

Patient and Family Advisory Council *Handbook*



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Saskatchewan Cancer Agency

The Saskatchewan Cancer Agency is a provincial healthcare organization with a legislated mandate to provide cancer control for approximately 1.17 million people in the province.

The Cancer Agency has a long history of providing cancer control since 1930. With more than 850 employees at the Agency, we have a large team with expertise in different fields related to cancer control and each staff member is committed to providing clients, patients and families with safe, quality treatment, innovative research, early detection and prevention programs. Our employees are also committed to continuously improve our delivery of programs and services.

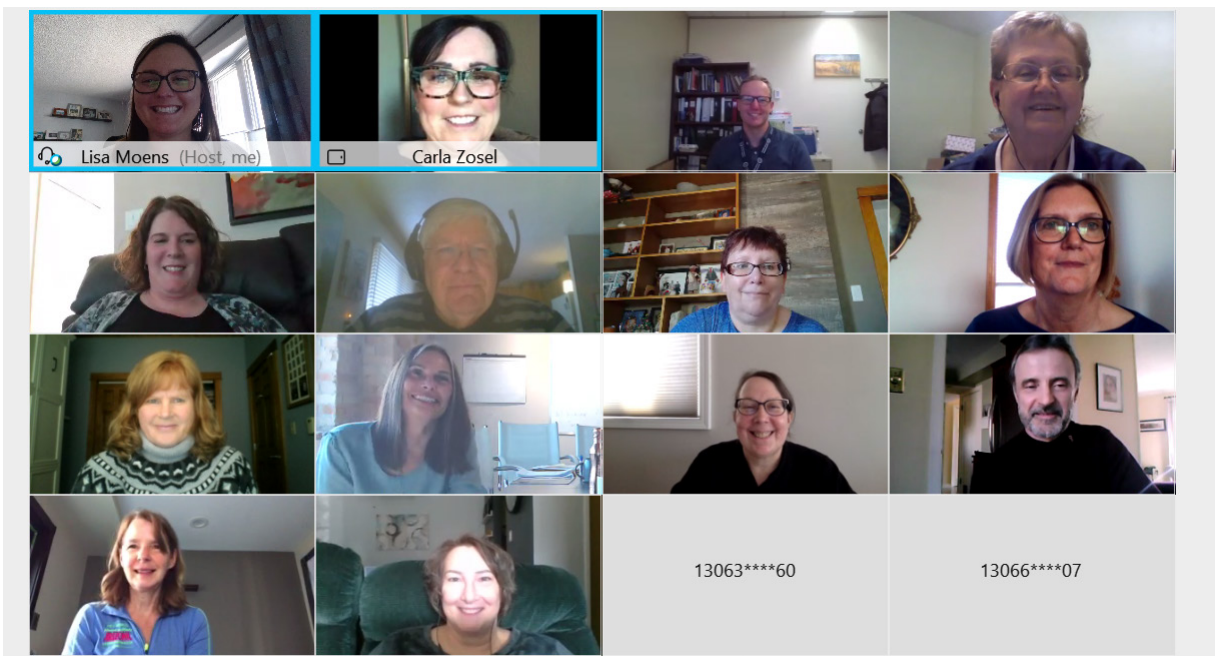
The Cancer Agency is subject to or governed by the following provincial legislation:

- *The Cancer Agency Act*
- *The Health Information Protection Act*
- *The Local Authority Freedom of Information and Protection of Privacy Act*
- *The Provincial Health Authority Act*

Our vision: A healthy population free from cancer

Our mission: To provide leadership in health promotion, early detection, treatment and research for cancer

Our values: Courage, Integrity, Vision-driven, Innovation, Collaboration



Patient and Family Advisory Council WebEx Meeting, April 2021

Patient and Family-Centred Care

Over the past few decades, there has been an international and, more importantly, a national movement regarding the nature of patient involvement in care and how decisions (personal and organizational) are made.

The movement has become known as Patient and Family-Centred Care (PFCC), and recently known as Person-Centred Care. PFCC is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients and families. It redefines the relationships in healthcare.

PFCC shapes policies, programs, facility design and staff day-to-day interactions. PFCC has been shown to lead to better health outcomes, wiser allocation of resources, and greater patient and family satisfaction.

