

# PATIENT-AND FAMILY-CENTRED CARE PROGRAM ANNUAL REPORT – 2022



Hôpital  
Hotel Dieu  
Hospital



Hôpital Général de  
Kingston General  
Hospital

## ***“Advancing understanding of KHSC’s commitment to implementing the principles of patient-and family-centred care by sharing patient experience stories at all levels of the organization.”***

Kingston Health Sciences Centre (KHSC) Annual Corporate Plan 2022-2023

### **Kerry’s Story**

Recently I was “accused” by a friend of being a crazy person because, in my retirement, I have chosen to give 30-50 hours a month of volunteer time to being a patient & family experience advisor at KHSC. In the past 10 years I have been a member of over 30 different work teams, committees and quality improvement projects, working collaboratively with skilled and dedicated health care professionals to improve the patient experience. During that same 10-year period, I have had 6 surgeries and been a patient in Cardiology, Orthopaedics, General Surgery and Neurology. My husband was a cancer patient. My father died at KGH on a Queens’ Homecoming weekend. All 5 of my grandchildren were born at KHSC. So, my experiences as a patient and family caregiver at KHSC are eclectic and extended over time. And I have a perspective that is difficult for staff to achieve, mainly because they know this health care system well and can usually navigate their way through it. It is my role to help staff make quality improvements and promote patient safety by sharing the good experiences I have had and identifying where improvements could be made.

I cannot go further without saying that I am still alive and mobile because of the highly skilled health professionals who have performed open heart surgery on me, replaced 3 major joints and who monitor my debilitating neurological disorder.

But it’s proven to be really hard to be respected and treated as a whole person when receiving care. You see, I am more than a left knee or a damaged heart or a person living with Parkinson’s disease and congestive heart failure. I am a complex combination of all those things, but I am too often treated in silos of care that do not consider this. Hospitals are really good at treating patient medical needs but have great room for growth in meeting their emotional needs.

As a patient, when my family doctor makes a referral for me to specialty care at KHSC, that referral drops into a black hole, often for many months, while I wait and fret over whether my referral is in the queue or has been lost somewhere along the way.

When my husband was a cancer patient, he would always arrive at his 8 am or 1 pm appointment only to discover that all other patients that day had been scheduled for the same two times. And so, when he counted his life in days, he waited hours to be seen by the doctor.

Medical speak is unique and not easily understood by the average patient who is reluctant to ask for information to be provided in simpler terms. It is hard for a patient to follow up on their own care when they haven’t understood what they were told.

For several years, it was not possible to get a wheelchair in Kingston on a weekend. That seems impossible but it happened to me twice. What do you do when suddenly on a Saturday, you are not mobile but you cannot get a wheelchair until Monday?

All of these experiences are unique to patients and if we don’t share them, we are making it hard for staff to work at the full scope of their professional practice. By sharing patient experiences in a positive, collaborative way with skilled caring staff, we can improve patient safety and enhance both the patient and the staff experience of care.

On a final note, yes, my Dad did die at KHSC on a Queens' Homecoming weekend. The ER staff kept him safe, comfortable and completely unaware of what else was happening in the other parts of the ER while he was dying. My family was well cared for and if such a thing can be said, my Dad had a really good death. It was important that I share this too. The whole point of patient engagement is to identify areas that need improvement and it is also equally to identify areas of best practice that must be preserved and cherished.

I am most thankful that KHSC is a hospital that welcomes and solicits the patient perspective as a standard way of doing business. It is a best practice for the hospital. And it is certainly best practice for patients.

Kerry Stewart

Co-Chair, KHSC Patient and Family Advisory Council

## **What is Patient- and Family-Centred Care?**

### ***“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.”***

We can learn about the experiences of patients and families through various methods of engagement. We may hear from patients through traditional approaches such as patient relations comments, surveys, interviews or focus groups as well as through innovative practices such as patient storytelling, feedback forums and patient journey mapping. Using this mosaic of methods, in combination with the partnership of Patient Experience Advisors (Patient Advisors) gives us a fulsome picture of what matters to patients and families.

The PFCC Lead, Angela Morin, supports staff and leaders with resources and coaching to identify patients to partner with, opportunities for engagement and methods for hearing this critical perspective.

