

| Alberta Health Services

Provincial Patient and Family Advisory Group

Annual Report

September 2018 – June 2019

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Message to Alberta Health Services and Patients & Families

The Provincial Patient & Family Advisory Group (PFG) is a formal collection of Patient & Family Advisors from across Alberta who advise Alberta Health Services (AHS), its senior and executive leaders, staff, and physicians on provincial and organization-wide policies, practices, planning, and delivery of services/initiatives/programs on what matters most to patients and families.

Each member of the group brings personal, lived experience and expertise of the Alberta health system to provide feedback and strategic advice on how AHS can improve the experience of healthcare services through advancing patient and family centred care.

Over this past year, PFG has offered their experience and expertise as patients and family members on numerous enterprise-wide policies, programs, and service models; these will be highlighted throughout the report. This report will further demonstrate the passion and dedication of our members to bring patient and family centred care to life.

The Provincial Patient and Family Advisor Group's strategy and work are aligned with AHS' [Four Foundational Strategies](#) and the objectives and measures in the [Health Plan & Business Plan](#).

This was a year of change and firsts for PFG: we welcomed a new Patient and Family Advisor Co-Chair and Vice-Chair, we increased our efficiency by meeting quarterly, dedicated additional time for the members to build strong working relationships in between the quarterly meetings, and focused on sharing the patient and family voice in increasingly large strategic projects and work.

“PFG is a group of people, all ages, races, genders, locations, and socioeconomic classes who work tirelessly to improve Alberta's healthcare from a patient and family perspective.”

-PFG Member, 2019

We close this year inspired by the dedication of patient and family advisors to improving healthcare for all Albertans. As well, we are invigorated by the increasing demand within AHS to seek the expertise of PFG to ensure their work will meet the needs of the patients and family members they serve.

PFG's work will be of utmost importance in bringing the patient and family perspectives on health and care in the current provincial and economic realities in Alberta.

Reflections from the Co-Chairs



Marian George,
*Patient & Family Advisor
Co-Chair*

During the past year, PFG patient advisors shared ideas with AHS staff on topics that range from dispute resolution and family presence policies to development of patient centred apps. The intent of advising by patients is to create a 'window' into the life of a patient and identify how policy and procedure can impact a patient and family in aspects that may not be understood or felt by the healthcare professional. This 'window' assists each of us to empathize with each other and support a care partnership. It is understood that AHS offers research informed knowledge; patient advisors offer experience informed knowledge. This past year was spent with AHS staff and patient advisors co-designing healthcare to improve patient experience. PFG is one of many patient groups that offer a space for co-design. Space and voices to be nurtured and heard by both.



Rollie Nichol,
AHS Co-Chair

In a time of transformative change, the Patient and Family Advisory Group continues to evolve and provide new value to the planning related to both service delivery experienced by Albertans and policy created to guide the behaviors of AHS clinicians.

The concept and reality of patient centred care continues to gather advocates and to gather momentum in all areas of the province impacted by AHS. Progress has not been linear. There are "hot spots" in our system where this has really become embedded in the local culture and there are services where there remains great opportunity to improve.

PFG, through its formal in-person consultation model, has provided substantive input to a great number of services and it has provided even more input through the virtual consultations.

The major challenge facing PFG is creating an effective model for supporting the integration of the large number of patient advisors largely functioning independently.

Provincial Patient and Family Advisory Group Highlights



44
Consultations



93% of members agree that
differing views are
expressed and welcomed
in PFG's work

