



Kingston Health
Sciences Centre

Centre des sciences de
la santé de Kingston

ANNUAL REPORT OF THE KHSC
PATIENT & FAMILY ADVISORY
COUNCIL – November 2020



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): it 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 perspective 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.

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 an organization, and can be translated to work at a regional and system level.

KHSC’s Patient Experience Advisors 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

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. 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 2019/2020 Patient Experience Advisors volunteered over 1,850 hours of their time which is extraordinary considering the 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 55 dedicated Advisors many of whom do not include preparation and travel time into their calculations. We also are not accounting for the resources that the Advisors are using to participate (e.g. gas, ink and paper and technology).

Patient & Family Advisory Council Meetings

The Patient and Family Advisory Council (PFAC) provides input into and makes 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 PFAC consists of a minimum of twelve Advisors 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. They meet monthly.

The KHSC PFAC is currently co-chaired by Advisor Kerry Stewart and PFCC Lead Angela Morin.

KHSC continues to be a leader in promoting and embedding patient and family-centred care across the organization, even during this time of pandemic. In addition to supporting the quadruple aims of delivering care that is patient-centred, timely, efficient and equitable, the engagement of Advisors during these unusual times has enabled KHSC to remain nimble in anticipating and responding thoughtfully to rapidly changing circumstances, and patient and caregiver needs. This active partnership between patients, families and professional caregivers working together, supports outstanding health care delivery at KHSC.

The KHSC PFAC members continue to be a highly engaged and committed group learning new technologies and adapting as needed to ensure their continued engagement. In the early stages of the pandemic, the Co-Chairs of the KHSC PFAC facilitated two combined PFAC meetings with the Regional PFACs to share what was happening across the organization. This helped to identify patient priorities and inform ongoing engagement strategies. The Advisors have requested that this be done on a semi-annual basis even after the pandemic ends.

Members of PFAC between September 2019 and September 2020 included the following individuals. The bios of the current PFAC members can be found on the KHSC website:

- Kerry Stewart (Co-Chair - KHSC PFAC)
- Josef Amann
- Mohamed Bayoumi
- Vivian Bethell
- Patti Cox
- Doug Davey
- Phyllis Davis (Co-Chair - Renal PFAC)
- Perlita Delaney
- Benton Duncan
- Betty Harlow
- Ron Manor
- Donna Perrin
- Anne O'Riordan
- Marla Rosen (Co-Chair - Oncology PFAC)
- Elizabeth Bardon (Staff)
- Leanne Wakelin (Staff)
- Angela Morin (Staff and Co-Chair - KHSC PFAC)

The PFAC annual work plan includes regular reports on the following topics:

- Redevelopment Planning
- Quality Improvement Plan (QIP)
- Terms of Reference for PFAC
- Review of Patient Experience Advisor recruitment strategies
- Review of Patient Experience Advisor involvement on committees
- Patient relations and patient satisfaction reports
- Patient Care (Quality, safety and risk)
- Ontario Health Team Application
- Corporate updates (e.g. surge reports, ALC numbers, COVID-19 preparedness, family presence changes)
- Patient- and Family-Centred Care Grants committee report
- Exceptional Healer Awards Committee

In addition to the initiatives mentioned above, this past year, PFAC members contributed to a number of different activities with corporate importance including:

- MAiD FAQ Sheet
- Elder Abuse Policy
- Teddy Bear Campaign
- Bundled Care
- KHSC@Home
- Hospital Annual Plan
- COVID-19 Planning and Preparedness
- New Staff Orientation
- Health Information System
- Workplace Violence and Risk Reduction

Advisors on PFAC also reported at each meeting on their contributions at KHSC. In addition they share information about their involvement as Advisors with external committees and organizations and share insights and lessons learned from that involvement. Some examples of those organizations include:

- KFL&A Moving on Mental Health Task Force
- HQO Quality Standards Committee
- Compassionate Communities Kingston
- Canadian Foundation for Healthcare Improvement
- Caregivers4Change
- Patient Advisors Network
- Institute for Patient and Family Centred Care
- Ontario Hospital Association (The Path Forward for Virtual Care in Ontario)
- Ontario Renal Network
- Canada Health Infoway (A Healthy Dialogue)

Bringing the Patient and Family Perspective to KHSC

Patient Advisors are members of key organizational working groups and initiatives including the Ontario Health Team Application Steering Committee, the Health Information System (HIS) team and the Redevelopment Design Working Groups and Subject Matter Expert Groups.

