Partnering with Patients and Families
2015 Patient and Family Advisory Group Members

Co-Chairs: Linda Howitt-Taylor, Dr. Verna Yiu & Dr. Rollie Nichol
Vice-Chair: Deb Runnalls
Amanda Proctor, Ben Chelkowski, Bonnie Hutchinson, Carmen Johnson, Holly Ekstrom, Hugh Sanders, James Demers, James Hajdarpasic, Jill Bernhart, Josephine Holt, Karen Rumball, Kari Bulger, Keighley Schofield, Lona Leiren, Marisa Vigna, Maya Charlebois, Maya Pajevic, Monica Enderlin, Nadia Clarke, Pat Demers, Rick Fraser, Sandy Isaac, Sahra Nodge, Tim Kenny, Tristan Pidner and Zahra Coulter.
AHS Support Staff—Joanne Ganton, Jim Gilray, Deanna Picklyk, Jennifer Rees and Tammy Pollock

Messages from Chairs
Dr. Verna Yiu - AHS President and CEO, Co-Chair Patient and Family Advisory Group

At Alberta Health Services, patients are at the centre of everything we do and every decision we make. We invite patients and families to be full members of their healthcare teams and also partners in the planning, implementation and evaluation of existing and future care and services. This is what makes the work of the Patient and Family Advisor Group (PFG) so important. Its unique perspective and unwavering commitment to improve the health system benefits everyone: from patients and families to doctors, nurses and other healthcare professionals.

PFG is changing the healthcare system in Alberta for the better. It’s no wonder the number of requests for engagement and consultation from PFG has increased every year since its inception. This is a testament to the value and expertise it provides. This past year alone, PFG has consulted on several major initiatives within AHS: Continuity of Care, our refreshed AHS values, Medical Assistance in Dying policy consultation, continued support of the Patient First Strategy, CoACT, Alberta Mental Health Review, and the redesign of the AHS external website. The PFG were also key to landing the AHS vision.

I have been fortunate enough to serve as a past co-chair of PFG, and have seen much of its work and passion firsthand. The members of the PFG are more than just advisors, they are colleagues and I want to thank all past and current PFG members for their excellent work and contributions. Thank you for making a difference to improving healthcare – for all Albertans.

Dr. Verna Yiu
AHS President and CEO
Messages from Chairs (con’t)

Linda Howitt-Taylor— Co-Chair, Patient and Family Advisory Group

“Fundamentally changed” are the words that those of us who started with the PFG at the beginning would cling to. Our aim and purpose in giving freely of our time, effort, and energy was to assist in moving the organization, AHS, towards an understanding of principles of Patient and Family Centre Care and to help make and encourage the changes needed to practicing those principles at every level and corner of health care in Alberta. Now the last of the original members except one have stepped away to take stock of the past 6 years. Was it worth it? Absolutely! Did we accomplish all that we set out to do? Probably not. Nevertheless, we can feel satisfied and rewarded that because of our contributions, the seeds of Patient & Family Centered Care as a philosophic standard on which to base health care provided to Albertans have been sown.

However, as I survey the innumerable consultations in which I have participated, I am compelled to ask a few questions. Has the health system in Alberta fundamentally changed how patients and family members are cared for or would we simply like to think it has? There is evidence of growing awareness of Patient and Family Centered Care principles and more discussion around changing organizational values and policies to reflect that changing attitude and vision. Buzz words fairly dance around meeting tables and there is increased demand to have patient/family representation at administrative meeting tables, an obvious sign of changing expectation. However, is practice changing where it counts? Are patients experiencing improved access and effective, timely communication with their significant health care providers? Are patients and family members involved in their own health care decisions and are they well informed to make those decisions? Is every person treated equitably? There still is much to do and much remains to be accomplished.

