



Exploring meanings of expert and expertise in patient engagement activities: A qualitative analysis of a pan-Canadian survey

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ABSTRACT

In this paper, we engage with claims of expert identities within the field of patient engagement. We do so through analysis of a subset of data collected as part of a 2020 pan-Canadian survey of patient partners. Our analysis is based on 446 qualitative responses to one target question: “Do you think the lived experience you bring to your patient partner role makes you an expert? Please explain in the box below”. Most respondents answered “yes” (n = 253 comments), a sizeable minority answered “no” (n = 161 comments) or declined to answer the target question while still providing comments (n = 32 comments). Through a discursive analysis of the comments, we explore the meanings ascribed to concepts of expert, expertise, and experience. Ultimately, we find nuanced and sometimes contradictory understandings. Thus, dilemmas of expertise in the patient engagement field may not be entirely about claims to specialized knowledge. Instead, discourses seem to be mobilized in response to the thorny, political question: “who is authorized to speak on behalf of patients”? To meaningfully advance the conversation within patient engagement research and practice, we argue for more sociological and political understandings of forms of expertise, objects of expertise, and deployments of expert status in different kinds of knowledge spaces.

1. Introduction

The concept of patient expertise has long occupied sociologists of health and illness (Prior, 2003). With the growing international momentum around patient engagement at all levels of healthcare implementation and governance, these debates about patient expertise have taken on a different flavour. In some patient engagement activities, there appears to be a uniform effort to declare, accept, and preserve the status of “expert patient” amongst all patients, members of the public, and caregivers that participate (Badcott, 2005; McLaughlin, 2009; Weiste et al., 2022). However, other streams of activity and research are attempting to problematize the concept of expert patient and how it is being deployed (El Enany et al., 2013; Fox et al., 2005; Voronka, 2016).

Thus, a polarity is developing between engagement-focused practitioners and analysis-focused researchers based on how they each orient towards the notion of “expert patient”. To further complicate matters, patient engagement is itself an umbrella term, encompassing a wide range of potential activities (Tritter, 2009; Tritter & McCallum, 2006) and a complex mix of patients and publics (Fredriksson & Tritter, 2017). These activities could be as varied as participating in one’s own care (e.g. patient engagement as shared decision making), informing health service organizations’ policies and programs (e.g. patient engagement in quality improvement), providing direct service (e.g. patient engagement in peer support programs), or informing broader health policy (e.g. citizen engagement in health policy). These kinds of activities necessarily pull together complex arrangements of stakeholders with different

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interests and priorities (Madden & Speed, 2017). Therefore, to advance the discussion of patient expertise and how it emerges in the course of such varied patient engagement activities, we require a broader understanding of how patients themselves make meaning of concepts like “expert” and “expertise”. Taking a perspective that spans beyond individual patient engagement programs, allows us to unearth complexities and contests about what expertise means in and across these diverse activities.

In this study, we explore how patients and caregivers who have been involved as patient partners in Canadian healthcare organizations make meaning of the concept of “expert”. This paper reports on a subset of data collected as part of a pan-Canadian survey of patient partners in 2021 (Abelson et al., 2022; Tripp et al., 2022). In this survey, eligible respondents included people with lived experience of the healthcare system (personally or as a family member or caregiver) who had engaged longitudinally with organizations to help shape systems-level decisions. Our analysis is primarily based on responses to one target question in the survey: “Do you think the lived experience you bring to your patient partner role makes you an expert? Please explain in the box below”. In adding this target question, we sought to gain access to discourses related to expert status and expertise as they are circulating through our respondent group. Our purpose in analyzing this subset of data is to better understand what the word expert means in practice and what one group of stakeholders argue the word *should* mean. Of the 603 survey respondents, 446 people provided additional comments in response to this question. This large, pan-Canadian dataset provided access to a broad set of participants involved in myriad of patient engagement activities. Discursive analysis of these responses allowed us to explore the work being done through the label of “expert” by asking three questions: Are patient partners defining themselves as experts? What meanings do patient partners put towards concepts of expert, expertise, and experience? What nuances exist in the ways patient partners ascribe these meanings of expert, expertise, and experience? It is in these intersections between competing discourses of “expert” where we focus our discussion and the potential implications for future patient engagement work.

Prior to describing our study and our findings, we first locate our inquiry within the broader debates about patient expertise. We then synthesize our conceptual framework, articulating how we approach the concept of expertise in our analysis. It is through this conceptual framework we suggest the broader significance of our study. What is at stake here is not just about the future of patient engagement activities, but broader questions about the role of expertise in public decision making. We pick up this thread again in our discussion before concluding with suggestions for practices of patient engagement.

