

PATIENT-AND FAMILY-CENTRED CARE PROGRAM ANNUAL REPORT – November 2021



Hôpital
Hotel Dieu
Hospital



Hôpital Général de
Kingston General
Hospital

What is Patient- and Family-Centred Care?

Kingston Health Sciences Centre (KHSC) has aligned its definition of patient and family-centred care (PFCC) to that of the Institute for Patient and Family-Centered Care (IPFCC): 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.”*

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 also aligns to the World Health Organization’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.

PFCC is based on the following four concepts:

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.

All the principles require active engagement among patients, families and staff at every level of the organization, and can be translated to work at a regional and system level.



Patient Experience Advisors at KHSC have developed an easily remembered definition: **“Respect me, Hear me, Work with me”**. This simplified description also translates such that expectations are applicable whether you are a patient or a staff member.

Patient Experience Advisors

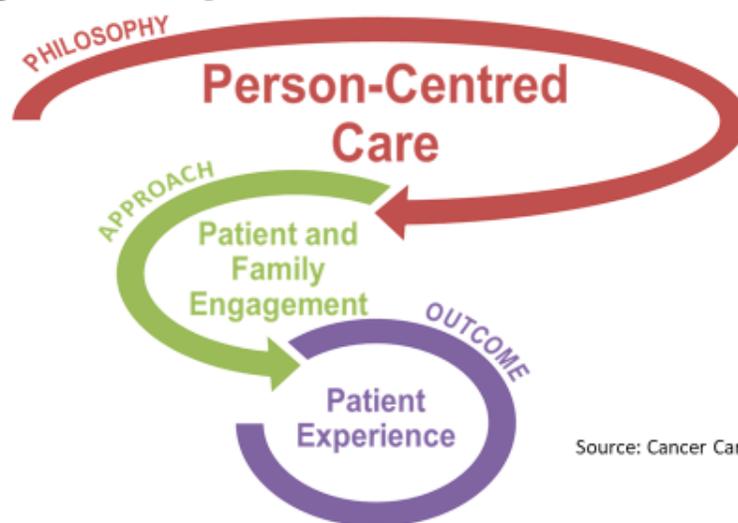
The role of Patient Experience Advisors is grounded in the acknowledgement that there is expertise in, and lessons to learn from, the experience of Patients and Families. Patient Experience Advisors (“Advisors”) play an integral role at KHSC. Patient Experience Advisors are patients or family members of patients who volunteer their time to be members of committees, councils and working groups and/or to partner on improvement teams across KHSC. They are people who have had, and often are currently having, an experience of care at Kingston Health Sciences Centre. Advisors are supported in becoming involved with work that aligns to their experience and interests. They participate as full members on all committees – including Board committees – making decisions materially affecting the patient experience.

In fiscal year 2020/2021 Patient Experience Advisors volunteered over 2,024 hours of their time which is extraordinary considering the on-going restrictions to being on-site due to COVID-19. We believe that this calculation is under-estimated given some of the challenges we have in receiving reported hours from all of our 60 dedicated Advisors, many of whom do not include preparation time into their calculations. We also are not accounting for the personal resources that the Advisors are using to participate (e.g devices, ink and paper) and the time spent installing and learning new virtual platforms to engage because they are not able to be on-site.

How it all fits together

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.

Key concepts



Source: Cancer Care Ontario

Patient Advisors at Decision Making Tables

Patient Advisors are sitting at key decision making tables and are members of a number of organizational working groups and initiatives including the Regional Health Information System (RHIS) team and numerous Redevelopment Design Working Groups and Subject Matter Expert Groups.



FLAOHT – The Co-Chair of the KHSC PFAC, Kerry Stewart, is Co-Chair of the FLAOHT Community Council and member of the Transitional Leadership Collaborative. Several KHSC Advisors are bringing their perspectives to Working groups and the Community Council of the FLAOHT. Angela Morin, Lead PFCC, is a member of the Communication and Engagement Working Group.

