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Questioning patient engagement: research scientists' perceptions of the challenges of patient engagement in a cardiovascular research network

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Background: Patient engagement in research is a dominant discourse in clinical research settings as it is seen as a move toward sustainable and equitable health care systems. In Canada, a key driver is the Strategy for Patient-Oriented Research of the Canadian Institutes of Health Research, which asserts that meaningful patient engagement can only be fostered when stakeholders understand its value. This study assessed researchers' perceptions of the meaning and value of patient engagement in research within a Canadian cardiovascular research network. In doing so, the secondary aim was to inform the development of a structured patient engagement initiative by identifying potential challenges and related mitigation strategies.

Methods: We employed a multi-method strategy involving electronic surveys and semi-structured telephone interviews with network research scientists across Canada. Interview data were analyzed using thematic and content analysis. Survey data were analyzed using descriptive statistics.

Results: Thirty-eight electronic surveys (response rate =33%) and 16 interviews were completed with network members. Some participants were uncertain about the meaning and value of patient engagement. While voicing guarded support, four challenges relating to patient engagement were identified from the interviews: 1) identification of representative and appropriate patients, 2) uncertainty about the scope of patients' roles given concerns about knowledge discrepancies, 3) a perceived lack of evidence of the impact of patient engagement, and 4) the need for education and culture change as a prerequisite for patient engagement. Research scientists were largely concerned that patients untrained in science and tasked with conveying an authentic patient experience and being a conduit for the voices of others might unsettle a traditional model of conducting research.

Conclusion: Concerns about patient involvement in research were related to a lack of clarity about the meaning, process, and impact of involvement. This study highlights the need for education on the meaning of patient engagement, evidence of its impact, and guidance on practical aspects of implementation within this research community.

Keywords: patient oriented research, health policy, medical culture, patient-centered care, stroke

Background

Patient engagement in research is currently a dominant discourse in clinical research settings, driven in part by Canada's Strategy for Patient-Oriented Research (SPOR) and its vision to shape a sustainable and equitable health care system.[1] In 2011, the Canadian Institutes of Health Research (CIHR) SPOR National Steering Committee led the development of a Patient Engagement Framework, based on the understanding of patients as "experts" with unique experiences and knowledge as a result of

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living with illness and navigating the health care system. It is expected that involving patients in research will improve its relevance and ultimately increase the quality of care.[1] Similar initiatives are well under way outside Canada, such as INVOLVE, funded by the National Health Service in the United Kingdom,[2] and PCORI, the Patient-Centered Outcomes Research Institute in the United States.[3]

Over the last 20 years, the international patient engagement movement has represented a collective, policy-oriented drive away from a traditional paternalistic model of health care. This trend is evidenced by the global proliferation of self-management programs, expert–patient shared decision-making initiatives, and participatory action research.[4–7] As Karazivan et al suggest, "including patients as full partners in the health care team entails a significant shift in both the medical practice and medical education cultures."[8] But if including patients in the health care team involves a significant culture shift, the engagement of patients in research teams potentially involves an even greater one. Differences in how different types of knowledge are valued, entrenched power relationships,[9] and widespread uncertainty about the meaning of patient engagement itself[9–11] are challenges that will require a rethinking of the traditional modes of research practice. The full embrace of patient engagement by researchers is also hindered by concerns about tokenism, logistics, and fear of patient bias;[6–8] lack of clarity about best practices;[8] practical concerns around defining and representing the community whose engagement is sought;[10] and a perceived lack of evidence of impact.[12,13] This work sought to build on these insights while also exploring the link between the meaning of and value attributed to the concept of patient engagement in research and researchers' perception of the challenges and barriers associated with it, of which there is little documentation in the literature.

Although few quantitative studies that measure the impact of patient engagement exist, three syntheses point to qualitative research exploring the impact of patient engagement in research.[13–15] They include studies demonstrating that in addition to encouraging equity, patient engagement has improved study outcome selection; helped shape research questions; led to potentially higher rates of participant recruitment and retention; increased the quality, credibility, and applicability of evidence; developed trust between researchers and service users; and facilitated knowledge translation. Yet because of concerns about the quality of evidence and the lack of quantitative, measurable data, all three reviews suggest that the overall impact of patient engagement remains unclear.

