

Engagement and Patient Experience

AHS Patient & Family Advisory Group Terms of Reference

August 2020

Background

Alberta Health Services is committed to collaborating with patients and families in the planning and delivery of safe, quality healthcare services for all Albertans.

The Patient & Family Advisory (PFG) Group is a council of volunteer patients and families 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 healthcare services are patient and family centred.

Purpose

To advise AHS, its' senior leaders, healthcare 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".

Specific areas of Group involvement may include:

- Advising on policies, practices and the application of Patient/Family Centred Care principles.
- Assisting in educating both staff and the public around Patient/Family Centred Care principles and practices.
- Bringing a Patient and Family Voice to advance Patient/Family Centred Care and patient engagement throughout the organization.
- Co-designing on projects, policies and strategies through consultations

Mission, Vision, Values and Principles

The AHS organizational values of respect, accountability, transparency and engagement are key principles that guide the work and relationships with PFG. The work of PFG is reflective of the AHS Vision:

Healthy Albertans.
Healthy Communities.
Together.

PFG Vision: Patients, families, and healthcare providers partner to understand, improve, and enhance the patient and family experience.

PFG Mission: Through advising, we provide the voice of Albertans and advocate for a patient and family centered, quality health system that is accessible and sustainable.

The principles of Patient and Family Centered Care represent the foundational framework by which the Alberta Health Services engages with patient and family partners. These principles are:

- Respect** – Patients and families are listened to and their perspectives and choices are honored;
- Information Sharing** – Health care practitioners communicate and share complete, accurate, timely, and unbiased information with patients and families.

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- Participation** – Patients and families are encouraged to participate in their care and decisions at the level they choose; and
- Collaboration** – Patients and families are partners at all levels of service planning.

AHS Values (June 2016)

Our values are at the heart of everything that we stand for – they inspire, empower and guide how we work together with patients, clients, families and each other.

The values provide us with a common understanding of what's important and guide our actions and interactions in support of providing health care that is truly patient and family centered.

Whatever we do and wherever we work, we contribute to building healthy communities because we are stronger together.

compassion: We show kindness and empathy for all in our care, and for each other.

accountability: We are honest, principled and transparent.

respect: We treat others with respect and dignity.

excellence: We strive to be our best and give our best.

safety: We place safety and quality improvement at the centre of all our decisions.



Membership

The Group is comprised of ~30 patients and family members from across Alberta who:

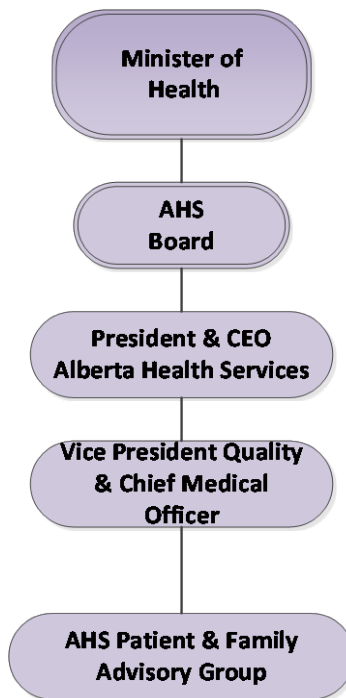
- Have a variety of patient/family health service related experiences.
- Bring diversity to the Group with respect to their location, age, sexual orientation, gender, gender identity, background, culture and patient/family health service-related experiences that reflects the population of Alberta.
- Bring other skills, abilities, experiences, and networks to help advance the work of the Group.
- Have a desire to work collaboratively with AHS in improving the quality, safety and experience of patient care.
- Recognize that participation in other work across AHS increases the richness of participation on the provincial group and thus commit to one other project or committee in addition to PFG specific work after the first year.
- Participate in meetings as scheduled between April-March of each year (with no regular meetings scheduled in July/August). A list of meetings will be provided for the coming year prior to each summer break.
- Optionally participate in additional, as-needed consultation sessions outside regular meetings times.
- Opportunities for informal networking sessions will be scheduled at the request of the members.
- Are not AHS Employees and have not been AHS employees for a period of one year

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The Group is co-chaired by the Associate Chief Medical Officer and an elected patient/family advisor member. There is also an elected Vice Chair who is patient/family advisor member. The Co-Chairs may invite individuals to attend and/or present to the Group at their meetings and/or appoint others as standing or ad hoc members of the Group. See additional information on elected Co-Chair and Vice Chair responsibilities on page 7.

