Patient and Family Advisory Group

2014 - 15 Annual Report
executive summary

reflections

purpose

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to AHS

to advisors

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recognizing & thanking

contact information

2014 PFG Members
Co-Chair Linda Howitt-Taylor  Co-Chair Dr. Verna Yiu  Vice-Chair Deb Runnalls
Alan Roth, Amanda Proctor, Ben Chelkowski, Bev Gersbach, Bob Gersbach, Carmen Johnson, Holly Ekstrom, Hugh Sanders, James Demers, Jill Bernhart, Josephine Holt, Kari Bulger, Lona Leiren, Marisa Vigna, Maya Charlebois, Monica Enderlin, Nadia Clarke, Pat Demers, Rick Fraser, Sandy Isaac, Sahra Nodge, and Tristan Pidner

AHS Quality Healthcare Improvement & Engagement and Patient Experience
Carolyn Hoffman, Joanne Ganton, Jennifer Rees, Ping Mason Lai, Alisha Thaver, Nicole Forbes and Tammy Pollock

Report prepared by Jennifer Rees & Alana Boutin – August 2015
The Patient and Family Advisory Group (PFG) has been helping to bring the patient voice into Alberta Health Services (AHS) since December 2010. The PFG is a formal collection of volunteer patients and family advisors from across Alberta, who bring a richness of diversity based on geography, age, gender, background, culture, and patient/family health experiences to their role as patient and family advisors.

The purpose of the PFG is to advise Alberta Health Services (AHS), its senior leaders, healthcare providers, staff and physicians on policies, practices, planning and delivery of Patient and Family Centred Care (PFCC). Advisors comment that “our purpose is to work with AHS”.

In the last year, the PFG did 27 consults, up from 19 in 2013/14. These included consults around policies such as Access to Continuing Care and Preferential Access. Other consults were Patient First, Clinical Pathways, and CoACT to name a few (see page 6).

The 2014-15 Annual Report is a reflection of the engagement and partnership between the advisors and AHS, and summation of the accomplishments, along with the significant growth and breadth of consultations with PFG between May 2014 and March 2015. The report highlights, in the voices of the patient advisors and the staff and leaders who have engaged with PFG members, the immeasurable value the PFG brings to AHS.
“My association with the Patient and Family Advisory Group (PFG) over the past year has at times been challenging, illuminating, invigorating, emotionally and physically draining, stimulating, enjoyable and, above all, immensely personally satisfying. This past year the PFG met with other volunteer groups including volunteers with the Strategic Clinical Networks and with professional groups such as the Alberta Clinician Council, and with the Senior Leadership Team to both raise our profile and to build alliances within the organization. We continued to contribute the patient/family perspective and advise through a number of groups and initiatives including CoACT, Patient Repatriation, People Strategy, Palliative and End of Life Care, Just Culture, First Available Living Options to name just a few. The Group has seen the departure of a few familiar faces this year including our previous Co-Chair and several long-standing members, but we have welcomed the arrival of new members who have joined our "family", bringing new strength, perspectives, and talent to the work we accomplish. We have shouldered the impact of cuts and changes in staffing assignments alongside our supportive staff in Engagement and Patient Experience and together we have not only weathered the storm, but have matured and grown as an advisory body within AHS.”

Co-Chair PFG, Linda Howitt-Taylor

“This has been an extremely exciting and challenging year for the PFG! We have been challenged by having major health issues touch some of our members and this always has an overall impact on the close knit group that we have become. We have seen the implementation of many recommendations from the advisor conference in October, 2014; several of which will be a direct guide into the release of the Patient First Strategy. We have been presented with a number of critical consultations, as well as, many in our Group have also begun speaking in the community about the work being done within the Group itself and the shift to Patient First within AHS. The collaboration between patients and AHS continues to grow. It is supported by the executive leadership of AHS and ensures that patient voices and experiences are reflected in both program development as well as policy.”

