



The Provincial Patient and Family Group (PFG) for Alberta Health Services Transforms How Care is Planned and Delivered: A Decade of Experience

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Abstract

Although many health care organizations made significant headway in building relationships with patients and families at the point of care, there continues to be opportunities to partner with them at the system level. One such opportunity is the Patient and Family Advisory Group (PFG) at Alberta Health Services (AHS). Developed 10 years ago as a formal group of patient and family volunteers, PFG has provided advice on over 350 key organization initiatives, including the Patient First Strategy and the Family Visitation policies and guidelines. Through the formal partnership with PFG and its members who bring their lived experiences with the health system and its services, AHS has demonstrated its commitment to designing and improving services with the user in mind. Now entering its second decade, PFG, supported by AHS leadership, continues to explore new strategic approaches with internal and external stakeholders to reinforce the importance of Patient and Family-Centered Care.

Keywords

patient and family advisors, patient and family engagement, patient and family partnership, patient and family-centered care

Introduction

“Where are the patient and family voices in healthcare?”

“Why does engaging patients and families in healthcare matter?”

Not new questions or concepts today but looking back 10 to 15 years, most health care organizations were just beginning their exposure to a shift in thinking about these questions, and how best to involve patients and families in their own care or more broadly in health care planning. This shift from thinking to actually involving patients and families in different aspects of health care has not been an easy journey, particularly as the process for involving them is complex and needs to be clearly described for and understood by health care leaders, providers, and patients/families. There is also the need for evidence to demonstrate that this shift in having patients and families involved as partners in health care decisions has resulted in improved experiences and outcomes.

Some studies confirmed a growing interest in the involvement of patients and families in health care discussions and decisions including “engagement-capable environments” (1-3) and the readiness of groups to apply the International Association of Public Participation (IAP2) continuum (4) of inform, consult, involve, collaborate, and empower. There was a particular interest in broadening the scope of practice for patients and families from being informed to being empowered. To further this movement the Institute for Patient- and Family-Centred Care (PFCC) introduced the concept of PFCC focusing on 4 key principles of dignity and

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respect, information sharing, participation, and collaboration (5). Patient- and Family-Centred Care positioned patients and families to not only participate as partners in their own health care but also to be meaningfully engaged with health care leaders and providers in health care safety and quality improvement (6). “True change occurs only when patients and families are equal collaborators in the wide range of decisions that are made in health care settings, from establishing vision for the organization and design of the facilities to hiring, policy development, quality improvement efforts, and bedside care” (7).

The infusion of different tools, resources, examples of why and how to engage or partner with patients and families, as well as overcoming barriers and challenges (5,8-10), incentivized health care staff, leaders, and patients/families to support organizations to become “engagement-capable” and to adopt the practices of IAP2 (4) and PFCC (5) while questioning: “How Can We Talk about Patient-Centred Care without Patients at the Table?” (11). Having patient and family voices supported through the application of IAP2 and PFCC principles, and embedded at every level of care and decision-making has more recently become an expectation and a standard measure of a health care organization’s performance as part of accreditation (1,12). For example, patients and families have become contributing partners involved in safety and quality improvement initiatives focused on patient-centeredness (13,14). Patient and family advisory committees or councils have also been endorsed by organizations to have collective input into the development and implementation of organizational strategies, policies, research, and other initiatives (8,15-18).

Many health care organizations including Alberta Health Services (AHS) have been part of the dynamic evolution and journey regarding the engagement and partnership of patients and families in all aspects of health care. Of the many great things, AHS has to reflect on and celebrate as part of its growth and evolution over the past 10 years (19), one achievement that has been instrumental in transforming how AHS does business is that more than 1200 Patient and Family Advisors (PFAs) are embedded across AHS at most levels of health care services and programs, decision-making processes, and quality improvement practices (20). In this article, we feature the provincial Patient and Family Advisory Group (PFG) celebrating a decade of partnership and contributions.

