



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

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ABSTRACT

Background Ideally, medical research provides crucial data about disease processes, diagnoses, prognoses, treatment targets and outcomes, and systems of care. However, medical research is costly, and funding is difficult to receive because the processes are highly competitive.

There is a paucity of data on the perspectives of researchers, funders, patients and the public about current funding paradigms. This study sought to understand the priorities and opinions of each group to better guide meaningful innovation in research funding processes.

Method In this Priorities & Expectations of Researchers, Funders, Patients and the Public Regarding the Funding & Conduct of Stroke Research study, we conducted in-depth interviews with medical researchers, funders, patients and members of the general public to learn their opinions of the current funding process and thoughts about alternative approaches. We used both purposive and snowball sampling to recruit participants and conducted semistructured interviews. The study ended when thematic saturation was attained. Qualitative analysis followed inductive grounded theory methodology.

Results 41 interviews were completed (11 researchers, 10 funders, 10 patients, 10 members of the general public; 61% female). Interviewees expressed a high interest in supporting a comprehensive evaluation of the research grant funding process while integrating funding mechanisms that are more inclusive and reduce bias in topic selection and researchers who receive funds. Participants acknowledged a gap in patient and public involvement in setting a research agenda, choosing topics to be studied and focusing on specific outcomes. Crowdfunding was identified as an alternative strategy that could facilitate research democratisation; however, participants emphasised the importance of expert review of research proposals, as in current processes to continue to support rigour and trust in research proposal quality.

Conclusion Our research revealed stakeholder concerns about the transparency and equity of current research funding paradigms. Suggestions to democratize research and explore alternative fundraising platforms necessitate

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Researchers, funders and patients reported important potentially unscientific biases in researcher success and topic selection that arise from conventional processes.
- ⇒ Exploring opinions from four stakeholder groups yielded rich content with respect to issues with current research funding processes, and ideas for potential solutions.
- ⇒ Further stakeholder discussion with a broader range of younger and visible minority patients and members of the public and less established researchers would add further to understanding a broader range of voices.
- ⇒ Follow-up dialogue with stakeholders might also yield additional insight given that the topic is dynamic, and experiences change as new issues in research funding emerge.

a fundamental shift in traditional research funding processes.

BACKGROUND

Medical research has the potential to confer several important benefits to society. Besides generating new treatments and innovations to improve human health, research provides data to advance medical treatment and enhance patient outcomes. Further, different approaches to, and knowledge bases within, research provide complementary insights.¹ With the increasing complexity of medical research, the associated costs continue to climb with annual medical research spending increasing from US\$93.7 million (US\$467 million when adjusted for inflation) in 1975 to over US\$4.1 billion in 2019 in Canada alone.² Nevertheless, medical research in many fields remains underfunded.^{3,4} The

funding process is highly competitive, favouring more established researchers and institutions and can operate slowly, with projects waiting 1 or 2 years from the time of granting to disbursement of funds.⁵

Research proposals are typically evaluated anonymously by panels of expert researchers. In the current paradigm, there are potential drawbacks such as inherent biases in funding inclusion, limited engagement from patients or the public regarding research topics or studies and an overall low chance of successful funding of projects for new researchers or applicants outside the traditional elite research paradigm. In particular, early career researchers have lower success rates in funding competitions,⁶ as do applicants from less established research centres,⁷ women,⁸ visible minorities⁹ and those from low-income and middle-income countries.^{10 11} There is also an imbalance between the burden of disease and the allocation of research funding. This pattern is mirrored in the philanthropic giving and industry-initiated trials.⁴

Public perceptions regarding medical research are also evolving. In the early 2000s, two investigations found that nearly 80% of Americans were interested in health research findings, believed they were important for health, and that maintaining world leadership in medical research was also important,^{12 13} while 90% of respondents agreed that developments in science have made society better and improved the quality of human lives.¹⁴ However, in subsequent decades, concerns have arisen about a loss of general trust in expertise and in medical research. Thrust into the foreground by the management of the COVID-19 pandemic, many people have rejected research-based recommendations such as vaccinations.^{15 16} Thus, maintaining and rejuvenating medical research requires us to better understand how to enfranchise the research community and to enhance patient and public engagement with respect to the conduct and funding of research.

There is growing interest in a 'new paradigm in rapid and integrated research efforts for students, community members and scientists around the globe.'¹⁷ To guide meaningful reform, it is essential to acknowledge the priorities and opinions of different stakeholder groups.¹ However, the perspectives of researchers, funders, patients and the general public about the current state of medical research remain under investigated, particularly with respect to the selection of research topics, which research is funded and the funding process. There is also little known about stakeholders' willingness to embrace changes or modifications to the established research funding process. In this study, we sought to develop new knowledge regarding what key areas of current research funding models are perceived as critically important and what opportunities and solutions would be considered by various stakeholders to guide meaningful innovation in this space.