KHSC Clinical Operations Committee recognizes that the patient voice is fundamental to good planning and decision making and has been intentional in ensuring that perspective is present by including a Patient Advisor on this committee. The Patient Co-Chair of the PFAC is a member and the patient perspective is a standing item on the agenda.

Board Committees

In early 2021, the Governance Committee of the KHSC Board considered committee membership and affirmed its commitment to appointing two patient advisors to serve on each of the three Board committees (Patient Care & Quality Committee; People, Finance & Audit Committee; Governance Committee). Interested advisors were invited to submit an application and participate in an interview with the Chair of the Governance committee and the Board Vice-Chair, along with an executive team representative, before being recommended for appointment. The Board policy was also amended to ensure that advisors, while appointed annually, may be reappointed up to a total of three years. This supports consistency, while also ensuring succession. All of the committees began the new board year July 1, 2021 with the patient advisor roles filled. This included renewing advisors Vivian Bethell and Betty

Harlow on Patient Care & Quality Committee, new member Gerhardt Wendt and renewing member Joseph Amman on People Finance & Audit, and new members Susan Bedell and Ron Manor on the Governance Committee. Advisors serve as full voting members of these committees.

“It is a remarkable opportunity to sit as a full member on the Board's Patient Care and Quality Committee. Not only has it given me a better understanding of the complexities and ever changing priorities that Board members and Executives must deal with in providing direction and leadership in this major healthcare centre, but also it has allowed me to represent patients and families in matters of patient care. KHSC is indeed a leader in embracing patients and family members as full voting members on Board committees, which I believe sends a clear message that we as PEAs are partners in healthcare and that our participation at all levels is valued.” Vivian Bethell – Patient Experience Advisor and member Patient Care and Quality Committee of the Board.

Making an Impact

“Little things can make a big difference. Patients appreciate having the opportunity to share ideas and to see those ideas put into action. In the dialysis room I shared that having somewhere to hang up our coats would be nice and coat hangers were installed. Little contributions by patient advisors and the Patient and Family Advisory Council are like Lego. Little individual pieces but together they build into something big.” Tim Slater, Patient Experience Advisor and Member of the Regional Renal PFAC

In addition to the committees mentioned above, this past year, Patient Advisors contributed to a number of different activities with corporate importance including:

COVID-19 Planning

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. Advisors were consulted on family presence policy changes to reflect changing provincial requirements (e.g. Stay at Home orders, lock downs, lifting of orders), local issues (e.g. low prevalence in our region during times of high prevalence elsewhere, Union St. alternate site design), information for patients, families, public (e.g. how to support safety at KHSC as a registered family visitor), and information for and about patients with COVID transferred to KHSC during the third wave. In addition, advisors provided helpful advice and input into policies such as the mandatory vaccination policy for staff and the mandatory vaccination policy for registered family visitors, along with input into exceptions required (e.g. unvaccinated parents of admitted children; unvaccinated persons required at end of life, etc.). PFAC members were provided with a monthly update about COVID and response at KHSC, along with requests for specific feedback and input. Smaller group meetings or emails provided another mechanism to receive timely input from patient advisors around any proposed changes at KHSC related to COVID. Patient Advisors provided rapid feedback and support to ensure equity, safety, and clear communications throughout the organization's response to the pandemic. Advisors also participated in regular ambulatory care COVID response team meetings, and ad hoc working groups as necessary.



Family Presence Exceptions Committee

Patient advisors were involved in discussions very early in the pandemic about family presence at the hospital as it became clear that the province, city, and hospital would be shutting down the usual ability to travel with abandon within the community. Knowing that visitors to KHSC would be restricted, advisors were included in imagining ways to continue to engage families to support their loved ones while restrictions to entry into our facilities became a reality. How do we balance safety from infection with knowing that family presence makes a positive difference to patient outcomes? As the hospital clarified its policy to reduce non-patient traffic, other groups creatively found ways to create a virtual presence for family, and to consider the level of tolerance for family bedside presence. Policy was created and revised as the public health situation changed.

