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Co-developing patient and family engagement indicators for health system improvement: A consensus study

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Article Summary

Strengths and limitations

- The consensus process utilized a participatory approach, by engaging diverse groups of experienced stakeholders, including patient and community advisors and health system staff and leaders
- This study used a modified Delphi consensus process to co-develop a set of indicators to measure patient engagement in health research and system transformation for a provincial health system.
- This particular specific set of indicators has not yet been validated or implemented.

Abstract

Objective To develop a set of patient and family engagement indicators (PFE-Is) for measuring engagement in health system improvement for a Canadian provincial health delivery system through an evidence-based consensus approach to ensure the PFE-Is reflect meaningful patient and family engagement.

Design This mixed-method, multi-phase project included: (1) identification of existing measures of patient and family engagement through a review of the literature and consultations with a diverse provincial council of patients, caregivers, community members, and researchers. The Public and Patient Engagement Evaluation Tool (PPEET) was selected; (2) consultations on relevance, acceptability and importance with patient and family advisors, and members of Alberta Health Services' Strategic Clinical Networks™. This phase included surveys and one-on-one semi structured interviews aimed to further explore the use of PPEET in this context. Findings from the survey and interviews informed the development of the final list of indicators; (3) a Delphi consensus process using a modified RAND/UCLA Appropriateness Method to identify and refine a core set of PFE-Is.

Participants The consensus panel consisted of patients, family members, community representatives, clinicians, researchers, and healthcare leaders.

Results From an initial list of 33 evidence-based PFE-Is identified, the consensus process yielded 18 final indicators. These PFE-Is were grouped into seven themes: communication, comfort to contribute, supports needed for engagement, impact and influence of engagement initiative, diversity of perspectives, respectful engagement, and working together indicators.

Conclusions This group of final patient, family and stakeholder informed indicators can be used to measure and evaluate meaningful engagement in health research and system transformation. The use of these metrics can help to improve the quality of patient and family engagement to drive health research and system transformation.

Background

Person-centred health system improvement and transformation requires the involvement of patients and families to shape system priorities and inform care delivery and outcomes.(1) Recent evidence has shown that engaging patients in health system transformation can enhance service delivery and drive system improvement.(2)

While there have been efforts to advance patient engagement in health research and health system transformation, there are currently few co-developed, system-embedded sets of indicators to evaluate patient engagement and its impact on this transformation.

Our objective for this project was to address this gap by developing a set of evidence-based patient and family engagement indicators (PFE-Is) that were informed and prioritized by patient and family advisors (PFAs) in the context of a large and complex fully integrated provincial health system to measure meaningful patient engagement at the system level.

Alberta Health Services (AHS) is the largest province-wide health delivery system authority in the Canadian province of Alberta.(3) Within AHS, the Strategic Clinical Networks™ (SCNs) address system-wide gaps in care, work together to get evidence into practice, improve patient outcomes and experience, and to support continuous quality improvement.(4) The SCNs are multi-stakeholder teams that are comprised of clinicians, patient and family advisors, operational leaders, researchers, policy makers and community partners.(4, 5)

As of June 2022, the 11 SCNs aim to advance improvements in specific areas of health: (1) Bone & Joint Health, (2) Cancer, (3) Cardiovascular Health & Stroke, (4) Critical Care, (5) Diabetes, Obesity & Nutrition, (6) Digestive Health, (7) Emergency, (8) Maternal Newborn Child & Youth, (9) Medicine, (10) Neurosciences, Rehabilitation & Vision and (11) Surgery; and within 5 Integrated Provincial programs: (1) Addiction & Mental Health, (2) Seniors & Continuing Care, (3) Primary Health Care, (4) Population and Public Health and (5) Indigenous Wellness Core.

Each SCN works to actively engage patients and families in priority setting and co-designing solutions to improve patient experiences and quality of care. The Patient Engagement Reference Group (PERG) includes patients and public that engaged regularly in quality improvement and research projects within the 11 SCNs and the 5 Provincial Integrated Programs.(6)
We undertook this project to co-develop PFE-Is which represent a key step towards ensuring that healthcare system measures remain responsive to what matters to patients.

Methods

This mixed method study is a multi-phased patient-oriented research study that was informed by recent literature on patient engagement in health systems,(7, 8) consultations with our provincial network of Albertans (Albertans4HealthResearch Collaborative Council),(9) a survey and interviews with AHS SCN staff, leadership and PFAs, followed by a modified Delphi consensus generating process(10) to identify indicators to be used by the AHS SCNs to measure patient and family engagement in their initiatives to transform health care system in Alberta (Figure 1).

Patient and Public Involvement

This study is informed by the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework, which states that patients are active partners in health research.(11) The four guiding principles of the framework are inclusiveness, support, mutual respect, and co-build.(11) We consulted with patients and family advisors with diverse lived experience as active collaborators through a participatory approach—doing research 'with' rather than 'on' them.(11) The team included two patient partners, people living with chronic conditions (GW and SZ), both of whom are graduates of the Patient and Community Engagement Research (PaCER) program(12) from the University of Calgary that trains citizens with lived experiences of a health condition how to conduct research projects by, for, and with patients. GW and SZ also lead patient engagement groups with extensive experience working on healthcare research and quality improvement projects and at governance level in the healthcare system.(6, 13) GW and SZ were involved in the planning of the project through working with the team members, SCN leadership and PERG to design the rollout of the project, providing feedback on the study proposal, supporting recruitment of patient and family advisors, co-conducting the project, and co-developing the manuscript.

Study participants and recruitment

The study population includes a diverse group of SCN leadership (individuals responsible for the organizational requirements for engagement activities- Scientific Directors (SD), Senior Provincial Directors (SPD), Senior Provincial Officers (SPO), Senior Medical Directors (SMD)), SCN Staff (Assistant Scientific Directors (ASD), Executive Directors (ED), Managers, Staff Liaisons, Senior Consultants) and (PFAs) within the SCNs.

Recruitment was supported by members of the research team (GW, MM, JP, and TW), working with and leading the AHS SCNs. Participants were invited to complete a survey and semi-structured interview. SCN leadership, SCN staff, and PFAs were also invited to participate in a modified Delphi consensus process.

The University of Calgary Conjoint Health Research Ethics Board (CHREB) has approved this project (REB20-1822).

Patient and public involvement: A multi-phase approach

The development of these indicators occurred over three phases, each involving significant patient and public engagement.

Phase 1: Selecting the measure

Phase 2: Stakeholder consultations including a survey and follow up with interviews

Phase 3: Modified Delphi Panel

Phase 1: Selecting the measure

This phase includes three steps.

Step 1: We identified patient engagement evaluation measures. A recently published Systematic Review(14) identified a number of validated patient engagement evaluation survey tools including; PEIRS (Patient Engagement In Research Scale),(15) PPEET (Public and Patient Engagement Evaluation Tool)(16) and WE-ENACT (Ways of Engaging- ENgagement ACtivity Tool).(17)

Step 2: We presented the identified patient engagement evaluation measures to our provincial council, the Albertans4HealthResearch Collaborative Council. Members of the council appreciated the scope and depth of the PPEET, as it captured the evaluation of patient and family engagement from the perspectives of different stakeholders (patient and family advisors, staff members, and organization leaders).(16)

Step 3: After identifying and selecting the measure, the PPEET was compared to existing PFA engagement measures used by SCNs. This step ensured that existing efforts aligned with the development of the final core of indicators.

Public and Patient Engagement Evaluation Tool (PPEET)(16) includes three types of questionnaires that can be used to assess public and patient engagement in health research and at health system level. The three questionnaires are:

1. A participant questionnaire for patient partners and staff members on their experiences working together in engagement initiatives. There are two versions available: one evaluating one-time engagements and another evaluating on-going/long-term engagements.
2. A project questionnaire that reviews and assesses three components of the process of engagement at health system level including the planning, execution, and impact of the engagement.
3. An organization questionnaire assesses how engagement is conducted within organizations.

Questionnaire 1 and 3 of the PPEET were chosen as they aligned best with the purposes of evaluating patient and family engagement within the SCNs.

Phase 2: Stakeholder consultations

This phase included two steps, an electronic PPEET survey, and semi-structured interviews with SCN staff, leadership and PFAs.

Step 1: Individuals from SCNs were contacted and invited to complete the PPEET as an anonymous on-line survey. This survey was populated into Qualtrics Software(18) for ease of use and widespread distribution. The aim was to assess the utility of the PPEET in capturing the experiences of participants in working together within their SCNs; as well as gathering potential barriers and facilitators in engagement in health research and system transformation.
Survey results were descriptively summarized and categorized according to the key areas of engagement: communication and supports for participation, sharing your views and perspectives, and impacts and influence of the engagement initiative. Frequencies were also reported.

Step 2: After completing the online survey, respondents were invited to a semi-structured interview. Interviews were conducted with a select number of SCN PFAs, leadership and staff members via a video-conferencing platform (e.g. Zoom) or by telephone. The interview guide was co-developed with patient and family partners and research team members. Interview guide questions were about the barriers and facilitators to engagement in health research and system transformation (APPENDIX 1). The semi-structured interviews were conducted by members of the research team (conducted by SZ, GW, SA, TM, qualitative research background).

The interviews were audio recorded, transcribed verbatim, and thematically analyzed, with deductive and inductive coding strategies.(19) Qualitative researcher (SA) followed the six-step thematic analysis Braun & Clarke method,(20) and had peer debriefing sessions at different stages of the analysis with MS to discuss themes and subthemes identified. After organizing codes into themes, they were presented back to the research team for feedback.

Phase 3: Delphi Consensus Process

Consensus methods are considered an effective tool for facilitating decision-making when there is insufficient information or when there is contradictory information.(21) The RAND/UCLA Appropriateness Method was used as a guide for the consensus process.(10) A consensus panel consisted of a diverse group of eight PFAs, five Scientific Directors, ten Assistant Scientific Directors/Managers/Staff liaisons.

The consensus process included three rounds. Round one was conducted via an electronic survey, round two via videoconference, and round three was completed via an electronic survey.

Round One: Using a modified Delphi technique,(10) panelists ranked each of the PFE-Is criteria according to a 9-point scale scoring as not relevant/to be discarded (1-3); consider more discussion (4-6) and relevant/accepted (7-9). Panelists were also given the opportunity to provide written comments and suggestions. Results from this phase were compiled and shared prior to the virtual face-to face Round 2.

***Round Two*:** the panel and moderators convened over 2 hours via zoom. Moderators shared the results of the first round and facilitated a workshop noting any areas of disagreement indicated by the ratings and answered any questions about the process. The group deliberated, until agreement on the new patient and family engagement indicators was achieved. Two AbSPORU team members took notes to capture modifications made to the indicators and discussions from the consensus meeting. After the notes were analyzed and select indicators were modified, the indicators were presented to the panelists for a final round of voting.

***Round Three*:** The discussed PFE-Is were refined based on the discussions and consensus that happened during Round Two. These PFE-Is were voted on 'overall importance' as keep or discard using an electronic survey.

Throughout the Delphi process panelists had the following information available to guide them through the consensus.

Scale

Panelists used a 9-point rating scale. Ratings of 1-3 indicated not relevant/to be discarded; 4-6 if more discussion was needed; 7-9 as relevant/accepted. PFE-Is were accepted when 75% of the panelist's ratings were 7,8,9 without disagreement on the scale. Disagreement was declared when 5 or more than 5 panelists rated the indicator in the top and bottom parts of the scale (1-3 or 7-9).

The rating criteria provided to the panelists is displayed in Table 1. Panelists used these criteria to rate PFE-Is through the Delphi process.

Table 1. Rating criteria

Criteria	**Definition**
Overall importance	This overall rating will be used to determine how important it is to measure and track this indicator for patient and family engagement within the SCNs A high score on this criterion indicates that compared with other indicators, this indicator is very important for measurement of patient and family engagement within the SCNs A low score on this criterion indicates that the indicator is not as important compared to the other indicators for measuring patient and family engagement within the SCNs When rating this indicator, consider how important is this indicator to you or your organization in promoting meaningful patient and family engagement.
Impact on Patient and Family Engagement	This rating will be used to determine whether this indicator will have a big impact on the engagement of patients and families within the SCNs

	A high score on this criterion indicates that compared with other indicators, this indicator has a big impact on the engagement of patients and families within the SCNs A low score on this criterion indicates that compared with other indicators, this indicator does not have a big impact on the engagement of patients and families within the SCNs Improvements on this indicator will mean improved engagement of patient and family advisors
Actionable by SCNs	This indicator reflects an area where improvements can be made. It can provide information to improve the engagement of patient and family advisors A high score on this criterion indicates that compared with other indicators, there is a big opportunity to change the results for this indicator within the SCNs A low score on this criterion indicates that compared with other indicators, there is not a big opportunity to change the results for this indicator within the SCNs This indicator could be measured to improve patient and family engagement within the SCNs, without too much difficulty
Interpretability	This indicator provides clear information that is easy to communicate to stakeholder groups, including patient and family advisors. A high score on this criterion indicates that compared with other indicators, this indicator is easy to communicate to different audiences, with little explanation A low score on this criterion indicates that compared with other indicators, this indicator is more difficult to communicate to different audiences with little explanations
Relevance	This indicator addresses areas of major importance or concern related to patient and family engagement within the SCNs A high score on this criterion indicates that the indicator is very relevant to patient and family advisors, and the strategic clinical networks

	A low score on this criterion indicates that the indicator is not as relevant as other indicators to patient and family advisors, and the strategic clinical networks

Results

The results of the three phases are described by phase.

Phase 1.

The AB4HR council members were consulted on the tool selection for measuring patient and family engagement. The criteria for selecting the initial measure tool was that the tool had to be free to use, relevant, actionable, measure engagement prospectively and from all members of the team and important to assess the engagement in health research and other initiatives informed by patients and family advisors. The council members completed the measures; the measures were discussed and the PPEET was selected because it was the one that met all the criteria.

Phase 2a

The online survey was emailed to 175 patient and family advisors, 69 SCN staff members, and 49 SCN leadership members. 96 participants responded, including 51 PFAs and 45 healthcare stakeholders (31 SCN staff and 14 SCN leadership).

In general, there was some consistency in the responses. Most patient and family advisors agreed/strongly agreed that they:

- have a clear understanding of the purpose of the SCNs they are involved in (94%)
- have supports available to contribute to the SCNs projects (92%)
- have enough information to be able to carry out their role in the specific projects (81%)
- can express their views freely when working in projects (96%)
- are confident the SCNs take the feedback provided by patient and family advisors into consideration (81%)

Similarly, most or all SCN staff agreed/strongly agreed that they:

- have a clear understanding of the purpose of engaging patient and family advisors in the SCNs (100%)
- have supports and information available to effectively engage with patient and family advisors (87%)
- are able to express their views freely (86%)
- SCNs take the feedback of patient and family advisors into consideration (100%)
- felt the involvement of patient and family advisors make a difference in the work of the SCNs (100%)

SCN leadership responded to a different module of the PPEET that focused on policy and practices that support patient and family advisor engagement, participatory culture, influence and impact, and collaboration and common purpose.

