

Patient and Family Advisory Committee (PFAC)

Terms of Reference

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PATIENT AND FAMILY ADVISORY COUNCIL (PFAC) TERMS OF REFERENCE

These Terms of Reference are fluid and flexible enough to meet the changing focus and needs of PFAC.

BACKGROUND

The Saskatchewan Cancer Agency (SCA) is committed to collaborating with patients and families in the planning and delivery of safe, quality oncology services for patients and families across Saskatchewan.

The Patient and Family Advisory Council (PFAC) is a formal group of patients and family members, and SCA staff from across the province of Saskatchewan. PFAC was established as a result of SCA's assurance to truly focus on meeting the needs of patients and families. The Council assists the SCA to blend the voices of patients and families with physicians and staff to provide excellent care and service.

In April 2011, the Allan Blair Cancer Centre and the Saskatoon Cancer Centre Lay Committees merged to form the Patient and Family Advisory Council.

PURPOSE

To engage and collaborate with patients and families across Saskatchewan to gather their advice on both advancing a patient and family-centred approach to health and improving the patient experience across the cancer journey. PFAC will advise the SCA senior leaders, healthcare providers, and staff to embed the patient and family perspective in all aspects of the SCA from design to evaluation.

VISION, MISSION, VALUES AND PRINCIPLES

PFAC Vision: Patients and families are fully integrated into the teams that develop, implement, and provide cancer services.

PFAC Mission: We are committed to advancing patient and family-centred care through health promotion, early detection, treatment, and research for cancer.

PFAC Values: Our Values are at the heart of everything that we stand for – they inspire, empower, and guide how PFAC works together. 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 centred. PFAC has adopted the SCA's Values:

- Courage – we are willing to do things that are difficult
- Integrity – we are fair and honest, open and accountable
- Vision Driven – we work collectively towards a healthy population free from cancer
- Innovation – we think and act creatively in the pursuit of excellence
- Collaboration – we work together as a team to achieve our common goals

PERSON CENTRED CARE PRINCIPLES

PFAC has adopted the four core concepts of person centred care:

- **Respect and dignity:** Care providers listen to patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
 - **Information sharing:** Communicating and sharing information with patients and families in ways that are supportive and useful to allow patients to actively participate in their care.
 - **Participation:** Patients and families are encouraged and supported in participating in care and decision making at the level they choose.
 - **Collaboration:** Healthcare leaders work together with patients and families to improve their experience and care.
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ROLES, RESPONSIBILITIES, EXPECTATIONS, AND CONDUCT

- Shall be committed to building a partnership of advisors and staff working to understand the needs of the patients and families they represent.
- Shall participate and support the review and implementation of programs and policies that address health care challenges within the organization and/or province.
- Shall prepare for and participate in Council meetings and in various committees or projects as required.
- Shall practice rules of healthy communication, be able to work collaboratively with staff and other advisors, be open to challenges and assist in communicating the activities of the group to others.
- Shall regularly attend and actively participate in meetings. When unable to attend, members will notify the PFAC Coordinator in advance. Council members will take responsibility to obtain updates as required.
- Shall ensure the confidentiality of all meetings and corresponding documentation.
- Shall respect and understand the differences between Advisory and Advocacy roles and the Council's duty to represent the collective voice of all patients, clients, and families.
- Shall adhere to the Council's adopted Rules of Order and Meeting Protocols.
- Shall act in good faith and place the interests of PFAC above their own personal interests.
- Shall act as representatives on behalf of PFAC when working on SCA Committees/groups and will bring forward topics and issues to PFAC as appropriate.
- Shall report of provincial and national committee activities outside of PFAC related to cancer.

Committees and working groups are formed for several reasons (i.e. Review a process, develop patient materials, etc.). It is the responsibility of the Council members to submit written reports that updates the Council on progress, results and any decisions or suggestions that need to be made that includes the Council. Notes can be made based upon meeting minutes that are shared with each working group.

