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Health researchers' experience collaborating with patient partners: a qualitative study

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Abstract

Background Patient-oriented research (POR) and patient engagement (PE) have been increasingly adopted over recent decades, as they generate many positive academic and patient outcomes within various health research fields. While there has been research on the barriers and challenges experienced by patient partners (PPs), we know little about the experiences of the health researchers working with them. It is therefore important to gain a better understanding of the experiences of health researchers who work with PPs to improve their collaboration. This study, which was initiated by PPs themselves, aims to enhance the understanding of health researchers' experiences regarding the challenges of working with PPs.

Methods This qualitative descriptive study involved 20 semi-structured interviews with researchers from various health science fields, such as primary care and general medicine, public health and health policy, specialized medical fields (i.e. cancerology, endocrinology, psychiatry, gerontology), biomedical engineering and medical technologies, and neuroscience. Participants, including researchers and research coordinators, were recruited through purposive sampling via email, newsletters, and social media, with their participation being voluntary and uncompensated. Thematic analysis was conducted over multiple steps, and the interview transcripts were coded to identify the main themes and subthemes relevant to the study's aims.

Results The analysis resulted in six main themes: 1) PP individual and health-related challenges; 2) institutional barriers to PP involvement; 3) challenges in genuine PP involvement; 4) collaboration challenges in research projects; 5) time constraints in research projects; and 6) PP recruitment and representation issues.

Conclusion The findings of this study provide an in-depth view of the challenges experienced by health researchers who have involved PPs in their projects. However, it is important to highlight that this study goes beyond simply identifying challenges. These challenges are often interconnected and complex and influence one another in such a way that controlling for one element may cause further constraints in another. This article provides recommendations regarding current practices, ethics-related questioning, and time-related challenges, which will be useful for the continued meaningful involvement of PPs in research teams and for navigating the challenges.

Keywords Patient-oriented research, Patient partner, Patient engagement, Patient involvement, Health research, Qualitative, Thematic analysis, Challenges, Recommendations

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Plain English Summary

Patient-oriented research (POR) and patient engagement (PE) generate many positive academic and patient outcomes within various fields of health research and have gained much recognition in recent decades. Researchers who conduct POR and work with patient partners (PPs) benefit from valuable insights into the subject at hand through their rich encounters with PPs. Meanwhile, there remain some challenges and grey areas within POR—specifically, PE—that need to be explored. Thus, this article, which was initiated by PPs themselves, aimed to explore the barriers and challenges experienced by health researchers collaborating with PPs. Thematic analysis was conducted using 20 semi-structured interviews. The analysis revealed six main themes and their subcategories: PP individual and health-related challenges, institutional barriers to PP involvement, challenges in genuine PP involvement, collaboration challenges in research projects, time constraints in research projects, and PP recruitment and representation issues. These challenges are often interconnected, complex, and influence one another in such a way that controlling for one element may cause further constraints in another. Suggestions regarding current practices, ethics-related matters, and time-related challenges are discussed with the hope of encouraging the inclusion of PPs in research teams and guiding the navigation of the challenges.

Background

Over recent decades, patient-oriented research (POR) and patient engagement (PE) have been integrated into policies guiding and funding health research [1–3]. POR refers to a "continuum of research that engages patients as partners, focuses on patient-identified priorities, and improves patient outcomes" [4]. It is centered on research on interventions and outcomes that patients, clinicians, and researchers consider important [1, 5]. Meanwhile, according to the Strategy for Patient-Oriented Research (SPOR) from the Canadian Institutes of Health Research (CIHR), PE refers to the involvement of patients in health care, research, governance, and priority setting [4]. The involvement of patients in research beyond their role as participants has many recognized benefits, including enhancing the quality of the research, improving patients' care, and resulting in better patient outcomes [2–4]. Patients who collaborate with research teams to achieve meaningful engagement are known as patient partners (PPs). In Canada, the engagement of PPs is guided by the SPOR. The SPOR articulates PE, which is employed in POR, around six principles: inclusive mechanisms and processes, multi-way capacity building, multi-way communication and collaboration, experiential knowledge of patients valued as evidence, patient-informed and directed research, and a shared sense of purpose [4].

Meaningful engagement can be fostered in all phases and contexts of research [1, 5]. Strategies for meaningful PE, such as establishing a clearly defined PE plan (roles, duties, and expectations) from the outset of a project, have been described in the literature [2, 5]. To support the engagement of PPs, research teams have implemented the following: providing orientation and education about research and PE, providing ongoing support for PPs, giving encouragement for and recognition of PPs' contributions, ensuring a trusting and positive environment by providing structural support, and including a plan for the evaluation of engagement [2]. Existing studies have examined the perspectives of health researchers regarding their experiences with PPs in research projects [6–8], addressing topics such as motivations, attitudes towards PE, the contexts in which PE occurs, and the barriers and facilitators to meaningful engagement. However, few studies have focused specifically on the challenges faced by health researchers working with PPs [7]. To our knowledge, no other study specifically focuses on the experience of researchers regarding the challenges they face when working with PPs. Other studies either included both PP and researcher perspectives [6–8], included family members of PPs [8], or used group discussions instead of one-on-one interviews [6, 8]. Some studies also focused on specific fields of research, such as cardiovascular health [8], or had different aims altogether. In addition, our study specifically examined the perspectives of health researchers working in Quebec (Canada), which, while sharing similarities with other regions or countries, is unique in many ways. Since PE is important to best address the needs of patients, identifying the challenges that researchers face when collaborating with PPs is therefore of high importance. This study, which stemmed from an idea conceived by the PPs in this project, seeks to provide additional information and insights pertaining to health researchers' experiences regarding the challenges they encounter with PPs.

Methods

Design

This project is a qualitative descriptive study [9]. This design was chosen because it allows for an in-depth exploration of the experiences of researchers and for understanding the context of their work with PPs. Semi-structured interviews were conducted with researchers who had collaborated with or were currently working with PPs on research projects to better understand their experiences and views regarding this type of collaboration. This project stemmed from an idea conceived by the PPs involved in this study (CW, DB). They were engaged at every stage of the project, from the grant application to the final revision of the manuscript, with the aim of better understanding researcher–PP collaboration and advancing research through valuable firsthand knowledge and experience (see Additional File 1). They helped with constructing the interview guide, analyzing the results, and revising this article. They provided feedback and constructive ideas based on their experiences with PE in research and with various teams within the health-care system, from the clinical field to high-level governmental strategic committees. Working with PPs (CW and DB) in this study allowed the authors to gain a deeper understanding of the dynamics of PP–researcher collaboration, including differing viewpoints, and more. The PPs provided a significant motivating factor for this study through their enthusiasm for the project and their strong desire to achieve results. Finally, while writing this article, the authors followed the Consolidated Criteria for Reporting Qualitative Research (COREQ), which is a 32-item reporting checklist, to ensure the quality and complete reporting of this qualitative research project, which involves participant interviews (see Additional File 2) [10].