1.1. History of lay expertise and expert patients

The label of “expert patient” has a long history in healthcare. Segal (2020) argues that the modern focus on empowered patients follows a trajectory initiated in the 19th century, where the “intelligent” patient was informed, vigilant, and prepared to intervene in their own health independently of physicians. However, in the mid 1950s institutions concerned with regulating medicine and advertising medications coalesced with professional institutions, positioning physicians as an intermediary between patients and entrepreneurial patent holders (Segal, 2020; Starr, 2015). An era of professional dominance followed, affording the profession of medicine nearly sovereign power over the definitions and scopes of the ever-expanding practice of healthcare (Freidson, 1970/2007; Starr, 2015). As patients were presumed to lack information on all things from diagnosis to treatment, medicine’s institutional role became one of addressing uncertainty. Taking up this role was a valuable proposition for physicians (Arrow, 1963; Haas–Wilson, 2001). In this societal context physicians, nurses, and allied health practitioners have jockeyed to successfully enclose and exercise singular authority over specialized fields of knowledge and activity

(Larson, 1977/2013; Saks, 2016). Thus, addressing uncertainty while maintaining closure on an area of specialized knowledge and action became central to the politics of healthcare (Abbott, 1988; Adams & Saks, 2018). What came to be known as “scientific medicine” provided those in the field of healthcare with a set of core values by which to navigate these uncertainties and protect professional turf. All uncertainties, including political ones about how healthcare should be produced, distributed, and consumed, were to be resolved through appeals to particular kinds of authoritative knowledge. Under these conditions, the mid-1900s saw substantial increases in health professional power, with various professionals’ claims to esoteric knowledge, expertise, and authority used on behalf of not just individual patients but to determine the public good (Freidson, 1970/2007, 1988).

Two separate movements began to revive the concept of “expert patient” in the later 1980s. First, social scientists studying social movements in health argued that through focused attention and a high degree of motivation, some patients are capable of acquiring sufficient biomedical knowledge to be nearly indistinguishable from researchers and healthcare professionals in the same domain (Brown et al., 2004; Epstein, 1995). Drawing upon these studies of social movements, the identity of “lay expert” became a feature of medical sociology in the 1990s. A separate but related body of work emerged about the creation of “expert patients” and “patient activation” in the United Kingdom, Canada, and United States (Badcott, 2005; Boulet, 2016; Vadiee, 2012; Wilson et al., 2007). For example, “expert patient programs” in the National Health Service (NHS) in the early 1990s were primarily designed to provide education and training for patients with chronic illness so that they would become more independent in managing their own care. Similarly, patient activation programs are primarily concerned with teaching patients self-management skills (Kinney et al., 2015). With the aspiration of increased self-management, the intended outcomes of these programs were primarily measured in psychometric and biomedical terms (Greenhalgh, 2009), or through the assessment of psychosocial and psychological factors that contributed to program success (Golubinski et al., 2020). Whereas “lay experts” generated through earlier social movements engaged in all levels of healthcare related to their illness, these “expert patients” were supported to become experts in their own illness, and in the process patient knowledge was often framed in authoritative biomedical terms (Fox et al., 2005; Francis et al., 2018; Wilson et al., 2007). Claims to expertise in these programs are complex but centre predominantly on the role of expert patients in navigating their own illness or perhaps supporting the development of other expert patients in the same domain. Thus, there were at least two threads of activity reviving interest in the construct of “expert patient”, but the history, antecedents, and realm of possibilities were distinct. Whereas social movements directly engaged with questions of power and voice, “expert patient” programs sponsored by health service organizations were less likely to disrupt existing hierarchies of knowledge and knowers.

1.2. Current debates and dilemmas: claiming and defending expertise

The domains of patient engagement have moved beyond these contained scopes of engagement in one’s own illness to now include engagement in all facets of healthcare design, delivery, research, education, and evaluation. Problems of claiming expertise permeate much of the literature on this broad range of patient engagement activities, taking different shape depending on the types of activities in question. Some programs address these dilemmas through declaration, arguing that the title of “expert patient” or “expert by experience” is available for all those who wish to claim it (Towle & Godolphin, 2011; Ward et al., 2022). Where the possibility of “expert patient” is taken as the conceptual entry point, social scientists have explored the complexity of the identity work involved in these ongoing claims to expertise (Maguire & Britten, 2018; Thompson et al., 2012). Renedo and Marston (2011) elegantly synthesize the dilemma in their study of community

participation initiatives: “being an involvee is about struggling first to assert a legitimate identity as a public participant, second to ‘survive’ as a lone outsider and a minority in complex expert-systems, third to exercise agency when having to adapt to institutional top-down forms of (patient and public involvement), and fourth to cope with threats to lay identities and derogated common-sense knowledge” (p. 278). Thus, much of this literature is concerned with the tensions people experience as they strive to be seen as legitimate sources of knowledge, trying to both align and differentiate themselves from more traditionally authorized knowers such as clinicians, researchers, and administrators (Jones & Pietilä, 2018; Maguire & Britten, 2018). In this vein, considerable training, education, and community support has been generated to assist patient partners, providing additional “credibility tactics” (Epstein, 1995) for participants in these roles.

1.3. Incoherencies and unintended consequences

Critical social science literature locates these dilemmas of expertise differently. These scholars suggests that the very concept of “patient expertise” is internally incoherent and produces some of the dilemmas experienced by participants in patient engagement programs. Tracing the emerging popularity of the phrase “lay expertise”, Prior (2003) argued that the concept was an understandable response and further challenge to the dominance of medicine. However, Prior continued, the hybrid concept problematically blurs together belief, knowledge, and expertise without distinction. Ives et al. (2012) take up this line of critique, exploring what they claim to be a paradox in the application of moral motivations of patient and public involvement into the pragmatic tasks of generating knowledge through research. Drawing upon feminist theory and Mad studies, critical social scientists have elaborated the connections between strong standpoint theory, the dangers of essentialism, and the ways patient engagement programs are potentially creating unintended consequences for participants asked to both speak for themselves and act on behalf of others (Voronka, 2016). Social scientists studying patient engagement activities have demonstrated the tensions experienced by participants as they become enrolled in engagement activities with unclear expectations about representation (Martin, 2008a, 2008b) and the intended use of patient knowledge (Rowland et al., 2021; Rowland et al., 2018). Other authors have noted a tendency for patients to pursue additional training, credentialing, and status markers, consistent with a professionalization process familiar in healthcare (El Enany et al., 2013). This creates the possibility for stratification within groups of patients, working against the espoused democratic ideals of engagement programs.