The Historical Development, Structure, and Function of PFG

The PFG was formally established in 2010, as one of many transformative changes proposed for the newly established AHS. Just 2 years earlier in 2008, the Government of Alberta made the decision to merge 9 regional health authorities and 3 government agencies into AHS, the largest single, province-wide health system in Canada (19). The inauguration of the first PFG in 2010 introduced 20 volunteer patients

and families from across Alberta who were selected because they would bring a balanced richness and diversity of perspectives based on age, sex or gender, geography, abilities, and cultural background. In addition, as individuals and as a group, they showed commitment to share their stories of their positive and negative lived health care experiences (eg, with patient safety or harm, family visitation, in-patient, or other care received) and make suggestions for improving AHS policies and delivery of care. Since 2010 the group has expanded and 10 years later PFG consists of 30 diverse PFAs from across Alberta. A summary of timelines, key events, and activities related to PFG’s development is presented in Figure 1.

The primary purpose of the group is to bring the patient “voice” to the planning table and advise AHS on provincial-level policies, practices, and service delivery (21). The mandate for the PFG members is that they will work together to advise AHS, its senior and executive leaders, staff and physicians on provincial and organization-wide policies, practices, planning, and delivery of services. Operating from an understanding of PFCC principles and lived experiences with the health care system, PFG aims to work with AHS to ensure health care services are based on the principles of PFCC (5). It is this provincial and strategic focus, and its direct link to the AHS Executive Leadership team, which sets PFG apart from other committees, programs, projects, and other initiatives within AHS which also have patient/family advisors.

The PFG is currently cochaired by an elected PFA member and a designated member of the AHS Senior Leadership Team who is the Associate Chief Medical Officer (21). Aside from the one cochair, it should be noted that there are no other AHS staff as members on the council. However, the PFG and AHS dynamic is open, transparent, and respectful to include leaders from different areas within AHS (eg, Quality and Healthcare Improvement or QHI) as well as Vice Presidents and the President/CEO as guests or coming to PFG seeking advice on initiatives.

Up until COVID-19, PFG met in-person several times each year. Currently, the 30 advisors come together through virtual monthly meetings which are often augmented by additional virtual, just-in-time consultations, as required.

Operational support for the PFG is provided by the Provincial Engagement and Patient Experience (EPE) Department within the broader QHI portfolio. This includes the support of 4 primary staff members who provide secretariat and consultative support, and the administration and stewardship of the annual budget required to support this advisory group.

Conceptual Framework

The PFG operates from a framework codeveloped by PFG advisors and EPE staff, which highlights the significance of and steadfast commitment to the *Voice of PFG Members*. Their voice is strengthened and reinforced by 3 interconnected