Under SPOR, "the patient perspective is integrated into every step of the research process including the development of research questions, defining research objectives, data collection and evaluation," with patients variously involved, from full membership in research teams to more limited, knowledge-specific ways.[1]

To realize SPOR goals, the Canadian Stroke Intervention Network (C-SPIN) moved to develop a patient engagement strategy in 2014. C-SPIN is a national multidisciplinary network of research scientists seeking to reduce atrial fibrillation (AF)-related stroke by sharing expertise, resources, and research. The C-SPIN collaboration has involved the design and initiation of eight randomized controlled trials aimed at preventing strokes due to embolic events primarily associated with AF and evaluating innovative strategies to increase uptake of stroke prevention interventions. Involvement in this research would be particularly appropriate for patients and families given that there are over 50,000 strokes each year, with AF being the cause of 15% of strokes overall.[16] However, as indicated by CIHR, meaningful patient engagement can only be fostered in a climate where health care professionals "understand the value of patient involvement and patients see the value of these interactions."[1] Therefore, the aim of this study was to assess the perceptions of patient engagement in research across the C-SPIN network to aid in the development of a structured patient engagement initiative and identify potential barriers and facilitators to implementation.

Methods

Following ethics approval from the Hamilton Integrated Research Ethics Board (HiREB #15-244), we employed a multi-method approach over a 9-month period in 2015 using semi-structured telephone interviews and an electronic survey with consenting C-SPIN members. Qualitative methods were used to explore in depth the meanings given to the concept of patient engagement, while an electronic survey was used to understand the extent of the acceptance and resistance to it. Both the approaches provided participants with a standard definition of patient engagement in the context of SPOR and a definition of "patient" as an overarching term that includes individuals with personal experience with a health issue (for C-SPIN, this was AF, stroke, or cardiovascular disease). The definition of patient also included informal caregivers, family, and friends with similar experiential knowledge of AF.

Semi-structured telephone interviews

We invited network member investigators to participate in semi-structured 15- to 45-minute telephone interviews, guided by the SPOR Patient Engagement Framework and informed by some content used previously by one of the

coauthors (JA) in a related grant (CIHR, HRA126902) (Figure S1). The interview guide was revised once adding demographic items and rewording two questions to enhance clarity. Interviews were conducted individually by the patient engagement leads of C-SPIN (SC and AD). Interview questions solicited participants' understanding of patient engagement, perceptions of its value, and facilitators and challenges. Participants were chosen from a purposeful sample of C-SPIN research scientists/members spanning early, mid-, and senior career trajectories.

Interviews were recorded, transcribed, anonymized, and analyzed with key categories iteratively identified and organized using NVivo 10. Transcripts were read numerous times by GE, a cultural anthropologist, and SC, a nurse scientist, in consultation with each other, to develop a holistic sense of the data, and open codes were identified interpretively and iteratively based on both the prevalence of a concept and its potential to enrich the emerging data pool. Through this process, we "treat[ed] research methods as living entities,"[17] drawing on insights from both thematic and content analysis to best account for our data. Inductive analysis was conducted with codes emerging from the data rather than a preexisting coding scheme.[18,19] In addition, two C-SPIN patient partners reviewed a draft of the manuscript and provided feedback.

Electronic surveys

Electronic surveys paralleling the semi-structured interview guide questions were delivered to 115 network members including stakeholder partners (Figure S2). The survey included five closed-ended questions, two open-ended questions, and demographics. Survey data were collected using Research Electronic Data Capture (REDCap) and exported to the Statistical Package for the Social Sciences (SPSS). Quantitative data were analyzed using descriptive statistics where continuous variables were summarized using measures of central tendency and categorical variables using percentages and frequencies. Open-ended survey questions were analyzed using content analysis.

Results

Semi-structured interviews

Twenty-three C-SPIN investigator members consented to participate in the semi-structured interviews, 17 interviews were scheduled, and 16 completed (20% female). The final sample was based purely on the response rates from the C-SPIN members who consented. Although scheduled, 7 interviews were not completed because of 1) time constraints (of the participants' clinical schedule) and 2) participant schedule changes. Three attempts were made to reschedule the interview, but the participants did not complete the electronic survey.

