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Abstract
Patient engagement (PE) is not well defined and little guidance is available to those attempting to employ PE in decision-making relevant to health system improvement. After completing a 2-year PE project, overseen by an Advisory Committee, our objectives were: 1) to evaluate how effectively the project team engaged the Advisory Committee, 2) to examine how Advisory Committee members perceived PE and their role in PE, and 3) to identify barriers and facilitators to PE in order to improve future efforts. Five members of the Advisory Committee completed semi-structured interviews post-project about their experiences. Thematic analysis identified four themes: the approach, participant contributions, participant understanding of PE, and barriers and facilitators to PE. The use of a committee approach was considered beneficial, providing an opportunity to discuss the project in depth, contributing to relationship building, and helping move the project forward. The social aspect of the committee approach was an important part of the engagement process. Participants felt they contributed primarily by participating in discussion, yet could not identify specific contributions they had made. All participants agreed that the experience was meaningful but not profound with regard to how it would impact their engagement, or their engagement of others, in the future. Although experiences were highly subjective, this study suggests that the act of participating in PE has meaning in and of itself to those involved, independent of the activities and/or outcomes of that participation, reflecting a broader public value that PE is an important component of transparent, accountable health systems.

Keywords
Patient engagement, quality improvement, advisory committee, evaluation

Background

Patient Engagement
In healthcare, patient engagement (PE) is thought to promote accountability and transparency of the health system to the public, create more knowledgeable and empowered individuals, build trust between patients and "the system" (i.e., healthcare providers, administrators, policy-makers, etc.), facilitate understanding of healthcare decisions amongst the public, and improve the ability of the health system to meet patient needs, thereby improving patient outcomes [1,2,3-7]. Despite seemingly widespread support for engaging patients in health system decision-making, there is little evidence demonstrating the effectiveness of engagement in this context (i.e., of improving services, patient outcomes, or cost-effectiveness) [8]. Part of the difficulty in establishing an evidence base in support of PE may lie in the lack of a common understanding of the concept itself.

PE is often discussed in terms of "citizen engagement," "community engagement," or "public involvement"; none of which are consistently defined within the literature [9]. These terms generally refer to a process by which stakeholders (whether patients, citizens, consumers, etc.) are involved in decision-making about public services, programs, or policies [1,2,10-12], or perhaps more simply, "a means to involve those who are affected by a decision in the decision-making process" [13]. In practice, PE can take many forms, including focus groups, surveys, one-on-one interviews, one-time meetings/workshops, citizen juries, committees, and advisory groups [2,10,13]. Given the potential involvement of various stakeholder groups and the many models of engagement to choose from, the concept of PE itself remains broad and its practical aspects are not well understood [1,6,8,9,14-18]. After conducting an extensive review of the literature as well as interviews and focus groups with stakeholders, Gallivan et al [9] defined PE as "a relative term subjectively defined by individuals or groups/organizations that are planning to actively involve

patients and their families in various healthcare advisory committees or care decision making activities." Unfortunately, this definition does little in the way of providing practical guidance for those who want to employ PE in decision-making relevant to health system improvement.

Patient Engagement Project
In 2011, the authors received funding to carry out a PE project (PEP) as part of a national initiative of the Canadian Foundation for Healthcare Improvement that aimed to improve the engagement of patients in the design, delivery, and evaluation of health services. Under this initiative, the provincial cancer agency, Cancer Care Nova Scotia (CCNS), received funding to carry out the two-year PEP, which was entitled "The Nova Scotia Cancer Patient Family Network: Evaluation, Development, Innovation."

