Engagement and Patient Experience

AHS Provincial Patient & Family Advisory Council

Terms of Reference

June 2022



Background

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

The AHS Provincial Patient & Family Advisory Council (PFAC) is a group of volunteer patients and families from across Alberta who bring a richness of diversity based on geography, age, disability, gender, sexual orientation, background, culture and patient/family health experiences, to their role as Patient & Family Advisors.

The work of the Council is based on the values of partnership, collaboration, engagement, respect, transparency, and a foundation of ensuring that healthcare services are patient and family centered.

In January 2022, the Provincial Patient & Family Advisory Group (PFG) and Connect Care Patient & Family Advisory Committee (CCPFAC) merged to form PFAC.

Purpose

To advise AHS, its senior leaders, healthcare providers, staff, and physicians on policies, practices, planning, and delivery of Patient & Family Centered Care.

Patient and Family Advisors (PFAs) comment that "our purpose is to work with AHS".

Specific areas of Council involvement may include:

- Advising on policies, practices, and application of Patient & Family Centered Care principles
- Assisting in education about and communicating to both staff and the public around Patient & Family Centered Care principles and practices
- Bringing Patient & Family voices to advance Patient & Family Centered Care and patient engagement throughout the organization
- Co-designing on projects, policies, and strategies through consultations
- Design, planning, implementation, refinement, and sustainability of Connect Care in direct projects and governance committees

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 PFAC. The work of PFAC is reflective of the AHS Vision:

Healthy Albertans. Healthy Communities.

Together.

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

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AHS Provincial Patient and Family Advisory Council Terms of Reference

PFAC 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 Alberta Health Services engages with Patient & Family Advisors. 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.

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 Council is comprised of ~30 patient and family members from across Alberta who:

- Have a variety of patient/family health service related experiences.
- Bring diversity to the Council with respect to their location, age, sexual orientation, gender identity, disability, 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 Council.
- 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 council and thus commit to one other project or committee in addition to PFAC 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

The Council 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 Chairs and PFAC Support Team may invite individuals to attend and/or present to the Council at their meetings and/or appoint others as standing or ad hoc members of the Council. PFAC aspires to represent best practices in respect and patient engagement and shares learnings with invited guests. See additional information on elected Co-Chair and Vice-Chair responsibilities on page 7.

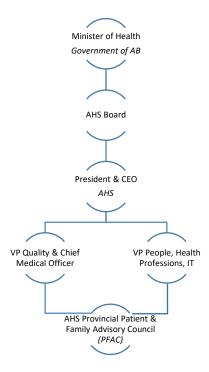
In addition to the Chairs, PFAC Support Team, and members, the following individuals will attend regular PFAC meetings:

- Senior Program Officer- Quality & Healthcare Improvement (or designate)
- CORe Lead- Connect Care Portals (or designate)

Accountability

The Council reports to (Executive Sponsors):

- 1. Vice President- Quality & Chief Medical Officer
- 2. Vice President- People, Health Professions, Information Technology



The AHS PFAC submits an annual report and presents its work to the Executive Sponsors for review by the appropriate Alberta Health Services executive committees, including, but not

limited to, the Executive Leadership Team, AHS Board, Quality and Safety Committee of the Board, and Connect Care Executive Committee (CCEC).

Secretariat support is provided to the Council by the Engagement & Patient Experience (EPE) department, reporting to the Senior Program Officer- Quality & Healthcare Improvement.

Roles, Responsibilities, Expectations, and Conduct

Alberta Health Services, the Engagement and Patient Experience department (EPE), and Connect Care welcome open and honest discussions and information sharing with the Patient and Family Advisory Council 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 PFAC meetings and participating in subcommittee work or other engagement opportunities where possible. Through sharing lived experience of AHS services, together, PFAC 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 Council members are volunteers, supported by the AHS Volunteer Policies and Guidelines.