Most SCN leadership agreed:

- that the SCNs have an explicit strategy and framework for patient and family advisor engagement (86%)
- the SCNs have explicit strategies for recruiting patient and family advisors, depending on the engagement initiative (79%)
- a commitment to the principles and values of patient and family advisor engagement is found in key SCN documents (e.g., transformational roadmaps, etc.) (93%)

However, there were some mixed responses on the following:

- 50% of respondents were neutral on the statement that the resources available for patient and family advisor engagement is adequate (43% agreed/strongly agreed, and 7% disagreed.)
- 43% of respondents agreed/strongly agreed to SCNs preparing reports that summarize the contributions from patient and family advisor engagement initiatives (36% of respondents were neutral and 21% disagreed.)
- The statement "Comprehensive patient and family engagement training and materials are available to support staff who are leading and supporting these activities." had 42% responding neutral, 41% agreeing/strongly agreeing, and 17% disagreeing.

Some of the SCN leadership that responded neutral for some statements indicated in the comments that this was due to lack of awareness on specific activities and resources. The results indicate variation among the 11 SCNs and 5 Provincial Programs in how patient and family engagement is conducted and reported.

Phase 2b - Interviews were conducted with 26 individuals including 13 with PFAs and 13 healthcare stakeholders (6 SCN staff and 7 SCN leaders). Interviews ranged from 25 to 94 mins. Figure 2 displays an overview of the themes and subthemes, and Table 2 provides more details on the themes, subthemes, and associated quotes.

Improving Patient Engagement within the SCNs

Both PFAs and SCN staff recognized the need for inclusive strategies for recruitment and retainment, to involve various other patients in health research and within SCNs. Some SCN staff expressed difficulties with recruiting new PFAs, and retaining current advisors. Strategies mentioned by some staff included the importance of reaching out to clinical, special interest, and non-profit groups for support in recruiting PFAs, bringing awareness to what a patient advisor is, and utilizing social media.

Some staff also noted some barriers to recruitment including the:

- onboarding process for the organization, which can be extensive for engagement especially those required for one-time or for a limited time.
- COVID-19 pandemic and how it impacted the time people have available.
- lack of compensation available for patient advisors which may exclude some advisors who represent marginalized and hard to reach communities (e.g. unhoused individuals).

Most PFAs who had felt supported in the engagement activities, mentioned having a strong relationship with their SCN team. SCN Leadership and staff also discussed their patient engagement strategy and how it evolved over time. Staff and Leadership felt supported in being able to carry out patient engagement in their work. To improve patient engagement within the SCN, participants highlighted various supports for patient engagement that are required to be consistent within the SCNs: resources about how to engage with patients and working together, mentorship for PFAs, capacity building opportunities for both SCN staff and patient and family advisors such as training and/or orientation. Some participants also discussed whether compensation for engagement would be needed as an acknowledgement of the time and contributions of PFAs. Finally, participants indicated a vital component for working together successfully included respectful engagement and the sincerity of those engaging patients. In various committees, participants indicated excellent partnerships were key to feeling respected and accordingly that they felt like they could contribute to the SCN.

Some participants highlighted the need for PFAs to be involved in decision-making processes through early engagement at the conception of the project and including PFAs in more leadership positions such as co-chairing or co-leading committees.

Communication with PFAs

Some PFAs emphasized needing clear and timely communication about the status of projects, e.g. when projects were being implemented, whether projects were moving forward, and updates on the general work of the SCN. Participants emphasized the importance of setting clear expectations for engagement activities and for the role of a PFA. Some PFAs described their role within the SCNs as advising on projects, acting as leaders or members in patient advisory groups, being invited to share their stories/perspectives on their healthcare experiences, and providing input on meeting agendas. However, there were also some PFAs who mentioned lacking clarity on their role within the SCN when they had initially joined the network.

Some SCN staff discussed some challenges in managing expectations of PFAs (regarding timeline of the project, or the priorities of the network), which may have not aligned with the expectations of the PFAs. Some staff expressed how they had to communicate to patients the difference between advisor versus advocate as the roles are different within the SCNs, and have the potential to lead to differing priorities. One staff member discussed developing a 'parking lot' to provide a safe space in bringing up topics of concern and interest to PFAs, but not aligning with current priorities of the SCN. The aim of this idea is to ensure PFAs' ideas are not lost but recognized for the potential to address at a later date.

Work Environment

Most PFAs described feeling comfortable in being able to contribute in meetings with other stakeholders and still feeling engaged in virtual meetings and projects, and adapting well to working in a virtual setting. There were few PFAs who expressed frustration with lack of patient engagement in the SCNs during COVID, and some who had stepped down from their PFA position as a result.

Almost all SCN staff also mentioned working virtually with SCN teams including PFAs have been a positive experience (such as alleviating burden from travel or facilitating engagement). However, both SCN staff and PFAs mentioned missing the personal connection and networking aspect of in-person meetings. Other concerns with virtual engagement were that it would be more difficult for new advisors to be engaged in a virtual environment, and some advisors may be uncomfortable with technology and encounter connection issues.

Motivations to Sustain Engagement

Most PFAs mentioned their reason for joining and staying was to have an impact on the healthcare system, and to feel like their contributions mattered.

There were mixed responses from PFAs on whether they felt acknowledged for their contributions and valued as team members. Some PFAs felt valued as members of their SCNs, and detailed ways in which they felt acknowledged for their contributions. There were also some PFAs who spoke about instances in which they felt they were low priority for the SCNs, or felt their involvement was tokenistic. Some PFAs also described how they valued learning from their SCN teams, learning about research, their conditions, and the healthcare system. For some PFAs, meeting people and building relationships was valuable in their engagement within the SCNs, and a reason for them to continue to stay involved.

Table 2. Themes, sub-themes and selected quotes.

Theme & subthemes	Quote

Improving Patient Engagement within the SCNs	"I sent a letter in about two years ago to Dr. and I said, "you know, I've really enjoyed being involved but, you know, you need to get more members of the public involved, more than just me." …, not 20 but you know, maybe- they probably have 2 or 3 now, members of the SCN, or maybe more…part of the core committee, so I think…those are the things that I would potentially change" (PFA3)
Inclusive recruitment strategies	**"**we have a real passionate group, right? And after two years I feel like a little bit of momentum has dropped. But I mean it was COVID for goodness sakes, right? … we did recruit four new advisors in January so we tried anyways. But we still—we want to get a sweet spot of about 15 where at last half of them attend a meeting, right, whereas right now if we have 11 then we only have five or six attending... And I mean not that that's bad it's just, you want more voices, right? And people aren't responding, they're not great at responding to emails. Even though we send out lots of opportunities sometimes it's just that reach out directly to the person that works best." (Staff4)
Supports for engagement	"one of the first things I did was develop a resource for Skype because our—I think AHS either was in the process of or didn't have one that I felt was kind of user friendly. So I developed that and actually shared that amongst the networks to say hey, here I have this Skype for patients and families to use. We developed an orientation PowerPoint, so it really—once they've been fully onboarded then we do this orientation and it's probably 45 minutes presentation and discussion and questions. And it really talks about all the three areas in the network …and it introduces who the network is all this kind of main subject areas… The other thing we did was a resource, it's like a dictionary…a glossary of terms for our network." (Staff4)
Views on Respectful Engagement	**"**the ones [that] are tokenism, and that decisions had already been made and they were just looking to tick a box on a form to say "yes, we had patient engagement". And although there was some effort…I can spot a project to nowhere and I'm just a bobblehead as a patient advisor after one meeting,…At the beginning had more of those type of experiences, and as you gain experience and knowledge of how AHS works, you know to pick and choose what projects you think are realistic and that will actually move forward." (PFA7)
Involvement in decision making	"the other place I think that I want to get to is, as an SCN and not just me personally, is to really kind of really push the envelope more in terms of our involvement of our patient advisors as leaders within the SCN. So to really try to get them to be a bit more leading in terms of bringing their ideas forward and getting sort of at the end of that IAP2 spectrum really coming up with the ideas and being able to run with them and work on it from that perspective. And I think some people are ready to do that, especially the PACER grads. But I think I'd like to see the whole community move that way." (SCNLead7)
Communication with PFAs Role clarity & expectations	"there was a long-time patient or family advisor who wanted the network to work on something that he was interested in. But it didn't align with operational priorities so it never rose to the top…We can't do everything and for him to be meaningfully engaged... we and he decided that how he contributed to the network would change. And he came more focused on other contributions to research and to providing inputs occasionally to surveys that we would do, and certainly continuing to receive communications, etc. But when there isn't that alignment, we can't force it." (SCNLead2)
Communication Strategies	"staff would call us to talk about the agenda… review the agenda...so we were really kept informed as to what was going on" (PFA6)

Work environment	“I remember when I went to my very first meeting, I was so nervous because I thought like they would be like “you interlopers, what are you doing here,” kind of thing. I thought we would stand out and be like really weird, and it was completely the opposite. It was incredibly welcoming” (PFA2)
Comfort to contribute	“I was on a side project…the person who was leading the project, …would ask a question. And one time – one question, the physician would answer first…high up EMS people would answer, and then she would ask us as family patient advisors. The next question: she’d flip it and she’d ask the EMS guys first, then the family patient advisors, then the physician…Never have I felt more like an equal than I did on that project.” (PFA11)
Adapting to virtual involvement due to COVID	“it depends on the meeting, like once it's too big, you kind of lose people and everybody is drifting off, but for smaller engagement it's- it's actually very effective. It's good for the environment, because there's less travel, and it's good for infection control, because before the pandemic, if we were getting people together face-to-face, if one person decided to go with a cold, they probably would leave some of that virus behind. So, it’s the future” (SCNLead4)
Motivations to sustain engagement Relationship-building	“I've also benefited from the relationships I've formed with people and from the respect I've gotten from that… it is satisfying to know that your voice is appreciated and that really is – really is the way – why I was involved and why I keep being involved with the research.” (PFA8)
Feeling valued	**“**I wanted to commend the SCNs in their ability to make patients feel like superstars. You know, to help us recognize that we are as important as the head of Nephrology. And there's a huge ego boost in that and that ego boost is necessary in order to give people the confidence to speak up.” (PFA5)
Learning opportunities	“that's been the joy of the SCN as well. Is really learning. The physician and medical experience which I want more of, as well as hearing other patient partners and building that network. I've had this opportunity and I've always been a lifelong learner, so every time I attend a presentation, every time I’m part of an event, I'm learning more about research, I'm learning more about kidney function, but I'm learning more about people even more important to me, so it has been really valuable.” (PFA4)
Having an impact on the healthcare system	‘I’ll admit, I was a little – not suspicious, but fatalistic at first, thinking, yeah, will it make any difference? But the more I found that they really took patient complaints or suggestions positively, and I saw things actually being enacted that made a difference. It kept me going and eager to do more.” (PFA12)

Phase 3

During phase 3, 23 participants (8 PFAs, 15 healthcare stakeholders) arrived at consensus on the core PFE-Is over three rounds of discussions. They rated each indicator based on the following criteria: overall importance, impact on patient and family engagement, actionable by SCNs, interpretability, and relevance. (Figure 3).

At the end of the third round, seven different categories of PFE-Is were developed, including:

1. **Communication**: Assess whether enough information has been provided to PFAs to have an overall understanding of the SCNs and specifically their role.
2. **Comfort to Contribute**: Assess whether PFAs are comfortable in contributing within their SCNs, through expressing their views freely.
3. **Supports for Engagement**: Assess whether there are necessary supports available for patient and family engagement within the SCNs for PFAs and SCN staff.
4. **Impact and Influence of Engagement Initiative**: Assess whether PFAs and SCN staff agree that involvement of PFAs make a difference in the work of the SCNs, and that SCNs take the feedback provided by PFAs into consideration.
5. **Diversity of Perspectives**: Assess whether individuals engaging in SCN teams represent a broad range of perspectives
6. **Respectful Engagement**: Assess whether individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together
7. **Working Together**: Assess whether PFAs work together with SCN staff to design, conduct, and disseminate SCN projects

The results from this Delphi consensus generating process are displayed in Table 3. A brief discussion of these results follows. Specifically, 33 PFE-Is were developed through phase 1 and phase 2 of this work. These 33 drafted indicators were presented to the panel for rating using the rating criteria: overall importance, impact on patient and family engagement, actionable by SCNs, interpretability, and relevance.

During the first round and based on final ratings, one indicator was discarded: Each SCN prepares reports that summarize the contributions from patient and family advisor engagement initiatives, as the overall importance was rated low.

During round 2, eight indicators were discarded by the panelists as these PFE-Is were perceived by the panelists as too broad and difficult to measure including: PFAs being meaningfully engaged virtually; PFAs have a supportive working environment to contribute to the engagement initiative; SCNs have mentorship opportunities for PFAs; Each SCN has an explicit strategy or framework for patient engagement; Each SCN is at the stage of established/making some progress in engagement with patient and family advisors; Each SCN has explicit strategies for recruiting patient and family advisors, depending on the engagement initiative; There are resources (documents, guidelines) available to SCN Staff for PFA engagement; The SCN is achieving its stated objectives.

Of the 24 indicators from round 2, eleven indicators were accepted by the panelists and 13 indicators needed to be refined by the panelists at the third round of voting. From round 3 of voting, six indicators were discarded by panelists: PFAs have received training on patient engagement (e.g. orientation to patient-oriented research by AbSPORU); SCN staff have received training on patient engagement (e.g. orientation to patient-oriented research by AbSPORU); The responsibilities related to patient engagement are clearly articulated in my job description; There are dedicated patient and family engagement leadership positions; AHS Resources for Patient Engagement are useful for partnering with patient and family advisors (answered by SCN staff); SCN staff work together with PFAs to disseminate SCN projects (e.g. co-presenting at conferences, sharing work widely) (answered by SCN staff)

A final core group of 18 indicators were accepted. Details of the final indicators (numerator and denominator) are included in APPENDIX II.