In short, the dynamics of expertise in patient engagement activities are implicated in the politics of healthcare. This is not unique to the domain of patient engagement. Healthcare is inherently political (Forest & Denis, 2012) and patient engagement activities have become implicated in the distributions of status, power, and financial benefit. Further, patient engagement activities and participants’ claims to expertise are incorporating both democratic and technocratic rationales, arguing for a representative role for publics *and* potential expert contributions of particular subgroups (Martin, 2008a). In these ways, the dilemmas of expertise that permeate patient engagement activities are not unique to those initiatives but reflect broader tensions between democratic and technocratic decision making in the public domain. Sociologists have argued that these tensions animate a broader crisis of expertise in society (Collins et al., 2020; Eyal, 2019).

1.4. Connections to the current study

In summary, the topic of patient expertise has long been of interest to social scientists. Further, there are many debates about the nature of expertise and expert status in patient engagement activities. These debates are not occurring in isolation but are in the context of broader debates about the nature and role of expertise in society. Where there

have been studies of the dilemmas of expertise manifesting in patient engagement activities, these studies have tended to contain themselves to a set of activities or programs. However, with so many potential discourses and disagreements about the nature of patient expertise available, it becomes useful to explore how these discourses are manifesting across a broad range of activities. In this study, we take the opportunity presented by a Canada-wide survey of patient partners involved in a range of engagement activities to access the range of discourses circulating about patient expertise and declarations of expert status.

2. Conceptual framework

In this study, we take up Eyal’s (2019) argument that expertise is an essentially contested concept. Consequently, the nature of expertise, what the word expert means in practice and what actors argue the word *should* mean, is a site of struggle and debate. Our purpose in this study is to better understand this debate and how it is manifesting in the patient engagement world. Rather than simply juxtaposing categories of “lay” and “expert”, we seek to examine the evolving boundary between expert and non-expert categories, how that boundary and the prerogatives in healthcare decision making it affords are being contested and constructed, what meanings and nuances stakeholders attribute to the concept of expertise, and where those nuances might be brushed aside. To contribute to this debate in a meaningful way requires a pragmatic orientation, understanding how the concepts are being used, taking into account the historical usage of the terms, who is talking, and for what purpose. In this study, we are focused on the implicit and explicit discursive strategies that participants draw upon to explain their positions in response to the target question: “Do you think the lived experience you bring to your patient partner role makes you an expert?” We are informed by arguments within the sociology of expertise (Collins & Evans, 2008b; Eyal, 2019) that draw our attention to: declared objects of expertise, types of knowledge privileged in declarations of expert status, arguments of legitimacy associated with these types of knowledge, and dynamics of trust implicated in these arguments.

3. Methods

Canadian patient, family, and caregiver partners were invited to participate in an online survey from October to December 2020. Eligibility for the survey was based on the respondents’ declared longitudinal experiences participating in activities in a Canadian health system or governmental organization with the aim of building on their lived experiences as a patient, family member, or informal caregiver in order to inform the organization in some way. The term “patient partner” was defined at the beginning of the survey: people (patients, clients, family members, and caregivers) who are drawing on their past or current experiences with the health system in some way, usually through their involvement in the activities of a particular health system group, organization, or government. This Canadian Patient Partner Survey (CPPS) was developed based on an extensive literature review, consultation with an expert panel, and in collaboration with patient partners from Patient Advisors Network. The CPPS focused on patient partner experiences, attitudes, and demographics and was available in both English and French. This survey is the first of its kind to examine at a population level, the characteristics, experiences, and dynamics of a large sample of self-identified patient partners. An online snowballing approach was used to recruit survey participants. A first round of emails was sent to members of the study team and external advisory committee, inclusive of patient partners, engagement researchers, and health systems professionals. These stakeholders were asked to distribute the survey widely through their networks. Survey information and links were also sent to health systems and patient groups across Canada, along with the request to distribute survey information directly with patient partner networks. Finally, the survey was promoted widely on social media platforms

(Twitter, Facebook, LinkedIn) at multiple times during the recruitment phase of the study. Survey completers were given the opportunity to enter a draw to win one of three \$200 (Canadian) cash prizes. A total of 603 individuals participated in this survey. Demographics for these participants are included in Table 1.

Given that the precise number of people in these roles in Canada is unknown, a response rate could not be calculated. More detail about the survey, confirmation of the ethical review process, and the broader results are published elsewhere (Abelson et al., 2022; Tripp et al., 2022). All comments written in French were translated into English by professional translators prior to analysis. A total of 503 participants answered the target question. Of those that answered the target question, more than half of respondents answered “yes” to this question (n = 314/503, 62.4%), while about a third of respondents answered “no” (n = 189/503, 37.6%). We conducted a between group analysis of the “yes”, “no”, and “no answer” respondents and did not find significant differences in the demographic distribution of participants as compared to the full dataset. In total, 446 people provided additional narrative comments in response to the question. There were 253 comments associated with the answer “yes”, 161 comments associated with the answer “no”, and 32 comments associated with the “no answer” option. These 446 comments provide the substance for the current analysis.

