

Alberta Children's Hospital Patient and Family Engagement Model

At Alberta Children's Hospital we have many years of experience in engaging patients and families as active partners to create better healthcare outcomes. We have used this experience to develop a comprehensive and sustainable framework that coordinates existing engagement efforts and supports long term engagement growth throughout the hospital. This framework includes an ACH engagement model that provides clear visibility and understanding of the different engagement opportunities patients and families can participate in depending on their interests, experience, and availability. It also speaks to what engagement options can be leveraged or initiated by healthcare providers to obtain the patient and family voice.

Key Components of the Model

The ACH Patient and Family Engagement Model places patients and families at the centre of all our work, emphasizing that they are the priority in guiding our efforts. The healthcare team surrounds

patients and families within the model, for any successful outcome relies on integral partnership between patients, families, and healthcare staff.

This model then reflects the different engagement levels and methods that have been formally established to incorporate the patient and family voice. These engagement levels reflect increasing levels of patient and family involvement, and their impact, as you move from the centre of the model to the outer circle. In essence, there is a move from a task-oriented focus at the centre of the model to a greater focus on partnerships at the outer levels. These partnerships thrive on mutual trust and involve diverse skill sets and discussions. Each engagement level is outlined below.

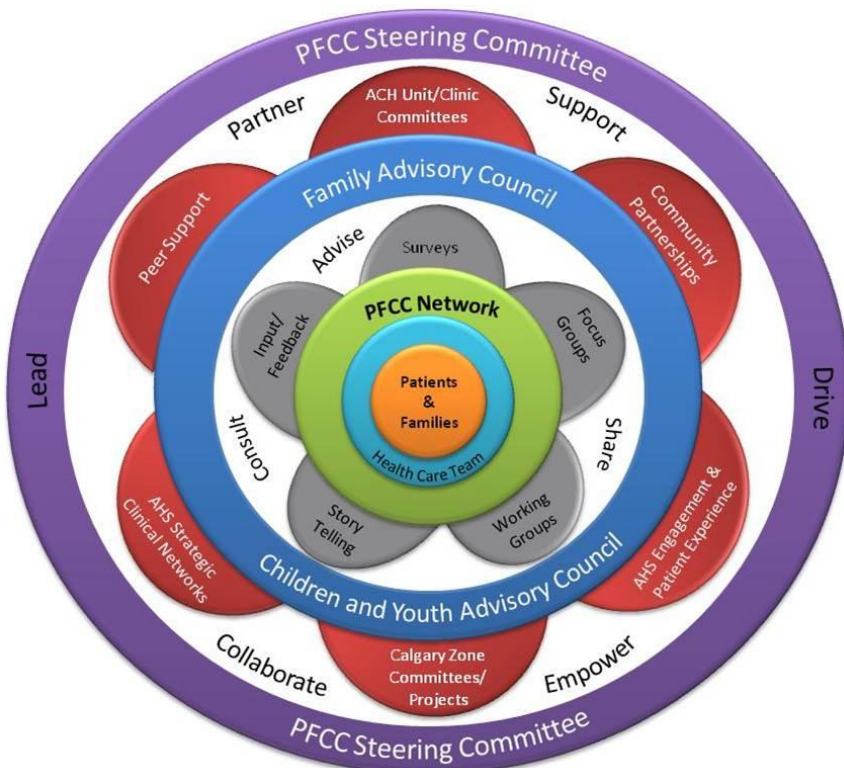
Level 1 - Patient and Family Centred Care (PFCC) Network

The PFCC Network is our entry engagement level where we welcome all ACH patients, family members, and staff volunteers to join. All PFCC

Network members have an online profile maintained in our volunteer database, which we use to send out monthly PFCC e-newsletters and PFCC Network engagement opportunities. These engagement opportunities allow members to share their personal and professional perspectives and participate in PFCC activities without sitting on a formal committee or project.

Some ways in which PFCC Network members participate include:

- becoming a member of a short-term working group
- participating in a focus group
- reviewing and providing input and feedback via email on written materials, websites, videos, survey design, etc
- sharing healthcare stories



- participating in education simulations
- other short-term, ad-hoc commitments

Members of our PFCC Network can choose how they want to be involved within the Network according to their areas of interest and time available to volunteer. PFCC Network members may also participate in the other engagement levels which will be discussed below.

Past PFCC Network Engagement Activity Examples: Whiteboard Template Review, Hand Hygiene Research Questionnaire, PACE Brochure, Pressure Sore Brochure, Room to Move Document for Families, Whiteboard Development, PFCC Week Planning, Transitions Working Group, Family Advisory Council Launch.

Note: PFCC Network members do not go through a formal screening process. All PFCC volunteers who are involved in higher levels of engagement are registered through ACH Volunteer Resources which includes conducting a background check and signing a confidentiality agreement and media release form.

