource constraints, systemic issues, and limitations in research infrastructure [6]. Therefore, given its rather global nature, addressing research inequity requires collective effort to support one another and foster a more inclusive and equitable research landscape.

To effectively address inequities in medical research, it is essential to gain deeper insights into current disparities by integrating diverse perspectives and voices as part of a democratic approach to these issues [7]. In this regard, there is a paucity of data on how key stakeholders– including researchers, funders, patients, and the general public– perceive inequities in medical research. Understanding these perspectives is crucial to guide policies and practices that best reflect stakeholder priorities and are therefore more likely to achieve successful adoption [8, 9]. Including members of the general public in this discussion is particularly crucial to maintain trust in the medical research establishment, whilst also acknowledging that the public as taxpayers fund the majority of medical research conducted worldwide.

To better understand stakeholders' perceptions of key challenges of equity in the medical research landscape, we conducted a qualitative study of researchers, funders, patients, and the public, looking at medical research; that is, research involving patients or their data, as well as Canadian and American funding contexts. Our study took a broad approach with respect to equity in both global and within-country considerations.

Methods

Design

The PERSPECT (Priorities and Expectations of Researchers, Donors, Patients, and the Public Regarding the Funding and Conduct of Medical Research) qualitative study employed a qualitative descriptive methodology within an interpretive grounded theory [10, 11]. We used the Corbin and Strauss (2015) approach, which provides a step-by-step guide of the qualitative research process. Through this approach, we used an iterative process during data collection and analysis through constant comparison, open coding, axial coding, and selective coding to develop a substantive theory [12]. This allowed us to explore stakeholder perspectives on equity in medical research and funding, while allowing for the surfacing of themes that extended past predefined categories. We referenced available literature within this area to substantiate identified themes [12, 13].

Participants

Stakeholders included (a) *Researchers*– individuals involved in medical research design and implementation and who contributed to at least one research grant or award application; (b) *Funders* - philanthropists contributing to medical or research initiatives or individuals serving on boards of research funding bodies; (c) *Patients*– individuals who self-identified as having a disease; and (d) *Members of the Public*– those who did not fit criteria within the other three stakeholder groups. A minimum of ten participants– 18 years or older– were interviewed from each stakeholder group.

Participant recruitment began with stakeholders affiliated with our research network, including [i.] American and Canadian medical researchers [ii.], representatives from governing boards of national/regional medical research funding organizations [iii.], volunteers from the Alberta Patient Engagement Platform and patient advisory groups, and [iv.] non-medical/non-research-affiliated individuals recommended by those in the first three groups as representatives of the public. Other participants were recruited through the University of Calgary's public research participation page (for the third and fourth groups), and through purposive and snowball sampling techniques [14]. Some researcher group participants had a pre-existing acquaintance with the interviewers.

Patient and public involvement

Interview guide questions were developed with individuals not routinely involved in medical research, to ensure that questions remained accessible to patients and members of the public who were expected to constitute half the study participants. A lay language version of the study proposal was initially posted on Let's Get Proof, an online public engagement platform for medical research to solicit comments, which informed our decision to focus on comparable Western countries with heavy public investment in medical research in the interest of study feasibility and to develop meaningful conclusions. Since then, a working group on Let's Get Proof has been created for those interested in updates on the project to join, and to allow for further discussion and collaboration [15].

Data collection

Participants were approached by email and those who were interested signed a consent form electronically. We conducted a series of in-depth semi-structured interviews where participants were asked about their perceptions of equity in medical research and funding (please refer to Appendix 1 for the interview guide). Interviews were held from 05/01/2022 to 15/07/2023 virtually through Zoom® and were conducted by members of the research team who were trained for qualitative interviewing. The interview team consisted of three women and two men. Interviews were scheduled for 60 min while allowing for participants to extend or shorten the length at interviewers' discretion and were monitored by an additional research associate when possible. Audio recordings were captured from interviews and subsequently transcribed.

Data analysis

We implemented constant comparison and open-coding of our data. We re-read interview transcripts, open-coded sentences that captured vital concepts, and sorted codes into themes and subthemes/domains on NVivo 12 software, version 12.6.1 (please refer to Appendix 2 - Figure S1 for the coding tree). While coding transcripts, we noted memos of thoughts about the interviewee's opinions. Six study team members conducted coding and theme development until a consensus was reached. Code saturation occurred when five or more consecutive interviews did not generate new important themes [16].

Next, we developed code definitions to ensure understanding and support rigor. We then implemented axial coding by condensing data into descriptive patterns, themes, and subthemes/domains [13]. Following this, selective coding was conducted through the interpretive grounded theory framework [17]. We organized key topics that captured multiple perspectives and priorities to formulate a substantive theory [17]. We synthesized our theory by exploring the nodes articulating specific themes across cases and then between groups. Our study followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist (Appendix 3) [18]. Figure 1 shows a graphic depiction of the interpretive grounded theory we followed.

Results

Fifty-one individuals were approached for participation in the study. Five participants did not respond, and five declined, giving a total of 41 participants. One withdrew their interview data, and one participant's interview was re-conducted due to a recording malfunction and the interviewee wanted to include their perspectives in the study. Table 1 displays a breakdown of the study participants.