The role of Patient 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. Patient Advisors are patients or family members of patients who collaborate with clinical program teams to help improve the quality of the patient experience at KHSC. They 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 being supported by the PFCC Lead and Administrative Assistant in becoming involved with work that aligns to their experience and interests.

Patient Advisors participate as full members on all committees – including Board committees – making decisions materially affecting the patient experience.

They sit on hiring committees, review patient education materials, website content and signage to ensure all are clear and meet the needs of patients and families. As policies and processes are developed and reviewed it is important that we consider the priorities for patients and families and how the policies may impact the patient experience. Over the past year, in the midst of an ongoing pandemic, staff and leaders have continued to partner with Patient Advisors who have volunteered over 2000 hours of their time to provide valuable input (using virtual platforms, email and phone calls) on Program Councils, working groups and committees including:

- Accessibility committee
- Accreditation steering committee, tracers and working groups
- 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
- Critical Care Program
- Cancer program Covid planning
- Choosing Wisely committee
- Covid planning and preparedness
- Eliminating wait times innovation projects
- Exceptional Healer Award committee
- Essential Care Partners
- Family Presence and screening (Balzacs Group)
- FLA Ontario Health Team (FLA OHT) Access to Primary Care
- FLA OHT Community Council
- FLA OHT Communication and Engagement Committee
- Inpatient mental health program model of care
- Kidney transplant working group
- Kingston and Area Social Prescribing Project
- Lumeo Regional Advisory Committee
- Medicine Program Council
- Multi Care Kidney Clinic Working Group
- New Employee Welcome presentations
- Patient transportation
- Palliative Care QIP
- Patient storytelling working group
- Professional Practice Council
- Shared care
- Renal program
- Renal health literacy

- Renal home therapies
- Symptom management QIP (Cancer program)
- Virtual care committee
- Women and Children’s Program Council
- Pediatrics program
- Disclosure and Patient safety incident policies
- Redevelopment design working groups

## Patient Resources

Patient Advisors continue to provide electronic feedback and input on communications, patient education and resources. They review materials to ensure the information provided addresses their priorities, are true to PFCC principles and are easy to understand. Some of the important resources that received Patient Advisor input this past year included:

- Feed tube education booklet
- Outpatient Specialty Clinics Survey
- Spinal anesthesia pamphlet
- Peripheral nerve block pamphlet
- Patient consent for email form
- Visitor support brochure
- Consent for patient story recordings
- Family presence changes flyers, letters and FAQs
- 4 Questions you can ask at your appointment

## Board Committees

In April 2022 an information session, hosted by Angela Morin and Vivian Bethell, Patient Advisor/Board Committee member, was held for Patient Advisors interested in learning more about the role of Patient Advisors on Board Committees. This informal conversation allowed advisors to ask questions and hear about the experience of other Patient Advisors prior to completing a Patient Advisor Expression of Interest to apply to join one of the Board committees.

Feedback was very positive, and we will be preparing another session for the new year that will be recorded and included in the resources available to Patient Advisors to support their meaningful engagement.

There are two Patient Advisors appointed to each of the three Board Committees.

Interested Patient Advisors were invited to submit an application and participate in an interview process before being recommended for appointment. Patient Advisors are appointed annually but may apply to be reappointed up to a total of three years. All of the committees began the new board year July 1, 2022 with the patient advisor roles filled. This included Patient Advisors Greg Brown and Hans Vorster on Patient Care & Quality Committee, Gerhard Wendt and Rachel Koven on People, Finance and Audit and Susan Bedell and Ron Manor on the Governance Committee.

Patient Advisors serve as full voting members of these committees and respect the confidentiality required of their participation.

## Patient Experience Advisor Highlights

Patient engagement and partnership is an active and purposeful collaboration with patients, families and caregivers that builds a culture of Patient-and Family-Centred Care and ensures people’s values, experiences and knowledge about their health are incorporated into care discussions. Organizationally,



it means partnering with Patient Advisors in defining and shaping policy, programs and initiatives that impact the patient experience at Kingston Health Sciences Centre.

There are so many great opportunities for staff and leaders to work with the Patient Advisors. Here are just a few examples of how that collaboration is making a difference.

