Pediatric Patient and Family Advisory Councils: A Guide to Their Development and Ongoing Implementation

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Abstract

Background: Patient and family engagement is increasingly recognized in the care of children with complex health conditions. Through the implementation of Patient and Family Advisory Councils (PFACs), health-care institutions are working to improve patient care by nurturing partnerships among patients/families, managers, and clinicians. Despite the potential for PFACs, empirical research about their implementation remains scarce. **Objective:** To address this gap, this study explored the recruitment, retention, and implementation strategies used by Canadian PFACs. **Design:** We used a qualitative descriptive design. **Participants:** We interviewed 10 spokespersons from Canadian PFACs. **Results:** We found themes within 2 stages of implementation. The first stage, getting PFACs started, included 4 themes: (1) using evolving recruitment methods, (2) preparing for effective participation, (3) ensuring diversity within PFACs, and (4) preparing terms of reference. The second stage involved strategies to support ongoing PFACs implementation and included 1 overall theme: facilitating optimal PFACs participation. The underlying link between themes was that establishing/maintaining PFACs is an ongoing learning curve. **Conclusion:** Our findings have the potential to inform new and existing PFACs.

Keywords

patient and family advisory councils, pediatric, children

Introduction

Approximately 15% to 18% of North American children have complex health conditions (CCHCs), which not only affect their health but also their quality of life (1). Children have complex health conditions may have 1 or more chronic physical, mental, behavioral, or developmental condition(s) that require health services from multiple care providers (2). Parents of CCHCs are usually the managers of their care and their advocates (3). Consequently, it is necessary for them to be informed about and engaged in their child's care.

Patient and family engagement refer to the process through which these individuals are included in the diagnostic, treatment, and administrative processes (4). Pediatric Patient and Family Advisory Councils (PFACs) are groups bringing patients and families together to provide guidance on how to improve the patient/family experience. Involvement in these councils is one way to ensure patients and family members are engaged with their health-care experience. Published literature on pediatric PFACs is scarce, particularly around the development and ongoing implementation of PFACs.

As such, this study aimed to fill this gap by examining the development and implementation of PFACs throughout Canada. Given the increasing use of PFACs related to health service delivery for children, along with the research team's expertise in this area, the focus of this study is on pediatric PFACs. This study addressed the following research question: What are the recruitment, retention, and engagement strategies of PFACs that have been used in their development and ongoing implementation? Our article aimed to

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Table 1. Description of the Patient and Family Advisory Councils (PFACs).[a]

Participant's Role on PFAC	Number of Members	Scope of Council	Type of Advisory Council
1 (Staff)	25-30	Provincial	Patient and Family Advisory Council with Pediatric Representation
2 (Staff)	14	Hospital based	Family Advisory Council within Pediatric Care
3 (Staff)	12	Hospital based	Patient and Family Advisory Council with Pediatric Representation
4 (Staff)	15-20	Hospital based	Family Advisory Network and Child Advisory Council
5 (Staff)	NA	Health Region	Parent Advisory Council
6 (Staff)	15	Hospital Based	Two entities: Adult Patient and Family Advisory Council & Pediatric Children's Advisory Council
7 (Staff)	8-10	Hospital based	Children and Youth Council &
	20	Hospital based	Family Advisory Council
8 (Staff)	10-20	Patient Safety	Families and Patients as Partners Committee
9 (Staff)	20	Hospital based	Patient and Family Advisory Committee
10 (Parent)	5	Hospital based	Family Advisory Forum

Abbreviations: NA, none available; PFAC, Patient and Family Advisory Councils.
[a]Participant 5 did not report the number of PFAC members.

inform new and existing pediatric PFACs and combined adult and pediatric PFACs in the areas of recruitment, retention, and engagement.

Methods

We used a qualitative descriptive design (5) to explore the research question. This method allows for the systematic interpretation of data through the extraction of themes that highlight important information discussed by participants throughout the interviews. Ethics approval was obtained from the Mount Allison University Research Ethics Board.

