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Attitudes and perceptions regarding knowledge translation and community engagement in medical research: the PERSPECT qualitative study

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Abstract

Background The medical research community widely endorses the importance of ensuring that research outputs are relevant and accessible to knowledge users, as well as the value of engaging the latter in the conduct of research to achieve these goals. However, it appears these principles are reflected in actual medical research practices to a limited extent. To better understand this dissonance, we conducted a qualitative investigation into the perspectives of key stakeholders on bridging the knowledge-to-action gap and patient and public engagement.

Methods The Priorities and Expectations of Researchers, Donors, Patients and the Public Regarding the Funding and Conduct of Medical Research (PERSPECT) qualitative study involved in-depth, semi-structured interviews with representatives of four stakeholder groups. Among other topics, participants were asked to discuss issues related to moving medical research knowledge into action (knowledge translation), including patient and public engagement during the research journey as a prerequisite to the success of this process. We analysed collected data employing an interpretative grounded theory approach. Data collection was ended once thematic saturation had been attained.

Results A total of 41 interviews were completed and analysed (with 10 patients, 10 members of the general public, 11 researchers and 10 funders). Many participants expressed a belief in the importance of engaging patients in the research process, as well as ensuring that study findings reach beyond academic communities. However, multiple challenges and barriers were identified to implementing these values in practice, including: researchers having limited knowledge and tools to foster partnerships with community members; research outputs being inaccessible to the wider public; and the public having insufficient capacity – in view of the required time, effort and knowledge – to assimilate findings and contribute to ongoing research. Cumulatively, interviews indicated a continuing disconnect between research and lay communities, where each stakeholder group holds some responsibility for improving the current paradigm.

Conclusions Existing gaps in communication, knowledge and relevant competencies are fuelling a disconnect between research and lay communities. Successfully moving research knowledge into action requires joint efforts

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of multiple stakeholder groups with support from external resources to ensure necessary training, expertise and credible dissemination platforms.

Keywords Knowledge translation, Patient and public engagement, Knowledge dissemination, Knowledge application, Implementation

Introduction

Each year, billions of dollars from public funds are invested in medical research worldwide [1, 2]. Concurrently, thousands of individuals devote their time and effort to participate in clinical studies [3], often exposing themselves to non-negotiable risks and costs, such as side effects of investigated treatments, fatigue from required study activities and distress associated with sharing sensitive personal information and experiences. Reliance on these essential contributions renders the research community accountable to the public, with a financial and ethical responsibility to minimize research waste and ensure that research findings reach those who can use them. In recognition of this accountability, the Canadian Institutes of Health Research propagated the term knowledge translation, defined as "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" [4, 5]. This and similar concepts have been adopted by many research-involved organizations, with variable terms gaining popularity in different disciplines and geographic locations, such as knowledge transfer, exchange or mobilization and research utilization [6].

Despite certain conceptual diversity, there is wide agreement as to a foundational agenda – to bridge the knowledge-to-action gap, and the key prerequisite for accomplishing it – the engagement of knowledge-users [5, 7]. There is a clear distinction between the latter and involving individuals in research as study participants. In what has been referred to, for example, as integrated knowledge translation, collaborative research or participatory (action) research, knowledge-users work with researchers in active partnership throughout the research process, leading to the co-production of knowledge [8–10]. Depending on the context, the term 'knowledge-users' may designate diverse stakeholders, including (but not limited to) healthcare providers, policymakers, patients and the general public. However, it is engagement of the two latter groups that has become a particularly prominent topic in the literature [11], as well as the focus of dedicated, national initiatives, such as the Patient-Centered Outcomes Research Institute in the United States [12–14].

Planning and carrying out research activities in partnership with patients and/or other members of the public aligns with democratic principles, acknowledging an individual's right to participate in research and healthcare decisions that may affect them, equalizing social relationships – formerly founded on professional elitism – and facilitating empowerment [15, 16]. There are also important pragmatic arguments to consider, with potential beneficial influences of community engagement pertinent to all stages of the research process [11, 17, 18].

In early research phases, community engagement has been suggested to promote defining or refining research questions to align with knowledge-user priorities [11, 19, 20]. Regarding study design and methods, reported effects encompass development of study protocols that are more ethically acceptable and less burdensome to participants, informing appropriate modes and timing of data collection, selection of outcomes relevant to knowledge-users, and planning culturally appropriate strategies to recruit specific populations [19, 21, 22]. These factors may in turn contribute to higher study enrolment and retention rates [19, 23–25]. Finally, end-users have been found to support more in-depth and accurate interpretation of study findings, and wider dissemination of results, as produced reports are perceived by the public as meaningful, understandable and credible [19, 26–28].

Despite these encouraging reports, however, engagement of knowledge-users in medical research remains suboptimal [29]. One study reported that across 3000 papers published in 2020 in a general health-research journal, only 21% included any form of patient and public engagement [30]. In another, focusing on randomized controlled trials in chronic conditions, the authors concluded that while 40% of analysed publications reported patient and public engagement activities, these infrequently occurred at a key stage of the research process [30, 31]. Such observations indicate a dissonance within the research community between the now widespread endorsement of the principles underpinning collaborative research as an integral component of knowledge translation and their practical adoption within current workflows.

