

# Kingston Health Sciences Centre

Centre des sciences de  
la santé de Kingston

## ANNUAL REPORT OF THE KHSC PATIENT & FAMILY ADVISORY COUNCIL



Hôpital  
Hotel Dieu  
Hospital



Hôpital Général de  
Kingston General  
Hospital

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

The phrase “patient- and family-centred care” has become part of the healthcare lexicon. It can, however, be interpreted in different ways and it is therefore important to define what we mean by it. At its heart, patient- and family-centred care is built upon four core 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.

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

## Philosophy

Kingston Health Sciences Centre (KHSC) embraces the Institute for Patient- and Family-Centered Care’s comprehensive definition of patient and family centred care as “*an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families and health care.*” 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.

## