

PATIENT-AND FAMILY-CENTRED CARE PROGRAM ANNUAL REPORT – November 2023



Hôpital
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Hospital



Hôpital Général de
Kingston General
Hospital

What is Patient- and Family-Centred Care?

Kaitlyn Chalmers, Patient Advisor: [What does PFCC mean to you](#)

“Respect me, Hear me, Work with me”

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.

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.

PFCC is based on the following four foundational principles:

Respect & 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.

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

Participation: Patients and families are encouraged and supported to participate in their care and decision-making.

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.

“Patients and families are full partners in our innovation, quality improvement and design initiatives.”

Gerhard Wendt, Patient Advisor: [Integrated Health Information](#)

We learn about the experiences of patients and families in a variety of ways...through front line feedback, patient relations calls, surveys, interviews, focus groups, patient journey mapping and feedback forums. Using this mosaic of methods, in combination with purposeful partnership with Patient Experience Advisors (PEAs/Patient Advisors) gives us a fulsome picture of what matters to patients and families.

Angela Morin, Lead PFCC, supports staff and leaders with resources and coaching to identify patients to partner with, opportunities for engagement and methods for hearing the critical perspective of the community we serve.

The role of Patient Experience Advisors is grounded in the recognition that there is expertise in, and lessons to learn from, the experience of patients and families. Patient Advisors play an integral role at KHSC in defining and shaping policy, programs and initiatives that impact the patient experience. Patient Advisors are patients or family members of patients who volunteer their time to be members of committees, councils and working groups and/or to partner on improvement teams. They are people who have had, and often are currently having, an experience of care at Kingston Health Sciences Centre. There are currently 60 Patient Advisors involved with work that aligns to their experience and interests.

Patient Advisors bring their perspectives as full members of committees and working groups including:

- Accessibility committee
- Ambulatory care transitions
- Ambulatory care medications list
- Ambulatory care “no-shows” working group
- Ambulatory care patient experience survey working group
- Ambulatory Care website review
- ALC and Bill 7
- Care Partners
- Breast Imaging Kingston
- Critical Care Program
- Cancer Program
- Covid planning and preparedness
- Exceptional Healer Award committee
- Family Presence and screening (Balzacs Group)
- FLA Ontario Health Team (FLA OHT): Access to Primary Care, Community Council, Communication and Engagement, Digital Health
- Information Services Guide project
- Inpatient mental health program model of care
- It’s Great to Ask
- Kidney transplant working group
- Lumeo Regional Advisory Committee
- Medicine Program
- Medication Safety Committee
- Mental Health and Addictions Program
- Multi Care Kidney Clinic Working Group
- New Employee Welcome presentations
- Patient transportation
- Palliative Care QIP
- Professional Practice Committee
- Shared care

- Santa's visit
- Renal program
- Renal health literacy
- Renal home therapies
- Women and Children's Program
- Pediatrics program
- Redevelopment design working groups

Patient Feedback

Patient Advisors continue to provide feedback and input on communications, patient education and resources. They review materials to ensure the information provided addresses patient and family priorities, answers their questions, are true to PFCC principles and are easy to understand. Patient Advisor input was sought on a number of important policies and documents this past year including:

- Falls Prevention Patient Education
- Skin Cancer Surgery Post Operative Instructions
- Flexor Tendon Exercises
- Free Flap Head and Neck Surgery
- Inclusion statement
- Holiday passes
- Dress code policy
- Laryngectomy booklet
- Low iron in pregnancy brochure
- Mallet injury
- Morgue viewing policy
- Parent Newborns SNCT – decision matrix
- Prostate SBRT Gold Seet Patient Instruction
- Shared Care Visitor information
- TAVI patient education booklet
- What Now booklet
- WSIB Psychology Consent
- Kidney biopsy
- Visitor booklet
- Family presence policy and Visitor brochure
- Covid recovery plan
- Animal presence policy
- Email consent form
- Hand hygiene compliance
- Quality Improvement Plan (QIP)

PFCC Highlights

Patti Cox, Patient Advisor: [Meaningful Impact](#)

Here are just a few examples of how that collaboration is making a difference in the patient and family experience at Kingston Health Sciences Centre:

Board Committees

Patient Advisors are appointed annually to board committees but may apply to be reappointed up to a total of three years. Patient Advisors serve as full voting members of these committees and respect the confidentiality of their participation.