Level 2 - Child and Youth Advisory Council (CAYAC)

The Child and Youth Advisory Council (CAYAC) is a dynamic group of up to 30 youth ages 12 to 22 from around Southern Alberta with a rich diversity of health and life experiences. Their role is to provide a youth voice for the development and delivery of child health related programs and services. The group can be consulted with at their Saturday meeting six times a year. They also do small group consultations and provide a youth perspective at relevant meetings and conferences.

Past CAYAC Engagement Activity Examples: ACH Neurosciences Transitions Model, ED Pain Initiative, ACH Outpatient Principles of Practice, Child Life

Services for adolescents, ACH patient meal experience, HOT Clinic waiting room redesign

Level 2 - Family Advisory Council (FAC)

The Family Advisory Council (FAC) is a new advisory committee established in January 2016. It is comprised of up to 30 family member representatives coming from diverse backgrounds with varied life and health experiences. At each meeting, Family Advisory Council members provide input from a family perspective on ACH policies, processes, and delivery of care processes through consultations. The group can be consulted with on the third Tuesday of every month in the evening, eight times a year.

Consultations: CAYAC and FAC are both available to provide feedback, suggestions, and recommendations on ACH policies, practices, programs, services, and strategies in the form of consultations. Most of these consults will arise from work being done within ACH but there may be times where we deem it a good fit to accept a consult for child health related AHS initiatives or research work.

The requesting consultation party might involve ACH leadership, physicians, nurses, and/or other staff. A broad range of consultations are possible. For example, the Councils may be asked to consult on:

- Facility redesign
- Research development
- Clinic or Unit processes
- PFCC initiatives
- Family and staff education materials
- Information materials and websites
- Hospital policies and procedures
- Program development or redesign
- Approaches to engage patients and families

Level 3 - AHS and ACH Advisory Committees/Projects

At this level, we strive to incorporate the patient and family voice as much as possible on AHS and ACH committees and/or projects. Currently, we have placed patient and family advisors on several AHS and ACH committees including, but not limited to, the following: ACH Pain Committee, ACH Ethics Committee, HOT PFCC Steering Committee, ACH Master Site Planning Committee, ACH PFCC Evaluation Committee, Calgary Zone Complex Airways Project, AHS Maternal Newborn Child and Youth (MNCH) Strategic Clinic Network, MNCY Child and Youth Standing Committee. These Advisors move from a focus on providing input and feedback, to a collaborative role as a partner in setting direction and decision making.

Level 4 - PFCC Steering Committee

The PFCC Steering Committee provides a forum for patients, families, and healthcare professionals to work collaboratively as partners in care to support, promote, guide, and advance PFCC for Alberta Children's Hospital. The PFCC Steering Committee is made up of an equal number of staff and family members. Site leadership has an active position on the Committee. Members of this committee are champions for embedding the philosophy and practice of PFCC and for demonstrating and sustaining effective, collaborative staff/family working relationships and practices.

The Committee meets on the first Thursday of every month in the morning, ten times a year. The PFCC Steering Committee is also available to participate

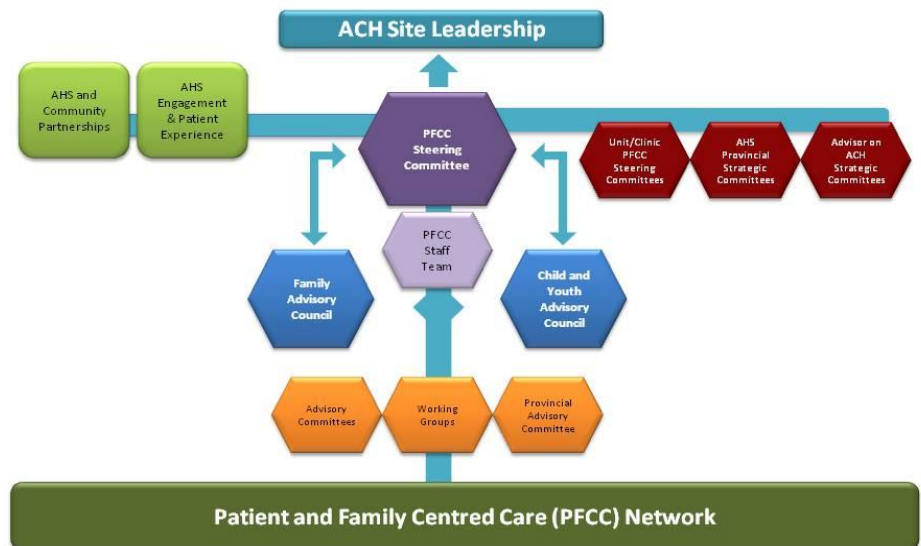
in consultations that require leadership and strategic discussions, input and feedback.

Past PFCC Steering Committee Engagement Deliverables: ACH Engagement Model, PFCC Rounds, and PFCC Week.