MEMBERSHIP STRUCTURE

PFAC membership will be reflective of Saskatchewan's population and the patients, clients and families who are served by the SCA. Members will bring perspectives and experiences based on their individual diversity. These may include:

- Cancer diagnosis and journey/other health-related experiences
- Geographic location
- Demographics
- Background (may include cultural and spiritual beliefs)

PFAC will have a maximum membership of twenty (20) representatives. Membership will include Patient Family Advisors (PFA), applicable SCA staff, and may include community stakeholders who affect the patient and family cancer journey. Council members will be no less than 60% of the membership. Membership will be fluid and flexible enough to meet the changing focus and needs of PFAC.

There will be no more than thirteen (13) PFA's appointed to the PFAC, led by two Co-Chairs. The remaining seven SCA members include the CEO, Board of Directors appointee, PFAC Coordinator, and four other staff members selected by the CEO.

The Co-Chairs are Council members who have been appointed by PFAC. The Co-Chairs will convene PFAC and Executive Committee meetings and ensure that PFAC's goals and objectives are met each year. The Co-Chairs will also be the PFAC spokespersons and attend meetings and events as requested. Co-Chairs will serve for two years. However, the terms will be staggered so that there are not two new Co-Chairs every second year. When the Co-Chair's term has ended, they will become the Past Chair for one year. There will never be more than one Past Chair at any one time. This structure will be fluid and flexible enough to meet the changing focus and needs of PFAC.

The SCA CEO sponsors PFAC. The CEO provides oversight to the direction of PFAC and ensures alignment with SCA's Vision, Mission and Values. The SCA CEO holds the ultimate authority for decision making and approval in all matters related to PFAC.

PFAC is provided with a line of sight and a relationship with the Board of Directors through ex-officio membership as determined by the Chair of the SCA Board of Directors.

The PFAC Coordinator, reporting to the CEO, will provide administrative and governance support for PFAC daily. The Coordinator will work closely with the Co-Chairs and the Executive Committee, as well as the Council and any internal/external stakeholders.

PFAC, in conjunction with the CEO's recommendation, will appoint the Executive Committee Council members. The Executive Committee consists of the two Co-Chairs and a maximum of three additional Council members. These additional Council members will be appointed based on their demonstrated leadership, experiences, and skillsets that align with PFAC's goals and objectives.

TERMS OF OFFICE

a) Recruitment

All PFAC members are encouraged to recruit members through interactions, personal networks and sharing approved social media messaging from the SCA social media platforms. These referrals will be sent to the PFAC Coordinator for initial contact and follow-up.

b) Eligibility

Consideration is given to ensure PFAC membership is appropriately reflective of the Saskatchewan population and the patients, clients and families who are served by the SCA. Eligibility for consideration of membership includes:

- Experience within the Saskatchewan cancer/health system as a client, patient, family member, caregiver or friend who is currently not employed by the SCA.
- Knowledge of any part of the cancer system such as prevention, screening, treatment, survivorship, or palliative care.
- 6 months to 1-year post active treatment (chemotherapy or radiation therapy) and those living with cancer (i.e. metastatic cancer) unless otherwise approved by the PFAC executive.
- Desire to work to improve quality, safety, and experience of patient care, and
- The ability to represent, think, and act on behalf of all cancer patients and families.

c) New Members

PFAC will offer prospective members an opportunity to explore the suitability of membership. New members are offered the opportunity to attend one or two consecutive PFAC meetings. This opportunity provides the prospective new member and PFAC to gauge competencies and compatibility. Prospective members will not be paid an honorarium, as they are guests at these meetings.

Once the prospective member has attended one or two PFAC meetings as a guest, the Coordinator will ask their engagement preference. They will be advised their appointment as a PFA for the SCA is subject to the PFAC Executive Committee's approval. The Coordinator will contact the prospective member with the Executive Committee's decision. The Orientation and Onboarding process will be followed and a mentor will be assigned to the new member. New PFA's will serve a 1-year probation period. See Section E. Terms.

d) Nomination and Appointment of Co-Chairs

The Co-Chair position is filled by two PFAs who are members of the Council. The nomination and appointment of the Co-Chair will occur annually at the last PFAC meeting of the term year. This will ensure the new Co-Chair has ample time for orientation with the CEO, the current Co-Chairs, and the Coordinator before the beginning of the next term year.