Core Concepts of Patient and Family-Centred Care

- **Dignity and Respect**

Healthcare practitioners listen to and honour 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**

Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

- **Participation**

Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

- **Collaboration**

Patients, families, healthcare practitioners, and leaders collaborate in policy and program development, implementation, and evaluation; in healthcare facility design; and in professional education, as well as in the delivery of care.

Patient and family-centred care is this and more.

It is a culture change, one in which the patient respects the commitment the healthcare provider has made to healthcare, best practices and evidence-based care, and treats the practitioner with respect and honesty, providing information needed so they can best assist the patient to make decisions. In effect, recipients of care and the providers of care share responsibility for care.

Many healthcare agencies have developed patient charters that outline this partnership between providers of care and recipients of that care.

Please see Appendix A for the Saskatchewan Cancer Agency Charter.

The constant of change in PFCC healthcare delivery is in the process of change. This change includes all facets of the healthcare journey for the patient and their families.

Process change is a change in how you do things. Culture change is a change in how you think about things. Person-centred care is not a process change. It is a culture change.

The difference in these two facets of change is both simple and complicated:

- A process change is how we will do things differently
- A culture change is how we will think differently about things. This is not an easy task and will continue to be a challenging task
- We will continue to learn the most from the patients and their families
- We are in the midst of a major culture change in healthcare delivery.

What PFCC is and isn't

What it isn't:

- Family-directed care
- Just another healthcare model
- Just another project to "get done" in a year or two
- Patient or family-focused care
- An overnight success
- A token involvement of patient and families in decision making related to their care

What it is:

- A profound change in culture
- A change in the way work is done and how decisions are made
- A journey that changes and evolves over time and with experience
- A full partnership
- A source of information and assistance
- A permanent, but flexible, change where the healthcare providers and patients and families become a true healthcare team

"I'm very proud of our involvement within the Cancer Agency, provincially and nationally. I feel we are really making a difference for patients and families."

~ PFAC member

Patient Voice in Cancer Care in Saskatchewan

For the past number of years, there has been a movement regarding the nature of patient involvement in care and how organizational and personal care decisions are made.

In Canada, this movement started to take shape 15 to 20 years ago when the Federal Government funded the Canadian Partnership Against Cancer (CPAC). This independent organization accelerates action on cancer control for all Canadians.

The CPAC's efforts cover the whole continuum of care from preventing cancer before it begins to ensuring patients and families have access to appropriate cancer and end of life care (www.partnershipagainstcancer.ca/about/who-we-are/partnership-overview/"cancer control strategy)

At its inception, the patients' voice arm of CPAC was the Canadian Cancer Action Network (CCAN). CCAN was comprised of representatives of cancer and tumour site groups, and patients and families from across the country.

Provinces also moved on this initiative. In Saskatchewan, the Patient First Report, authored by Commissioner Tony Dagnone and developed in collaboration with patients, families, providers and health system leaders, was published and tabled with the Government in 2009. A key finding included embedding patient first as a core value in healthcare.

The Patient First Report stipulated that:

"...the health system make patient and family-centred care the foundation and principal aim of the Saskatchewan health system, through a broad policy framework to be adopted system-wide, and this policy framework should serve as an overarching guide for healthcare organizations, professional groups and others to make the Patient First philosophy a reality in all work places."

In many healthcare organizations, this movement has evolved to the point where any decision where there is a material impact on the experience of patients, a patient will be at the table.

Patient and Family Advisory Councils

So what are patient and family advisory councils? They are:

- A formal assembly of patients, families and partners who bring together a richness based on the diversity of our location, age, gender, background, culture and patient/family/health-related experience to their role as patient family advisors
- The voice of the patient
- Working to strengthen communication and collaboration amongst and between patients, families, caregivers and partners
- Helping to evaluate patient and family resources
- Promoting patient and family involvement at all levels of the organization
- Providing expertise by being a liaison to other similar councils
- Practice respect and dignity in all interactions between patients and healthcare personnel

Why involve patients and families as advisors?