Patient Advisors who have been appointed to a board committee have shared that they find the experience very interesting and consider it a great learning opportunity. Most importantly, however, they feel supported, valued and heard.

Brenda Carter, EVP Quality and Partnerships, shared information regarding the recruitment process for Patient Advisors to apply to join board committees at the April 2023 PFAC meeting. An information session led by Renate Ilse, EVP Corporate Services and COO, included Patient Advisors who had experience sitting on a Board Committee as well as a few Advisors interested in learning more about the role prior to submitting an Expression of Interest. All board committees have at least one Patient Advisor member this year.

Patient Advisors on 2023-2024 Board Committees are:

Joanne Angelis (newly appointed to People, Finance and Audit)

Hans Vorster (Research)

Ron Manor (Governance)

Rachel Koven (Research)

Greg Brown (Patient Care and Quality)

Gerhard Wendt and Susan Bedell stepped down at the end of their terms. The KHSC Board of Directors expressed their appreciation for their time and expertise and for bringing the voice of patients and families to board committee discussions.

A recruitment information session for all Patient Advisors will be held again in the spring of 2024.

Patient Stories

“Advance KHSC’s commitment to embedding the principles of PFCC by sharing patient experience stories at all levels of the organization.”

KHSC Annual Corporate Plan 2023-2024

Over the past year Angela has worked with patients and families supporting them in sharing their stories in various ways across the organization to help us understand what matters to patients and families and their experiences of care.

- Patient advisors collaborated on reviewing existing feedback forum processes and updating resources for video recorded feedback forums.
- Patient stories education session was presented to provide guidance on the value of sharing your story and how to do it effectively.
- 6 in-person patient stories were shared at Regional Renal Strategy planning retreat, Ambulatory Care Services visioning day, Regional Systemic Treatment retreat, Women's program feedback forum, Nursing Council.
- 24 New Employee Welcome (NEW) sessions included a patient welcoming new staff and sharing their story about why PFCC is important to them.
- 6 recorded patient stories shared at Patient Care and Quality Committee of the Board followed by generative discussion and loop back with patient storytellers.
- Community outreach (Street Health, Dawn House) to hear more diverse perspectives and develop relationships with individuals from equity deserving groups.
- In past year recorded 12 patient stories that share experiences from across the organization including mental health and addictions, medicine, post-surgical, critical care, morgue, renal, emergency, women and children's and stroke.

Family Presence and Care Partners

The de-escalation of Covid restrictions provided an opportunity for a review of the family presence policy. The review was led by Renaud Golsse, former Manager Protections Services (now Director) in collaboration with stakeholders including Natasha Salt, Director Infection Prevention and Control and Angela Morin as well as the "Balzacs Group", a team of Patient Advisors that have provided guidance on family presence from February 2020 to present.

The review of the policy reinforced our commitment to creating an environment supportive of patient -and family- centred care in balance with the safety and security of patients and families.

A new Care Partner process and policy was created to support the inclusion and facilitation of the safe presence of Care Partners at the bedside as active partners in care while continuing to ensure patients receive ongoing quality care in a healing environment. This work was led by Dan Hogan, Director Patient Transitions and Clinical Resources, in collaboration with Angela Morin and other stakeholders including patients, families and the PFAC. Care Partners play a critical role in providing physical and emotional support to family members who are patients at KHSC. Patient Advisors have emphasized the importance of patients being supported by Care Partners to the level the patient and Care Partner chooses.

Family presence is about more than just opening the doors, it is about understanding the value it brings to the care experience. To support families to safely engage in care a Visitor Brochure was created that provides guidance on the ways they might support a patient while they visit.

Remote Travel Grant

The Ontario Renal Network (ORN) selected the KHSC Regional Renal Program to pilot a new program called the Remote Travel Grant. It was created to provide a streamlined financial support program that would allow remote patients to access training more easily for home dialysis throughout the province, something Renal PFAC members had identified as a need for renal patients. The grant can provide funding in combination with other existing grants to cover things like; accommodations, meals, travel and parking expenses.