In the instance that there is only one Co-Chair to lead the Council for circumstances out of the Council's control, approval must be obtained from the SCA CEO to proceed with one Chair until such time that the request for nominations are sent out for the next terms.

One month before the last PFAC meeting of the term year, the Coordinator will seek from PFAC nominations for the Co-Chair vacancy for the new term. To be nominated for Co-Chair, the PFA must have served on PFAC for at least one full year.

The nominations must be in written form and include the competencies and skillsets of the nominee that will align with the PFAC's strategic goals and objectives. Once the Coordinator has received all nominations, the Coordinator will present the nominations to the CEO and Executive Committee for review. The Executive Committee will select from the nominations a candidate that will best represent PFAC, their values, goals and objectives. A recommendation will be submitted at the next PFAC meeting for approval.

If one or both Co-Chairs cannot preside over the Council, then the Chair/Co-Chair will be designated by the Executive with guidance and approval from the CEO.

e) Terms

All PFA's will serve two years, regardless of the choice of engagement. Two months prior to the end of their term, the Coordinator will contact each PFA to ask if they would like to renew their appointment for another two years. New PFA's will serve a 1-year probation period from the date of the signed contract. The appointment renewal is subject to the PFAC Executive Committee's approval. The Executive Committee will take into consideration the PFA's commitment, attendance, and skills before they approve or do not approve, for an additional term.

The maximum term length is six-years or three consecutive terms. There is a waiting period of two years to rejoin PFAC after serving the six consecutive years.

Advisors who have completed their maximum six-year term, have gained an extensive knowledge of the SCA and its operations, have two options available that they could seek out:

- Apply to volunteer at the cancer centres; or
- May remain active as a PFAC Partner for 1-year on a committee or project, following the final term on PFAC and written updates are provided to the Coordinator prior to each Council meeting. This is subject to Executive Committee approval.

If the Past Chair has served their maximum six consecutive years on PFAC, they will serve one additional year on the Executive Committee as the Past Chair. If at the end of the Past Chair's time on the Executive they have remaining time in their term on PFAC, they will revert and complete their time on the Council.

Executive Committee members (not including the Co-Chairs or Past Co-Chair) will serve for two years on the Executive with staggered terms. Upon completion of terms, advisors can re-apply through the normal process of a call of interest to be part of the Executive.

f) Former Past-Chairs

Past Chairs who are no longer members of PFAC due to the end of the six-year term, or for other reasons, can still play an integral part of PFAC. Past Chairs may be called upon as Partners/Mentors to participate in areas that would require the Past Chair's skillset and expertise.

g) Attendance

The SCA respects the voluntary nature of PFAC membership and understands and supports PFAC/life balance. Regular meeting attendance and participation are required and encouraged. Attendance support discussions will occur in the event the Advisor is absent for more than two consecutive meeting occurrences and/or at the end of the year, if it is determined the Advisor was absent more than they were present at the meetings. The Coordinator will inform the Executive and discuss the next steps if an attendance support discussion is required or not.

The Co-Chairs will confidentially conduct the attendance support discussions with the PFA. The Co-Chairs may ask the Coordinator to attend these discussions in an administrative capacity. The Coordinator will track attendance for Council, Executive, Committee, Working Group and other types of engagement (if available).

h) Discontinuing Membership

The changing needs of PFA's such as availability, competing priorities, employment and health status may result in the PFA choosing to discontinue their membership before the end of their term. If the PFA chooses to discontinue their membership before the end of their term, they will email the PFAC Coordinator two months' before the end of the term. In emergency situations, there may be exceptions to the notice period. The PFAC Coordinator will notify the Executive Committee of the PFA's decision.

If the Co-Chairs choose to discontinue an advisor's membership before the end of their term, the Co-Chairs will inform the Executive followed by a review with the member of any unresolvable conflict, significant attendance issues, conflict of interest, and breach of confidentiality or inappropriate actions/behavior that has been brought to their attention. After their review, the Co-Chairs will bring their recommendations to the Executive Committee for a decision. If the membership is revoked by the Executive Committee, the member will be removed and will not be permitted to apply again to be a member in any capacity. The Executive Committee decision cannot be appealed by the member.