Participants

To take part in the study, participants had to be health researchers above the age of 18 who were based in Quebec and had incorporated one or more PPs into the framework of one or more research projects. The only exclusion criterion was if potential participants were unavailable at the time of data collection. Recruitment was conducted via email, newsletters, and social media (Facebook and LinkedIn). Among the cohort of people interested in participating, 20 initial volunteers were recruited through purposive sampling and no participants declined to participate when contacted. The participants included a greater number of women (65%) (*n*=13) than men (35%) (*n*=7). In terms of employment, positions included: assistant professors (*n*=4), full professors (*n*=4), associate professors (*n*=3), doctoral students (*n*=2), research coordinators (*n*=2), research professional (*n*=1), postdoctoral fellow (*n*=1), doctoral student/research supervisor (*n*=1), medical doctor/assistant professor (*n*=1), and researcher/associate professor (*n*=1) (see Table 1). The team ensured a diverse sample of experiences regarding occupations and fields of expertise. Additional participants were not solicited because empirical saturation was reached [11]. In other words, the authors aimed to recruit 20 participants, and as the interviews progressed, the authors observed that new data became repetitive, signaling that saturation had been reached. Participation was voluntary and did not include financial compensation.

Table 1 Study participants' characteristics

Participant code	Gender	Employment	Health research field
PP-CH-002-F	F	Assistant professor	Nursing science
PP-CH-001-H	M	Full professor	Breast and brain cancer
PP-CH-007-F	F	Assistant professor	Health and social services policy and management
PP-CH-004-H	M	Associate professor	Health economy
PP-CH-010-H	M	Full professor	Mechanical engineering, medical imaging
PP-CH-005-F	F	Associate professor	Physiotherapy
PP-CH-003-H	M	Medical doctor, assistant professor	Nuclear medicine
PP-CH-006-F	F	Research professional	Health and social services management
PP-CH-009-F	F	Research coordinator	Schizophrenia and other psychotic disorders
PP-CH-008-F	F	Assistant professor	Nursing science
PP-CH-013-F	F	Research coordinator	Primary health care services
PP-CH-011-F	F	Doctoral student	Health in general
PP-CH-014-F	F	Doctoral student and research supervisor	Strokes, health services management, mental health
PP-CH-015-H	M	Doctoral student	Mental health, interdisciplinary perspective
PP-CH-017-H	M	Assistant professor	Diabetes, obesity, cardiovascular complications
PP-CH-016-F	F	Full professor	Hypertensive disorders of pregnancy
PP-CH-019-F	F	Associate professor	Occupational therapy, gerontology
PP-CH-018-H	M	Researcher, associate professor	Substance use disorders and other addictions
PP-CH-020-F	F	Postdoctoral fellow	Complex addiction disorders (psychiatry, homelessness, etc.)
PP-CH-021-F	F	Full professor	Epidemiology of chronic pain

Semi-structured interviews

Twenty semi-structured interviews lasting between 30 and 90 minutes were conducted between January 20, 2023, and February 24, 2023, to obtain the rich and in-depth data required for descriptive qualitative research [11]. An interview guide based on the scientific literature [12] was created by members of the research team (SA-C, A-MA) and the principal researcher (MB). It was critically co-constructed and reviewed by PPs-coresearchers (CW, DB) and a research assistant (M-MP). The objective of the interviews was to map the experiences, views, opinions, and processes concerning researchers' collaborations with PPs. For instance, it covered subjects such as support, researcher–PP relationships, the perceived utility of PP involvement, memorable events, challenges, potential areas in need of improvement, and researchers' satisfaction. A research professional (SA-C) conducted and recorded the interviews for this study via videoconference using Microsoft Teams. SA-C holds a master's degree in anthropology and has extensive training and experience in conducting qualitative research. Specifically, she has been trained to conduct interviews with patients and carers. In addition, this research professional did not have any prior relationships with the interviewees or any personal views on the benefits or limitations of patient partnerships or on the participants' experiences in taking part in the study. Once the first couple of interviews had been completed by SA-C, A-MA listened to the recordings for validation. Finally, the interviews were professionally transcribed into verbatim text for analysis.

Analysis

Thematic analysis started in May 2023 using NVivo data software (version 14.23.0) [13, 14]. First, the semi-structured interviews were coded line by line and then classified by theme by OF under the bi-weekly supervision of A-MA, MD, and MB. Next, the themes were grouped together by similarities to create a thematic tree. DB and CW were consulted on the classification. Their concerns and questions were addressed, and modifications were made. Then, repeated phases of analysis were conducted by OF to familiarize herself with the content and the codification process as well as to contextualize and define themes [15]. DB and CW were consulted again, and they provided their perceptions regarding the orientation of the results identified. They reemphasized the importance of reporting the challenges experienced by the participants in a constructive way to encourage further reflections and recommendations on improving PE practices. In this article, the analysis is centered on the challenges and difficulties experienced by health researchers who have collaborated with PPs on research projects.

Results

This study sought to discover and understand the challenges and difficulties experienced by 20 health researchers when collaborating with PPs in Quebec. The results encompass six main themes and their subcategories: PP individual and health-related challenges, institutional barriers to PP involvement, challenges in genuine PP involvement, collaboration challenges in research projects, time constraints in research projects, and PP recruitment and representation issues. These main themes and their subcategories are listed in Fig. 1, and additional interview quotes are categorized in Table 2.

PP individual and health-related challenges

For patients, illness comes with many uncertainties that affect whether, as PPs, they can participate in projects and the extent to which they can do so. Individual and health-related barriers were commonly mentioned as inevitable challenges that health researchers must confront, as they encompass issues concerning PP scheduling and availability, retention rates, mortalities, mobility and transportation as well as technology access and proficiency.

PPscheduling and availability challenges

The researchers explained that scheduling meetings with PPs was a challenge for them and their teams and that PPs' availability was their greatest concern. They made it clear that they were aware that PPs have their own personal lives (careers, family, etc.) and often deal with illnesses, which makes it difficult to coordinate schedules. PPs were reported to prefer certain times of the day (evenings or lunch hours), and the time at which they could ensure being at an optimum state for research was limited. They were also often unable to guarantee long-term commitments, whether in months or years, due to their illnesses. Certain factors in PPs' lives, including being a parent, being an elder, having multiple engagements, or struggling with chronic illness, influenced their availability limitations. The researchers were also faced with decisions on how to proceed if participants suddenly ceased communication or became unavailable (see 1.1 in Table 2).