We identified an overarching theme labelled as "Addressing Inequities in Medical Research". Through analyzing stakeholder perspectives, our central theory proposed that addressing inequities in medical research and funding can lead to more extensive research impact for society, regardless of demographics, socioeconomic status, and geographical residence. We outlined our overarching theme, domains of inequities, and theory in Fig. 2. We also provided a summary of identified domains of inequities in Table 2.

For a more thorough understanding, we categorized identified inequities into the following domains: research participation/engagement, research funding, research topic prioritization, and international collaborations with emphasis on low-and middle-income countries (LMICs). A coding matrix is provided in Fig. 3 to display the densities of references to these domains of inequities among all four stakeholder groups. Additionally, an exemplar table with an expanded collection of quotes is provided in Appendix 4.

Research participation/engagement

Participants perceived that the lack of current representation of various social and demographic factors including language, race, and culture played a large role with further hindering individuals from participating in research studies.

> *"As an immigrant, my parents never learned to speak English, for example, I know that lots of research will exclude people who don't speak English. Or if that's if it's being done in a country where English is the dominant language, then you just exclude these people. And I think that's unfortunate. I think it limits the findings. So wherever possible, I do think that the effort needs to be made. And part of it is by including groups that serve these popula-*

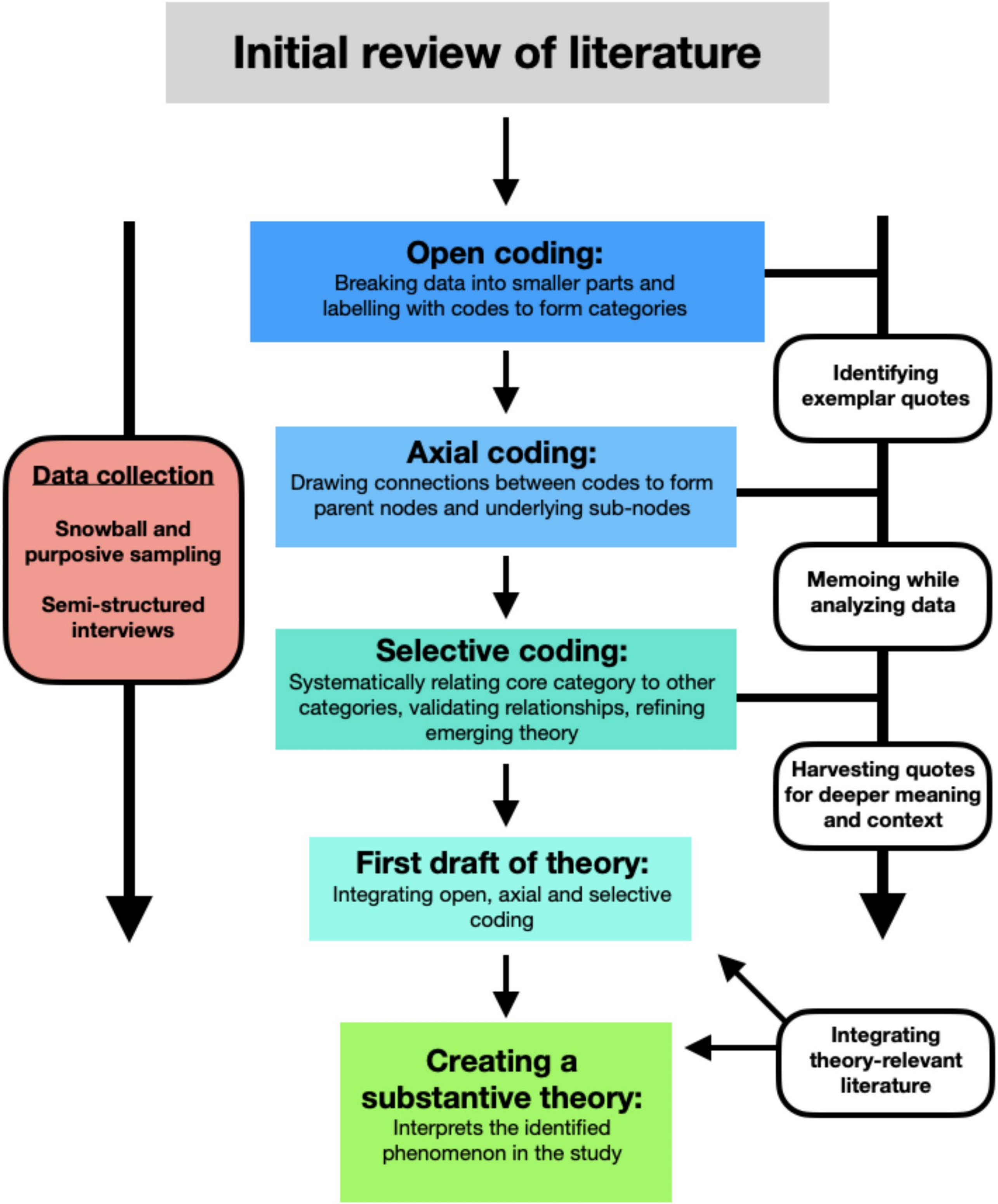

Fig. 1 Graphic depiction of interpretive grounded theory based on the Corbin & Strauss (2015) methodology

Table 1 Participant characteristics ($N=41$: 11 researchers, 10 funders, 10 patients and 10 members of the public)