Advisor Engagement Reporting Relationships

All of the engagement groups are now connected into the PFCC Steering Committee that reports to the ACH Site Leadership Committee, which includes senior executives and physician leaders. The Family Advisory Council and CAYAC have a representative sitting on the PFCC Steering Committee to ensure two-way communication. The PFCC Steering Committee, in collaboration with the PFCC Staff Team, maintains strategic relationships with key AHS and community partners and ACH and AHS strategic committees.

Advisor Engagement Reporting Relationships



Successful Engagement

Patient, family, and healthcare professional partnerships involves working together across the care continuum. It truly goes beyond partnering with patients and families at the clinical encounter level to include active participation in other areas of the hospital and beyond. Examples of successful engagement include answering surveys, participating in a working group, participating on a clinic advisory committee, being a part of a quality improvement project, and participating on one of AHS' provincial strategic networks.

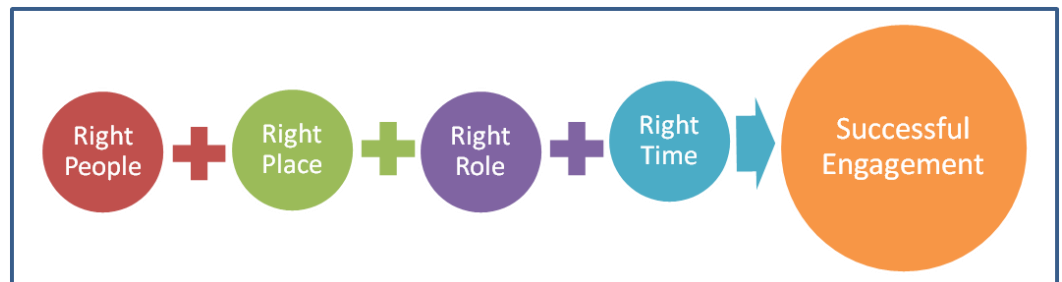
Although it is of great importance for healthcare professionals to encourage this active partnership at these various and different operational points, we need to honour and respect what degree and level a patient and family would like to participate. We recognize the importance of selecting the **right people, in the right place, for the right role, and at the right time** in order for it to be a **successful and meaningful engagement experience**. It is not enough to simply have a patient and family representative at the table if it is not the right fit.

Our engagement strategy provides advisors with entry level engagement experience and the

orientation and training to advance to other engagement opportunities that fits their interest and experience. We support staff members in involving patient and family advisors to help ensure successful engagement happens.

This comprehensive and sustainable engagement model was developed by the Patient and Family Centred Care Steering Committee at ACH in collaboration with staff, patients, and families.

To explore your engagement needs and to connect with any of these engagement opportunities, please contact the ACH PFCC Staff Team. We are available to assist anyone in understanding the best engagement option(s) to meet your clinical practice, research, educational needs, and/or other needs.



Contact us at ACHFCC@AHS.ca or visit us at www.fcrc.albertahealthservices.ca

Testimonials

“Having the opportunity to listen to patient and family voices helps us understand how patients experience all that we do. We cannot assume that we understand how what we do operationally will impact those that we are caring for, we need to ask. Having our own family centered care committee offers us the opportunity to do this on a regular basis. As a result, I believe we are more in touch and aware of what is happening within our program. We may not be able to fix everything, but awareness is a great gift. Our care can be influenced for the better by this understanding.”

T.Rent, Co-Chair of PFCC HOT Steering Committee

It is hard for health professionals to write documents that will truly be helpful and informative for patients and families. After months of writing and editing, we sent our draft to the PFCC Network and received quick and comprehensive feedback from a number of families. Their comments were helpful and encouraging and we're pleased to say we've posted a new family centred care approved reference *Does My Child Have Asthma?* to our pediatric asthma website. We are quite confident it will become one of our most popular handouts.

Shirley van de Wetering , The Community Pediatric Asthma Service

Patients and families can ask some tough questions in program design as they are not stuck in the “we've always done it this way” thought process. These questions almost always lead to positive change, or at the very least, a new way of looking at a problem.

Staff Committee Member

Sharing patient and family stories at the beginning of our committee meetings focuses us on the reason why we are here and sets a positive tone for the meeting.

Staff Committee Member

I sit on a number of ACH committees and I have been impressed with the quality of the commentary and interactions of the committee members with Patient and Family Advisors - K.Carter

CAYAC provides a structured and productive way to engage a diverse group of youth which benefits our program by providing access to youth voices to inform our program and service planning. Another benefit of CAYAC is demonstrating that youth want and can be active participants in their care and have valuable insights to share about how we can provide quality care that is safe and accessible to everyone.

Tammy Troute-Wood, The Sexual and Reproductive Health (SRH) Program, CAYAC consult

Having two Family Advisors involved in the CCAN educational working group has provided not only the family lens for the educational materials that we are creating as a group, and the end goal at the same time – we see them with their children in clinic often and it acts to ground the work that we are doing for all the future families like them. They have such great insight into how we can improve the experience that CCAN families have in this context.

Juanita Davis, Trach/Sim/CCAN