Low retention rates

Since most projects undertaken with PPs were long term and exceeded one year, the requirement for an extended commitment among PPs became a challenge. Some researchers noted a very low retention rate within large pools of PPs and were unsure about how to resolve this issue. The challenge of low PP retention rates was explained to arise when projects extend beyond their initially estimated duration. As a result, PPs sometimes became unavailable or were unwilling to continue their

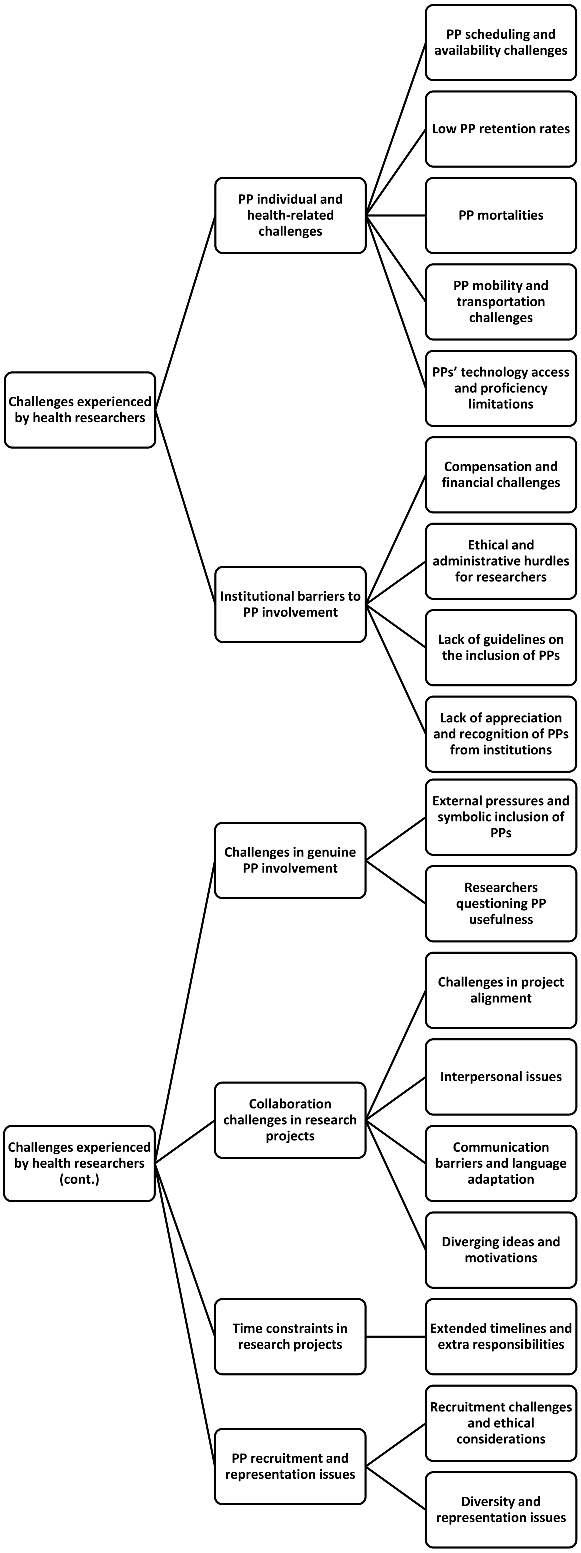


Fig. 1. Thematic tree

engagement, which impacted the continuity of the project. As one participant explained, their own expectations regarding a research project's duration did not always align with PPs' views: "*It's part of the reality of a researcher, but for someone on the outside, two years is an eternity*" (P18). Another researcher explained that it is important for PPs to have a sense of freedom and cease engagement at their convenience: "*It's not a lifelong commitment, you know; it's really that idea of having the liberty to sometimes not commit long term; that was one [issue]*" (P19). Finally, maintaining communication to facilitate retention is another challenge that was mentioned, since PPs sometimes miss meetings or stop answering emails and phone calls, thereby becoming unreachable.

PP mortalities

Declining health and the imminent mortality of PPs presented significant challenges for researchers, particularly in terms of scheduling and availability. PPs' deteriorating health often meant that they became unreachable, cut contact, or left projects unexpectedly. When PPs passed away, research teams were sometimes left scrambling to find other PPs to continue the project, adding another layer of difficulty to the research process. This created an emotional burden for research teams, who not only faced the challenges of losing participants but also felt pressured to accelerate the research process. As one researcher explained regarding the timeline of the project in relation to disease progression, "*The life expectancy for them, or someone close to them—the timer goes off at the same time as someone who has breast cancer, but the countdown is much faster. So, they are pushing a lot harder; they're impatient*" (P01). In other words, the declining health and impending mortality of PPs sometimes led them to push for faster progress, further stressing research teams to meet their expectations before it was too late. This urgency, combined with the emotional strain of knowing that participants' health was rapidly declining, often left researchers feeling unequipped to manage the situation.

PP mobility and transportation challenges

Researchers, particularly those working with chronically ill PPs with cancer or other diseases, made remarks pertaining to the difficulties of meeting with PPs in person due to mobility and transportation reasons. Arranging punctual in-person gatherings was especially difficult due to elements such as the progression of their illnesses, cognitive limitations, reduced mobility, and more because "*some people aren't supposed to be moving around. You see they're not people who go into the community from one week to another*" (P18). The transportation of PPs thus