PFA's may be asked to discontinue membership if the following events occur:

- Unresolvable conflict with other patient and family advisors, staff or otherwise, and/or,
- Significant attendance issues, conflict of interest, breach of confidentiality or inappropriate actions/behavior.

EXECUTIVE COMMITTEE

The Executive Committee will provide oversight to PFAC. This Committee will be comprised of the two Co-Chairs, the Past Chair, the CEO, the Vice President Care Services, and three additional appointed PFAC members, as well as the Coordinator. The maximum number of PFA's shall be five with a total Executive Committee membership of eight. The Executive will meet on a bi-monthly basis by videoconference, teleconference, or other means to conduct the meeting. The schedule will be set in advance, but flexible in the event quorum cannot be met and to maximize attendance.

Duties and Responsibilities of the Executive Committee shall include but not limited to:

- Development of PFAC Strategy and operational priorities for PFAC approval
 - Recommendation of PFAC committees and work groups for PFAC approval
 - Review of proposed PFAC meeting agendas
 - Investigate and research applicable items to provide background, content and preliminary recommendations and/or feedback to PFAC for approval
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- Review of Terms of Reference, Rules of Order, policies, and other governance documents for recommendation for Council approval
- Interviews with potential advisors
- Approval of PFA membership
- Attendance support discussions
- Conflict management and issues resolution
- Review and oversight of emergent issues
- Delegate as ex-officio on the Board Quality, Safety and Risk Committee

Executive Committee members may be required to participate in additional and complex projects/committees on behalf of PFAC. This participation will ensure the patient and family voice is included along with the advisor's experience and knowledge.

PATIENT AND FAMILY ADVISORY COUNCIL

The Patient and Family Advisory Council serves as the patient voice and provides an opportunity for patients and family members to help the SCA improve the overall cancer experience. PFAC shall meet at least quarterly by videoconference, teleconference, or other means to accommodate the members to conduct the meeting. The Council meeting schedules shall be set annually and are flexible to adapt to lack of quorum and to maximize membership. PFAC's scope is to impart concepts based on the patient, family member, and client experience in order to:

- Encourage a greater understanding of the healthcare experience through the eyes of the patient and family.
- Identify opportunities for improving the patient and family experience.
- Assist in the evaluation of patient and family resources.
- Participate in SCA projects and committees and advise on policies and practices that support patient and family engagement.
- Act as a liaison and resource for patient centred care activities external to SCA.
- Support patients and family members to be full partners in their cancer treatment and care.
- Generate areas of focus and priorities for the improvement of the patient experience and advise on strategies for partnering with patients and families in designing, planning, and improving cancer care services.

Potential members may fall into one of the following levels of engagement. These are:

- Council Members (i.e. Advisors): PFAC is comprised of Advisors who are engaged in all facets of Patient and Family-Centred Care (PFCC) work in SCA. The Council members are responsible for championing the direction of PFCC in the SCA through partnership and collaboration with other patients and staff.
- Mentor: Mentors are current Council members who have substantial experience and knowledge of SCA and PFAC principles. Mentors are responsible for fulfilling the responsibilities of education and coaching.
- Partners: Patient and Family Partners are those who have finished their maximum term. They also have a comprehensive understanding and working knowledge of the SCA. Partners have transitioned as active Council advisors to a Partner who may be involved in Strategic Initiatives, Committees or Working Groups with the Agency. See section E. Terms.

COMMITTEES AND WORKING GROUPS

Committees and/or Working Groups, of PFAC, may be formed as needed to address specific issues, priorities, or projects upon the Executive Committee's recommendation to Council for approval. Membership of these committees and working groups will be determined based on PFAC priorities and availability of advisors.

Each of the Committees and/or Working Groups will be Ad Hoc, chaired by a Council member that is appointed by the Committee and/or Working Group membership. The Executive Committee may recommend to PFAC that the Ad Hoc Committee(s) become Standing Committee(s).

The Committees and Working Groups will be supported by two Agency staff specific to the initiative. The maximum PFAC membership, excluding staff, shall be no more than five for any Committee and/or Working Group.