The majority of interviews (9) were conducted with cardiologists (including electrophysiologists) and also with two neurologists, a pharmacist, a social scientist, an internist, a clinical epidemiologist, a family physician, research trainees, a C-SPIN external advisory committee member, and 2 patient partners. Participants' professional work experience ranged from 2 to 44 years, with a mean of 16 years (Table 1). With the exception of one participant in the United States, participants were based in Canada across four provinces.

Electronic surveys

The electronic survey response rate was 33%, with 38 electronic surveys fully completed. Survey participants represented a similar range of professional fields as interviewees. Whereas many interviewees and survey participants were mid- to late career researchers, others were early career professionals.

Understanding and valuing patient engagement

By contrasting electronic survey results with interviews, we revealed differences in how participants understood and described their perceptions of patient engagement in research. From the survey results, it was found that when participants were asked if they understood the meaning of patient engagement, 32 of 38 (84%) said they did (Figure 1). However, the narrative content of the interviews revealed a greater degree of indeterminacy in respondents' understanding of

Table 1 Interview participant characteristics

Respondents	Years in practice/ profession	Introduction to patient engagement (PE), as defined by respondent
A	3	Introduced to PE concept in last 1–2 years
B	13	Introduced to PE concept 3 years ago
C	27	Has experience with PE activity
D	30	Introduced to PE concept within the last year
E	26	Has experience with PE activity
F	30	New concept
G	16	Has experience with PE activity
H	20	Has experience with PE activity
I	6	Introduced to PE concept 1–6 years ago
J	15	Introduced to PE concept 5 years ago
K	8	Introduced to PE concept recently
L	3	Introduced to PE concept 2 years ago
M	22	Has experience with PE activity
N	28	Introduced to PE concept "several years ago"
O	9	Introduced to PE concept 1 year ago
P	37	Introduced to PE concept "recently"

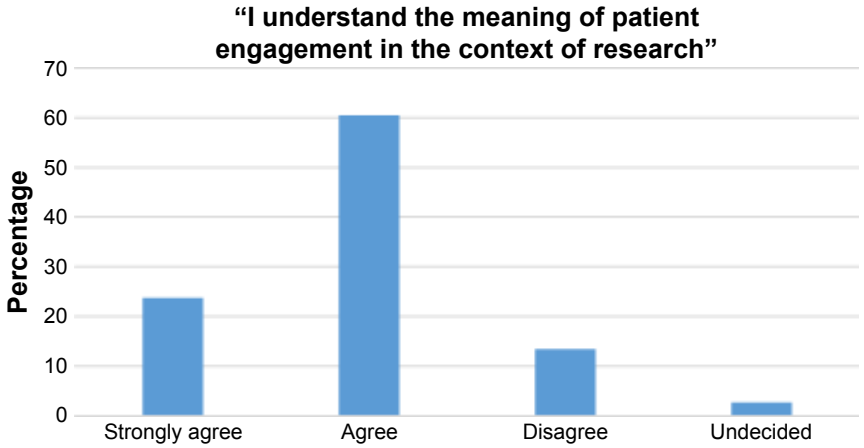

Figure 1 Meaning of patient engagement survey item (n=38).

patient engagement, which then informed perceptions of its value. Interview participants fell along a continuum, with one half seeing value in patient engagement despite voicing concerns about it and the other half seeing the value of patient engagement as overshadowed by concerns surrounding process and desirability.

Those who espoused a more holistic understanding of patient engagement (eg, thinking of patients as partners in research, involved in all aspects of the research process) were more likely to confer value to patient engagement, even though they too critiqued the concept. "I think it's getting a different perspective on value from a societal measure of what we're doing in a very focused academic environment," said one participant, who also worried about the education patients would require to understand the research process [Participant O]. Those who were more negative about the concept also tended to know less about it or have a narrower definition of the term. "I've heard so little about [patient engagement] and I've read so little about it; I'm going to have to invent it as we go along," said another, who claimed to be "skeptical," voicing concerns about the challenge of identifying a representative patient and the lack of an established "curriculum" to guide patient engagement training [Participant F].

Both the electronic surveys (Figures 1 and 2) and the interviews indicated that patient engagement was valued because patients could identify research priorities, help with knowledge translation of findings, and provide a different perspective of value. Participants thought this would lend research legitimacy, relevance, and meaning while also balancing power and leading to the democratization of science, making it "very difficult to maintain that very sort of paternalistic approach that doctor knows best" [Participant H].

