

Patient- and Family- Centred Care (PFCC) Annual Report - November 2024



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Patient-and Family- Centred Care

2023-2024

Executive Sponsor(s): Dr. Mike Fitzpatrick (2024 to present)

Brenda Carter (2023-2024)

Lead Patient-and Family Centred Care: Angela Morin (3 day/week)

Patient Experience Advisors (54 - volunteering)

KHSC Patient-and Family Advisory Council (PFAC)

Southeast Regional Cancer Program PFAC

Regional Renal PFAC

Mental Health and Addictions PFAC (in development)

Family Experience Council (KidsInclusive)

I Respect you, hear you & work with you

Patient-and family-centred care (PFCC) is an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families and health care providers at all levels of health care. KHSC has embraced PFCC as a founding principle. The PFCC portfolio supports individuals who have experienced care at the Hotel Dieu site or Kingston General Hospital site in partnering with KHSC, and supports and advises leadership and programs in the principles of patient-and family-centred care leading to better understanding of the priorities of those with lived experience.

This philosophy of care is based on the recognition that patients and families are essential allies for quality and safety—not only in direct care interactions, but also in quality improvement, safety initiatives, education of health professionals, research, facility design, and policy development. It aligns to the World Health Organization and Accreditation Canada's people-centred approach to health care that recognizes that patients are persons with individual preferences, needs and abilities who are full partners in their care and in health system design.

We partner with patients and families to ensure they have a strong voice in helping us to provide the best and safest care possible.

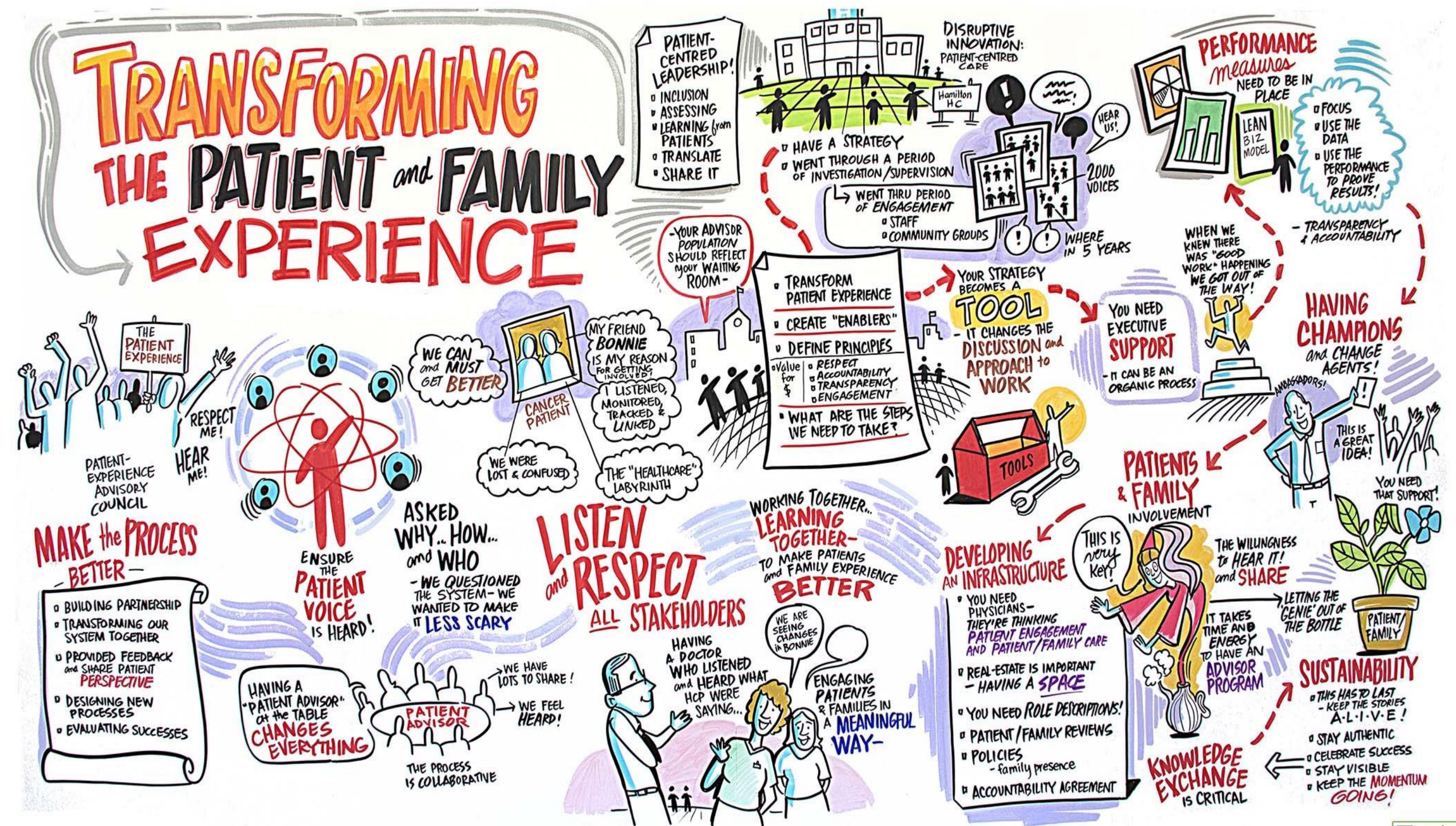
Foundational Principles of Patient-and Family-Centred Care