The project was focused on an existing program at CCNS, called the Cancer Patient Family Network (CPFN). The program facilitates patient-centered cancer care in Nova Scotia by connecting its members— patients/survivors and their family/friends—with opportunities to participate in activities related to the improvement of the cancer care system (e.g., research, quality improvement). A project team, consisting of organizational staff (including the coordinator of the CPFN), local health services researchers, a cancer survivor, and a Project Coordinator, was responsible for leading and implementing all aspects of the project. The project consisted of three phases:

1. Evaluation of the CPFN—This consisted of three activities: i) a database analysis to develop a descriptive demographic profile of CPFN members, ii) a content analysis of all communications sent to members to assess what they were being told about the purpose of the CPFN and their role as a member, iii) a survey of current members to assess their reasons for joining, satisfaction with involvement, and opinions on how the CPFN could be improved. Several key findings of this evaluation included a lack of diversity (in terms of gender, income level, age, and ethnicity) amongst members, confusion around membership (e.g., some members completed and returned a membership form but did not realize they had joined the CPFN), and a discrepancy between members' reasons for joining (primarily related to receiving information and support) and the intention of the CPFN (to engage patients and families in cancer system improvement initiatives).
2. Development and implementation of 'interventions'—Based on the findings of the evaluation, interventions included the implementation of a formal communications plan to clarify the purpose of the CPFN, a change in recruitment strategies to increase diversity, an education and

awareness campaign to promote the CPFN and its goals, and the development of a formal PE policy within CCNS.
3. An evaluation of the interventions—At the end of the two-year funding period, these interventions were evaluated. Due to the short duration of the project, we were unable to evaluate whether there had been any impact on patient or health system outcomes so evaluation activities were primarily concerned with process evaluation (i.e., how and the extent to which the interventions in (2) had been implemented, intervention reach, and so on).

Importantly, in alignment with the emphasis on PE, a Patient Engagement Project Advisory Committee (hereafter referred to as the Advisory Committee) was formed at the onset to oversee all project activities. This 15-member committee included healthcare professionals and administrators from the Nova Scotia cancer system, community-based cancer patient advocacy groups, cancer survivors, and family members. Thus, the project was concerned with PE at two levels: improving CCNS' mechanism for PE (the CPFN), and using PE to do so (via the Advisory Committee). The Advisory Committee's involvement in the project consisted of:

- Attending meetings—Meetings were held between the Advisory Committee and the project team approximately 3 times per year to provide comprehensive project updates, review findings-to-date, discuss ongoing project-related issues, and plan next steps.
- E-mail communication—The Project Coordinator used email to communicate with Advisory Committee members to distribute and seek feedback on documents and to put forth specific questions related to the project. Advisory Committee members were also encouraged to contact the Project Coordinator with any questions or concerns as they arose.

As CCNS is not involved in the delivery of front-line cancer care, but rather in the design, delivery, and evaluation of cancer programs and services, our definition of PE was guided by the Integrated Primary and Community Care Patient and Public Engagement Framework developed in British Columbia, Canada [3], which identifies three levels of patient and public engagement: (1) individual care, (2) program and service design, and (3) system and community. For the purpose of the larger PEP, PE was defined as moving beyond the provision of one-time input opportunities to having patients actively inform program and service design and improvement, policy, evaluation, and delivery of care (largely PE directed at the program and service design level, identified above). Given the paucity of information on *how* to engage patients and stakeholders in health system decision-making, the use of an advisory committee in the context of the PEP represented an important

learning opportunity. Thus, at the end of this two-year PEP, we interviewed Advisory Committee members with the following objectives:

1. To evaluate how effectively the project team engaged the Advisory Committee (i.e., was the experience meaningful/engaging for those involved? Why or why not? What did they learn or take away from their experience?)
2. To examine how Advisory Committee members perceived PE and their role in PE (i.e., what expertise did they bring? How did they contribute to the project?)
3. To identify barriers and facilitators to PE in an effort to improve future PE initiatives (i.e., in what ways did the project team facilitate engagement? In what ways did it impede engagement? How can the project team better meet the needs of those involved in PE?)

This paper presents the findings of these Advisory Committee interviews. A summary of the PEP is provided in Figure 1.