Table 3. Summary of consensus panel ratings on overall importance for the final 18 patient and family engagement indicators

Patient and Family Engagement Indicators	**Round 1 remote panel rating** (Median score on 9-point scale and (IQR))	**Round 2 online consensus meeting decision**	**Round 3 remote panel decision** (% of panelists voting to keep on select indicators)	**Evidence Sources** (PPEET I=interviews C=consensus)
1. Enough Information about the role	8 (7-9)	Keep	N/A	PPEET, I
2. Clear understanding of the purpose of the SCN that I am a part of	7 (6-9)	Keep, with edits	Keep (90%)	PPEET, C
3. Able to express views freely	8 (8-9)	Keep	N/A	PPEET, I
Supports for Engagement Indicators (n=2)				
4. PFAs have supports available for engagement (e.g. technology, travel)	8 (7-9)	Keep, with edits	Keep (80%)	PPEET, I, C
5. AHS Resources for Patient Engagement are useful for partnering with patient and family advisors	Not developed	Newly developed derived from previous "Resources for Patient Engagement Indicator"	Keep (80%)	C
6. Involvement of PFAs make a difference in the work of SCNs (answered by PFAs)	9 (8-9)	Keep	N/A	PPEET, I
7. Involvement of PFAs make a difference in the work of SCNs (answered by SCN staff)	9 (8-9)	Keep	N/A	PPEET, I
8. SCNs take the feedback provided by PFAs into consideration (answered by PFAs)	8 (7-9)	Keep	N/A	PPEET, I
9. SCNs take the feedback provided by PFAs into consideration (answered by SCN staff)	8 (7-9)	Keep	N/A	PPEET, I
10. Individuals engaging in SCN teams represent a broad	8.5 (7.25-9)	Keep	N/A	PPEET, I

range of perspectives (answered by PFAs)				
11. Individuals engaging in SCN teams represent a broad range of perspectives (answered by SCN staff)	8.5 (7.25-9)	Keep	N/A	PPEET, I
12. Individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together (answered by PFAs)	9 (8-9)	Keep	N/A	I
13. Individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together (answered by SCN staff)	9 (8-9)	Keep	N/A	I
14. PFAs work together with SCN staff to design SCN projects (e.g. in priority setting & planning, development of proposals) (answered by PFAs)	Not developed	Newly developed derived from previous “Working Together Indicator”	Keep (95%)	C, CS
15. SCN staff work together with PFAs to design SCN projects (e.g. in priority setting & planning, development of proposals) (answered by SCN staff)	Not developed	Newly developed derived from previous “Working Together Indicator	Keep (95%)	C, CS
16. PFAs work together with SCN staff to conduct SCN projects (e.g. collaborate in data collection, analysis/interpretation, advising on project as it is carried out) (answered by PFAs)	Not developed	Newly developed derived from previous “Working Together Indicator	Keep (79%)	C, CS
17. SCN staff work together with PFAs to conduct SCN projects (e.g. collaborate in data collection, analysis/interpretation, advising on project as it is carried out) (answered by SCN staff)	Not developed	Newly developed derived from previous “Working Together Indicator	Keep (90%)	C, CS
18. PFAs work together with SCN staff to disseminate SCN projects (e.g. co-presenting at conferences, sharing work widely)	Not developed	Newly developed derived from previous “Working	Keep (75%)	C, CS

		Together Indicator		

Discussion

Working in partnership with the AHS SCN teams, their advisors in the Patient Engagement Reference Group, and the Albertans4HealthResearch Collaborative Council, we co-developed patient and family engagement indicators to measure engagement in health system transformation. Through an initial synthesis of the evidence and a consensus approach using the PFE-Is we were able to select 18 indicators that reflect meaningful patient engagement. The findings align with the core principles highlighted in the CIHR SPOR Patient Engagement framework: Inclusiveness, Support, Mutual Respect, and Co-Build.(11)

The final 18 evidence-based and patient, family and stakeholder informed indicators are ready to be used to measure and evaluate meaningful engagement in health system transformation. The use of these indicators promotes the changes needed to improve the quality of health research and health system improvement that is informed by patients and families. The use of the indicators within the healthcare system to learn from and evaluate health policy and practice related to what matters to patients and families is a critical next step.

The strength of this study is the participatory approach used to develop PFE-Is, which ensures that engagement was evaluated from the perspective of those who provide and receive care. To our knowledge, this is the first study to develop a set of PFE-Is using a rigorous evidence-based and person-centred approach and involving the patient and caregiver throughout the research process—from inception of the project to manuscript development including dissemination activities.

Using a highly participatory approach, we sought to ensure that the study was guided by the perspective of individuals with lived experiences, and that diverse perspectives were reflected in the development of the PFE-Is.

While measures of engagement were identified in Boivin et al. review,(14) these were not considered indicators as per the definition of indicators suggested by the Agency for Healthcare Research and Quality - as units of measurement, such as percentage or proportion.(22) The selected measure, PPEET,(16) was identified by patients, caregivers and other individuals from diverse communities in Alberta as the measure to use given it was relevant and addressed important domains measuring patient engagement.

These newly developed indicators present an opportunity to improve meaningful engagement ensuring that the voices of the individuals with lived experiences are incorporated into health systems supporting the transformation of healthcare. To drive changes in healthcare policy and practice, there is a need to develop and implement standardized ongoing mechanisms to measure and evaluate healthcare incorporating the patients' perspectives. In doing so, the effectiveness of engagement practices can be strengthened and advanced across the system.

A limitation of this project is that this set of indicators have not been evaluated. However, a future direction of this work is to evaluate and implement the indicators within the current healthcare system. We have started consultations with AHS SCNs stakeholders to assess the feasibility of data collection processes. Only by attempting real-world data collection can we determine whether the indicators meet the traditional standards of 'good-quality measures', to be acceptable, reliable and valid.(23) Moreover, studying the implementation of the PFE-Is could shed light into their effectiveness for promoting improvements in patient engagement across the SCNs for specific projects (health research and quality improvement). It is also important to identify any unintended consequences as a result of the implementation of these PFE-Is, of their use for benchmarking and other issues that may arise, such as implications on staff workload and their cost-effectiveness.

Additionally, while this method has generated these 18 PFE-Is using a validated consensus method, they may not necessarily be universally applicable in all settings and countries due to differing healthcare systems. Different cultural settings in different healthcare regulatory environments may mean that different measures may be more appropriate for certain settings. Further work can be done to tailor and adapt these PFE-Is, recognizing that a consideration of the local context will ensure a more universal relevance. Future steps for this work include the evaluation of implementing these indicators within the SCNs.

Author Contributions: MS and TW conceived and designed the study**.** TM, GW, SZ, SA conducted data collection. SA and MS worked on the analysis and interpretation of findings, with feedback from TW, PF, GW, SZ, MM, JP, TM. MS, SA, PF drafted the article, and all authors (TW, GW, SZ, PF, MM, JP) provided critical feedback and approved the manuscript to be published.

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Ethics Approval: The University of Calgary Conjoint Health Research Ethics Board (CHREB) has approved this project (REB20-1822).

Competing Interests: None declared.

Patient consent for publication: Not applicable.

Data Sharing: This study analyzes qualitative data and the participants did not consent to have their full transcripts made publicly available. Other additional data available upon reasonable request.

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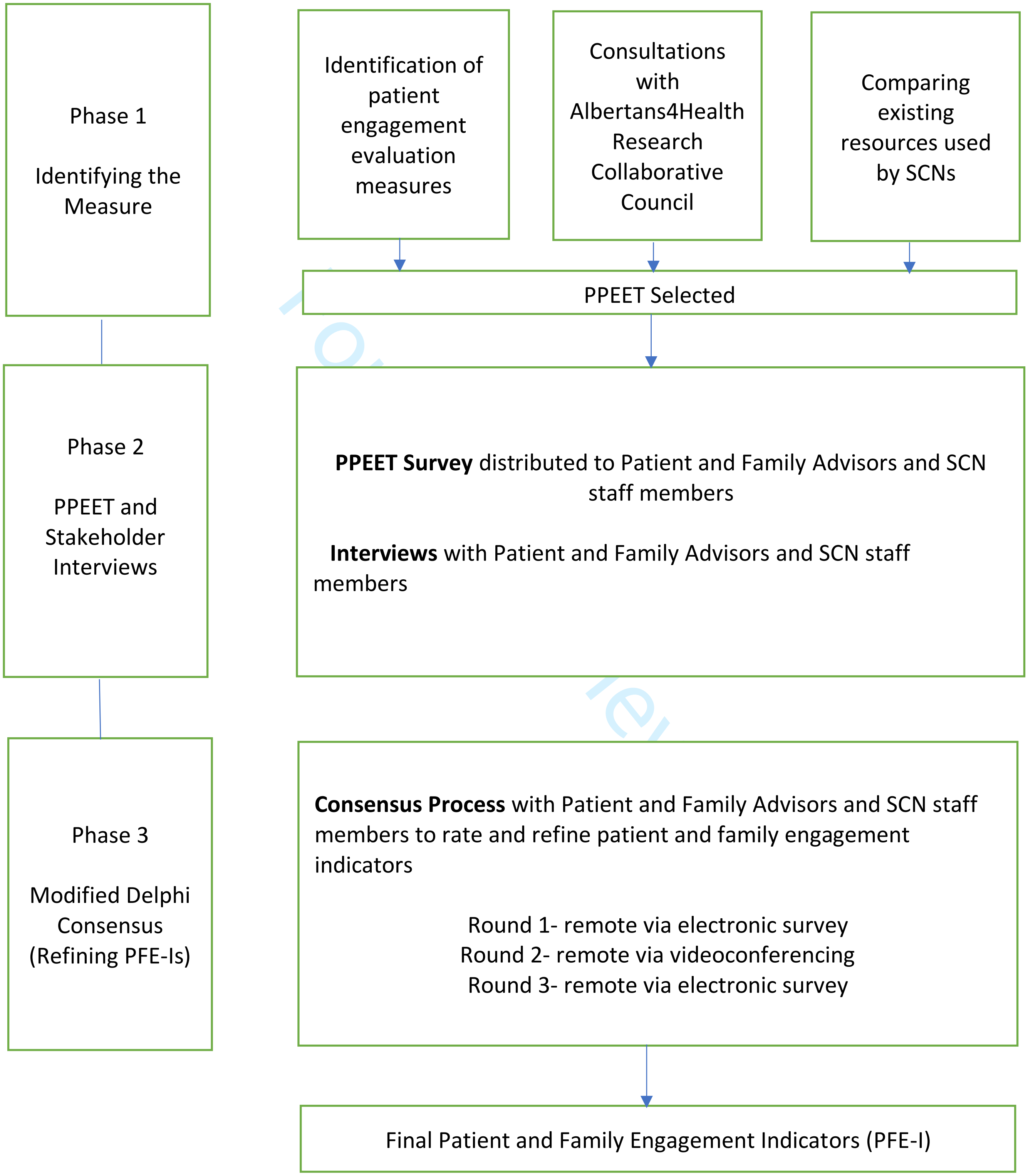
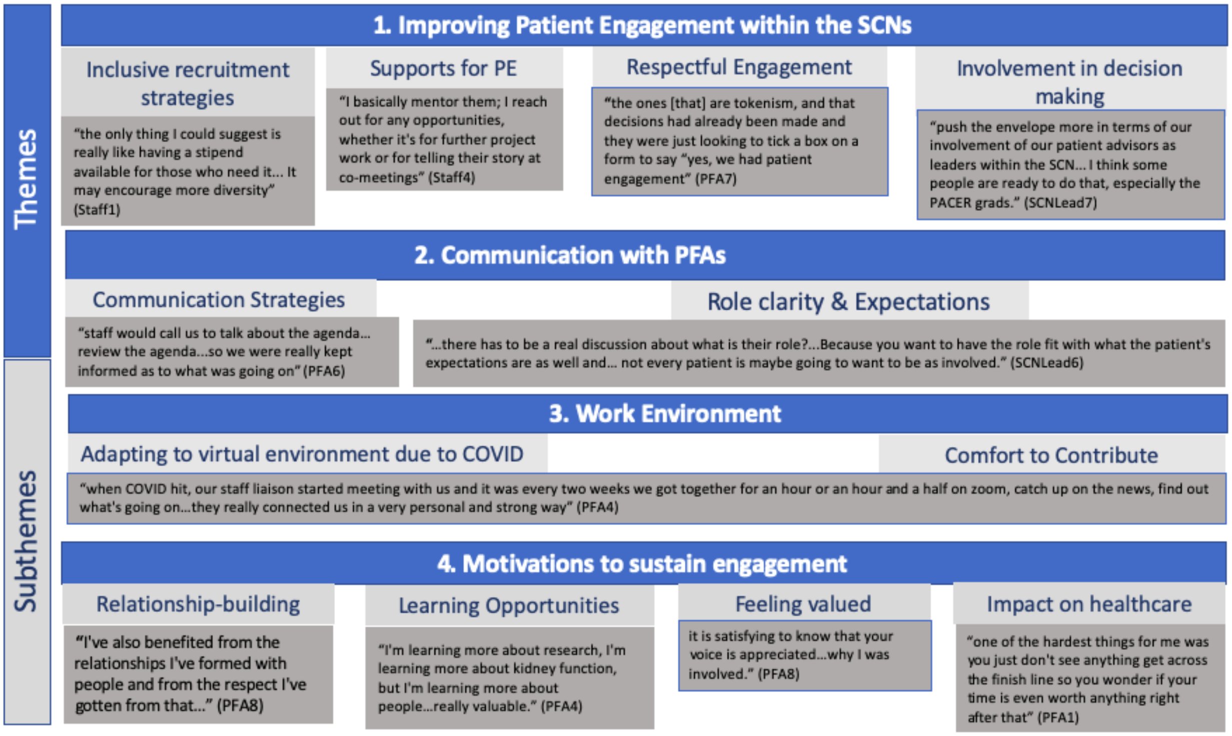


Figure 1. An overview of the program of research on the development of patient and family engagement indicators

Figure 2. Overview of themes and sub-themes identified from interviews with PFAs and SCN staff



1. Improving Patient Engagement within the SCNs

Inclusive recruitment strategies

"the only thing I could suggest is really like having a stipend available for those who need it... It may encourage more diversity" (Staff1)

Supports for PE

"I basically mentor them; I reach out for any opportunities, whether it's for further project work or for telling their story at co-meetings" (Staff4)

Respectful Engagement

"the ones [that] are tokenism, and that decisions had already been made and they were just looking to tick a box on a form to say "yes, we had patient engagement" (PFA7)

Involvement in decision making

"push the envelope more in terms of our involvement of our patient advisors as leaders within the SCN... I think some people are ready to do that, especially the PACER grads." (SCNLead7)

2. Communication with PFAs

Communication Strategies

"staff would call us to talk about the agenda... review the agenda...so we were really kept informed as to what was going on" (PFA6)

Role clarity & Expectations

"...there has to be a real discussion about what is their role?...Because you want to have the role fit with what the patient's expectations are as well and... not every patient is maybe going to want to be as involved." (SCNLead6)

3. Work Environment

Adapting to virtual environment due to COVID

Comfort to Contribute

"when COVID hit, our staff liaison started meeting with us and it was every two weeks we got together for an hour or an hour and a half on zoom, catch up on the news, find out what's going on...they really connected us in a very personal and strong way" (PFA4)

4. Motivations to sustain engagement

Relationship-building

"I've also benefited from the relationships I've formed with people and from the respect I've gotten from that..." (PFA8)

Learning Opportunities

"I'm learning more about research, I'm learning more about kidney function, but I'm learning more about people...really valuable." (PFA4)