Accountability

The Group reports to the AHS Vice President, Quality & Chief Medical Officer and is accountable to the Quality and Safety Committee of the Board.



Secretariat support is provided to the Group by the Engagement & Patient Experience (EPE) department, led by the Executive Director, EPE, reporting to the Senior Program Officer, Quality and Healthcare Improvement.

The Group submits an annual report and presents on its work to the Vice President, Quality & Chief Medical Officer, for review by the appropriate Alberta Health Services executive committee(s).

Roles, Responsibilities, Expectations and Conduct

Alberta Health Services and the Engagement and Patient Experience Department (EPE) welcomes open and honest discussions and information sharing with the Patient and Family Advisory Group members.

Members are encouraged to assist in the valuable work of providing the patient and family voice to various projects and work undertaken by AHS by contributing at the PFG meetings and participating in subcommittee work or other engagement opportunities where possible. Through

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sharing lived experience of AHS services, together, PFG members advocate for the value and benefit of co-designing health care services with patients and families to advance patient and family centered care.

Patient and Family Advisory Group members are volunteers, supported by the AHS Volunteer Policies and Guidelines.

Expectations and Conduct:

Patient and Family Advisory Group meetings are conducted respectfully with an emphasis on listening and understanding to ensure that all members have an opportunity to participate and that all perspectives are heard. It is the responsibility of the Co-Chairs to ensure that conflict, when it arises, is managed respectfully of all parties and in a timely manner.

Additional expectations on participation and conduct are as follows:

- regularly attend the scheduled PFG meetings and will notify the Senior Consultant/Coordinator if he/she are unable to attend;
- be prepared for the meetings by doing their pre reading work and seeking clarification, if required, in regard to upcoming topics;
- have a demonstrated interest in the health of the community, representing the patient and family voice and health issues;
- demonstrate mutual respect to each other and visitors to the Group;
- uphold Patient & Family Centered Care principles and serving the patient & family interest;
- act in good faith and place the interests of PFG above their own private interests;
- disclose an apparent disagreement or conflict to the AHS EPE Support staff when he or she becomes aware of it;
- will act as representatives on behalf of PFG when working on other AHS Committees and groups and will bring forward topics and issues to PFG as appropriate and within the Group member's expertise or experience;
- participate on quality, safety, and patient experience improvement committees at a governance and senior leadership level, and with specific health service operational leaders and providers, to ensure that the patient/family perspective is included;
- Group members collaborate with and participate in relevant health quality, safety and patient engagement/experience initiatives with other councils within AHS and with other organizations and stakeholders at the provincial and national levels.

The Group's activities are guided by a priority setting Work Plan that is used to help guide the work of the Group and develop the PFG Agendas.

Follow the *AHS Patient and Family Advisory Group Simple Meeting Rules*.

- Keep it concise and focused
- Ask, share, listen, learn and consult respectfully
- Appreciate similarities and differences
- Stay curious and dig deeper
- Remember why we're here
- Strive for better while having patience

Meeting Attendance

A meeting schedule is established at the beginning of each year. A goal for the Group is to have 20 Patient and Family Advisors in person at each meeting. Meetings are held using a virtual platform. AHS EPE staff will assist and acclimate new Advisors to the technology to ensure comfort participating in the meetings. In the event that an in-person meeting is scheduled, arrangements will be coordinated by the PFG Support Team. Flexibility and accommodation of members' needs and abilities is a priority to ensure participation. Meetings are recorded to assist with minutes/notes of consultations.

In addition to the actual meeting times, there is additional time required for reading and preparation work for some meetings.