Methods

Design and Methods
A qualitative research design using semi-structured key informant interviews was used. Qualitative data "document the world from the point of view of the people studied" [19] thereby providing insight into how people make sense of their experiences. Such insight cannot be easily provided by other methods [20]. Qualitative research is often used when there is little existing knowledge (or data) regarding the research topic and to help explain and/or interpret the results of quantitative research [21]. This study focused on *how* to effectively engage patients and other stakeholders in health system decision-making. This topic has not been widely addressed in the literature, and requires exploration from the point of view of those who have participated in a PE initiative or process. This study was approved by the Capital Health Research Ethics Board.

In-depth semi-structured telephone interviews were conducted. Semi-structured interviews use a set of general questions that explore a set of themes, but permit the use of follow-up questions. This approach allows the interviewer to remain focused so that the research goals are achieved and participant's time is used efficiently, yet provides the freedom to probe emerging issues that may be pertinent to the current research but are not specifically addressed by the interview script [22]. Project team members were closely involved in drafting/revising the interview guide to ensure appropriate phrasing of questions that all topics of interest were explored. All interviews were audiotaped and transcribed verbatim by the team member [CK] who conducted the interviews.

Methodology
This study employed a grounded theory approach, which is characterized by the simultaneous and concurrent process of coding and analyzing the collected data [23]. As interview data were collected, thematic analysis was performed. This method was selected because it is an

Figure 1. Patient engagement project summary. (*focus of current study)
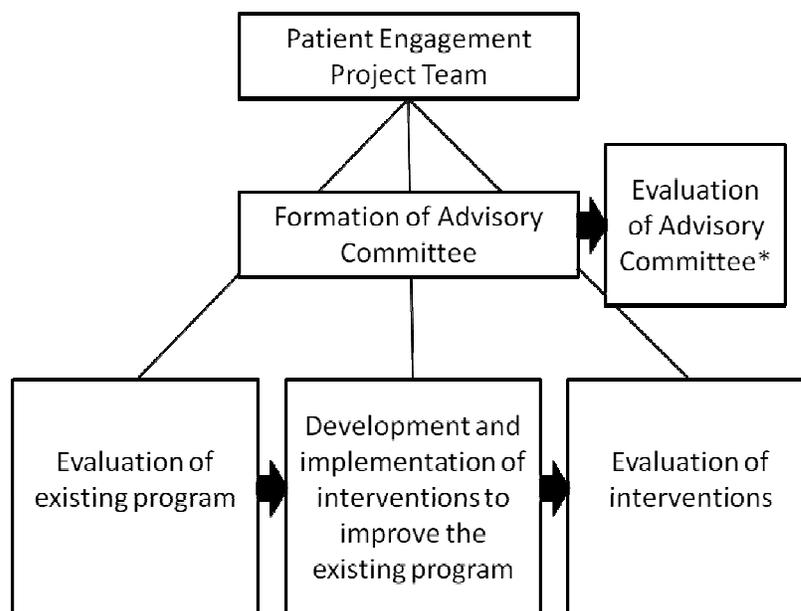
accessible and flexible approach [24] to identifying, analyzing and reporting patterns. Thematic analysis involved coding the data and identifying data patterns and emerging themes [25]. Coding is defined as the process of grouping participants' responses into categories that bring together similar ideas, concepts, or themes that the researcher has discovered through familiarity with the interviews and text [26]. This approach was employed with the understanding that only a limited number of potential participants were available and thus theoretical saturation (i.e., the stage of data collection in which newly collected data does not further contribute to theory development) might not be achieved by the end of data collection.

The use of constant comparative analysis, by which existing themes are refined (i.e., expanded upon or merged) as new data are introduced, contributes to credibility. As stated by Fernandez [27], "triangulation is embedded in the methodology, which facilitates achieving conceptualizations based in multiple perspectives and data sources." The robustness of this approach ensures that the emergent theory is representative of the experiences of the participants.

Data analysis was done by the interviewer and reviewed by another team member [RU] trained in qualitative methods.

Participants and Recruitment

Advisory Committee members were contacted via email by a project team member and invited to participate in an interview about their experience. By the final six months of the project, three of the 15 members had resigned due to personal or health-related reasons. Of the remaining 12 members, five agreed to participate in an interview with a project team member. This group of five contained a mix of patients, health professionals/administrators, and representatives of community-based organizations, with several participants 'wearing multiple hats.'