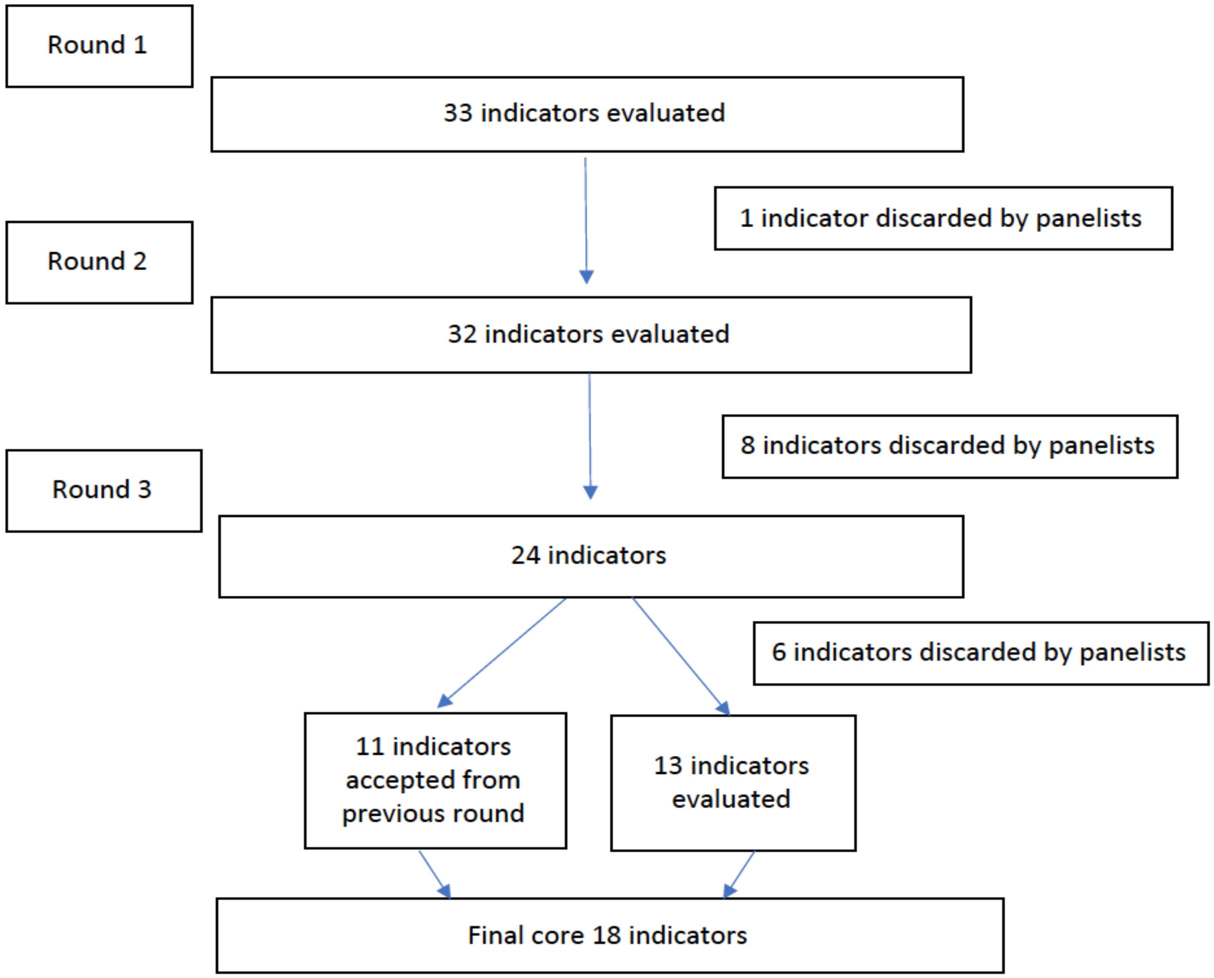
Feeling valued

it is satisfying to know that your voice is appreciated...why I was involved." (PFA8)

Impact on healthcare

"one of the hardest things for me was you just don't see anything get across the finish line so you wonder if your time is even worth anything right after that" (PFA1)

Figure 3. A flow chart of the PFE-Indicators Modified Delphi Process



Evaluation of Patient Engagement in the SCNs: Interview Guide

Interview Guide

1. How long have you been or were you involved with the SCNs?
2. Why did you decide to get involved in the SCNs?
3. How well was information about the patient and family advisor role communicated to you when you began your involvement with the SCNs? (*Was the purpose of patient/family engagement clear? Did you understand your role*?)
4. Can you describe how you have been involved?

   Probes: *What was your role? How have you contributed?*
5. On a scale of 1-10, with 1 being not good at all, and 10 being excellent, how would you rate the way the SCN team (clinicians, researchers, patient partners) works(ed) together?

   Probes*: Please comment on the way the research team worked together (clinicians, researchers, patient advisors)*

   How were expectations/instructions communicated?

   How comfortable were you in contributing?
6. Would you change anything regarding your involvement with the SCNs? (*e.g. time commitment, expectations, deadlines etc.*) / (**if project has ended**): If you could do it again, what would you change?
7. Sometimes there are challenges when researchers, patients, and other stakeholders work together. Have you encountered any challenges with your involvement in the SCNs?
8. Thinking about your contributions so far, what impact do you think you have had on SCN work?

   (considering both short- & long-term impacts, outputs of this work)

   Probes*: Impact of your involvement to this specific research project? To health research in general?*
9. How have you benefitted from your involvement?
10. When thinking about your involvement, why do you continue to do what you do?

11. What do you need to strengthen your involvement?
12. What has been your experience working with teams virtually?

    Probes*: Did you feel like you could contribute, ask questions, raise concerns?*
13. Based on your experience, do you have any suggestions for improvements that SCN teams could make when working with patient and family advisors?

14. Do you have any other comments/observations about your experience?

APPENDIX II- Patient and Family Engagement Indicators

Indicator Name	Numerator	Denominator
1. Enough information about the role	Number of PFAs who responded agree or strongly agree to having enough information about their role	Total number of PFAs responding to this question
2. Clear understanding of the purpose of the SCN that I am a part of	Number of PFAs who responded agree or strongly agree to having a clear understanding of the purpose of the SCN they are a part of	Total number of PFAs responding to this question
3. Able to express views freely	Number of PFAs who responded agree or strongly agree to being able to express their views freely	Total number of PFAs responding to this question
4. PFAs have supports available for engagement	Number of PFAs who responded agree or strongly agree to having supports (i.e. technology, travel) available for engagement	Total number of PFAs responding to this question
5. AHS Resources for Patient Engagement are useful for partnering with patient and family advisors (for PFAs)	Number of PFAs who responded agree or strongly agree that AHS resources* for partnering with patient and family advisors are useful ***** AHS Guidebook for engaging patient and family advisors	Total number of PFAs responding to this question
6. Involvement of PFAs make a difference in the work of SCNs (answered by PFAs)	Number of PFAs who responded agree or strongly agree to the statement that involvement of PFAs make a difference in the work of SCNs	Total number of PFAs responding to this question
7. Involvement of PFAs make a difference in the work of SCNs (answered by SCN staff)	Number of SCN staff who responded agree or strongly agree to the statement that involvement of PFAs make a difference in the work of SCNs	Total number of SCN staff responding to this question
8. SCNs take the feedback provided by PFAs into consideration (answered by PFAs)	Number of PFAs who responded agree or strongly agree to the statement that SCNs take the feedback provided by PFAs into consideration	Total number of PFAs responding to this question
9. SCNs take the feedback provided by PFAs into consideration (answered by SCN staff)	Number of SCN staff who responded agree or strongly agree to the statement that SCNs take the feedback provided by PFAs into consideration	Total number of SCN staff responding to this question
10. Individuals engaging in SCN teams represent a	Number of PFAs who responded agree or strongly agree that individuals engaging in the	Total number of PFAs responding to this question

broad range of perspectives (answered by PFAs)	SCN teams represent a broad range of perspectives	
11. Individuals engaging in SCN teams represent a broad range of perspectives (answered by SCN staff)	Number of SCN staff who responded agree or strongly agree that individuals engaging in the SCN teams represent a broad range of perspectives	Total number of SCN staff responding to this question
12. Individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together (answered by PFAs)	Number of PFAs who responded agree or strongly agree that the engagement was respectful and sincere to working together	Total number of PFAs responding to this question
13. Individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together (answered by SCN Staff)	Number of SCN staff who responded agree or strongly agree that the engagement was respectful and sincere to working together	Total number of SCN staff responding to this question
14. PFAs work together with SCN staff to design SCN projects	Number of PFAs who responded agree or strongly agree that they work together with SCN staff to design SCN projects (e.g. in priority setting & planning, development of proposals)	Total number of PFAs responding to this question
15. SCN staff work together with PFAs to design SCN projects	Number of SCN staff who responded agree or strongly agree that they work together with PFAs to design SCN projects (e.g. in priority setting & planning, development of proposals)	Total number of SCN staff responding to this question
16. PFAs work together with SCN staff to conduct SCN projects	Number of PFAs who responded agree or strongly agree that they work together with SCN staff to conduct SCN projects (e.g. collaborate in data collection, analysis/interpretation, advising on project as it is carried out)	Total number of PFAs responding to this question
17. SCN staff work together with PFAs to conduct SCN projects	Number of SCN staff who responded agree or strongly agree that they work together with PFAs to conduct SCN projects (e.g.	Total number of SCN staff responding to this question

	collaborate in data collection, analysis/interpretation, advising on project as it is carried out)	
18. PFAs work together with SCN staff to disseminate SCN projects	Number of PFAs who responded agree or strongly agree that they work together with SCN staff to disseminate SCN projects (e.g. co-presenting at conferences, sharing work widely)	Total number of PFAs responding to this question

Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	**Interviewer/facilitator**	**Which author/s conducted the interview or focus group? (pg.6)**
2.	**Credentials**	**What were the researcher's credentials? *E.g. PhD, MD* (pg.6)**
3.	**Occupation**	**What was their occupation at the time of the study? (pg.6)**
4.	**Gender**	**Was the researcher male or female? (pg.6)**
5.	**Experience and training**	**What experience or training did the researcher have? (pg.6)**
Relationship with participants		
6.	**Relationship established**	**Was a relationship established prior to study commencement?** (pg.4)
7.	**Participant knowledge of the interviewer**	**What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*** (pg.4)
8.	**Interviewer characteristics**	**What characteristics were reported about the interviewer/facilitator? e.g. *Bias,***

		assumptions, reasons and interests in the research topic
Domain 2: study design		
Theoretical framework		
9.	**Methodological orientation and Theory**	**What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis* (pg.4)**
Participant selection		
10.	**Sampling**	**How were participants selected? *e.g. purposive, convenience, consecutive, snowball* (pg.4)**
11.	**Method of approach**	**How were participants approached? e.*g. face-to-face, telephone, mail, email* (pg.4)**
12.	**Sample size**	**How many participants were in the study? (pg.9)**
13.	**Non-participation**	**How many people refused to participate or dropped out? Reasons? (N/A)**
Setting		
14.	**Setting of data collection**	**Where was the data collected? e.*g. home, clinic, workplace* (pg.4)**

15.	**Presence of non-participants**	**Was anyone else present besides the participants and researchers? (No)**
16.	**Description of sample**	**What are the important characteristics of the sample? *e.g. demographic data, date* (pg.9)**
Data collection		
17.	**Interview guide**	**Were questions, prompts, guides provided by the authors? Was it pilot tested? (pg.6)**
18.	**Repeat interviews**	**Were repeat interviews carried out? If yes, how many? (no)**
19.	**Audio/visual recording**	**Did the research use audio or visual recording to collect the data? (pg.6)**
20.	**Field notes**	**Were field notes made during and/or after the interview or focus group? (yes)**
21.	**Duration**	**What was the duration of the interviews or focus group? (pg 10)**
22.	**Data saturation**	**Was data saturation discussed? (pg6)**
23.	**Transcripts returned**	**Were transcripts returned to participants for comment and/or correction? (no)**
Domain 3: analysis and findings		

Data analysis		
24.	**Number of data coders**	**How many data coders coded the data? (pg.6)**
25.	**Description of the coding tree**	**Did authors provide a description of the coding tree? (pg.6)**
26.	**Derivation of themes**	**Were themes identified in advance or derived from the data? (pg.6)**
27.	**Software**	**What software, if applicable, was used to manage the data? (pg.6)**
28.	**Participant checking**	**Did participants provide feedback on the findings? (pg.5)**
Reporting		
29.	**Quotations presented**	**Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number* (pg.13-16)**
30.	**Data and findings consistent**	**Was there consistency between the data presented and the findings? (pg.10-16)**
31.	**Clarity of major themes**	**Were major themes clearly presented in the findings? (pg.10-16)**
32.	**Clarity of minor themes**	**Is there a description of diverse cases or discussion of minor themes? (pg.10-16)**

BMJ Open

Co-developing patient and family engagement indicators for health system improvement with healthcare system stakeholders: A consensus study

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Primary Subject Heading:	Health services research
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Co-developing patient and family engagement indicators for health system improvement with healthcare system stakeholders: A consensus study

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Article Summary

Strengths and limitations

- The consensus process utilized a participatory approach, by engaging diverse groups of experienced stakeholders, including patient and community advisors and health system staff and leadership
- We used a modified Delphi consensus process to co-develop a set of indicators to measure patient engagement in health research and system transformation for a provincial health system.
- This particular specific set of indicators has not yet been validated or implemented.

Abstract

Objective To develop a set of patient and family engagement indicators (PFE-Is) for measuring engagement in health system improvement for a Canadian provincial health delivery system through an evidence-based consensus approach.

Design This mixed-method, multi-phase project included: (1) identification of existing measures of patient and family engagement through a review of the literature and consultations with a diverse provincial council of patients, caregivers, community members, and researchers. The Public and Patient Engagement Evaluation Tool (PPEET) was selected; (2) consultations on relevance, acceptability and importance with patient and family advisors, and staff members of Alberta Health Services' Strategic Clinical Networks™. This phase included surveys and one-on-one semi structured interviews aimed to further explore the use of PPEET in this context. Findings from the survey and interviews informed the development of PFE-Is; (3) a Delphi consensus process using a modified RAND/UCLA Appropriateness Method to identify and refine a core set of PFE-Is.

Participants The consensus panel consisted of patients, family members, community representatives, clinicians, researchers, and healthcare leadership.

Results From an initial list of 33 evidence-based PFE-Is identified, the consensus process yielded 18 final indicators. These PFE-Is were grouped into seven themes: communication, comfort to contribute, supports needed for engagement, impact and influence of engagement initiative, diversity of perspectives, respectful engagement, and working together indicators.

Conclusions This group of final patient, family and health system leaders informed indicators can be used to measure and evaluate meaningful engagement in health research and system transformation. The use of these metrics can help to improve the quality of patient and family engagement to drive health research and system transformation.

Background

Person-centred health system improvement and transformation requires the involvement of patients and families to shape system priorities and inform care delivery and outcomes.(1) Recent evidence has shown that engaging patients in health system transformation can enhance service delivery and drive system improvement.(2)

While there have been efforts to advance patient engagement in health research and health system transformation, there are currently few co-developed, system-embedded sets of indicators to evaluate patient engagement and its impact on this transformation.