Age range (*N*, %)	
18–34	11 (26.83)
35–64	26 (63.41)
65+	4 (9.76)
Sex (*N*, %)	
Female	25 (60.98)
Male	16 (39.02)
Race (*N*, %)	
Others, non-White	10 (24.39)
White	31 (75.61)
Region (*N*, %)	
Canada	26 (63.41)
USA	11 (26.82)
Other	4 (9.76)
Expertise (*N*, %)	
Fund Administrator	4 (9.76)
Philanthropist	6 (14.63)
Member of the public	11 (26.82)
Patient	10 (24.39)
Researcher	10 (24.39)

> *tions, including them in any research efforts."– Member of the public 409.*
> *"It's getting increasingly challenging for proper enrollment into clinical trials. And so often times, that leads to very skewed patient backgrounds from, different, you know, cultural groups, different ethnicities, things like that."– Funder 207.*

Participants also noted that in high-income countries (HICs), participant representation tended to skew towards the majority racial or ethnic group, suggesting that unless efforts were made to enrich patient samples with minority racial or ethnic groups, data for these groups would remain sparse.

> *"In the United States for example, I don't know the exact numbers, but I think it's like 50% of the population is White and 12% of the population is non-White. If you randomly select people for clinical trials, you're going to have lower statistical power for smaller proportion of the population, which means that medical researchers would need to make proactive efforts to ensure that they have sufficient representation from groups with a smaller proportion of the population."– Member of the public 403.*

Participants also perceived that differences in socioeconomic status contributed to inequity in medical research. For instance, a member of the public identified various barriers that those from marginalized socioeconomic backgrounds faced to participate in research, and a patient highlighted the importance of acknowledging the often vastly different experiences of disease and care of patients from socioeconomically marginalized groups when including them in medical research.

> *"[Medical research is] totally inaccessible to people with language barriers, technological barriers, like we've got people out on the street trying to get people who are in a relationship with their substance use to get their opinion and fill it out. They don't have the technology to do it." - Member of the public 410.*
> *"In our students' study, we had one person who lived on the street and slept at the shelters. […] When we wrote up our study, we wrote that person up as a separate piece in the study because their experience of living with [disease] was so different than the rest of [our participants]. I think in terms of socioeconomic culture, or different orientations, I think equity is a huge issue."– Patient [Research Partner] 307.*

Research funding

Participants perceived several inequities in funding that impacted medical research. Some felt that funding opportunities were especially more accessible to prominent institutions and investigators, regardless of the quality of the proposed research.

> *"There's a bit of a tendency for more senior investigators to get funding, that the rich get richer and new investigators have trouble getting a foothold, when they're held to the exact same standard." - Researcher 101.*
> *"If you are a Harvard graduate and you work at a Harvard institution, those institutions don't really have to do a whole lot to get funding. I think in the grand scheme of things, their finance issues are far fewer with those kinds of institutions and the people who are financing them are kind of well embedded in the system."– Member of the public 407.*

Some participants perceived that there were nuances involved in seeking to maximize research impact by investing in researchers and institutions that had in some sense proved their mettle. Nevertheless, they also recognized how this might prevent important research focus on less studied areas, novel ideas, and types of enquiries from less well-established researchers or institutions.

> *"There is not an equal playing field, and I understand that because there's only so many dollars, and they want them to have the biggest impact on people and research. So, in that regard, I think that what's*