Sample

The participants consisted of a convenience sample of spokespersons of Canadian PFACs with a pediatric component that we obtained through a Google search of potential institution websites. To be as comprehensive as possible, there were no restrictions in terms of the populations the PFACs served. However, to be included, they were required to include the pediatric voice within their PFAC, either through pediatric involvement or through the inclusion of parents or caregivers of pediatric patients. The scope of the PFACs included in this study is represented in Table 1.

Data Collection

We contacted potential participants by e-mail and invited them to participate in the study. We interviewed participants individually by phone between January and February 2017. The interviews, which were guided by a semistructured interview guide with 13 open-ended questions, lasted approximately 30 minutes. We audio-recorded and transcribed the interviews to reduce the occurrence of errors or misinterpretations.

Data Analysis

After transcribing the interviews, we analyzed the data using an inductive thematic analysis approach (5), which allowed us to identify, analyze, and report themes within the data. We followed the 6 phases of inductive thematic analysis: (1) familiarizing the self with data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) providing the report (5). Preliminary codes and themes were generated to guide the subsequent analysis while moving through Braun and Clark's 6 phases (5).

Results

As shown in Table 1, there were 10 spokespersons from various Canadian PFACs with a pediatric component. Table 1 illustrates each participant's position within their PFAC, the number of members within the PFAC, and the scope and type of the council. Findings regarding the recruitment, retention, and engagement of participants during the development and implementation of PFACs are presented below. Findings indicated several themes within 2 stages of implementation. The first stage involves getting started, and the second stage involves supporting the ongoing implementation.

Stage 1: Getting Started—Necessary Steps for Creating the PFAC

When creating a PFAC, the first stage involves getting started and includes the following 4 themes: (1) using evolving recruitment methods, (2) preparing for effective participation, (3) ensuring diversity within the PFAC, and (4) preparing terms of reference.

   Theme 1: Using evolving recruitment methods. Before establishing a PFAC, participants stated that it is

Table 2. Recruitment Methods of the Patient and Family Advisory Councils.

Strategies	Definition
Verbal communication	Discussions carried out between or by individuals to promote joining the institution's PFAC. These can be formal presentations or informal discussions
Visual promotion	Any visual representation of the PFAC that opens information channels for potential members. These can be internal and/or external to the organization
Virtual communication	This refers to any of electronic methods to inform or refer potential members to the PFAC
Specific referrals	When a potential PFAC member is singled out or identified individually as someone who might be interested in participating, he or she is provided information about joining based on this identification. These potential PFAC members can be staff, patient, or self-referrals
Personal interest	This can be recruitment for a specific project due to an individual's knowledge in the area or the interest in joining the PFAC due to a drive to make a difference in a specific area
Staff and PFAC collaboration	This refers to the partnership between staff and existing PFAC members when recruiting potential new members
Group accommodations	This refers to any accommodations that are made on behalf of or for the group to allow PFAC members and potential members to have as easy access to participation as possible to make membership a viable option for as wide a variety of individuals as possible
Combination of methods	This is the strategic use of multiple strategies to recruitment mentioned above

Abbreviation: PFAC, Patient and Family Advisory Councils.

necessary to understand that recruitment of members is a "work in progress" and methods need to be adapted as the PFAC and its institution progresses. Participants stressed the importance of utilizing as many recruitment methods as possible when developing a PFAC. These methods could include public recruitment through discussions, advertisements, and virtual communication such as e-mails. Participants reported the use of "marketing material (newspapers, brochures, newspaper ads) and posters" and "e-mails to staff members throughout the program to see if there is anybody they think would be interested in joining the PFAC" as well as an "external web page for people to express their interest." Table 2 illustrates a more detailed overview of potential recruitment strategies as identified by the participants.