Alberta Health Services (AHS) is the largest province-wide health delivery system authority in the Canadian province of Alberta.(3) Within AHS, the Strategic Clinical Networks™ (SCNs) address system-wide gaps in care, work together to get evidence into practice, improve patient outcomes and experience, and to support continuous quality improvement.(4) The SCNs are multi-stakeholder teams that are comprised of clinicians, patient and family advisors, operational leaders, researchers, policy makers and community partners.(4, 5)

As of June 2022, the 11 SCNs aim to advance improvements in specific areas of health: (1) Bone & Joint Health, (2) Cancer, (3) Cardiovascular Health & Stroke, (4) Critical Care, (5) Diabetes, Obesity & Nutrition, (6) Digestive Health, (7) Emergency, (8) Maternal Newborn Child & Youth, (9) Medicine, (10) Neurosciences, Rehabilitation & Vision and (11) Surgery; and within 5 Integrated Provincial programs: (1) Addiction & Mental Health, (2) Seniors & Continuing Care, (3) Primary Health Care, (4) Population and Public Health and (5) Indigenous Wellness Core.

Each SCN works to actively engage patients and families in priority setting and co-designing solutions to improve patient experiences and quality of care. The Patient Engagement Reference Group (PERG) includes patients and public that engaged regularly in quality improvement and research projects within the 11 SCNs and the 5 Provincial Integrated Programs.(6) The current annual survey, deployed by the SCN Patient & Family Engagement team, does not measure patient engagement but rather the overall performance or satisfaction of participation. Additionally, engagement efforts are inconsistent across networks and often uncoordinated.(7) Developing indicators will enable AHS and the SCNs to be able to effectively measure patient engagement across networks. These measures will lend themselves to assessing impact with respect to effective engagement of patient and family advisors.

Our objective for this project was to address this gap by developing a set of evidence-based patient and family engagement indicators (PFE-Is) that were informed and prioritized by patient and family advisors (PFAs) in the context of a large and complex fully integrated provincial health system to measure meaningful patient engagement at the system level.

Methods

This mixed method study is a multi-phased patient-oriented research study that was informed by recent literature on patient engagement in health systems,(8, 9) consultations with our provincial network of Albertans (Albertans4HealthResearch Collaborative Council),(10) a survey and interviews with AHS SCN staff, leadership and PFAs, followed by a modified Delphi consensus generating process(11) to identify indicators to be used by the AHS SCNs to measure patient and family engagement in their initiatives to transform health care system in Alberta (Figure 1).

Patient and Public Involvement

This study is informed by the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework, which states that patients are active partners in health research.(12) The four guiding principles of the framework are inclusiveness, support, mutual respect, and co-build.(12) We consulted with patients and family advisors with diverse lived experience as active collaborators through a participatory approach—doing research 'with' rather than 'on' them.(12) The team included two patient partners, people living with chronic conditions (GW and SZ), both of whom are graduates of the Patient and Community Engagement Research (PaCER) program(13) from the University of Calgary that trains citizens with lived experiences of a health condition how to conduct research projects by, for, and with patients. GW and SZ also lead patient engagement groups and have extensive experience working on healthcare research and quality improvement projects and at governance level in the healthcare system.(6, 14) GW and SZ were involved in the planning of the project through working with the team members, SCN leadership and PERG to design the rollout of the project, providing feedback on the study proposal, co-conducting the project, and co-developing the manuscript.

Study participants and recruitment

The study population includes a diverse group of SCN leadership (individuals responsible for the organizational requirements for engagement activities- Scientific Directors (SD), Senior Provincial Directors (SPD), Senior Provincial Officers (SPO), Senior Medical Directors (SMD)), SCN Staff (Assistant Scientific Directors (ASD), Executive Directors (ED), Managers, Staff Liaisons, Senior Consultants) and (PFAs) within the SCNs.

Recruitment was supported by members of the research team (GW, MM, JP, and TW), working with and leading the AHS SCNs. Participants were invited to complete a survey and semi-structured interview. SCN leadership, SCN staff, and PFAs were also invited to participate in a modified Delphi consensus process. Participants are drawn from the same pool for all the phases, however since the survey is anonymous we did not confirm with all interview respondents or Delphi consensus participants whether they completed the survey.

The University of Calgary Conjoint Health Research Ethics Board (CHREB) has approved this project (REB20-1822).

Patient and public involvement: A multi-phase approach

The development of these indicators occurred over three phases, each involving significant patient and public engagement.

Phase 1: Selecting the patient and family engagement tool
Phase 2: Stakeholder consultations including a survey and follow up with interviews
Phase 3: Modified Delphi Panel

Phase 1: Selecting the measure

This phase includes three steps.

Step 1: We identified patient engagement evaluation measures. A recently published Systematic Review(15) identified a number of validated patient engagement evaluation survey tools including; PEIRS (Patient Engagement In Research Scale),(16) PPEET (Public and Patient Engagement Evaluation Tool)(17) and WE-ENACT (Ways of Engaging- ENgagement ACtivity Tool).(18)

Step 2: We presented the identified patient engagement evaluation measures to our provincial council, the Albertans4HealthResearch Collaborative Council. Members of the council appreciated the scope and depth of the PPEET, as it captured the evaluation of patient and family engagement from the perspectives of different stakeholders (patient and family advisors, staff members, and organization leaders).(17)

Step 3: After identifying and selecting the measure, the PPEET was compared to existing PFA engagement measures used by SCNs. This step ensured that existing efforts aligned with the development of the final core of indicators.

Public and Patient Engagement Evaluation Tool (PPEET)(17) includes three types of questionnaires that can be used to assess public and patient engagement in health research and at health system level. The three questionnaires are:

1. A participant questionnaire for patient partners and staff members on their experiences working together in engagement initiatives. There are two versions available: one evaluating one-time engagements and another evaluating on-going/long-term engagements.
2. A project questionnaire that reviews and assesses three components of the process of engagement at health system level including the planning, execution, and impact of the engagement.
3. An organization questionnaire assesses how engagement is conducted within organizations.

Questionnaires 1 and 3 of the PPEET were chosen for phase 2 as they aligned best with the purposes of evaluating patient and family engagement within the SCNs.

Phase 2: Stakeholder consultations

This phase included two steps, an electronic PPEET survey, and semi-structured interviews with SCN staff, leadership and PFAs.

Step 1: Individuals from SCNs were contacted and invited to complete the PPEET as an anonymous on-line survey. This survey was populated into Qualtrics Software(19) for ease of use and widespread distribution. The aim was to assess the utility of the PPEET in capturing the experiences of participants in working together within their SCNs; as well as gathering potential barriers and facilitators in engagement in health research and system transformation.
Survey results were descriptively summarized and categorized according to the key areas of engagement: communication and supports for participation, sharing your views and perspectives, and impacts and influence of the engagement initiative. Frequencies were also reported.

Step 2: After completing the online survey, respondents were invited to a semi-structured interview. Interviews were conducted with a select number of SCN PFAs, leadership and staff members via a video-conferencing platform (e.g. Zoom) or by telephone. The purpose of conducting the interviews was for participants to expand on their patient engagement experiences working within the SCNs, and to gain an in-depth understanding of the barriers and facilitators to engagement in health research and system transformation. The interview guide was co-developed with patient and family partners and research team members (APPENDIX I). The semi-structured interviews were conducted by members of the research team (conducted by SZ, GW, SA, TM, qualitative research background).

The interviews were audio recorded, transcribed verbatim, and thematically analyzed, with deductive and inductive coding strategies.(20) Qualitative researcher (SA) followed the six-step thematic analysis Braun & Clarke method,(21) and had peer debriefing sessions at different stages of the analysis with MS to discuss themes and subthemes identified. After organizing codes into themes, they were presented back to the research team for feedback.

PFE-Is were drafted from the PPEET survey and qualitative interviews for the consensus process.

Phase 3: Delphi Consensus Process

Consensus methods are considered an effective tool for facilitating decision-making when there is insufficient information or when there is contradictory information.(22) The RAND/UCLA Appropriateness Method was used as a guide for the consensus process.(11) A consensus panel consisted of a diverse group of eight PFAs, five Scientific Directors, ten Assistant Scientific Directors/Managers/Staff liaisons.

The consensus process included three rounds. Round one was conducted via an electronic survey, round two via videoconference, and round three was completed via an electronic survey.

Round One: Using a modified Delphi technique,(11) panelists ranked each of the PFE-Is criteria according to a 9-point scale scoring as not relevant/to be discarded (1-3); consider more discussion (4-6) and relevant/accepted (7-9). Panelists were also given the opportunity to provide written comments and suggestions. Results from this phase were compiled and shared prior to the virtual face-to face Round 2.

Round Two: the panel and moderators convened over 2 hours via zoom. Moderators shared the results of the first round and facilitated a workshop noting any areas of disagreement indicated by the ratings and answered any questions about the process. The group deliberated, until agreement on the patient and family engagement indicators was achieved. Two research team members took notes to capture modifications made to the indicators and discussions from the consensus meeting. The indicators (after modifications) were presented to the panelists for a final round of voting.

Round Three: The discussed PFE-Is were refined based on the discussions and consensus that happened during Round Two. These PFE-Is were voted on ‘overall importance’ as keep or discard using an electronic survey.

Scale

Panelists used a 9-point rating scale. Ratings of 1-3 indicated not relevant/to be discarded; 4-6 if more discussion was needed; 7-9 as relevant/accepted. PFE-Is were accepted when 75% of the panelist’s ratings were 7,8,9 without disagreement on the scale. Disagreement was declared when 5 or more than 5 panelists rated the indicator in the top and bottom parts of the scale (1-3 or 7-9).

The rating criteria provided to the panelists is displayed in Table 1. Panelists used these criteria to rate PFE-Is through the Delphi process.

Table 1. Rating criteria

Criteria	Definition
Overall importance	This overall rating will be used to determine how important it is to measure and track this indicator for patient and family engagement within the SCNs A high score on this criterion indicates that compared with other indicators, this indicator is very important for measurement of patient and family engagement within the SCNs A low score on this criterion indicates that the indicator is not as important compared to the other indicators for measuring patient and family engagement within the SCNs When rating this indicator, consider how important is this indicator to you or your organization in promoting meaningful patient and family engagement.
Impact on Patient and Family Engagement	This rating will be used to determine whether this indicator will have a big impact on the engagement of patients and families within the SCNs A high score on this criterion indicates that compared with other indicators, this indicator has a big impact on the engagement of patients and families within the SCNs A low score on this criterion indicates that compared with other indicators, this indicator does not have a big impact on the engagement of patients and families within the SCNs Improvements on this indicator will mean improved engagement of patient and family advisors
Actionable by SCNs	This indicator reflects an area where improvements can be made. It can provide information to improve the engagement of patient and family advisors A high score on this criterion indicates that compared with other indicators, there is a big opportunity to change the results for this indicator within the SCNs A low score on this criterion indicates that compared with other indicators, there is not a big opportunity to change the results for this indicator within the SCNs This indicator could be measured to improve patient and family engagement within the SCNs, without too much difficulty
Interpretability	This indicator provides clear information that is easy to communicate to stakeholder groups, including patient and family advisors.

	A high score on this criterion indicates that compared with other indicators, this indicator is easy to communicate to different audiences, with little explanation A low score on this criterion indicates that compared with other indicators, this indicator is more difficult to communicate to different audiences with little explanations
Relevance	This indicator addresses areas of major importance or concern related to patient and family engagement within the SCNs A high score on this criterion indicates that the indicator is very relevant to patient and family advisors, and the strategic clinical networks A low score on this criterion indicates that the indicator is not as relevant as other indicators to patient and family advisors, and the strategic clinical networks

Results

The results of the three phases are described by phase.

Phase 1.

The AB4HR council members were consulted on which tool to utilize for measuring patient and family engagement. The criteria for selecting the initial tool was that the tool had to be free to use, relevant, actionable, measure engagement prospectively and from all members of the team and important to assess the engagement in health research and other initiatives informed by patients and family advisors. The council members completed the PPEET to provide their feedback on what was being asked within the survey, and council members found the PPEET met all the criteria.

Phase 2a

The online survey was emailed to 175 patient and family advisors, 69 SCN staff members, and 49 SCN leadership members. 96 participants responded, including 51 PFAs, 31 SCN staff, and 14 SCN leadership. PFE-Is were then drafted based on the questions from the PPEET survey.

In general, there was some consistency in the responses. Most patient and family advisors agreed/strongly agreed that they:

- have a clear understanding of the purpose of the SCNs they are involved in (94%)
- have supports available to contribute to the SCNs projects (92%)
- have enough information to be able to carry out their role in the specific projects (81%)
- can express their views freely when working in projects (96%)
- are confident the SCNs take the feedback provided by patient and family advisors into consideration (81%)

Similarly, most or all SCN staff agreed/strongly agreed that they:

- have a clear understanding of the purpose of engaging patient and family advisors in the SCNs (100%)

- have supports and information available to effectively engage with patient and family advisors (87%)
- are able to express their views freely (86%)
- SCNs take the feedback of patient and family advisors into consideration (100%)
- felt the involvement of patient and family advisors make a difference in the work of the SCNs (100%)

SCN leadership responded to a different module of the PPEET that focused on policy and practices that support patient and family advisor engagement, participatory culture, influence and impact, and collaboration and common purpose.

Most SCN leadership agreed:

- that the SCNs have an explicit strategy and framework for patient and family advisor engagement (86%)
- the SCNs have explicit strategies for recruiting patient and family advisors, depending on the engagement initiative (79%)
- a commitment to the principles and values of patient and family advisor engagement is found in key SCN documents (e.g., transformational roadmaps, etc.) (93%)

However, there were some mixed responses on the following:

- 50% of respondents were neutral on the statement that the resources available for patient and family advisor engagement is adequate (43% agreed/strongly agreed, and 7% disagreed.)
- 43% of respondents agreed/strongly agreed to SCNs preparing reports that summarize the contributions from patient and family advisor engagement initiatives (36% of respondents were neutral and 21% disagreed.)
- The statement “Comprehensive patient and family engagement training and materials are available to support staff who are leading and supporting these activities.” had 42% responding neutral, 41% agreeing/strongly agreeing, and 17% disagreeing.

Some of the SCN leadership that responded neutral for some statements indicated in the comments that this was due to lack of awareness on specific activities and resources. The results indicate variation among the 11 SCNs and 5 Provincial Programs in how patient and family engagement is conducted and reported.

Phase 2b - Interviews were conducted with 26 individuals including 13 with PFAs and 6 SCN staff and 7 SCN leadership. Interviews ranged from 25 to 94 mins. Figure 2 displays an overview of the themes and subthemes, and Table 2 provides more details on the themes, subthemes, and associated quotes. The identified themes highlighted additional considerations in patient and family engagement and additional PFE-Is, such as mentorship for PFAs, capacity building opportunities for PFAs and SCN staff members in POR (training/orientation), and virtual engagement of PFAs.

Improving Patient Engagement within the SCNs

Both PFAs and SCN staff recognized the need for inclusive strategies for recruitment and retainment, to involve various other patients in health research and within SCNs. Some SCN staff expressed difficulties with recruiting new PFAs, and retaining current advisors. Strategies mentioned by some staff included the importance of reaching out to clinical, special interest, and non-profit groups for support in recruiting PFAs, bringing awareness to what a patient advisor is, and utilizing social media.

Some staff also noted some barriers to recruitment including the:

- onboarding process for the organization, which can be extensive for engagement especially those required for one-time or for a limited time.
- COVID-19 pandemic and how it impacted the time people have available.
- lack of compensation available for patient advisors which may exclude some advisors who represent marginalized and hard to reach communities (e.g. unhoused individuals).