ORIENTATION OF NEW MEMBERS

A detailed orientation and onboarding process will be provided to all new advisors of PFAC. All new advisors will have the support of the Coordinator, Co-Chairs and a mentor until they are comfortable with PFAC's responsibilities and culture.

Orientation will be provided to all new advisors prior to attending their first Council meeting (not as a guest), whether a mentor is assigned yet or not.

GOVERNANCE

PFAC shall follow Appendix A attached to these Terms of Reference. Appendix A is the PFAC's *Statement of Philosophy, Rules of Order, and Council and Committee Meetings Procedures*.

These Terms of Reference and Appendix A shall be reviewed annually by the Executive Committee. The Executive Committee will submit recommendations of revisions to PFAC for approval.

All Patient and Family Advisors are required to sign and adhere to the SCA Confidentiality Agreement as per SCA Policy HR501. On an annual basis, PFAC members will be required to review the SCA Confidentiality Agreement.

All Patient and Family Advisors are required to submit the results of a Vulnerable Sector Criminal Record Check as per SCA Policy HR507.

All Patient and Family Advisors will be offered the opportunity to receive an honorarium and travel expenses as per SCA Policy F521.

All Patient and Family Advisors are required to sign and adhere to PFAC Contract.

TRANSITION

These Terms of Reference and Appendix A will come into effect once the Council has approved them.

Adopted by the Saskatchewan Cancer Agency Patient and Family Advisory Council on September 26, 2023

Created: February 15, 2011

Revised: August 31, 2023

APPENDIX A – PFAC’S STATEMENT OF PHILOSOPHY, RULES OF ORDER, AND COUNCIL AND EXECUTIVE COMMITTEE MEETINGS PROCEDURES

Statement of Philosophy

The Patient and Family Advisory Council (PFAC) governance philosophy encompasses the Agency’s values, behaviors, traditions and organizational culture, structures, accountability, and decision-making processes.

Rules of Order

PFAC’s governance model is consensus based. PFAC will govern through its Terms of Reference.

As an advisory body, the Saskatchewan Cancer Agency (SCA) values and encourages the input of all members of PFAC on behalf of the patients, clients, and families we serve. All patient and family advisor ideas, input and feedback are taken into consideration fully and equally in decision-making. Decisions that are rendered and made final by the Council will be supported by all members.

Recommendations the Council develops on operational-related matters of the SCA are submitted to SCA leadership for final decision and implementation where appropriate. SCA leadership respects the advice of the Council. Recommendations are given significant consideration to enhance the quality, safety, and delivery of care to patients and families.

The purpose of these rules is to ensure that the meetings of the Council and Executive Committee are purposeful, efficient, and are carried out with fairness, reasonableness and in good faith.

Robert’s Rules of Order shall be used as a guideline in assisting the Co-Chairs in conducting the business of the Council and Executive Committee. In the case of a challenge to a ruling of the Co-Chairs on a particular procedural question, the will of the Council, as determined by a majority vote, shall decide the issue.

A. The Co-Chairs

The Co-Chairs preside at all of meetings of the Council. In the absence of the Co-Chairs, the position will be filled by the CEO appointee. Control of the meeting is the responsibility of the person presiding.

B. Quorum

The PFAC Terms of Reference provide the quorum requirement as a majority of Council members. Majority quorum is 50% of the membership plus one based on Robert’s Rules of Order. Once a quorum has been established, the continued presence of a quorum is presumed to exist only until the Co-Chairs or any other member notices that a quorum is no longer present. The Co-Chairs should declare this fact before taking the vote or stating the question on any new motion, as no business will transact in the absence of a quorum. The meeting will adjourn without motion to another date and time to finish the business, or, the PFAC Coordinator will conduct a *Written Resolution*, via email, for termination of the meeting. All Council members must respond for the *Written Resolution* to be valid. Council members should ensure their schedules adhere to the meeting time requirements to avoid loss of quorum during a meeting.