Vice-Chair PFG, Deb Runnalls
“This past year has been another great year for the AHS Patient and Family Advisory Group. We had our first provincial PFG conference in October 2014 that brought together all of the patient and family advisors in the province, not only within AHS, but also included Health Quality Council of Alberta advisors. A report with recommendations was developed from that conference which further informed the AHS Patient First Strategy. We have also had integral participation and leadership from PFG on the implementation and roadmap development of the strategy which we hope to launch in October 2015.

We have been receiving more and more requests for patient and family engagement throughout the organization as well. For example, patient and family advisors have been active participants in ‘search and selection’ processes for AHS staff. For the first time ever in the history of the organization, we had a joint Patient and Family Advisor and AHS Senior Leadership Team meeting and, subsequently, another joint meeting with members of the Alberta Clinician Council and the Wisdom Council. It is clear that the PFG is garnering more and more of a voice and an important presence in AHS.

These are exciting times for AHS. The Patient First Strategy represents AHS’ commitment to Albertans. The Patient and Family Advisory Group advises AHS on how we can get there and when we will know that we are making a difference. Thank you to our wonderful group of advisors who are making significant contributions to ensuring that the patient/family voices are being heard throughout the province.”

Co-Chair PFG & AHS VP Quality & Chief Medical Officer, Dr. Verna Yiu
The Patient and Family Advisory Group has been helping to bring the patient voice into Alberta Health Services since December 2010.

The PFG is a formal collection of 24 volunteer patients and family advisors from across Alberta who bring a richness of diversity based on geography, age, gender, background, culture and patient/family health experiences to their role as patient/family advisors.

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”.
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.

External to the organization, the advisors have been asked to be a part of the Citizens’ Advisory Panel of Healthy Debate.ca. Two members have also taken part in national research “think tanks” in Ottawa, as well as, symposiums with Alberta Innovates.

In the past year, this Group has completed numerous consults (shown in the diagram). A new opportunity has emerged with this Group over the last year with two areas that have come back multiple times to connect and get advice from the advisors in regards to their work. This has been CoACT (Dr. Ann Colbourne and Team) and the Access to Continuing Care Group (Dr. James Silvius and Signe Swanson). The ongoing connection has really helped to partner with one another and help drive change in our system.
PFG Advisor Involvement in AHS

Other Committees
- Quality & Safety Executive Committee
- AHS Policy & Forms Steering Committee
- People Strategy Steering Committee
- Calgary Zone Quality Committee
- North Zone PFCC Committee
- Policy Working Group on Preferential Access
- Edmonton Zone UAH Medicine Meta Council
- Provincial Palliative Care Steering Committee
- Co-Chair Patient First

Public Speaking Opportunities and Meetings
- 1st Annual Patient Advisor Conference - Oct 2014
- 1st Meeting with Senior Leadership & Advisors - Oct 2014
- FFCC 101 Training Videos
- UofC 2nd Year Medical Students
- President Series with Dr. Bridgett Duffy
- Posters & Presentations at the International Conference for Patient & Family Centred Care in Vancouver
- ACC/Wisdom Council/PFG
- Just Culture Video & Training
- Citizen Advisory Panel for HealthyDebates.ca
- Media Launch Patient First
- Shades of Grey Conference
**What is the value?**

Anecdotally, the Group continues to hear they are of value. This year, both the people who consulted with the PFG and the PFG members themselves were sent questions to give us some facts and feelings about what PFG has done, and if what has happened has been of value.

**Was there value in consulting with PFG? (Comments from those PFG consulted with)**

“Absolutely - particularly because we used an interactive process of obtaining feedback at key steps in the Continuing Care Access to a Designated Living Option policy development.”

(Signe Swanson)

“Very much so. Patients are moved throughout the province from site to site, and although most of repatriations are logistical, the important aspect of communication is pivotal especially with patients and families.”