“I was asked by someone. What is the true definition of Patients and Healthcare providers being Partners in improving our lives and our Healthcare. The answer lies in the journey that KHSC started two and half years ago to find a true digital HIS system for the future. Patient Advisors were partners with a true voice and input to the Executive committee and all evaluation committees. All six regional Hospitals established a plan, an RFP and now will deliver a true digital system in the future. Throughout the journey, patients were the focus, and had input, to all the discussion and complexities that bring us all together to make us better.”

Gerhard Wendt, Patient Experience Advisor
(Partners with Dino Loricchio, Director of Regional HIS Project)

Angela Morin and seven Advisors are participating in the “Eliminating Wait Times from Primary Care to Specialists” Innovation Project led by Dr. Elizabeth Eisenhauer as members of multiple working groups ensuring the priorities and perspectives of patients and families are considered in the identification and implementation of innovative solutions to barriers to timely access to specialists.

Exciting research and quality improvement work that is happening in Virtual Care includes Advisors helping to identify the challenges and opportunities faced by patients and families in receiving virtual care. They are inspiring and informing the development of tools and resources to support equitable, safe and quality experiences of care.

“I remember the PFAC meeting in which Dr. Appireddy and his research associate Sophy presented their virtual care research proposal and asked for patient advisor input. Raising my hand that day opened the door to an ongoing collaboration that led to partnering in the original project, co-authoring a publication, and broader patient-partnered research initiatives. I believe this collaboration is improving the quality of care for patients.”

Anne O’Riordan, Patient Experience Advisor

“Working with KHSC PFAC member Anne O’Riordan and Angela Morin, Lead PFCC over the last two years has been indeed an incredible learning experience in better understanding various aspects of patient engagement in research. They have been instrumental in some of our on-going patient-partnered research activities.”

Dr. Ramana Appireddy, Physician/Researcher

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 concepts of PFCC. Information about the winners of last year’s Exceptional Healer Award, Dr. Lysa Lomax and Jerry Haffner, can be found here:

<https://kingstonhsc.ca/khscconnect/news/annual-award-recognizes-two-exceptional-healers-kingston-health-sciences-centre>.

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 this year’s 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. Instead, a letter from the Committee is being written that will highlight advisors' appreciation for all of the time, energy and dedication that healthcare professionals and other staff have put into keeping patients and community members safe during the pandemic.

Once the pandemic is over (hopefully next year!), the Award will continue to be presented annually in winter at the same ceremony as other KHSC awards to ensure both a high profile for this honour, and to ensure that winners are formally celebrated in front of their peers.

"Thanks to their exceptional efforts on the front lines during this pandemic, I feel safe every time I enter the hospital. Everyone at both KHSC sites appears to be going above and beyond to serve patients. Our community is indebted to them. Surely, history will remember all hospital staff as heroes."

Sue Bedell, Patient Experience Advisor and
Co-Chair Exceptional Healer Award Committee

COVID-19

KHSC has committed to "engage patient and family partners in all corporate plan initiatives that impact the patient experience". Given that a considerable effort in 2020 has revolved around access to care while maintaining our pandemic response, family presence in the context of access has been and will continue to be an issue.

In the spring of 2020 Elizabeth Bardon brought together a group of Advisors to provide some early thinking and input into potential scenarios to try to plan forward proactively. This group of 8 Advisors plus Angela Morin (PFCC Lead) met at a local coffee shop called Balzac's for coffee and a conversation about what might be coming with COVID-19 and how they might inform a KHSC response to any internally or externally required changes to access and/or family presence. The "Balzac's Group", as it has been affectionately known, has come together multiple times over the past eight months between meetings of the larger PFAC as a whole to continue to provide advice, guidance, and input into tools, messaging, improvements, and challenges related to family presence. This team has been absolutely invaluable in guiding KHSC's approach to family presence during COVID-19, and continues to support KHSC's efforts with honest, helpful and rapid feedback. The principles to guide decision-making around the approach to family presence include advice and input from Advisors.

This is a clear example of where partnership with patients has measurably improved KHSC's approach. In addition to their ongoing input and advice regarding family presence Advisors have also contributed to COVID-19 planning in identifying key areas of concern, challenges and opportunities for improved messaging and processes such as lack of facilities for families dropping off loved ones, confusing appointment slips during the implementation of virtual care and miscommunications about visitor exceptions.

KHSC Sharing Lessons Learned in PFCC!