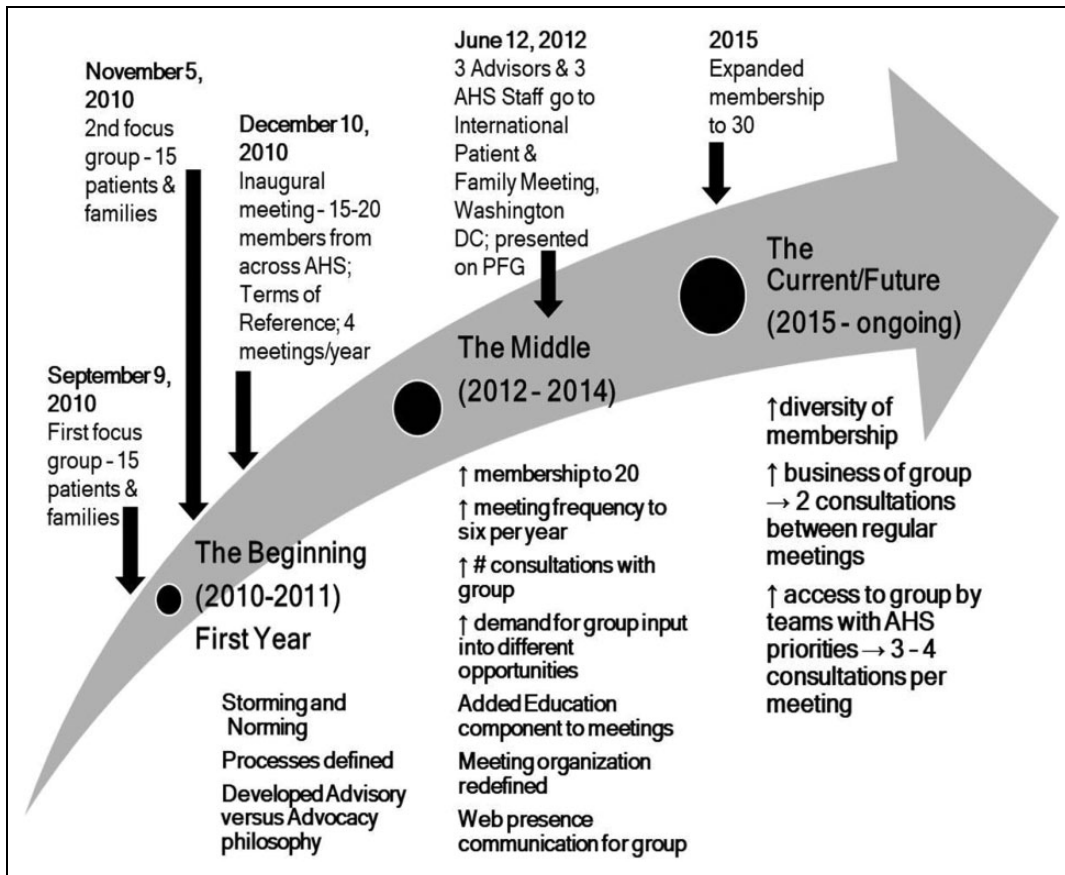


Figure 1. Timeline of events for the development and evolution of Patient and Family Advisory Group (PFG).

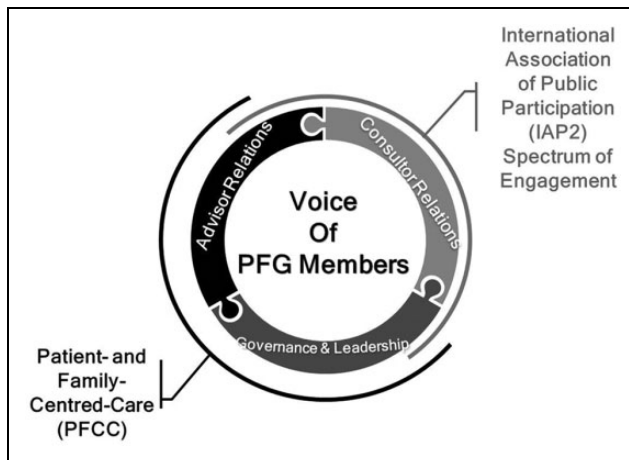


Figure 2. Patient and Family Advisory Group (PFG) conceptual operational framework.

elements: *advisor relations*, *consultor relations*, and *sound governance and leadership* (see Figure 2).

Advisor Relations involves ongoing recruitment and retention of volunteer PFAs for PFG, including activities that build capability and capacity within the group and attend to the importance of diversity and sustainability. One key aspect of PFG is that its members are aligned with rural and

urban locations across the 5 zones of AHS, as shown in Figure 3.

Advisor Relations is closely connected with *Consultor Relations*, through which PFG builds its consultation capacity and relationships with care teams or program staff (called “consultors”) within AHS who come to PFG seeking advice or feedback for their initiatives. Some of the consultors have not previously partnered with patients or families in this way. The final interconnected relationship area is the presence of *Governance and Leadership*. The involvement of many levels of leadership, from volunteer PFG Chairs to organizational executives, provide consistency and an organizational foothold to the group. With regular connections to key leaders in the organization, not only are the relationship and dynamics between these leaders and PFG enhanced but PFG is also well positioned to be meaningfully and quickly engaged to deliver on results that are timely and applicable to current system priorities (eg, including Designated Family Presence and Visitation needs during COVID-19 into subsequent practice guidelines). All relationships and practices within AHS are aligned to one or more of AHS’ Four Foundational Strategies (22)—Patient First, Our People, Innovations and Analytics, and Information Management/Information Technology. Table 1 provides a brief description of these strategies and some context for the work of the PFG.