Most PFAs who had felt supported in the engagement activities, mentioned having a strong relationship with their SCN team. SCN Leadership and staff also discussed their patient engagement strategy and how it evolved over time. Staff and Leadership felt supported in being able to carry out patient engagement in their work. To improve patient engagement within the SCN, participants highlighted various supports for patient engagement that are required to be consistent within the SCNs: resources about how to engage with patients and working together, mentorship for PFAs, capacity building opportunities for both SCN staff and patient and family advisors such as training and/or orientation. Some participants also discussed whether compensation for engagement would be needed as an acknowledgement of the time and contributions of PFAs. Finally, participants indicated a vital component for working together successfully included respectful engagement and the sincerity of those engaging patients. In various committees, participants indicated excellent partnerships were key to feeling respected and accordingly that they felt like they could contribute to the SCN.

Some participants highlighted the need for PFAs to be involved in decision-making processes through early engagement at the conception of the project and including PFAs in more leadership positions such as co-chairing or co-leading committees.

Communication with PFAs

Some PFAs emphasized needing clear and timely communication about the status of projects, e.g. when projects were being implemented, whether projects were moving forward, and updates on the general work of the SCN. Participants emphasized the importance of setting clear expectations for engagement activities and for the role of a PFA. Some PFAs described their role within the SCNs as advising on projects, acting as leaders or members in patient advisory groups, being invited to share their stories/perspectives on their healthcare experiences, and providing input on meeting agendas. However, there were also some PFAs who mentioned lacking clarity on their role within the SCN when they had initially joined the network.

Some SCN staff discussed some challenges in managing expectations of PFAs (regarding timeline of the project, or the priorities of the network), which may have not aligned with the expectations of the PFAs. Some staff expressed how they had to communicate to patients the difference between advisor versus advocate as the roles are different within the SCNs, and have the potential to lead to differing priorities. One staff member discussed developing a 'parking lot' to provide a safe space in bringing up topics of concern and interest to PFAs, but not aligning with current priorities of the SCN. The aim of this idea is to ensure PFAs' ideas are not lost but recognized for the potential to address at a later date.

Work Environment

Most PFAs described feeling comfortable in being able to contribute in meetings with other stakeholders and still feeling engaged in virtual meetings and projects, and adapting well to working in a virtual setting. There were few PFAs who expressed frustration with lack of patient engagement in the SCNs during COVID, and some who had stepped down from their PFA position as a result.
Almost all SCN staff also mentioned working virtually with SCN teams including PFAs have been a positive experience (such as alleviating burden from travel or facilitating engagement). However, both SCN staff and PFAs mentioned missing the personal connection and networking aspect of in-person meetings. Other concerns with virtual engagement were that it would be more difficult for new advisors to be engaged in a virtual environment, and some advisors may be uncomfortable with technology and encounter connection issues.

Motivations to Sustain Engagement

Most PFAs mentioned their reason for joining and staying was to have an impact on the healthcare system, and to feel like their contributions mattered.

There were mixed responses from PFAs on whether they felt acknowledged for their contributions and valued as team members. Some PFAs felt valued as members of their SCNs, and detailed ways in which they felt acknowledged for their contributions. There were also some PFAs who spoke about instances in which they felt they were low priority for the SCNs, or felt their involvement was tokenistic. Some PFAs also described how they valued learning from their SCN teams, learning about research, their conditions, and the healthcare system. For some PFAs, meeting people and building relationships was valuable in their engagement within the SCNs, and a reason for them to continue to stay involved.

Table 2. Themes, sub-themes and selected quotes.

Theme & subthemes	Quote
Improving Patient Engagement within the SCNs Inclusive recruitment strategies	“I sent a letter in about two years ago to Dr. and I said, “you know, I've really enjoyed being involved but, you know, you need to get more members of the public involved, more than just me.” …, not 20 but you know, maybe- they probably have 2 or 3 now, members of the SCN, or maybe more…part of the core committee, so I think…those are the things that I would potentially change” (PFA3) “we have a real passionate group, right? And after two years I feel like a little bit of momentum has dropped. But I mean it was COVID for goodness sakes, right? … we did recruit four new advisors in January so we tried anyways. But we still—we want to get a sweet spot of about 15 where at last half of them attend a meeting, right, whereas right now if we have 11 then we only have five or six attending… And I mean not that that's bad it's just, you want more voices, right? And people aren't responding, they're not great at responding to emails. Even though we send out lots of opportunities sometimes it's just that reach out directly to the person that works best.” (Staff4)
Supports for engagement	“one of the first things I did was develop a resource for Skype because our—I think AHS either was in the process of or didn't have one that I felt was kind of user friendly. So I developed that and actually shared that amongst the networks to say hey, here I have this Skype for patients and families to use. We developed an orientation PowerPoint, so it really—once they've been fully onboarded then we do this orientation and it's probably 45 minutes presentation and discussion and questions. And it really talks about all the three areas in the network …and it introduces who the network is all this kind of main subject areas… The other thing we did was a resource, it's like a dictionary…a glossary of terms for our network.” (Staff4)
Views on Respectful Engagement	“the ones [that] are tokenism, and that decisions had already been made and they were just looking to tick a box on a form to say “yes, we had patient engagement”. And although there was some effort…I can spot a project to nowhere and I'm just a bobblehead as a patient advisor after one meeting,…At the beginning had more of those type of experiences, and as you gain experience and knowledge of how AHS works, you know to pick and choose what projects you think are realistic and that will actually move forward.” (PFA7)
Involvement in decision making	“the other place I think that I want to get to is, as an SCN and not just me personally, is to really kind of really push the envelope more in terms of our involvement of our patient advisors as leaders within the SCN. So to really try to get them to be a bit more leading in terms of bringing their ideas forward and getting sort of at the end of that IAP2 spectrum really coming up with the ideas and being able to run with them and work on it from that perspective. And I think some people are ready to do that, especially the PACER grads. But I think I'd like to see the whole community move that way.” (SCNLead7)
Communication with PFAs Role clarity & expectations	“there was a long-time patient or family advisor who wanted the network to work on something that he was interested in. But it didn't align with operational priorities so it never rose to the top…We can't do everything and for him to be meaningfully engaged... we and he decided that how he contributed to the network would change. And he came more focused on other contributions to research and to providing inputs occasionally to surveys that we would do, and certainly continuing to receive communications, etc. But when there isn't that alignment, we can't force it.” (SCNLead2)
Communication Strategies	“staff would call us to talk about the agenda… review the agenda...so we were really kept informed as to what was going on” (PFA6)

Work environment	“I remember when I went to my very first meeting, I was so nervous because I thought like they would be like “you interlopers, what are you doing here,” kind of thing. I thought we would stand out and be like really weird, and it was completely the opposite. It was incredibly welcoming” (PFA2)
Comfort to contribute	“I was on a side project…the person who was leading the project, …would ask a question. And one time – one question, the physician would answer first…high up EMS people would answer, and then she would ask us as family patient advisors. The next question: she’d flip it and she’d ask the EMS guys first, then the family patient advisors, then the physician…Never have I felt more like an equal than I did on that project.” (PFA11)
Adapting to virtual involvement due to COVID	“it depends on the meeting, like once it's too big, you kind of lose people and everybody is drifting off, but for smaller engagement it's- it's actually very effective. It's good for the environment, because there's less travel, and it's good for infection control, because before the pandemic, if we were getting people together face-to-face, if one person decided to go with a cold, they probably would leave some of that virus behind. So, it’s the future” (SCNLead4)
Motivations to sustain engagement Relationship-building	“I've also benefited from the relationships I've formed with people and from the respect I've gotten from that… it is satisfying to know that your voice is appreciated and that really is – really is the way – why I was involved and why I keep being involved with the research.” (PFA8)
Feeling valued	**“**I wanted to commend the SCNs in their ability to make patients feel like superstars. You know, to help us recognize that we are as important as the head of Nephrology. And there's a huge ego boost in that and that ego boost is necessary in order to give people the confidence to speak up.” (PFA5)
Learning opportunities	“that's been the joy of the SCN as well. Is really learning. The physician and medical experience which I want more of, as well as hearing other patient partners and building that network. I've had this opportunity and I've always been a lifelong learner, so every time I attend a presentation, every time I’m part of an event, I'm learning more about research, I'm learning more about kidney function, but I'm learning more about people even more important to me, so it has been really valuable.” (PFA4)
Having an impact on the healthcare system	‘I’ll admit, I was a little – not suspicious, but fatalistic at first, thinking, yeah, will it make any difference? But the more I found that they really took patient complaints or suggestions positively, and I saw things actually being enacted that made a difference. It kept me going and eager to do more.” (PFA12)

Phase 3

During phase 3, 23 participants (8 PFAs, 15 SCN staff members) arrived at consensus on the core PFE-Is over three rounds of discussions. They rated each indicator based on the following criteria: overall importance, impact on patient and family engagement, actionable by SCNs, interpretability, and relevance. (Figure 3).

At the end of the third round, seven different categories of PFE-Is were developed, including:

1. **Communication**: Assess whether enough information has been provided to PFAs to have an overall understanding of the SCNs and specifically their role.
2. **Comfort to Contribute**: Assess whether PFAs are comfortable in contributing within their SCNs, through expressing their views freely.

3. **Supports for Engagement**: Assess whether there are necessary supports available for patient and family engagement within the SCNs for PFAs and SCN staff.
4. **Impact and Influence of Engagement Initiative**: Assess whether PFAs and SCN staff agree that involvement of PFAs make a difference in the work of the SCNs, and that SCNs take the feedback provided by PFAs into consideration.
5. **Diversity of Perspectives**: Assess whether individuals engaging in SCN teams represent a broad range of perspectives
6. **Respectful Engagement**: Assess whether individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together
7. **Working Together**: Assess whether PFAs work together with SCN staff to design, conduct, and disseminate SCN projects

Specifically, 33 PFE-Is were developed through phase 1 and phase 2 of this work. These 33 drafted indicators were presented to the panel for rating using the rating criteria: overall importance, impact on patient and family engagement, actionable by SCNs, interpretability, and relevance.

During the first round and based on final ratings, one indicator was discarded: Each SCN prepares reports that summarize the contributions from patient and family advisor engagement initiatives, as the overall importance was rated low.

During round 2, eight indicators were discarded by the panelists as these PFE-Is were perceived by the panelists as too broad and difficult to measure including: PFAs being meaningfully engaged virtually; PFAs have a supportive working environment to contribute to the engagement initiative; SCNs have mentorship opportunities for PFAs; Each SCN has an explicit strategy or framework for patient engagement; Each SCN is at the stage of established/making some progress in engagement with patient and family advisors; Each SCN has explicit strategies for recruiting patient and family advisors, depending on the engagement initiative; There are resources (documents, guidelines) available to SCN Staff for PFA engagement; The SCN is achieving its stated objectives.
Slight modifications were made to some of the indicators that were considered 'keep' such as clarity in the wording. For instance, the indicator "Clear understanding of the purpose of the SCN" was modified to include "SCN that I am a part of" to make it clear to respondents that the indicator is measuring the purpose of a specific SCN that the PFA belongs to, and not all the SCNs. Panelists also recommended breaking the 'working together' indicator into separate indicators to reflect the many ways PFAs work together with the SCNs. For instance, in the design of projects, conducting projects, and in the dissemination of projects.

Of the 24 indicators from round 2, eleven indicators were accepted by the panelists and 13 indicators needed to be refined by the panelists at the third round of voting. From round 3 of voting, six indicators were discarded by panelists: PFAs have received training on patient engagement (e.g. orientation to patient-oriented research); SCN staff have received training on patient engagement (e.g. orientation to patient-oriented research); The responsibilities related to patient engagement are clearly articulated in my job description; There are dedicated patient and family engagement leadership positions; AHS Resources for Patient Engagement are useful for partnering with patient and family advisors (answered by SCN staff); SCN staff work together with PFAs to disseminate SCN projects (e.g. co-presenting at conferences, sharing work widely) (answered by SCN staff)

A final core group of 18 indicators were accepted. The final indicators from this Delphi consensus generating process are displayed in Table 3. Certain indicators were developed based on previous indicators (e.g. indicators 14-17), some indicators were developed after round 2, and then introduced again for voting in round 3. Details of the final indicators (numerator and denominator) are included in APPENDIX II.

Table 3. Summary of consensus panel ratings on overall importance for the final 18 patient and family engagement indicators

Patient and Family Engagement Indicators	**Round 1 remote panel rating (Median score on 9-point scale and (IQR))**	**Round 2 online consensus meeting decision**	**Round 3 remote panel decision (% of panelists voting to keep indicator)**	**Indicator Source (PPEET I=interviews C=consensus)**
1. Enough Information about the role	8 (7-9)	Keep	N/A	PPEET, I
2. Clear understanding of the purpose of the SCN that I am a part of	7 (6-9)	Keep, with edits	Keep (90%)	PPEET, C
3. Able to express views freely	8 (8-9)	Keep	N/A	PPEET, I
Supports for Engagement Indicators (n=2)				
4. PFAs have supports available for engagement (e.g. technology, travel)	8 (7-9)	Keep, with edits	Keep (80%)	PPEET, I, C
5. AHS Resources for Patient Engagement are useful for partnering with patient and family advisors	No rating (not developed yet)	Newly developed derived from previous "Resources for Patient Engagement Indicator"	Keep (80%)	C
6. Involvement of PFAs make a difference in the work of SCNs (answered by PFAs)	9 (8-9)	Keep	N/A	PPEET, I
7. Involvement of PFAs make a difference in the work of SCNs (answered by SCN staff)	9 (8-9)	Keep	N/A	PPEET, I
8. SCNs take the feedback provided by PFAs into consideration (answered by PFAs)	8 (7-9)	Keep	N/A	PPEET, I
9. SCNs take the feedback provided by PFAs into consideration (answered by SCN staff)	8 (7-9)	Keep	N/A	PPEET, I
10. Individuals engaging in SCN teams represent a broad	8.5 (7.25-9)	Keep	N/A	PPEET, I

range of perspectives (answered by PFAs)				
11. Individuals engaging in SCN teams represent a broad range of perspectives (answered by SCN staff)	8.5 (7.25-9)	Keep	N/A	PPEET, I
12. Individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together (answered by PFAs)	9 (8-9)	Keep	N/A	I
13. Individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together (answered by SCN staff)	9 (8-9)	Keep	N/A	I
14. PFAs work together with SCN staff to design SCN projects (e.g. in priority setting & planning, development of proposals) (answered by PFAs)	No rating (not developed yet)	Newly developed derived from previous "Working Together Indicator"	Keep (95%)	C
15. SCN staff work together with PFAs to design SCN projects (e.g. in priority setting & planning, development of proposals) (answered by SCN staff)	No rating (not developed yet)	Newly developed derived from previous "Working Together Indicator	Keep (95%)	C
16. PFAs work together with SCN staff to conduct SCN projects (e.g. collaborate in data collection, analysis/interpretation, advising on project as it is carried out) (answered by PFAs)	No rating (not developed yet)	Newly developed derived from previous "Working Together Indicator	Keep (79%)	C
17. SCN staff work together with PFAs to conduct SCN projects (e.g. collaborate in data collection, analysis/interpretation, advising on project as it is carried out) (answered by SCN staff)	No rating (not developed yet)	Newly developed derived from previous "Working Together Indicator	Keep (90%)	C
18. PFAs work together with SCN staff to disseminate SCN projects (e.g. co-presenting at conferences, sharing work widely)	No rating (not developed yet)	Newly developed derived from previous "Working	Keep (75%)	C

		Together Indicator		

*N/A= voting not required/applicable as PFE-I accepted in previous round

Discussion

Working in partnership with the AHS SCN teams, their advisors in the Patient Engagement Reference Group, and the Albertans4HealthResearch Collaborative Council, we co-developed patient and family engagement indicators to measure engagement in health system transformation. Through an initial synthesis of the evidence and a consensus approach using the PFE-Is we were able to develop 18 indicators that reflect meaningful patient engagement. The findings align with the core principles highlighted in the CIHR SPOR Patient Engagement framework: Inclusiveness, Support, Mutual Respect, and Co-Build.(12)

The final 18 evidence-based and patient, family and stakeholder informed indicators are ready to be used to measure and evaluate meaningful engagement in health system transformation. The use of these indicators promotes the changes needed to improve the quality of health research and health system improvement that is informed by patients and families. The use of the indicators within the healthcare system to learn from and evaluate health policy and practice related to what matters to patients and families is a critical next step.