(John Montpetit)

“There is tremendous value in consulting with the PFG, given that one of CoACT’s principles and end goals is Patient/Family Centred Care (PFCC) for all Albertans. The AHS PFG is mission-critical to the CoACT agenda. The consultations are rich in depth and maturity of dialogue and input into helping the CoACT program refine its approach specifically to the PFCC deliverables. Additionally, our ability to “blue sky” some of our approaches, gives us a very real check-in regarding what we are thinking and what the Advisory Group tells us is the current reality and next best steps.”

(Dr. Ann Colbourne)

“Absolutely - it was very valuable! For the Repatriation and the 811 branding initiatives, meeting with the PFG was an excellent opportunity to make them aware of the initiative and it was essential to obtain the patient/family perspective.”

(Sue Conroy)

“Yes, great value in the ability to connect with members of the public who care about the health care system and could provide a non-health care view about the marketing campaign and materials for launching 811.”

(Lara Osterreicher)

“. . . the biggest benefit (in presenting) came in the form of generating interest for patient representatives to sit/be a part of our Policy Working Group. While one patient representative decided to resign her post (she simply did not have the time she felt was necessary to commit to the WG) we did have - at one time - 3 patient representatives on our WG. Their perspectives and input were most beneficial to what we ultimately developed.”

(Doug Bulwalda)
How did the information that you received from the patient and family advisors affect your project or work? (More quotes from AHS Staff and Medical Staff)

“It pointed out the lack of patient and family implications within the policy and procedure.”

“We were able to, on both occasions, integrate feedback into our projects and presentations to ensure we captured the perspective of patients and families.”

“The feedback helped shape the policy and procedure development, particularly on the processes imbedded in both.”

“The feedback provided was most helpful in assisting the Health Link Team to make decisions on how to brand 811. We were not sure that the three digit number would be readily identified as a phone number, and whether dashes between the numbers and/or graphic representation of a phone would be recommended. The feedback provided was very clear and provided us with a direction to take.”

“We also took into consideration the feedback we received on the campaign images adding in a third variation to the campaign to meet the needs of those outside of the parenting age group.”

“Patient Repatriation Policy review - we will be including a specific appendix in the policy which outlines key PFCC principles.”

“811 implementation marketing materials - the PFG confirmed that the concepts/materials we presented were on track. We also received some additional suggestions that we subsequently included in the marketing plan.”

“The feedback that was received from the PFG was considered by the Policy WG. This was in addition to feedback that was received from other key stakeholders. Where appropriate, the concepts and ideas that were shared by the PFG were incorporated into our final product (a policy and procedure).”
What was your experience partnering with PFG?

“Just consultative during a meeting - very good feedback and opinions. Good to hear vs. some internal meetings where no one speaks.”

(John Montpetit)

“The experience was seamless for us as a business. Jennifer Rees arranged all aspects of the meeting and disseminated the materials before and after to the Group members. They all seemed very engaged, interested and appreciative of the opportunity to participate which helped reinforce the opportunity to participate which helped reinforce the benefit of making the change to 811.”

(Lara Osterreicher)

“Very positive. I felt welcomed when I presented, and I felt that the feedback the PFG provided was very helpful/insightful.”

(Doug Bulwalda)

“The advisors are honest in their feedback and I felt it was a respectful, meaningful relationship that developed over the year.”

(Signe Swanson)

“A very positive experience. The PFG was very engaged in both topics and most members provided comments (verbal and written).”

(Sue Conroy)

“Collaborative, open, honest, organized – overall great! No concerns at all.”

(Laurel Stretch)

“Our experience has been fantastic! We glean as much as we can from this Group – the discussions and experiences are especially valuable. It is also special to be continually invited back to the table and develop relationships with the Advisory Group on a personal level. We treasure every opportunity to work with the Group and very much consider this Group to be a part of the CoACT Team and network.”

(Dr. Ann Colbourne)
Other insights...

“I think there have been many great moments, but one of my favorites was in the most recent consultation when we were thinking through the notion of patients and families truly leading their personal health agenda. We were thinking about what skills and behaviors patients and families may require to be in a much more enhanced role on the collaborative care team. It was a real “a-ha” moment to think about the cultural shift required for patients and families and that we need an intentional pacing of the required shifts and thoughtful language to communicate the vision. Some of us are ready to run, but in reality, many are learning to walk. We will get there, but we have to have the patience and tenacity to stay on the path to a great destination.