Respect & Dignity

Information Sharing

Participation

Collaboration





Thank you to all of the individuals with lived experience, patients and caregivers, who generously share their perspectives and stories with us! Thank you to all who respect, listen and learn from those powerful stories and perspectives.

<https://kingstonhsc.ca/news/its-life-changing>



Respect and Dignity

We listen to and honour patient and family perspectives and choices. Their knowledge, values, beliefs and cultural backgrounds are respected and incorporated into everything we do.

Strategic Direction: Ensure quality in every patient experience

F24 Objective: Advance KHSC's commitment to embedding the principles of PFCC by sharing patient experience stories that reflect the diversity of the community we serve at all levels of the organization.

In the past year patient stories were shared for the purposes of learning and identifying opportunities to improve across KHSC. The stories touched on the priorities of patients and families and their experiences.

Where we heard patient stories:

- 6 Patient Care and Quality Board Committee meetings.
- 24 New employee welcome sessions
- 2 Lumeo videos
- 8 external website stories
- Social media posts
- PFAC meetings
- Knowledge Exchange with Kingston Immigration Partnership: The Newcomer Experience
- Stand up to Stigma series

Programs:

KidsInclusive, regional renal care, cancer services, critical care, cardiac, medicine, emergency room, ambulatory, mental health and addictions, labour and delivery, women and children's, stroke, MAiD, inclusion.

Participation

Patients and families are encouraged and supported to participate in their care and decision-making. **Patient advisors are offered opportunities to engage in projects and working groups which align to their experience and interests.**



- **Patient experience advisor rounding project:** An innovative method designed for collecting patient/family experience data and implementing changes in real-time based on what was identified as being important to the patient/family at the time. This pilot project is being piloted on Connell 9 by Emily McMillan, Medicine Program Manager and Patti Cox, patient advisor. Supported by Laura Cassidy, PSQS and Angela Morin, PFCC Lead with the aim to establish a standardized process for expansion across KHSC.
- **Lost belongings project:** This project has been endorsed by the KHSC PFAC as a priority initiative for patients and families and is being co-led by PFCC Lead, Angela Morin and Astrid Strong, Patient Experience Specialist (Patient Relations). A working group, including patient advisors, is reviewing current state and looking for best practice opportunities to implement that will help mitigate the loss of patient belongings with particular emphasis on assistive devices that are critical to respect and dignity, quality of life and patient safety such as glasses, hearing aids and mobility aids.
- **Patient rights and responsibilities statement:** Ensuring this statement is in place at KHSC is standard practice and required under many of the program-specific accreditation standards. The KHSC PFAC members reviewed the document and suggested the addition of an introductory sentence to help reflect the intention of partnership *“Holistic and compassionate health care requires an effective partnership between people who need care and people who provide care.” (World Health Organization)*. They also endorsed the addition of rights and responsibilities related to patient belongings, family presence and the role of learners. [Link: patient-rights-and-responsibilities](#)
- **Family presence in critical care:** 11 Patient Advisors and Angela Morin provided feedback and joined a small working group with nursing retention committee members, critical care leadership and protection services leadership to discuss challenges with family presence in critical care spaces and explore patient centred opportunities to address those challenges. Existing resources such as the Patient Rights and Responsibilities statement were shared for consideration and relevant policies discussed and reinforced to assist in addressing concerns.