The strength of this study is the participatory approach used to develop PFE-Is, which ensures that engagement was evaluated from the perspective of those who provide and receive care. We aimed to adhere to the guiding CIHR principles for patient engagement. Our process was inclusive- we engaged patient and family advisors from different SCNs who bring diverse healthcare experiences and conditions. Supports- financial compensation was provided to the patient partners in our team, and flexibility given to patient and family advisors engaged in the consensus process (survey to rate indicators could be completed at own pace, feedback encouraged over zoom using chat features and during meeting). Mutual respect- acknowledging and valuing expertise and experiential knowledge of all members of the research team and members of the consensus. Co-build- working with our patient partners to design, review, conduct, and disseminate the findings of the project. To our knowledge, this is the first study to develop a set of PFE-Is using a rigorous evidence-based and person-centred approach and involving patients and caregivers throughout the research process—from inception of the project to manuscript development including dissemination activities.

Using a highly participatory approach, we sought to ensure that the study was guided by the perspective of individuals with lived experiences, and that diverse perspectives were reflected in the development of the PFE-Is. Consensus methods have been utilized in patient and family engagement research with patient and family advisors. For instance, the study by Anderson et al.(23) identified 32 recommendations for optimizing patient engagement in hospital planning and improvement. Their recommendations align with the findings identified from our interviews with SCN members, such as inclusive recruitment strategies, providing patient and family advisors supports for engagement, and respectful engagement.

While measures of engagement were identified in Boivin et al. review,(15) these were not considered indicators as per the definition of indicators suggested by the Agency for Healthcare Research and Quality - as units of measurement, such as percentage or proportion.(24) The measure, PPEET,(17) was identified by patients, caregivers and other individuals from diverse communities in Alberta as the measure to use given it was relevant and addressed important domains measuring patient engagement.

These newly developed indicators present an opportunity to improve meaningful engagement ensuring that the voices of the individuals with lived experiences are incorporated into health systems supporting the transformation of healthcare. To drive changes in healthcare policy and practice, there is a need to develop and implement standardized ongoing mechanisms to measure and evaluate healthcare incorporating the patients' perspectives. In doing so, the effectiveness of engagement practices can be strengthened and advanced across the system.

The findings from the survey and interviews reflected priorities that focused on the process of patient engagement as they were from the perspectives of patient and family advisors and SCN staff members working together within the SCNs. Impact of patient engagement on patient and family advisors and SCN staff members on themselves are captured in some of the PFE-Is. However, indicators assessing impact of patient engagement on the organization were not developed (such as changes in policies, procedures, and resources), which may be a limitation of this work. Similarly, the review by Boivin et al.(15) and Dukhanin et al.(25) found most evaluation tools assessing context and process of evaluation. Dukhanin et al.(25) notes that measuring outcomes of engagement is needed, such as documented changes in policies, procedures, or programs, however current measures do not sufficiently capture these aspects. Another limitation of this project is that these set of indicators have not been evaluated. However, a future direction of this work is to evaluate and implement the indicators within the current healthcare system. We have started consultations with AHS SCNs stakeholders to assess the feasibility of data collection processes. Only by attempting real-world data collection can we determine whether the indicators meet the traditional standards of 'good-quality measures', to be acceptable, reliable and valid.(26) Moreover, studying the implementation of the PFE-Is could shed light into their effectiveness for promoting improvements in patient engagement across the SCNs for specific projects (health research and quality improvement). It is also important to identify any unintended consequences as a result of the implementation of these PFE-Is, of their use for benchmarking and other issues that may arise, such as implications on staff workload and their cost-effectiveness.

Additionally, while this method has generated these 18 PFE-Is using a validated consensus method, they may not necessarily be universally applicable in all settings and countries due to differing healthcare systems. Different cultural settings in different healthcare regulatory environments may mean that different measures may be more appropriate for certain settings. Further work can be done to tailor and adapt these PFE-Is, recognizing that a consideration of the local context will ensure a more universal relevance. Future steps for this work include the evaluation of implementing these indicators within the SCNs.

Author Contributions: MS and TW conceived and designed the study**.** TM, GW, SZ, SA conducted data collection. SA and MS worked on the analysis and interpretation of findings, with feedback from TW, PF, GW, SZ, MM, JP, TM. MS, SA, PF drafted the article, and all authors (TW, GW, SZ, PF, MM, JP) provided critical feedback and approved the manuscript to be published.

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Ethics Approval: The University of Calgary Conjoint Health Research Ethics Board (CHREB) has approved this project (REB20-1822).

Competing Interests: None declared.

Patient consent for publication: Not applicable.

Data Sharing: This study analyzes qualitative data and the participants did not consent to have their full transcripts made publicly available. Other additional data available upon reasonable request.

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Figure 1. An overview of the program of research on the development of patient and family engagement indicators

Figure 2. Overview of themes and sub-themes identified from interviews with PFAs and SCN staff

Figure 3. A flow chart of the PFE-Indicators Modified Delphi Process

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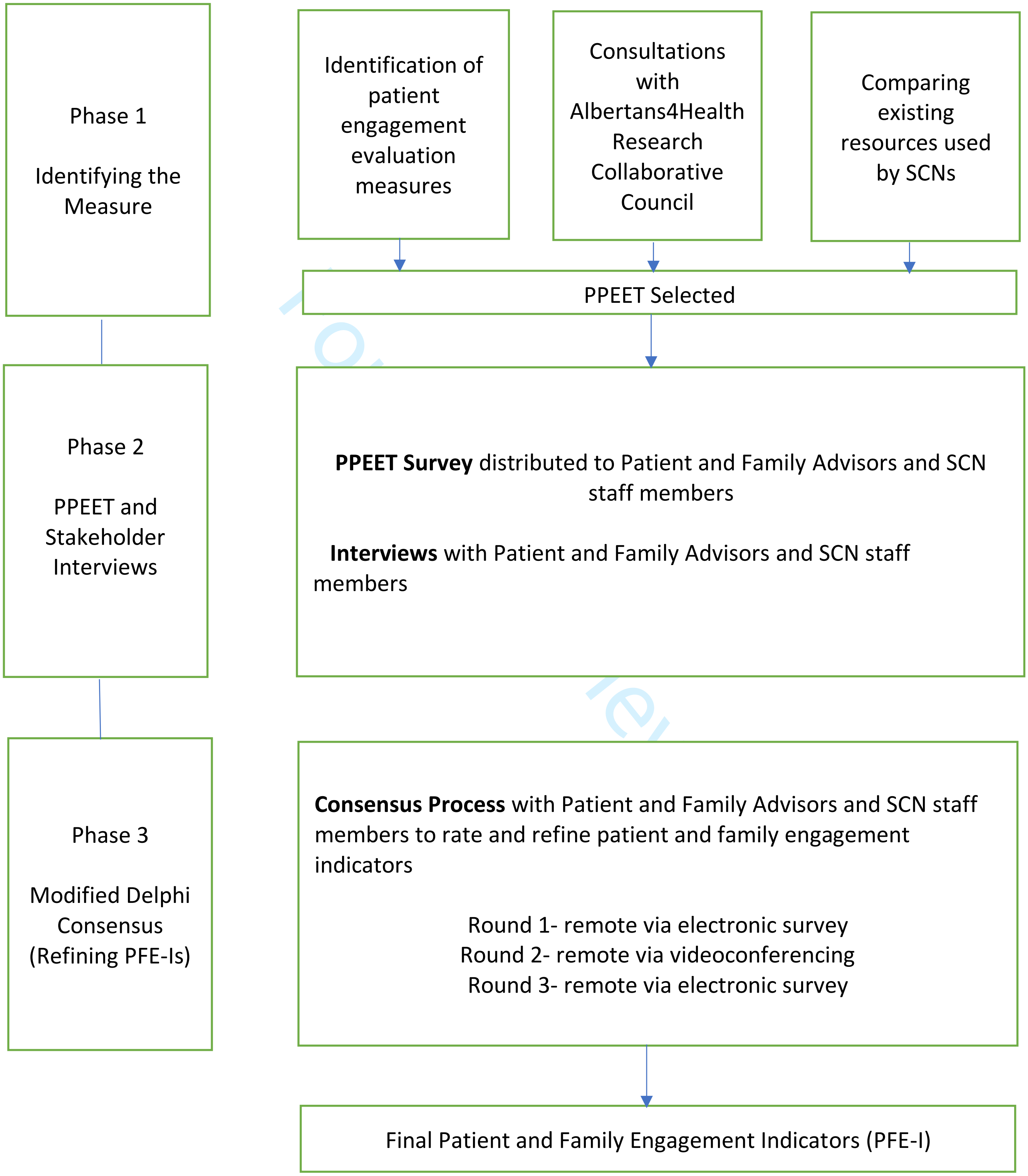
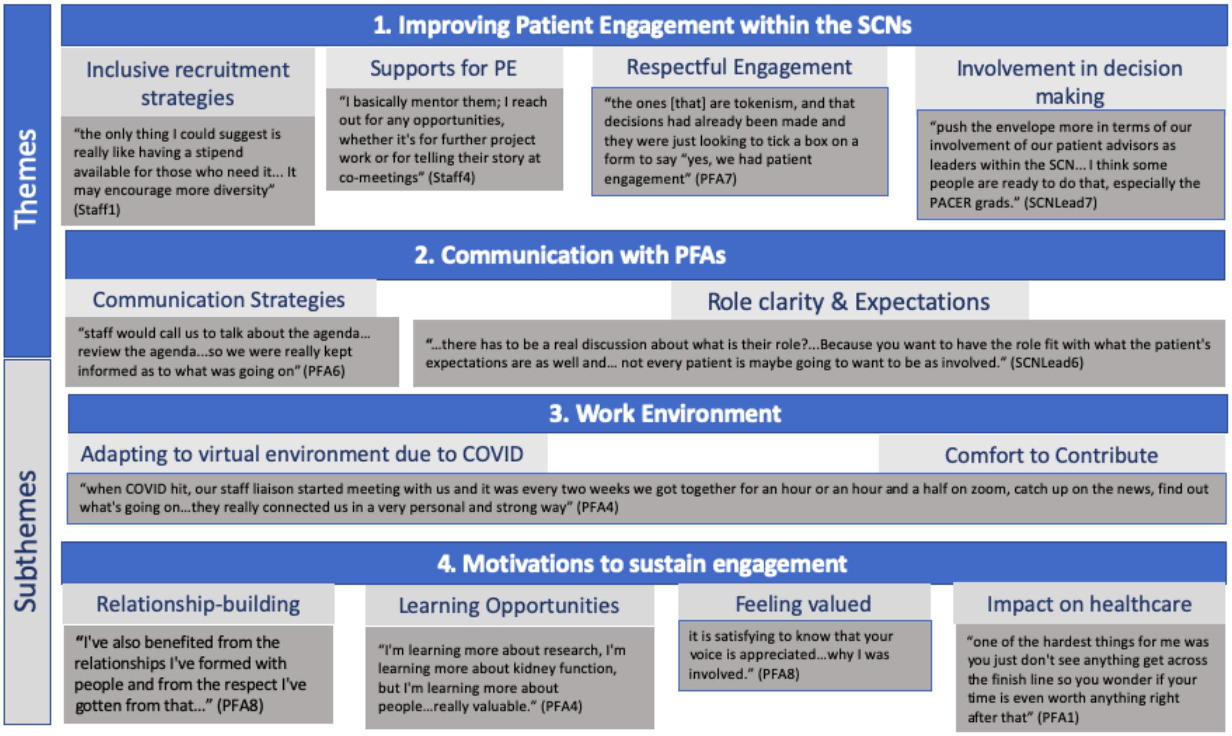


Figure 1. An overview of the program of research on the development of patient and family engagement indicators

Figure 2. Overview of themes and sub-themes identified from interviews with PFAs and SCN staff



1. Improving Patient Engagement within the SCNs

Inclusive recruitment strategies

"the only thing I could suggest is really like having a stipend available for those who need it… It may encourage more diversity" (Staff1)

Supports for PE

"I basically mentor them; I reach out for any opportunities, whether it's for further project work or for telling their story at co-meetings" (Staff4)

Respectful Engagement

"the ones [that] are tokenism, and that decisions had already been made and they were just looking to tick a box on a form to say "yes, we had patient engagement" (PFA7)

Involvement in decision making

"push the envelope more in terms of our involvement of our patient advisors as leaders within the SCN… I think some people are ready to do that, especially the PACER grads." (SCNLead7)

2. Communication with PFAs

Communication Strategies

"staff would call us to talk about the agenda… review the agenda…so we were really kept informed as to what was going on" (PFA6)

Role clarity & Expectations

"…there has to be a real discussion about what is their role?…Because you want to have the role fit with what the patient's expectations are as well and… not every patient is maybe going to want to be as involved." (SCNLead6)

3. Work Environment

Adapting to virtual environment due to COVID

Comfort to Contribute

"when COVID hit, our staff liaison started meeting with us and it was every two weeks we got together for an hour or an hour and a half on zoom, catch up on the news, find out what's going on…they really connected us in a very personal and strong way" (PFA4)

4. Motivations to sustain engagement

Relationship-building

"I've also benefited from the relationships I've formed with people and from the respect I've gotten from that…" (PFA8)

Learning Opportunities

"I'm learning more about research, I'm learning more about kidney function, but I'm learning more about people…really valuable." (PFA4)