Health Link also met with members of the Health Advisory Council (HAC). I felt that the Patient and Family Advisory Group was more “representative” of the general public; there was a better cross-section of ages, genders and rural/urban participants. We were particularly pleased to have feedback from a mom with young kids who has used Health Link in the past as this was one of our main target audiences.”

“I’ve been impressed with the patience and generosity demonstrated by members of the Patient and Family Advisory Group as they work with us to clarify our thinking, and to develop and deepen our understanding of patient education. It is through these meetings that I’ve realized at a deeper level than ever the importance of embedding the patient’s voice throughout the health care system.”
What does the Group mean to you as an advisor? The Patient and Family Advisors provided these quotes.

**Inspiring.** “To hear stories of other people at the table, to work with the staff that provides support, and to interact and provide valuable input into the consults. I feel inspired in terms of the complexity of the work and commitment of AHS to ensuring the patient and family voice is included. I appreciate the strategic thought given to the organizational issues. It’s inspiring to know that AHS staff are dedicated to this complex challenge in such a coherent way, in such a chaotic environment.”

**Authenticity.** “Authentic participation of everyone who comes to the table. Example: Dr. Verna Yiu sharing the death of Cy Frank - it shows a human side which increases the bond at the table.”

“When I first joined, it was making a means out of my husband’s death. I did this as a tribute to him - to be able to make a change to policy and heal my confidence. This has been such a positive experience.”

**Progress.** “Thinking about where it started, and where it is now – in terms of how many in AHS know about us, and how many want to present to us for input.”

**Community of people** (both AHS and advisors) – “collaborating to keep care in health care.”

**Sincerity.** “People are sincere in their commitment to the group.”

**Presence.** “Reading Peter Senge right now; being with other people and sensing what it is they are feeling, their passions, their hurts - being mindful. It is difficult to create the physical space necessary and have the ability to have presence. This Group has that presence and it provides for an enriching experience.”

“Everyone on the committee has stories – some more positive than others, but no one brings negativity into the room. There is hopefulness.”
What have you felt the Group has contributed to AHS?

- **The big picture** - it is a way to ground the organization in the patient experience and patient oriented care. There is good diversity at the table that is not always in agreement - it speaks to the need for patient oriented care (care that is more personally reflecting in the diverse needs of patients).

- **It is a safe place** - consultants may think that they are coming to an angry place. What they experience is dialogue (dialogue being better than presentations). This allows for vulnerability - we all want to work for what will improve person-centred care in Alberta. Belief around the table is that AHS staff are doing their best; system issues can get in the way of doing that work.

- **Presence** – “even though tired and frustrated, the Group continues to be present and always giving it their all - possibly because of the transition into doing more work in their communities. This presence is a sign of the commitment of the Group to all that come to the meetings (as guests or presenters/consulters). This shows AHS the commitment of the community to Patient First/Patient Voice and impacting the policy and work within AHS.”

- **Advisors continue to be advocates** for AHS in the community - showing the importance of relationships. These can be used as good news stories (should look into growing this idea!)."
What have you felt the Group has contributed to AHS?