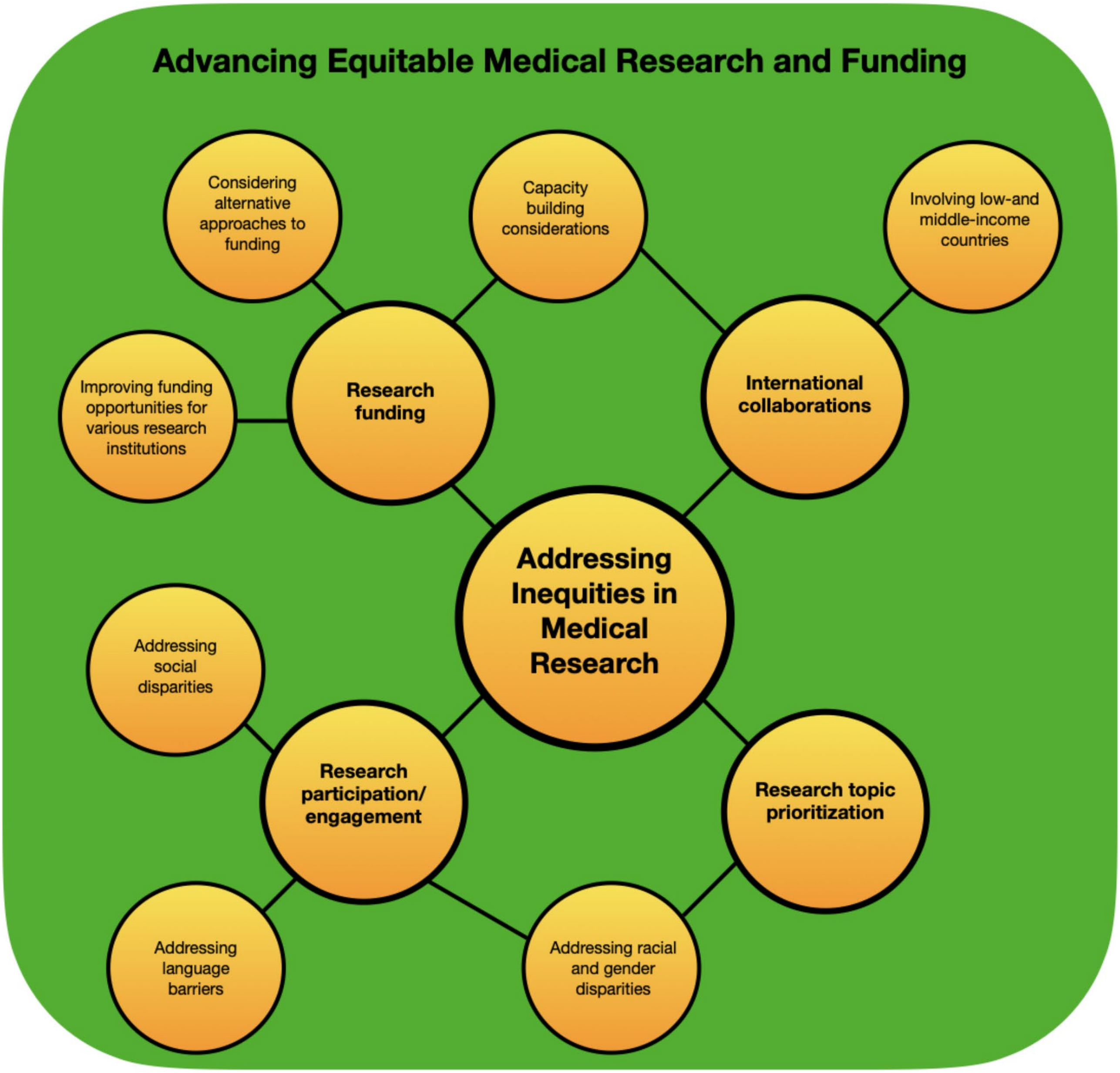

Fig. 2 Graphic depiction of our main theme, four associating domains, and topics within these domains. Developed through participants' perspectives, our central theory proposes that addressing inequities in medical research and funding can lead to greater research impact that extends to more people, regardless of demographics, socioeconomic status, and country they live in. Ultimately, the aspiration is to continue striving towards more equitable medical research and funding.

> *chosen is not always maybe what might be really exciting unless it's really obvious."– Patient 308.*

In this regard, some participants perceived that funding inequities affected capacity building and improvements to research infrastructure in underfunded institutions.

> *"How do you fund trainees? How do you build up a research group or an institute and make sure everyone stays employed, and everyone's happy […] that's a lot of work and constantly thinking about grants and funding."– Researcher 106.*

"You can't do the research without that [funding]. But again, you need that capacity. So, we need the academic institutions, they need to be there […] They need to be teaching, they need to have students who are doing graduate work, who want to do the research."– Member of the public 409.

Another discussed aspect of equity in research funding involved considerations of alternative funding

Table 2 Summary of domains of inequities identified by participants

Domain	Inequity Identified	Opportunities Identified
Research Participation/ Engagement	• Less representation of minority background or non-English-speaking subjects • Clinical investigations bias white subjects	• Involve more non-English speaking participants in research • Recruit representative minority groups in research studies
Research Funding	• Elite institutions secure most of the funding • Senior established researchers have an advantage and receive more funding • Money drives topic selection • Researchers with high output are valued more • Emerging treatments harder to get funding for than traditional interventions • Unequal access to funding from emerging areas of enquiry • Western-centric funding • Funding supports better marketed diseases i.e. cancer	• Consider blinding research proposal reviewers to institution and researcher names so proposals are judged on their own merit/quality • Raise awareness of emerging biases • Use an equity lens to help inform funding allocations • Build research capacity by allotting funding for teaching, graduate student work and mentorship initiatives
Research Topic Prioritization	• Skewed topic selection to people who run trials • Most 'trendy topics' selected • Topics are selected with impassioned campaigns or personal experience of funders • Topics do not reflect all populations or population health priorities • Study focuses on illness and not health disparities • Topics that do not fit within a single discipline are often underexplored	• Explore patient priorities • Promote research of health issues that impact females and gender minorities • Promote more interdisciplinary collaboration
International Collaborations	• Unequal distribution of resources posing a barrier to inclusion of LMICs in international collaborations • Under-investigation of diseases that primarily impact LMICs	• Incentivize international collaboration between research groups • Share ideas and methodologies between different world regions • Invest in generation of research data on diseases that impact specific LMIC populations • Build research capacity by connecting expert researchers from HICs to other parts of the world, reach out and provide support for budding leaders and research structures