METHODOLOGY

Design

We conducted an interpretive grounded theory qualitative exploration of priorities and considerations in the medical research landscape. We followed a Corbin and Strauss method of interview guide development, data collection, data analyses and theory development.¹⁸ We conducted in-depth interviews with researchers; research funders, donors or philanthropists; patients and members of the public regarding the current state of medical research and perspective regarding alternatives to current funding models. We asked questions about their perceptions of the current state of medical research topics, and their opinions regarding the processes and patient and public involvement. These themes were prompted by available theory and the emerging body of work in this area.^{4 6 11 19} We wanted to add to the literature by exploring the opinions of each group to better understand priorities and opinions to guide meaningful innovation in research funding processes.

Participants

Each group interviewed was represented by at least 10 stakeholders. Selected participants were 18 years of age or older and met one of the following criteria: (1) Researchers: Involved in the design and conduct of medical research as investigators or subinvestigators, with experience participating in at least one research grant or award application; (2) Funders: Philanthropists known to have donated to medical or research causes or people on the board of directors of research funding organisations; (3) Patients: People who self-declared as having any non-communicable disease and (4) Members of the public: People who did not belong to any aforementioned group. We began with stakeholders in our research network, namely: (1) cardiovascular and neuroscience researchers in the USA and Canada, (2) representatives from the board of directors of regional cardiovascular and neuroscience funding organisations, (3) volunteers recruited from the Alberta Patient Engagement Platform and other patient advisory groups and (4) non-medical/non-research-affiliated individuals suggested by participants in groups 1–3 as representatives of the public who were not practising physicians or scientists. We added other participants using purposive and snowball sampling in each group. For participants in the research group in particular, some of the interviewees had an acquaintance relationship with the interviewers. The sampling process focused on participants primarily from Canada and the USA, with researchers and funders having experience in the Canadian and American funding landscape.

Data collection and analysis

After receiving an introductory email message, willing participants electronically signed a consent form; interviews were scheduled and conducted via Zoom using a semistructured topic-specific interview guide. (online supplemental material appendix A). Interviewers were

research associates (NC and AS) and radiology fellows (JF and TJ) all with training in qualitative interviewing. There was a gender mix of researchers. Participants committed 30 min for interviews, allowing for a shorter or longer duration at the initiative of participants. Interviews were audio and digitally recorded and then transcribed. Where possible, interviews were monitored by one other member of the research team. The sample size provided us with enough information to perform concurrent open coding and a thematic analysis with code saturation.²⁰ We reached code saturation when more than five consecutive interviews did not generate any new themes.

Identifiable information was removed at the transcription stage and the interviews were uploaded with a study ID. Transcripts were imported into NVivo V.12 Plus software. Open coding was concurrent with data collection to allow sampling until code saturation and constant comparison was maximised. Following the practice of constant comparison and open coding, we named and categorised dominant and subcodes. This work involved reading and re-reading interview data in their entirety to acquire an overall sense of the phenomena, open coding sentences that captured key concepts, documenting memos of initial impressions and interpretations; and sorting codes related to each other into themes and subthemes. While reviewing and coding the transcripts, we made memos regarding responses and thoughts about the interviewee's opinions. Coding and theme development were conducted by four members of the study team (NC, BAD, TJ and AG) until a consensus was reached. Following this work, definitions were developed for codes to ensure understanding and support rigour. This activity was followed by axial coding where we condensed the data into descriptive patterns, themes and subthemes. Selective coding followed an interpretive grounded theory method.^{18 21} We identified commonalities and organised key topics, capturing a wide variety of experiences and priorities to synthesise a substantive theory from multiple perspectives.^{18 22} To achieve this synthesis, we explored the proportion of nodes articulating specific themes across cases and between groups. Along with the thematic coding, we triangulated the constructs, exploring opinions about medical research and the perspectives of participants from each stakeholder group. This work involved using the researchers' opinions about the data, exploring the constructs from thematic coding, and thoroughly exploring between-group similarities and differences from the perspective of the research team. The research steps followed the Consolidated criteria for Reporting Qualitative research.²³ We adapted the interpretive grounded theory following the Corbin and Strauss method in this graphic depiction ([figure 1](#)).

Patient and public involvement

The researchers paid particular attention to patient and public involvement, with almost half of the interviewees representing one of these groups. A lay language version of the study proposal was posted on an online public

engagement platform for medical research (<https://www.letsgetproof.com/>) to solicit comments, which informed our decision to focus on a few comparable Western countries with heavy public investment in medical research in the interest of study feasibility and to develop meaningful conclusions. The interview guide questions were developed with individuals who are not routinely involved in medical research to ensure that the questions remained accessible to patients and members of the public, who were expected to constitute half the study participants. A lay language summary of study results will be posted on the same webpage to stimulate further discussion.