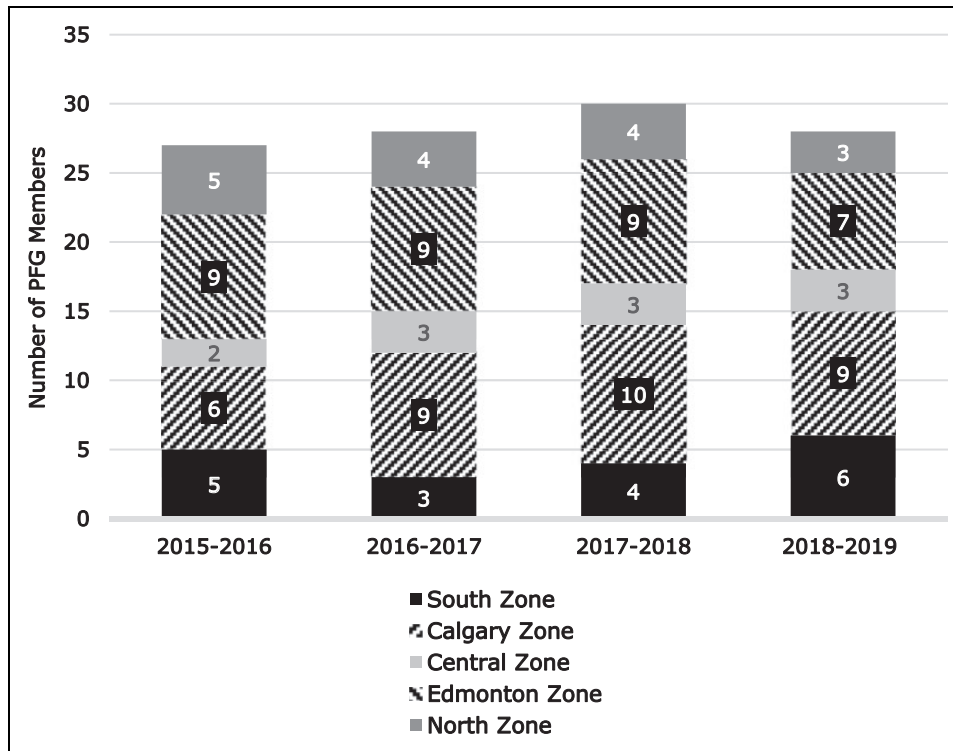


Figure 3. Patient and Family Advisory Group (PFG) membership by zone within Alberta Health Service (AHS; 2015-2019).

Table 1. The Four Foundational Strategies of Alberta Health Services – (22).^a

Strategy	Main objective
Patient first	Strengthen AHS' culture and practices to ensure patients and families are at the center of all health care activities, decisions, and teams.
Our people	Our People Strategy is about how all AHS staff, physicians, and volunteers support each other. It is about creating a culture in which everyone feels safe, healthy, and valued and can reach their full potential. Through Our People Strategy, workforce engagement will be higher, and patient and family experiences will improve as a result.
Clinical Health Research, Innovations & Analytics	Generate, share, and use evidence in the delivery of care to improve patient outcomes and to solve the complex challenges affecting the health system.
Information Management/ Information Technology	Making the right information available to the right people at the right time across the health system, so that providers and patients across the province have access to complete information at the point of care and to learn from in the future.

Abbreviation: AHS, Alberta Health Service.

^aThe AHS Four Foundational Strategies were officially adopted in 2015.

Encompassing the 3 connected elements and the voice of PFG members in Figure 2 are the 4 principles of PFCC (7), and the 5 levels of engagement described by the IAP2 (4). The PFG approaches all its work related to its goals, including consultations, from these foundational principles and levels of public engagement.

Challenges and Successes—Striving for Positive Outcomes

As with most dynamic and evolving groups, the PFG experienced its share of challenges over its 10 years of existence, most resolved through open discussions among the members

and/or with AHS leadership. Also to be expected, the diversity of the PFG brought out the differences of opinions and experiences regarding various aspects of their roles, responsibilities, and overall function within AHS. For example, in the first year, the advisors struggled with articulating the PFG philosophy and purpose, as alluded to in Figure 1. Through strong facilitation, the group developed a philosophy of primarily focusing on advisory work instead of advocacy and activism. This decision helped to frame the PFG terms of reference which set out the group's purpose, structure, roles, and responsibilities. Financial support for PFG was another area considered challenging for advisors and AHS leadership. All agreed that advisors should be