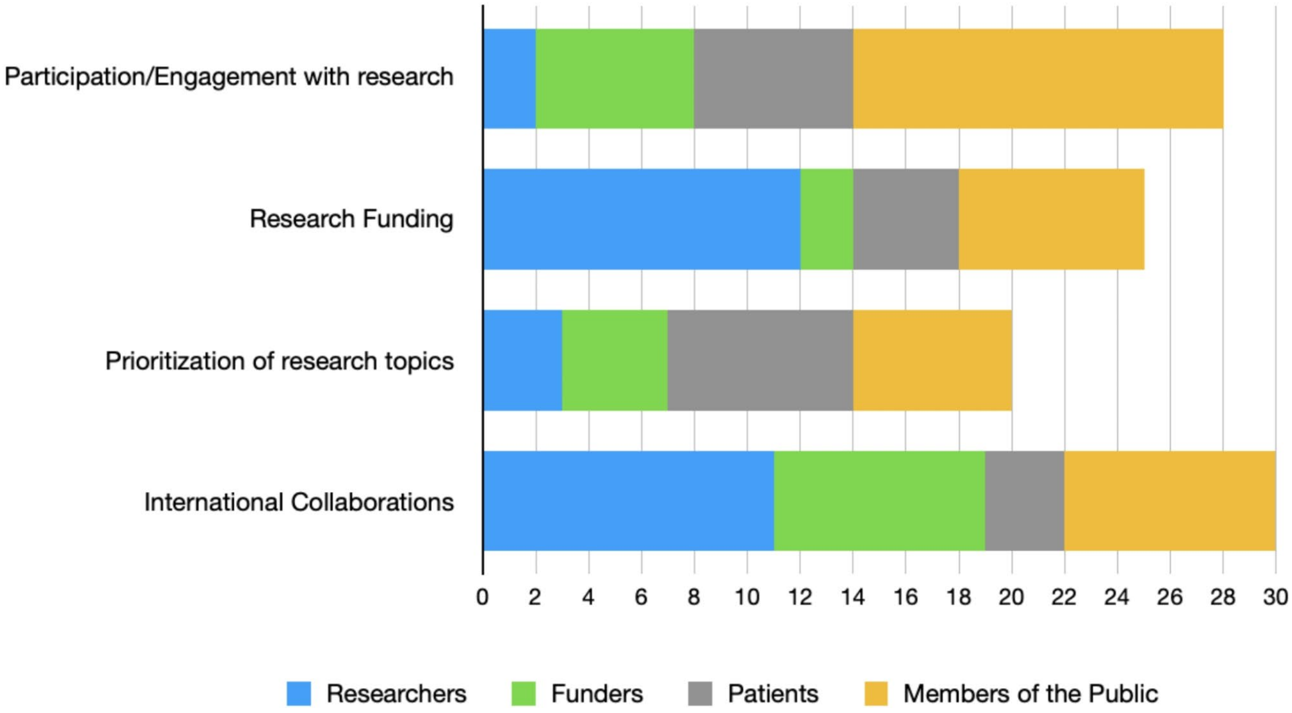

Fig. 3 Coding matrix chart displaying proportional coding densities of the four stakeholder groups' perspectives in relation to the four identified domains of inequities in medical research and funding

approaches. For instance, participants perceived crowdfunding in the medical research atmosphere as an opportunity to improve funding inequities.

"[Researchers] would have a wider variety of funding potential, and I don't feel like they would have to worry so much about bias, because, again, I feel like when they're submitting research applications to a bunch of councils, they probably have to be more focused on prominent issue, whereas if you had like a GoFundMe page you're going to reach out to everybody in the world who potentially has that issue or know someone with it."– Patient 301.

On the other hand, when considering a greater role for the general public as representatives or decision-makers for funding allocation, some participants felt that knowledge disparities could pose challenges to alternative consensus-based or crowd-sourced approaches to funding decision-making.

> *"The problem with having input from the general public is I'm not sure it's ever going to lead to any kind of consensus, any kind of clear way forward, and there are very well-informed people in the public and there're very ill-informed and smart people of the public. And we don't want ill-informed people dictating what happens in research. And how do you differentiate the two, how do you know what groups to ask?" - Researcher 106.*

Research topic prioritization

Participants noted that certain topics were ranked higher in importance, with some perceiving that such prioritization propagated gender disparities in research. There was also a notion that researchers' topic priorities were driven by research funding itself, and likely fuelled inequity in recognition of other promising areas of research.

> *"From a global perspective, 100% we focus on men's diseases… like I've just been recently entered the perimenopause or menopause stage and to find like there's hardly any books. There's hardly any research, there's hardly even any conversation or dialogue around menopause and what you might experience, like people just don't speak about it."– Patient 309.*
> *"Often researchers end up having to pursue topics that are in vogue at the moment, or that through political lobbying has received a disproportionate amount of funding. And not necessarily to follow the most promising leads they have, if those are not in currently favored funding areas."– Researcher 101.*

Other participants pointed out the implicit bias entrenched within one's own personal understanding or connection to the topic that potentially contributed to disparities in topic prioritization.

> *"I guess AIDS was kind of like that originally. It was seen as a marginal thing. Sort of underground almost thing. So then not studied at first, when it was hard to get the daylight on this thing, because people felt it was a marginal thing. And it didn't apply to most people."– Funder 210.*
> *"When I think of medical research, the first thing that comes to mind is cancer research, because it's such a relevant disease, and it's so far-reaching that I think that everybody, whether that's passively or actively, is some way involved, because they're either impacted by somebody who's had cancer, or they do fundraisers to be involved with it, and therefore have a little bit more understanding."– Member of the public 407.*

International collaborations

Participants perceived international collaborations as favorable in medical research. They agreed that collaborating with other researchers and institutions globally could fill in gaps of disease awareness and international representation of health issues.