Results

Four themes were evident in the data. These were labeled as: the approach, participant contributions, participant understanding of PE, and barriers and facilitators.

1) The approach: Participants reflected on the overall approach employed by the project team including the use of PE for program evaluation and design and the use of an advisory committee as a model for PE.

In this particular project, PE was used to inform program evaluation and design. When asked if this use of PE was appropriate, several participants did not perceive differences between PE at the patient care level, and PE at the system level. Those who did understand this nuance believed that the use of PE in this project had value since the ultimate goal of the CPFN is to improve patient care.

There was also a general trust that the organization would not use PE if it wasn't appropriate to do so.

"So, um, these kinds of programs are going to help all the patients in different ways, right? Whatever, however, CCNS brings patients together for focus groups or whatever, I'm sure there's a reason for it because patients have said so and it's gonna help others."

When asked about the use of a committee specifically, participants felt that it was beneficial and provided an opportunity to discuss the project in depth, contributed to relationship building, and helped keep the project moving forward. The social aspect of the committee, particularly the coming together of different people with different opinions, was seen as an important part of the process. In terms of group composition, all participants noted that certain groups (e.g., young adults with cancer, health professionals) were underrepresented or not represented on the Advisory Committee, when in fact representatives for these groups *were* actually on the Advisory Committee. Evidently, there was a lack of clarity about who was present at the table, their roles, and the groups represented. Despite this, participants consistently indicated that they were comfortable voicing their opinions in the group setting, and described the committee as "balanced," "respectful," and "a joy to work with."

"I'm not sure how else you could have done it. You know, it was a pretty intense process. Um, and given that it was time sensitive, it needed, um, what's the word I'm looking for? It needed cohesiveness, it needed strong leadership, it needed agendas, it needed it all…to accomplish what you needed, what we had to accomplish in the period of time given to us."

2) Participant contributions: Participants reflected on their perceived contributions to the PE process, including the perspectives they brought, their role in the decision-making process and specific contributions they made to the project.

While each individual was invited to participate because of a specific perspective they were believed to hold (i.e., that of a cancer system administrator, clinician, or patient), participants typically brought a combination of perspectives. For example, someone invited to participate as a health professional or cancer system administrator may have also had a family member or spouse currently undergoing cancer treatment. Similarly, those who represented community-based patient advocacy groups typically became part of those groups after having cancer themselves. Thus, these individuals brought a personal perspective, but also an organizational perspective—both of which impacted participation.

"…so I understand probably a lot more than the average patient who just goes through [cancer] and at the same time my experience as a patient once upon a time makes a huge difference with [the Advisory

Committee] *as far as bringing that voice to the table. So I guess in some ways I can just more easily wear my patient hat than the [community organization] hat, because the patient part always comes with it right?"*

With regard to decision-making, participants generally felt that they were adequately involved. While some felt that the project team took the lead in decision-making, participants recognized their input was welcome. Only one participant was unsatisfied with the Advisory Committee's level of involvement in decision-making, but this individual also recognized that the project team was continually receptive to members' input.

"I mean the framework and the impetus to move forward was coming from the project team and there was check-ins at different junctures to say, you know, how is this? You know, this is what we're thinking, what do you think?"

"And like I say, we were entitled to, and we were given, freedom to say what we wanted. Buy maybe [the project team] did more than what I thought they would do or something."

When asked whether they would consider themselves an advisor, consultant, or co-decision maker, participants identified themselves as being either an advisor or a consultant. Individual reasons for identifying with a specific role varied, with some basing their decision on their level of participation, or their amount of expertise. Others could not articulate why they made a specific choice. One participant said s/he felt as if her/his role changed with time, and that s/he sometimes felt like a consultant, and sometimes like an advisor. No one identified as a co-decision maker, even though decision-making was generally thought to be shared.

"Consultant….because there were some people at the table who participated to a great degree. I was not one of those people."

"As an advisor I give my advice about how I see certain things, different perspectives, that type of thing."