Opportunities will be presented to the Patient and Family Advisors to participate in other committees and other advisory related work that they can volunteer for as they are able. Outside committee work may require additional travel or expense payment arrangements.

Agendas and meeting minutes are prepared through collaboration of the Co-Chairs and with assistance from AHS EPE staff. Members may submit agenda items to the Co-Chair. Agendas, pre-reading materials and meeting minutes are distributed to Group members in advance of meetings.

Terms of Office

Length of Term

- New members agree to serve as advisors on the Group for a minimum of 3 years.
- Members can serve a maximum of six consecutive years. A term commences from September to August or March to February annually.
- As each member graciously volunteers their time and experience, we recognize that personal commitments, such as family, work, etc. come first. Members may end their term early, as outlined in "Leave of Absence", "Alumni Status", and/or "Step Down".

Renewal

- At the end of any term, and after self-reflection and discussion with the Co-Chairs, AHS Executive Director, Engagement and Patient Experience, and/or designated EPE staff member(s), Group members may be invited to serve an additional term.
- After a two year break former PFG members can reapply to be part of the Group.

Leave of Absence

- Members can take time off up to a year without removing themselves from the Group. A member may request a leave of absence at any time after a discussion with the PFG Support Team. This leave of absence is not counted as time in the six year possible commitment to the Group.

Alumni Status

- For those members who do not renew their term or for those members who have started a term but are unable to continue, an alumni status can be chosen.
- Alumni will be provided with invitations to non-meeting consults and given appropriate information as needed to participate.
- Alumni can be involved with mentoring new Patient and Family Advisors.

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- Alumni will continue to have their name on a registry so will continue to be contacted to be involved with volunteer patient/family advisory work with AHS. Members on the Alumni list would be held to the same rules and guidelines as other Patient and Family Advisors if they take on commitments to partner with AHS. This would include signing confidentiality agreements and following the AHS Code of Conduct.

Commitment

- Members must commit to attend an orientation session, at least 60% of regular meetings each year and a maximum of 2 hours of pre-reading preparation time for each meeting.
- On an annual basis, members will be asked to evaluate their contribution to PFG and to AHS as a whole. .

Step Down

- Members wishing to step down from -PFG during their term should communicate this intention in writing to the Co-Chairs and PFG support team. An exit interview will be offered.

Recruitment

- Recruitment of no more than 10 new members in any one year. The intent is to have staggered numbers of members coming in and going out of the group, so that there is some continuity established between the current and incoming advisors to foster positive and strong relationship building. Term start and end dates for advisors are September and January.

Other Volunteering Opportunities

- Members may choose and are encouraged to volunteer as Patient and Family Advisors in other groups and projects in AHS in addition to this particular group.

Orientation of New Members

A detailed orientation package will be provided to all new members to the Patient and Family Advisory Group.

All new members will have the support of designated Engagement and Patient Experience staff for PFG, and if so desired a current PFG advisor mentor until they are comfortable with the Group's responsibilities and culture.

New members can choose between a fall start and a spring start for their term.

Orientation will be provided to all members prior to attending their first meeting.

Confidentiality and Code of Conduct:

Political Activity: Alberta Health Services (AHS) is a politically neutral organization and does not support or endorse any political party or candidate at any level of government. The Patient and Family Advisory Group is a public body and extension of Alberta Health services (AHS). As a publicly funded organization, volunteers and others who act on behalf of AHS are to maintain a neutral political position (non-partisan). The AHS Political Activity Policy (#1148) recognizes the personal right of AHS representatives to participate in political activities and that any action is done in compliance with AHS's Code of Conduct, the Conflict of Interest Bylaw and other relevant governance documents.