Organizations contacting KHSC since Sept. 2019

Ottawa Hospital Patient Relations

Patient Advocate-Ireland Ptf for Pt Safety

Niagara Health

Royal Ottawa

Ross Memorial Hospital

St. Lawrence College

Brockville General Hospital

Canadian Foundation for Health Care Improvement

Lake of the Woods District Hospital Kenora

Royal University Hosp-Saskatoon

Uof T Research Project

Brockville General Hospital

Unity Health, Toronto

Trillium Health Partners

Canadian Institute Health Information

Ontario Hospital Association

A Patient Advisor sits on the Clinical Operations Committee and Advisors have provided critical guidance on such things as:

- Patient and Caregiver screening
- Frequently Asked Questions
- Essential Caregiver Guidelines
- Staying Connected and the Virtual Visits program
- Virtual Care information, resources and support

“2020 had brought increased opportunities for me to work with Patient Experience Advisors on Committees, new initiatives (e.g. Virtual Visits) and ramp-up meetings for the HDH site. I have the upmost respect for the contributions, perspectives, professionalism and collaborative approach of these PEA’s. Their insights and observations have kept patients and families at the forefront of incredibly complex and difficult decisions resulting from the pandemic. I suspect these PEA’s often carry a heavy feeling of responsibility. I would personally like to say “Thank You” for your effort to ensure we continue to provide respectful, accessible, efficient and compassionate care in this complex world of health care.”

Lynda Laird, Manager Volunteer Services

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 Patient Experience Advisors.

Last autumn, the PFAC members provided input into a revised methodology and survey to better understand the

experience of being a Patient Advisor. PFAC members provided reflection and thoughtful advice about what information we may want to better understand that the existing survey did not capture. Several Advisors offered to serve as a smaller working group to consider possible changes to the questions and process.

The survey results from January 2020 reflected that being a Patient/Family Experience Advisor provides a sense of accomplishment, that they feel heard and respected, there is a positive climate of teamwork between staff and Advisors, that the work of a

Patient/Family Experience Advisor improves patient and family care and makes the organization better.

The areas where we saw some opportunity to be stronger include 1) more guidance on how to be an effective advisor; 2) broader understanding by staff as to the role of Advisors and 3) communication of how their input has made a difference.

In response to this feedback, work is underway to develop a more robust orientation process for new Advisors, identify and share opportunities to participate in webinars and review articles, and a new “Buddy System” introducing experienced Advisors willing to mentor and coach new Advisors. In addition, we will continue to seek out opportunities to share more about the role of Advisors and highlight their contributions.

Education

To support the orientation and ongoing educational needs of our staff, education about PFCC is provided at each new hire orientation, which takes place on a monthly basis for KHSC. The education 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.

Completion of PFCC online education modules are required of each new staff member. Due to COVID-19 restrictions to on-site presence, the PFCC new staff orientation session was transitioned to a virtual presentation. Advisors were supported in utilizing virtual platforms to continue to participate in a meaningful way and meet the needs of increased numbers of orientation sessions. In the fall of 2020, a working group of advisors will begin co-designing a digital PFCC staff orientation resource in partnership with Professional Learning and Development.

Webinars to support PFCC education are identified and made available to staff and patient Advisors. Advisors have attended educational webinars and share learnings with the organization on topics such as “Creating Your Tele-Health Platform Hand in Hand with Patients”, “Family Presence and Partnership: Promising Hospital Practices in the Time of COVID-19” and “How is COVID-19 impacting patients and their care”.

Presentations on the importance of patient engagement in the creation and sustainability of a patient and family centred culture have been given by the KHSC PFAC Co-Chairs at Family Medicine Grand Rounds and the Medical Oncology Residents Academic Session. These opportunities to connect help to raise awareness and open doors to new relationships.

Regional PFACs

The South East Regional Cancer Patient and Family Advisory Council 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.

“It is gratifying to be involved in projects that should enhance the well-being of patients while meeting the clinical and administrative requirements of physicians and staff. Recently, I have been involved with the Cancer Programme as a new women’s imaging centre becomes established. I have been privy to business arrangements and the logistics of setting up a comprehensive clinical space. The lens of the patient advisor is vital in imagining how such spaces can be comfortably and safely used by patients from our region. The advisor’s voice is critical to the design process.”