The KHSC Visitor Exceptions Committee was created to ensure consistency and fairness in reviewing exception requests to the KHSC Family Presence Policy. The committee helps balance the unique individual needs of patients and their families with the need to keep all of our patients, their families and staff safe from COVID.

“I have been pleased to be part of a small committee that was given the task to consider requests for family presence that were different than what policy explicitly stated. The challenge was to relieve staff of burdensome decision-making about visitors when they were so involved in managing other aspects of care. The committee runs a tight but compassionate ship. We are guided by the policy of the time and the need to be fair and consistent but consider unique circumstances. My fellow committee members have been thoughtful, respectful, supportive, and dedicated. Their perspective as staff provides a take on a situation that may be somewhat different than mine; but consensus has been quite easily achieved. The work of this committee seems to fill a need to make challenging decisions that satisfy both the greater institutional requirements during the pandemic while supporting patients and families.”
Patti Cox – Patient Experience Advisor

“Having a patient advisor participate in the committee has been instrumental in helping to ensure that the committee’s decisions can reflect the difficult yet essential balance between the particular needs of individual patients and their families and the hospital’s need to provide a safe environment during the pandemic. Patti has provided invaluable input by looking at the individual merits of each request and balancing compassion and safety. She provides careful, thoughtful analysis to each request in order to ensure that the committee is being fair and consistent in its decisions.” David Campbell – Ethicist

Virtual Care Access Toolkit Project



A partnership between Queen's University researchers, the Kingston General Health Research Institute (KGHRI), and members of the Patient and Family Advisory Council (PFAC) of the Kingston Health Sciences Centre (KHSC) has led to the creation of a series of resources to improve patient education and access to virtual care. Patients and caregivers with lived experience locally and from different parts of the country provided expertise, insight, and direction to ensure the toolkit addressed specific areas of need.

A website (<https://virtualcareresearch.com/>) has been created to share resources and ultimately incorporate feedback as person-centred virtual care best practices evolve.

"This project has partnered with patients and caregivers from the very beginning, incorporating our suggestions, insights and expertise into the toolkit. Our partnership has created tools that are truly informed and useful and will lead to greater success in virtual care for patients, caregivers and health care providers. I look forward to ongoing collaboration in sharing and expanding virtual care resources." Anne O'Riordan – Patient Experience Advisor and Member KHSC PFAC

"Partnerships such as this ensure KHSC will remain on the leading edge of patient-centered care and as a model for other healthcare organizations to truly engage patients in research. This means that patients in southeastern Ontario will now have access to resources that improve digital literacy so that they can continue to access healthcare closer to home or even in the comfort of home." Dr. Ramana Appireddy – Physician/Researcher

Satellite clinic for dialysis patients inspired by patient and family feedback

For some patients on dialysis, having a dedicated satellite site for treatment in Kingston has long been identified as an opportunity to offer continuity of care. Now, as a result of that feedback a new satellite clinic model has opened with a dedicated physician and nursing staff.

“With a satellite clinic model, patients have a dedicated care team that gets to know them, their care needs and build rapport and personal relationships. We are proud to have partnered with our patients and families to create a model that will deliver the same continuity of care as a satellite site within a hospital setting. This has been an exciting initiative to work on with our patients and families to help deliver care in a manner that they identified for us as most appropriate. Our Renal Program looks forward to continuing to partner with patients on advancing the care that we provide.” Justin Tennant, Program Manager, Regional Renal Services

The new satellite clinic model will be physically located within the walls of the Kingston General Hospital site but will otherwise operate as its own satellite site. This means that there will be two dedicated physicians and nurses rotating through the clinic as well as administratively following the same procedures and protocols as a satellite site.

For Tim Slater, a dialysis patient and member of the Patient and Family Advisory Council who helped shape this new satellite model, its opening will be a welcome change for some dialysis patients.