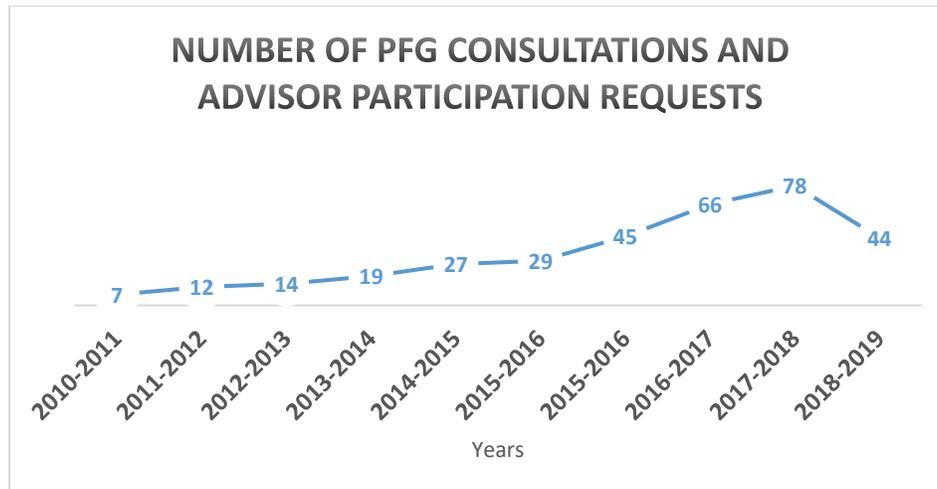


93% of members agree that their
views and opinions are
listened to and valued



86% of members agree with "I feel that
the contributions of PFG
will result in the
improvement of person-
centred experiences
within AHS"

Operational & Strategic Summary



**Number reflects actual consultations with PFG and additional requests sent to members outside of regular meeting times.*

PFG consults with many programs and areas in AHS that are working to improve the quality of services and care across the province. We have seen an increase in total number of requests to come to the PFG table since the group's inception.

In 2018 - 2019, we have been prudent in the selection process of which projects come to PFG in order to provide optimal feedback and advice in work that is of organizational priority. From September 2018 - June 2019, there were 44 distinct consultations.

Each year, PFG meets with the AHS Board and Executive Leadership Team to allow leaders, patients and families the opportunity to share their high priority items. PFG works with the Performance and Planning and Accreditation departments to ensure the work coming to PFG for advice is of strategic importance and value.

Key Organizational Impacts:

- Prioritizing Initiatives throughout Connect Care Implementation
- Family Presence Policy Suite
- Dispute Resolution in Critical Care Policy Suite
- Human Resources (HR) – Bridging the Gap Between HR Metrics and Patient Experience/Safety

Key Impact:	Prioritizing Initiatives throughout Connect Care Implementation	
Initiative	<p><i>“... [PFG] has helped to clearly delineate the core set of values that the organization must consider as Connect Care approaches. Their ideas and suggestions will ensure we make ethical decisions...”</i> -AHS Staff, November 2018</p>	
In fall 2019, AHS will begin its launch of a province-wide clinical information system designed and built to enhance care for patients and families as well as providers. Due to the large scope of this work, many resources will be required from across the organization.		
PFG Involvement		
Prior to launch, PFG members were asked to discuss programs and services that are most important to patients and families in Alberta, in order to prioritize projects that could be appropriate to be paused while implementation is underway. PFG was also asked to share their values related to health services to confirm what matters most to patients and families.		
Impact & Next Steps		
PFG members validated that programs/services directly related to care and those that are designed to enhance the patient experience are valuable to Albertans. Members highlighted that while the group is representative of Alberta’s communities, more in-depth consultation with affected stakeholders ought to be completed when specific projects are considered.		

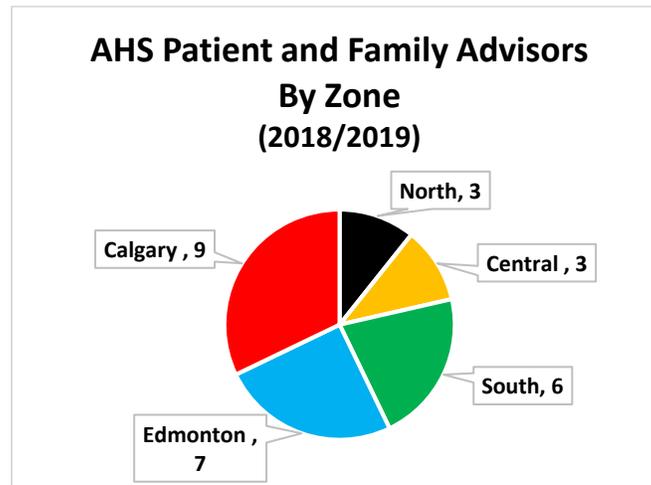
Key Impact:	Family Presence Policy Suite	
Initiative	<p><i>“Formally welcoming family members as full partners in care would not be successful without the clear direction being set by PFG. ... [PFG] has provided insight and experiences that we would not understand if we did not enter into this partnership.”</i> -AHS Staff, February 2019</p>	
The Engagement & Patient Experience Department in partnership with PFG and the Policy Services Department are creating a provincial, level one policy on family presence in all AHS facilities and care areas. The policy suite will see family members, as defined by the patient, as full members of the care team, that are welcome at all times.		
PFG Involvement		
PFG has collaborated on and co-developed key aspects of the policy suite since February 2017 through a series of consultations and working sessions. This policy suite is the first of its kind to be co-developed with patients and families, and is projected to rollout in 2020.		