Table 2 Additional interview quotes summarized by theme

Themes	Quotes
1. PP individual and health-related challenges	1.1"First of all, these people have their own schedule too, it's not their job so they really are doing this because they want to, often on a volunteer basis, sometimes because they're paid. In the end they have their own schedule, they work eight to four, they have kids, some are retired. So, it can be difficult to integrate them because they don't have the same schedule."(P06). 1.2"They have issues of not being able to get up on time where an appointment in the morning doesn't work for them, it's complicated. There's also some who have cognitive issues, they'll forget their appointment and we have plenty of strategies; we'll call them four times so that they will be there, we will reserve their adapted transportation, we will go get them if necessary."(P05). 1.3"There is still, I think three hundred thousand people in Quebec who don't have access to the Internet, there are I don't know how many who go very infrequently, there are many who don't have phones either, and ultimately these are orphan clients in a sense. It's very difficult really, you must go into the non-profit sectors that help people who are in need."(P04). 1.4 "And we encountered some problems with patients regarding difficulties with technology, it made the deployment of the project difficult as well. Ultimately it led us to realize that we really need to recruit based on certain criteria because, yes, we want to be inclusive, but we also have a research project to advance, and we have funding constraints. Therefore, we need patients who possess a certain level of technological proficiency." (P06).
2. Institutional barriers to PP involvement	2.1"The way to remunerate them, the administrative process, how much you pay them, it's complicated, and there are guidelines, I know our partners do it with the support unit but for the hourly wage it's not clear how I should be remunerating. If the person works, it's clear we can match their hourly wage but at the same time it adds up. So, we need to reach agreements, but remuneration also requires a significant budget, so we must ensure that we have the budget to do it."(P02). 2.2 "There is a delay the moment I submit the applications. There are administrative and institutional procedures that all champions of engagement have had to go through; this is something that I have heard across Canada. All researchers have the same experience in Canada when they are the first to conduct this type of research at their university. They have to go through human resources, finances, and sometimes even the scientific leadership of the research center to ensure that everything is set up for machinery to function with the same culture and vision." (P07). 2.3"I find it unfortunate that sometimes we must be kind of semi-dishonest just to make it work. It's like sometimes I feel that the ethics committees have somewhat lost their role in keeping things ethical, personally, it's a whole other debate."(P20). 2.4"Well I think it would be interesting to have a type of community of practice from the researchers'side and the users' side, maybe something a bit mixed, I don't know. It would be interesting because I find that really we're shooting in the dark."(P20). 2.5"There was an attempt to find a solution to establish a status, that's something in itself. This means that in our case, we didn't have that issue because they're not hired. It's really more like we meet with him and then we provide him with that amount. […] It's a bit troublesome because in that case there's a difference in treatment between people, but at the same time you think if he's on salary it's because he has a standard level, he has a foundation on competencies."(P18).
3. Challenges in genuine PP involvement	3.1"Sometimes you're told that you should do it, even though it doesn't even make sense in your project, so in that sense, yes sometimes you feel pressure, and it's not really because I don't agree with the purpose of patient partners, it's just that depending on the project, sometimes they are useful and just sometimes it just doesn't make sense […]."(P13).
4. Collaboration challenges in research projects	4.1"I don't want to frustrate them, I don't want to be rude because I'm thinking if they don't answer it's because there's a reason, it's not just they decided not to answer. But at the same time, you tell yourself, well I still have things to get done, what do I do? Do I just move on as if they're not there? It's a question of at what point to be collaborative, participative, we took someone on who wasn't available."(P18). 4.2"At a certain point it's no better if the patient partner is just there and they feel like they can't contribute or understand because, yes, you can do certain trainings beforehand but sometimes we're really in the scientific terminology, or even in the search for funding that can be a bit heavy for patients."(P14). 4.3"It's not clear, sometimes I got the impression, even in training, that there's a goal, some researchers have this objective that patient partners emancipate through the experience. It's like, yes, I want them to emancipate and everything but at the same time there's a paradigm that is patient partnership."(P02). 4.4"We had this issue that you must not do an intervention. Well, I agree that it's not a support group. But something between the two things; a research panel and an intervention. I think you have to find something in between the two."(P18).
5. Time constraints and representation issues	5.1"We are very structured and maybe people from outside won't see that picture. I find it can be an obstacle sometimes. You have to explain to patient partners that if you want to participate in the project, the schedule is really important, you have to respect it."(P10). 5.2"I spent so much time making Teams and doing outreach that in the end I had so little time for the science part. Every time I told myself I really believed in it, but it's so energy consuming that I lack time for the scientific aspect."(P19).

becomes an issue for teams, since they cannot gather PPs at short notice, and it requires extra effort to organize and strategize meetings (see 1.2 in Table 2).

PPs' technology access and proficiency limitations

Challenges concerning the use of and access to technology and software were raised on two separate accounts. On the one hand, using technology was said to facilitate meetings by many researchers. On the other, requiring PPs to use technology and have internet access may be a limiting factor for some PPs (see 1.3 in Table 2).

Further, some participants mentioned that technology use becomes an issue when it requires supplementary time to train PPs on how to use such technologies, including Microsoft Teams for virtual meetings (see 1.4 in Table 2).

Institutional barriers to PP involvement

Institutional barriers present in hospitals, universities, and other settings across the country represented the largest umbrella of challenges for the participants when they incorporated PPs into their projects. Going forward, institutional barriers will be referred to as standards, regulations, or expectations imposed by either organizations or colleagues that entail specific requirements for the process of PP collaboration. Institutional barriers to PP involvement can be broken down into compensation and financial challenges, ethical and administrative hurdles for researchers, lack of guidelines on the inclusion of PPs, and lack of appreciation and recognition of PPs from institutions.

Compensation and financial challenges

Participants often mentioned difficulties relating to funding and monetary resources. For instance, they cited that working with PPs requires additional budgetary funding. As one researcher stated, "*There are some [researchers] who don't have the funds to pay them [PPs] but want to get them involved. It becomes problematic*" (P13). Some stated that a lack of funding hinders projects from progressing or being implemented, since there is no longer any means to compensate PPs. Other researchers mentioned that they faced challenges in taking difficult decisions, such as not being able to incorporate some of PPs' valuable ideas due to budget restrictions.

Furthermore, financially compensating PPs was often mentioned as a challenge or an element to be improved because of its complexity. Understanding the acceptable methods of compensating PPs was said to pose a challenge, as not all establishments have rules in place. Settling on a fair way to compensate PPs was also seen as difficult due to the lengthy and complex administrative process, which often delays a project's commencement. This inflexible system was also said to make it difficult for the researchers to negotiate alternate forms of retribution, such as gift cards, as well as salary versus hourly wages. The complications and confusion associated with remuneration were explained by a few researchers (see 2.1 in Table 2).

Ethical and administrative hurdles for researchers

The administrative processes that researchers undergo to incorporate PPs into a project were described as lengthy and time-consuming and said to require additional efforts to overcome hurdles encountered with ethics boards, human resources, and finance departments (see 2.2 in Table 2). The researchers commonly reported that incorporating PPs into projects increased the initial administrative workload, with many experiencing delays during the onboarding process, which impacted project timelines. As one researcher put it, "*[To] hire people—well, it was difficult, like they had to go through a lot of barriers*" (P20). The administration process was described as complex, acting as a significant deterrent to incorporating PPs into projects.

Ethics boards were viewed as barriers due to the complexities and lengthy administration processes involved in onboarding PPs, sometimes denying ideas suggested by PPs and making their remuneration very difficult. These frustrations led participants to either avoid working with PPs or to take measures to accelerate the process, such as frequently asking ethics committees about the status of their ethics review applications or stretching the truth in such applications (see 2.3 in Table 2).

Lack of guidelines on the inclusion of PPs

Many researchers expressed concerns about the lack of clear standards and guidelines on how to include and effectively integrate PPs into their teams as collaborators. Participants reported that the research community lacks clear guidelines or steps to follow, leaving them to take difficult decisions and question the ethical implications and consequences of their pursuits. For instance, some researchers expressed concerns regarding the possible vulnerability of some PPs and the implications of such involvement: "*And so they said they didn't need to file an ethics request to involve patient partners, but I didn't agree because, well, it's just not ethical the way they are used*" (P02). These concerns were especially present when researchers felt there were no clear ethical criteria or lacked guidance on incorporating PPs. Furthermore, one researcher had noticed that instructions were sometimes unclear between establishments and suggested a community of practice that would integrate both patients' and researchers' perspectives (see 2.4 in Table 2).

Lack of appreciation and recognition of PPs from institutions

Some participants saw the lack of appreciation and recognition from institutions as a factor that led to other challenges that they faced when working with PP's. Some expressed that the current "structures" or "culture" in academia are not built to value the involvement of PPs, with traditional performance indicators not coinciding with this type of research. Some participants mentioned that although the value of PE is acknowledged more and more over time, its recognition remains relatively low. One participant shared their opinion that, in the field of cancer research, a researcher's career when working with PPs is not profitable because "*when you submit a grant application to the Canadian Institute of Health Research, they strongly prioritize supporting fundamental research that does not involve patients*" (P01).