“When you’re in the hospital setting for dialysis but don’t require that level of care, you’re seeing different nurses and doctors who you don’t have that familiarity with. In a satellite site you meet the same nurses who get to know you, how to needle you and there’s good consistency of care,” says Tim. *“A lot of work and time went into planning this mode. It was a real team effort and I’m proud to be part of the process to bring the satellite clinic concept to KGH.”*

Cancer care closer to home

Spinal stereotactic body radiotherapy (SBRT) is a highly effective treatment for spinal metastasis which delivers high doses of radiation and requires a specially designed platform to ensure that the patient is immobilized. That treatment is now available at the Cancer Centre of Southeastern Ontario. Prior to this therapy being offered in Kingston, patients had to travel to Ottawa or Toronto for spinal SBRT treatment which could require up to 10 days of radiation.

“My wife and I wanted to give some money to a worthwhile cause,” says Ken Sedgewick, who donated the funds to purchase the equipment. *“I was introduced to the radiation department last year for cancer treatment and wanted to say ‘thank you’ for their care. We couldn’t be happier that our gift will help patients and their families access this more effective treatment closer to home.”*

“Being able to offer this treatment here allows the patient to take less time off work, stay closer to the comforts of home, and save money on the expenses of travelling to a larger city,” Dr. Ynoe de Moraes says. *“These are some real barriers to care that are significantly reduced now that we have this equipment in Kingston.”*

<http://cancercaresoutheast.ca/new-treatment-spinal-tumors-now-available-kingston>

Eliminate Wait Times for Specialty Access

This initiative, led by Dr. Elizabeth Eisenhauer, began in mid-2020 and includes Angela Morin on the Steering and Evaluation Committees as well as Advisors, Gerhard Wendt, Marla Rosen, Perlita Delaney, Kerry Stewart, Anne O’Riordan and Phyllis Davis on five evidence based innovation working groups. Over the past year the groups have been working toward piloting and implementing:

- Central referral and triage using digital tools
- Pathways for primary care management of common, non-urgent consults
- Direct specialist phone access for primary care
- Optimizing virtual care to increase capacity
- Embedding specialty clinics in primary care offices

Committees and policy input

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 Patient Advisors have provided input on Program Councils, many working groups and committees including:

- Emergency Mental Health
- Ambulatory care ramp up
- Essential Care Partners
- Hemodialysis working group
- Palliative care ethical framework
- Cancer program Covid planning
- Inpatient mental health program model of care
- Kidney transplant working group
- MAID internal resource group
- Multi Care Kidney Clinic Working Group
- Professional Practice Council
- Accreditation Planning Task Force and working groups
- Renal health literacy
- Renal home therapies
- Special needs steering committee
- Symptom management QIP (Cancer program)
- Virtual health project
- Disclosure and Patient safety incident policies
- Redevelopment user design and subject matter planning groups
- After death policy review

Patient Resources

Many advisors provided electronic feedback and input on patient education and resources. They reviewed materials to ensure the information provided addressed their priorities, was true to PFCC principles and was easy to understand. Some of the resources that received patient input included:

- Pain block brochure
- Home feeding tube education booklet
- MRI with cardiac devices
- Patient and family feedback forms
- Screening and testing before procedures
- Script for outpatient surveillance swabbing
- Total knee replacement guidebook
- Should replacement patient guidebook
- A Patient's Guide to Hip Replacement Surgery

Building Awareness

New Employee Welcome (NEW)

An introduction to PFCC and the role of Patient Advisors at KHSC is provided at each new employee welcome (NEW), which takes place on a monthly, and this past year twice a month, basis for KHSC. Due to COVID-19 restrictions to on-site presence, the PFCC new staff orientation session continues to be a virtual presentation. The session is presented by the Lead for PFCC in partnership with an Advisor. Feedback from the participants reflects great appreciation for the contribution of the patient advisor and a strong interest in PFCC and the role of the PFAC and Advisors within the organization.