> *"There is not much of data available from Asia where we see maximum cerebral venous thrombosis. So, information is lacking in this area, so lot of these kind of areas where the diseases could, for example, intracranial atherosclerotic disease, which is most prevalent in Asians, need more information which we need to concentrate on from the LMICs."– Researcher 104.*

Several participants referred specifically to collaborations with LMICs. Not only did they feel that gaps in topic awareness could be filled, but that investing in LMICs also provided the opportunity to improve health outcomes. These collaborations were seen as means of capacity building that could enable LMICs to improve their basis for higher-quality research.

> *"There's [a need for] creating equity in research funding worldwide and there's a need for those with resources, and also with expertise in the developed world to reach out and provide support for the incipient leaders and research structures and other parts of the world, because that will pay off and […] then become productive for decades to come."– Researcher 101.*
> *"I don't think there's an equal balance of sharing the wealth [with LMICs] in terms of fostering research or even mentoring people in more in those areas to become good researchers."– Funder 201.*

Participants also recognized that learning from LMIC-based research could also benefit researchers and patients in HICs and potentially work as a time-effective strategy to spread important findings.

> *"I think if others have already researched certain things in other parts of the world, whether it be China, Australia, whatever, if we can glean that information and use it, then further efforts or research means we don't have to go down the same path twice. Right? You know, it means we can use somebody's information and move forward in a new direction, possibly for research."– Patient 306.*

Taken together, international collaborations were perceived as an effective approach to involving LMICs as essential contributors to research while addressing their respective challenges and competing priorities that potentially interfered with their research progress.

Discussion

Using our findings from participant perspectives, the central theory we determined was that addressing multifaceted inequities in medical research could enhance the societal impact of research, such as improving accessibility and applicability of findings to diverse public audiences regardless of demographics, socioeconomic status, or country of residence. The main domains of identified inequities were research participation engagement, funding allocation, topic prioritization, and international collaborations - particularly with LMICs. While some insights may also be relevant to broader fields, our findings primarily allude to the need for improving equity in these particular realms of medical research. Interestingly, the discussion with participants was found to be more apolitical in nature, with participants not explicitly pointing out one particular movement to turn to the answers but rather pointing out general policies or frameworks that they would like society to adopt.

We observed a common perception that numerous factors played a role in fuelling disparities with who could comfortably participate in medical research. These factors included language barriers, disproportionate racial representation, and socioeconomic status. Our findings support previous literature identifying similar issues. A recent narrative review alluded to the lack of health literacy in current research design, and the importance of tailoring this aspect towards more diverse audiences to improve participant recruitment [19–21]. Furthermore, a conceptual analysis by Baumann (2019) also touched on the continuing challenges in disseminating research due to cultural and geographical differences, and stark disparities in "language, literacy, and linguistic" aspects of presenting research [22]. Thus, introducing more interpretative resources during research studies and recruitment would be essential to address language inequities [23], which is what participants in our study would likely support based on their perspectives.

Participants touched on funding inequities within researchers and institutions, highlighting various factors including prominence and establishment, and nuances involved with seeking maximized research impact by investing in those who had proven their capabilities. These perspectives echo findings from a previous Canadian study that quantitatively analyzed the evaluations of grant proposals and subsequent funding trends, and found that funding success and grant amounts received were consistently lower for applicants from smaller institutions across all levels of experience [24]. With regards to alternative funding approaches such as crowdfunding and open-forum consensus-based funding, participants provided mixed perspectives consistent with literature also highlighting potential advantages and drawbacks in regard to feasibility and impact [25, 26]. There overall appear to be several nuances to consider, and while it gives hope for novel strategies of accessible funding, further investigation remains essential in determining which avenues are optimal for improving equitable research funding.

Many of the equity challenges identified by our stakeholders interconnect with the impacts of colonialism affecting the opportunities of equitable research [27, 28]. Western medical knowledge is typically ranked at the top of the hierarchy in terms of a referencing source of understanding health [28, 29]. As a result of prioritizing Western medical knowledge, non-Western health knowledge and systems such as that of Indigenous Peoples are further discounted. Research practices often fail to consider negative aspects intertwined in the history of Western medicine's development, such as colonialism and racism, that impede progress towards equitable research and healthcare [27, 28].

Our findings align with literature supporting that improving inequities in medical research could accelerate its societal impact and improve global health equity among diverse populations [30, 31]. Particularly in LMICs, there are limited research facilities, technologies, funding, and collaborations between other institutions [32, 33]. Thus, increasing research capacity in LMICs can complement and ideally synergize with the current Western-dominant research presence. This intersects with the notion that collaborative efforts inclusive of LMICs could improve health awareness in underrepresented countries and incentivize funding towards studies tailored to their research institutions and populations. It is important to add a caveat that participants did not adopt a naïve view of international collaboration as being a direct and immediate beneficial exercise for LMICs. Rather, participants recognized the importance of investing in capacity building to help mitigate predatory practices that could lead to unequal representation and recognition of research in those particular areas.

We also believe that aforementioned potential alternatives to research funding including crowdfunding and more consensus-based decision-making could intersect with international collaborative efforts inclusive of LMICs, provided we address practical challenges to their execution such as ensuring sufficient baseline health literacy of participants [34].