## Accreditation 2022

*“It was a joy to see PCC woven throughout this organization. You truly are walking the walk and talking the talk. You will transform care one step at a time, together.” Surveyor*

“Accredited with Exemplary Standing” is something worth celebrating! KHSC met all criteria for the priority process of People-Centred Care. The Patient-and Family-Advisory Council (PFAC) and Patient Advisors played an important role in achieving this accomplishment and were very excited to have a patient surveyor included in the survey team.

In preparation for Accreditation Angela Morin, PFCC Lead pulled together PFCC evidence to share with the Survey team which included PFAC terms of reference, workplans, agendas and minutes, patient and family guidebooks, Patient Rights and Responsibilities poster, Patient Advisor education and recruitment materials and a summary of committee involvement. Angela Morin and Anne O’Riordan, Patient Advisor, were asked to join the Accreditation Task Force group and Accreditation was added as a standing item on the KHSC PFAC agendas. Patient Safety, Quality Specialists Taralynn Richmond and Erika Peterson partnered in creating and delivering education sessions on what to expect during Accreditation and how to participate in mock tracers for Patient Advisors interested in supporting Accreditation planning. Patient Advisors signed up to do mock tracers and provided input into the development of the “Show what we know” resource on how we partner with patients and families. This resource helped staff to consider and articulate how they partner with patients and families in the work they do, how they demonstrate the principles of patient- and family-centred care, and how Patient Advisors are involved at KHSC.



Patient Advisors also participated in on-site surveyor focus groups. The Patient Surveyor attended a PFAC meeting and, based on what she heard, suggested the Survey team tour the Breast Imaging Kingston site. Patti Cox and Vivian Bethell, Patient Advisors were invited to join the tour and were able to share more about the importance of their partnership experience with the surveyors.

Providing resources to PFACs and Patient Advisors clearly demonstrated formalized structures that support and encourage authentic patient engagement in the operations and activities throughout the organization. The PFAC seal of endorsement was cited as being a visible demonstration of the contributions of Patient Advisors and of the importance KHSC places on patient and family partnerships.

In the final accreditation report examples such as having Patient Advisors involved in the Visitor Exception committee, inter-professional quality and patient safety committee, HIS development, quality improvement projects, redevelopment and facility planning were all mentioned. The inclusion of Patient Advisors at leadership tables and as members of Committees was considered to be innovative

engagement and we were encouraged to continue to lead through sharing and publication of identified leading practices.

The report also encouraged us to seek out voices that may not often be heard, to be creative, be mentors to others and to celebrate our successes.

*“It is great how you and Kerry were able to have Darlene and Joanna present at PFAC and we were able to implement the thoughtful feedback right away. At our ambulatory care accreditation leadership meeting yesterday, we mentioned this group and our other ambulatory care projects. The question that prompted it was: How are you certain that the projects you are doing are of value to patients and families and capture the patient voice? So, we were able to illustrate that our ambulatory projects are started with our PEAs and only after they have been vetted and shaped by the PEAs and deemed to be a good place to spend some energy do we proceed.” Deanna Abbott-McNeil, Program Operational Director, Ambulatory Services.*

## **Pandemic planning**

The engagement of Patient Advisors during these challenging times has enabled KHSC to remain nimble in anticipating and responding thoughtfully to rapidly changing circumstances, and patient and caregiver needs. This active partnership of patients, families and professional caregivers working together, continues to support outstanding communication with the public and health care delivery at KHSC.

In the final Accreditation report there was recognition of the key role Patient Advisors played in Covid-19 planning with specific mention of the “Balzac Group” of Patient -Advisors and their role in the proactive identification of patient and family priorities and potential impacts of a pandemic on family presence.

At a time when many health care organizations were ramping down on engagement with their Patient Advisors, at KHSC, Patient Advisors became a pivotal resource to supporting COVID-19 response. As such, other organizations have reached out to learn from the KHSC experience as they struggle to re-engage Advisors post-pandemic.

KHSC’s commitment to partnering with Patient Advisors during the pandemic continues as we prepare for more changes in family presence and screening.

Just as they were consulted on family presence policy changes during times of lock downs and mandates Patient Advisors are providing input into re-opening of patient entrances, passive screening, IPAC measures, refreshing of family presence and shared care models. They are aware of the challenges being faced and partner in finding ways to support staff in addressing them, like creating protected time for ICU nurses during handoffs, while staying grounded in the impacts on patients and families.