Key Impact:	Family Presence Policy Suite
Impact & Next Steps	
PFG has influenced the value set that serves as the foundation for the policy suite, as well as reviewed and provided language that will guide the policy and procedure documents. PFG has also informed education and communication resources that will accompany the policy suite rollout. This collaborative relationship will continue regarding the family presence work.	

Key Impact:	Dispute Resolution in Critical Care Policy Suite
Initiative	
The Dispute Prevention and Resolution Working Group was tasked with reviewing the current policy suite, and to update it to reflect the current state of the organization. PFG was consulted to ensure the patient and family perspective of dispute prevention and resolution is accurately captured and reflected in this guiding document.	
PFG Involvement	
PFG was asked the following questions in relation to the policy suite: <ul style="list-style-type: none"> • What matters most to patients and families in preventing disputes? • How well does the policy suite support communication between patients/families and the healthcare team? • What is the most important thing you want healthcare professionals to know that would help prevent formal disputes? 	<p><i>“We theoretically knew how important this process was to patients, but until we came [to PFG], we did not have the deep understanding of the patient experience and how best to reflect that. This is just the start of a larger conversation.”</i></p> <p><i>-AHS Staff, November 2018</i></p>
Impact & Next Steps	
PFG members confirmed that in-principle, the policy included the perspectives of patients and families, and was responsive to their needs. The group stated the need to have a patient/family-specific set of resources for them to use in the case of a dispute, as well as a rollout to areas beyond critical care. This work and future iterations will be brought back to PFG for consultation.	

Key Impact:	Human Resources – Bridging the Gap Between HR Metrics and Patient Experience/Safety	
Initiative		
<p>The People Analytics and Performance Reporting department have started to explore new measures and metrics that best demonstrate the experience of the AHS workforce. As part of this work, there was a curiosity if there are metrics that formally tie the patient/family experience with the provider/staff experience.</p>		<p><i>“Consulting with Patient and Family Advisors is critical to our work. We’ve heard very clearly that patients do see a strong connection between the staff experience and the patient experience. We hope that by formalizing HR measures with patient experience, we will be able to better meet the expectations and needs of patients.”</i> -AHS Staff, September 2018</p>
PFG Involvement		
<p>PFG members were asked to consider the AHS Four Foundational Strategies, current People metrics, and answer the following questions:</p> <ul style="list-style-type: none"> • What connections do you believe exist between the Patient First Strategy and Our People Strategy? • We often hear about “happy staff, happy patients” – do you think we have closed the gap between what we know (the importance of the Patient First Strategy and Our People Strategy) and what we do (building the connections between our staff and the patient experience through the strategies)? • Are there gaps between the two strategies? What are the gaps and how do you see Patient Advisors and AHS bridging them? • If there are no gaps, what improvements can be made to enhance the existing connection between the Patient First Strategy and Our People Strategy? • In your opinion, what other metrics, in addition to the ones we currently track, would be beneficial to capture? 		
Impact & Next Steps		
<p>PFG members discussed and concluded that there is a connection between the two strategies, and that both are reliant on the other to work effectively. Members stated that there are countless factors of influence to the staff and the patient experience, and provided examples of potential metrics to track. This work and the connection between the strategies will be discussed at an upcoming PFG meeting.</p>		