RESULTS

51 individuals were approached for participation in the study, of whom 5 did not respond and 5 declined to participate. 41 participants completed interviews. One member of the public withdrew the data collected from their interview for personal reasons. One member of the public interview was reconducted due to a recording failure during the first interview. 41 people participated in interviews, with 3 of 11 researchers having experience with research in their home country as well as in partnership with low-income and middle-income countries. Of the fund administrators, all had experience with awarding grant dollars and two of the philanthropists also had experience with awarding research grants. The majority of participants were from North America. And we had one participant from India, Holland, Germany and Iran. Please see [table 1](#) for further description of the study participants.

We triangulated the data into three dominant themes. These key themes uncovered salient perceptions of the current state of medical research, interest in engagement and involvement of patients and the public and an openness to explore alternative funding and topic selection options. The thematic analyses yielded emerging theories about innovation in research. The conversations situated the research in experience with competitive public/governmental sources of funding and philanthropic foundations as opposed to internal institutional funding sources. Select codes and variability across themes and subthemes for each participant group are presented in [figure 2](#).

Theme 1: the current state of medical research funding

What works well currently

There are many facets of the current state of medical research that respondents viewed as particularly important. These included the medical research's emphasis on expert peer review, scientific rigour and dedication to the greater good. Patients and members of the public noted their overall high regard for many aspects of medical research.

Researchers who were interviewed also emphasised the value of building capacity for research in both centres of

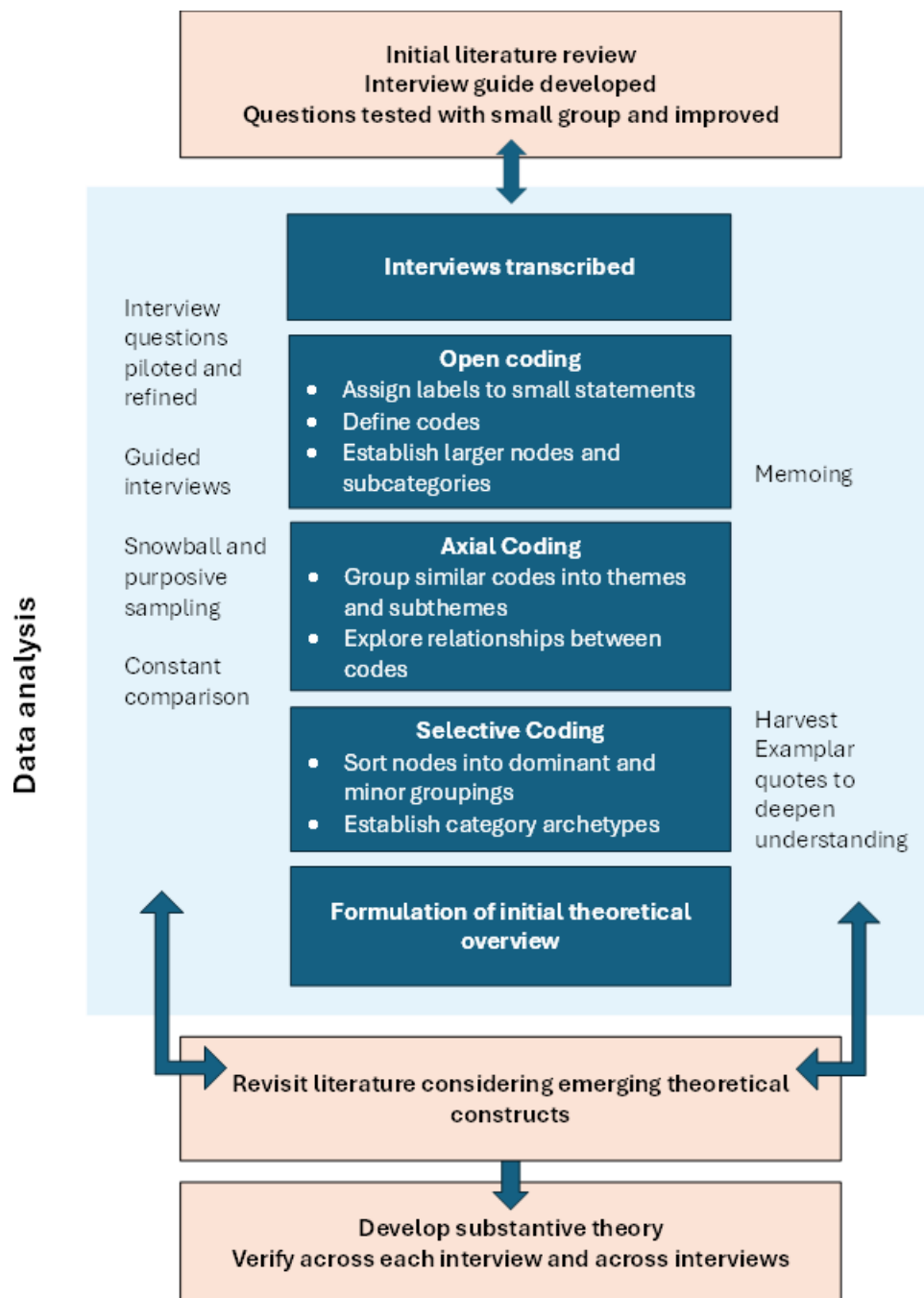


Figure 1 Methodology.