## **It’s Great to Ask**

Communication, information sharing and participation are foundational principles of PFCC and this project, led by the Director of Ambulatory Services, Deanna Abbott-McNeil and her team, demonstrates and supports these principles both in its outcome and impact but also in the process that was used to create it. Ambulatory or clinic appointments can be fast and overwhelming for patients. The purpose of the “It’s Great to Ask” tool is to help patients get the most out of their outpatient specialist appointment and to help facilitate good communication between patients, families and their health care team.

The four-question tool is based on the IHI's "Ask Me Three" and has been revised based on a series of PDSA cycles held in KHSC waiting rooms with actual patients.

The Patient and Family Advisory Council (PFAC) was also a major contributor to the development of this tool. PFAC Members were integrated into the working group and the PFAC assisted with language, messaging, and distribution planning.

The "It's Great to Ask" tool has been endorsed by PFAC and is available in English and French. Collaboration with Ininew Patient Services is underway to adapt the resource for Indigenous patients.

The tool has been added to the electronic inpatient "My Discharge Plan". It will be included in appointment notices, posted on the KHSC website, and posters will be visible throughout the organization. Further tests of change are underway to consider how to best make the tool available within clinic settings.

At KHSC we value partnership and look for ways to empower patients. This tool is an innovative approach to strengthen the connection between patients and the healthcare team in our pursuit to deliver quality care.

*"This tool is great. How do we get this in the hands of other doctors?" Physician feedback*

*"Wonderful work. I am sure this that using this tool will help create an opening, and comfort level, for many patients to ask questions at their appointments." Gerhard Wendt, Member KHSC PFAC*

## Security with a Friendly Face

Visitors coming to Burr 4, especially for the first time, can feel nervous and uncertain especially when having to navigate a unit that must be secured for safety reasons. *"The presence of a Security Ambassador is set to change that experience for the better, especially for newcomers to the MHAC program," she says. "Now there will be a human touch right from the moment the visitor or patient arrives. This is about security with a friendly face." Patient Experience Advisor, Anne O'Riordan.*

*"We are very proud of this project, and so happy we can finally bring it to fruition. This was Anne's vision, and I am just so happy she kept our feet to the fire so we could make it a reality" Nicholas Axas, Program Operational Director, Mental Health and Addictions.*

In April 2022, the Mental Health and Addiction Care (MHAC) program introduced the Security Ambassador to the inpatient unit on Burr 4. A security professional with additional training in mental health, addiction and stigma issues greets visitors providing a welcoming presence as well as providing information about the unit and ensures that all safety and screening precautions are met before admitting visitors onto the floor.

While the role also involves supporting Burr 4 staff through a dedicated response to incidents, emergency codes and other assistance as needed, its main goal is to create a positive patient- and family-centred care experience.

*"This is a truly collaborative effort by the MHAC team, Protection Services and our Patient Experience Advisor who share the goal of ensuring people are treated with compassion, fairness and professionalism." Nicholas Axas*





## A Brand New Day

Planetree International is a not-for-profit global healthcare leader setting the global standard for person-centered excellence across the continuum of care with a strong focus on improved patient and family engagement [Who We Are | Planetree](#). The theme for the 2022 Planetree International Conference on Person-Centered Care was “A Brand New Day”. Anne O’Riordan, a member of the Balzac Group of Patient Advisors took the lead on making a submission to present at this year’s conference. The submission, Pandemic Patient Engagement Success: Maintaining Family Presence Through Partnership, focused on best practice of patient engagement during Covid and was accepted as a breakout session. Angela and Anne were supported in attending the conference in the fall of 2022. The session was well received by participants and spotlighted as well at a Planetree Fellows luncheon. Anne also showcased the patient engagement work at KHSC and the importance of hearing the patient perspective at a plenary session of Chief Experience Officers as the sole Patient Advisor panelist on the topic: Best Practices for Accessing and Integrating Patient Voices.

Exciting new connections and opportunities to share resources were made with Patient Engagement specialists from a number of world-renowned hospitals including Brigham Women’s Hospital, Johns Hopkins School of Medicine and with the author of “Why We Revolt” Victor Montori of the Mayo Clinic.