“This presentation was my favourite. Hearing from Gerhard and what their experience was like was very heartwarming. I like that the hospital works with past, and present patients to help improve patient care.” New staff feedback

In the spring of 2021, a two-part educational session focused on the Advisor role in the new employee welcome (NEW) was co-designed with Advisors Tanya M. and Gerhard Wendt and Jennifer Wakelin, Talent and Leadership Advisor. The sessions were facilitated by Angela Morin, Lead PFCC to raise awareness about the opportunity for Advisors to participate and provide guidance in developing their stories. As a result two more Advisors, Perlita Delaney and Phyllis Davis, have joined the NEW team of Advisors, Gerhard Wendt, Anne O’Riordan and Tanya M. in sharing their story to demonstrate the importance of PFCC and welcoming staff to KHSC.

“Sharing my lived experience with new employees on the first morning of their first day is truly an honour for me. I enjoy connecting directly with dozens of individuals who are choosing to respond to a heartfelt calling to serve our community. I genuinely appreciate the opportunity to inspire patient- and family-centred care in their daily practice across all roles in our organization.” Tanya M. – Patient Experience Advisor

“The value that the Patient and Family Experience Advisors bring to the KHSC New Employee Welcome (NEW) could never be overstated. Their experiences offer a foundation for the policies and practices discussed through the day and provide practical examples of the KHSC Mission and Values. Reliving these experiences is not always an easy thing to do, but the words of wisdom that they bravely share serve as an important reminder of the work that new employees will do as they start their roles at KHSC. That small acts of kindness can and do make a difference in the lives of not only the patients we care for, but for those we work with and support.” Jennifer Wakelin – Advisor, Leadership and Talent Development

PFCC education

- 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 are given to staff, leaders and learners by Patient Advisors and Lead PFCC on the role of Advisors and the principles of PFCC.
- Guest speaker, Heather Thiessen, Co-Chair of the Saskatchewan Health Authority's Patient and Family Leadership Council and Patient Surveyor with Accreditation Canada presented at the December Virtual PFAC meeting.
- A review of the Patient Experience Advisor recruitment brochure has been completed and endorsed by the KHSC, SERCP and Renal PFACs. The brochure has been written through the lens of Patient Experience Advisors encouraging other patients and families to get involved and will provide staff with information on the role of Advisors.
- Participation of Advisors in Open Forums and Leadership Forums.

System Level Impact



“As a surgical inpatient at Kingston Health Sciences Centre (KHSC), I learned that nurses call it “Arts and Crafts” when they use scissors and various adhesives to create customized wound coverings for patients. Nurses are not allowed to remove unused materials once they are placed in a patient’s room so I brought the extras home with me and used them in this piece as a tribute to the extraordinary care I received at KHSC.” Tanya M. – Artist and Patient Experience Advisor. Tanya’s piece was chosen to be included in the HeART of healthCare Exhibition curated by Patients for Patient Safety Canada. March 2021

Many Advisors bring the expertise of their lived experience and their experience as an Advisor at KHSC to other organizations locally, Provincially, Nationally and Internationally. They also share insights and lessons learned from that involvement with other Advisors and staff at KHSC. Some examples of the external involvement of Advisors this past year include:

- 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
- Canadian Foundation for Healthcare Improvement
- Caregivers4Change
- Patient Advisors Network (PAN)
- Institute for Patient and Family Centred Care
- Ontario Hospital Association (The Path Forward for Virtual Care in Ontario)
- Canada Health Infoway (A Healthy Dialogue)
- National Healthcare Engagement Network

Exceptional Healer Award

“The Exceptional Healer Award is back. After almost two years of health care professionals offering care well beyond our expectations to keep patients, staff, and our community safe during the pandemic, we are delighted to bring back the award, which had been lapsed for one year. We must let our health providers know that we are grateful for the extra shifts worked, for the vacation time postponed, and for the evidence-based care provided every day. This is a patient and family generated award that this particular year offers much gratitude to those who have cared for us across in-patient and ambulatory settings during challenging times. Although we may identify as few as one recipient for the award, we recognize the exceptional effort of all staff in the clinical setting. With the clear support of the hospital’s patient and family advisory council, we have put the 2021 award cycle in motion.” Sue Bedell, Co-Chair Exceptional Healer Award

The Exceptional Healer Award is firmly rooted at KHSC as a way of celebrating how clinicians embody the principles of PFCC in their work with patients and their families. Initiated at the HDH site prior to integration, this award recognizes physicians, nurses and allied health professionals for the ways through which they live the 4 principles of PFCC.