Furthermore, some participants pointed out an existing dichotomy whereby funding institutions incentivize PE while the field itself maintains the same traditional values. As one researcher summarized, "*Yes, there are policies that value [PE], but concretely, it pays off more to write publications than to engage in [PE], and when you really conduct research in which people participate from start to finish, you necessarily publish less*" (P15). Some researchers had found that universities had no official title for PPs, which they thought demonstrated symbolically a lack of appreciation for their role and gave them a lesser status (see 2.5 in Table 2).

Challenges in genuine PP involvement

Avoiding issues of symbolic involvement, where PPs are included merely to meet formal requirements without meaningful participation, was a common topic among the researchers in this study. Some noted having witnessed such involvement in their colleagues' projects and then taking steps to avoid replicating the same behaviours. For example, ensuring regular consultation with PPs and involving them in decision-making throughout the research process. The issues related to genuine PP involvement can be further broken down into the following sub-themes: researchers questioning PP usefulness, and external pressures and symbolic inclusion.

Researchers questioning PP usefulness

Some researchers had found themselves in the uncomfortable position of questioning the purpose and usefulness of PP participation. For instance, after following requirements to include PPs in their research, some reflected on if and how PPs could improve their projects. They noted that the tactical element of what to do with PPs may be well described but that some researchers "*forget the conceptual element behind" and "overuse or misuse those resources*" (P02). To some researchers, it was unclear why some teams use PPs in certain projects since they perceived that they offered little to no value and only seemed to be included because everyone else was doing so (see 3.1 in Table 2).

External pressures and symbolic inclusion of PPs

Some participants explained feeling bothered and uncomfortable when witnessing the symbolic involvement that PPs often experience in research projects. Because multiple funding applications require PPs, this encourages some researchers to "*find someone just to tick a box for the CIHR*" (P03). Another researcher mentioned that because of the pressure of PP inclusion when submitting grant applications, some researchers tend to perceive PPs as "*buzzwords*" since they "*look nice*" (P05), despite not having any involvement in the research. Furthermore, some expressed that exaggerating the usefulness of the role of PPs in grant applications to serve as a selling point seems to symbolize that a PP is "*only a name that's there, without any real collaboration*" (P21). Another participant expressed that PPs are sometimes left aside, like "*decorative plants*" (P14), without any tasks or adding any value to the research project in which they've been asked to participate. Thus, incentives have a perverse effect in cases in which PPs are included in the grant application but are not involved in the various steps of the research process.

Meanwhile, over the course of the interviews, some participants expressed their feelings of being obligated to involve PPs in their projects. There was a great sense of pressure coming from institutions, giving rise to an equally prevalent social pressure to include PPs. One researcher said, "*Sometimes, I get the impression that there is too much—there is a bit too much pressure on [us] to try to put on doing [PE] to involve people without really being given the skills to do it*" (P18). Another researcher thought that they had been pressured to involve PPs in a very rushed way, without a justified rationale as to why they should be incorporated into their projects. To conform to funding and social pressures, some participants saw projects being modified to include PPs, although they questioned the value they added to their studies: "*When you break it down, ultimately, a clinical trial is a clinical trial even if it's centered on patients*" (P15). Some participants observed that, for some, the usefulness of PPs is exaggerated on their applications for funding, and once the requirement for PPs is fulfilled, "*it ends there*" (P18).

Collaboration challenges in research projects

Collaboration between researchers and PPs was a challenge for the participants, especially those who were not equipped for or had little background experience in managing others in a new setting. These difficulties were divided into the following sub-themes: challenges in project alignment, interpersonal issues, communication barriers and language adaptation, and diverging ideas and motivations.

Challenges in project alignment

Once PPs had been brought onto teams, some researchers found it challenging to deal with the additional opinions that influenced the direction of the projects. Sometimes, PPs come to a team with intentions that diverge from the vision originally held by the researchers. Some researchers found that PPs could be very passionate and hold strong beliefs about how they saw the project taking form, putting researchers in an uncomfortable position regarding how to bridge these issues. Adapting and modifying projects so that the ideas of all team members were considered generated difficulties for participants. Further, sharing the responsibilities of one's project and harmonizing all the ideas to align with ethics committees was especially challenging.

One aspect that some researchers brought up concerned diverging objectives related to PPs' understanding of the field of research. PPs with little prior experience with research are unaware of common practices, such as structures and "*the temporality when we write a publication*" (P18). This challenged the researchers to work with PPs' goals in mind, while accepting that not everything would be well understood. A similar issue encountered by researchers working with PPs who were unfamiliar with the field concerned when ideas did not fit into funding requests or when their ideas could not be supported financially. Some researchers expressed hesitation regarding how to "*conceptualize*" projects to "*arrive at a point that is acceptable for everyone*" (P03), especially when they were faced with turning down suggestions from PPs.

Furthermore, it was reported that not all PPs voice their opinions or bring perspectives outside their personal experiences. Thus, their vision for a project could sometimes be biased when it revolved solely on first-hand accounts. PPs were described as "*having their own agenda*" (P14) and holding strong values that do not always align with the overall positive outcome for most patients. In doing so, their contributions may not be holistic or representative of the general patient population's experience.

Interpersonal issues

Additional collaborators joining teams required researchers to cultivate teamwork and stronger interpersonal skills, which had not always been acquired prior to PPs' involvement. Moreover, clinician-researchers noted that working with PPs caused them to revisit the types of relationships they had with patients outside the clinical setting. Questions and reflections about how to engage in relationships with PPs were a challenge for participants, especially when PPs had unstable health conditions, because "*it's not related to the project but it's linked indirectly to the project*" (P07). Interacting and communicating with PPs in an appropriate and efficient manner was a new challenge in terms of how to open discussions and collaborate with people with unstable conditions. Along the same lines, contemplating how PPs would react to the extent and manner of communications, as well as which actions to take without causing frustration or appearing insensitive, was a concern (see 4.1 in Table 2).

Achieving the right balance of communication to build bonds with and for the long-term interest of PPs was difficult, since aspects of a project are somewhat imposed on PPs. On a separate note, managing the diversity of personalities, avoiding conflicts within teams, and ensuring PPs are comfortable and encouraged to participate become further tasks. Researchers need to create a good environment of reciprocity to foster engagement, which is something that not everyone is familiar with.

Communication barriers and language adaptation

Ensuring the PPs' understanding of a project in terms of vocabulary and structure demands an abundance of effort and time. Some researchers commented on the challenges PPs experience in integrating into projects and keeping pace during meetings. They were often described as not understanding the terminology or vocabulary used during meetings, which created communication barriers and language modifications: "*[It] pushed us to adapt quickly to change our level, our language, to try to be well understood at their level too, so that we made it OK for everyone*" (P03). Researchers put additional work into forming committees and meetings to keep PPs informed, develop a common language, and keep PPs up to date on the development of projects. During meetings in which terminology was an issue, some researchers said they had to adjust their language and cultivate the habit of presenting information in a suitable manner for their target audiences. It was found that, even with these modifications, some researchers needed to repeat the information multiple times (see 4.2 in Table 2).