3.1. Analytical approach

The first phase of analysis involved sorting and coding the 446 comments associated with our target question. First, the data was sorted by initial answer to the question “Do you think the lived experience you bring to your patient role makes you an expert?”. Answer possibilities included “yes”, “no”, or “no answer”. Comments were uploaded into NVivo™ for additional sorting and coding. Treating each of those three answer categories as a case, the first author engaged in line-by-line inductive coding of each comment. This line-by-line coding directed attention to how the respondents elaborated on their initial responses and articulated their understandings of experts, expertise, and experience. For example, this included coding for objects of expertise (i.e. what is expertise directed towards), verifications of expertise (i.e. how is

Table 1
Respondent characteristics^a.

Characteristic	Statistic	All (n)
Age	Mean	57.5; SD = 14.4
	Median	60; range = 16-90
Gender	Female	76.6 (412)
	Male	21.0 (113)
	Transgender	0.7 (4)
	Non-binary	0.2 (1)
Education	Decline to answer	1.5 (8)
	Completed university education or higher	70.2 (380)
Household income	>CAD \$90 000	43.3 (181)
Race	White	84 (462)
Self-reported health status	Excellent/very good/good	74.3 (399)
	Poor/fair	24.8 (132)
Disabilities/health conditions	Chronic illness	49.0 (269)
Employment	Employed full-time	17.5 (96)
	Retired	43.2 (237)
	Receiving disability and/or income replacement benefits	11.9 (72)
Experience individual drew upon for first engagement activity (all that apply)	Experience as unpaid caregiver	48.9 (295)
	Patient with acute/chronic illness	62.0 (374)
	Patient who accesses periodic care/screening	46.8 (282)

^a Non-responses have been removed from each data point; total number of responses per question ranged from 418 to 602.

expertise recognized), declared relationships between experience and expertise, and boundaries of expertise. This phase of the analysis was informed by our reading in the sociology of expertise, particularly Eyal’s (2019) typology of debates about expertise and Collins and Evans’ (2008a) periodic table of expertises.

The initial result was a set of themes across the three cases: “yes expert”, “no expert”, and “question not answered”. These initial themes were taken to the authorship team for additional discussion and clarification. This discussion involved critical inquiry into how the themes relate to one another across the cases and how these interactions inform understandings of experts, expertise, and experience in the patient partner context. For example, we noted that the concept of “lived experience” was being deployed in support of both answers: “yes, I am an expert” and “no, I am not an expert”. These observations prompted our final phase of the analysis, where we focused on declarations of nuance, reflexively contradictory arguments, and discursive “hedgies” around the concepts of expert and expertise. In this way, we draw out how respondents were accessing potentially contradictory discourses about experts and expertise (Becker, 1998; Potter & Wetherell, 1987). This analysis was facilitated by memo-taking, ongoing coding of the data, discussion within our authorship team, and reference to existing bodies of literature. Our approach aligned with descriptions of abductive analysis (Tavory & Timmermans, 2014) as we regularly compared our emerging analysis with existing theories, sought out variation within our dataset, and worked with outliers as analytical puzzles to help us better understand our phenomenon of interest.

4. Results

Our analysis is based on the 446 comments provided in response to the target question in the survey. These comments varied in depth, with some being as short as a few words conveying a single idea (e.g. “my lived experience is expertise”, “I don’t pretend to be an expert”; n = 58), some providing two or three sentences with at least two key ideas (n = 223), and others providing several sentences or full paragraphs with three or more ideas conveyed (n = 165). The distribution of depth was relatively similar across the three categories of response types (i.e. “yes”, “no” and “not answered”) with about half of the responses in each category conveying two or more ideas (see Table 2). Even though some comments were relatively brief, their repetition across the dataset (e.g. “my lived experience makes me an expert”) renders them analytically interesting. Taken as whole, these 446 comments provide access to the various discourses available within patient partner communities navigating the question “do you consider yourself an expert?”.

In this section, we synthesize the various discursive possibilities deployed when respondents answered the target question in the affirmative (e.g. “Yes, I think the lived experience I bring to my patient partner role makes me an expert”) and those who answered the target question with the response “no”. In each section, we draw attention to how expertise was discursively positioned and how expert status was recognized.

Table 2
Distribution of responses and comments in relation to target question.

Answer	Count of Answer	Count of Comments
Yes	314	253
No	189	161
No answer ^a		32

^a This category reflects participants who chose to not answer the target question but still provided comments in the open text box.