The objective of this study was to gain a better understanding of this seeming discrepancy in the medical research world between endorsing and implementing knowledge translation principles, the cornerstone of which is engagement of knowledge users throughout the research process. To this end, we conducted a qualitative investigation into the perspectives of key stakeholders on issues pertinent to bridging the knowledge-to-action gap. We further aimed to develop a theoretical model grounded in captured stakeholder views, to spotlight potential avenues towards improving the real-world impact of medical research.

Methods

The present study forms a part of the Priorities and Expectations of Researchers, Donors, Patients and the Public Regarding the Funding and Conduct of Medical Research (PERSPECT) project. PERSPECT was a qualitative investigation, adopting interpretive grounded theory methodology [32, 33]. During semi-structured interviews, participants representing different stakeholder groups were asked about their views on the current state of medical research and alternatives to established funding models. Here, we focus on issues that were discussed in relation to knowledge translation and patient and public engagement. In reporting this study, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ).

During the study period, members of the research team were based at the University of Calgary in Canada, holding the following credentials and occupations: A.G. (MD, PhD) – neurologist, assistant professor of neurology and principal investigator for the study, A.S. (BA) – research assistant, B.A.D. (PhD) – postdoctoral associate, J.F. (MD) – neurologist, M.G. (MD PhD) – radiologist, N.C. (PhD) – research associate, R.M. (MD) – radiology fellow and T.J. (MD) – stroke fellow. All interviewers and coders underwent supervised training in qualitative research methods, with N.C. and A.G. having expertise in this area through conducting previous qualitative studies. All authors had either direct or indirect (e.g. through participation in lab meetings, hearing colleagues' testimonies) exposure to issues discussed during the interviews.

Participant sampling

Participants were selected with an aim to provide equal representation of four stakeholder groups: (i) researchers – investigators in basic and clinical sciences, previously involved in at least one research grant or award application; (ii) funders – board members of research funding organizations and philanthropists focussed on medical and research causes; (iii) patients – persons with lived experience (PWLE) of any noncommunicable disease; and (iv) members of the general public. We began with purposive sampling within our own research network, inviting researchers and funders in areas of cardiovascular medicine and neurosciences, as well as patients from local advisory groups. Subsequent participants, including all those representing members of the general public, were recruited through snowball sampling, that is, following contact recommendations made by prior interviewees [34].

As entailed by our sampling strategy, a subset of participants had been professionally acquainted with A.G. or M.G. prior to study commencement. All participants were approached through an introductory email. Its content, together with the provided participant information sheet and consent form, briefed participants on the purpose of the study.

Data collection

Five members of the research team (A.G., A.S., J.F., N.C. and T.J.) conducted semi-structured interviews with participants via Zoom, following a topic-specific interview guide (Additional file 1). Participants were initially requested to allocate 60 min for the virtual study visit, however, its ultimate duration was determined on a case-by-case basis according to participant initiative. Interviews were digitally recorded and then transcribed. Transcripts were supplemented with memos, noted after the interviews to capture initial impressions. Data collection was ended once saturation had been achieved, defined as the point at which five consecutive interviews did not lead to any new emergent themes [35].

Data analysis

Figure 1 provides an overview of the iterative approach we followed, representing an adaptation of Corbin and Strauss' interpretive grounded theory method [33]. The analysis was conducted concurrently with data collection by four members of the research team (N.C., B.A.D., T.J., A.G.). We imported interview transcripts into NVivo 12 Plus software, where they were coded across three stages. In the first stage of open coding, we read and re-read the transcripts line-by-line to ensure full immersion, and generated initial codes to capture key concepts in the data. In the second stage of axial coding, we identified relationships between the initial codes, organizing them into categories and subcategories. In the third stage of selective coding, we further refined and integrated the categories to establish core themes and form a theoretical framework for a comprehensive understanding of the data.

The analysis was facilitated by a consistent use of memos to document initial impressions and interpretations. We employed the constant comparative method throughout the entire process, continuously comparing and contrasting different data excerpts, codes and categories. Emerging constructs were validated through triangulation, which involved an exploration of differences