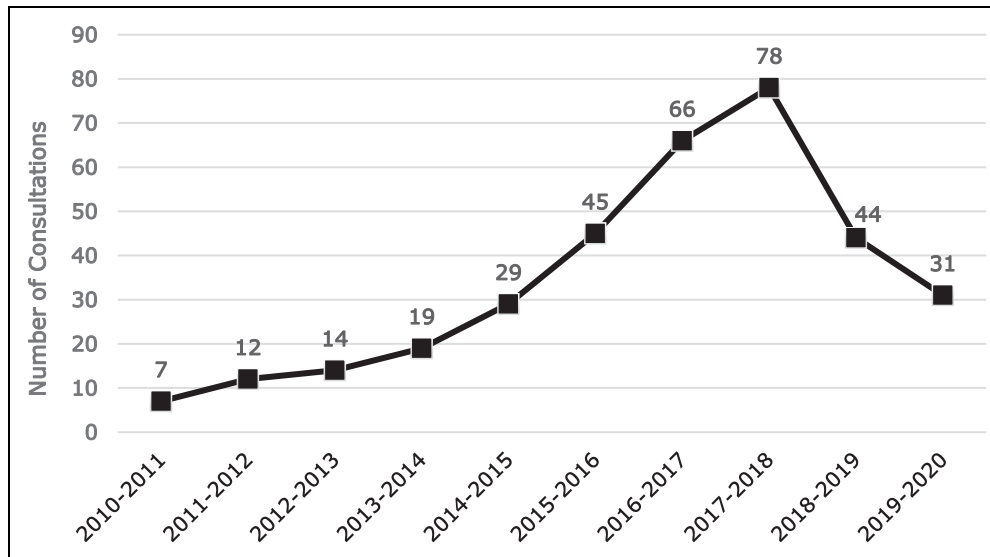


Figure 4. Patient and Family Advisory Group (PFG) completed consultations, 2010-2020.

reimbursed for their incurred expenses to participate as members of PFG. However, the debate included paying honoraria to advisors for their time and effort. The latter was viewed as counterintuitive to AHS' volunteer services policies. In the end, the volunteer role was seen as the best fit for advisors. They could be more autonomous in their advisory role and have less constraints as would be presented by contractual agreements for paid advisors. Each challenge PFG has faced, it has been able to manage.

Since 2010, the PFG has established itself as a credible advisory body sought after by AHS' internal and external stakeholders. The group has completed more than 325 formal consultations at various levels within AHS and with external consultants, all to help improve the quality of Alberta's health care system. Figure 4 illustrates the breakdown of completed consultations each year over a decade, some years having more consultations than others. The number and type of consultations taken on each year varied based on a number of factors including what issues were deemed priorities for consultation as well as timelines for completion. Each consultation was aligned with one or more of the AHS Four Foundational Strategies (22). Figure 5 shows the number of consultations by the various Foundational Strategies. Many consultations often captured and were counted in more than one Foundational Strategy; hence, the higher consultation numbers compared with Figure 4. The majority of consultations over the years align with the Patient First Strategy, but in the last 2 years more focus has been on Our People Strategy.

Patient and Family Advisory Group has helped transform AHS, bringing it to a state of being more patient and family centered, and positioning AHS as a leader among health care systems for bringing direct patient and family voices to high, strategic decision-making levels of the organization (20). It is the goal of PFG to transform the culture and perspectives

across AHS, one consultation and one success story at a time. Although the group has established many strategic partnerships for the 325 consultations over the 10 years, there are a number of consultations that are examples of transformative moments because of their positive impacts on patient and family point of care or system-wide policy improvements. A few of these examples stand out because of their sensitive topic areas or the fortitude needed by AHS to stand by its Advisors in making executive decisions. One is the development of the Continuing Care Appeals Process (24), where having the inclusion of PFAs as voting members on the appeal panel demonstrated firm commitment and openness to the inclusion of the patient and family perspective in high risk and/or sensitive situations the system encounters. This and other examples of key initiatives aligned with AHS' strategies are briefly described in Table 2.

As well, PFG is often asked to provide guidance and consultative advice to other engagement teams across Canada, such as assisting organizations as they develop similar PFGs.

Lessons Learned and Future Directions

The success and longevity of PFG over the past decade can be attributed to many enabling factors and lessons learned along the way, some of which are identified in Table 3. Many of these link back to PFG's evolution and its operational structure and function. For those interested in developing a similar advisory body, these factors are worth considering.