Approximately half of all participants had been introduced to the concept of patient engagement within the last 2 years (Table 1). Yet patient engagement fostered a sense of uncertainty, even among those who claimed that they are

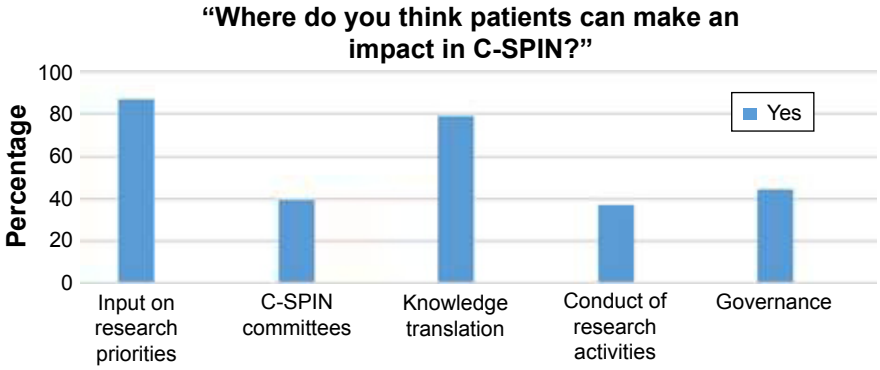

Figure 2 Patient engagement impact survey item (n=38).
Abbreviation: C-SPIN, Canadian Stroke Intervention Network.

"already doing it" and spoke about it in terms similar in scope to that forwarded by CIHR:

> I think it means involving patients at multiple levels in the process of choosing research topics, designing research studies, and also potentially analyzing results and translating the results into new knowledge.… I'm really not sure…. I don't know a lot about it [Participant B].

Concerns about patient engagement

The survey results indicated that the most frequently cited concern was a perceived lack of knowledge about research among patients, followed by the representativeness of patients and the challenge of selecting appropriate patients. Other challenges included researchers' resistance to patient engagement, practical concerns such as funding and transport for patients, the difficulty of finding a common language, the need for role clarity and evaluation of patient engagement activities, the danger of tokenism, and the possibility of intimidated patients (Table 2).

Concerns raised by interview participants about patient engagement related to four challenges: 1) patient selection – who would be chosen? 2) role clarification – what would be the scope of patient engagement? 3) lack of evidence – why engage in patient engagement given the lack of evidence demonstrating its impact? and 4) the need for education (for patients and researchers) and culture change as a prerequisite for patient engagement.

Table 2 Survey – benefits and challenges of patient engagement

	No of respondents
Benefits	
I. Patients provide a different perspective/knowledge	7
II. Patients identify priorities; ensure research is patient centered and relevant	19
III. Knowledge translation	6
IV. Strengthens research impact; improves outcomes (patient/systems outcomes)	11
V. Democratization of science	4
Challenges	
VI. Patients' lack knowledge, need to be educated; scope should be limited	16
VII. Patient selection (representation, appropriateness)	12
VIII. Resistance; lack of knowledge from health care providers; culture change required	10
IX. Tokenism	1
X. Need to find common ground/language	3
XI. Role clarity needed	1
XII. Patients intimidated	3
XIII. Evaluation/measurement	1
XIV. Practical concerns (transport, time, interest, funding)	9

Patient partner selection

Many participants were uncertain about how a patient engagement strategy may be practically implemented. They wondered about whom to include and how to include them meaningfully:

> … Is it the smartest, the richest, the one with the most time on their hands, the one that's most articulate, the one that's the sickest because they had most interaction with the healthcare system; is it going to be men, women, young, old, well educated, less well educated…. How do we come up with a fair, reasonable process for finding those patients? [Participant F]

Researchers also worried about what constituted a "good" patient. An appropriate candidate, most agreed, would have to be a conduit for the voices of other patients, but there were inherent concerns about one patient representing others without simultaneously institutionalizing and professionalizing their roles. It seemed that a paradox lay at the heart of patient engagement: the need to retain the authenticity of a patient's unique experience while simultaneously representing a global disease experience, represented by population-level data yielded by trials and observation studies. Furthermore, the patients who would tend to be chosen as likely candidates for patient engagement initiatives could not be "typical" or "representative" in many ways because of the need for them to be articulate, understand research, and engage with other health care professionals and other patients:

> … when we've been asked to try to identify patient advocates to sit on this committee or that committee, we tend to look for people that are exceptional examples of people with the disease, not garden variety examples of people with the disease … and I'm not sure that that's giving us what we want in patient engagement. [Participant P]

Research scientists also noted that practical concerns relating to time and money could inhibit participation from certain socioeconomic groups.