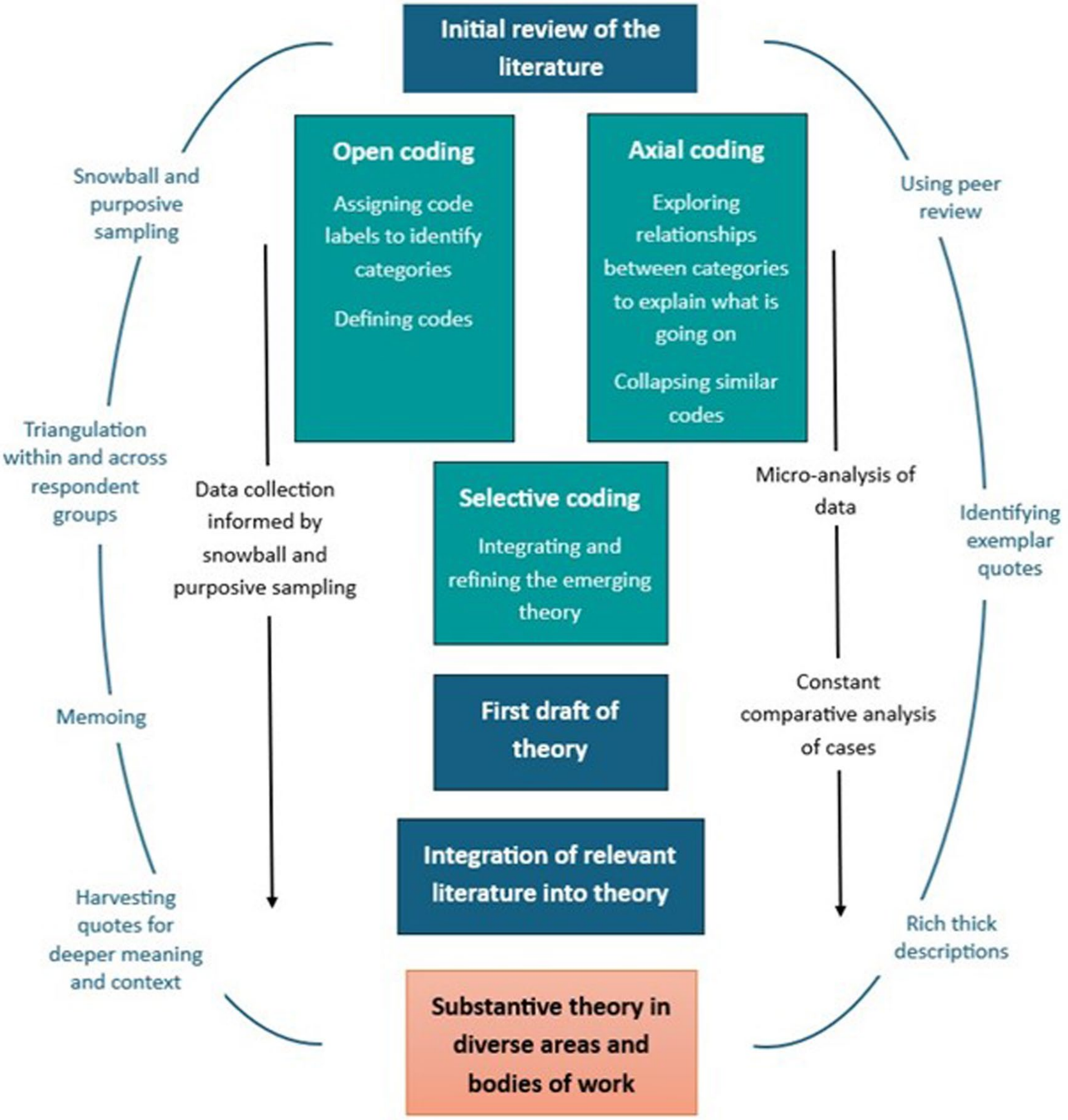

Fig. 1 Graphic overview of methodology

and similarities between stakeholder groups, and utilizing the perspectives and interpretations contributed by each investigator.

Public engagement

We sought external feedback regarding our project through publishing a lay summary of the PERSPECT protocol on an online public engagement platform for medical research (https://www.letsgetproof.com/project/perspect-1648878988). The discourse that followed informed our decision to focus the investigation on North American/European countries with substantial public investment in medical research, supporting greater study feasibility and ability to interpret study findings in light of existing, comprehensive literature. The interview guide was further developed with non-academic partners, ensuring that presented questions would be accessible to all participants, regardless of background and current occupation.

Results

We invited 51 individuals to take part in the PERSPECT study, of whom 5 did not respond and 5 declined participation. In total, we conducted 42 interviews with 11 researchers, 10 funders, 10 patients and 11 members of the general public. One transcript was withdrawn from analysis by a member of the public for personal reasons. Participant demographics are presented in Table 1. In reporting our findings, we used the term "lay community members" to jointly denote patients and members of the general public, aiming to distinguish this population from those professionally committed to research conduct or utilization of research knowledge (researchers, funders, clinicians and policymakers).

The central phenomenon that we observed from the data was a disconnect between the research and lay communities. Contributing to it were three main themes, highlighting barriers and limitations to: (i) engagement of lay community members in the research process, (ii) sharing research findings with non-academic audiences (knowledge dissemination) and (iii) moving research knowledge into action (knowledge application). Conversely, the importance of addressing this disconnect was underscored by a fourth theme, indicating that collaborative contributions are necessary to ensuring meaningful impact of medical research. A detailed description of the four themes and associated subthemes is provided below, complemented by a summary table with exemplar quotes in Additional file 2.