In addition to getting to share the great work of KHSC on a global stage, sessions such as “Individualizing the Care Experience”, “A Diversity Recruitment Guide for the Patient Family Partnership Council” and “Improving Communication with Nurses” were particularly relevant to the work of the PFCC Program and Accreditation person-centred care standards.

*“All this to say THANK YOU for supporting our attendance at this conference. I feel renewed and excited about my ongoing commitment to KHSC as a patient advisor.”* Anne O’Riordan, Member KHSC PFAC



In its fifth year, The Exceptional Healer: Patient- and Family-Centred Care Excellence Award recognized two health care professionals who best demonstrated exceptional performance in patient- and family-centred care (PFCC). The common theme that ran through the nominations was an expression of gratitude for the human kindness attached to the skill and competence of care providers. The two winners were oncologist Dr. Chris Booth and nurse practitioner Kristine Canty of

the Bariatric Centre, both of whom exemplified the best in PFCC at the hospital. It was noted that Dr. Booth was skilled at putting into action the hospital’s most fundamental values, i.e., compassion, respect, partnership, excellence and innovation.

Ms. Canty was praised for listening without judgement. She sought out the patient perspective and supported the understanding that every person is unique. Ms. Canty encouraged the full involvement of everyone on the health care team.

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 majority of nominations come from patients and family members; some from staff. The selection committee comprises a majority share of patient advisors, as well as staff. Decision-making involves lively discussion, and mindfulness that the winner must have demonstrated an exceptional ability to relate to and with patients and families, on top of their fine clinical skills.



## Supporting the Culture of PFCC

- All New Employee Welcome (NEW) sessions include a presentation by a Patient Advisor in partnership with the PFCC Lead. The presentations which include a story and an overview of PFCC and the role of Patient Advisors at KHSC were all done using Teams. A recording has been created to be played if the Lead or a Patient Advisor is not available to present live. A total of 24 sessions were done live by 5 Advisors in the past year: Phyllis Davis, Gerhard Wendt, Tanya M., Perlita Delaney and Anne O’Riordan. Feedback from the participants consistently reflects great appreciation for the contribution of the patient story, a strong interest in PFCC and the role of the PFAC and Patient Advisors within the organization. Starting out on Day 1 with a patient story sends a powerful message about how important the patient experience is to everyone who works at KHSC.

*“Very impressed with all the patient engagement. Looking forward to working closely with you.”  
NEW staff participant*

*“Brought me to tears, thank you for sharing!” NEW staff participant*

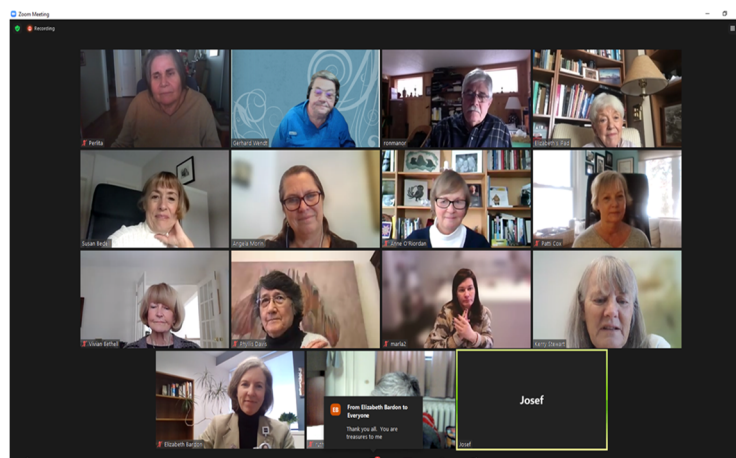
*“Patients always need to be treated with respect because they are not aware of what happens or the procedures that take place in the medical field. We are what makes or breaks a Health Care experience.” NEW staff participant*

- 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.
- Presentations on the role of Patient Advisors and the principles of PFCC are shared with staff, leaders and learners by Patient Advisors and the PFCC Lead.
- New Patient Advisor recruitment brochure, co-designed and endorsed by members of the KHSC, SERCP and Renal PFACs has been printed and is available electronically. The brochure has been written through the lens of Patient Advisors encouraging other patients and families to get involved and provides staff and patients and families with information on the role of Patient Advisors. The brochure is shared with new leaders by email with a note of congratulation from the PFCC Lead to raise awareness of the program and the support available.
- New Patient Advisor business cards have been created for Patient Advisors to share as a more personal recruitment and information sharing tool in their community networks.

