Partnering with Patients and Families in Alberta Health Services

PROVINCIAL PATIENT AND FAMILY ADVISORY GROUP ANNUAL REPORT 2016-2017

“The provincial Patient and Family Advisory Group (PFG) is a group of diverse individuals that provides valuable personal experiences and knowledge to better the healthcare system for Albertans.”

- PFG Member, 2017
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The Future of Patient and Family Centered Care in Alberta Health Services
As usual, 2016/2017 in PFG was an action-packed year. We provided the patient and family perspective on important and diverse topics: from family presence and visitation, to pharmacy drug changes, community rehabilitation, patient safety reporting and learning system to the new Clinical Information System. Members also helped elevate the patient and family voice in many other AHS co-design processes, such as the AHS Quality Summit, AHS Change Day, the Patient First Co-design Day, and the Surgical Wait Times Transformaton.

While a challenging topic, a particular privilege for the PFG was supporting Dr. Silvius and his diverse AHS team in thinking through the patient and family centered implications when designing and implementing the legislated program of Medical Assistance in Dying. This project is one of many that illustrate the tremendous value and impact of embedding the patient and family perspectives from the start.

I want to thank all our passionate and committed volunteer patient advisors, my Vice Chair Maya Charlebois and Co-Chair Dr. Rollie Nichol, as well as the great AHS team that supports us in providing timely and relevant input to AHS. I know the PFG is an important presence to help reinforce the intention of Patient First.

- Lona Leiren, Co-Chair, Provincial Patient and Family Advisory Group
The Alberta Health Services provincial Patient and Family Advisory Group (PFG) is comprised of 28 patients and family members from across Alberta with a 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. The diverse members of the PFG provides healthcare leaders and project planners insights in the provincial patient and family experience.

**Figure 1.** Geographical distribution of PFG members (20 respondents) as of June 2017
Provincial Patient and Family Advisory Group Members

Types of Healthcare Service Experiences Represented

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Percentage</th>
</tr>
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<tbody>
<tr>
<td>Women's Health</td>
<td>4%</td>
</tr>
<tr>
<td>Sexual Health</td>
<td>4%</td>
</tr>
<tr>
<td>Rheumatology</td>
<td>9%</td>
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<tr>
<td>Respiratory</td>
<td>13%</td>
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<tr>
<td>Renal</td>
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<tr>
<td>Pediatric</td>
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<tr>
<td>Palliative</td>
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<tr>
<td>Otolaryngology</td>
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<tr>
<td>Orthopedic</td>
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<tr>
<td>Neurological</td>
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<tr>
<td>Mental Health</td>
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<td>Endocrinology</td>
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<tr>
<td>Digestive</td>
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<tr>
<td>Cardiac</td>
<td>39%</td>
</tr>
<tr>
<td>Cancer</td>
<td>39%</td>
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<tr>
<td>Addiction</td>
<td>13%</td>
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</tbody>
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Age Ranges Of PFG Members

- **Up to 21 Years**: 22%
- **Between 22-35**: 22%
- **Between 36-60**: 45%
- **Between 61-75**: 6%
- **76+ Years**: 5%

Figure 3. Distribution of age ranges of PFG members (20 respondents) as of June 2017

Figure 2. Distribution of PFG members’ (23 respondents) health experiences as of September 2017. Members have multiple health experiences.
Value of the Provincial Patient and Family Advisory Group

The value of the experiential knowledge that the members of the provincial Patient and Family Advisory Group (PFG) share with AHS is difficult to quantify. However, using the organization volunteer investment ratio (OVIR) to measure the value, for every dollar AHS invested in PFG in 2016-2017 it received a return valued at $2.45 in unpaid volunteer time.¹

Benefits of the Provincial Patient and Family Advisory Group (PFG)

“Going forward I see a huge opportunity now that I am aware of the intent and function of the [PFG] group. The inclusion of staff and patient and family advisors is critical so we don’t develop a product that is not going to be embraced and won’t contribute to goals and objectives of AHS.”

- AHS Staff Member, 2017

81% of PFG members strongly agree or agree with the statement “I feel that my views and opinions are listened to and valued”.

86% of PFG members strongly agree or agree with the statement “I feel that the contributions of the PFG will result in the improvement of person-centered experiences within Alberta Health Services”.