While we gained diverse perspectives from four distinct stakeholder groups, participants in our study were primarily from Canada and the United States, which are both high income Western countries that compose a large proportion of medical research and literature. Hence, we do not have as much current insight from individuals from LMICs about the state and quality of medical research. However, given the qualitative nature of our study, we felt that it was important to focus our discussions around a reasonably similar medical research landscape, prioritizing depth over breadth, and increasing the likelihood of identifying mitigating strategies that can be applied in this context. Learning about medical research inequities at a more global level is an essential future step which could also leverage international collaborations with LMICs - an important priority identified by our stakeholders [35].

Additionally, and more recently, efforts to address equity in health and medicine have become a political target [36]. While efforts to implement the proposed methods in this paper are unlikely to improve currently prevailing political atmospheres with regards to EDI tensions and uncertainties, our findings nevertheless demonstrate the importance of diverse stakeholder groups. While our study was conducted in a primarily Canadian context, participants appeared to draw on global contexts; this inclusive and empathetic outlook is one that we hope continues to be maintained in the years to come.

Conclusions

Our qualitative study identified various domains of inequities in the medical research landscape perceived by diverse stakeholders. However, based on the insights that we gained into potential solutions, we are optimistic that sustained efforts to mitigate these inequities will contribute to broadening societal impact of medical research, whilst fostering valuable international collaborations with LMICs.

Abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
HIC	High-income countries
LMIC	Low-and middle-income countries
PERSPECT	Priorities and Expectations of Researchers, Donors, Patients, and the Public Regarding the Funding and Conduct of Medical Research

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12939-025-02458-7.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

Acknowledgements

Not applicable.

Author contributions

RR (research assistant) wrote the first manuscript draft. NC (research associate), BAD (post-doctoral researcher), WB (graduate student), RR and AG (physician-researcher) analyzed the data and revised the manuscript. RM (physician-researcher), JF (physician-researcher), TJ (physician-researcher), NC, and AG conducted participant interviews. AG and MG (physician-researcher) co-conceived the study and AG provided funding and supervision. All authors critically revised and approved the final the manuscript.

Funding

This study was supported by the Panmure House Prize and by individual donations raised through Let's Get Proof (Collavidence Inc). Furthermore, Dr. Ganesh received salary support through the Heart and Stroke Foundation of Canada.

Data availability

Data generated or analyzed during this study are included in this published article and its supplementary information files. Requests for access to anonymized thematically analyzed data will be considered by the corresponding author when accompanied by a well-justified proposal.

Declarations

Consent for publication

Not applicable.

Competing interests

A. Ganesh reports membership in the editorial boards of Neurology, Stroke, and Neurology: Clinical Practice; consulting fees from Atheneum, MD Analytics, Figure 1, Alexion, Biogen, Servier Canada, and CTC Communications Corp; research support from the Canadian Institutes of Health Research, Alberta Innovates, Brain Canada, Campus Alberta Neuroscience, the Heart and Stroke Foundation of Canada, the Government of Canada INOVAIT program and New Frontiers in Research Fund, the France-Canada Research Fund; stock/stock options from SnapDx and Let's Get Proof (Collavidence Inc). A. Ganesh and M. Goyal report research support from Microvention, the Krembil Foundation, and the Philips Foundation. A. Ganesh, R. McDonough, and M. Goyal report a patent application (US 63/326,027) for systems and methods for enhancing the efficiency of initiating, conducting and funding research projects.

Ethics approval

The study was approved by the University of Calgary Conjoint Health Research Ethics Board (REB21-1592), in accordance with standards of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Human Participants (TCPS2). All participants provided informed consent.

Author details

[1]Department of Clinical Neurosciences, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada
[2]Department of Radiology, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada

[3]Faculty of Medicine, Ramathibodi Hospital Mahidol University, Bangkok, Thailand
[4]Hotchkiss Brain Institute, Cumming School of Medicine, University of Calgary, Calgary, AB, Canada