excellence and within individuals, as well as the value of transferring findings into clinical practice. For example:

I think research has very big impact, because it's the main driving force of change in clinical practice, and of course change in the guidelines and everything ...a lot of stuff is changing quite quickly in the last couple of years, you know, so there is a big impact of research in that sense. - Researcher 9

We found that, overall, specific concerns about the current state of medical research were less salient for researchers, as were the emphasis on expert review,

forging partnerships, and other domains as presented in the bar graph in [figure 3](#).

Funders were particularly concerned that scientific rigour remains a vital part of the research cycle. As one funder noted:

As new therapies and technologies get developed, we need a rigorous process for testing and comparing to make sure that things we choose to change in practice are based on evidence, and the only way to get solid evidence is through rigorous research-
Funder 1

Table 1 Characteristics of PERSPECT participants

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

N=41, 11 researchers, 10 funders, 10 patients and 10 members of the public.
 PERSPECT, Priorities & Expectations of Researchers, Funders, Patients and the Public Regarding the Funding & Conduct of Stroke Research.

Funders also acknowledged the importance of progress and timely development of new ideas. One funder lauded the fact that the time from testing to implementation can be short.

I think what does work well, is just the rate at which we're able to advance our knowledge and the fields that are getting the most traction, I think that's always very exciting. I think, you know, the rate of events, it's always very, very impressive. - Funder 7

Patient participants and members of the public had similar high praise for the contributions of medical research, noting the necessary contributions of expert review in the research process.

I think peer review and the ability to duplicate results and those kinds of things, I think is essential. -Patient 304

I think that there are lots of people who are very well suited to do that very important work, and they have the correct expertise for it. -Member of the Public 401

Issues with current funding paradigm

Participants also acknowledged the limitations of the current state of research funding. Three subthemes emerged and will be discussed separately—the inefficiencies in the research funding process, limited transparency and a tendency for traditional funding sources to be myopic or risk averse regarding both the research topics and the people who receive funding. Examples and a brief discussion of these subthemes are presented below.