When participants were asked to identify specific examples of how they contributed to the project, they could not. Two participants mentioned suggestions they had made regarding specific changes to CPFN registration forms and recruitment efforts. Generally, participants felt they contributed primarily by participating in discussion and providing feedback when asked.

"I'm just trying to think, you know, if I weren't sitting at the table, would it have been any different? …It's interesting because you don't know what it would have been like if you weren't there, but I did feel valued and heard."

3) Participant understanding of PE: This includes participant comments related to the definition and

importance of PE, the intrinsic value placed on PE, and the perceived benefits of PE.

Since PE was the focus of the larger project (i.e., improving PE via the CPFN), participants were asked to reflect on the definition of PE and why it was important. Interestingly, participant definitions of PE varied greatly, despite the fact that an operational definitional of PE was developed over the course of the project. The definitions they provided included giving feedback on the system, patients advocating for other patients, and participating in decision-making (in general, and specific to care delivery). PE was felt to be important by all participants. Although their reasons varied, PE was seen as key in ensuring that patient needs are met, whether those needs are care-related, informational, or psychosocial.

"What patient engagement means to me, basically, is being the strongest and best advocate for yourself, or your family, or for the person that you might be, you know, providing care for."

"We make decisions that affect people, and we need to understand what their perception of that change may be, or implementation of something, or a process change, or anything we do really….validating what we're doing or giving us food for thought around the impact and whether or not that decision makes sense from that lens of things, looking from the patient's side, the patient and family side."

In an attempt to understand the intrinsic value of PE, participants were asked if the experience was meaningful and whether they felt valued. All participants agreed that the experience was meaningful, but for different reasons—being invited to participate(in and of itself) was meaningful; contributing to something important was meaningful; meeting, working with, and hearing the perspectives of a diverse group of individuals was meaningful. This latter aspect represents the social component of participation and seemed to be particularly important to participants. All participants felt valued throughout their involvement, typically equating feeling valued with feeling that project team members had listened to and heard their input.

"Um, it was meaningful in that I felt that I was influencing something important for others. Um, it was meaningful in that it introduced me to some new people. Um, it was meaningful, um, you know, I'm going back to a point I made earlier…it was meaningful because I was flattered to have been asked. "

"I did feel heard and I certainly felt that my opinion was taken into consideration."

Despite feeling that the experience was valuable, overall, members stated that participation was not a 'profound' experience and did not have a substantial effect on how participants viewed PE or how they would do PE moving forward (i.e., how they would engage others, or how they

would participate in PE initiatives). Rather, through participation in this project, they were reminded of the importance of PE.

"Um, I'm not sure it's going to change anything. Um, I think it just kind of reinforces the importance and the need and really does, um…..I think it makes me more apt to engage [patients]."

Participants also discussed benefits they gained from their participation, though these varied greatly between individuals. Benefits included increased confidence in the ability to participate, improved communication skills, and forming new relationships. All participants indicated that they would participate in a similar opportunity in the future and that they would encourage others to participate. The latter was primarily related to understanding health system change processes.

"People can be helped to see that things are happening and things are being done, even if they think maybe nothing is happening."

4) Barriers and facilitators: There were few barriers identified, although time to participate (i.e., attend meetings, read emails) was identified as something that had to be balanced with other responsibilities. In addition, there was recognition of the challenges of balancing the various perspectives involved in the process of PE—health professionals, project team members, partner organizations, and patients/survivors. While these things did not create barriers as such, they did have to be managed.

The primary facilitator of PE was organization on the part of the project team, specifically with regard to meetings. Participants noted that the availability of video conferencing (i.e., 'telehealth'), and the comfort of the project team with this technology, allowed for the inclusion of people from rural areas, which was seen as beneficial. Scheduling meetings several months in advanced allowed Advisory Committee members find time to attend, and having them only when needed (i.e., cancelling meetings that were unnecessary) was appreciated. Finally, the provision of food and travel reimbursement made participants feel "taken care of". The individuals involved also helped facilitate PE: the project coordinator was considered essential to keeping the project moving forward and to facilitating communication between the project team and the Advisory Committee, while the Committee Chairperson ensured that everyone had a chance to participate in discussions. Finally, trust was a facilitator at two levels: 1) participants placed great trust in the organization in which the project was situated and believed the organization would make change happen as a result of their involvement, and 2) there was a great deal of mutual respect and trust between individual Advisory Committee

members, which fostered discussion and the exchange of information.