Advisors:

- Bring important perspectives
- Teach providers how systems really work
- Keep staff grounded in reality
- Provide timely feedback on ideas
- Inspire and energize staff
- Lessen the burden on staff to solve problems; staff don't have all the answers
- Offer an opportunity to give back
- Provide positive outcomes for everyone

Successful advisors need similar traits as successful healthcare providers. Patient and family advisors:

- Need clarity on the role they play in an organization, such as advisor, mentor and/or peer support
- See the world with different eyes and respect the expertise of all members around the table
- Act on behalf of the greater good or collective, discarding personal agendas, and not generalizing their own experiences as the truth of all patients and families

SCA Patient and Family Advisory Council: Background

A bit ahead of the game in Saskatchewan, the Saskatchewan Cancer Agency already had in place a Lay Advisory Committee whose primary purpose was to hear specific geographical site/location-based complaints and comments and to work with the local administrations in Regina and Saskatoon.

This group also served in an advocacy and consultation role. The Lay Advisory Committee was in effect two very separate groups, and was not reflective of the provincial nature of the SCA.

In 2011, evidence learned from the Institute for Patient and Family-Centred Care and from consultation with others in our province as well as nationally and internationally, resulted in a rejuvenation/evolution of those two former patient groups.

Representatives of the former Lay Advisory Committee, provincial networks of cancer support groups, including the provincial arm of the CCAN - the Saskatchewan Cancer Action Network (SCAN), patients and families, and SCA staff came together to form the SCA's Patient and Family Advisory Council.

The result was a council with a broader and very different membership and mandate, one with a vision that fostered development of partnerships in care and focused on the shared responsibility for making things better for patients that come after.

Our Journey to Where We Are Now

Our journey mimics group formation theory: forming, storming, norming, and performing.

Forming Phase

During the forming stage, we focused on coming together, developing terms of reference, interview guides, soliciting feedback, working on initiatives that provided tangible evidence of successes and our value to the SCA.

Storming Phase

As our development took us to the storming phase, we continued those activities but also began questioning and challenging policy. Some successes continued.

We became a more cohesive group, weathering some stormy events. In that phase, we engaged each other, and came to appreciate each other and the skill sets that each brings to the table. Most importantly, we learned to trust one another, imperative for a successful PFAC. We all know we have the same shared goals regarding patient-centred care. We are past the stage where it's about getting things done and having concrete items, that tangible evidence of our value to the SCA and patients.

The value of those tangibles: wireless Internet in cancer centres, scrolling TVs in waiting rooms, involvement and presence in 3P activities, events, committees, comment boxes, development of process for recruitment, etc., should not be minimized. Continued development of those tangibles will remain important to patient care.

Norming Phase

We are now transitioning to the norming phase of development. We continue to solicit feedback, question and challenge, as it should be, but we are moving from that stage of group development where developing tangible evidence and being physically present to receive information was enough for the Council, to a phase of development where we recognize the need to be more engaged and work in a different way.

We are putting in place processes that facilitate inclusiveness and clarify assumptions being made. We are doing more in-depth homework/research as to what the evidence says and understanding and learning about the context of the initiative we are working on.

Performing Phase

Once as a Council we began to work more effectively together, doing our homework, sorting out processes and we became more familiar with our own context and our Agency, our desire to do more, to effect change and become more involved has continued to grow as well.

We are a work in progress, not totally there yet but well on the way. We know it takes both the commitment of SCA staff and PFAC membership in walking the talk of patient and family-centre care. This is imperative if the organization and PFAC members are to take a PFAC and PFCC forward. Staff and PFAC membership need to trust each other and come to realize they have the same goals.

To do this, both need to share, see, include and listen. We look at comments we receive from patients undergoing care, surveys being done internally, objective information from themes of areas for attention from our quality of care coordinator, as well as ideas from our staff and physicians.

We routinely survey PFAC membership and staff regarding:

- What's working, what's not working
- Trends in other jurisdictions
- Determining what good looks like for the SCA from the patient and family perspective
- Looking at what the evidence says and what they are hearing...bouquets, concerns

What we've learned:

- Engagement on a basic level doesn't result in effective PFCC, it is only a start
- Effective engagement is part of organizational culture change
- Building trust is key
- A cookie cutter approach to development isn't likely to result in a successful PFAC using various kinds of evidence all along the way is imperative if PFCC and true engagement is to be realized
- Most importantly, what all team members of those initial events learned was that patients and families are in their world and they want to make it their world as well

Every group has to evolve and our Council isn't any different. We came to understand that as a provincial council, we don't control everything and the patient voice doesn't naturally trump everything.