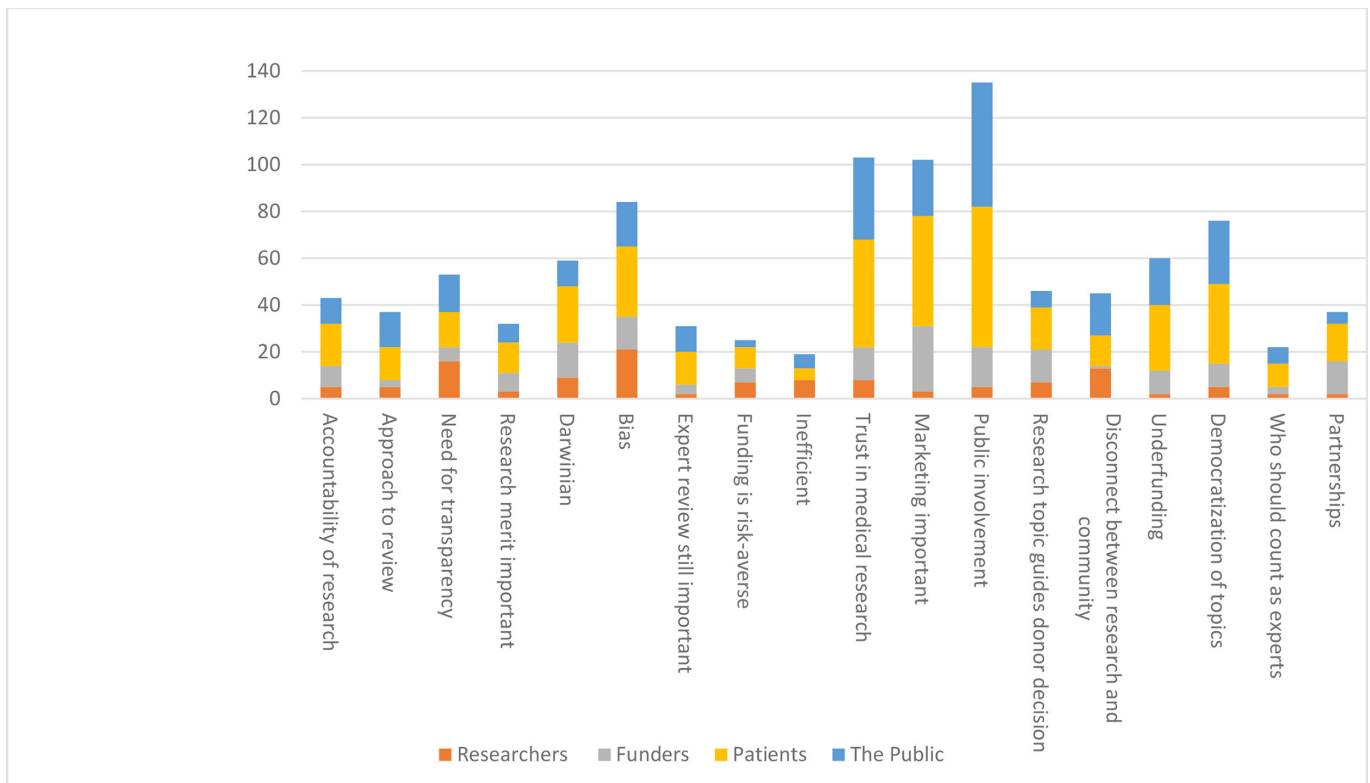


Figure 2 Count of comments by group.

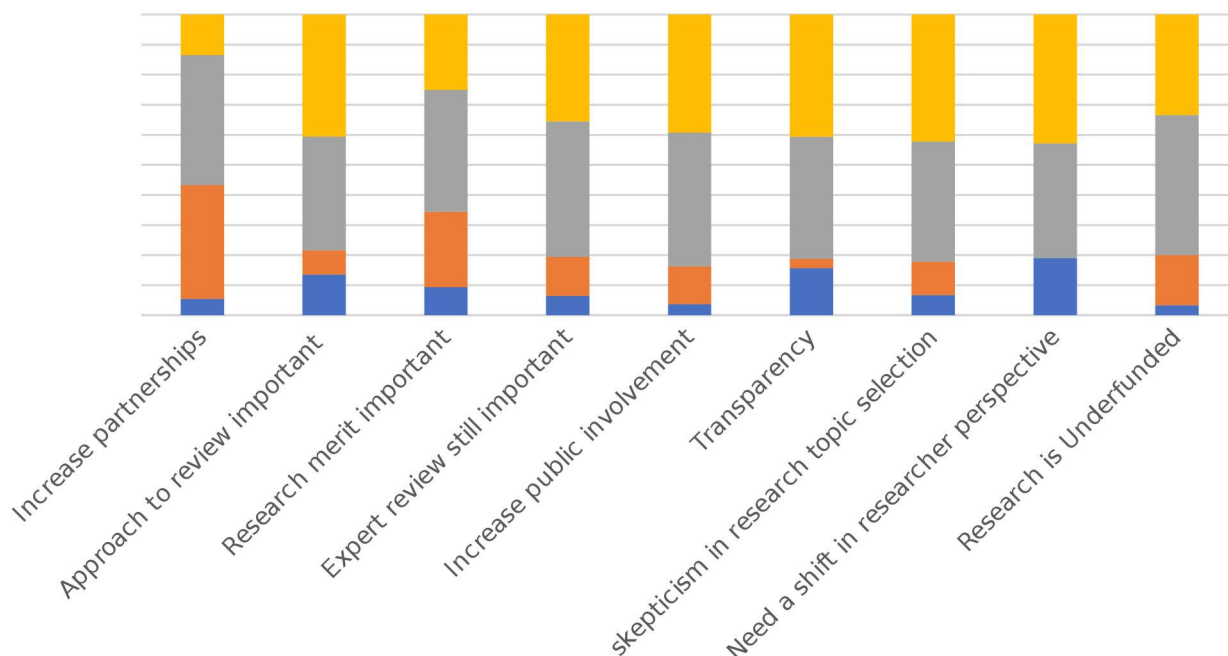


Figure 3 Topics with fewer comments for researchers.

Inefficiencies in the process

Respondents noted the many steps necessary to submit proposals in an often tedious process to earn research funding. While they acknowledged the importance of expert review, they noted the inefficiencies that can arise from the presence of too many intermediaries in the funding allocation process—which can lead to contradictory comments from reviewers which can detract from the original intent of a research proposal. Participants expressed a willingness to embrace more pragmatic and simplified funding options that have a closer connection to patient care. As one patient stated:

I think medical research and medical funding should come from the people who know what's best, they know what they need, they know where they're going, and they're hoping to get there on the right direction. I think when you get too many cooks in the pot, it doesn't do a good stir. – Patient 6

Limited transparency

Participants also expressed concerns about the low visibility of research initiatives, with the funding allocation process seen as elitist, occurring in isolation and mired in difficulties with knowledge translation and dissemination. For example, a researcher noted the lack of wide distribution of research results and need to balance the often dynamic and uncertain nature of various medical research findings.