Table 1 Participant characteristics ($N=41$)

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

Theme 1: Engagement of lay community members in the research process

Across all participant groups, many statements spoke to the importance of engaging those outside academia in research. However, there were apparent differences in how interviewees perceived the role of lay community members, what aspects and stages of the research process they should be involved in and who is capable of making a meaningful contribution. On the basis of multiple interviews, it appeared that endorsed avenues of input consistently differed for patients as compared with members of the general public.

Role of the general public

A prominent subtheme defined the general public's role as contributors to research funding through private donations and tax payment, as well as through cause advocacy (public shows of support for a particular initiative, for example, charity walks/runs). Here, it was noted that increasing public awareness of ongoing research through improved dissemination is a promising avenue towards gaining financial support.

> *I do think that if different studies were presented to the public for the value that they can provide towards advancing medical care, when they should have high level overview of understanding of what the research is trying to achieve. Then, [...] having public aware that there's potential to help fund some research, the public that is interested in funding important research, then I think that can be an enormous opportunity, because [...] funding is obviously lacking in anything that we're trying to do, when it comes to research (Researcher 102).*

Some participants highlighted that the nature of this relationship renders reciprocity critical, with expectations not only of a meaningful impact of conducted research, but also a transparency as to how public funds are being used. As stressed by one of the participants: "I don't think taxpayers should fund any of it, if it doesn't benefit us, if we don't know what the benefit is" (Patient 302).

Beyond financial contributions, the idea of the general public's involvement in other aspects of research was met by some with scepticism, particularly in relation to determining research directions and study design. A key concern was that a multiplication of opinions to incorporate, voiced by people with minimal background knowledge on research methods or topics of interest, would ultimately hinder research progress rather than support it.

> *But currently as you ask me right now, I'm just not so excited about the public necessarily being involved in research decisions, maybe because I haven't thought of that before and I'm not thinking about the right avenues where that can happen, and that can actually be productive. So I'm very much open to ideas with regards to that. But it's just challenging right now for me to imagine a way to for that to be helpful without just wasting a lot of money and time (Researcher 106).*
>
> *It's always tough, because just like in anything else, it's always good to democratize. But the general public also has no idea what they want and what they're talking about, and they often prioritize the wrong things. So you do need some actual forward thinkers, professionals, people that really understand these things (Member of the public 402).*

Role of patients

The lived experience of a disease was considered by many participants a crucial asset for ensuring relevance and impact of conducted research, complementing the professional knowledge and skills possessed by researchers. This notion was mostly emphasized in relation to research priority-setting and informing salient aspects of study design. Reflecting on an attended research project meeting, one patient explained:

> *It was quite enlightening how many things the professionals – people that are much smarter than I – were saying and making decisions on and yet I'd listened to it and think but that wouldn't work [for patients], and this is why. And that's the piece they miss, right? They don't know that wouldn't work because they don't live with it. So that was the first I think big sort of a light bulb moment where it's like we really need to be working together so that – you know – you've got the brains and the intellect but I've got the lived experience that I know what it's like, because, unfortunately, I'm living it (Patient 308).*

Common agreement regarding the value of patient engagement was coupled with variable views on its status in current research practice. Some participants spoke to an evident improvement in this area in recent years.

> *There seems to be a really strong push towards getting patients involved even at the research level. And more and more often, we're getting trained up to do that. And my understanding is a big part of the reason for that is to make sure that the there is relevance that what patients actually need is what's been studied (Patient 304).*

More commonly, however, participants expressed the opinion that there is a continued lack of opportunities for patients to meaningfully engage in the research process. Among identified issues were: (i) maintaining the research community a "closed world" (Patient 303), where the potential value of patient input is disregarded; (ii) including patients in research activities in a "superficial or tokenistic way" (Researcher 105), only to satisfy requirements of funding agencies or to obtain validation of predetermined research directions; and (iii) insufficient support for patients who within research teams "don't have the confidence to participate, that feel that they're out of their league" (Member of the public 409).

Overall, this first theme indicates that while input of lay community members into the research process is to some extent valued, particularly insights gained through lived experience of a condition, research-related competencies continue to be prioritized. This contributes to a disconnect between academics and non-academics through undermining the potential of the two communities to work in partnership and upholding a power imbalance in research decision-making processes.

Theme 2: Knowledge dissemination

Many participants expressed the opinion that research knowledge is being inadequately shared with non-academic audiences. Within this issue, we identified two distinct subthemes – one focussing on perceived challenges to knowledge dissemination, and one involving suggestions as to how it can be improved.

Challenges to knowledge dissemination

Participants' statements pointed to the dual nature of challenges, with apparent limitations pertaining to the communication of knowledge by researchers, on the one hand, and the ability to assimilate that knowledge by the public, on the other. Speaking to the former, a member of the public emphasized:

> *I think that they're sharing [medical research knowledge] with each other. Medical researchers are sharing with medical researchers. It's so deathly boring, that the average general public can't even get through like a medical journal, a published medical research paper, like, I would say that I am at least average intelligence. And I really struggled, like I said, inaccessible information. Completely inaccessible (Member of the public 410).*

Barriers to accessibility were further discussed in relation to paywalls maintained by medical journals and the experience that "for the average person finding any kind of credible information on the internet can be really difficult" (Patient 301). These circumstances were in turn considered inducive to misinformation.