4.1. Yes, I am an expert

4.1.1. Experience and skill in managing illness and navigating health systems

In this category, we place comments that indicate respondents answered “yes” to the question of expert status based on their experience and skill in managing their illness and navigating the health system. This category was by far the most coded in our dataset with 151 coded references. Sometimes, the answers were very brief, simply saying “I am the expert on my life” or “been through a lot”. Other times, the answers relayed the depth and breadth of experience as a patient or a caregiver (e.g. “navigating the system for 30 years as a caregiver, yes”, “23 years running a home ICU for our son, his 98 hospitalizations with multiple surgeries, now navigating support for his medical group home”). Some respondents emphasized their response, “OF COURSE WE ARE EXPERTS OF OUR OWN EXPERIENCES! Who else is the expert of what’s happened to me? A health professional? They treat me like a diagnosis, not a person” (emphasis in original). At times, experience was equated with expertise (“I have lived my experience so I am an expert on my own experiences”). These comments found discursive agreement with others that approached expertise as an acquisition of skills and knowledge through practice (“In accordance with Malcolm Gladwell’s 10, 000 h rule of mastering anything, 20 h per week for 10 year would qualify you as an expert or ‘world-class’”). In other comments, the question of “are you an expert” was wrapped up with risk, accountability, and self: “It is my life and my body and I make the final decisions on care with their expertise of course”. What is unique about this category of comments and the associated arguments is the incontestability. Expertise is stated in a way that grounds personal experience, leaving no need – and perhaps no room – for external validation of expertise or expert status. One respondent was explicit about this discursive incontestability: “There is no argument for the things you experience. This allows you to share information/knowledge in a confident way”. Creating the conditions for incontestability may be one way in which meanings of expertise and dynamics of power overlap in the domains of patient engagement. As Lukes observes “Without observable conflict (overt or covert) one must assume ‘consensus’ to be ‘genuine’. But why should one exclude the possibility that power may be at work in such a way as to secure consent and thus prevent conflict from arising?” (Lukes, 2005, p. 7). By rendering “lived experience” uncontestable, any associated struggles related to the meanings of expertise may be displaced but not eliminated.

4.1.2. Expert status is conferred as expertise is recognized

We illuminate this category of responses as a point of contrast to the previous category. Whereas the first category relies on discourses of personal experience that do not require external validation, there was also a subset of responses that suggests expert status is warranted based on *externally* located displays of appreciation, respect, and success. Here, respondents provided examples of feedback received, positive responses to participation, and materials produced to substantiate their response of “yes” to the target question. Exemplar comments include: “I have written two books and honed my skills in partnering in research studies”, “part of a team that presented this in a poster at four international conferences and that was later published”, “my lived experiences were and still are being widely received by students and other healthcare persons and things they have learned from me are being passed on ... so yes ... I do feel I am an expert and very proud of that feeling 😊” and “based on the reaction to my input/feedback/contribution I feel that I have become recognized for my knowledge and insights into communication gaps”. In each of the above examples, respondents refer to external recognition of their contributions as indications of their expertise and as a discursive rationale for their affirmative response to the target question.

4.1.3. Lived experience as a patient is necessary for expert claims, but is not sufficient

However essential lived experience was to the notion of “expert”, for some respondents it was not entirely sufficient to be able to claim expertise. These respondents identified and elevated skills they saw as necessary supplements to lived experience if the authority of being an “expert,” and achieving positive change was to be achieved. These authority bolstering statements included additional training and experience. Exemplar quotes include: “experiencing the unique serious range of health issues I have combined with my training as a lawyer and current young age make me an expert” and “patients are expert on their own health and some of us have expertise that is relevant to the healthcare system operations/management and should be use(d) much more”. In other comments, this additional experience was not necessarily anchored to formal training or work experience, but still related to forms of relational expertise necessary for creating position change. Exemplar quotes include “my lived experience makes me an expert but my ability to communicate and network with others and advocate for others elevates where I can sit and contribute within the health system” and “an expert in what? For me it would be in partnership. That is where my expertise lies. Knowing how to collaborate, work in a team, in partnership, without having to make demands to my healthcare team”.

This idea of supplemental, or accretive, expertises that layer on top of lived experience suggests the potential for stratification, where some patient partners claim higher forms of expertise. This potential for stratification has been raised by social scientists concerned with the possible unintended consequences of patient engagement programs and the professionalization of patient partners (El Enany et al., 2013). Indeed, some comments from participants explicitly indicated a stratification of patient partners where:

There is NO DOUBT that lived experiences make one an expert - but not everyone has the ability, or capacity to translate that expertise into action. Partly, that requires an ability to communicate your story to stakeholders in a way that can be valued and appreciated, and partly, the system itself fails to recognize that expertise. When both of those are present, true change and improvements in patient outcomes can occur (emphasis in original).

Thus, within this category of respondents that answered affirmatively to our target question about claims to expert knowledge, there was nuance in responses and the associated rationales. However, what we are pulling forward in this last set of answers is not a contested definition of experts or expertise so much as a stratification of the kinds of experience, training, and forms of knowledge considered more or less necessary or sufficient to claim expertise and so bring authority to one’s claims in a healthcare decision making discussion.

4.2. No, I am not an expert

4.2.1. Experts voluntarily seek additional training and credentialing

For those respondents that answered “no” to our target question, the rationales were more varied. For some respondents, the answer was relatively simple and even traditional. For these respondents, the term “expert” was reserved for those individuals with formal biomedical training and associated credentials. This rationale is evident in the following exemplar quotes: “Yes we have lived experience but the professionals are experts” and “Who is an expert? While I am an expert in my experience, the experts I am most interested in are researchers and medical professionals who have the training and ability to find a cure”. The latter respondent goes on to say, “so while I would like to influence priority setting, I don’t want to do anything to diminish that it’s their expertise we need!”. This comment implies clear boundaries between bio-medical expertise and lived experience knowledge, suggesting that a dissolution of the boundary might diminish the potential to achieve the intended goals of patient engagement. Others denied the expert role, not just because of the element of training, but the additional element of

choice:

I don't like the term. It implies there is a level of education that a person has chosen to experience. That these experiences have been sought out to expand knowledge. More often than not, these experiences as a patient are unwanted and less than desirable. I agree with the term lived experience, it is specific in describing how the knowledge was gained.