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The members of the PFG came together and identified five priority areas for consultations that aligned with the AHS Business Plan and also proactively addressed the care needs of patients and families across Alberta.
Collaboration to Spark Culture Change: The Patient First Strategy

The Patient First Strategy is one of Alberta Health Services (AHS) four key organizational strategies. It seeks to strengthen AHS’ culture and practices to fully embrace patient and family centred care (PFCC). The PFCC model of care sees patients and families as integral members of the health care team and encourages their active participation in all aspects of care including in planning, implementation and evaluation of existing and future care and services.

The PFG acts as a key collaborator promoting the Patient First Strategy. The PFG supports the Patient First Strategy in two ways. First, it seeks to provide a representative group of patients and families across the province where leaders, project managers, physicians and clinicians can access the patient and family perspective. Second, when consultations come to the group, members of the PFG work with consulters to make the project, policy or strategic plan more patient and family centred.

“Based on the feedback from the PFG members we are more clearly aligned to the Patient First Strategy.”
- AHS Staff, 2017

“PFG helps to improve the focus on patients and families (recipients of care) and thereby improves the quality of healthcare and health outcomes”
- PFG Member, 2017
Impact of the Provincial Patient and Family Advisory Group (PFG) on Alberta Health Services

The PFG consults with a variety of groups in AHS working to improve the design and delivery of healthcare services in Alberta. Over the past 7 years, the PFG members have participated in an increasing number of consultations and become more integrated into the organizational decision making process in AHS. Below are a summary of 2016/2017 consultations where the impact and outcomes could be directly attributed to the PFG.
Key Impacts: Ambulatory Community Rehabilitation Service Re-Design

Initiative
In September 2015, the AHS Rehabilitation Forum recently identified the Ambulatory Community Rehabilitation Service Re-Design initiative as a top priority for Alberta. Together with a wide variety of stakeholders, the project team will plan, design and implement a provincial service delivery model and prioritized clinical pathways for adult and for children’s services.

PFG Involvement
The PFG was asked to provide input on the concepts presented in the Future State document. Specific questions the PFG was asked to answer:
1. Do the elements that underpin the future state for rehabilitation resonate with you?
2. Are there key concepts or elements that are missing?
3. What is the most important thing to you and your family about community-based rehabilitation?
4. What advice would you give to those planning rehabilitation services?

Impact and Next Steps
- The PFG validated and reinforced the concepts underpinning the Future State Model
- The input highlighted particular aspects that focussed attention on components in the model that mattered most to patients and families
- Some of the feedback themes heard from the PFG (access and wayfinding issues, coordinating transitions across programs without having to repeat background stories and assessments, flexibility in how and what services are delivered)
- Planning to bring back work that has been done for a future PFG consult

"[Consulting with the PFG] produced relationships that helped us develop our own advisory group. Having [a PFG member] join the group was important. She provided a role model for members of our Rehabilitation Client & Family Advisory Group."

- AHS Staff, Ambulatory Community Rehabilitation Services, 2017
Key Impacts: After Visit Summary

An After Visit Summary is a document that would contain the desired health information from the patient’s perspective. An After Visit summary enables patients and their families to participate in care planning and goal setting in a more transparent manner. An After Visit Summary could be generated from the new Clinical Information System (CIS) and would provide the patient with information from their individual record.

PFG Involvement
The PFG was asked to review the draft material to provide their thoughts and feedback on a draft After Visit Summary Report. Sample of questions the PFG was asked to answer:

- How would you describe the information sharing between Patients and Providers (current state)?
- Would you like a summary of your clinic appointment?
- Would you see it as a valuable use of your provider’s time to prepare a document that you can take home after your appointment?
- How would you like to receive this summary (e.g. on paper during the appointment, by email, via a patient portal)?
- Who would you share it with such as family, other health care providers, school?

Impact and Next Steps
- The PFG confirmed what we suspected, in terms of patients and families feeling that transition information is important for them to have
- It confirmed that they want an after visit summary
- Confirmed that we are on the right path with the items we are creating, namely the safe transition checklist and integrated care suite
**Key Impacts: Continuing Care Appeal Process**

**Initiative**
The Provincial Home Care Development Team is responsible for administering the *Continuing Care Appeal Process*. The current version of the process was formally implemented September 2015, and is now due for revision.

**PFG Involvement**
The PFG was asked to provide feedback on the current process, specifically related to:
- Size of the review panel, and membership of the review panel (balance of public and/or AHS representatives)
- How the process is made available to the public

**Impact and Next Steps**
- Based on the successful participation of PFG members in the current continuing care appeals process and to ensure that the patient and family voice is equally represented, AHS will increase the voting membership to two patient and family advisors per appeal.