It's more than simply building the patient voice into everything. It's working with the evidence from multiple sources, listening and hearing to what is being said, collaborating to find the best outcome for the patient.

“The strength of the team is each individual member. The strength of each member is the team.”

~ Phil Jackson, former NBA coach

Our Patient and Family Advisory Council

The Patient and Family Advisory Council (PFAC) is a formal assembly of patients, families, community partners and Saskatchewan Cancer Agency staff from across Saskatchewan.

Collectively, based on the diversity of their location, age, gender, background, culture and patient/family/health related experiences, this Council brings strength and wisdom to their role as patient family advisors.

PFAC's voice improves PFCC by providing guidance in the planning, delivery and evaluation of programs and services. PFAC's foundation is based on the PFCC values of partnership, collaboration, engagement, respect and transparency.

PFAC also incorporates the SCA's values of courage, integrity, vision driven, innovation and collaboration in its initiatives.

PFAC's purpose:

- Strengthen communication and collaboration among and between patients, families, caregivers and/or community partners
- Evaluate patient and family resources
- Promote patient and family involvement at all levels of the organization;
- Act as liaison and resource for provincial and regional advisory councils and steering committees external to the SCA
- Assist with quality and safety initiatives for the purposes of pursuing excellence
- Ensure the voices of patients and families are represented in improving care
- Support operations to implement Person Centred Care policies, processes and practices that engage patients and families to improve their experience

The Patient Family Advisory Council is accountable to the SCA's Chief Executive Officer.

Our membership is structured to ensure diversity of the patient/family members, relevant SCA staff, and community partners who impact the patient and family cancer journey. Membership consists of core members, but will be fluid and flexible enough to meet the changing focus and needs of the PFAC. The council will be no less than 60 per cent patient/family advisors with a maximum membership of 20 members.

Evolution in the World of PFCC: Advisor versus Partner

In early 2020, PFC membership reviewed, discussed and deliberated the pros, cons and impacts of changing the name of patient and family 'advisor' to 'partner'.

SCA patients and families are partners on care teams similar to any other team members, such as nurses, pharmacists and doctors. However, their knowledge of all of us as partners does not preclude us from role clarification within the team of partners.

We all have a distinguished role and work has been conducted to also understand the role of the patient and family members in this way. We are all partners, but advise is what the SCA PFAs do.

An advisor is generally a person with a deeper knowledge in a specific area with cross-functional and multidisciplinary expertise. An advisor's role is that of a mentor or guide. A partner is someone who shares or is associated with another in some action.

They believe the role is much more than that. It is consistent for PFAC to focus on their role in a similar way to other collaborative partners within our teams. This is what works for SCA and makes sense to all of our patient and family advisors.

SCA's PFAC has worked very hard for our patients and clients and the community to recognize us as patient and family advisors. This has been an evolution for us. We know that our PFAs are our partners in care.

However, the purpose and function is that of an advisor. SCA believes the PFAs have always been our partners, but through the phases of development, maturity, education and mentoring, our PFAs have evolved to advisors.

PFAC is confident and comfortable with their decision. They appreciate that other organizations have chosen to change the wording from advisor to partner or are already using the word partner.



What Does PFAC Do?

PFAC serves as the patient voice and provides an opportunity for patients and family members to help the Cancer Agency improve the overall cancer experience: Council members:

- 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 on SCA projects and committees and advise on policies and practices that support patient and family engagement
- Act as liaison and resource for patient-centred care activities external to the SCA
- Support patients and family members to be full partners in their cancer treatment and care



PFAC members Michelle and Dawne at the 2019 Patient Engagement Day

Appendix A: Patient and Family Advisory Council Charter

Partners in Care: Our Shared Responsibility *Patients, clients, families, and staff charter*

At the Saskatchewan Cancer Agency, patients, clients, and their families are at the center of everything we do. There is a genuine partnership between care providers, patients, clients and families. This collaborative approach to caregiving and decision-making is the foundation for our shared responsibility as partners in care.