- “**Voice** is being heard in a number of places that has not been heard in quite a while in the form of the variety of committees that advisors are being asked to participate on.”
- “There is **recognition** that there are contributions to AHS to build the synergy around the idea of the shift to Patient First/Patient & Family Centered Care.”
- “It has been a long journey, but the **involvement** of the committee and **recognition** of its importance has grown over the years; witnessed by the increasing number of consults taking place (like bees to honey).”
- “The importance of seeing the **ongoing relationship** with CoACT and Signe’s group (Access to Continuing Care). Being able to see the impact of input and the relationship of trust that has been built. AHS sees the **value** of advisors and the insight/perspective that is provided to help AHS do its work.”
- “An **understanding** of who the organization is actually providing service to. It provides a humanizing perspective that has been brought forward to those working within AHS, thereby actually building the quality of health care that AHS provides; a fundamental principle of living, and remembering that it is all about relationships.”
- “The Group has given AHS a different **perspective** on what the ordinary citizen expects from the organization.”
- “I think that our Group is made up of amazing people with great **attitudes**. I think it has been instrumental in bridging the gap between AHS and patients merely by being not angry, not the enemy, not critical, but really wanting to help, really wanting partnership, and to understand the other side. I think where there has been resistance to patient involvement, there is more acceptance and welcoming when their experience with us has been positive, not defensive, and perhaps experiencing the benefits of our contribution.”
PFG Expenses

AHS’ operating costs for advisors to attend meetings are displayed as such. Expenses include travel, over-night accommodation if necessary due to weather/health reasons, and meals for full-day meetings.

*All expenditures follow the AHS Expense Policy.

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<th>Year</th>
<th>Dedicated Hours</th>
<th>Cost</th>
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<tr>
<td>2014 - 2015</td>
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“The Group is an example of bringing together two different sides and finding that the similarities are far greater than the differences, and that the sky is the limit on what can be achieved.”

“I feel that the Group has garnered more respect from decision- makers in AHS and that our opinions are valued, considered and utilized. If AHS really believes that they can be the highest performing health care system on the planet, they must make patients and families the centre of everything that they do. The only way to find out how to do that is by asking the ‘clients’ themselves.”
What has your personal experience being on the Patient and Family Advisory Group been like?

In general, members who responded to this question talk about their experience as being very positive, that they have learned and understood the AHS system much better from this experience. There is also a sense of accomplishment from contributing, but also of fatigue at times. Overall, the positive comes through.

For members who have been onboard a while, there is a sense of increased intensity and busy-ness of the Group; a sense that the demands of the role are increasing. Comments state enjoyment of watching the evolution of the Group and the organization.

There is a real feeling of family within the Group and a sense of things being accomplished. The in-person meetings are very effective, and advisors piggyback on each other’s feedback, making the conversation much deeper.

All respondents refer to the fact it takes a while to feel comfortable in their contributions, but all are welcomed in from the first day.

The PFG has made strides forward in helping the system to change. It is a Group that is no longer being seen as just a service group - it has moved forward to where it is now a respected consultation group for improving patient and family centred care.

“PFG is a close-knit group of people who open their hearts and expose their vulnerabilities to try to improve a system that is badly in need of it.”
What has your personal experience being on the Patient and Family Advisory Group been like?

“In one word – Wow! It is difficult, but the Group means mentors, friends, people who share my values and care about others.”

“It is INTEGRAL to AHS; to the furthering of PFCC and educating the public. It should be recognized as such as it matures to take its place within the system.”

“It is a voice without being an advocate. A place where all opinions are heard and valued, and where the consults improve services for all Albertans rather than addressing personal issues.”
What was your favorite consult or meeting for this last year?

- “The Clinical Strategic Pathways (Elford and Mork). It provided an opportunity for engagement with the Primary Care (PC) physicians, which hadn’t taken place up until that point. I was very excited to hear the presentation and Dr. Elford’s passion for the project. It was interesting to see the link through the Strategic Clinical Pathways for patient care through the system, including the piece on Patient Care Plans with the PC physicians. I appreciated that Dr. Elford thanked the Group for the connection and that he was able to take away learnings; he valued the input from the advisors and appreciated hearing the patient side. It is good for the advisors to be able to have input into strategic change – an excellent use of time.”

- “January Meeting - having almost the entire Group together. There was a sense of a ‘change in energy’ and the feeling of connectedness was evident (all positive), alleviating any concern that the size of the Group doesn’t take away from the process.”
What was your favorite consult or meeting for this last year?