> *I think, you know, through the pandemic, there's been sort of a general sort of confusion and misunderstanding, and especially with social media, and how information is shared online. And, you know, there's a lot of fake news, there's a lot of people who are, you know, sort of spewing, you know, maybe with good intentions, but still spewing incorrect facts about different medicines (Funder 207).*

Independent of shortcomings attributed to the research community, some participants recognized that the public's potential to engage in medical research is stifled by the consuming demands of daily life. As concerns around "putting food on the table" and "housing and family issues" (Member of the public 409) take priority, many people are unable to contribute the time and effort needed to understand and evaluate ongoing research.

Ways to improve

Participants, particularly patients and members of the general public, highlighted a number of ways in which dissemination of research knowledge could be improved. Suggestions focussed on showcasing only key messages, using plain, easy-to-understand language, with "short, punchy, in your face stuff" to "pique your interest" (Patient 304). With reference to increasing accessibility of research knowledge, a member of the public proposed:

> *There's very little attempt by anyone to make it understandable for regular people. So maybe something like that where there's some way of summarizing these things in a way that people can actually understand. I just imagine having a system where there was more research out there, and it could actually make more headlines and be and be more available to people. That there are these systems that are created for people just being able to check up on research (Member of the public 402).*

In summary, this second theme indicates a perceived need to address a disconnect in communication, as the language and knowledge dissemination channels used by researchers tend to be poorly aligned with the needs, preferences and prior knowledge of wider audiences.

Theme 3: Knowledge application

This theme captures perspectives on the process of moving research findings into action and the real-world effects this has. Regarding the latter, many participants conveyed a belief that medical research provides the necessary knowledge and tools to drive improvements in healthcare, individual health outcomes and quality of life. As illustrated by the quotes below, some participants expressed their reflections in general terms, while others pointed to specific, personal experiences.

> *It's critical, like it's, we absolutely need to have medical research to inform, you know, appropriate care and treatment. And 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 201).*
>
> *Medical research is how somebody like me is able to cope really well with my disease, because 15 years earlier, I wouldn't be. So I think it's great (Patient 304).*
>
> *I can still remember going to the beach as a young child, and burning, you know, because it was just considered part of the experience. We now know that those early burns do increase the risk for skin cancers later in life. So we, I think, are learning to be much more respectful about our exposure to sun. So there's lots of ways that my own behaviours, including even how much alcohol I'm comfortable drinking, how are my behaviours are being impacted by evidence and by science. I'm very grateful for that (Member of the public 409).*

In contrast, several statements focussed on challenges to implementing research findings in practice as a consequence of research processes being flawed, even from the earliest stages. Here, participants indicated doubts as to whether available funding, resources and the capacity of research teams are utilized to their full potential. Issues related to research priority-setting, established value systems, standard forms of conduct and inadequate knowledge dissemination were viewed as barriers to efficiently moving new knowledge into action, at the expense of those who could benefit from it the most.

> *I think medical research there's a lot of challenges, challenges related to funding, challenges related to what is actually where the funding is going and if we're doing the right things, if we're doing the most optimal, most efficient things, or if we're spending a lot of money on things that might not turn out to be useful. And then in those things that do end up being useful, or clinically applicable. How can we translate those into practice quickly, and actually use those findings in a positive way (Researcher 106).*
>
> *I think because [research findings are] not out there, not only does it take away our right to that*

> *knowledge, it takes away our right to use that knowledge to better our health care. And that's a failure on the system (Patient 303).*
>
> *How many years does it take for a study to get into practice? You know, you known that I was in nursing education most of my life. And 30 years ago, or 2 years ago, it was the same story, same story. And that I don't think that's changing much. And I don't think there's the potential for it to change a whole lot. Given the way academia rewards researchers, long as the published articles in peer reviewed journals are the primary way of getting rewards that won't change, in my opinion, and I've said this in many venues, the research findings need to get to the patient first, I'm the ultimate user, to get the research findings (Patient 307).*

The above quotes convey how issues addressed by the first two themes – limited knowledge-user engagement and ineffective dissemination – impede real-world application of research outputs. Specifically, the latter may either not reach knowledge-users or prove to be irrelevant to their actual needs, indicating another facet of detachment between the research and lay communities.

Theme 4: Shared responsibility

The last theme, reflected throughout the ones prior, encapsulates the notion that successful knowledge translation requires joint efforts of multiple stakeholders. Although here researchers are proposed to maintain the role of primary project executors, other stakeholder groups meaningfully contribute to different stages of the research process, ultimately improving its real-world impact.

The majority of participants considered the value of such combined effort in the context of cooperating dyads, invariably including researchers as one of the partners. Most apparent examples relate to theme 1, where the relevancy of conducted studies was recognized to rely on successful collaboration between researchers and patients.