C. Meetings

Council and Executive Committee meetings take place as set out in their annual work plan calendars. Special meetings are booked on notice from the CEO or Council members through the Co-Chairs or called by the Co-Chairs. The PFAC Coordinator will send to Council or Executive Committee members all documentation seven (7) days before the meeting. All Council members

publicly support decisions made by the Council or Executive. All authority is held by the Council as a whole. Council members do not have individual authority to act on behalf of the organization or to bind it in any way.

D. Business of the Meeting

The business of the meeting will be conducted through the proposal of motions to be debated, reports from Committees and/or persons, and questions.

E. Discussion

A member asking to speak to any of the items brought forth during the meeting, must firstly be recognized by the Co-Chairs and shall raise their hand. Once recognized, the member will have the floor. Discussions must be relevant to the subject and impersonal. If the speaker does not adhere to the subject in a courteous, expeditious manner, or otherwise violates the rules of order, they shall be warned.

All members will adhere to the following Ground Rules for Dialogue:



F. Motions

The decision item before the Council will be called for discussion by the Co-Chairs. The Co-Chairs will recognize those members that wish to speak to the item. Once discussion has concluded, the Co-Chairs will ask for a motion (mover) and a seconder. The Co-Chairs may ask again for any discussion before asking “all in favour”. This discussion may result in the motion being amended. If it is amended, the motion must be moved and seconded again. The mover and seconder do not have to be the original mover and seconder.

Withdrawal of a motion is made by the original mover and seconder. If either object to the withdrawal, the motion to withdraw must be put to a vote.

Those wishing to abstain and those wishing to oppose will be captured in the minutes. A majority of those entitled to vote will validate the motion.

G. Lay on the Table

The purpose of *Lay on the Table* is to put off or delay a decision until later in the meeting or until another meeting. The Co-Chairs will decide after discussion if there is not sufficient facts for the Council to make an informed decision. If there is not, the Co-Chairs will ask for a motion to lay on the table the item to another time in the agenda or to a later meeting. This motion will require a mover and seconder. Postponing decision-making is not a preferred method of good governance.

H. Termination

The meeting will terminate when the Co-Chairs ask for a motion to terminate. This motion requires a mover and does not need a seconder.

PFAC Meeting Procedures

The Rules of Order stated above will guide the debate and voting of the meetings of the Council and Executive Committee.

The Agenda for Council meetings will include, at a minimum, reports from the Co-Chairs, the CEO, Committees, and other reports and items for discussion and decision. The Agenda items align strategically with the organization, and the Council will receive regular reports on all on-going matters of significance. The Agendas are developed by the Co-Chairs, the CEO and the PFAC Coordinator. The Co-Chairs will ask for additions or revisions to the Agenda after the meeting has commenced. Additionally, members may submit agenda items for discussion to the Co-Chairs for Council or Executive Committee as appropriate. The Co-Chairs will advise the PFAC Coordinator of these additions.

Advisors that participant on SCA Committees, Working Groups or conduct document reviews (as a few examples) shall provide a written report to the PFAC Coordinator at least one week in advance of scheduled Council meetings. Reports are not necessary for Committee meetings as the minutes will be provided to the Council. Members are encouraged to ask questions or discussion on any of the items referred to within the reports. Committees and working groups are formed for several reasons (i.e. Review a process, develop patient materials, etc.). It is the responsibility of the Council members to submit a written report that updates the council members on progress, results and any decisions or suggestions that need to be made that includes the Council. Notes can be made based upon meeting minutes that are shared with each working group.

An In-Camera session can be called at any time during the meeting. Through the Co-Chairs, a member may request an in-camera session, or if the Co-Chairs believes there is a need for an in-camera session. The Co-Chairs may ask for an adjournment (mover and seconder) to discuss the request with the member, or the Co-Chairs may ask for a mover and seconder to go in-camera. The CEO may be invited to stay through the session, as well as the PFAC Coordinator. No minutes will be taken during an in-camera session. The time, the motion, and the time returning to the regular session of the meeting will be noted in the minutes.

After the meeting has been called to order, entrance and exit times of Council members and guests will be noted in the minutes.

All Committees, Ad Hoc Committees and Working Groups shall follow the Council Meeting Procedures.