Information Sharing

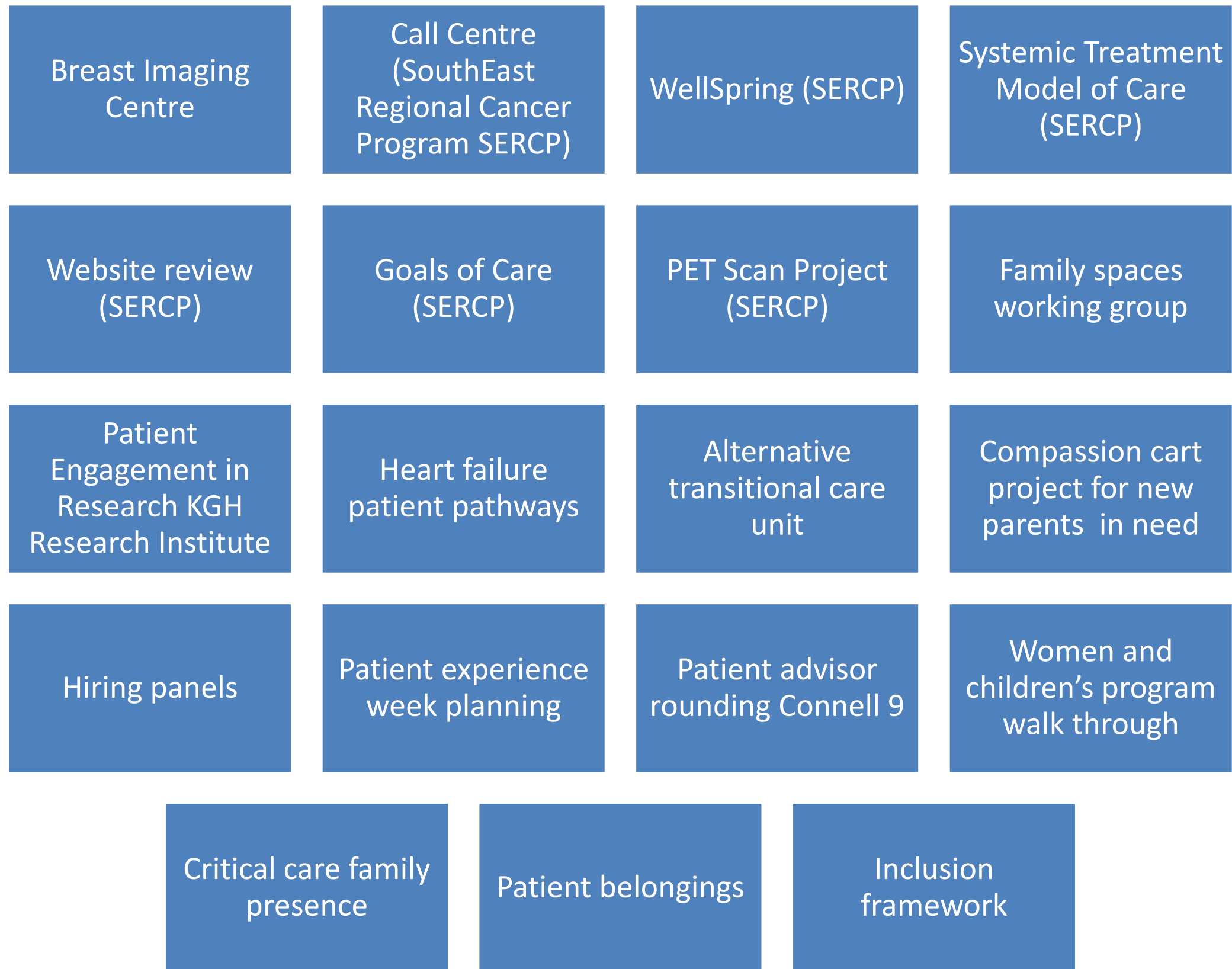
We share complete unbiased information with patients and families to help them participate in their care.