With input from patients and families, the program quickly developed a process that would allow them to reimburse the patients straightaway. Thanks to the Renal program's leadership and dedication to delivering care closer to home, to-date the program, the first in the province, has provided assistance to 12 patients with just over \$31,000. Starting November 1st, the grant will be available to patients of all regional renal programs. Special shout out to Mary Thorne, Renal Program Administrative Assistant, for her commitment to making this initiative a success.

Information Services Guide Project

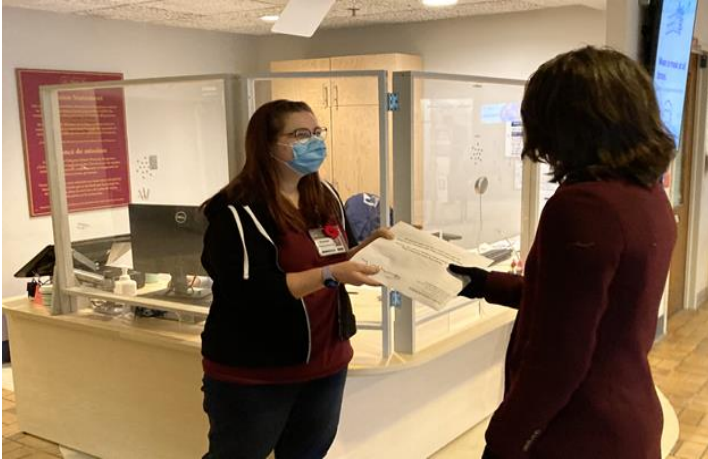
In November of 2022, with the removal of active screeners and fewer volunteers on-site, we observed a greater need than ever for a presence in the lobbies to support patient inquiries, patient safety and a positive patient experience. Not having a physical presence in the main entrances caused congestion, wayfinding issues, delays arriving to appointments and vulnerabilities around safety including falls.

The Senior Leadership Team approved a six (6) month pilot co-led by Lynda Laird, Volunteer Services and Angela Morin of a new Information Services Guide role at the HDH and KGH main entrances. Two Information Services Guides reporting to the Manager, Volunteer Services, were hired on 6 month temporary employment contracts effective March 1, 2023.

Stakeholders, including a Patient Advisor on the working group, staff and PFAC, helped to validate the need for this role. Staff and patient surveys also assisted in gaining a better understanding of the lobby experience.

The Information Services Guides collected statistics on the assistance requested in nearly 7400 engagements with patients and visitors. The majority of inquiries (83%) were related to appointments and inpatients which resulted in wayfinding, obtaining appointment details in PCS and supporting patient needs such as coordinating porter services and wheelchair locating.

An extension of the project was granted in August 2023. A recommendation, with PFAC endorsement, for the roles to become permanent is now under consideration.



“Daniel truly is a shining example of patient centred care at KHSC. He is so incredibly kind and patient with all of the people needing help. He really does make a great first impression of KHSC with all those that he interacted with.” Patient Advisor, KGH site

“Living our values is priceless. Can not leave vulnerable people to fend for themselves.” Staff member, HDH site

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

Sue Bedell, Patient Advisor: [Exceptional Healer Award](#)

In its seventh 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). Many of the nominations this year highlighted the little things and everyday actions that health care professionals do that differentiate exceptional from the expected standards of professional practice.

This award, in contrast to other awards supported by the hospital, was conceived of by a patient experience advisor and involves a patient and family driven campaign chaired by patient advisors. The selection committee comprises a majority share of patient advisors, along with staff. Sixty per cent of nominations came from patients and family members; the remainder from colleagues or co-workers (with patient support).

This year, two winners were chosen: Tara Carey, an obstetrical nurse in labour and delivery, and Dr. George Gray, an oncologist in Obstetrics and Gynaecology.