Role clarification

Many understood scientist and patient as occupying two different worlds, debatably equal but unequivocally separate. There was keen appreciation of stark differences in knowledge and power between patient and researcher. One spoke of "a knowledge gap," "a power differential, like a teacher/student differential" [Participant G]. "Does the patient really need to read the whole research proposal and comments?"

wondered another [Participant E]. Yet another suggested that patients "would not have sufficient knowledge to be able to choose the priorities for research…." [Participant D]. They may be able to provide "important elements of a given area," but they should not "be assessing the science or the methodology" [Participant N]. Others voiced the need for "a bunch of education" for patients [Participant O] and for "orient[ing patients] to this world so that they can play a part [as] we have a research speak that nobody else understands" [Participant E].

The need to delimit patient engagement was echoed in survey data, where one respondent suggested that patient-entered data should be "audited against source data" to ensure "accuracy" and "objectivity" as the patient would tend to "provide subjective information". Another similarly claimed that "the scientific approach of researchers does not work with the patient approach" and that the patient training required would be so significant that "very few patients would qualify for effective input".

Concerns about the lack of patient knowledge of the research process were linked to concern about a shift in a historically well-established research paradigm. Allowing patients potentially untrained in scientific methods to dabble in research worried many and led to a broader concern about preserving the integrity of science itself.

Lack of evidence

Many participants were concerned about the lack of evidence demonstrating the impact of patient engagement. They wanted to "measure" patient engagement outcomes – a difficult proposition given that it was not clear what these outcomes should be (Participants D and H) or what statistical methods should be used to generate results (Participant K):

> We actually don't have a lot of evidence that it changes research, in what ways, in what situations, what type of patients…. [Participant H]

Furthermore, only certain, familiar modes of "measurement" were deemed appropriate:

> … ultimately it's … going to be descriptive. Whereas knowledge translation, you can measure things, you can do randomized trials…. [Participant D]

Without such familiar, dependable evidence, many respondents felt unable to attribute value to patient engagement. They feared that the interest in patient engagement was the "flavor-of-the-day" [Participant D] or tokenistic "window dressing" [Participant H] and said that researchers engaged in it because "we're required to do it, not because we know what it is and how to go about it" [Participant P].

Need for culture change

A few participants reflexively identified the need for education and culture change around the concept of patient education for researchers themselves. As one participant put it, a "major barrier is challenge to [a] conventional model and acceptance by [the] research community", whereas another wondered "how to change researcher culture to be more inclusive and more power sharing/co-creating".

A few participants also reflexively suggested that health care providers' hesitance in fully embracing patient engagement sprang from the shift it represented from a familiar and established mode of conducting research:

> … there's been an awful lot of structure and process put in place to help support patients…, but in fact I think it's almost to support the researchers and the health care providers to have a level of comfort that it's okay to invite people in. [Participant C]

It is noteworthy that the survey included two patient partners whose concerns about patient engagement echoed those of health professionals. When asked to check boxes indicating if patients could make an impact in a range of C-SPIN activities, from research priority setting to governance, only 3 of a possible 10 boxes were checked by the patients themselves. As another participant indicated, there is perhaps a need for "training for patients so they understand the research process [and] training for researchers so they understand how to meaningfully engage patients".

Strengths and limitations

This study aimed to assess researchers' perceptions of the meaning and value of patient engagement in research within the context of a Canadian cardiovascular research network. Our targeted recruitment of network member participants assisted our team to achieve our aim, and the knowledge gleaned from this work will inform further development of our patient engagement strategy. Although the survey response rate was low, limiting generalizability to similar networks, our multi-method approach to data collection allowed for greater reach across the network. While the ratio of cardiologists included in our interviews echoes the make-up of C-SPIN as a research network, and is therefore representatives of perspectives within this group, it may not be representative of researchers at large.