In these responses, we see expertise presented as something that is actively pursued and achieved through additional training, rather than accrued through experience. In this sense it is separate from and even exclusive of lived experience. This is not a surprising approach to defining expertise given the history of the term and the ways it has been deployed to serve authority claims of the professions (Burns, 2019).

4.2.2. The concept of expert is an unreachable end state

Whereas the previous discursive thread was not surprising, the following themes reflect some of the ways in which the concepts of experts, expertise, and experience remain essentially unfixed. Some respondents argued that the concept of expert implies an end state that is unachievable. 'No,' these respondents answered, I am not an expert because I am "always learning". Other exemplar quotes along this theme of endless learning, and aspirational expertise, include: "We're never going to be experts. There is always something to be learned. If you think you've learned it all, start back at the beginning and see what all has changed. Then start all over again" and "How can you know everything? There is always room for improvement and knowledge". Going further, some respondents seemed to imply that the concept of expert should be rejected all together as they saw it as antithetical to continued learning. "Perhaps I feel there are too many people who think they are experts - there is always so much more to learn" and "if you are considered an expert, then you have already put yourself in a position whereby you do not want/need to learn more".

4.2.3. Singular experience is valuable but not equated to expertise

Some respondents actively rejected the notion that lived experience equated to expertise. This thread is particularly interesting, as it stands in contrast to the earlier category of "yes, I am an expert" answers that anchored their rationale within lived experience. Table 3 displays respondent answers along these two categories, focusing on how respondents deployed the concept of "lived experience" to warrant either their "yes, I am an expert" or "no, I am not an expert" response. When respondents focused on "lived experience" as part of their explanation for their "no" response, they focused on the singularity of their experiences. While they stated that their experiences were useful and might provide insight for others, they argued that those experiences might not be generalizable. It was this generalizability that seemed to be foundational to their answer. This was the most frequently coded category in this subset of answers (58 coded references). We have provided a selection of exemplar quotes in Table 3. To demonstrate the discursive distinctions from the previous categories, we have also included examples of affirmative responses that also centred on the notion of lived experience. Juxtaposing the comments in this way draws attention to how lived experience is deployed to substantiate the two opposing answers: "yes, I am an expert" and "no, I am not an expert" (see Table 4).

Table 3
Distribution of depth of responses in relation to the target question.

Answer	One sentence or sentence fragment conveying one core idea	Two or more sentences conveying two core ideas	Three or more sentences conveying three or more core ideas
Yes	25/253 (9.8%)	130/253 (51.4%)	98/253 (38.7%)
No	30/161 (18.6%)	75/161 (46.6%)	56/161 (34.8%)
No answer ^a	3/32 (9.4%)	18/32 (56.2%)	11/32 (34.4%)
Totals	58/446 (13%)	223/446 (50%)	165/446 (37%)

^a This category reflects participants who chose to not answer the target question but still provided comments in the open text box.

Table 4

Comments centring the role of lived experience in response to the target question.

Answered the target question with: Yes	Answered the target question with: No
I know there can be great debate over the word expert here – but I think there is something special about the type of knowledge we acquire when we experience something and then have an opportunity to reflect on it. That knowledge, to me, does equate to a type of expertise and should be valued more than it is. It's whole-body learning, as opposed to purely intellectual learning, and it can be transformative. Nobody else has had your experiences therefore they need to hear our stories in order to improve I can help shed light on the cracks in the healthcare system that I have fallen into while getting treatment, etc. In that way, I have a lot of expertise. People who have not had the illnesses themselves can only study patients as objects separate from themselves, and thus cannot truly be an expert through patients' first-hand experiences. I am the person who knows my condition the best. To have a doctor or researcher tell me how I am feeling or what I need researched or done is insulting.	I am not an expert. I am a patient who has lived with the disease for over 40 years and can simply help bring change based on my experience. I am an expert only with regard to my own experience, not a collective voice. I have a lot of knowledge about caregiving as a role, but I am not an expert. Everyone's experience is unique and affected by many variables, however, there are some commonalities and I can only speak to my experience and hope that it helps others who may have similar experience Each situation in healthcare ends up unique in some sense so though I can bring in some first-hand experience it does not make me an expert. My lived experience is essential but it is NOT ENOUGH to be an n = 1. Need to be able to represent a diversity of patient experiences, situations vs telling about ONE experience that might not be representative I am only an expert in my own lived experience. Others are experts in theirs. Expert is a loaded word. I don't think lived experience alone makes me an expert on anything or anyone but myself

4.2.4. Not expert but very knowledgeable

We would be misrepresenting the respondents' answers if we did not also include their comments seeking to nuance to the question. Some respondents rejected the binary of expert versus not-expert all together, either by declining to answer the question or by using the comments section to indicate their misgivings. One respondent who chose not to answer the question indicated in the comment section:

This is an unanswerable question for me. An expert in what? The concept of patient partner is still fuzzy for me and I have difficulty chopping my experiences into discrete pieces. If having a lot of years under my belt implies expertise, then maybe I'm an expert. But it comes down to understanding whether I've had 20 Years of experience or one year's experience 20 times.

Others that answered the question in favour of "no, not an expert" used the comment section to argue for the value of lived experience while simultaneously declining its essentialness to expertise. Exemplar quotes include: "have trouble with the term expert - I think of this to describe technical skills and is very limiting. I have knowledge and experience, however there is much I am not an expert on ...", "expert may not be the best word ... but definitely a voice that deserves to be heard", "not an expert, but a knowledgeable and concerned participant" and "(my lived experience) makes me an informed resource - NOT an

expert” (emphasis in original). In this category of responses, we are left with the impression that the term “expert” is inadequate and potentially misleading. In addition, there were clear claims to particular kinds of knowledge based on experience of illness and of health system. Through their comments, respondents were arguing for the value of that knowledge. However, the term “expert” carried meanings, and implied authority, that did not satisfy these respondents.