So far, [research has] been kept internally within the medical society and culture. I think it's going to be very, very difficult problem to solve, because [there is] so much in medicine we don't know, and the public overall thinks that there are right and wrong

answers to every question and that most of life is kind of like engineering principles- Researcher 8

Current funding processes are risk averse and myopic

We also noted that respondents found that funding sources were more challenging to access for rarer diseases and more complex problems despite the evident paucity of, and need for, research funding. A bias in topic selection was also noted, with funding opportunities generally favouring more short-term investments as opposed to longer pay-off investigations. Some respondents, even funders, had an impression that the funding process also favoured potentially biased and myopic priorities in Western culture. A funder commented,

Research is not reflective of the health needs of women broadly, just by virtue of, I don't know, how they organize these like trials for people, or they are biased heavily towards like, I don't know White urban populations., –Funder 5

Using the initial investigation of the AIDS epidemic as an example, another funder noted the slow uptake in raising research dollars for an initially more marginalised and stigmatised illness.

Rich people's diseases probably get more interest, more direct funding than something that's more marginalized, or that's really restricted to a small group of people. Yeah, like, 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... -Funder 10

Some researchers and funders also opined that the choice of research topics was restricted by the preferences of review committees.

Review committees tend to support funding for directions that review committee members themselves are interested in the pursuing rather than more novel directions. – Researcher 1

Along with the diseases and topics being studied, the current state of medical research was described by researchers and members of the public as being socially Darwinian, with already elite and well-established research groups receiving most of the funding dollars.

[My] dislikes include that there's a bit of a tendency for more senior authors, 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 1

From a country [Canada] with a lot of resources and good English-speaking capabilities, you're much easier going to do big research, going to write papers, do sub-studies, have higher output and become more known. If you're from a small center, you also try to do your research, but there are smaller groups, probably less well written manuscripts and from the analysis as well, so there's a big inherent gap over there that's very difficult to close. - Researcher 9

These academic institutions themselves are steeped in racism and sexism and bias against the younger generation. -Member of the public 10

Perceived inequity in the distribution of funds was also noted by funders as a barrier to full participation in the research process.

It's a very elite group yeah, that are able to move forward with their research ideas. And it is a very, very competitive process, very competitive. I think that gets back to maybe why some of the [Ivy League Universities] have an edge because everything is so competitive. So, it's small things that may give you an edge that you may not anticipate; having that reputation is something that is naturally going to give you a little [edge]. - Funder 9

One funder underscored the need to bring in new and early career researchers as a way to build capacity and be more inclusive.

I think the other critical issue around medical research right now is the sort of the demographic profile of the research community and the need to bring young people into research as a career. So, I think building a pipeline for researchers is really critical right now, and also increasing the diversity of that community. – Funder 2

Although the interviewees shared the view that the current state of research funding is entrenched in bias

that favours more established researchers and traditional deductive methodologies, there was also agreement that the core values of rigour, scientific merit and responsible stewardship should remain a central part of the research funding process. Participants expressed a high level of interest in exploring new researcher voices and participation while integrating the current system's checks and balances.

Theme 2: disconnection of patients, funders and public from researchers in the current paradigm

Participants identified a gap in patient and public involvement in setting a research agenda, choosing topics to be studied as well as informing the selection of relevant outcomes.

As one researcher and one patient participants explained:

I think a lot of the time that engagement is done in a fairly superficial or tokenistic way, where patients and community members are not given decision-making authority or power in the research and the researchers still hold the locus of power, and there's a lot of tokenism that happens that people say that we do patient engaged research, but when you actually look at how engaged the patients were, you see that it was done more in a consultative role as opposed to a directorship rule. – Researcher 5

I think it's a money game. So, the big pharmacies who have all this money and pay off people to sway their findings, that's what's missing is the doctor-patient relationship is missing. – Patient 2

Some funders acknowledged the need for public engagement as responsible stewardship of tax dollars.

So, if you're getting public funding, that should be pretty much of interest to the public, like there should be public benefit, and I feel pretty confident there is... I think it's challenging to get funding for less researched areas. –Funder 6

Researchers claimed that public and patient involvement would increase an overall understanding of research that might provide opportunity for more funding sources. Participants described how large sums of money for research can be initiated by reach of media campaigns and having high profile champions. They also noted that people who do not usually give to charitable campaigns can contribute to a new cause that has personal appeal or that reaches them in a more grass roots appeal. Also, patient and public involvement was recognised by all groups as a means to facilitate research that would have the most benefit to patients.

I think there are certain areas of medicine in which the science still hasn't caught up to what patients are looking for. And then sometimes, we're so desperate to approve a drug that sometimes we may overlook weaker clinical data in hopes of, you know, being able

to provide any sort of additional benefits to patients.
– Funder 7

As this funder explains, the research agenda may be perceived as not reflecting issues that patients would view with the same importance. This perspective was reiterated by other participants with one member of the public describing medical research as advancing interests that are potentially only shared by an elite group and not for the benefit of the wider community, the public or what was described as ‘the real world’.