> *I find quite often in research, the researchers and medical professionals – they all have these questions they want to answer but once you talk to patients, you will find out the questions you wanted to answer actually are not the questions that need to be answered or the questions that impact patients in their day-to-day life right? It's stuff that sure is great and interesting, but there needs to be the tying of how that impacts, so that together – that research is really strong (Patient 308).*

In ensuring that instigated projects address issues of community priority, the role of members of the general public was also noted – in this case, through supporting researchers in securing funding. On the basis of personal experience, one participant recalled:

> *I know even in small city [Name], before I left, we were able, the community was able to secure some Health Canada funding to do research on substance use that would never have been funded if it hadn't been for federal money. So yes, those interest groups have a role to play. And, and I mean, look at breast cancer research. You know, they have a role to play from the bottom up, they appeal to people (Member of the public 409).*

Taken together, such examples indicated that through different avenues multiple stakeholder groups can meaningfully contribute to a particular stage of the research process. This idea was also crystallized in singular participant statements. As one patient elaborated on the issues of improving knowledge dissemination:

> *The researchers themselves as part of the funding model should be responsible for making sure it's been disseminated properly. Also, the funding agency, these, I think need to be accountable for where they're directing their dollars. And as part of that, making sure the right messages are getting out. I also think the consumer of information has got some responsibility. And that's the piece that we don't have a lot of control over. And we've all become really lazy viewers and readers of information, and everybody wants a sound bite, and you can't get a lot of this information in a sound bite. So I think everybody shares the responsibility in different ways (Patient 304).*

Improving research impact: a conceptual model

We synthesized key messages from all our themes, regarding barriers and suggested solutions to bridging the disconnect between research and lay communities, and the roles of multiple stakeholders in the research process. This yielded a conceptual model, presented in Fig. 2, which showcases potential avenues of improving the real-world impact of medical research through enhanced contributions of community members. Integral to this model is the concept that successful knowledge translation requires joint efforts of multiple stakeholders, which was at the heart of theme 4.

As depicted, more accessible and effective knowledge sharing by researchers can lead to increased awareness and understanding of medical research among lay community members, in turn supporting them to

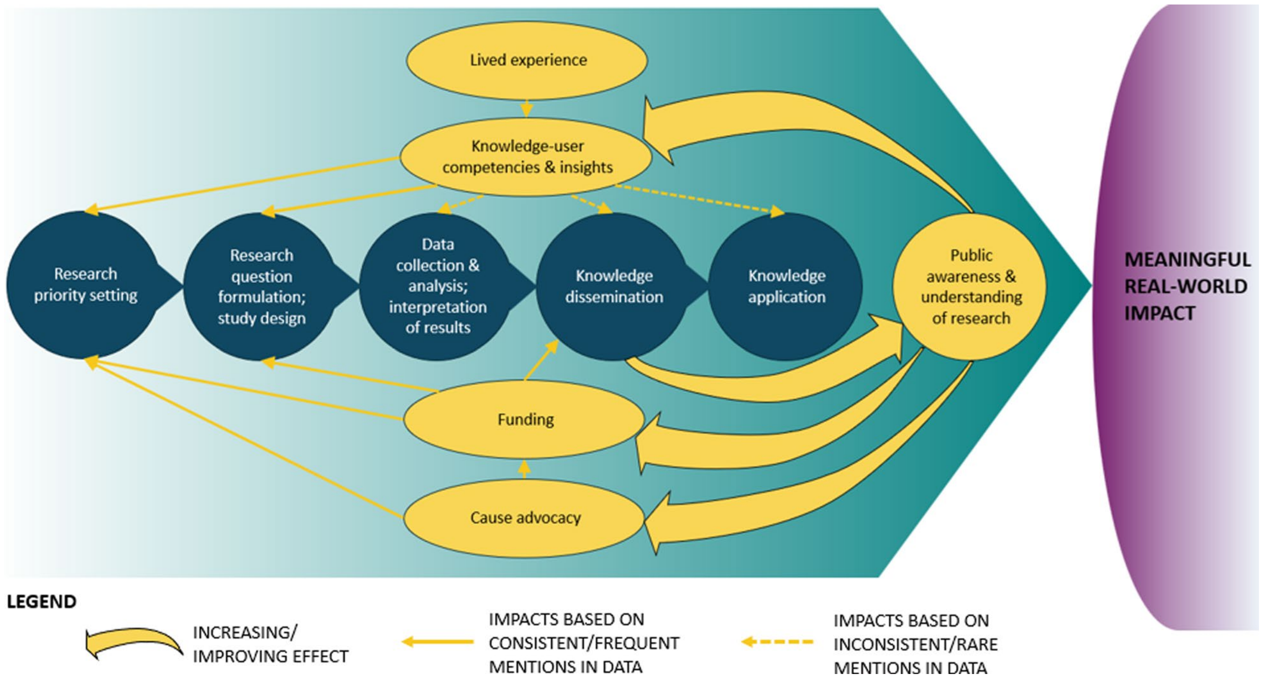

Fig. 2 Data-informed conceptual model of improving real-world impact of medical research through enhanced contributions of lay community members. Teal circles represent core stages of the research process, while yellow ovals represent sources of contribution from lay community members. "Cause advocacy" relates to public shows of support for a particular initiative, for example, charity walks/runs. "Knowledge-user competencies & insights" collectively refers to: **a** knowledge and skills gained through lived experience of a condition, other life experiences and research exposure and **b** the ability to share these assets with researchers