Theme 2: Preparing for effective participation. Before establishing the PFAC, participants also reported the importance of putting proper training in place so that PFAC members can effectively participate within their organization. It was suggested that this training should be available to all members, including pediatric representatives. Training was reportedly completed using an orientation manual that includes "expectations, ways to stay engaged and connected, legislative requirements like accessibility and privacy" as well as in person orientation on "how they can tell their story, teaching them about the organization and what they can expect." To promote participation, participants also expressed the importance of setting a standard for continuous communication that is established from the outset of the PFAC. As one participant stated, "if you are going to bring patients and families in, bring them in early and bring them in right at the design phase." This will also address any gaps in knowledge between staff and PFAC members, as PFAC members can be provided with "education and medical literacy understanding" so as not to be overwhelmed and to effectively contribute to the council.

Theme 3: Ensuring diversity within the PFAC. Participants repeatedly discussed the importance of ensuring that the PFAC is representative of the population being served. Therefore, in a pediatric setting it was suggested that this would include the pediatric voice as well as various ethnic, religious, geographic, and socioeconomic backgrounds. It was stated that the PFAC should "look like your waiting room." Some strategies utilized to promote diversity within the PFAC include targeted recruitment for members of underrepresented groups; recruitment of individuals who work with members of minority and underrepresented groups; provision of certified interpreter services that allow individuals with language barriers to effectively and efficiently participate; virtual participation options for those who may not always be able to physically attend meetings; and finally, meeting with individual groups outside the institution to gather information from minority groups that can be brought back to the PFAC. The use of standardized diversity surveys where PFAC members could self-report their ethnic and cultural backgrounds was also suggested to determine whether the PFAC is representative of the population being served. Diversity within the council would also help ensure that varying perspectives are heard and that there are "open, transparent discussions around the group" so as not to have "all white, middle class . . . retired individuals." Although it was acknowledged that differences in personal beliefs and ideas may cause conflict among members, participants stressed the importance of ensuring all these beliefs and ideas are identified and

respected, as they bring more diverse priorities and concerns to light.

Theme 4: Preparing terms of reference. Many PFACs have produced terms of reference documents that establish regulations around membership and recruitment. It was suggested that the terms of reference should be living documents that provide guidelines to PFAC members, including how to "recruit and retain members and outline how they would be involved in the council." It was recommended that the members should be the ones who "choose when the meeting dates are going to be, how they want to set up the council." The terms of reference may also include guidelines around the term of membership within the PFAC, which most participants reported as being between 2 and 3 years with the opportunity to return for a second term. Any rewards and or benefits, including intrinsic rewards and "compensation to minimize expenses incurred as a result of their membership," should also be included in the terms of reference.

Participants also discussed the importance of ensuring that the PFAC effectiveness was continuously being evaluated so that it could evolve with the health-care institution. It was suggested that these evaluation strategies be included in the terms of reference and may be informal, such as discussions at each meeting, along with more formal annual evaluations to look at "what's working for them and what's not working for them." When collecting feedback on the effectiveness of their PFAC, participants found that it was important to ensure that members "get the big picture of where [the project] fits within where the organization is going."

Stage 2: Supporting Ongoing Implementation

The second stage involves strategies to support the ongoing implementation and includes the fifth theme in this study: strategies to facilitate optimal PFAC participation.

Theme 5: Facilitating Optimal PFAC Participation. Many participants noted the importance of ensuring that members remain engaged in the PFAC. One way to do this was to continuously determine "what's next" in terms of projects for the PFAC. They also suggested that communication strategies both between meetings and after the completion of their term of membership can also be used to ensure that this knowledge is passed on to other PFAC members. These could include a "formal mentorship role so that they can help transfer knowledge about a certain project." For example, incoming members could be paired with new members to help them integrate within the PFAC. They could also ensure "minutes from the last meeting are distributed with the next meeting's agenda" and "e-mail

communication between meetings" to keep everyone informed. This was suggested in light of the fact that a major barrier to participation was that members are often "still actively engaged in the healthcare system and have children who become ill and are hospitalized." Therefore, "sometimes illness can get in the way of some of the commitments," and meetings can be missed.