I think that this has been a long-standing relationship between the world of research and the world of real life, but we're at a precipice of change and it takes a long time to turn a big ship. But we have to turn the ship, what we're doing is not working...They [researchers] are beholden to themselves. – Member of the public 10

Participants felt there was a disconnect between patients and the public and research topics selected, diseases being studied, research paradigms, fundraising strategies and donor–patient relationships. Respondents considered the challenges for increasing patient and public involvement and integrating solution-oriented research that addresses the goals of both researchers and the end users.

Theme 3: alternative models and new frontiers in research funding

There was openness across participant groups to explore new frontiers for democratising access to funding dollars. Our findings acknowledged the emergence of different voices, and a shifting epistemology on who are considered experts and end users of research. Participants viewed crowdfunding and other web-based research engagement platforms as avenues to unite researchers.

[Crowdfunding] is a way to get crowd design and the wisdom of the crowd in the research development and funding, and to be able to bring together a statistician in Mumbai, an imager in Beijing and a young scholar in Manitoba who each have parts of the puzzle that when brought together can be very rich, but they don't currently have a way of connecting... by having an open public forum for input into the design of studies, we can enrich the strengths and power of studies going forward. – Researcher 1

Participants also acknowledged that web-based platforms could promote patient involvement.

They'd need to engage a group of the public [in a crowdsourced research initiative] as an advisory group, and a guide group to work with the scientists in the agency to do that. It would need to be a partnership with some legitimate funding kind of processes. And it would be a matter of where the funding is coming from. Following the public interest would be a really interesting way of getting at the lived

experience interest of people living with chronic illness. – Patient 7

Participants regarded crowdfunding platforms as a means to improve various aspects of the research process. These aspects include democratising research topics, encouraging inclusivity of patients' voices, decreasing bias, achieving a wider reach beyond local/regional research communities and making research more relevant. Ultimately, crowdfunding could use public involvement in topic selections to promote research that reflects issues viewed as more relevant to the general public. A member of the public summarised key considerations in crowd-based funding initiatives:

There is a fundamental philosophical question around democratic control of funding. But there's a tension between, on the one hand, desiring people with subject matter expertise to be able to ensure that funding goes to the highest value uses. But, on the other hand, the extent that the subject matter experts are removed from and not representative of the general public. – Member of the Public 3

Participants noted that crowdsourcing financial support is a means to bring a more personal connection between funders and fund recipients. Participants had the impression that crowdsourcing could be more effective in raising money for research than traditional illness-specific funding campaigns. Participants thought that how the request for funding is presented is also important, recognising the need to present interesting interactive depictions of the research goals, have targeted marketing, high-interest campaigns and attach a story, location and idea to the funding proposal. Respondents described being more likely to ‘give to something that has a face, whether literally or something you can quantify.’ (Member of the public 2).

Please see online supplemental material table 2 for a summary of exemplar quotes on selected themes.

DISCUSSION

In this broad review of perspectives on medical research, we found that participants have high regard for the rigour of the current practices in medical research funding. However, there was also a lot of interest in more transparency in the funding process, a more democratic approach to topic selection and access to funding dollars, exploration of different funding frontiers and opportunities to explore different research topics. Many respondents mentioned that current processes should evolve in a direction that reduces bias and is more inclusive. There was wide agreement that emerging funding platforms that integrate expert reviews will assist in establishing trust in more innovative approaches to funding and enquiry. There was also wide interest in building capacity for less established researchers and centres and mobilising

strategic partnerships for researchers and funders with interests in the same areas.

While we uncovered subtle differences in emphasis, we did discover that the four groups of stakeholders had similar overarching observations and concerns regarding medical research. We acknowledge the limitations mentioned and also note that participants were asked their perceptions of medical research in a very broad way and perspectives reflect a general opinion of personal or professional experiences and attitudes. We did find that researchers, funders, patients and public participants expressed an overall desire for greater transparency with grant funding processes, and concerns that current models fostered bias towards certain less established institutions, topics and researcher attributes such as junior researchers, women and visible minorities. Participants noted that the conventional processes were disconnected from public and patients' interests. Some may find this sentiment controversial given contemporary examples of how research efforts meaningfully address critical issues affecting our communities, such as the rapid development of mRNA COVID-19 vaccines,²⁴ or advances in acute stroke care, largely led by the emergence of endovascular thrombectomy.²⁵

In this context, it seems important to consider that the unfavourable perceptions participants expressed might not be fundamentally indicative of faults in how research priorities are set, funds allocated, studies conducted and the findings implemented in practice. Rather, in some instances, these perceptions might reflect an inefficiency in how medical research is communicated with the public.