Dignity and Respect

As partners in care, we are all committed to treating each other with dignity, kindness, honesty and understanding. We will listen and honour each other's perspectives. Members of the care team are committed to being compassionate and respectful of the patient's values, needs and personal preferences. Care providers, patients, clients, and family members are committed to accepting the responsibility the care team has to healing and healthcare.

Information Sharing

To ensure the best care possible, we will be open and honest, sharing timely, accurate information with each other. Patients, clients, and families will be supported and provided with access to their personal information when they need or want it. The care team will keep this information confidential and will communicate sincerely and with compassion if things have not gone according to plan.

Participation

Together we will develop a plan that is based on best practice, is equitable, and is right for the patient. Patients, clients and family members will be encouraged to participate actively in their healthcare and decision-making at a level with which all are comfortable. Everyone involved in the care will respect the patient's decision about who is involved in their care and will ask permission before involving others. Patients, clients, family members and care providers will feel empowered to ask for assistance from the healthcare team when needed and will share concerns and ask questions to help the patient make informed decisions.

Collaboration

We are committed to working together to address questions and concerns in a timely way. Patients and clients will provide informed consent for care with the opportunity to change direction and the care team will respect those decisions. Working together, patients, clients, families and the care team will maximize use of resources to ensure seamless care and services that meet the needs of everyone involved.

June 2016

Appendix B: Acronyms and Definitions

3sH	3sHealth
ABCC	Allan Blair Cancer Centre
AHA	Athabasca Health Authority
Alos	Allogenic transplant (patient receives bone marrow or blood stem cells from another person)
APHON	Association of Pediatric Hematology/Oncology Nurses
AOPSS	Ambulatory Oncology Patient Satisfaction Survey
Autologous	Autologous transplant (a patient is their own stem cell donor)
Benign	Tumour with non-cancerous cells
BMT	Bone marrow transplant
CA	Clinical associate/assistant
CADTH	Canadian Agency for Drugs and Technologies in Health
CAPCA	Canadian Association of Provincial Cancer Agencies
CAR-T	Chimeric antigen receptor (CAR) T cell therapy
CCAN	Canadian Cancer Action Network
CCHSA	Canadian Council on Health Services Association
CCRA	Canadian Cancer Research Alliance
CCSA	Canadian Cancer Surveillance Alliance
CFS	Cancer Foundation of Saskatchewan
CIHI	Canadian Institute of Health Information
CIHR	Canadian Institute of Health Research
CLS	Canadian Light Source
CMS	Clinical Management System (electronic system used at the Cancer Agency to create an electronic medical record for patients)
COG	Children's Oncology Group (a clinical trials group devoted to childhood and adolescent cancer research)
COPS	Community Oncology Program of Saskatchewan (program where chemotherapy is offered in 16 hospitals in the province)
CPAC	Canadian Partnership Against Cancer
CPOE	Computerized physician order entry
CPQR	Canadian Partnership for Quality Radiation Therapy
CSCC	Canadian Strategy for Cancer Control
CPG	Clinical practice guidelines
DAC	Data Access Committee
DCO	Death certificate only

ED	Early Detection (SCA department)
eHR Viewer	Electronic Health Record viewer (secure website for healthcare providers to access patient information)
EHS	eHealth Saskatchewan
ELT	Executive Leadership Team
EPIC	Earlier Palliative Integrated Care
ER	Emergency room
FTE	Full-time equivalent
HL	Harbour Landing (SCA Parliament Avenue location)
HQC	Health Quality Council
JPCH	Jim Pattison Children's Hospital
LAFOIP	Local Authority Freedom of Information and Protection of Privacy (legislation governing request for information)
HIPA	<i>Health Information Protection Act</i> (legislation protecting the Personal health information of patients)
LINAC	Linear accelerator (equipment used to deliver radiation therapy)
LP	Lumbar puncture
LTS	Long-term survivors
Malignant	Tumour with cancerous cells
MO	Medical oncology/Medical oncologist
MHO	Medical Health Officer
MRP	Most responsible physician
NAACCR	North American Association of Central Cancer Registries
NCIC	National Cancer Institute of Canada
NP	New patient
NPO	New Patient Office
OR	Operating room
pCODR	pan-Canadian Oncology Drug Review
Peds	Pediatric oncology
Ped Hem/ Oncs	Pediatric hematologist-oncologists
PFAC	Patient and family advisor
PFAC	Patient and Family Advisory Council
PFCC	Patient and family-centred care
PIA	Privacy impact assessment
PICU	Pediatric Intensive Care Unit
PIP	Patients in program