Further, some respondents expressed concern about stretching the concept of experts beyond its bounds. Here, one respondent indicated “I think ‘expert’ is used far too loosely in this area. What I do can be very valuable, but it’s not expert knowledge”. The respondent went on to differentiate lived experience from what they considered to be the hallmarks of truly expert, and thus authoritative, knowledge: “carefully and narrowly defined, periodically assessed, built on lots of foundational knowledge, etc.”. Therefore, whereas some respondents in the survey replied affirmatively to the target question and indicated they felt expertise and the authority it conveyed was essentially linked to lived experience, others were less sure about the labelling convention. However, many of these respondents sought ways to attribute value to, and so authorize, their knowledge without invoking the word “expert”.

5. Discussion

5.1. Nuanced and contradictory understandings of expert

Through our analysis of the comments provided by respondents to the target question in this pan-Canadian survey of patient partners, we see a complex and sometimes contradictory treatment of the concept “expert” and the associated concepts of expertise and experience. Through our initial level of analysis, it is clear that the concepts of experts and expertise remain essentially contested for the respondents in our survey. In our dataset, we had responses that ranged from: certainty that a patient’s lived experience was essential to, sufficient for, and even synonymous with expertise, to ambivalence about how lived experience and more traditional and externally validated approaches to expertise interacted, to certainty that expertise is unrelated to lived experience and perhaps even an unhelpful concept altogether. Along this continuum of responses, we see appeals to objective knowledge, skillful practice, additional training, and relational expertise (Edwards, 2012) as well as embodied experience and unique standpoints. There are also divisions within the comments about the object of expertise. At times, respondents answered the question to refer to their expertise in navigating their own bodies and their own experiences. These forms of knowledge were treated as uncontested. At other times, respondents were answering the question to refer to their expertise in navigating their roles as patient partners and their capabilities in participating in creating strategic changes. The target question in the survey did not direct respondents to one standpoint or another. The observation that respondents answered from both standpoints reflects the fluidity within the field. It is not entirely clear where and how patient partners are locating their lived experience and knowledge, even as they are encouraged to make claims as expert patients.

Our dataset also illuminates substantive nuance in respondents’ answers. Far from presenting a single, unified, and uncontested claim to the label “expert”, participants instead reflected on the boundaries of the concept and indicated wariness about the kind of “epistemic trespassing” (Ballantyne, 2019) that can happen if any individual steps outside of their knowledge domain. In some comments, this wariness may reflect long established deference to formal expert systems and the associated credentialism. This might be interpreted as yet another instantiation of medical dominance (Illich, 1976/2013) and successful professional enclosure of a knowledge area (Friedson 1988; Abbott, 1988). In this way, debate about the nature of patient expertise is directly implicated in dynamics of professional power. An alternative interpretation is that the field of patient engagement is ripe for the kinds of nuanced conversations about knowledge spaces initiated by Gibson et al. (2012),

where different kinds of knowledge are valued and treated equally.

5.2. Dilemmas of expertise and dilemmas of representation

What seems to be at stake in our dataset is how the status of “expert” affords an individual the authority to speak on behalf of themselves or on the behalf of others in the present politics of healthcare. In this framing, claiming the title of “expert in my own experience” affords the authority to speak on behalf of oneself. Furthermore, invoking the title “expert” sets a clear boundary, setting the stage for accusations of epistemic trespassing should someone else attempt to challenge the interpretation of one’s lived experience. However, when the title “expert” is used to confer the authority to speak on behalf of others there are additional complexities. It is when the concept of expert is used in this way that we see participants begin to invoke claims of extended skills sets, legitimization, and external recognition. Only some are authorized to speak on behalf of others. It appears the label “expert” is being used to stratify who is, and is not, authorized to do so. This suggests that, in the patient engagement field, the binary of “expert” vs “non-expert” hinges less on claims to specialized technical knowledge – as the sociology of professions literature suggests – and more on the current politics of representation. This is to say the concept of “expert” is being deployed to address the thorny question: “who is authorized to speak on behalf of patients”?

This interrelationship between claims to expert status and claims of representation is central to the politics of expertise. It is not just that expertise is conceptualized differently by different actors. Instead, it is that “different definitions or theories of expertise *apportion social worth* to certain actors, entities, statements, and performances, and withhold it from others” (Eyal, 2019, p. 19, emphasis added). It is this dynamic of appropriating social worth that renders debates about patient expertise to be political, rather than primarily a contest about the nature of knowledge. As result, the very definition of expertise, what it is and what it means, will always be an unfixed site of disagreement, perhaps even struggle and contest. What is at stake here is not just what expertise is, but what it *should* be. Taken together, the varying approaches taken by the respondents indicate expertise is not merely about knowledge, skill and capacity, but also about power, influence, authority, credibility, and legitimacy.