Received: 24 December 2024 / Accepted: 23 March 2025

References

1. Chaiyachati KH, Beidas RS, Lane-Fall MB, Rendle KA, Shelton RC, Kaufman EJ. Weaving equity into the fabric of medical research. J GEN INTERN MED. 2022;37(8):2067–9.
2. McNulty M, Smith JD, Villamar J, Burnett-Zeigler I, Vermeer W, Benbow N, et al. Implementation research methodologies for achieving scientific equity and health equity. Ethn Dis. 2019;29(Suppl 1):83–92.
3. Marmot M, Allen JJ. Social determinants of health equity. Am J Public Health. 2014;104(S4):S517–9.
4. Dewidar O, Elmestekawy N, Welch V. Improving equity, diversity, and inclusion in academia. Res Integr Peer Rev. 2022;7(1):4.
5. MacKinnon NJ, Emery V, Waller J, Ange B, Ambade P, Gunja M, et al. Mapping health disparities in 11 High-Income nations. JAMA Netw Open. 2023;6(7):e2322310.
6. Van Zyl C, Badenhorst M, Hanekom S, Heine M. Unravelling 'low-resource settings': a systematic scoping review with qualitative content analysis. BMJ Glob Health. 2021;6(6):e005190.
7. Pratt B, Merritt M, Hyder AA. Towards deep inclusion for equity-oriented health research priority-setting: A working model. Soc Sci Med. 2016;151:215–24.
8. for the Multi Stakeholder Engagement (MuSE) Consortium, Concannon TW, Grant S, Welch V, Petkovic J, Selby J, et al. Practical guidance for involving stakeholders in health research. J GEN INTERN MED. 2019;34(3):458–63.
9. Laird Y, Manner J, Baldwin L, Hunter R, McAteer J, Rodgers S, et al. Stakeholders' experiences of the public health research process: time to change the system? Health Res Policy Sys. 2020;18(1):83.
10. Cristall N, Drozdowska BA, Fladt J, Jaroenngarmsamer T, Sehgal A, Victoria McDonough R, et al. Priorities and expectations of researchers, funders, patients and the public regarding the funding of medical research: results from the PERSPECT qualitative study. BMJ Open. 2024;14(11):e084655.
11. Drozdowska BA, Cristall N, Fladt J, Jaroenngarmsamer T, Sehgal A, Victoria McDonough R, et al. Health research policy and systems. Attitudes and perceptions regarding aspects of knowledge translation and community engagement in medical research: results from the PERSPECT qualitative study. Health Research Policyand Systems.2025; 23:29.
12. Corbin JM, Strauss AL. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory [Internet]. 4th ed. Thousand Oaks, CA: Sage Publications; 2014. 456 p. Available from: https://us.sagepub.com/en-us/nam/basics-of-qualitative-research/book235578
13. Rieger KL. Discriminating among grounded theory approaches. Nurs Inq. 2019;26(1):e12261.
14. Browne K. Snowball sampling: using social networks to research non-heterosexual women. Int J Soc Res Methodol. 2005;8(1):47–60.
15. Let's Get Proof. https://www.letsgetproof.com/working-groups/perspect-priorities-and-expectations-of-researcher. Accessed 3 December 2024.
16. Hennink MM, Kaiser BN, Marconi VC. Code saturation versus meaning saturation: how many interviews are enough?? Qual Health Res. 2017;27(4):591–608.
17. Sebastian K. Distinguishing Between the Strains Grounded Theory. In. 2019. Available from: https://api.semanticscholar.org/CorpusID:202253728
18. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57.
19. El-Galaly TC, Gaidzik VI, Gaman MA, Antic D, Okosun J, Copland M, et al. A lack of diversity, equity, and inclusion in clinical research has direct impact on patient care. HemaSphere. 2023;7(3):e842.
20. Carmona L. Reducing bureaucracy in clinical trials, now is the time! RMD Open. 2022;8(1):e002202.
21. Pietrzykowski T, Smilowska K. The reality of informed consent: empirical studies on patient comprehension—systematic review. Trials. 2021;22(1):57.
22. Baumann SL. Lost in translation: the promise and problems of the globalization of research. Nurs Sci Q. 2019;32(1):68–72.
23. Corneli A, Hanlen-Rosado E, McKenna K, Araojo R, Corbett D, Vasisht K, et al. Enhancing diversity and inclusion in clinical trials. Clin Pharma Ther. 2023;113(3):489–99.
24. Murray DL, Morris D, Lavoie C, Leavitt PR, MacIsaac H, Masson MEJ et al. Bias in Research Grant Evaluation Has Dire Consequences for Small Universities. Dorta-González P, editor. PLoS ONE. 2016;11(6):e0155876.
25. Renwick MJ, Mossialos E. Crowdfunding our health: economic risks and benefits. Soc Sci Med. 2017;191:48–56.
26. Valančienė L, Jegelevičiūtė S. VALUATION OF CROWDFUNDING: BENEFITS AND DRAWBACKS. Ecoman. 2013;18(1):39–48.
27. Frohlich KL, Ross N, Richmond C. Health disparities in Canada today: some evidence and a theoretical framework. Health Policy. 2006;79(2–3):132–43.
28. Yoeli H, Dhital R, Hermaszewska S, Sin J. A meta-ethnography of participatory health research and co-production in Nepal. Soc Sci Med. 2022;301:114955.
29. King C, Bennett M, Fulford KWM, Clarke S, Gillard S, Bergqvist A, et al. From Preproduction to coproduction: COVID-19, whiteness, and making black mental health matter. Lancet Psychiatry. 2021;8(2):93–5.
30. Huynen MM, Martens P, Hilderink HB. The health impacts of globalisation: a conceptual framework. Global Health. 2005;1(1):14.
31. Tinetti ME, Hladek M, deCardi ED. One size fits All—An underappreciated health inequity. JAMA Intern Med. 2024;184(1):7.
32. Rahman MM, Ghoshal UC, Ragunath K, Jenkins G, Rahman M, Edwards C, et al. Biomedical research in developing countries: opportunities, methods, and challenges. Indian J Gastroenterol. 2020;39(3):292–302.
33. Malekzadeh A, Michels K, Wolfman C, Anand N, Sturke R. Strengthening research capacity in LMICs to address the global NCD burden. Global Health Action. 2020;13(1):1846904.
34. Kpokiri EE, Sri-Pathmanathan C, Shrestha P, Navaid S, Wiwatpanit T, Wijegunawardana A, et al. Crowdfunding for health research: a qualitative evidence synthesis and a pilot programme. BMJ Glob Health. 2022;7(7):e009110.
35. Harris M, Marti J, Watt H, Bhatti Y, Macinko J, Darzi AW. Explicit bias toward High-Income-Country research: A randomized, blinded, crossover experiment of english clinicians. Health Aff. 2017;36(11):1997–2004.
36. The Lancet. American chaos: standing up for health and medicine. Lancet. 2025;405(10477):439.

Publisher's note