Patti Cox, Patient Experience Advisor and SERCancer PFAC Member

The Renal Patient and Family Advisory Council for the South East Regional Renal Program welcomed Phyllis Davis, Patient Experience Advisor and Cindy Fitzpatrick, Social Worker as the new Co-Chairs in January 2020. Great appreciation was expressed by the members to the former Co-Chairs, Vivian Bethell and Lori Van Manen. They are joined on the Council by 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 Renal Advisors are involved in numerous working groups focused on improving the patient experience not only at the Kingston site but also at the many satellites throughout the Region. The overall aim is to have Patient Experience Advisors participate and advise on all quality improvement initiatives. The Advisors have led the work in the creation of a well received quarterly newsletter and have contributed to updating the website, the development of health literacy resources, peer support planning, a pilot project for Providence Care Hemodialysis and other important issues to patients and families.

“Being a Patient Experience Advisor is the best position I have ever held. It gives me the opportunity to give voice to many areas of concern within the medical system as well as to give praise. My husband always said to me, ‘Make my journey help others have a better experience with the medical system’. Since his death, I believe I have. I have worked on numerous projects and committees. The staff have embraced the views of Advisors using their expertise to make the patient more comfortable and better served during their stay.”

Phyllis Davis, Patient Experience Advisor and Co-Chair Regional Renal PFAC

“One of the things I am proud of is the assistance I provided the renal team to carry out a Transplant Companion Program in Belleville and Kingston which consisted of providing information to patients on the wait-list to get a kidney transplant.”

Charles Benson, Patient Experience Advisor and Renal PFAC Member

Cassandra Millen, Clinical Social Worker in the child and youth mental health program welcomed and continues to support Brittany Marshall, Psychotherapist, as the new Co-Chair of the **Child & Youth Mental Health Family Advisory Partnership** during Cassie's maternity leave. The Committee has a youth Co-Chair and has been running since February 2019 with support of the Lead PFCC to be in alignment with the accountabilities of the patient advisor program.

Some highlights over the past year include the committee's active participation in grant proposals, the creation of COVID support documents for the CYMH program, an in-depth service mapping initiative to identify future direction for the committee, and preliminary work on updating the CYMH program's webpage to be more youth and family centered. Looking to the future, the youth Co-Chair and members have expressed a lot of passion and interest in developing a strategy to lessen mental health stigma for youth in our community.

Challenges & Opportunities

The challenges we have faced this year have also created opportunity: in not being able to meet in person we have expanded access for Advisors through virtual platforms. Virtual access may open up opportunities to engage with populations that have historically found it difficult to participate and for wider geographic representation.

Not meeting in person is challenging to developing and sustaining relationships but has challenged us to think of new and creative ways to stay connected and acknowledge contributions.

The explicit expectation that patients and families will be engaged in the integrated annual corporate plan supporting KHSC strategy will create a demand for broader, more diverse and more innovative approaches to engagement that will challenge existing processes, infrastructure and resources.

Increased interest and expectations for patients and families to be included in quality improvement, education and research, not as participants but as team members, has opened up new opportunities for engagement that will require ongoing support and education for all involved.

Finding new ways to share and learn from the patient experience will help to ground us in the identification of priorities and measures of success from a patient and family perspective that will help to ensure that the culture at KHSC is indeed Patient and Family Centred.

KHSC and the PFAC has an opportunity to lead by example and share lessons learned with the broader community as we look forward to a more integrated system that will require a community based patient and family engagement framework that does not currently exist.

“Having our interested, thoughtful and perceptive experience advisors sit on operational committees at KHSC has really helped ground our decision-making,

widen our line of sight, and has helped enrich our thinking towards a collaborative patient-centred approach.”

Dr. Mike Fitzpatrick, Chief of Staff & VP Medical and Academic Affairs

Summary

COVID-19 has presented many unique challenges to healthcare and to PFCC. The same things that are causing many of us - staff, healthcare providers, leaders and Advisors alike – distress are also a testament to our commitment as an organization to PFCC. We know what “feels” right and we want to be sure we are making decisions grounded in the principles about which we feel so strongly.

We recognize that quality consists of different dimensions and a dimension such as safety must be balanced with those of equity and respect. KHSC’s strong foundation of PFCC as a north star in guiding decisions requires ongoing engagement with the patients and families who are experiencing care. It is the foundation of trust and goodwill developed and nurtured over years that has not only sustained patient engagement during this challenging time but has strengthened it. There is much more for us to do, many more ways we can engage diverse perspectives and voices in all aspects of KHSC, and it will be in partnership that we make that happen.

Respectfully submitted,

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

Angela Morin, PFCC Lead
Co-Chair, KHSC PFAC