I depart from the Patient Family Advisory Group knowing that the work will continue in the competent hands of a Group who have new energy and renewed commitment. It is up to those who will take our places at the meeting tables of AHS to speak plainly, firmly, and fairly as they continue to nurture the seeds of PFCC to full maturation. They will need to be the wisdom and conscience for the organization, ever alert to remaining a separate Patient and Family cell with a specific ancillary function, contributing members of a health system but not part of that system. The Group must exemplify for all Albertans the autonomy of the Patient Voice. This “fundamental change” must take place throughout Alberta Health Services before patients and families are truly heard and recognized as full partners in their own care. I wish the members and staff well in this great endeavor.

Linda Howitt-Taylor

Deb Runnalls - Vice-Chair Patient and Family Advisory Group

As I step away from PFG and reflect back at the amazing journey that we have all been on together, I am profoundly moved by the unfolding of a story I could never have anticipated. The formation of this Group more than 6 years ago came from the hopes and dreams of a few committed patient and family members who were desiring to use their own stories, often stories of horror and pain, as a means of transformation within a system that many felt hurt by. This small group, supported by dedicated and passionate AHS staff members and Dr. Chris Eagle, soon realized that we were not in actuality gathered to transform a system, but rather to be part of transformation of ourselves. We were witness to each of us finding our voices and our passion and commitment to this cause, while becoming a family, united by the bond of vulnerability. In the telling of the story each of us was willing to look into the eyes of the others and accept pure understanding, shared wisdom and the strength to become advisors on behalf of all Albertans.
Messages from Chairs (con’t)

This then was the beginning of a group who gathered with the hopes of transformation and soon realized it was much more than that…this was an opportunity to be the conscience of a giant system, but one filled with individuals very similar to us. And because the Group was always represented with leaders from the top of AHS, it ensured that the work done by PFG, the recommendations, the wisdom, the sharing, was reflected in all levels, inclusive of policy and leadership. And this is where the transformation became apparent. PFG was able to speak into and represent the Patient and Family Voice at all levels of AHS. This was the level of commitment given to this group and therefore was the level of work produced.

As the Group moves forward, it will require the continued level of excellence from the highest levels of AHS in commitment to having leadership sit at this table. This will build sustainability and ensure that the recommendations from the group are carried forward and respected. This would honour the fact that this group and its wisdom represents health care for all Albertans and ensure the integrity of the work done is supported.

I have been honoured to serve on behalf of Albertans in working to grow a better and more connected health care system. Putting patients first and ensuring that the system never deviates from truly representing a united health care system is critical and the PFG is the one voice that can ensure this.

Deb Runnalls

Lona Leiren—Incoming Co-Chair Patient and Family Advisory Group

It is a privilege and an honor to have the opportunity to help steward PFG over the next two years. This feeling was underscored for me at our June 2016 meeting, where we heard from our "historians" - founding Vice-Chair Roger McAdam and other original members sharing observations on their learning journey over the last 6 years. Their passion and early vision to become a strong, relevant and effective voice for Patients and Families throughout AHS still resonates with intention and purpose of PFG members today.

Our Group holds a unique view, as we work "with" AHS but are not "of" AHS. We strive to ensure that our work informs the strategic priorities of AHS; we also remain attuned to the emerging issues, pressures and the "lived experiences" in the health care systems of our home communities. Our representatives from across Alberta's diverse rural and urban areas can always be counted upon to provide direct, authentic, holistic and pragmatic feedback.

As such, it was affirming to hear the words of our past Co-Chair, Dr. Verna Yiu, who relayed that PFG "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 a patient and family lens." It also exciting to hear of the 475 Patient and Family Advisors now also serving throughout AHS, and that this is becoming the "new normal" for the organization.

I am looking forward to working with Co-Chair Dr. Rollie Nichol, Vice-Chair Maya Charlebois and the great team of AHS Patient Engagement staff who will help us steward this legacy and over the next 2 years.