## System Level Impact: Sharing and Learning

Many Advisors bring the expertise of their lived and well-respected experience as a Patient Advisor at KHSC 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:

- Presentation Planetree International Conference Person-Centred Care
- Planetree Fellowship in Person-Centred Care
- Institute for Patient and Family Centred Care membership and webinar presentation.
- Healthcare Excellence Canada
- Ontario Health and FLA-OHT
- Centre for Digital Health Evaluation
- Digital Health Canada
- Beryl Institute (peer review editor)
- 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
- HQO Quality Standards Committee (OH OQSC)
- Compassionate Communities Kingston Canada
- Caregivers4Change
- Patient Advisors Network (PAN)
- Ontario Hospital Association (The Path Forward for Virtual Care in Ontario)
- Canada Health Infoway (A Healthy Dialogue)
- National Healthcare Engagement Network
- St. Lawrence College, Medical Laboratory Science



## Patient & Family Advisory Councils (PFACs)

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

The KHSC PFAC, currently co-chaired by Patient Advisor, Kerry Stewart and PFCC Lead, Angela Morin, consists of a minimum of twelve Patient Advisors, an Executive Sponsor (Brenda Carter, EVP Quality, Partnerships and RVP Cancer), Director of Professional Practice (Jennifer Achim), Director Patient Safety, Quality and Risk (Gina Miller) and is supported by a communications specialist (Anne Rutherford) and the PFCC Administrative Assistant. Ex-Officio advisor positions include the Chairs of both the Southeast Regional Renal Program PFAC and the Southeast Regional Cancer Program PFAC and those Patient Advisors who sit on the Committees of the Board. The bios of the current KHSC PFAC members provide wonderful insight into the motivation of these committed individuals to be involved and the value of the role and the Council. Their bios can be found on the KHSC website at <https://kingstonhsc.ca/about-us/patient-and-family-advisory-council>.

This past year the KHSC PFAC said a fond farewell to Elizabeth Bardon on her retirement and enthusiastically welcomed our new Executive Sponsor Brenda Carter to the group. The program's Administrative Assistant Cathy Hitchins also retired this year and we are examining the needs of the evolving work of the PFCC program as we embark on recruiting her replacement.

A summer, in-person, Patient Advisor gathering held at Lake Ontario Park was well attended and very much appreciated. It was a great opportunity to thank the Patient Advisors for their dedication and invaluable contributions, to introduce new members to the group, to share ideas for the future as well as to wish Cathy well on her upcoming retirement.

The valuable contributions of Vivian Bethell, Josef Amann and Elizabeth Harlow were acknowledged by the organization and the PFAC Chair upon the end of their terms. With the addition of three more Patient Advisor Board committee members the Council has grown in numbers.

The Council agreed to hold membership steady for stability during COVID. This continuity of experience and trusting relationships was incredibly important at a time of so much change but we are now looking to recruit new members that will bring more diversity of perspectives to the Council. 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.

One perspective identified as missing from the group is that of younger patients. Outreach to Queen's was initiated by Council members Doug Davey and Perlita Delaney in the creation of a recruitment poster in partnership with the Queen's Kinesiology Program and the support of the PFCC Co-chairs and Communications. Council member Anne O'Riordan shared the information when she presented on the patient/family perspective in the course "Professional Issues in Allied Health" for Queen's Kinesiology and Health Studies students resulting in five applications for new student age Patient Advisors with one being invited to explore an opportunity for membership on the KHSC PFAC.

As part of the on-going work of the Council an evaluation of the voices missing and hearing from diverse groups will continue.

The PFAC Co-Chair opens every meeting with a welcome and land acknowledgement.

Midge Rouse, Director Ininev Patient Services, was invited to attend the June PFAC meeting and provided a powerful overview of the complexity and uniqueness of providing healthcare to remote indigenous communities in the north. The Council members heard how Ininev Patient Services is working to create a culturally safe experience designed with consideration for the comfort and needs of Cree patients including having an interpreter to help patients navigate a very different system and educate providers to interact in a way that recognizes those differences.