Some examples of patient advisor feedback requested and provided:

Lumeo communication	Day surgery brochure	Child Life brochure	Engagement in research presentation	Head and neck cancer surgery transportation and accommodation	ICU family presence
Intranet information for staff discussion about non-traditional care spaces	IPAC March Madness campaign poster	NICU patient education and welcome brochure	Pain Pamphlet	Patient Experience Measurement Survey process	Private rooms and non-traditional spaces feedback
Escalation process for patient transfer	Sydenham St. entrance restoration	Transitional Care Unit escalation process	What is Palliative Care brochure	MAiD policy	Facility planning

Collaboration

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



Committees (some examples of this year's patient advisor involvement)

Patient Safety and Quality Specialist Executive Committee
Quality & Safety Committee (Cancer)
Infection Prevention and Control Committee
STP: Systemic Treatment Program Committee
Lumeo IT Advisory Committee
Cancer Clinical Trials
PSO Oncology Committee
IROC Interprofessional Radiation Oncology Committee
Regional Systemic Treatment Program
SERCP Regional Leads Committee Meeting
Board Committees
Nutritional/ Food services Committee,
Accessibility committee
Ontario health digital team (External)
Regional Lumeo
Quinte health experience partners (External)
Palliative care QIP
Exceptional Healer Award committee
NICU/Labour and Delivery
Mental health and addictions program
PFCC grant committee

Presentations and External Engagement: Patient advisors bringing their perspectives and patient advisor expertise into the broader community.

Accreditation Canada: Anne O’Riordan, patient advisor, has successfully completed Patient Surveyor training

FLA-OHT Ontario Health Team Community Council, working groups and support structures members.

Presentation to KFLA Health Teams Council by Patti Cox

Cancer: Systemic Treatment Retreat presentation by Wanda Williams

4th year kinesiology students lectures by Kerry Stewart

Occupational health practice patient - Perlita Delaney

Research funding application (collaborators) - Patti Cox , Angela Morin,

Multiple research funding applications (cardiology/heart failure pathways, collaborator/ co-author) - Kerry Stewart

St. Lawrence College: Medical Lab Technician education. Patient storytelling curriculum development and participation – Tanya Marwitz, Laura Patterson, Angela Morin

Quinte Health Experience Partners presentation - Angela Morin and Jessica Bonney

Common Sense Oncology presentations, research and articles - Rachel Koven <https://www.cbc.ca/news/health/cancer-kingston-common-sense-oncology-1.7136127>

Transplant Ambassador Program (TAP) – Jim and Lynne Anne Anfield

Ontario Health East – Vivian Bethell

CanSolve and Advancing Clinical Trials national database - Hans Vorster

PFCC Project Grants

The KHSC PFAC members were excited to refresh the PFCC Project Grant Initiative this year after a brief hiatus due to Covid pandemic

The grant is available for one-time projects or initiatives that enhance PFCC at KHSC and the successful applicants are chosen by a committee of patient experience advisors.

The committee, in partnership with UHKF, was able to fully fund 6 projects in Mental Health and Addictions, Children's Outpatient, Orthopedics Kidd 6, Endoscopy (HDH), Kidney Health/nutritional services for a total of \$9053.00!

Exceptional Healer: Patient-and Family-Centred Care Excellence Award

In its eighth year, *The Exceptional Healer: Patient and Family-Centred Care Excellence Award* recognized two health care professionals who are exemplars in patient -and family-centred care (PFCC). This award was conceived of by a patient experience advisor and involves a patient and family driven campaign chaired by Sue Bedell and Patti Cox, patient advisors. The selection committee comprises a majority share of patient advisors, along with staff.

Nominations must be submitted by or supported by a patient or family member to be eligible for consideration.

Nominations representing five disciplines including physicians, physiotherapists, occupational therapists and a physician assistant were received this year.

“The ongoing popularity and meaningfulness of this award has been gratifying. The stories of the nominees and how they have supported such positive experiences for patients and families have illustrated the heart of patient and family-centred care.” Patti Cox

Kingston Health Sciences Centre’s (KHSC) Patient and Family Advisory Council (PFAC) is thrilled to announce that Dr. Garth Smith and RN Lisa Thibeault, are the winners of this year’s Exceptional Healer Award.

“This award means everything to me as it validates what I have strived to do and gives me a degree of satisfaction that my efforts have been recognized by those that matter most to me in my more than 35 years of practice.” Garth Smith

“Receiving the Exceptional Healer Award is an incredible honour and deeply meaningful to me. This acknowledgment validates the efforts I’ve invested in providing high-quality, patient-centered care over the past 22 years at KHSC.”