“A special thanks once again to Hugh Sanders and Lona Leiren, for your continued assistance, effort, and expertise with appeals.”

-AHS Staff, Provincial Home Care Development Team, 2017
Key Impacts: Prevention of Violence

Initiative
In alignment with the Alberta Health Services People Strategy, the purpose of the Prevention of Violence pilot project is to contribute to the reduction of incidents of type 2 violence to staff by enhancing the communication of aggressive and violent behavior by patients. A refresh has taken place over the past year. Prior to commencing the pilot, it was critical to engage the PFG for their thoughts, feedback and have discussion over the concern of creating stigma and impacting the quality of care for patients.

PFG Involvement
The PFG was asked to review the draft policy and related documents for AHS Workplace Health and Safety’s Violence Alerts Communication Strategy for staff for the prevention of violence in the workplace.

Impact and Next Steps
- Created a script to share with patients and families based on input from PFG members using softer language such as a ‘loved one’ removed the word ‘violence’ and replaced with ‘aggression’
- The pamphlet approach was discarded for a conversation guide
- Based on feedback from the PFG members on the signage, we removed references to violence and caution and will simply have the symbol on the door
- Based on the suggestion from the PFG members, we engaged with Indigenous Health
- There was concern among the PFG members about communication between providers when transferring to different locations. As a result, we reached out to CoACT
- PFG members also wanted a more holistic approach to violence-related training because patients often have reasons and triggers
- Reassessment was something the PFG members were concerned about. Specifically the timing of re-assessments. Re-assessments will be built into existing practices at specific sites eg. rapid rounds- daily, resident assessment instrument- quarterly
- The PFG feedback was included in the process and the pilot

“Overall, consulting with the PFG members allowed us to be able to validate the work that was done and provide us direction to get closer to the mark.”
- AHS Staff, Workplace Health and Safety, 2017
Key Impacts: Medical Assistance in Dying

Initiative
Due to changes in federal legislation that made Medical Assistance in Drying (MAID) permissible, AHS needed to draft a policy to reflect the province's new legal and policy framework. This included creating resources to support AHS physicians and staff with this legal and clinical change.

PFG Involvement
PFG was asked to provide feedback on the MAID policy and the process map for patients and families.

Impact and Next Steps
- Identified risks for vulnerable persons in the context of MAID
- Identified a need to have a statement around the family role in the process
- Identified two major risks: Personal Directive requests are not to be part of this policy and process and that there will be barriers to access this process for some Albertans
- The consultation process with the PFG group was an iterative process and produced a product that was far better than what was originally presented, even though it was assumed that the policy was doing the right thing before it was presented to the PFG
- Members of PFG were invited to a full-day workshop with Alberta Clinician Council to re-design the process map for patients and families. As a result, an entirely differently product was jointly created

“The PFG has, on a number of occasions, provided assistance on a variety of projects and always to the benefit of what we are trying to do. Because it brings the perspective of the people we are trying to help into the picture.”

- AHS Physician, 2017
The Future of Patient and Family Centered Care in Alberta Health Services

AHS and the Patient Family Advisors continue on their journey of discovery as we explore new territory of collaboration and mutual understanding. AHS is the provincial steward for a health system unique in Canada. For the past 7 years, our Patient Family Advisory Group has led the way in affecting how the people within AHS understand the meaning and actions congruent with being patient-centered. Both the relationship and the impact of the PFG are unique within the Canadian milieu.

As we look forward, two challenges are apparent.

The hundreds of patient family advisors within AHS need to have a more organized and supportive information system and network to encourage shared learning and dissemination of success stories. AHS has facilitated the presence of patient and family advisors within our planning activities, Strategic Clinical Networks™, project implementation groups, and many other areas. However, these individuals are frequently isolated and unaware of the activities of many of their peers. We can help them be much more effective by leveraging their input.

Secondly, we must expand our understanding and the potential for co-design of our health system. We have moved well beyond an understanding of the benefit of reactive input from the people we serve. We can now explore new territory as we transform the health system and realize the intrinsic strength and value of co-designing our services and co-learning from our experiences.

- Dr. Rollie Nichol, AHS Patient and Family Advisory Co-Chair
“Being a part of this group was an honor and let me see that exemplary leadership does exist and that it doesn’t have to be done by those in a traditional, hierarchal type of leadership role.”

- Observer, Nursing Student, University of Alberta, 2017

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