PIS	Patient Information Services (SCA department)
PO	Pediatric oncology/Pediatric oncologist
PSO	Psychosocial oncology
P&T	Pharmacy and Therapeutics Committee
PT	Physical therapy/therapist
PTS	Patients
QCC	Quality of Care Coordinator
QSR	Quality, Safety and Risk (SCA department)
RGH	Regina General Hospital
RN	Registered nurse
RO	Radiation oncology/Radiation oncologist
RP	Review patient
RPIW	Rapid Process Improvement Workshops
RT	Radiation therapy/Radiation therapist
RUH	Royal University Hospital (Saskatoon)
SAHO	Saskatchewan Association of Health Organizations
SAYCW	Saskatchewan Alliance for Youth and Community Well-being
SCA	Saskatchewan Cancer Agency
SCC	Saskatoon Cancer Centre
SCPOR	Saskatchewan Centre for Patient-Oriented Research
SHA	Saskatchewan Health Authority
SHRF	Saskatchewan Health Research Foundation
SLT	Senior Leadership Team
SOP	Standing operating procedure
SPBC	Screening Program for Breast Cancer
SPCC	Screening Program for Cervical Cancer
SPCRC	Screening Program for Colorectal Cancer
SW	Social worker
TATM	Take a TEAM Moment (Together Everyone Accomplishes More)
UH	University Heights (Saskatoon McOrmond Drive location)
UOMS	Unusual Occurrence Management System

Appendix C: Terms of Reference

Patient and Family Advisory Council Terms of Reference

The Patient and Family Advisory Council (PFAC) is a formal assembly of patients, families, Saskatchewan Cancer Agency (SCA) staff, and community stakeholders 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.

PURPOSE

PFAC shall engage and collaborate with patients and families from across Saskatchewan and 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 embed the patient and family perspective in all aspects of the SCA from design to evaluation.

VISION

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

MISSION

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

VALUES

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.

MEMBERSHIP

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 per cent of the membership. Membership will be fluid and flexible enough to meet the changing focus and needs of PFAC.

All members of the Patient and Family Advisory Council:

- 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.

A. STRUCTURE

There will be no more than thirteen (13) PFAs appointed to the PFAC, led by two Co-Chairs. The remaining seven SCA members include the CEO, Board of Directors appointee, Vice President Care Services, Director Supportive Care, Director Patient Information Services, Communications Consultant, and the PFAC Coordinator.

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.

The President and CEO sponsors PFAC. The CEO provides oversight to the direction of PFAC and ensures alignment with SCA's vision, mission and values.

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, SCA Board of Directors.

The PFAC Coordinator, reporting to the CEO, will provide administrative and governance support for PFAC on a daily basis. The Coordinator will work closely with the Co-Chairs and the Executive Committee, as well as all PFAC and Partners.

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.

B. NOMINATION AND APPOINTMENT OF CO-CHAIRS

If one or both Co-Chairs cannot preside over the Council, then the Co-Chair(s) will designate a member of the Executive to act on their behalf. No more than one of the Co-Chairs can be staff at any time.

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.

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.

C. 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 and/or palliative care
- One-year post active treatment (chemotherapy or radiation therapy)
- Desire to work to improve quality, safety and experience of patient care, and
- The ability to limit advocacy to represent, think, and act on behalf of all cancer patients and families.

D. RECRUITMENT

All PFAC members are encouraged to recruit members through interactions and personal networks. These referrals will be sent to the PFAC Coordinator for initial contact and follow-up. Potential members may fall into one of 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 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 that 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 SCA. See section E. Terms.

E. TERMS

All PFAs 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 and ask if they would like to renew their appointment for another two years. New PFAs will serve a one-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 one-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.

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 back and complete their time on the Council.

Executive Committee members (not including the Co-Chairs) will serve for two years on the Executive. The terms will be staggered with the option to renew for another two-year term.

F. 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 PFAs will serve a one-year probation period. See Section E. Terms.