Lisa Thibeault

<https://kingstonhsc.ca/news/exceptional-healer-recipients-show-simple-human-kindness-and-contagious-positive-energy>

The patient perspective and Lumeo

Lumeo, regional integrated electronic health information system, will have a transformative impact on the patient and family experience at KHSC. Lumeo is a standing item on all PFAC agendas allowing the members to share their perspectives, ask questions, raise concerns and articulate their priorities.

Christine Fader, patient advisor, brought a family member's perspective to a KHSC Lumeo video. Link to Christine's video:

<https://youtu.be/4pPtdLRLTyM?si=bdETUUV9SXRJP0FV>

The PFCC Lead is helping to identify patient advisors who are using the services of KHSC to participate in the HealthLife Patient Portal pilot project launching in December 2024.

Gerhard Wendt, patient experience advisor and member of the KHSC PFAC has generously volunteered his time to Chair the Regional Experience Advisory Council and brings updates to the local patient-and family advisory councils and patient questions to the Lumeo Regional team.

Gerhard's perspective:

Six years ago, I was asked to be part of what our New Digital Health information system would look like from a Patient Advisory perspective. From the very beginning of creating the Steering committee for our six Regional Partners. I have been part of this journey and want to continue to support it in any way we can. Experience Advisors have been an integral part of building this at every opportunity that was provided and included input on Vendor presentations during the evaluation process.

I Know that everyone we touch will receive help from this in the end. It truly is a new partnership in our Healthcare journeys.

What we ask of our providers is huge commitment at this time, but I also promise in return we will engage and use Lumeo as clients or patients to do our part to make our Healthcare Journey easier for you and us.

Providers have an incredibly special role in all our lives and families in this difficult change we are on.

To me Patient- and family-centered care is about working "with" and partnering with providers. I continue to be excited and inspired by all those that provide, empower, and give to each other, as we Partner in Transforming Care Together in our Area.

What does the Lumeo HealtheLife Portal mean to me?

We are making this change for all of us. Our clinicians, providers, parents, our kids, our grandchildren, and for everyone in our region. Lumeo will transform all our experiences through easy access and record sharing. In the past I have struggled like many of us. We have no place in our system to put my current meds or my Blood glucose numbers or my Blood Pressure readings. These are integral to empower us to manage our Health together, proactively. I get appointments by mail and have no ability to manage that and must phone to confirm or change the appointment, adding more stress on our system. Referrals go off into the Fax world and I have no idea who I am being referred to or when. I am lost till someone contacts me. It will equip us with the information that we need to make best decisions in your care planning, and help us to coordinate safe, high-quality people and family-centered care. It will standardize our providers' tasks more efficiently, and help avoid duplication, and deliver cost savings.

The Healthelife portal will empower us. People will be able to manage their own personal health much more than we can today. You can add things to your patient portal and communicate better with your care providers. Right now, it is challenging. You cannot text or fax your doctors, so to be able to add things to your own profile will be so beneficial.

Doctors can see their patients' medical history, which will help with triage and diagnosis. Also, the chance of errors, for example with medications, will be drastically reduced because the information is all in one place.

It will allow us to be engaged in our health – in a way that is not available to us right now. Engaged and empowered. Healthcare is really a connection and partnership that transcends all other things that we do.

It is a beacon of hope for a future where healthcare is more connected, efficient, and patient-centered and allows us to manage our healthcare together if we choose to.

Lumeo is truly about providing and receiving better Care. It will Improve outcomes in a more seamless [manner](#). Equal Access, Empowerment and Ownership and Encourage [collaboration](#) and inform us about our choices we make on our journey.

Down the road, this will be the foundation to give us access to data that will improve population health across our region. Gerhard

<https://quintehealth.ca/news-story/lumeo-will-empower-us-a-patient-advisors-take-on-lumeo/>



Kingston Health
Sciences Centre

Centre des sciences de
la santé de Kingston

KHSC PFAC

KHSC Patient and Family Advisory Council serves in an advisory capacity, making recommendations on matters that impact the experience of patients and their families at Kingston Health Sciences Centre. The Council also monitors and provides input into the activities and involvement of Patient Experience Advisors within the organization.

Co-chairs: Patti Cox (Patient Advisor)
Angela Morin (Lead PFCC)

- 14 Patient advisor members. 4 staff. PQSR administrative support for minutes.
- In-person meetings held at Kingston Community Health Centre and KHSC.
- 9 meetings this past year – hybrid and virtual via Zoom.