Lona Leiren
Messages from Chairs (con’t)

Dr. Rollie Nichol —Incoming Co-Chair Patient and Family Advisory Group

The impact of the Patient Family Advisory Group continues to gather strength and energy as the value of its experience and wisdom is experienced by an ever increasing number of AHS groups. An increasing number of AHS initiatives are experiencing it for the first time and some projects return for additional insight and deepening their focus on the Patients served. This year saw the Group stretch ourselves strategically and display a willingness to explore new areas of potential value and transformation within AHS.

Dr. Rollie Nichol

Maya Charlebois —Incoming Vice-Chair Patient and Family Advisory Group

In looking forward to this next year as part of the PFG, I am thrilled to be able to continue to be working with colleagues, including patient family advisors and staff, that truly are focused on enabling the ability of Alberta Health Services to become patient and family centered in all areas and at all levels of the organization. What is most exciting is that with expansion of the PFG by the addition of new members we will be able to provide even a better breadth and depth of perspective for processes that will enrich the relationship between patient, family and care giver.

Maya Charlebois
What the Patient and Family Advisory Group Does

The Patient and Family Advisory Group (PFG) has been helping to bring the Patient and Family Voice into Alberta Health Services since December 2010.

The PFG is a formal collection of 28 volunteer Patient 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 centered. 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 centered care. Advisors comment that “our role is to work with AHS to improve the Patient Experience”.

Value for Dollars

The Group continues to be an economical, value for money investment especially when one considers how this group has contributed to help change the culture of the organization to be more Patient and Family Centered. As our CEO 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.”

PFG and Beyond

The Group has contributed in many ways over the last year - through their work, together as a group of Advisors, individual commitments presenting at conferences and events, sharing their stories 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 symposiums with Alberta Innovates, and have presented at the International Patient and Family Advisory Conference in New York. In the past year, this Group has completed 45 consults. These consults occur both during and outside of regular meeting times. There continues to be consistent asks for the Advisors to sit on various projects, committees, etc., both inside and outside the AHS organization.

This year the trend has continued for large ongoing priority projects to come back continually to consult with this Group. This year that has included CoACT (Dr. Ann Colbourne and team), Assisted Living Options work (Signe Swanson and team) and the Medical Assistance in Dying Initiative (Dr. James Silvius, Leeca Sonnema and team). The ongoing connection has really helped to partner with one another and help drive change in our system.
The year has also been a year of reflection and questioning for many of the Advisors on the Group and the staff who support this Group as 2016 marked six years of existence for the Group and an opportunity for reflection of where does this Group focus their efforts. On June 16, 2016, the current PFG Group and some Alumni took the day to reflect and brainstorm on what should be the priorities for the Group in the future.

From this day, further work happened with the Co-Chairs over the summer to refine priorities and start on some of the recommendations made at that day. Priorities and values for the group identified were:

- Continue with the strong desire of the Group to only be involved in those areas that are priority areas for the organization as well.
- A desire to better connect this Group with other advisory groups within and outside the organization.
- To be strongly linked and involved with Patient First Implementation. The potential role of Patient and Family Advisors is critical for this work.
- To support the IM/IT Work for the provincial CIS.
- To continue to understand and work for health promotion and prevention.
- To support work in transitions in care to improve the patient experience.
Value to the Organization (Comments from those who consulted with the Patient and Family Advisory Group)

All groups that consult or work with the Patient and Family Advisor Group are annually sent a questionnaire to determine how they have used the information obtained from the Group.

This year some comments obtained started to show the need in certain projects for the partnership of Advisors and Providers to start much sooner and be more focused and sustained. This illustrates what our Advisors have told us for a while, “Bring us in early and we work alongside each other to co-create and co-design.”

General comments:
- “Tremendous value, wish we could do it more.”
- “If we worked with such groups and advisors on a continued and sustained basis we could establish a better understanding and solicit more impactful feedback.”
- “Connection begets connection – the more we know about possibilities the more we consider possibilities for engagement and involvement – we are building organizational capacity to have patients and families involved in our work.”
- “The representation at the Patient and Family Advisory Group offered many different perspectives and backgrounds. The chairperson was quite skilled at keeping the discussions on track and focused. The participation and level of expression within the group was quite impressive.”