Tara Carey was nominated by co-workers, some of whom had been her patients. Tara’s phenomenal patient care, supportive nature towards junior staff and learners, seemingly limitless empathy, and desire to improve the lives of everyone made her an ideal recipient of this prestigious award. Tara provided patient-centred, compassionate care to all regardless of patient age, cultural background, spoken language, anxiety level, beliefs or attitude;

understanding how stressful the birth experience can be. Tara was kind, caring, and respectful always.

Dr. Gray was praised for helping his patients navigate through appointments and recovery without the aid of their family due to covid restrictions. His nominator noted that he was honest with compassion – never giving false promises but providing positivity through facts and knowledge.

Both winners, as well as other nominees, while skilled clinicians, demonstrated the values of patient and family-centred care, and the mission and values of the hospital, in exemplary ways. They showed special approaches to partnering with patients and families, and developing respectful and compassionate relationships that supported the patient experience.

Nominations for the 2024 Exceptional Healer Award are open until early March.

Susan Bedell and Patti Cox, Exceptional Healer Award Co-Chairs

Raising Awareness

- Presentations on the role of the PFAC, the role of Patient Advisors and the principles of PFCC were shared with the Nursing Practice Council and Professional Practice Committee by Patient Advisors Kerry Stewart and Patti Cox in partnership with the Lead for PFCC.
- Angela Morin in partnership with Lisa McAvoy, Clinical Research Liaison Office KGHRI co-presented “Patient Engagement in Research” Clinical Investigator Program lecture.
- Anne O’Riordan, Patient Advisor and Angela Morin co-presented “Pandemic Patient Engagement Success: Maintaining Family Presence Through Partnership” virtually at the International Conference on Integrated Care hosted in Belgium.
- All New Employee Welcome (NEW) sessions include a presentation by a Patient Advisor in partnership with the PFCC Lead. A total of 24 sessions sharing a patient story were delivered by Phyllis Davis, Gerhard Wendt, Tanya M. and Perlita Delaney.
- PFCC education is embedded in the mandatory orientation modules for all new staff. Webinars and resources to support PFCC education are identified and made available to staff and Patient Advisors.
- Recruitment brochure is shared with new leaders by email with a note of congratulation from the Lead PFCC to raise awareness of the program and the support available.

System Level Impact: Sharing and Learning

Many Advisors bring the expertise of their lived experience as a patient to other organizations locally, provincially, nationally and internationally. They also share insights and lessons learned from that involvement with other Patient Advisors and staff at KHSC. Some examples of the external involvement of Advisors this past year include:

- ACT-Advancing Clinical Trials (CIHR)
- Healthcare Excellence Canada
- Ontario Health
- FLA-OHT, LGL-OHT, HPE-OHT
- Ontario Health East PFAC
- Centre for Digital Health Evaluation

- Digital Health Canada
- Canadian Transplant Research Project
- Organ Donation and Transplantation Committee
- International Society of Renal Nutrition and Metabolism
- Can-SOLVE CKD Network
- Diabetes Canada
- Ontario Hospice Association
- KFL&A Moving on Mental Health Task Force
- Transition Aged Youth Mental Health Steering Committee
- Queen's School of Nursing
- HQO Quality Standards Committee (OH OQSC)
- Compassionate Communities Kingston
- Dartmouth Children's Hospital
- Common Sense Oncology
- Caregivers4Change
- Patient Advisors Network (PAN)
- Ontario Hospital Association
- Canada Health Infoway
- Canadian Institute for Health Information (CIHI)
- National Healthcare Engagement Network
- St. Lawrence College, Medical Laboratory Science curriculum
- Pathways for Primary Care
- Smile cookie campaign
- Poplar- Primary Care Research Network
- Health Innovation Council
- Cancer Care Ontario
- Ontario Renal Network

Kingston Health Sciences Patient & Family Advisory Council (KHSC PFAC)



(December 2022 PFAC Meeting. Patient Advisors: Doug Davey, Rachel Koven, Phyllis Davis, Kaitlyn Chalmers, Greg Brown, Marla Rosen, Kerry Stewart, Perita Delaney, Patti Cox, Hans Vorster, Anne O'Riordan, Susan Bedell, Gerhard Wendt. Angela Morin, Lead PFCC. Guests: Lisa Keitel, Shirlene Stafford, Jill Adolphe (Missing from picture: Ron Manor, Brenda Carter, Jennifer Achim, Gina Miller)