The Exceptional Healer Award Committee, Co-Chaired by the Award’s founder Sue Bedell and Advisor Patti Cox, decided, after consultation with the KHSC PFAC, to cancel the 2020 campaign. It was felt that the internal focus on COVID-19 combined with reduced presence of patients and families on-site, would challenge the intention and success of the campaign.

As we find ourselves still dealing with the unprecedented challenges of Covid-19, the Co-Chairs, with KHSC PFAC support, have decided that this important Award will provide some much needed appreciation and support to KHSC’s hardworking and dedicated healthcare providers. Patients, families, caregivers, staff and learners are encouraged to nominate a healthcare care professional for the Award that celebrates health care excellence and exemplars in patient-and family-centred care. “At the award ceremony, the winner(s) will be invited to briefly describe their approach to patient-and family-centred care in their clinical practice. It is hoped that such sharing will be inspiring to health care learners and colleagues.” (source: *Exception Healer Award terms of reference*)



Nominations for the 2021 Exceptional Healer Award are open until December 31, 2021.

KHSC Sharing Lessons Learned with other organizations

Topics included:

Starting a PFAC, Roles and Processes
Engagement and Orientation of new Advisors
Staff PFCC education and resources
Role of Advisors and methods of engagement
Engagement Capable Environments
Role of Patients on Board and Board Committees
Virtual Care Data Forum participation
PFCC Lead Role
Family Presence

Organizations:

Campbellford Memorial Hospital
FLA-OHT
Cornwall Hospital
Woodstock Hospital
Canadian Institute Health Information
Arnprior Regional Health (Board)
Quinte Heath Care
Ontario Shores
VON Canada

Providence Care Kingston
Sinai Health
One way Home & Community Support Services

KFLA Child and Youth Mental Health Advisory Council

Patient Experience Advisor satisfaction/ experience survey

The survey, which measures the satisfaction and experience of being a patient experience advisor at KHSC, is completed every two years. It is intended to measure how well the program is meeting the needs of the Advisors and to identify opportunities for improvement. The survey was created in partnership with members of the KHSC Patient and Family Advisory Council (PFAC) and is reviewed bi-annually prior to being sent out to the broader advisor group. The next survey has been reviewed and will be sent out for completion late November 2021.

As mentioned in last year's annual report, opportunities identified from the survey completed in January 2020 included more guidance on how to be an effective advisor; broader understanding by staff as to the role of Advisors and communication of how their input has made a difference.

In response, the Lead PFCC has worked in partnership with staff and advisors to co-design and deliver education sessions on topics of mutual interest to build capacity of advisors to partner in specific ways and to build resources to support staff in meaningful partnerships with patients and families at the organizational level.

The sessions delivered to date include:

1. Hello my name is....How to introduce yourself as an Advisor on Working Groups and Committees.
2. New Employee Welcome (Information session and work shop)....How to share your story and build awareness of the importance of PFCC and the role of Patient Advisors at KHSC.
3. Role of Advisors on Recruitment Interview Panels
4. Accreditation Walk Abouts.

The sessions included both the staff and Advisor perspective on how these methods of engagement have an impact within the organization.

Stories that highlight PFCC work within the organization are shared with all Advisors via email and follow up presentations to the PFAC on topics such as Post-Discharge phone calls, Staying Connected Virtual Family Presence, Hand Hygiene Compliance and Wound Care close the loop on initiatives that the PFAC has previously provided advice and input on.