Diverging ideas and motivations

When asked about team environments, some participants mentioned noticing a clash concerning the motivations among researchers in guiding PE in the field (see 4.3 in Table 2). These intentions for PE were said to bring feelings of discomfort and conflict regarding the purpose and intentions of their work. On the one hand, some researchers pointed to the overarching school of thought, which promotes PP empowerment as the primary objective by taking a therapeutic approach. As such, researchers using this approach focus on ensuring that PPs experience personal growth, evolution, and overall satisfaction with their experience. On the other hand, this contradicts their mission when bringing PPs onto their teams. Thus, they envision a more pragmatic approach—that is, ways to contribute to the project, provide information, and improve services. For them, being overly cautious of PPs' mental and personal development was thought to taint the research. They also felt that their performance was evaluated based on PPs' satisfaction with their experiences. Finally, one participant expressed a longing for the middle ground between a research panel and an intervention (see 4.4 in Table 2).

Time constraints in research projects

As with most competitive or demanding fields, time was said to be an issue for the health researchers in this study. Adding PPs to teams requires additional time investment and extended project durations, as well as increased responsibilities without sufficient resources.

Extended timelines and extra responsibilities

When asked about challenges and difficulties, participants commonly highlighted time as a major concern. PE often required additional meetings, communication, and sometimes committees. In addition, the length of existing meetings that include PPs is often extended because of the need for clarification and repetition. As one researcher shared, "*They asked a lot of questions. The meetings, which were usually short, got extended a lot, and we had to repeat ourselves. We had to do it over a longer period of time*" (P03). Many researchers expressed that there had been delays to starting up their projects and that it had taken longer to pick up the pace than originally anticipated. One researcher emphasized the challenge of following a planned schedule when PPs are involved (see 5.1 in Table 2).

Researchers also pointed to additional responsibilities such as coordinating meetings, forming committees, conducting follow-up, handling administrative tasks, organizing activities, and training PPs. They explained that these tasks are time- and energy-consuming and are seen as work in addition to their already busy schedules (see 5.2 in Table 2). Additionally, PPs sometimes lacked technological skills, requiring further time investment from the research teams for support and training. Overall, the participants stressed how projects with PPs require more time, which is a limited resource in the field.

PP recruitment and representation issues

PP recruitment was seen as an issue for researchers who found it difficult to strike a balance between profile diversity and having a pool that is representative of patients. The main challenges were divided into two sub-themes: recruitment challenges and ethical considerations, and diversity and representation issues.

Recruitment challenges and ethical considerations

Questions and concerns pertaining to who are recruited as PPs on a team are a challenge, particularly concerning accessibility and ethical standards. Researchers reported that, depending on the project, there are specific requirements that must be met, such as an initial interest, a bachelor's degree or certificate, and having experience with an illness. However, this creates a double standard whereby these qualifications do not always align with the people who experience a particular health condition. This narrows the scope, thereby challenging recruitment and creating biases when PPs are highly motivated and well educated: "*Recruiting [less motivated and educated PPs] is more difficult than recruiting people who have a bachelor's degree, [who] are much more active on social media and accessible by email*" (P04). PPs who fit this desired profile represent a limited pool, while others who face barriers are often not included as PPs. Researchers' desire to recruit very competent PPs is an ethical challenge, considering that the majority do not have the background experience and are targeted to represent and help a wider population of patients with the condition. Regarding the ethical and practical dilemmas presented when recruiting PPs, one researcher pondered the question: "*What distinguishes engagement in [PE] from conventional studies, let's say as participants?*" (P19).

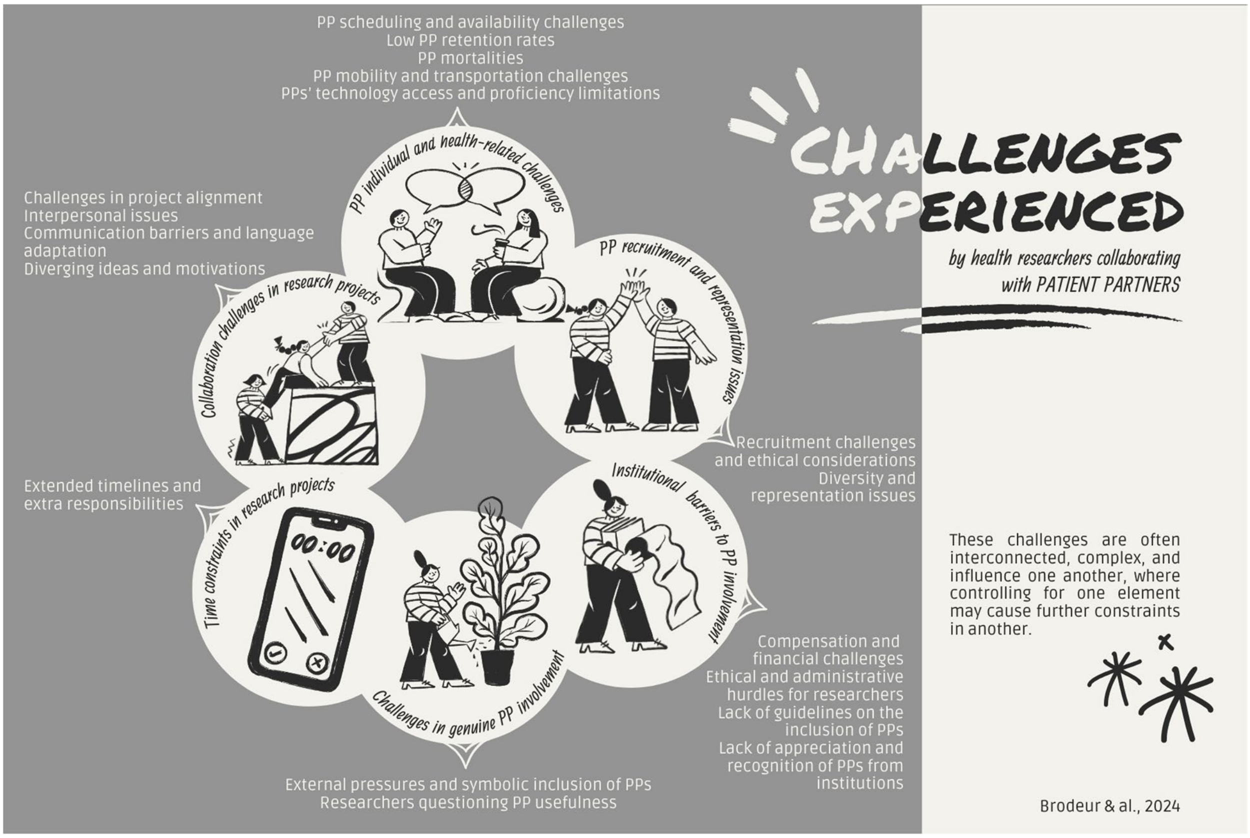
Diversity and representation issues

The researchers mentioned fair representation was a weakness in PE and was difficult to rectify. They observed that the PPs who collaborate in projects often have a specific profile in that they are usually highly motivated and, as described by one participant, "*champions*" (P19). This limits the diversity of representation, especially for vulnerable populations, who are usually less educated and have varying degrees of functioning and motivation. However, in other researchers' experience, looking for certain diversity characteristics in minority groups was seen as limiting diversity by not representing the majority and the general population who live with a disease. One researcher explained that many illnesses are so heterogeneous that patients often do not have the same experience as one another, and thus, "*If they speak to many other patients who have the same pathology as them, they're still specialists of their own experience*" (P13).