By extension, patient engagement programs with their associated assumptions about what does, and does not, constitute patient expertise, become squarely located in these dynamics of struggle. When these programs attempt to influence health care decision making, what is at stake are contests about the various forms of knowledge that can, and should, be used to represent the various needs, wants, interest, and experiences of patients. These struggles are not neutral and are not value free, but instead reflect the wide range of interests and stakes that shape patient engagement endeavours (Madden & Speed, 2017). Thus, to deeply engage with the politics of expertise is to also wrestle with the concept of representation in a meaningful way. This kind of nuanced exploration of representation lives within the domain of political science (Pitkin, 1967; Saward, 2010), where political scientists ask what it means to *re-present* the hopes, wishes, experiences, and needs of others. Further, these political scientists recognize the distinction of speaking for others as compared to acting for others. These nuances of representation are at the heart of the politics of expertise. It not simply “who has what knowledge”, but who is authorized to speak for or act for others in these patient engagement domains (Rowland & Kumagai, 2018).

5.3. Implications for patient engagement practices

This foray into the politics of expertise allows us to anticipate and grapple with particular tension points within practices of patient engagement. First, we are able to see that the blunt binary between expert/lay is unsatisfactory. What we require is a more nuanced way to

be able to talk about various kinds of expertise, the objects of expertise, and the intended applications of expertise in patient engagement practices. Second, the politics of expertise points our attention to where we are most likely to see tension points around claims to expert status. The real tension seems to be about the proper use of expertise in decision making spaces. Thus, there may be very little tension when people are claiming expert status when speaking to their own experiences and lifeworlds (see Gibson et al., 2012). However, when the communicative space is concerned with directing strategic action, the legitimacy of expertise is more likely to be questioned. Finally, we argue that understanding dynamics of patient engagement through the lens of the politics of expertise is enormously useful and will continue to be important as dynamics of expertise continue to shift in a post-pandemic world. What we have described in our paper is a thread of a much larger dynamic where there are more and more stakeholders claiming expert status, with ever more heterogeneous claims to knowledge, and the risk of insufficient mechanisms to discern between conflicting forms of advice (Collins et al., 2020).

6. Limitations

In this study, we drew upon responses from a survey directed towards patient partners. Eligible respondents included people with lived experience of the healthcare system (personally or as a family member or informal caregiver) who had engaged longitudinally with organizations to help shape systems-level decisions. Based on the over-arching frame of this survey, and given that our target question directed respondents towards their experiences as patient partners in these organizational spaces, our analysis is oriented to dynamics of expertise in formal decision making spaces. We recognize that participation in formal decision-making spaces is just one domain in which patients develop knowledge and exercise agency. For example, Gibson et al. (2012) have proposed a theoretical framework that grapples with the pluralism of values, ideologies, and forms of knowledge that shape patient engagement practices. Other researchers have also explored how agency and autonomy within one's lifeworld interacts with institutional spaces towards the broader ambitions of health (Sullivan, 2017). While the constraints of our data set in this study restrict our analysis to dynamics of expertise manifesting within institutional settings, future research should continue to explore dynamics of autonomy and authority that span the many lifeworlds of patients and the associated implications for patient engagement practices.

Finally, we recognize the limits of our dataset. In grounding our analysis in the qualitative responses to a target question in a survey, we recognize the limits of depth in each response. However, this approach provided much needed breadth, allowing access to a large group of stakeholders involved in a wide range of patient engagement activities. Given that many patient partners are involved in many kinds of patient engagement activities, this breadth has been essential in helping us exploring our phenomenon of interest, namely the range of discourses of expert and expertise available in the broader field of patient engagement activities. Our intention is to follow-up on this study with more in-depth qualitative work to further explore these findings and their implications.

7. Conclusions

Following the analysis of more than 400 comments in a pan-Canadian survey of patient partners, we argue that the meanings that underlie the concepts of expert, expertise, and experience remain essentially contested. Drawing from sociological inquiries into the politics of expertise, we argue for a more nuanced understanding of forms of expertise, objects of expertise, and deployments of expertise in different kinds of knowledge spaces. We further argue that the politics of expertise take on different dimensions in decision making spaces that bring into question who is authorized to speak on behalf of patient interests, experiences, needs, or wants. Future research could explore how these

discursive strategies are distributed in society and to what potential effect.

In conclusion, we reflect on the events of the world, particularly in light of the COVID-19 pandemic. Since the declaration of the COVID-19 pandemic in March 2020, the world has witnessed the evolving science of a novel virus paired against the need to make large-scale, consequential decisions. We have also collectively witnessed the difficulty of calibrating various forms of expertise in these high-stakes decisions. In the last two years, we have lived what Eyal (2019) anticipated as the true crisis of expertise, "a situation which the number of contenders for expert status has increased, the bases for their claims have become more heterogeneous and uncertain, and the struggles between them have become more intense ... yet the institutional demand for expert discourse is ever-increasing" (p. 19–20). In many ways, engagement activities that position patients as experts are adding to the cacophony of voices seeking to influence healthcare organizations, processes, and people. While this has long been true in patient engagement practices, the associated struggles and contested meanings of expertise may be taking on a new form of urgency in the wake of very public, very controversial arguments about the nature of knowledge, the certainties of science, and the desired role of expert knowledge in shaping societies. The social and political events that have transpired through the COVID-19 pandemic will require continued attention to dynamics of power, responsibility, and authority manifesting in increasingly polarized spaces characterized by broader debates about the nature and value of expertise.

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Ethics approval statement

This study received ethics approval from all associated institutions.

Data availability statement

Anonymized and aggregated data upon which this paper is based is available upon reasonable request to the corresponding author.

Declaration of competing interest

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