To improve the trustworthiness of the findings, several strategies were applied. The inclusion of qualitative interviews helped corroborate and provide further insight into survey responses through participants own narratives. Our sample included a range of participants in terms of years in practice, profession, and role in the network. Finally, the background and experience of the investigative team with this subject matter offers credibility to the interpretation of our findings.

Conclusion

Despite the lack of knowledge about how to best implement and realize meaningful patient engagement, the value that most saw in the overall goal of patient engagement must be acknowledged. Participants valued patient engagement because they thought patients could assist in selecting research activities, lend research relevance and legitimacy, and balance power by unsettling a traditionally paternalistic model of health care. However, few were prepared to embrace patient engagement unreservedly.

A key concern of participants related to patient selection: who would qualify as an "appropriate patient," and how could researchers ensure the democracy of the selection process? These concerns reflected a dilemma over how to negotiate the "crisis of representation,"[20] the problem of a possibly atypical patient speaking for others, with the potential for misrepresentation and loss of experiential authenticity. However, as Staniszewska et al have reminded us, in this context, the patient is an active collaborator and member of the research team, not a subject of data collection, and as such "would not necessarily be expected to provide a representative view of all patients, in the same way as a researcher would not be expected to provide a representative view of all researchers within a collaborative team."[21] As such, they suggest along with Hanley et al that "it might be helpful to think about seeking [patient] perspectives rather than [patient] representatives."[22]

A related concern had to do with the scope of patients' roles in research given perceived stark differences in knowledge and power between patient and researcher. As outlined by SPOR, although patients have the option of participating in research in circumscribed ways (eg, in developing research questions or as knowledge brokers), patients with the appropriate "readiness" may also contribute as fully fledged members of research teams. Researchers are encouraged to ensure that "the patient perspective is integrated into every step of the research process,"[23] suggesting a significant reorienting of research, with patients' perspectives potentially having equal weight to those of the researchers. As a few C-SPIN researchers pointed out, this represented a new way of conducting research that could potentially be unsettling. Their concerns about patients' inability to understand, interpret, or even pay attention to scientific information have been voiced elsewhere.[24,25]

Finally, many wondered if patient engagement was justified given a perceived lack of evidence demonstrating impact. Their need for outcomes that could be "measured" in specific ways revealed a strong positivistic bias that displayed unfamiliarity with the existing, although limited, qualitative research noted above that documents the impacts of patient engagement as experienced by patients and researchers – research that CIHR could perhaps highlight in making an argument for patient engagement, quelling concerns that it is merely the flavor of the day.

Underpinning these concerns was uncertainty about what patient engagement actually means. This could be seen not just in the wide range of meanings it had for C-SPIN research scientists but also in the lack of clarity about the concept for individual respondents. The little available scholarship on the acceptability of patient engagement in research has similarly noted the varied meaning of patient engagement for different stakeholders;[26–28] differences in understanding that have been shown to be linked to stakeholder positionality and value accorded to the concept.[29] Indeed, a key observation we take from this study is the need for conceptual clarity. The results can be used to 1) ensure that research scientists are educated on the conceptual meaning and scope of patient engagement, 2) offer guidance to select patient partners with requisite knowledge and skills to engage in targeted roles, 3) facilitate access to resources and tools enabling the operationalization of patient engagement strategies, and 4) ensure that new evidence demonstrating the impact of patient engagement is disseminated within the research community.

For patient engagement to be seriously adopted and strategies developed, researchers must also be convinced that 1) patients' knowledge and potential to be involved in research are commensurate with (although different from) those of researchers and 2) patient engagement has a meaningful impact on research outcomes. The former requires a rethinking of well-entrenched modes of producing research that has traditionally privileged the scientific knowledge and expertise of the researcher, and the latter requires researchers to rethink a traditionally positivistic mode of producing research and take seriously the qualitatively reported outcomes of patient engagement that do exist. Both entail a significant culture shift, a rethinking of how we conceptualize scientific epistemology itself.

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Disclosure

The authors report no conflicts of interest in this work.

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Supplementary materials

Semi-structured interview guide with C-SPIN members

Thank you for agreeing to this short interview. Our objective for this interview is to learn more about your opinions surrounding patient engagement in the C-SPIN network and research in general.

First, the term "patient" is an overarching term we are using that includes individuals with personal experience with a health issue (here we mean stroke, atrial fibrillation, cardiovascular disease). Patients may also include informal caregivers, family, and friends.