- “My favorite consult was the ongoing one with Signe (Access to Continuing Care). I think this is because we watched the transition from hesitation of sharing, or even considering we had value in the process, to full-on acceptance, trust, and wanting/needling our involvement! It was the consult that wasn’t “in and out” in one session and not knowing if we were really valued, or had impact. It alleviated the question as to whether we were only consulted because they had to have the "yes, patient voice had input". The experience with Signe was the tangible "proof" I needed that we were needed and were making a difference in AHS, and it probably was one of the deciding factors for me to continue volunteering with this Group.”

- “Really appreciate the continuity of seeing CoACT and Long Term Care at the meetings. It provided a continuous opportunity to provide feedback; a strong example of continuation of work as it evolves over the stages of development. There is tangible evidence of the advisor input being incorporated into every stage of their planning.”

- “Love the Patient First Strategy and People Strategy consults; being able to watch them evolve and have input.”

- “CoACT presentations – interesting and valuable work; being able to see the system through CoACT vision.”

- “CoACT – having the streaming from meeting to meeting and being able to see growth and continuity. Also, Seniors Consults - growth seen in the Group is incredible.”

- “I like that fact that CoACT is a standing consultation on our agenda. It keeps us in the loop of what is happening on a practical level with improvements in the system as they are happening. Dr. Colbourne and her Team are so invested in making our health care system one to be envied and they walk the talk as far as including the patient voice at every step.”
“As members of a dynamic working group within Alberta Health Services, over the coming year we look forward to creating new ways to meet the growing demand for the expertise that has been developed within the Patient Family Advisory Group. We look to provide increased availability for meeting with volunteer and professional groups within and outside of AHS to build collaborative connections, and continue to work with staff in support of educating the public on their role and responsibilities in their own health care. At this juncture in the history of AHS, the Patient and Family Advisory Group is well-set to be part of creating a safe, welcoming, and just workplace for staff and patients alike”. ~ Co-Chair PFG Linda Howitt-Taylor

Issue for health care in the future? The aging population. Physicians who have historically had a culture to overprescribe, in terms of intervention - this may or may not be a person’s choice. There is an important need for patient-orientated care. Patients have a sense of what they want in terms of quality of care, etc., not necessarily the system’s approaches in the past. Anything we can do to improve the care (palliative, end of life, etc.) to help the system to help patients and families have the experience to think steps through, and to be able to make informed choices would be of incredible value.

It is good to have new advisors come on board and there needs to be more diversity. This Group is really heading in the right direction and it doesn’t feel like the Group is a window dressing at consults, they’re actually making an impact.


**Quote:**

“It takes more than one time on the agenda to build trust with the Group. I know that many things come before them just once or as an afterthought when the work is done, and I wonder if there is true value added in that. The gift that this Group can really give to the organization is to be involved closer to the beginning of a project and be engaged longer in the process.

I recently reviewed a project that incorporated patient/family information sheets into the tool kit. When I asked if patients and families had reviewed and provided feedback to them, they hadn’t. My response was: “That was too bad. If they had, they wouldn’t look at all like the finished product and would be something those patients and families could actually use.”

My point is that I learned a great deal through the interactive process and the feedback was transformational in both the policy and the patient information that we are developing.

In addition to the work of the Group as a whole, numerous advisors have taken on additional work in being on other committees within the organization at levels ranging from ad hoc members, to members, to Co-Chairs of the committee.

Thank you for the opportunity,
Signe”
**Contact Information**

Patient & Family Advisor information, please visit [http://www.albertahealthservices.ca/info/Page6620.aspx](http://www.albertahealthservices.ca/info/Page6620.aspx)

To become/recommend a member, or to request a consult with the Patient and Family Advisory Group (by bringing the patient and family perspective to your work), please email patient.engagement@albertahealthservices.ca

For additional inquiries regarding the PFG, please contact Jennifer Rees, Lead Senior Consultant, Engagement and Patient Experience [Jennifer.Rees@albertahealthservices.ca](mailto:Jennifer.Rees@albertahealthservices.ca) or (780) 735-0332