Partnering with Patients and Families
2017/18 Patient and Family Advisory Group Members

**Co-Chair** Lona Leiren, **Co-Chair** Dr. Rollie Nichol, **Vice-Chair** Maya Charlebois
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Reflections from Engagement & Patient Experience

This past year has been an interesting period of reflection and growth not only for the group itself but also for the Organization, as time was taken to see why and where PFG should continue to be within AHS. We have been receiving more and more requests for patient and family engagement throughout the Organization as well. For some of the group, it has been a painful year in some ways as many felt they were no longer sure the Organization knew and supported Patient Engagement.

At the end of this soul searching year, decisions were made and PFG has emerged stronger and more focused on working strategically with AHS to transform the Patient Experience through ensuring the culture of PFCC is modelled and believed throughout all levels.

Co-Chair PFG, Lona Leiren

In the last year, PFG continued to play a vital role in elevating the patient voice in AHS policy and program shifts. From input on preferred accommodations policy or mobile integrated healthcare, to visitation policy and care after death in the home, PFG provided robust feedback reflecting the diversity of Alberta’s patients. In addition, our own Karen English led us in the impactful Blanket Exercise. Dr. Rollie Nichol also facilitated our discussion of the book "Better Now" by Dr. Danielle Martin, the highlights of which we were able to share in a teleconference with the author at our January meeting. I know PFG will continue to show strong leadership and thoughtful patient voice in the coming year.
Co-Chair PFG, Dr. Rollie Nichol

AHS and the Patient Family Advisors have experienced several iterations of renewal and the recent year demonstrates the sustainability of our current model. Advisors come forward energized by their personal story/narrative – either their story of interaction with the health system or the story of a family member. This energy, at its core, pushes Advisors forward motivated to create new patient experiences within the AHS system of care.

Although Patient Family Advisors are welcomed in many settings of health system change within AHS, there remains significant angst (may I say fear) in many other settings. This discomfort is traced back to the very energy that motivates our Advisors. I believe that discomfort is based on a perception that the personal narratives act as constraints on their input; a belief exists that the Advisors will be advocates limited to their personal experience.

In my opinion, the core strength of the AHS PFG model is the transformation of the nature of advocacy within its members. The advocacy voice has been transformed from that related to micro-system processes to that of guiding the mechanism of change for all of AHS – Co-Design. Our Advisors are clearly advocates for the process of Co-Design at the macro level of AHS and the permeation of its concepts throughout all of AHS. This is a revolution but one that will support ongoing evolutionary, sustained, transformative change throughout Alberta’s health system.

In the past year we have seen consultative interactions occurring at much earlier stages of service and policy development. There has been greater impact on these developments as the patient voice has nudged the process and outcome significantly. These are markers for our success in advancing the value of Co-Design.

Challenges persist with respect to our need to have an organized information system and network to support the diversity of our large number of Patient Family Advisors. The nuances of Co-Design are understood to varying degrees by many of our Advisors as well as the AHS professionals.
The Patient and Family Advisory Group (PFG) has been helping to bring the patient and family voice into Alberta Health Services since December 2010. It is comprised of 30 Patient and Family Advisors from across Alberta with a wide variety of backgrounds and healthcare experiences. Each Member volunteers time to share their experiences in Alberta’s health system to improve the quality, safety and patient experience of the health system. The diverse membership of PFG provides Health Care providers and leaders insights into patient experience and what PFCC looks like from the other side. The work of the Group is based on the values of partnership, collaboration, engagement, respect, transparency, and a foundation of ensuring that health care services are patient and family centred. The purpose of the Group is to advise AHS, its senior leaders, health care providers, staff and physicians on policies, practices, planning and delivery of patient/family centred care. Advisors comment that “our purpose is to work with AHS”.

### AHS Patient and Family Advisors By Zone (2017/18)
- Calgary, 10
- Central, 3
- South, 4
- Edmonton, 9
- North, 4

### AHS Patient and Family Advisory Group by Gender (as identified by the individual members) (2017/18)
- Male, 10
- Female, 20
The Group was active in providing advice and support to 28 individuals or groups that came to the PFG meetings to consult with the Advisors. In addition, there were 54 other opportunities presented for individual involvement or group participation. Topics and subjects ranged from Policy consults such as restraints use, refresh of the Drug and alcohol policy in time for legalization of Cannabis, the visitation policy, searching Patients at risk of harm to themselves, strategic consults around the AHS Values, Patient First Strategy and People Strategy, EMS consults around the Mobile Integrated Healthcare project, accreditation and many others.
PFG continues to ask, “Are we of value? Have we made a difference?” One of the ways we evaluate is by sending out surveys to both the Advisors and those who consult with us. These are some of their comments. (Quotes from AHS Staff and Medical Staff)

Organizational Effectiveness & Design, Human Resources
Thank you very much for the ongoing opportunity to consult with Patient & Family Advisors. This group reminds us, at every step of the way, what drives our work and how we can ensure we are a reliable Organization. We look forward to continuing our relationship with this group in relation to our shared values.

Clinical Quality Metrics
We received so much valuable feedback from PFG that will inform our public reporting going forward. The Advisors were engaged and ready to assist us when we needed their perspectives.