Discussion

The results of this study emphasize the subjective nature of PE. Each individual has a unique set of ideas and opinions based on his/her own experiences. As such, individual motivations for participation vary greatly, as do individuals' understanding of the concept of PE and perceived benefits of participation. Certainly, the small sample size in this study meant that theoretical saturation could not be achieved, whereas a larger sample size may have permitted a more robust analysis and the identification of additional common themes or further development of existing themes. However, the highly subjective nature of PE has been noted elsewhere in the literature [9,7], lending support to the findings of the current study. Moreover, this study provides valuable insight with regard to the practical considerations of carrying out PE relevant to decision-making at the 'system level' (i.e., program evaluation and design). Evaluations of such initiatives are essential for improving the effectiveness with which they are carried out [28,29].

It is interesting that despite the differences in individual perspectives on PE, participants unanimously enjoyed the experience, felt engaged and valued, and found the experience to be meaningful. There are several reasons why the experience may have been so positive for those involved. Firstly, although PE has been part of the mandate of CCNS since its inception, involvement in this externally sponsored PE initiative may have influenced the efforts of the project team by prompting self-reflection and critique throughout the course of the project, leading to a more mindful approach to interacting and communicating with the Advisory Committee. In addition, participation bias may be present such that those who agreed to be interviewed about their experience were those who felt the most engaged.

It should also be considered that for participants, the act of participation was valued in and of itself. When asked to elaborate on why the experience was meaningful, or personally important, participants' responses varied. Meaningfulness was attributed to being invited to participate; contributing to something important; and meeting, working with, and hearing the perspectives of others. In looking to the data, the intrinsic value placed on participation was evidenced by several findings. First, the experience was broadly considered positive and meaningful, even though participants could not articulate specific contributions or ways that they shaped or impacted the project beyond participating in discussions and providing feedback. Importantly, participants felt that these contributions were valued, wherein value was equated with being "listened to" and "heard." Second,

although participants did not perceive themselves as co-decision makers, they expressed satisfaction with their level of involvement in decision-making. The preference for shared decision-making has been noted elsewhere [14], however, in this instance, committee members may have preferred to provide feedback and to defer to the expertise of the project team regarding final decision-making. This seems particularly likely given that participants trusted CCNS as an organization. Finally, involvement was perceived as beneficial, but as having a limited impact on participants' future work beyond reinforcing the importance of PE. Thus, the 'meaning' of participation seemed to come from some basic or fundamental value related to the *act of participating* versus perceiving that one made (or received) significant contributions to (or from) the project.

While there were instances where participants noted that participation provided a 'behind-the-scenes' look at healthcare decision-making, pointing to the value of accountability and/or transparent systems, the data suggested that participants collectively valued the social aspects of being involved in a committee setting. The use of a committee as a model for PE was chosen based on the project team's desire to establish relationships with those involved, and to use an approach that could address project needs as they arose. The use of a committee was certainly more resource intensive that other potential models of engagement (e.g., a focus group, survey, interviews), but was preferred by participants and considered beneficial. While it may have been difficult for participants to identify another approach that would have been better suited to the project after the fact (i.e., to envision how things could have been done differently), the preference for the use of a committee is consistent with the literature. Gagliardi et al [14] found that patients preferred a model of engagement that occurred over time in which they were appointed to a board or committee, their opinion solicited, and feedback incorporated, such that decisions-making was shared with health professionals. In comparison to other approaches to engagement, a committee approach is quite active, requiring a greater commitment on the part of participants. However, it also provides a social or community component whereby participants are able to come together in person, connect with others who share a common interest, and form relationships. The importance of interaction with others and relationship-building has been noted by others [14,30], suggesting that the use of committee model of engagement may fill a social need for participants.