Second, patient engagement pertains to meaningful, active collaboration in priority setting, conducting research, governance, and knowledge translation.

Consenting procedure provide copy to participant (remind participant that they have signed consent). As a reminder, we are recording our call today. We will summarize the discussions with all our C-SPIN members and produce a document/paper from what we find. No one will be identified by name.

Let's begin.

1. When did you first hear about patient engagement?
2. What do you think it means? Please tell us what you know about patient engagement? In research? [What are your expectations?]
3. How do you think patients can contribute to the research process? [not as consented research participants] [reminder – priority setting, conduct of research, governance, knowledge translation]
4. Where do you think patients/partners can make an impact?
5. What do you think the value of patient engagement in research is (overall)? [provide a definition of value]
6. What is your personal view regarding some of the potential barriers or challenges to patient engagement in the research context? [if they have this view] [probe]
7. What could make participation easier?
8. What could help patients become involved? How else?
9. As a researcher, would you be interested in training to engage and include patients? [workshop]
10. If not, why? _____
11. If yes, preferred method?
    Online modules
    Videos
    Workshop

Before we finish, I would like to collect some basic demographic information from you. All will be anonymized.

12. Are you:
    a. EP cardiologist
    b. Neurologist
    c. Cardiologist
    d. General practitioner
    e. Fellow (EP? Or neuro?)
    f. Other health professional _____
    g. Academic researcher (ie, social scientist, non MD) _____
    h. Patient/family member _____
    i. Study coordinator/researcher assistant _____
13. If you are a health professional, how many years have you been in practice? _____
14. If you are a stakeholder, how many years have you been in the role? _____
15. If you are a study coordinator/research assistant, how many years? _____
16. Province of practice _____
17. Male _____ Female _____

Figure S1 Patient engagement prevention network (C-SPIN) – interview guide.
Abbreviations: C-SPIN, Canadian Stroke Intervention Network; EP, electrophysiologist; MD, medical doctor.

Please take a few moments to complete this brief survey to provide us with your perceptions and knowledge about patient engagement in research. This survey will assist us to further develop our patient engagement strategy within the C-SPIN network.

Patient engagement is defined as meaning and active collaboration in governance, priority setting, conducting research and knowledge translation.

The term "patient" is an overarching term we are using that includes individuals with personal experience with a health issue (here we mean stroke, atrial fibrillation, cardiovascular disease). Patients may also include informal caregivers, family, and friends.

Your responses will be collated and de-identified. Your consent is implied by completing the survey.

1. When did you first hear of patient engagement in the context of research?
   ○ <6 months ○ 6–12 months ○ >1 year ○ >5 years

Please rate your response to the following statements:

2. I understand the meaning of patient engagement.
   ○ Strongly agree ○ Agree ○ Disagree ○ Strongly disagree ○ Undecided
3. Patients can contribute meaningfully to the research process.
   ○ Strongly agree ○ Agree ○ Disagree ○ Strongly disagree ○ Undecided
4. I understand the value and benefits of patient engagement in research.
   ○ Strongly agree ○ Agree ○ Disagree ○ Strongly disagree ○ Undecided
5. Where do you think patients/partners can make a meaningful impact in C-SPIN?
   Select one or more.
   - ☐ Providing input on new priorities and strategic plans
   - ☐ Membership on C-SPIN committees
   - ☐ Knowledge translation/community outreach/dissemination
   - ☐ Conduct of research activities
   - ☐ Governance
6. What is your personal view regarding the potential barriers or challenges to patient engagement in the research?
7. What is your personal view regarding the potential benefits to patient engagement in research?

Almost finished, we would like to collect some basic information.

8. Please select. Are you:
   - ☐ Electrophysiologist
   - ☐ Neurologist
   - ☐ Cardiologist/internal medicine
   - ☐ Family physician
   - ☐ Pharmacist
   - ☐ Academic researcher (Social scientist, epidemiologist, non-MD)
   - ☐ Trainee
   - ☐ Patient/family member
   - ☐ Other health professional _____
9. If you are a health professional, how many years have you been in practice? _____
10. Province of practice/profession
11. Male/female

Figure S2 Electronic survey patient engagement.
Abbreviation: C-SPIN, Canadian Stroke Intervention Network.