Discussion

This study, which stemmed from an idea proposed by PPs in this project, aimed to enhance the understanding of health researchers' experiences regarding the challenges of working with PPs. Some of its findings have also been reported in other systematic and scoping reviews, especially those related to illness as a barrier to PP participation in research projects [7, 16, 17]. Previous research has identified barriers to PE, such as challenges in virtual communication and engagement [6], recruiting diverse PP profiles [6–8, 16], managing large groups across time zones [6], technical issues with information sharing [6], and unclear roles at the project's start [6, 8]. Other obstacles include unmet expectations from PPs [6, 17], administrative burdens [6, 7, 16], emotional labor with PPs [7], lack of support from senior colleagues [7], and added workload without compensation [7]. Power dynamics [7], specialized language [7], and concerns over the value of PPs also arose [7], along with difficulties in fostering meaningful participation [7, 16], lack of resources [7, 8, 16, 17], and time constraints [6–8, 16, 17]. However, as noted earlier, to our knowledge, no other study focused solely on the experiences of researchers regarding the challenges they encounter when working with PPs. This study highlights six main themes and 18 sub-themes, focusing on researchers' challenges and barriers. In general, the findings of this study, which seem to be interconnected and influencing one another, demonstrate that there are significant gaps in understanding and agreement regarding PE requirements and functioning (see Fig. 2). This reflects the need for support and a shared framework.

In this study, the participants reported that social pressures and demands in the field can lead to the cultivation of symbolic inclusion of PPs; therefore, they made a particular effort to combat this phenomenon. It is worth noting that the 'symbolic inclusion' of PPs is otherwise known as 'instrumentalization' or 'tokenism' within the literature on the matter, and it is considered a negative practice in PE because it limits meaningful engagement [18]. One potential strategy to avoid such practices is to actively involve PPs by seeking their input and feedback on specific tasks. For example, research teams can involve them in rehearsing the interview guide, listening to their opinions and questions, and adjusting the language or phrasing as needed, before sending it to the ethics board. Additionally, researchers can include them in meetings and solicit their feedback when decisions are being made.



These challenges are often interconnected, complex, and influence one another, where controlling for one element may cause further constraints in another.

Brodeur & al., 2024

Fig. 2. Challenges experienced by health researchers working with PPs

By providing clear guidance on how PPs can contribute, researchers can offer suggestions for their active support throughout the process.

The findings of this study demonstrate that institutional barriers encompass a wide range of challenges, including ethical and administrative hurdles, insufficient funding, and a lack of appreciation or recognition for PPs within the research community. These obstacles were also identified as ethical issues in the scoping review by Martineau et al. [16]. Researchers expressed frustration with various institutional barriers, such as the hiring process for PPs, the paperwork and administration required to have them on a team, and the submission of ethics-related requests. Their complaints appeared to be primarily linked to time constraints. It seems that the length of time added to projects is due to additional back-end paperwork and waiting periods. Such issues seem to be off-putting for researchers who, on top of having to do their own work, must now go through additional steps and take on further responsibilities to onboard PPs compared to those who do not partake in PE research. Much of this workload (requests and funding approval, human resources for financial remuneration, activity approvals from ethics boards) is mandated by institutions, yet despite all these requirements, researchers portray a sense of confusion from a lack of knowledge and understanding of how to go about PE in a project and of the procedural steps for working with PPs.

Meanwhile, there is currently no coherent national or provincial reference guide with consolidated and structured instructions to which researchers can refer when navigating PE. On the contrary, in the province of Quebec (Canada) for example, there are multiple different guides available to researchers and PPs [19–26], with one of them being the only guide entirely created by PPs in Quebec [19]. Overall, these proposed guides and practices are developed in isolation, which creates significant confusion. For example, in Quebec's healthcare services, compensating PPs is prohibited, while in research conducted in the province, compensation is supported. In practice, within a research center, a patient's work is recognized as deserving compensation. However, once we cross the boundaries of the research center and enter a hospital, the same involvement is no longer recognized. In addition, according to the organizations involved in creating these guides and practices [19–26], the term"partnership"is used in many ways, and the interpretation of the role and tasks a PP can undertake varies. This duality of over-bureaucratization and incoherent guidance seems to be a problem that could be resolved by directing information to one area accessible for consultation.

In addition to structural challenges, another issue arises from the ambiguity surrounding ethical concerns. The participants explained that in their experience, many internal personal questions and concerns were raised regarding how PPs were being recruited, paid, and involved. There seems to be an underlying disconnect concerning PPs' status as a possibly delicate or at-risk group of individuals who also warrant being protected by ethical standards as participants in a study. For example, PPs who have mental health diagnoses may be more at risk, depending on how and when they are implicated in the project. Communicating with them in specific and well-thought-out ways was not done in every aspect of some participants' projects, which could result in what some researchers saw as malpractice. Martineau et al. [16] highlighted issues similar to those reported by the participants in this study—specifically, the absence and or impact of PP funding, harm caused to PPs, logistical and practical barriers, conflicts of interest, and challenges in the selection of PPs. We categorized these ethical issues under institutional barriers, since ethical research methods and ethics boards have frameworks that limit and prevent the proliferation of such issues among regular study participants, yet there do not seem to be structures in place for PPs.

The inclusion of a diverse and representative pool of PPs was also a challenge for the participants in the same way that Upretty [27] mentioned that the new reality of technologies and remote work in participatory research creates demands that further limit minority groups. Researchers in this study reported their awareness of the importance of incorporating a diverse pool of PPs and that they faced similar barriers as those found in the literature, including bias in the selection of PPs in terms of the recruitment methods, qualifications, and access. This issue may also be linked to the lack of a coherent reference guide mentioned previously. It is possible that researchers' attempts to compensate for limited minority representation among PPs lead to secondary issues arising from limiting the actual representation of patients affected by the illness in question. If the majority of PE projects are similar to those described by the researchers in this study, and if only a small number of PPs are involved in each project, then selecting PPs based on diversity alone may not adequately represent the broader population affected by the issue being studied. In addition, the requirements and criteria that facilitate PP partnerships, such as literacy, cognitive abilities, and technological abilities, are also possible barriers to diversity and participation in research projects, as mentioned by Upretty [27].