meaningfully contribute to ongoing projects. Avenues of contribution involve cause advocacy, funding support and direct informational input and involvement in decision-making. The latter was particularly associated with the role of patients, whose capacity to benefit the research process, resulting in relevant, implementable outputs was seen as enforced by the lived experience of disease. As community contributions enhance the effectiveness of knowledge dissemination (amongst other stages of research), the model represents a continuous cycle of improvement.

Discussion

In this qualitative investigation into perspectives on knowledge translation and patient and public engagement in medical research, the central phenomenon we identified was a continuing disconnect between research and lay communities. Specifically, the first theme highlighted the perceived prioritization of research-related competencies over community members' insights regarding investigated topics (including those stemming from lived experience), in turn upholding a power imbalance in relationships between academics and non-academics. The second theme captured the notion that the language and communication channels used by researchers are often inaccessible to wider audiences. The limitations in meaningful engagement of lay community members and effective knowledge dissemination were in turn recognized as important barriers to real-world application of research outputs, as the latter either do not reach intended end-users or are irrelevant to their actual needs (third theme).

At the same time, we observed a common desire to bridge this divide. Multiple participants expressed a belief in the value of engaging patients in the research process, particularly at the early stages of priority-setting and study design. There was also high interest in ensuring that study findings reach beyond academic communities. These observations confirm cumulative conclusions from the existing literature [36]. Namely, initiatives to reduce the knowledge-to-action gap through collaborative research approaches are not undermined by a failure to recognize their importance by key stakeholders. Rather, as emphasized by some of the study participants, there are persistent challenges and barriers to implementing relevant conceptual recommendations in day-to-day research practice.

Challenges and considerations regarding the researchers' role

Focussing on the role played by researchers, identified issues reflected uncertainty as to how to engage community members in ways that are meaningful and advantageous to a project, particularly given existing time and resource constraints. A perceived lack of relevant knowledge and tools to foster partnerships with patients or members of the public may dissuade from collaborative pursuits or lead to attempts that are unproductive and even harmful. In a recent publication authored by patient partners, [37] four problem statements were described in relation to real patient engagement situations, including: (i) tokenism, where patients become involved as part of a "box-ticking" exercise, [38] with no true influence over the research process; (ii) unconscious bias towards formal credentials, devaluating lived experience; (iii) insufficient support to allow patient partners full participation as team members; and (iv) a failure to recognize the vulnerability of patient partners, as they share personal, emotional experiences. The first three of these issues were echoed in our interviews, underscoring the ongoing need for training and educational resources to support researchers in efficiently implementing collaborative research principles in their work.

Challenges and considerations regarding the patient and public's role

In view of the role of lay community members, the potential to be active partners in research was considered limited by an insufficient knowledge of topics under study, as well as research methods and gold standards of practice. It was also highlighted that understanding research outputs requires time and effort, which many people are unable or unwilling to contribute. Following a 2017 survey including more than 12 400 participants from 68 countries, the authors concluded that the public's awareness of clinical research conduct and processes remains limited, with most participants unable to name a place where studies are undertaken (59%) or an agency that oversees research safety (66%), while only a third of respondents correctly estimated the typical duration of a drug-development cycle [39]. One way to facilitate public understanding of what medical research involves and how it is done, and in turn – the capacity for building equitable partnerships between researchers and lay community members, could be through more effective knowledge dissemination – an initial link in a chain of effects to improve real-world research impact, as indicated in our data-informed model.

At the same time, it is important to stress that while a certain understanding of the research world is an asset, meaningful engagement of lay community members is not contingent on developing research-specific competencies [40]. The experiential knowledge of living with a disease as possessed by patients is in itself a foundation for impactful contributions, which can be further strengthened by skills relevant to sharing that knowledge [41]. For obvious reasons, the same type of insights cannot be offered by members of the general public. It is, however, this lack of a direct, personal connection to a particular medical topic that allows for their impartial involvement in decision-making processes on matters of broader societal interest, such as funding allocation across different areas of medical research [42]. Ultimately, what kind of lay and research-related expertise is needed for meaningful engagement of community members will depend on the individual project characteristics and at what stage lay input is sought.

Importance of joint stakeholder contributions

As alluded to above, the unique, complimentary nature of competencies possessed by different stakeholders, where the representative of one group cannot replace that of another, makes joining efforts key to the success of knowledge translation. This point can be illustrated through the example of effective knowledge dissemination. It is typically the researchers' responsibility to produce reports (or other forms of presenting information) that are accessible to the wider public. However, accomplishing this task could be ensured by the research funders' requirement to do so, on the one hand [43], and the knowledge-users' involvement in co-production of research outputs, on the other [23, 26]. Additional aid could be obtained from resources external to a given project. For example, established web-based platforms provide not only a means to showcase conducted research, but also a forum to create an active dialogue between researchers and knowledge-users [44–46]. Finally, for knowledge to be shared, it not only needs to be provided in an accessible manner, but also assimilated in changed behaviours or other clinical uptake, the responsibility of which lies with the intended audience.