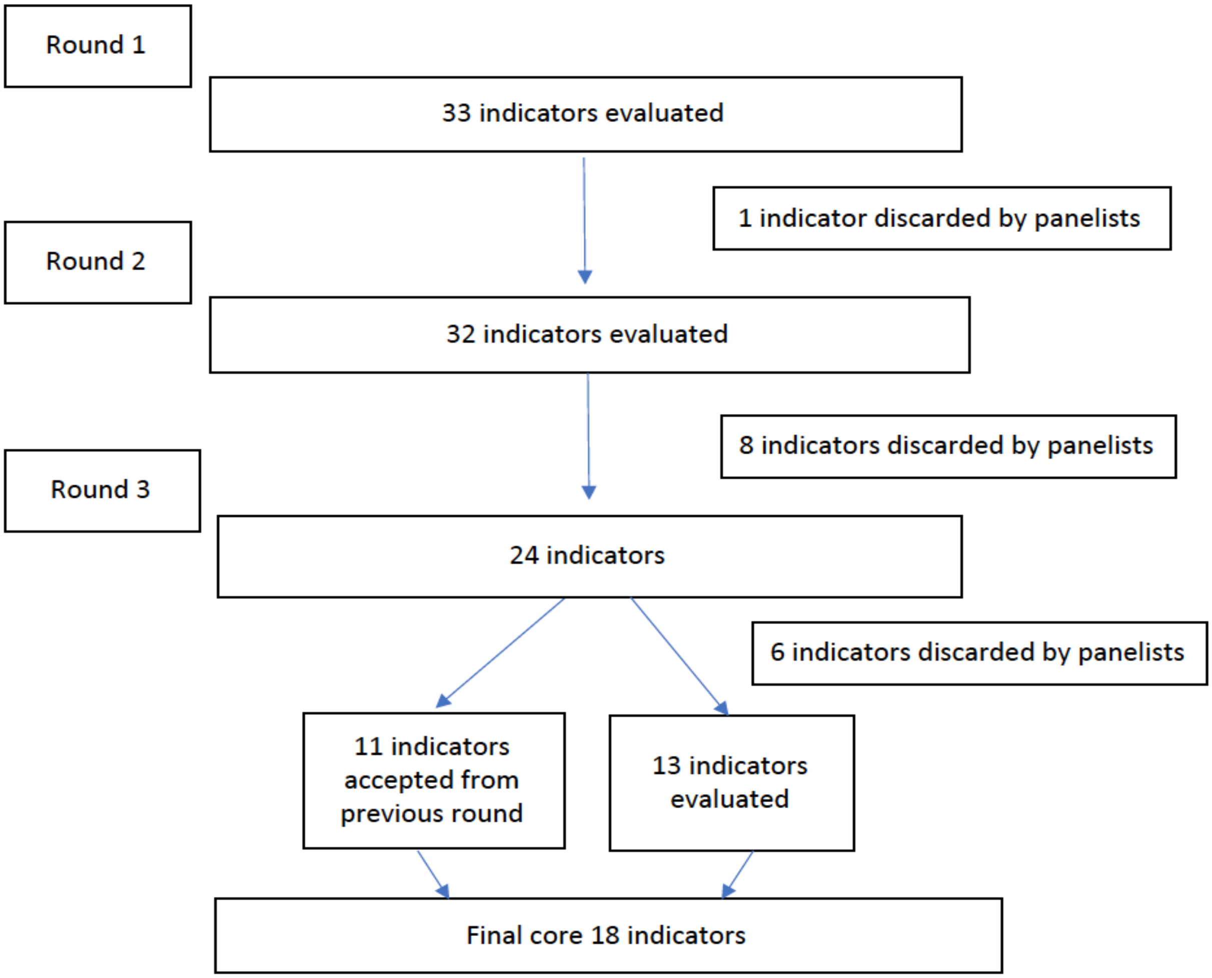
Feeling valued

it is satisfying to know that your voice is appreciated…why I was involved." (PFA8)

Impact on healthcare

"one of the hardest things for me was you just don't see anything get across the finish line so you wonder if your time is even worth anything right after that" (PFA1)

Figure 3. A flow chart of the PFE-Indicators Modified Delphi Process



Evaluation of Patient Engagement in the SCNs: Interview Guide

Interview Guide

1. How long have you been or were you involved with the SCNs?
2. Why did you decide to get involved in the SCNs?
3. How well was information about the patient and family advisor role communicated to you when you began your involvement with the SCNs? (*Was the purpose of patient/family engagement clear? Did you understand your role*?)
4. Can you describe how you have been involved?

   Probes: *What was your role? How have you contributed?*
5. On a scale of 1-10, with 1 being not good at all, and 10 being excellent, how would you rate the way the SCN team (clinicians, researchers, patient partners) works(ed) together?

   Probes*: Please comment on the way the research team worked together (clinicians, researchers, patient advisors)*

   How were expectations/instructions communicated?

   How comfortable were you in contributing?
6. Would you change anything regarding your involvement with the SCNs? (*e.g. time commitment, expectations, deadlines etc.*) / (**if project has ended**): If you could do it again, what would you change?
7. Sometimes there are challenges when researchers, patients, and other stakeholders work together. Have you encountered any challenges with your involvement in the SCNs?
8. Thinking about your contributions so far, what impact do you think you have had on SCN work?

   (considering both short- & long-term impacts, outputs of this work)

   Probes*: Impact of your involvement to this specific research project? To health research in general?*
9. How have you benefitted from your involvement?
10. When thinking about your involvement, why do you continue to do what you do?

11. What do you need to strengthen your involvement?
12. What has been your experience working with teams virtually?

    Probes*: Did you feel like you could contribute, ask questions, raise concerns?*
13. Based on your experience, do you have any suggestions for improvements that SCN teams could make when working with patient and family advisors?

14. Do you have any other comments/observations about your experience?

APPENDIX II- Patient and Family Engagement Indicators

Indicator Name	**Numerator**	**Denominator**
1. Enough information about the role	Number of PFAs who responded agree or strongly agree to having enough information about their role	Total number of PFAs responding to this question
2. Clear understanding of the purpose of the SCN that I am a part of	Number of PFAs who responded agree or strongly agree to having a clear understanding of the purpose of the SCN they are a part of	Total number of PFAs responding to this question
3. Able to express views freely	Number of PFAs who responded agree or strongly agree to being able to express their views freely	Total number of PFAs responding to this question
4. PFAs have supports available for engagement	Number of PFAs who responded agree or strongly agree to having supports (i.e. technology, travel) available for engagement	Total number of PFAs responding to this question
5. AHS Resources for Patient Engagement are useful for partnering with patient and family advisors (for PFAs)	Number of PFAs who responded agree or strongly agree that AHS resources* for partnering with patient and family advisors are useful * AHS Guidebook for engaging patient and family advisors	Total number of PFAs responding to this question
6. Involvement of PFAs make a difference in the work of SCNs (answered by PFAs)	Number of PFAs who responded agree or strongly agree to the statement that involvement of PFAs make a difference in the work of SCNs	Total number of PFAs responding to this question
7. Involvement of PFAs make a difference in the work of SCNs (answered by SCN staff)	Number of SCN staff who responded agree or strongly agree to the statement that involvement of PFAs make a difference in the work of SCNs	Total number of SCN staff responding to this question
8. SCNs take the feedback provided by PFAs into consideration (answered by PFAs)	Number of PFAs who responded agree or strongly agree to the statement that SCNs take the feedback provided by PFAs into consideration	Total number of PFAs responding to this question
9. SCNs take the feedback provided by PFAs into consideration (answered by SCN staff)	Number of SCN staff who responded agree or strongly agree to the statement that SCNs take the feedback provided by PFAs into consideration	Total number of SCN staff responding to this question
10. Individuals engaging in SCN teams represent a	Number of PFAs who responded agree or strongly agree that individuals engaging in the	Total number of PFAs responding to this question

broad range of perspectives (answered by PFAs)	SCN teams represent a broad range of perspectives	
11. Individuals engaging in SCN teams represent a broad range of perspectives (answered by SCN staff)	Number of SCN staff who responded agree or strongly agree that individuals engaging in the SCN teams represent a broad range of perspectives	Total number of SCN staff responding to this question
12. Individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together (answered by PFAs)	Number of PFAs who responded agree or strongly agree that the engagement was respectful and sincere to working together	Total number of PFAs responding to this question
13. Individuals engaging in SCN teams perceive the engagement as respectful and sincere to working together (answered by SCN Staff)	Number of SCN staff who responded agree or strongly agree that the engagement was respectful and sincere to working together	Total number of SCN staff responding to this question
14. PFAs work together with SCN staff to design SCN projects	Number of PFAs who responded agree or strongly agree that they work together with SCN staff to design SCN projects (e.g. in priority setting & planning, development of proposals)	Total number of PFAs responding to this question
15. SCN staff work together with PFAs to design SCN projects	Number of SCN staff who responded agree or strongly agree that they work together with PFAs to design SCN projects (e.g. in priority setting & planning, development of proposals)	Total number of SCN staff responding to this question
16. PFAs work together with SCN staff to conduct SCN projects	Number of PFAs who responded agree or strongly agree that they work together with SCN staff to conduct SCN projects (e.g. collaborate in data collection, analysis/interpretation, advising on project as it is carried out)	Total number of PFAs responding to this question
17. SCN staff work together with PFAs to conduct SCN projects	Number of SCN staff who responded agree or strongly agree that they work together with PFAs to conduct SCN projects (e.g.	Total number of SCN staff responding to this question

	collaborate in data collection, analysis/interpretation, advising on project as it is carried out)	
18. PFAs work together with SCN staff to disseminate SCN projects	Number of PFAs who responded agree or strongly agree that they work together with SCN staff to disseminate SCN projects (e.g. co-presenting at conferences, sharing work widely)	Total number of PFAs responding to this question

Discarded Indicators from Round 2

Indicator	Comments from panelists
1. PFAs being meaningfully engaged virtually	Different concepts – meaningful engagement & virtual, difficult to measure & action Group suggestion: incorporate this indicator into others already listed
2. PFAs have a supportive working environment to contribute to the engagement initiative	Repetitive indicator, and confusion regarding how supportive working environment is defined
3. SCNs have mentorship opportunities for PFAs	Confusion regarding who the mentor would be, could be incorporated in another indicator
4. Each SCN has an explicit strategy or framework for patient engagement	Seems more like a policy than an indicator doesn't need to be an indicator that is surveying staff
5. Each SCN is at the stage of established/making some progress in engagement with patient and family advisors	Wording is confusing and hard to understand
6. Each SCN has explicit strategies for recruiting patient and family advisors, depending on the engagement initiative	More policy related, and not informing what needs to be improved
7. There are resources (documents, guidelines) available to SCN Staff for PFA engagement	Redundant
8. Each SCN prepares reports that summarize the contributions from patient and family advisor engagement initiatives	Discarded in round 1 (Median rating on overall importance was 5)
9. The SCN is achieving its stated objectives	Too broad and difficult to measure Would need to clarify what the objectives are

Table 1

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	**Interviewer/facilitator**	**Which author/s conducted the interview or focus group? (pg.6)** members of the research team (SZ, GW, SA, TM)
2.	**Credentials** qualitative research background, SA (MSc) and TM (PhD) training , 2 other members were patient partners with PaCER training (SZ, GW)	**What were the researcher's credentials? *E.g. PhD, MD* (pg.6)**
3.	**Occupation** researchers and patient partners	**What was their occupation at the time of the study? (pg.6)**
4.	**Gender** female	**Was the researcher male or female? (pg.6)**
5.	**Experience and training**	**What experience or training did the researcher have? (pg.6)**
Relationship with participants		Recruitment was supported by members of the research team (GW, MM, JP, and TW), working with and leading the AHS SCNs.
6.	**Relationship established**	**Was a relationship established prior to study commencement? (pg.4)**
7.	**Participant knowledge of the interviewer** Individuals from SCNs were contacted via email to provide information about the study and who would be conducting the interviews	**What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research* (pg.4)** and 5
8.	**Interviewer characteristics**	**What characteristics were reported about the interviewer/facilitator? e.g. *Bias,***

	researchers and patient partners are working in patient-oriented research teams and engage patient partners as members of the research team.	***assumptions, reasons and interests in the research topic***
Domain 2: study design		
Theoretical framework		
9.	**Methodological orientation and Theory** this study is informed by the CIHR Patient Engagement Framework	**What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis* (pg.4)**
Participant selection		
10.	**Sampling** purposive- SCN leadership, staff members and patient and family advisors	**How were participants selected? *e.g. purposive, convenience, consecutive, snowball* (pg.4)**
11.	**Method of approach** email	**How were participants approached? e.*g. face-to-face, telephone, mail, email* (pg.4)**
12.	**Sample size** 96 participants responded to the survey. Of those 26 participated in interviews	**How many participants were in the study? (pg.9)**
13.	**Non-participation**	**How many people refused to participate or dropped out? Reasons? (N/A)**
Setting		
14.	**Setting of data collection** online	**Where was the data collected? e.*g. home, clinic, workplace* (pg.4)** and 5

15.	**Presence of non-participants**	**Was anyone else present besides the participants and researchers? (No)**
16.	**Description of sample** 51 PFAs and , 31 SCN staff, and 14 SCN leadership	**What are the important characteristics of the sample? *e.g. demographic data, date* (pg.9)**
Data collection		
17.	**Interview guide** interview guide was co-developed patient and family partners and research team members. Interview guide included in appendix	**Were questions, prompts, guides provided by the authors? Was it pilot tested? (pg.6)**
18.	**Repeat interviews**	**Were repeat interviews carried out? If yes, how many? (no)**
19.	**Audio/visual recording** yes	**Did the research use audio or visual recording to collect the data? (pg.6)**
20.	**Field notes**	**Were field notes made during and/or after the interview or focus group? (yes)**
21.	**Duration** interviews ranged from 25 to 94 mins	**What was the duration of the interviews or focus group? (pg 9)**
22.	**Data saturation** (table 2 presents the full list of themes. From our analysis those were the themes identified and capture the experiences and views of our participants. We didn't identify new information when coding, and reviewing transcripts)	**Was data saturation discussed?**
23.	**Transcripts returned**	**Were transcripts returned to participants for comment and/or correction? (no)**
Domain 3: analysis and findings		

Data analysis	Qualitative researcher (SA) followed the six-step thematic analysis Braun & Clarke method,(21) and had peer debriefing sessions at different stages of the analysis with MS to discuss themes and subthemes identified	
24.	**Number of data coders**	**How many data coders coded the data? (pg.6)**
25.	**Description of the coding tree**	**Did authors provide a description of the coding tree? (pg.6)**
26.	**Derivation of themes** derived from the data using inductive and deductive coding strategies	**Were themes identified in advance or derived from the data? (pg.6)**
27.	**Software** Nvivo	**What software, if applicable, was used to manage the data? (pg.6)**
28.	**Participant checking** yes, through meetings with SCN teams and via round 3 of the consensus process	**Did participants provide feedback on the findings? (pg.5)**
Reporting		
29.	**Quotations presented** presented within table 2	**Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number* (pg.13-16)**
30.	**Data and findings consistent**	**Was there consistency between the data presented and the findings? (pg.10-16)**
31.	**Clarity of major themes**	**Were major themes clearly presented in the findings? (pg.10-16)**
32.	**Clarity of minor themes** minor themes weren't identified, but rather sub themes	**Is there a description of diverse cases or discussion of minor themes? (pg.10-16)**