G. 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.

H. 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 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.

I. DISCONTINUING MEMBERSHIP

The changing needs of PFAs 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. PFAs are asked to provide two month's notice if they wish to discontinue their term. In emergent situations, there may be exceptions to the notice period.

PFAs 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.

J. DISCONTINUING MEMBERSHIP PROCESS

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. The PFAC Coordinator will notify the Executive Committee of this PFA's decision.

If the Co-Chairs choose to discontinue an advisor's membership before the end of their term, the Co-Chairs will review with the member any unresolvable conflict, significant attendance issues, conflict of interest, 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.

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 other appointed PFAC members, as well as the Coordinator. The maximum number of PFAs shall be five with 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:

- 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
- 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 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 on 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.

COMMITTEES AND WORKING GROUPS

Council committees and/or working groups 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.

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 SCA staff specific to the initiative. The maximum PFAC membership, excluding staff, shall be no more than five for any committee and/or working group.

GOVERNANCE

As the SCA follows, as per *The Cancer Agency Act* and SCA Bylaws, Rules of Order, PFAC has adopted Robert's Rules of Order.

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 Protocol.

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.

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.

Appendix A to the Terms of Reference

Statement of Philosophy, Rules of Order and Council and Committee Meetings Procedures

Statement of Philosophy

The Patient and Family Advisory Council (PFAC) governance philosophy encompasses the Saskatchewan Cancer Agency's (SCA) values, behaviours, 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 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 Committees 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/Chairs in conducting the business of the Council/Committee. In the case of a challenge to a ruling of the Chair on a particular procedural question, the will of the Council, as determined by a majority vote, shall decide the issue.

A. The Co-Chairs/Chair

The Co-Chairs presides at all of meetings of the Council. In the absence of the Co-Chair, 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. Once a quorum has been established, the continued presence of a quorum is presumed to exist only until the Co-Chair or any other member notices that a quorum is no longer present. The Co-Chair 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 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 Committee members all documentation seven (7) days before the meeting. All Council members publicly support decisions made by the Council. 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-Chair. Members shall raise their hand and state "through the Chair". Once recognized, the member will have the floor. Discussions must be relevant to the subject, impersonal and directed to the Co-Chair. If the speaker does not adhere to the subject in a courteous, expeditious manner, or otherwise violates the rules of order, he or she shall be warned. If the speaker persists, the Co-Chair may rule him or her "out of order", thereby withdrawing the right to speak to the discussion and/or motion.

F. Motions

The decision item before the Council will be called for discussion by the Co-Chair. The Co-Chair will recognize those members that wish to speak to the item. Once discussion has concluded, the Co-Chair will ask for a motion (mover) and a seconder. The Co-Chair 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 objects 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-Chair will decide after discussion if there is not sufficient facts for the Council to make an informed decision. If there is not, the Co-Chair 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. Point of Order

A member may interrupt another member who is speaking by stating Point of Order. This is only used when a member feels that improper language has been used, irrelevant arguments introduced or a rule or procedure is broken. The Point of Order must be stated definitely and concisely. The Co-Chair shall decide, without debate, although the Co-Chair may ask for opinions.

I. Termination

The meeting will terminate when the Co-Chair asks 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 its committees.

The Agenda for Council meetings will include, at a minimum, reports from the Chair, the CEO, Committee Chairs, 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 Council Agenda is developed by the Co-Chairs, the CEO and the PFAC Coordinator. The Committee Chair, the staff liaison if one has been assigned, and the PFAC Coordinator develop committee Agendas. 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 of the Council or Committee as appropriate. The Co-Chair will advise the PFAC Coordinator of these additions.

Committee Chairs shall provide a written report of their Council presentation to the PFAC Coordinator at least one week in advance of the scheduled Council meeting. Reports are not necessary for Committee meetings. Members are encouraged to ask questions or discussion on any of the items referred to within the Committee Chair reports.

An in-camera session can be called at any time during the meeting. Through the Co-Chair, a member may request an in-camera session, or if the Co-Chair believes there is a need for an in-camera session. The Co-Chair may ask for an adjournment (mover and seconder) to discuss the request with the member, or the Co-Chair 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.

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

Adopted by the Saskatchewan Cancer Agency Patient and Family Advisory Council December 2, 2021

My notes