Topics for discussion, input and requests for engagement or endorsement included:

Organizational update and discussion (standing item)
Patient Advisor sharing of engagement and experiences (standing item)
Research grant application: Meaningful Partnerships. Queen’s Office of Professional Development and Educational Scholarship
Patient engagement in research: Kingston General Hospital Research Institute
Trillium Award of Excellence - update
Minister’s PFAC Co-Chair presentation Link here: Chair Minister's PFAC
F25 Quality Improvement Plan
Lumeo (standing item)
3 Wishes project
Solar eclipse planning
Nutritional services
KHSC Strategic Plan and Annual Corporate Plan
Family Spaces planning
Volunteer services update
Patient experience week planning
Patient Safety Quality and Risk update
Patient feedback report
Patient experience survey
PFCC learning exchange with Kingston Immigration Partnership planning
MAiD patient story
MAiD policy update
Goals of care (Lumeo)
Kingston Community Health Centre and Kingston Immigration Partnership presentation
Midtown Kingston Health Home - presentation
Medical Advisory committee – role for patient advisor?
Patient Advisor rounding project
Infection Prevention and Control - opportunities for engagement
Patient rights and responsibilities – review and endorsement
Discharge policy – update and discussion
Healthlife patient portal - update and request for advisors
Peer resource project

SouthEast Regional Cancer Program (SERCP)PFAC

Serves in an advisory capacity, making recommendations on matters that impact the experience of cancer patients and their families across the full spectrum of cancer care (prevention, screening, diagnosis, treatment, supportive & palliative care and survivorship) in Southeastern Ontario

Co-Chairs: Marla Rosen, Patient Advisor and Renee Hartzell, Program Operational Director and Regional Director of Cancer Services.

- Membership: 10 Patient Advisors, 4 staff and Cancer Program administrative support.
- Met 6 times in past year with one newsletter update. Meeting virtually by Zoom.
- Gratitude expressed for the contribution of Vivian Bethell, long standing member who has stepped down after moving out of the region.
- Grieved the loss of exceptional member Jason Manuge. <https://thewhig.remembering.ca/obituary/jason-manuge-1089558682/>
- Began co-chair transition process for 2025. Thankful to founding chair, Marla Rosen, for her passion and commitment to the SERCP PFAC.

Topics for discussion, input and requests for engagement or endorsement included:

Director’s update (standing item/discussion)
Program Managers’ updates (standing item/discussion)
Strategic plan priorities
Committee participation: gaps and opportunities to get involved
Wellspring peer support: opportunities for partnership
This is the Place: campaign and signage
Lumeo: impact on Cancer patients’ appointments
Lumeo: Patient portal, Regional Community Experience Council
Patient Advisor Handbook review
Rose of Hope presentation by patient advisor Wanda Williams
Advisor recruitment planning
Letter of intent review: engaging with advisors on working groups.
Indigenous guidance group update
Website review
Queens Cancer Centre Research Institute outreach
Regional systemic treatment retreat participation
Quinte Health Experience Partnership Program – regional patient advisor partnership opportunities
Cancer centre phone tree
PET Scan
Terms of Reference review



SouthEast Regional Renal PFAC

Comprised of individuals affected by chronic kidney disease (CKD) and staff from across the South East Region, the Renal PFAC serves as an advisory group on strategies and action points related to improving the experience of renal patients.

Co-Chairs: Lorne Kinsella (Patient Advisor) and Lori VanManen (Program Operational Director Renal and Palliative Care)

- Membership: 13 Patient Advisors. 3 Staff (alternating Program Managers). 2 Physicians (as available). 3 Community Partners. Renal Program administrative support. times per year
- Meet 4 times annually with ad hoc meetings at the discretion of the co-Chairs as needed. Meeting virtually by Zoom.
- Patient Advisor Co-Chair represents the PFAC at the SouthEast Integrated Renal Program Council bi-monthly meetings.