The KHSC PFAC, welcomed a new co-Chair, Patti Cox, with the end of Kerry Stewart's term in June 2023. We are very grateful to have had Kerry's strong and compassionate leadership during a tremendously challenging time. Kerry played a key role in keeping the PFAC vibrant and engaged throughout the pandemic. The PFAC co-chaired by Patti Cox and Angela Morin, is currently comprised of 13 Patient Advisor members, Executive Sponsor (Brenda Carter, EVP Quality, Partnerships and RVP Cancer), Director of Professional Practice (Laura Mitchell), Director Patient Safety, Quality and Risk (Gina Miller) and is supported by a communications specialist (Gary Buffet). Ex-Officio advisor positions include the Chairs of both the Southeast Regional Renal Program PFAC and the Southeast Regional Cancer Program PFAC. PFAC meetings take place monthly except for July.

Some of the many interesting discussions and opportunities for feedback:

- The intention is for the Council to reflect and encourage diverse and inclusive perspectives of the greater KHSC community through council membership and community partnerships. Guest presenters from Planetree International Patient and Family Partnership Council, Lisa Keitel (St. Paul, Minnesota) Shirlene Stafford (Atlanta, Georgia), Jill Adolphe (Toronto) shared their experience and lessons learned in building a diverse patient and family advisory/partnership council.
- With the move from active to passive screening the Patient Advisors sent an E-Card with messages of gratitude to the outgoing screeners for their patient centred service over the past few years.
- Potential impact of Bill 7 on patients and families
- Live demonstration of virtual interpretation services being implemented for patients whose first language is not English
- Post-procedures patient transportation challenges
- Patient feedback/patient experience reports
- Post-discharge phone calls update; strong endorsement by PFAC members to spread across programs
- Stroke Tracers - Real time mapping of the patient journey to identify themes for improvement; PFAC members endorsed creation of a manual to spread process to other programs.
- Information Services Guide Pilot Project - PFAC applauded the work and see great value in the roles from a patient perspective and provided input on how to survey patients on the impact.
- Discussion regarding the potential uses of security cameras in patient rooms for monitoring changes in particular patient populations
- Communications strategy - Suggestions from members "This is the place..." of partnership, of compassion, of hope, of care
- Lumeo One Chart - Members are anxious to hear more about patient portal and how they will be engaged in the implementation process.
- Indigenous acknowledgement introduced and adopted by PFAC
- Medical Genetics proposed division name change

The South East Regional Renal Patient and Family Advisory Council

This Council is co-chaired by Phyllis Davis, Patient Advisor and Lori Van Manen, Renal Program Operational Director. The Council is very appreciative of Cindy Fitzpatrick's support and contributions during her term as co-Chair which ended in January 2023. The Council is currently made up of 12 Patient Experience Advisors, the heads and managers of the Nephrology Department, representatives from the Kidney Foundation and Queen's Student Kidney Club and are supported by the Lead PFCC, Angela Morin.

Phyllis Davis' term as co-Chair ended in the fall of 2023. Phyllis' warmth, sense of humour and strong leadership will be greatly missed. The Council and members of the Renal program thank her for her years of generous service and commitment to improving the experience of renal patients across the region. An election process was undertaken and a new Patient Advisor co-Chair will begin in November. Congratulations and thank you to Lorne Kinsella for accepting the role!

The past year was one of evolution for the Renal PFAC. The members decided to try a new model changing from a scheduled 9 meetings a year to 4 scheduled meetings annually with ad hoc meetings as needed. Meetings are currently virtual. Updates and requests for committee involvement or feedback were shared by email between scheduled meetings. The model worked well for both Patient Advisors and staff and will continue into next year.

The members of the Renal PFAC had input into a number of important processes and resources for renal patients including a "consent to be called" for wellness checks, screening/masking, opening of the GIDRU entrance, Regional renal program work plan, the Ontario Renal Plan 4, health literacy and nutrition "Grocery Games", patient goals of care education, patient and family survey, GN patient manual and patient journey mapping.