Patient & Family Advisory Councils (PFACs)

As the PFCC program evolves, we look for opportunities to provide support and guidance to ensure mutually beneficial partnerships and consistency in onboarding and education of all Advisors. The last two years have reinforced that successful partnerships with patients and families are built on strong and trusting relationships. Over the course of the summer, we transitioned the Administrative Support role for the Regional Renal and Cancer PFACs to the Administrative Assistant for PFCC, Cathy Hitchins. This alignment will assist us in seeing opportunities for collaboration between PFACs and ensure consistency of Patient Advisor administrative support by someone with a strong foundational relationship with the Advisors, especially during times of change. This transition has been generously supported by the Regional Program Assistants, Kimberly Sawyer and Mary Thorne, who continue to play a key role in working with Advisors within their Regional Programs and providing back up assistance to the Regional PFACs as needed.

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



In addition to the many activities Patient Advisors advise and partner on across the organization, the KHSC PFAC meets monthly to serve in an advisory capacity, making recommendations on matters that impact the experience of patients and their families at KHSC. Information and requests flow into PFAC through hospital-wide committees, councils or individuals seeking the perspective of patients and families.

The Council, currently co-chaired by Advisor Kerry Stewart and PFCC Lead Angela Morin, consists of a minimum of twelve Advisors, an Executive Sponsor (Elizabeth Bardon) and two staff, plus a recording secretary. Ex-Officio advisor positions include the Chairs of both the Southeast Regional Renal Program PFAC and the Southeast Regional Cancer Program PFAC and those 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 members discussed and 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.

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. As part of the on-going work of the Council an evaluation of the voices missing and hearing from diverse groups is a priority. On June 21st, National Indigenous Peoples' Day, Council Members were honoured to hear about the important work of the Southeast Regional Cancer Program Indigenous Guidance Group and to discuss the purpose of Land acknowledgements. After the session, the Members voted unanimously to include a land acknowledgement at the opening of every PFAC meeting and have committed to continuing to learn from and build relationships with Indigenous members of the community served by KHSC.

The 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 & 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.

In addition to supporting the quadruple aims of delivering care that is patient-centred, timely, efficient and equitable, the engagement of 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, supports outstanding health care delivery at KHSC.

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 made up of 15 Patient Experience Advisors, the heads and managers of the Nephrology Department and representatives from the Kidney Foundation and are supported by the Lead PFCC.

The spectre of COVID-19 coloured everything, from admitting patients to their haemodialysis sessions to obtaining the operations that would make dialysis work the best for each patient. These issues were solved with the help of the PEAs and the haemodialysis manager working together.

It has been a difficult year for our patients and staff alike. Meetings were held virtually. This made us aware of the numerous problems people have using the internet. We had to abandon our newly created newsletter and attempted to make the Renal Website user friendly.

The isolation of the pandemic has had an effect on mental health. The Kidney Foundation teamed with the co-chairs and Dr. Iliescu to search out ways to alleviate this problem. We continue to find new ways to help both patients and caregivers cope.

The Renal PFAC worked with the Multi Care Kidney Clinic manager in getting a new Clinic available in Brockville. This has been very successful.

The Importance of Transplants is high on our radar this year and we are pleased to have Lynne Anne and Jim Anfield two members of the Renal PFAC working in this area. The Renal Program is making good use of their expertise as they share a kidney. All of the working groups now have a Patient Advisor present and often report back their work to the PFAC.

Health Literacy continues to be part of our work as well and will be reported on in January.

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)

The SERCP-PFAC advises on cancer care at KHSC's Cancer Centre and across the South East, and at a provincial level provides input to Cancer Care Ontario. Up to 15 Patient Experience Advisors from across the region who have had experience with cancer may sit on this council along with 5 staff members. It is co-chaired by Patient Experience Advisor Marla Rosen and Kardi Kennedy, Program Operational Director of the Oncology Program.