The value of joint stakeholder efforts can be similarly anticipated for all stages of the research process. In addition to shared experiential knowledge of lay community members informing research questions and salient aspects of study design (e.g. ethical considerations, recruitment strategies, choice of outcome measures), our interviewees highlighted two other prominent areas of contribution, sourced beyond researcher groups. This included agency funding, which – in addition to providing essential financial resources – can influence standards of research conduct through setting specific requirements for grant applicants (e.g. regarding evidence of patient engagement and comprehensive dissemination strategies). Secondly, there is financial support and promotion of prioritized research causes undertaken by the general public (e.g. through organizing and participating in fundraisers and awareness campaigns), indirectly influencing research trends. However, many publications indicate that for the key actors (researchers, funders, patients and the public) to work together in a sustainable, meaningful and equitable collaboration, substantial external resources are also needed [47].

Importance of external resources

Among these resources are programs aimed at increasing research literacy of lay community members, facilitating their engagement in research projects and participation in the review of grant proposals [48–50]. One of their intended effects – developing competency as critical consumers of research outputs – is further relevant regardless of intentions to be involved in research, and could enhance the public's recognition and assimilation of health information on the basis of high-quality evidence. As such, it has been postulated that research literacy should be addressed as part of the compulsory education curriculum [51, 52]. Similarly, there is an evident need for researchers to undertake capacity-building training in knowledge translation approaches and processes, comprising tools to support patient and public engagement and dissemination [53, 54].

Even with these provisions, the required time commitment and complexity of building research partnerships are such that recent publications have emphasized a clear need for staff members devoted to patient and public engagement [55–57]. As part of a permanent (rather than project-limited) entity within research institutes, these groups of experts play a vital role in recruitment of community members – forming stable networks – planning and managing engagement activities across projects, and supporting community-partners to become full-fledged members of research teams [55]. Finally, for all of the identified training and resource needs to be addressed, funding bodies must plan their budgets in view of associated costs and adjust grant proposal requirements accordingly.

Strengths and limitations

The presented findings are based on interviews with near-equal representation of four stakeholder groups, each offering a unique perspective on issues of interest. Most of the researchers were also practising clinicians, and thus had broad experience not only in conducting research, but also in implementing evidence in patient care. The interview guide was developed in collaboration with non-academic partners to ensure that questions were accessible to all participants. We applied a rigorous, prespecified approach to data analysis, incorporating data source and investigator triangulation, [58] continuous memoing and development of definitions for identified codes and themes. Moreover, in line with the aims of the larger PERSPECT project, the interview guide covered a breadth of topics on the current conduct of medical research and both established and alternative funding paradigms. We found that this enriched our data, as participants had additional opportunities to speak to issues of knowledge translation and patient and public engagement, beyond responding to targeted questions.

At the same time, however, it was not feasible to specifically address all relevant aspects. For example, with there being no corresponding prompts, few participants spoke to lay member involvement in data collection and analysis, or the practicalities of using research findings to guide policymaking and healthcare-system-level change. Another important limitation relates to a lack of representation of policymakers in our study sample. Compared with patients and the general public, this population experiences distinctive challenges related to knowledge use in a professional context, where decisions impact entire practice communities. As such, their insights are much needed to gain a holistic understanding of current issues in knowledge translation, and should be addressed in future studies.

Conclusions

We found that existing gaps in communication, knowledge and relevant competencies are fuelling a continuing disconnect between research and lay communities. At the same time, there was a common desire to bridge this divide in the interest of producing research knowledge that is relevant to end-users. Our findings underscore the importance of collaboration between multiple stakeholder groups for successful knowledge translation, with support from external resources to ensure necessary training, expertise and credible dissemination platforms.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12961-025-01306-y.

Additional file 1: Additional file 1_Interview Guide.pdf

Additional file 2: Additional file 2_Summary of themes with exemplar quotes.docx

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Author contributions

B.A.D. and N.C. analysed the study data and drafted and revised the manuscript. J.F., T.J., A.S. and R.M. performed data collection and critically revised the manuscript for important intellectual content. M.G. contributed to study design and manuscript revision relating to critical content. A.G. conceived and designed the study, obtained funding, provided supervision and revised the manuscript. All authors approved the current version of the manuscript.

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Availability of data and materials
The datasets generated and/or analysed during the current study are not publicly available due to the potential risk of identifying participants from interview content, but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
The study was approved by the University of Calgary Conjoint Health Research Ethics Board (REB21-1592). All participants provided informed consent.

Consent for publication
Not applicable.

Competing interests
AG reports stock options from Let's Get Proof (Collavidence Inc.).

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