Renal Advisors have also been engaged with hemodialysis, home dialysis, transplant, multi-care kidney clinic and Glomerulo nephritis working groups. Members of the Council have also used their experience as transplant patients to tell their stories at TAP (Transplant Ambassador Program), a Peer Support Program for transplant patients and by raising awareness in Kingston and beyond.

Sarah's story: <https://www.ctvnews.ca/mobile/video?clipId=2672992>

The South East Regional Cancer Patient and Family Advisory Council (SERCP-PFAC)



(SERCP PFAC members Kerry Stewart, Jason Manuge and Vivian Bethell attending 2023 Regional Systemic Treatment Retreat)

The 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 across the South East region and provides input provincially to Cancer Care Ontario. Council members help develop resources for patients and family members and provide insight on patient experience. They come from across the Southeast region and have had a cancer experience as a patient or as a family member of a patient.

There are currently 11 Patient Advisors on the Council. Patient Advisor Marla Rosen co-Chairs the Committee with the Program Operational Director of the Oncology Program, Renee Hartzell. In September of 2023, Kerry Stewart generously stepped in as interim co-Chair to support the Council during Marla Rosen's temporary leave. Angela Morin provides support and acts as a resource to the Council.

In addition to attending the 10 SERCP-PFAC meetings per year, Patient Advisors are engaged in working groups and committees including the Quality and Safety Committee and SERCP Regional Leads Committee. In the fall of 2023, a review of new and current committee membership is underway to identify new opportunities for Patient Advisors to get involved in meaningful ways and a recruitment strategy for broader regional representation bringing more diverse perspectives to the Council is being implemented.

“Thousands of patients and their loved ones find themselves at the cancer centre each year, so each decision and policy has a huge impact. Including feedback from individuals with lived experience ensures that the patient and their family are top of mind at all times. It’s a collaborative relationship between healthcare professionals and advisors.

It’s been a privilege to share my perspective as a patient and caregiver working to improve the patient experience.” Jason Manuge, Patient Advisor

KHSC PFAC Co-Chair's Reflections

The role of co-chair of the PFAC is still somewhat novel to me but being a patient experience advisor is not. I am an advisor by virtue of being a patient using our local health care resources both personally, and as a loved one. A potentially life-limiting diagnosis a while ago led me to frequent both KHSC sites, making good use of every resource offered to me; and I have experienced care at other hospitals within, and outside of, this region. By nature, I tend to find satisfaction and contentment in most things. By profession, I have a certain understanding of the health care environment. My eye has become more critical with time, which does not mean that I seek the negative aspects of things and situations. It means that I have that patient and family lens that helps me to identify that which can support patient safety, comfort, and satisfaction and that which is likely to detract and compromise. I have experienced a host of caring, sensitive health care providers focused on what matters to a patient rather than what's the matter with the patient, whether that be at the chairside/bedside or at a committee table. I have seen what a paucity of resources (often human) can do to the spirit of providing care; but I have seen that passion and compassion for the patient can exist nonetheless. And when our stories are heard, whether positive or negative, they help to inform care. Our stories may need to be prompted.

It is a humbling, awesome, rewarding opportunity to partner with health care providers. I see several foci looking forward. As information technology becomes increasingly sophisticated, and the electronic patient record is engineered, I trust that the human element remains an integral consideration; that patient portals are developed to improve access to one's information and ability to manage a health journey; that a patient passport can be developed to provide important information for patients who otherwise might not be able to express themselves, and for those who can; that white boards in rooms remain a tool for providing timely information; that care-giver focus does not shift too greatly from a patient/family face to a screen. I trust that, as a council and as a broader advisor group, we continue to consider how to encourage diversity by seeking conversations with voices little heard, by recruitment, and by continuing to be a welcoming presence at the hospital. I hope that we can think outside the box about who might have those quiet voices. I hope that we can continue to mentor and support our patient experience advisors as they seek ways to be meaningfully engaged with the hospital community.

Patti Cox, Co-Chair, Patient and Family Advisory Council

Respectfully submitted,



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



Angela Morin, PFCC Lead
Co-Chair, KHSC PFAC