Evaluations with PFG advisors regarding these factors and their experiences have been essential to guide improvements or addressing challenges encountered. Through all the efforts over the past decade, the majority of PFG advisors (>80%) indicated their satisfaction with their overall roles as

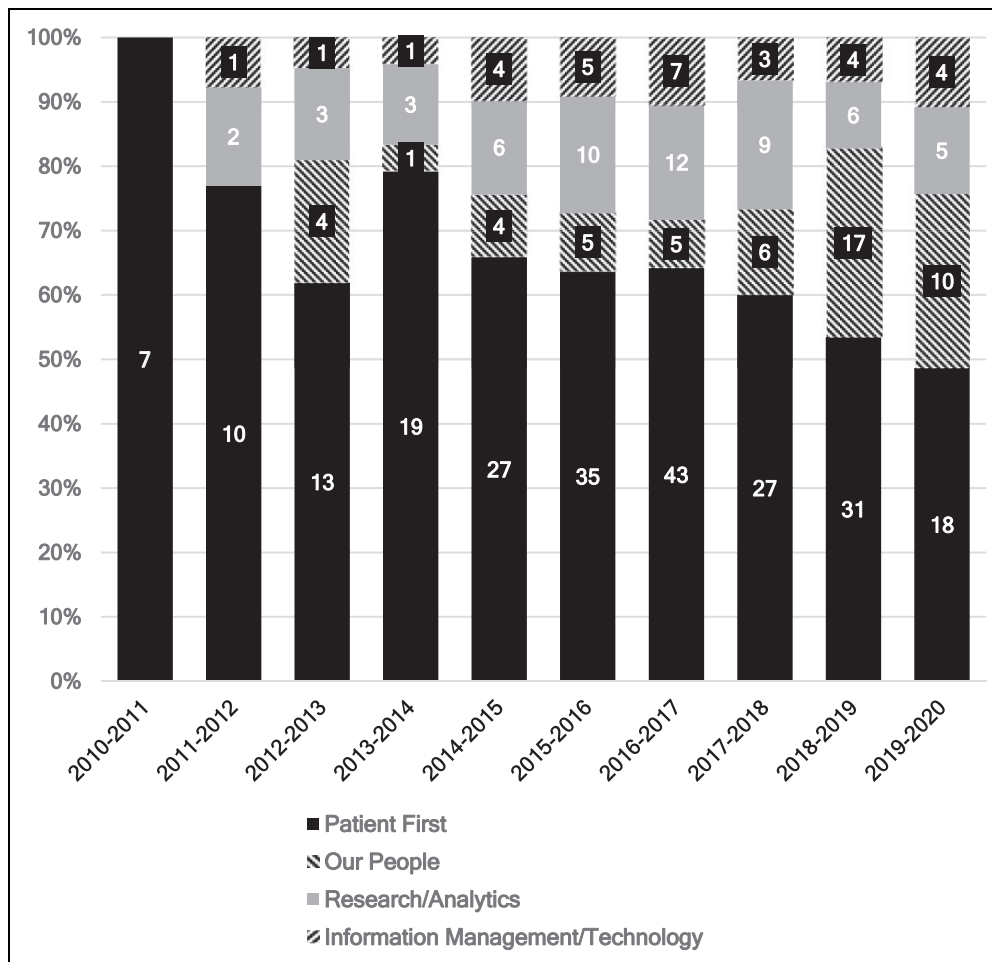


Figure 5. Distribution (numbers and percent) of Patient and Family Advisory Group (PFG) consultations by Alberta Health Service (AHS) Foundational Strategy (2013-present) (22,23).

advisors and with PFG's contributions to improving application of PFCC across AHS. More specifically, many (90%) confirmed their appreciation for being able to express themselves, being supported, having opportunities to participate, and being listened to and valued.

The success of the PFG over the past 10 years has laid the foundation for exploring innovative ways for how the patient and family voice can be included in all areas of AHS (22), and for recognizing its impact. The members of the group comment that one of their most valuable roles, in addition to advising on what matters most to patients and families, is the opportunity to educate leaders and staff from a perspective of lived experience. These core roles will continue to guide the group's work in the coming years.

The group has also acknowledged the desire to be actively involved in defining its desired impact, beyond group purpose, mission, and values, and how that impact is measured within the organization. Together with the secretariat team for the group, PFG has begun the development of a measurement framework to better articulate and capture impact-related metrics. One example is having a "promise-back" to participants by consultants, to demonstrate how feedback from PFG

was or was not utilized, or the impact which the PFG-advised work/project had after being implemented.

Additional work is underway to continually refine and improve internal communication and relationship-building processes including formalizing learnings and best practices from 10-plus years of engagement and exploring new methods of building engagement capacity in leaders and staff who come to PFG. Complementing this work, AHS' corporate communications department is working with PFG to promote the group and creating a province-wide understanding of the group's role in helping to shift health care to be more patient and family centered.