The composition of the Advisory Committee was something the project team grappled with at the onset of the project, specifically with regard to who should be represented, how to ensure adequate representation while keeping the group size manageable, and how to recruit.

While convenience sampling is commonly used in PE [31], Advisory Committee members were recruited using purposive sampling, such that all members had an existing relationship with Cancer Care Nova Scotia or individual members of the project team. The reason for this approach was to ensure that members varied according to role (e.g., health professional, patient, family member, patient advocacy group), demographics (e.g., age, place of residence), and cancer site (e.g., breast, colorectal, prostate, lymphoma), and possessed specific characteristics that were felt to be central to their participation in a committee, along with experience and knowledge of the cancer system. These characteristics included the confidence to converse with clinicians and other health professionals and the ability to communicate by email and travel to meetings. Rowe and Shepherd [6] identified skills and attitudes of those involved as potential barriers to PE, but in this case, participants were identified because they were believed to have the necessary attitudes and skills conducive to engagement – including an inclination towards PE.

On the surface, the concept of representation seems to be simple and one could argue that, in a group of this size (approximately 20 individuals in total for the Advisory Committee and project team), there was adequate representation. However, in practice, representation can be quite complex, with questions regarding how much representation is sufficient and how it can be achieved. One PE focused group has stated that "engagement must be meaningful and include a diversity of voices – not one patient speaking for many" [3]. If this is the case, PE initiatives involving only one or two patients are problematic, particularly if a single patient is intended to represent the broader patient population. We chose to include representatives from community-based advocacy groups in hopes of capturing a broader viewpoint, however, in reflecting on the composition of the Advisory Committee, it was not representative of many communities within Nova Scotia. Unfortunately, increasing the size of the Advisory Committee to include even more individuals was not feasible. As noted elsewhere [6,31], our experience was that PE was time and resource intensive, requiring funding and a dedicated coordinator (i.e., to answer questions, obtain and collate feedback on documents, send project updates, organize meetings, issue travel reimbursements, etc.), and would have been even more so had the group been larger.

A recent literature review of PE [7] identified a number of patient-focused barriers to PE that included issues related to availability of time and resources, not seeing the direct personal benefit of involvement, involvement fatigue, and participant health considerations. With the exception of the time required to participate, these barriers were not identified by participants. Individual health did come into play to some extent, with two individuals ceasing participation because of ongoing health-related issues. In

this case, having a large group proved beneficial by permitting the larger project to continue as planned, with a variety of perspectives guiding the project as it moved forward. By project end, involvement fatigue may have occurred, and could explain why only 5 of 12 Advisory Committee members opted to participate in this study. Many potential barriers were likely mitigated by the availability of funding dedicated specifically to the project's "engagement infrastructure," defined by Kovacs et al [7] as the financial and human resourcing and related supports needed for PE. By having an individual dedicated to managing communications and logistical arrangements, and providing travel and parking reimbursement, the components necessary for a successful engagement opportunity—time, resources, and capacity [32]—were present, helping to optimize engagement and minimize the potential for tokenism [33].

Conclusion

In this project, the use of a committee as a model for PE was perceived by Advisory Committee members as an effective means of engaging stakeholders and of creating an experience that was enjoyable and meaningful for those involved. While each individual experienced the PE process differently based on his/her previous experiences and individual motivations, this study suggests that the act of participating in PE had meaning in and of itself to those involved, independent of the activities and/or outcomes of that participation. This likely related to the social benefits gained from committee involvement, but may also reflect a broader public value that PE is an important component of transparent, accountable health systems.

Based on the experience of the project team and the findings presented in this paper, we propose that designing a PE opportunity requires consideration of: (i) the most appropriate model for engagement, (ii) the relevant patient and stakeholder groups to be included, (iii) the recruitment strategy, and (iv) the availability of human and financial resources. With no one-size-fits-all approach to PE, the importance of planning cannot be overstated, particularly in relation to ensuring the appropriate resources are available.

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