Moreover, the challenges, difficulties, and irritants that appeared more complex in nature were particularly related to human factors. First, the issues related to time were described by the participants in terms of the time and effort required to ensure that PPs are well integrated into projects. They viewed this as crucial because they recognized the importance of reducing symbolic inclusion of PPs and fostering a positive team environment. The complexity arises from the need to properly communicate, simplify, and convey project information to PPs, which inevitably demands additional time and energy to ensure a sufficient level of understanding.

Furthermore, as noted by Martineau et al. [16] and Thompson et al. [28], the time required to involve PPs in research, compared to traditional approaches, is often perceived negatively by professionals, creating barriers to or irritants in their career progression. Working with PPs who are ill presents challenges to the research community, since disease timelines are beyond one's control. These time-related uncertainties clash with academic expectations and some PPs' desires, in that researchers face significant pressure to publish before the health of PPs deteriorates. Time, particularly related to the length of a project being drawn out and the extra workload and time necessary for in-depth contributions from PPs, was also raised in other studies [6–8, 16, 17]. In Gonzalez et al.'s article [29] time barriers were elaborated on in the same way as in the present study, noting that improving communication requires time and can increase the administrative workload when it comes to emails and meetings.

In terms of collaboration, this theme encompasses the issues of coming to agreements, avoiding power dynamics, working with people outside the field, creating a common language, and aiming for PPs to keep a sense of objectivity and generality. These issues align with the second-order issues described by Martineau et al. [16] and with what is often referred to as communication [17, 29].

In the present study, the collaboration with PPs (CW and DB) provided the authors a deeper insight into the dynamics of PP–researcher collaboration. The PPs regularly shared their opinions on various aspects of the study, including the interview guides, consent forms, and manuscript. Their insights were valuable, leading to multiple modifications and improvements where appropriate and necessary.

Finally, it is important to highlight that the challenges and obstacles mentioned by the researchers represent only a portion of the interviews. The researchers who were interviewed reported mostly positive experiences with the PPs involved in their projects. However, this article focuses on detailing the various obstacles that can complicate the experiences of both researchers and PPs.

Recommendations

We argue that an ethical framework and clear guidelines surrounding PPs, co-created in partnership with PPs, researchers, and authorities, would resolve many issues touching on ethics and inclusion. This could allow researchers, institutions, and PPs to feel more supported. For instance, funding bodies that incorporate PPs and researchers in the development of a systematic approach and create centralized spaces for such partnerships, with clear and defined rules, could contribute to centralizing efforts. For instance, funding institutions such as the Fonds de recherche du Québec, the CIHR, and the Social Sciences and Humanities Research Council could play a key role, as they often already require PP inclusion when researchers apply for funding. These bodies could also offer guidance on PP compensation and address ethical considerations.

Furthermore, we also recommend that researchers and PPs interested in partaking in PE should seek training on the subject before starting the process, as it could greatly enhance the experiences and the collaboration of both parties. Having this shared space before the start of a project could also encourage reflection and co-development with PPs. Finally, Martineau et al. [16] identified specific recommendations in the literature that we perceive as relevant to the issues raised by the participants in the present study, including using a random sampling method for PP recruitment, having patient organizations play a role in recruitment for access to difficult-to-reach patients, and having patient ethics committees derive guidelines according to patients' preferences.

Strengths and limitations

The strength of this study lies in the inherent aspect of qualitative analysis, which is that a large and diverse pool of participants was included in the sample. The 20 semi-structured interviews allowed researchers from various fields in health research to go into detail about their experiences of and opinions on PE, thus giving a broad overview of the issues encountered. Furthermore, the structure of the interviews allowed the participants to steer the discussion toward their most pressing concerns and experiences. They could focus on certain topics that fell outside the scope of the research question, paving the way for a vast and diverse set of data.

The authors acknowledge that there are limitations to this study, particularly when it comes to the shortcomings of qualitative analysis. When considering the data, although the sample size was large for this type of study, not all existing points of view, experiences, or opinions could be represented from the current sample of participants. Additionally, this sample was drawn from the Quebec context, thereby reflecting a healthcare system pertinent to the participants' environment. Expanding studies to the Canadian and international contexts would address gaps in the data, highlight region-specific weaknesses, and provide insights into best practices. The findings could contribute to the co-creation of a coherent reference guide to standardize PE and facilitate collaboration between researchers and PPs.

Furthermore, due to the subjective nature of qualitative analysis, the results cannot be generalized. While the authors are confident that the descriptions and citations provide a strong justification for the experiences and views shared by this sample, larger sample sizes and further investigation are required to draw more robust conclusions as to the difficulties and challenges that health researchers face when working with PPs. This study may be subject to volunteering bias, as the participants who chose to engage with the research might differ from those who did not volunteer to share their experiences. Finally, to gain a more thorough and well-rounded pool of opinions, further qualitative studies that investigate possible recommendations and improvements concerning the challenges and difficulties reported in this study are required.

Finally, it is important to note that the coding of the interviews was conducted by one research team member, and although supervised by three members, no other member independently performed the coding.

Conclusion

This article originated from an idea proposed by PPs in this study and aimed to explore the barriers and challenges experienced by health researchers collaborating with PPs. The findings indicated that researchers who had involved PPs in their projects experienced challenges and difficulties surrounding six main themes: PP individual and health-related challenges, institutional barriers to PP involvement, challenges in genuine PP involvement, collaboration challenges in research projects, time constraints in research projects, and PP recruitment and representation issues. The reported challenges were interconnected and reflect the need for improvements in institutional structures and incentives. Further qualitative research is needed to identify better practices to address the issues experienced by the participants in this study. Additionally, shifting from a traditional focus on quantity to a quality-oriented approach in research publications that moves beyond classic evaluation criteria could potentially have the greatest impact on addressing the challenges and irritants associated with PE.

Abbreviations

CIHR	Canadian Institutes of Health Research
COREQ	Consolidated Criteria for Reporting Qualitative Research
GRIPP2	Guidance for Reporting Involvement of Patients and the Public
PE	Patient Engagement
POR	Patient-Oriented Research
PP	Patient Partner

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Authors' contributions
MB led the conception and design of this study in collaboration with all team members, including PPs (CW, DB). OF performed the data extraction and analysis under the supervision of A-MA and MB. OF, A-MA, MB, and PPs (CW, DB) contributed to all research steps. The co-writing was done by OF, AD, and M-MP, under the supervision of MB and in collaboration with the research team (including CL, M-EP, and M-CB), who provided comments and validated the manuscript at various stages during the co-writing process. Finally, all authors read and approved the final manuscript.

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Data availability
All data and material used for this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate
This research project was approved by the *Comité d'éthique de la recherche du CIUSSS de l'Estrie – CHUS*. Project number: 2022-4452-PP-CRCHUS.

Consent for publication
All participants read and signed a consent form.

Competing interests
The authors declare no competing interests.

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