Topics for discussion, input and requests for engagement or endorsement included:

Patient Advisors Roundtable (standing item)
Program Director and Manager updates (standing item): discussion and input
Integrated Regional Renal Program Council update and feedback
Kidney Transplant program
Renal Communications: web content, patient stories
Lumeo: impact on flow, patient appointment messaging, slips/ reminders/ Go-Live information, patient portal
Lumeo training
Patient advisor orientation review
Patient & Family experience survey design and result review
RSV vaccination roll out
Kingston Kidney Foundation opportunities to get involved (standing item)
Home dialysis training https://kingstonhsc.ca/renal/news/expanding-possibilities-dialysis-care
Strategic 4 year plan input
Ontario Renal Program updates and input
Patient communication reviews
Inclusion criteria for specialized care.
Satellite sites – patient flow,
Ontario Kidney Foundation Updates (standing item)
Transplants program Health Canada audit results



Adult Mental Health & Addictions PFAC

(In development) Will serve as an advisory committee for both outpatient and inpatient programs at both HDH & KGH sites. with the intention of strengthening partnerships amongst patients, families, community partners and healthcare providers, making recommendations on matters that impact client and family experience, as well as program functioning and development, and work to ensure the patient and family perspective is always heard and incorporated within all levels of care in order to improve patient care and enhance the experience of patients and families.

Tri –chair model: One KGH site staff member, one HDH site member, one patient and family advisor.

- Membership: Recruitment planning in development. Program administrative support provided by the office of the Program Operational Director to Mental Health & Addictions.
- Planning committee led in partnership by program leadership and two patient experience advisors with support of PFCC Lead.
- Terms of Reference complete
- Advisor onboarding process complete

Family Experience Council - KidsInclusive

The Family Experience Council at KidsInclusive includes a group of family caregivers of children who receive service at KidsInclusive to advise and act as a resource to the Leadership Team at KidsInclusive. This is done by providing valuable input to support highest quality care and supports in programs and services for young people and their families.

People of KHSC: Patti Cox

Portraits of caring, compassion and commitment.

Patti Cox has been part of KHSC's Patient and Family Advisory Council since 2012. A retired health-care professional herself, Cox also knows what it's like being a patient at KHSC.

Every now and then you'll find Patti Cox armed with her trusty clipboard and pen making the rounds at Kingston Health Sciences Centre (KHSC).

As a patient experience advisor, she's on the lookout for ways to improve different aspects of the care journey.

And she's not the only one. Cox is the co-chair of the Patient and Family Advisory Council, which partners with KHSC to enhance the patient experience.

"Only the patient and family knows what an experience has been for them, so they can offer a lens as to what supports comfort, safety and trust," explains Cox.

"The council serves in an advisory capacity, making recommendations on matters that impact the experience of patients. Understanding what matters to them can help shape decisions about care moving forward."

Cox says she's proud to be part of the Patient and Family Advisory Council. She adds the authentic work they do matters and their influence is real.

Cox is no stranger to health care.

Fun fact... she was a candy striper at 15-years-old, as well as a nurse educator for more than 30 years.

She also knows what it's like being a patient at KHSC.

"Being a retired health-care professional, I can appreciate the joys and challenges of frontline staff and marry that with my experience as a patient and a loved one of patients.

"Over the past 12 years, my family and I have had many care experiences. I'm a breast cancer survivor. Early detection led to early treatment including surgery, chemotherapy, radiation treatments, and targeted therapy over the course of about 15 months.

"I experienced a host of caring, sensitive health-care professionals and support staff all along the way."

Cox says understanding what matters to patients and families is important because it helps KHSC shape decisions about care moving forward.

Now in her volunteer era, Cox wants others to have that same experience.

That's why she's been sharing her expertise and keen eye with the council for the last 12 years.

"There's no lip-service in involving patients and families. Patient partners support quality improvement for decisions affecting patient care.

"I enjoy being in the company of my fellow advisors, all of whom are very engaged, compassionate, thoughtful, resilient, and articulate people. I'm proud that the work of the council is authentic. We're involved in things that matter and our influence is real.

"We've developed trusting relationships, and I marvel at how respectful and mindful KHSC is of the council's ability to critically explore decisions that affect patients, identify nuances and simplify seemingly complex circumstances. There's mutual respect and that's gratifying."

Cox believes patient partners support quality improvement by offering a lens as to what supports comfort, safety and trust for patients and families.

And by teaming up, Cox and council are not only supporting positive patient experiences, but also helping advance KHSC's commitment to patient-and family-centred care.

June 10, 2024

Article: Nikki Jhutti Photos: Matthew Manor



Submitted by,

Patti Cox, Patient Experience Advisor
Co-Chair, KHSC PFAC

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November 18, 2024



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