Policy:
- “Experience was positive, however, it was so time-limited (2 months between meetings and very short time allotted due to a packed agenda) that it was challenging to really provide the appropriate context for the Advisory Group to respond adequately. It was challenging to get feedback at the appropriate time when the project itself was less than 4 months in duration. I really enjoyed working with a smaller group which was facilitated rather quickly (timely) and allowed for more in depth discussion than with the larger group.”
- “. .Patient repatriation affects many patients, moving to and from different health care facilities within, into and out of Alberta. The perspective of patients and families is an important one to capture when it comes to communication and expectations in the repatriation process.”
- “I have gone to PFG several times (over the last several years) and I really enjoy it. I believe the input and insights shared within this venue are valuable and very informative.”
Organization comments:
- “Always some good moments and ideas that we take back from the Group. Sometime we are really guided in a direction that was previously outside-the-box.”
- “Very positive. Well organized, good processes.”
- “The CoACT team brought several topics for discussion. This Group represents a wide range of opinions and experiences with the healthcare system and gave us honest and timely feedback. Consulting with the PFG is essential to the design of our patient facing elements. Without their feedback, our work would be lacking the critical input of our more important stakeholders – the people we serve every day. The PFG is a wonderful group of people – very caring and generous with their time and ideas. They exude the feeling that they are doing important work!”
- “The Group shared many insights regarding the importance of word usage and the vertical dynamics of the healthcare system. We draw from their energy and try to present their feedback in our work in a way that we hope reflects their passion.”
- “. . . It was an excellent forum to share the information about our program (Interpretation and translation) as well as hear back about the needs of the patients in the community.”

Strategy comments:
- “We found the PFG – both individually and as a team – very engaging and positive in their recommendations. While they definitely identified challenges and concerns, they were also quick to move to possible solutions – although not always viable solutions for us to follow. The Group is always high in demand, so is sometimes difficult to find enough time on their agenda.”
- “It informed the both the individual elements of the Patient Experience Risk Assessment and the prioritization of cause and impact.”
- “We engaged with PFG on organizational objectives for the 2017-20 three-year fixed Health Plan, and we found the discussion very valuable. It was crucial for us to have a patient perspective on AHS’ direction over the next three years. We were pleased that they tackled all four of the quadrants up for discussion even with being given the chance to focus on only a couple (Four quadrants: Patient Experience, Health Outcomes, Our People, and Financial Health). Their broad understanding of the health system can only benefit the whole organization.”

External Comments:
- “. . .there was great value in consulting with the patient advisors. The feedback from the patients alerted me to many of the issues that patients face in the community pharmacy. Second, pharmacy students benefited from hearing about patients’ experiences with medication first hand, from patients themselves.”
- “. . . It was great to hear multiple voices from a public perspective. We were actually able to incorporate this perspective early on by having a Patient and Family Advisor on our working group. This was deemed to be important from the beginning because of valuable feedback received from this Group on a past version of this brochure. Having this contribution from the beginning was very helpful in terms of incorporating elements that were important to the public (but less obvious to us, such as stating explicitly that this was a free service) and ensuring that the content, format, layout, and language used was appealing and accessible to lay people. The Group asked why we were creating a brochure for the public
and for AHS staff, when AHS staff has other opportunities to learn about the service. As a result, we targeted the case studies in the brochure specifically toward the public (rather than having some case scenarios more relevant to the public and some more for staff).”

- “When students hear stories, they reflect on their own lives. It is this reflection that internalizes learning. In the meeting, I was again surprised by how patients did not have experiences with community pharmacists that truly supported their medication needs. I would like to see how the Patient and Advisory Board could help our faculty in ensuring that patients are well represented in our curriculum.”

Value to the Advisors

This Group continues to get stronger because of those individuals who chose to come to be a part of it but at the same time it creates a space for the advisors themselves to reflect, heal and grow.