Policy Services
PFG was able to give us information about implementation of the policy/procedure suite. We were not anticipating the high level of feedback from the group; we will come with more in-depth questions next time.
Patient Safety
It is so important for us to obtain the patient perspective, even for an internal strategy. PFG will keep us focused as we build the final strategy. We hope to come back to share our work.

Engagement and Patient Experience
We always get an incredible amount of actionable feedback from PFG; it is truly a pleasure working with the Advisors. Their voices helped us plan our WMTY campaign, and even better, helped drive the conversation throughout Alberta.

Mobile Integrated Health, Emergency Medical Services
Thank you for the opportunity to engage with PFG. In a topic such as providing care in the home, the Advisors were able to use their experiences to inform us of what patients and families need to have in order for this project to be successful. A very engaged group!
Value for Dollars

The Group continues to be an economical, value for money investment, considering how this group has contributed to help change the culture of the Organization to be more Patient and Family Centered.

As our President & CEO, Dr. Verna Yiu, has said, “This Group has effectively provided the Organization with sound and valuable advice on numerous programs, policies and issues from a Patient and Family perspective and has established itself as a proven approach for the Patient and Family Lens.”
Value to the Advisors

PFG continues to grow stronger because of the individuals who choose to offer their time, energy, and expertise. At the same time, PFG creates a space for the Advisors themselves to reflect, heal, and grow. These are a sample of their comments from the annual survey:

What has your personal experience being on the Patient and Family Advisory Group been like?

- It has been a very educational, eye opening experience. It has been eye opening in that such a diverse group of people really basically have the same needs and aspirations. It also has been a growth experience.

- I really appreciate the opportunity to listen with intent and to be heard. The PFG provides me with the opportunity to do both of these things.

- Being a part of PFG has been a transformational journey - both at a personal level and Institutional (AHS) level. PFG exists to make sure that the patient and family voice is heard and never missed when the consultations come to the table. We strive to improve the system and keep it on a consistent, long term path. When it veers from the path, we're there to help it adjust. The connections we make are important, just as important as our unique healthcare experiences.
What have you felt the Group has contributed to AHS?

The stories and wisdom the advisors on PFG have shared with many of the consultants is what I believe to be the most impactful contribution we have provided for AHS.

PFG is known for its insight and creativity when tackling real world, difficult problems. Each advisor sees things in a unique way, so to bring that depth of diversity to each meeting is priceless. The stories that are shared are learnings for AHS to take back.

PFG is a safe space where advisors are comfortable sharing traumatic and personal/confidential experiences that wouldn't normally be heard. The group is nonjudgmental and welcoming, and in that sense it's a healing and therapeutic experience for advisors. Everyone benefits.

I feel the group has contributed, in depth insight into many aspects of health care service delivery by sharing their, knowledge and personal experiences and expressing what matters to them and others that have touched their lives.

As a group, we continue to remind those that consult with us, the importance of keeping the 'care' in healthcare. The collaboration that occurs between PFG and AHS staff/consultants models how AHS is striving to live out their 5 core values.
What was your favorite consult or meeting from this past year?

My favorite consult was with Kathy Kovacs-Burns on the Patient Experience Pilot Project. Firstly, it is an action towards a goal, not just words on a text, and I think it is family or people who can connect the system to the users.

In June we had a consult about reporting of patient safety & experience. It was hands on, so many perspectives were shared & key topics were truly brought forward as to what is needed to make a report on.

The November meeting where the blanket exercise allowed me to learn and understand the Indigenous community more.

This was a tough question, but I would say in the June meetings we went over the drug and alcohol policy which included the forthcoming cannabis policy for October legalization. Given that this is such a current event and will affect many Canadians, it was great to provide recommendations that the guests hadn’t thought of. I was impressed that they welcomed our feedback so readily, even when we picked apart many of their decisions and went deep into the policy. It was also cool to see so many advisors attend the Calgary meetings, this goes to show the loyalty of the group.

It is hard for me to choose a favorite consult, as I have enjoyed most of the consults over the last year. I personally thought that the conversation we had with Dr. Danielle Martin was incredible and inspiring to me! As always, I loved the AIW Fundamentals Training. It effectively helps people to understand some of the inefficiencies in the system and to look for creative ways to ‘fix’ some of these problems. It also functions as a teambuilding event.

In a sentence or word, what is the Group to you?

A community of people united in improving patient’s health outcomes.
An amazing group of diverse individuals making a strong difference.
Forward thinking! The group is doing something unique and in my opinion is ahead of the curve.
PFG is both caring and compassionate.
Patient and Family Advisory Group Participation
“PFG & Beyond”

The Group has contributed in a variety of ways over the last year through their work: together as a group of Advisors, individual commitments presenting at conferences and events, sharing their story with others to help kick start projects, and serving on other committees and groups across the Organization. AHS is truly starting to embrace the voice that patient and family Advisors can bring. The Group has clarified where they wish to partner in the Organization and that is at the strategic level. In 2018/19, PFG will have a different Executive Leader bring consults and questions to every meeting. The outcome of this is anticipated to be increased connection of the patient and family voice throughout strategic leadership tables.
Thank you to all who reach out to partner with this group and thank you to the Advisors who so graciously and authentically share their time, wisdom, and experience for the betterment of AHS.
Questions? Comments? Interested in Participating?

Email: patient.engagement@ahs.ca

Patient and Family Advisory Group website