Conflict of Interest: Recognizing that PFG members have interests outside of AHS, they are expected to fulfill their responsibilities in a manner that avoids involvement in any potential, apparent or real conflict of interest situations, and to promptly disclose and address any conflicts should they arise. As outlined in the Conflict of Interest Bylaw, AHS Representatives shall act honestly, in good faith, leaving aside personal interests to advance the public interest, and in accordance with the mandate of Alberta Health Services. Members of PFG are required to take steps to ensure that conflicts of interest are avoided and that any conflicts of interest to which they may be unavoidably subjected are disclosed and appropriately managed and do not affect, or reasonably appear to affect, a decision taken by Alberta Health Services. In the event that a conflict has been identified, it may be necessary to request the affected PFG advisor to step down from the AHS Patient and Family Advisory Group and any other associated AHS volunteer activities.

Confidentiality: Members are reminded they will receive confidential information and therefore, they will not distribute or relay information outside of their volunteer work with AHS. Members must sign a confidentiality agreement in accordance with the Alberta Evidence Act and the Health Information Act.

Diversity and Inclusion: All who are part of or who interact with Alberta Health Services are protected from discrimination on the grounds of race, religious beliefs, colour, gender, gender identity, gender expression, physical disability, mental disability, age, ancestry, place of origin, marital status, source of income, family status and sexual orientation (Alberta's Human Rights Act, amended December, 2015).

Patient and Family Advisory Group Elected Co-Chair and Vice Chair

The PFG Co-Chair and Vice Chair will be elected members from the Patient and Family Advisory Group.

The Co-Chair is elected biannually and serves a two year term.¹ This is followed by a one year term as Past Co-Chair, Ex Officio if the member is at the end of their full term (6 year or extended per footnote below). The Vice Chair is elected annually. The Vice Chair position does not automatically become the Co-Chair.

The AHS Associate Chief Medical Officer also Co-Chairs the Group. The PFG Co-Chair and Vice Chair will be responsible to set the agenda and lead the meetings. The Co-Chairs, working with the AHS EPE support staff, will provide an annual report for distribution to all parties interested in the work of PFG.

Role of the Elected PFG Co- Chair and Vice Chair (if Co-Chair unavailable)

- To help ensure that the work of PFG is meaningful for all members.
- To represent the views and the input of PFG.
- To capture recommendations for meeting agenda items from PFG members.
- To collaboratively review and approve meeting agendas with the other Co-Chairs and with designated staff member from Engagement and Patient Experience (supporting PFG).
- To attend PFG meetings regularly in order to:
 - stay well-informed of the members' activities;
 - help coordinate and lead meetings as needed;
 - ensure the skills and experience of all members are used to their potential.

¹ Those members in their final 2 years of their second term can have their name put forth in the election for Co-Chair. An extension to their term will be granted to fulfil the 2-year term of Co-Chair.

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- To present PFG's work to various audiences as required.
- To provide feedback, when needed, on the design of consultations prior to delivery at PFG
- To help manage conflict within PFG.
- In partnership with AHS Co-Chair and Executive Director, Engagement and Patient Experience, to help manage any conflicts of interest (defined as: potential, apparent or real, please refer to Conflict of Interest By-Law) if they come up for any members while doing the work of the PFG.

Decisions

As an advisory body, the input of all members is valued and will be received by AHS. Consensus of ideas, input and feedback is not required of the group.

Remuneration for Travel and Accommodation

In the event that there would be a requirement for members to travel (i.e., ad-hoc in-person meeting), members will be remunerated in a timely manner for pre-approved travel and accommodation expenses they have incurred for group related work, as per established AHS guidelines upon submission of expense invoices and supporting receipts (AHS Policy Document 1122 – Travel, Hospitality, Working Session Expenses – Approval, Reimbursement and Disclosure).

AHS Patient and Family Advisory Group Support

Direct support and coordination for the Group is provided by Alberta Health Services Engagement and Patient Experience department. This includes administrative support with meeting logistics, timely distribution of pre-reading materials, preparing responses and/or summary materials on behalf of the Group, and assisting the Group in preparing and circulation of minutes, work plans and annual reports. (e.g., strategic planning, recruitment coordination, assisting with Annual Report preparation, etc.).

Review of Terms of Reference

This is a living document and will be reviewed as required, at a minimum on an annual basis by the Co-Chairs and PFG Support Team.