### **Responsibilities of the KHSC PFAC:**

- Inform and make recommendations about the implementation and evaluation of the KHSC Strategy and Annual Integrated Corporate Plan.
- Provide direction in the implementation and evaluation of Patient -and Family-Centred Care at Kingston Health Sciences Centre.
- Actively promote and create new and unique opportunities for communication, collaboration and partnering among patients, families and staff.
- Identify and support opportunities for improvement within Kingston Health Sciences Centre from the patient and family perspective.
- Identify opportunities to communicate about PFCC and Council successes and outcomes within broader KHSC community
- Receive annual reports from the HDH site PFCC Grants Committee.



## **The South East Regional Renal Patient and Family Advisory Council**

This Council is co- chaired by Cindy Fitzpatrick, Social Worker and Phyllis Davis, Patient Advisor. The Council is currently made up of 13 Patient Experience Advisors, the heads and managers of the Nephrology Department and representatives from the Kidney Foundation and are supported by the Lead PFCC.

This year in the Renal PFAC we have listened to many member's personal stories and concerns and have used them to improve the Renal Patient's journey.

Camp Dorset was again opened for Renal Patients. Here they were able to enjoy a vacation where their dialysis needs were part of the holiday package. And as an added bonus, the Kidney Foundation helped finance patients who wanted to go.

A new MCKC (Multi Care Kidney Clinic) was established in Brockville which shortened trips to the kidney clinic for many. And the easy parking availability was a pleasure for clients who were used to fighting for a space in Kingston.

We are happy to have Members of our Council who have used their experience as transplant patients to tell their stories at TAP (Transplant Ambassador Program) which is a Peer Support Program for transplant patients.

A new study is underway to improve the menu selection and size portions for meals during a hospital stay. This is a study that goes way beyond the likes and dislikes of hospital food. This also spurred discussions about the importance of the special kidney diet and how it is so important in helping keep your kidneys healthy.

The Council was able to endorse a pamphlet to help patients better understand the need for a kidney biopsy and the steps that a patient must go through to get one.

They also endorsed a plan for Integrated Dialysis Care. The Bayshore Team will help develop 'Care Plans' for patients by expanding Home Care into the Renal Program giving care where patients are receiving peritoneal dialysis and other home assisted supports.

We even discussed how people on dialysis could travel more comfortably and a patient that does this often explained the pros and cons. The Kidney Foundation made us aware of travel funding which they could provide for every dialysis treatment out of the province.

It was brought up at one of our meetings that surgeries that give kidney patients an access point for dialysis have been lessened and through our advocacy more scheduled surgeries are taking place.

We have been a very busy Council that has done its best to make the kidney treatment easier for their patients."

*Phyllis Davis, Patient Advisor and  
Cindy Fitzpatrick, Social Worker and Co-Chairs Renal PFAC*

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

*"It is an honour and a privilege to sit on the 2024 CAT-Scan committee coming to Kingston. This cancer detection machine has so many applications and will move the needle higher for health care at KHSC." John Price, Member SERCP PFAC*

The SERCP-PFAC advises on cancer care services at KHSC's Cancer Centre and across the South East, and at a provincial level provides input to Cancer Care Ontario. The Council may have up to 15 Patient Experience Advisors from across the region who have had experience with cancer along with 5 staff members.

There are currently 11 Patient Advisors on the Council. Patient Experience Advisor Marla Rosen Co-

Chairs the Committee with the Program Operational Director of the Oncology Program. Leslie Young stepped into the Co-Chair role in June 2022 in her interim role replacing Kardi Kennedy, Program Operational Director of the Oncology Program.

## **Mental Health and Addictions Advisory Councils**

The Child and Youth Family Partnership Committee, started in February 2019, is comprised of staff, patients/clients and caregivers who meet monthly to share their expertise grounded in experience to provide guidance and input on priorities and goal setting for the program of Child & Youth Mental Health & Addiction Services. The committee went to a virtual platform due to Covid and was paused over the summer months. Recruitment for new members is underway.