All Advisors feel the pressure of trying to ensure they get the context and understanding of each consult that comes to the table and that can be very tiring and stressful, but it is also rewarding. Each year the Advisors are asked “In a sentence or word what is the Group to you?” These are their responses.

- “A practical, "real time" perspective from patients and family members from front line to high level strategic issues (e.g. CoACT; providing the patient and family voice in appeal discussions; quality improvement, innovation, policy and ethics discussions; "just in time" policy and practice development).”
- “Being a new member I am unsure of the concrete contributions that have solved or aided in health care management. However I am aware of the conscientious efforts being made to change in a positive, kind manner.”
- “Most of all, I hope that the Group has contributed inspiration to AHS and to the staff that must respond to new initiatives, continuing change, and a over-burden of work and responsibility. I think we have pointed the way toward the realization of PFCC at every level. We have also contributed a collegial sense of sharing, of trust in each other as exemplified by how we work together with each other and with staff. We have supported AHS and shown the way that patients and families should and can expect of AHS in their health journeys in any area of the province and for any clinical reason. AHS now has to get down to earth, pick the weeds in the garden, and examine the opportunities that are lost or compounded due to ineffective communication and bureaucratic ‘filler’. Get human, get responsive to each other at a staff level, care about each other, and then those working in the system will be able to care effectively for ‘us’.”
- “The honesty and integrity. The patients’ voice has been heard on many levels within the organization. This group has made people rethink how they practice. They show respect
and have eliminated some of the fears people have working with patient and family advisors. Passion to do the right thing at the right time for the right people, not just for patients and families but staff as well. They have slowly tried to bridge the gap.”

- “I believe that the most important contribution that PFG brings to AHS is our ability to remind all healthcare professionals of why they continue to do their job daily...to remember that patients are people first, rather than just a number in the system. We are the faces of Albertans and a reminder for all to stay focused on keeping the “care” in healthcare.”

- “The Group in my mind has immensely contributed to AHS and helped ensure that AHS keeps its promises about patient centered care and to hear the patient voice. We are AHS’ best business partners because we have experienced the system and we know from those experience that some things work, others don’t and we need AHS to listen and start changing to make sure that our positive experience become the norm and the bad experiences are a thing of the past.”

- “The Group very much contributes opinions and experiences from the grass roots level. Since we come from all areas of the province and from all walks of life, we have varying views on health care and its implications. AHS needs to know that not everyone lives in Calgary and Edmonton and that for some getting to medical facilities and appointments is very difficult and at times not even possible.”

- “I feel the Group lends AHS credibility in its claim to be reorienting itself into a patient centered organization. The consults with AHS relating to strategy and business planning give the policy development departments and other non clinical staff an opportunity to have contact with patients and families to exhibit the values that the organization espouses. The Group provides a place for prototyping or test driving ideas.”

- “Our group has influenced the AHS by sharing examples of their personal sacrifices and working with AHS to make the system accountable, more transparent, treating patients as people and not numbers and remind them that these patients are their own friends and family too. Accountability is key to succeed.”

- “It is obvious which groups are talking with us because they are eager for our honest feedback versus the ones who are meeting with us for the first time and are more cautious or skeptical about what we have to offer.”
Having seen items return to us I have noted the changes made to materials to be more easily read by the lay person and to be more a tone of talking with someone versus talking to them. Now believe we are one of many groups with advisors that are contributing the voice of patients and families!”

Diversity

The Future

The future is bright and busy for the Provincial Patient and Family Advisory Group over the next few years. The Co and Vice chairs are strategically working to establish relationships with other internal and external advisory groups to create synergies and further value. The organization continues to mature in understanding patient engagement in order to partner with Patient and Family Advisors to co-create and design the necessary changes needed in our system. This means the wisdom and experience of the Advisors on this Provincial Group will continue to be essential to support these efforts and to mentor new Advisors and Staff as they want to get involved. The opportunities appear to be limitless constrained only by time and resource.
AHS Patient and Family Advisory Group

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@ahs.ca](mailto:patient.engagement@ahs.ca)

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