Expectations and Conduct:

Patient and Family Advisory Council 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 PFAC meetings and will notify the PFAC Support Team if they 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 Council;
- uphold Patient & Family Centered Care principles and serving the patient & family interest;
- act in good faith and place the interests of PFAC above their own private interests
- disclose an apparent disagreement or conflict to the AHS EPE Support staff when they become aware of it:
- will act as representatives on behalf of PFAC when working on other AHS Committees and groups and will bring forward topics and issues to PFAC as appropriate and within the Council 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; and
- 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.

Members, Chairs, consultors, and guests are expected to follow the PFAC document "How We Gather" (Appendix A).

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 Provincial Patient and Family Advisory Council 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 PFAC 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 PFAC 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 PFAC advisor to step down from the AHS Provincial Patient and Family Advisory Council 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).

Meeting Attendance

A meeting schedule is established at the beginning of each year. A goal for the Council 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 PFAC 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 Council members in advance of meetings.

Terms of Office

Length of Term

- New members agree to serve as advisors on the Council for a minimum of 3 years.
 - As CCPFAC members did not have firm membership terms, transitioning CCPFAC members began the first year of their 1st term with PFAC in January 2022.
- 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 the first term, and after self-reflection and discussion with the Co-Chairs, and PFAC Support Team staff, Council members may be invited to serve an additional term.
- After a two year break, former PFAC members can reapply to be part of the Council.

Leave of Absence

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

Alumni Status

- For those members who do not renew after their first term concludes or for those members who have started their second 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.
- 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 pre-reading preparation time for each meeting.
- On an annual basis, members will be asked to evaluate their contribution to PFAC and to AHS as a whole.

Step Down

 Members wishing to step down from PFAC during their term should communicate this intention in writing to the Co-Chairs and PFAC 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 council, 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 council.

Orientation of New Members

A detailed orientation package will be provided to all new members to the PFAC.

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

Elected Co-Chair and Vice Chair

The PFAC Patient and Family Advisor Co-Chair and Vice-Chair will be elected members from the Patient and Family Advisory Council.

- The PFA Co-Chair is elected every two years and serves a two year term.
- 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 years or extended per footnote ¹ below).
- The Vice-Chair is elected annually and serves a one year term.
- The Vice-Chair position does not automatically become the Co-Chair.

Non-Elected, AHS Co-Chair

The AHS Associate Chief Medical Officer also Co-Chairs the Council. The PFAC 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 PFAC.

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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 fulfill the two year term of Co-Chair.

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

- To help ensure that the work of PFAC is meaningful for members.
- To represent the views and the input of PFAC.
- To capture recommendations for meeting agenda items from PFAC members.
- To collaboratively review and approve meeting agendas with the other Chairs and with the PFAC Support Team.
- To attend PFAC meetings regularly in order to:
 - o stay well-informed of the members' activities;
 - help coordinate and lead meetings as needed;
 - o ensure the skills and experience of all members are used to their potential.
- To present PFAC's work to various audiences as required.
- To provide feedback, when needed, on the design of consultations prior to delivery at PFAC
- To help manage conflict within PFAC.
- In partnership with the AHS Co-Chair and PFAC Support Team, help manage any conflicts of interest if they arise for any members while doing the work of the PFAC

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 regularly required of the council. If decisions or votes are required, a full record of responses will be provided to the consulting group. Although not required, PFAC can put forward recommendations regarding Patient Experience to the appropriate AHS senior leader.

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 council 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).

Council Secretariat Support

Direct support and coordination for the Council 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 Council, and assisting the Council 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

The Terms of Reference will be reviewed as required, at minimum on an annual basis by the Chairs and PFAC Support Team.

Appendix A – How We Gather

AHS Provincial Patient & Family Advisory Council How We Gather

Engagement Guidelines for Members, Chairs, Consultors, and Guests

- Ask, share, listen, learn, and consult respectfully
- PFAC is a safe space to share relevant personal experiences and feedback, at all times: during and outside of
 consultations
- Compassion for self and others
- Maintain a growth-mindset
- Respect the boundaries of other members
- Stay curious and dig deeper
- Feedback loops and consultation follow-up are provided regularly
- Listen to understand, not respond
- Appreciate similarities and differences
- Come prepared

Revised: June 15, 2022