A new Adult Mental Health & Addictions Advisory Committee is in the early planning stages. Two Patient Advisors and the Lead PFCC are partnering with and supporting Program leaders in creating a Draft Terms of Reference. The purpose of the committee is to serve as a patient and family advisory committee for the Kingston Health Sciences Centre (KHSC) Adult Mental Health (AMHP) outpatient program at the HDH-site, and the acute adult inpatient units at the KGH-site with the intention of strengthening partnerships amongst patients, families, community partners and health care providers, making recommendations on matters that impact client and family experience, as well as program functioning and development.

## **Transforming care, together**

This past year we have re-committed to sharing and hearing patient experience stories at all levels of the organization, including at the Board Committee level, in the KHSC Annual Corporate Plan for 2022-2023. Times and technologies have changed, and we now have an opportunity to capture patient stories using various methods. In addition to introducing a patient story to the Patient Care and Quality Committee of the Board meetings, part of this work has involved looking at our processes around such things as Feedback Forums and adapting them to a virtual process. A working group has been formed, led by Angela Morin, that partners with Patient Advisors to review guidance materials, frameworks and a “consent for recording” form has been finalized. This change to providing opportunities to record patient stories will help to facilitate more engagement with a more diverse population of patients and ensuring their stories are being heard by those who need to hear them.

## **Even better if.....**

In times of stress many organizations withdraw into their core positions and ways of doing business, with perceived optional programs temporarily relegated to the back shelf. KHSC is one of the few hospitals in Ontario that has ramped up the engagement of Patient Experience Advisors with staff during the on-going Covid pandemic. This has only been possible as a consequence of the high regard that hospital staff have for authentic patient input into organizational decision making. It speaks strongly of the depth of the collaborative partnership among patients, families and health care professionals. It is a cornerstone of how we do business at KHSC. It is why we are considered a leader in PFCC.

Advice from the surveyors during Accreditation was to consider reaching out to community partners and collaborate on bringing in more diverse perspectives. The PFAC members are taking that advice to heart when considering their membership but broader relationship building takes time and creativity, especially during a pandemic. Building trust is a sensitive process and easily broken if not nurtured.

Our greatest challenge is having the time and resources to do all we could be doing. The contributions of the Patient Advisors who volunteer their time and wisdom are truly a gift, but we need to be able to provide them with support, training and appreciation. As we look to the future through a lens of equity,

diversity and inclusion we need to ensure that the resources will be there to support that engagement in an authentic and respectful way.

KHSC and health care organizations everywhere are dealing with unprecedented challenges. The way forward must be grounded in caring and kindness, for patients and families but also for staff, leaders and providers. We have never needed to remind people more about why what they do is so important and how to connect on a human level. The members of the PFCC program will be considering their role in supporting an evolution of patient- and family- centred care to one of person- centred care as part of an overarching future strategy.

## **Douglas Davey, Patient & Family Advisory Council Member**

I have been part of the Patient and Family Advisory Council from its beginning and am amazed that I have been privileged to do that. I feel like I am accomplishing something and that my opinion is heard and respected. Patients are fieldstones, not bricks—no two are the same—and so hearing different perspectives is important. I feel it is my responsibility to speak up, and while change may not be as fast as I like I do see progress.

I am very proud of the feedback forums where patients and families get a voice by sitting down with the professionals who worked with them to talk about their hospital experience. Those health care workers cannot know how we feel if we do not get a chance to tell them. I also enjoy partnering in the hiring process as an interviewer and have been a strong supporter of the smoking cessation program. On the social side, I really enjoy the annual Strawberry Socials, when it is nice to see staff interacting with each other and enjoying themselves as a team. I always enjoy seeing them working together. It gives me confidence that they are looking after me, the patient, as a team.

I have been a Patient Experience Advisor for over 10 years. I am volunteering because I care. I am a straight shooter—you do not have to sugar coat it with me. I keep it real and can tell staff exactly how I think. Being a Patient Experience Advisor gives me the opportunity to make a difference. If we all sit in the background nothing is going to change. I feel proud of myself for speaking up when I see change happen after sharing my perspective. I am not a professional, but I am treated with respect and my opinion is valuable. I treasure the relationships that I have built as a Patient Experience Advisor.



Respectfully submitted,

Kerry Stewart

Kerry Stewart, Patient Experience Advisor  
Co-Chair, KHSC PFAC

A handwritten signature in black ink, appearing to read 'Angela Morin', written in a cursive style.

Angela Morin, PFCC Lead  
Co-Chair, KHSC PFAC