Member Demographics



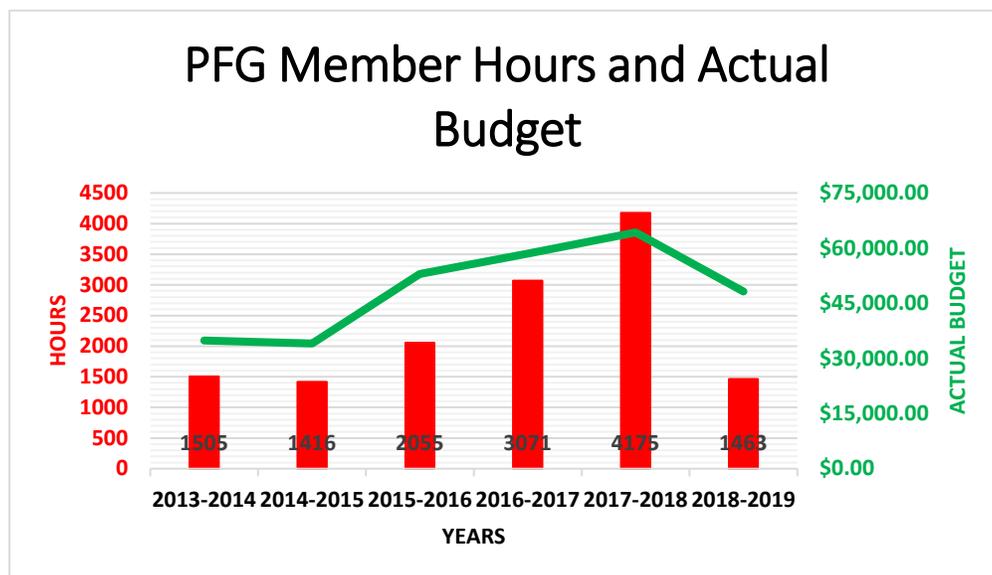
*Geographical distribution of PFG members by Zone

PFG members bring diverse backgrounds and health experience that reflect Alberta's communities. We know health services differ across the province, and we work to ensure a wide-range of patient voices are included. Member demographics, such as geographical location and self-identified gender, guide our recruitment and provide target ratios for new members.

"...PFG is breaking the barriers between the system and the people. We are changing the conversation from 'What's wrong with you?' to 'What matters to you?'. To some, it's a difficult question. We're not used to it. But it's a conversation that needs to be had in order for culture [change] to happen. The changes that we are empowering provincially will spread and start a conversation throughout the country. While PFG is small, small steps turn into big leaps."

—PFG Member, 2019

Financial Stewardship Summary



**Only the hours self-reported by PFG members are reflected. The budget numbers are the total actual costs for meetings and PFG member expenses.*

Each year, a projected budget is calculated in order to host our consultative meetings, with details included below. The projected budget is based on 100% attendance from our members, with a consideration of attrition and recruitment each year. This past year, in-person meetings were reduced from six to four, resulting in an actual budget with a greater differential than in previous years. Historically, PFG meetings have trended at ~58% actual cost to estimated cost.

	Estimate	Actual	Diff.
September 2018 - June 2019	\$100,014.90	\$48,212.25	48.21%
September 2017 - June 2018	\$108,399.92	\$64,262.48	59.28%
September 2016 - June 2017	\$87,836.57	\$58,544.49	66.65%

Looking Ahead

In order to remain increasingly effective, a focus in 2019 - 2020 will be to build the virtual capacity of the group. Adding virtual practices to our process will allow for more just-in-time consultations that emerge, and may give the opportunity for new members to join the group who have not been able to historically meet the demands of in-person meetings.

Our attention to the diversity of the group's membership will continue to be of utmost importance as we move into recruitment cycles; ensuring there is a balanced mix of members representing urban/rural communities, experiences of care, as well as personal background.

As we look ahead to the coming year, we will continue to improve our internal processes to remain nimble and responsive to the needs of AHS, providing insight on what matters most to patients and families across the province.

PFG has a robust history of providing input into some of the large, critical decisions that are made by AHS. Our experience in this regard will be valuable during the transitions we will face as an organization in 2019 - 2020, and beyond.

"...PFG represents what all Albertans expect as a part of their healthcare – a system built around the interests of patients and families first. Without PFG, it would be very challenging to have the needs of patients truly reflected in the underlying structure of AHS. Including the patient voice at a high level reminds everyone in the organization who and what they need to be fighting for. Not for the bottom line, but for the patients this system should be protecting."

-PFG Member, 2019



For More Information

If you are interested in learning more about PFG, would like to consult with Patient & Family Advisors, or become a member, please:

Visit [the Provincial Patient and Family Advisory Group webpage](#) or;

Email patient.engagement@ahs.ca.

Prepared by: Engagement & Patient Experience – Quality & Healthcare Improvement