As the group enters its second decade, the relationship with senior leaders and policymakers within AHS has shifted to co-development whereby patients and families will help define the level of their inclusion. This shift in roles and level of engagement is even more critical to understand during times of crises such as with COVID-19. There may be a "new reality" for PFG that will need to be defined, which may present with some different opportunities for engagement and partnership. The journey for PFG and AHS continues!

Table 2. Sample of Impactful Consultations Aligned With AHS' 4 Strategies (This Table Presents a Sample of the More Than 325 Consultations Completed Since 2010).

Consultation/initiative	AHS Four Foundational Strategies			
	Patient first	Our people	Research/ Analytics	Information Management/Technology
Family Presence & Visitation Policy (2015-present) <u>Key Impacts</u> - Co-developed provincial policy - Set value framework for future policy/procedure iterations - Contributed to provincial appeals process	X			
Medical Assistance in Dying (MAID) (2015-2017, 2020) <u>Key Impacts</u> - Prioritized inclusions to provincial practice guidelines - Contributed to educational resources	X			
Virtual Health (2018-present) <u>Key Impacts</u> - Contributed to Provincial Virtual Health Strategy - Provided advice regarding >15 Virtual care patient resources - Member participated as voting member of Virtual Health vendor selection process	X	X	X	X
CoACT Collaborative Care (2010-2018) <u>Key Impacts</u> - Contributed to Patient & Staff Rights and Responsibilities - Guided Name, Occupation, Duty (NOD) practice guidelines - Collaborated on provincial implementation plans for the program	X	X		
AHS Website/Mobile App (2015) <u>Key Impacts</u> - Determined foundational layout of information and resources available to the public - User testing of new webpage and resources	X		X	X
Connect Care (2012) <u>Key Impacts</u> - Expressed initial patient and family need for provincial electronic medical record - Guided the formation of Connect Care dedicated patient and family advisory group - Contributed to the development of a patient-facing portal to access their own medical records	X	X	X	X
Beyond COVID-19 Innovations (2020) <u>Key Impacts</u> - Identified organization successes and opportunities - Validated findings from the largest, integrated, Canadian health authority for future publication	X	X	X	X
Clinical Ethics Framework (2013, 2015, 2017) <u>Key Impacts</u> - Provided lived experience lens to the Framework - Prioritized initiatives for strategic plan - Validated Executive Ethics Decision Framework	X	X		
Health & Business Planning (2014, 2018) <u>Key Impacts</u> - Contributed patient and family priorities to the highest-level organizational plan - Validated future directions for the organization	X	X	X	X
Continuing Care Appeals Process (2017-2018) <u>Key Impacts</u> - Contributed patient/family/caregiver priorities to concerns management process - Implemented Patient/Family Advisor voting membership on appeal panels - Embedded PFCC principles in accompanying continuing care policies	X	X		

Abbreviations: AHS, Alberta Health Service; PFCC, Patient- and Family-Centred Care.

Table 3. Factors to Consider for Patient and Family Advisory Groups.

Factors
1 Members who are patient and family volunteers.
2 A cochair model which fosters and models the partnership between our patient advisors and senior leadership in AHS.
3 A comprehensive orientation provided to PFG members, including a review of the principles and practices of PFCC, the use of patient storytelling, and the IAP2 spectrum of engagement.
4 Consistent and dedicated operational staffing support for PFG by AHS.
5 Diversity and mix of the 30 members.
6 Adequate and consistent financial resources provided by AHS.
7 A blend of regular and ad hoc virtual meeting opportunities to accommodate PFG business and relationship building.
8 Engagement support to the consultors seeking advice from PFG including preparation, framing, and defining their pre and post consultation engagement.
9 A strategic partnership with the AHS, embedded in the Patient First Strategy (25).
10 Active champions and supporters for PFG from AHS senior leadership.

Abbreviations: AHS, Alberta Health Service; IAP2, International Association of Public Participation; PFCC, Patient- and Family-Centred Care; PFG, Patient and Family Advisory Group.

Authors' Note

Ethics was not required for the content of this paper, but consent to provide the work of the Patient and Family Group (PFG) at Alberta Health Services was obtained from our leadership and coauthors who coordinate PFG.

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