Further stakeholder concerns were revealed in relation to equity and impartiality of the current research funding paradigm. It has been noted in prior research that funding allocation decisions have been rooted in deep systemic gendered bias and other health equity biases,^{26 27} with resulting lack of diversity and limited innovation.²⁶ Chaiyachati *et al* noted the lack of formal training in health equity, or attention to equity issues in the research review process.²⁶ As a result, structural racism may persist in who designs and who is recruited in clinical trials and other studies.²⁷ Cookson *et al* note that mainstream research has prioritised effectiveness and averaging outcomes, with little attention to equity-informed research methodology.²⁷

As well, bias in the selection of topics being studied, publication bias and selected research outcomes have also been identified in previous research.^{4 19} For example, in relatively understudied areas such as mental health, eating disorders, personality disorders and trauma in particular, the paucity of philanthropic funding sources and research centres of excellence have been identified as barriers to research progress, with a substantial gap identified between available funding and the immense burden of disease.^{4 26}

Respondents reiterated the value and desire for more patient and public involvement at each stage in the research cycle. Our findings were comparable to others

who have documented the need for patient engagement that is meaningful, helps build capacity and builds on partnerships,^{28 29} and ultimately, to align research better with community interests. Infrastructure such as dedicated treatment centres to support impactful engagement will be needed to advance a full range of patient and public involvement.³⁰

Different fundraising platforms, innovations in methodology, crowdfunding and other pioneering strategies were identified as ways to advance the democratisation of research culture. Alternative funding platforms can broaden topics studied, explore new frontiers, appeal to a broader group of citizens, integrate more diverse research methods and develop capacity building for less established researchers and centres. However, participants emphasised the importance of expert review, as seen in current processes, in maintaining trust in research quality. They noted that successful crowdfunding and other non-traditional funding strategies would require innovative approaches from the research community to ensure such confidence. Alternative approaches would also require researchers to develop different strategies to present the value of their research and to promote their work.

In a qualitative synthesis and pilot project, Kpokiri *et al*⁶ found that crowdsourcing presented an opportunity to decentralise research and dismantle elite power that can have roots in colonialism. Crowdsourcing presents an opportunity to democratise the process and encourage the evolution of research as part of healthy communities. Kpokiri *et al* also noted that crowdfunding was a way to enhance bidirectional communication, public engagement and trust, bridging the gap between the science community and society.

Along with the high interest in alternative funding approaches, interviewees identified the importance of mitigating potential risks in crowdsourced research. As others have found, particular oversight attention is required to counter risks of selection bias, manage regulatory hurdles and provide oversight.¹⁷

This study uncovered robust findings as an initial review of opinions about the current state of medical research from multiple perspectives.⁶ Several themes and a pathway for ways forward to more impactful and inclusive approaches to funding were uncovered and presented. We plan to explore further other findings pertaining to more finite topics such as knowledge translation and equity in funding in subsequent articles.

This investigation had limitations regarding the recruitment of participants. With purposive and snowball sampling, it was difficult to recruit representatives from broader members of each group such as researchers from broader areas of investigation, younger patients and members of the public who are more transient or not as easily reached in snowball or purposive sampling. We sought out participants who had some lived experience with medical research funding in their work, as research subjects, or as research scientists in other disciplines.

We acknowledge that sampling of researchers in our own network may have resulted in less generalisability of findings. While this common context and funding landscape to reference and find shared experiences, this limited the breadth of research experiences outside of the neuroscience community. As well, we did not have any participants who identified as Indigenous or gender diverse. Thus, a broader representation of research expertise and points of view may have also uncovered more diverse perspectives, and we acknowledge this selection bias. The findings show that further exploration and trial of alternative funding and infrastructure to support researchers are necessary to maximise the reach and impact of high-impact investigations. Suggestions to democratise research and explore alternative fundraising platforms necessitate a fundamental shift in how researchers can access necessary funds to support emerging areas of scholarship and innovation. As the research and research funding landscape is dynamic and the public has seen first-hand that great strides have been made in many areas such as the rapid response to the COVID-19 pandemic and the vaccine roll out, there appears to be further opportunity to expand the medical research platform into non-traditional areas of funding.

These findings will ideally contribute to the field by highlighting key considerations in developing modified or new funding paradigms. The research funding landscape is changing, and new funding models are emerging to counterbalance inequities in opportunity for new researchers and less established institutions. We found a high interest in further steps to democratise research funding and explore alternative fundraising platforms. We also found that international partnerships and more extensive patient and public involvement are welcomed new frontiers in research funding. Ongoing dialogue and collaboration in the research cycle will ultimately benefit a wider community of research end users. Further stakeholder discussion with a broader range of younger and visible minority patients and members of the public and less established researchers would add further to understanding a broader range of voices. Follow-up dialogue with stakeholders might also yield additional insight given that the topic is dynamic, and experiences change as new issues in research funding emerge.

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Patient consent for publication Consent obtained directly from patient(s).

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