When encouraging PFAC participation, participants reported the importance of taking travel into consideration, as this may limit attendance at meetings if individuals are required to travel a long distance to attend meetings. Video or teleconferencing technologies were suggested to overcome this obstacle. This ties into the idea of minority representation within the PFAC as well by acknowledging and addressing obstacles to participation that may differ across groups.

After leaving the PFAC, individuals can also be asked to "list areas of interest so if something came up and we needed a Patient and Family Partner . . . we could pull your name," which aids in promoting continuous transfer of knowledge from former to new PFAC members. Finally, it was also suggested that institutions build "in a requirement that if anyone requests engagement of advisors, they have a requirement to loop back and share what they've done with the feedback" to the PFAC so that members are kept informed and do not feel as though their participation is going to waste.

Discussion

This study aimed to fill a gap in the scarce literature around pediatric PFACs, specifically addressing the research question: What are the recruitment, retention, and engagement strategies of PFACs that have been used in their development and ongoing implementation? The study uncovered lessons learned for the development of new PFACs and ongoing implementation of existing PFACs. Overall, the overarching theme that emerged is that the development and implementation of a PFAC is an ongoing evolution and that a partnership between patients/families and staff is critical. Below are recommendations for new PFACs to utilize during the development process.

Recommendation 1: Fostering Ongoing Recruitment. This study found that effective recruitment of members involves ongoing work that requires a combination of methods, which varied by institution and the population being targeted. The latter finding corroborated Ponte et al's (6) results about the adult PFAC within the Dana-Farber/Brigham and Women's Cancer Centre, which emphasized the constantly evolving nature of recruitment in which one must engage existing and potential members efficiently while keeping in mind that changes to

the institutions' structures could impact their PFACs.

Recommendation 2: Creating an Orientation Manual. It is necessary to acknowledge that PFAC members may not have the same medical or health service delivery knowledge base as institution staff. As our data suggested, an orientation manual for new PFAC members could be informative to support the orientation process. Furthermore, the use of a Terms of Reference, within the orientation manual, would allow for easily accessible living documents, including all PFAC guidelines and reference tools developed by PFAC members and institution staff. This document could also include guidelines for staff on how to effectively engage patients as found by Ponte et al (6). The Terms of Reference and the Orientation manual would need to be developed in partnership between staff and PFAC members to ensure the inclusion of relevant material and differing levels of medical and institutional knowledge.

Recommendation 3: Addressing Barriers to Participation. It is necessary to acknowledge that barriers to participation differ among individuals. Participants also highlighted the importance of taking into consideration travel challenges that may inhibit members from attending meetings. To overcome these barriers, PFACs could explore the use of video and teleconferencing technologies for members who are not always able to attend meetings face-to-face. This study also indicated that varying levels of membership might allow members who cannot commit to full-time membership to participate in a specific project without the full-time commitment of joining the PFAC. This could provide PFAC participants with different opportunities to contribute to having a direct influence on the policies and programs relevant to them (7).

One additional major barrier to participation in PFACS identified in this study is that members of PFACs are caregivers to children with complex needs themselves. This barrier could be overcome by offering members the option of pausing their term and completing it at a later date to aid in prioritizing the health of their loved ones; allowing them to participate at the level they feel is appropriate at the time.

Strengths and Limitations

Although timely, this study was limited by a small sample size. However, given the relatively small number of pediatric PFACs in Canada and the study's rich qualitative data, our results would likely be transferable across a range of Canadian pediatric institutions and other organizations. Future research could involve interviews with different participants within the same PFAC, particularly patient representatives,

as well as across various PFACs to see whether the results would remain consistent.

Conclusion

This study explored the recruitment, retention, and implementation strategies used by 10 Canadian PFACs with a pediatric component to help provide guidelines around the effective implementation of PFACs. The link that emerged between all the themes is that developing and implementing a PFAC is an ongoing evolution that should occur as a partnership between PFAC members and care team staff, including institution management.

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