Child & Youth Mental Health Family Advisory Partnership Committee

The Committee, which started in February 2019, is Co-Chaired by Brittany Marshall, Psychotherapist, a youth/family member Co-Chair and supported by Cassie Millen, Social Worker. Staff, patients/clients and caregivers 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. COVID created a challenge for in person meetings and a virtual alternative was established. The committee was in a member turnover phase in early 2021 as members' two year terms came to an end. This provided an opportunity to explore the creation of an engagement evaluation survey for the committee members and identify opportunities to improve and/or celebrate. In addition, a recruitment poster was designed by the members to build awareness of the opportunity and build membership.

Summary

Clearly there have been many challenges for everyone working in and receiving healthcare this past year. Staffing challenges and an on-going pandemic have put PFCC to the test. At KHSC we have had the opportunity to assess what really matters and to let that guide and motivate us.

Restrictions on family presence have challenged us to find new ways to reinforce our commitment to the premise that family members are partners in care, not just visitors, and are welcome at the bedside. Not having caregivers present has highlighted the importance of good communication, information sharing and the important role family play in patient safety. Recognizing patients and families as part of the care team means co-designing processes that will enable that. Our current redevelopment planning must prioritize building an infrastructure that supports partnership and respect such as private rooms that will accommodate an overnight stay by a loved one, places for quiet reflection or a spot to grab some ice chips.

Implementing Virtual Care has helped to build the infrastructure to deliver care differently and revealed that there is work to do to ensure that practices become patient centred, virtually. What does compassionate virtual care look like and how will we know we are delivering it?

Many advisors are patients or caregivers still in care, experiencing care at KHSC during the time of Covid, and committed more than ever to bringing their voice and perspective to KHSC.

They send messages of support, reinforcement and gratitude and they also hold up the mirror and challenge us to do better, to walk the talk.

*"Next to the hospital's many HC professionals ensuring that I retain my vision, this (including Advisors in the Covid vaccination roll out) is **THE** best thing KHSC has done for me. I've been stressing out lately about not having had my shot now that the third wave is upon us. Thank you, thank you, and thank you!"* Kristen S., Patient Experience Advisor

Patient Advisors, like staff, are also experiencing fatigue and burnout and are seriously sick of virtual meetings. Those who have been heavily engaged since the beginning of COVID are starting to practice some self-care, they are trying to find the balance between wanting to say yes to every opportunity to engage and realizing they cannot do it all.

There have been challenges with access to documents and missed meeting requests with more use of internal systems, such as Teams and Outlook Calendar that are not easily navigated as an external stakeholder. We continue to explore options to make access more seamless and the technology more accessible and fun. Advisors look forward to being back on-site and meeting in person.

As we look to the future the commitment to PFCC by the Advisors has never been stronger. Advisors are being engaged more and more at every level of the organization. Strong leadership at the Executive level ensures that Advisors at decision making tables have an equal voice. Working groups across both sites are engaging Patient Advisors in their planning, in identifying priorities and in co-designing solutions. Advisors are on the Accreditation task force and included in education to participate in working groups and walkabouts. Innovative projects include patient advisors committed to making the experience of patients and families, and ultimately the system as a whole, better.

In the year ahead we will continue to learn through partnership where there are champions and where we have gaps. With many changes in leadership roles, further education through lunch and learns, the creation of a PFCC resource site for both staff and advisors and developing a common understanding of the guiding principles of engagement at KHSC will be needed to ensure consistency and meaningful engagement across the organization. The opportunities for KHSC to continue to be an exemplar in PFCC and Patient Engagement are growing and we will need to give some thought to the resources needed to prioritize and support that work.

With so many competing priorities it is more important than ever that we have a common goal, a north star, to guide us through. Creating opportunities to learn from patients and families is going to be critical to identifying priorities and rebuilding after the devastation of COVID. Sometimes “what counts can’t be counted”. Taking tangible action on many small things can have a big impact when those actions make a difference to the experience of patients and families and empower staff to live the principles of PFCC every day.

Respectfully submitted,

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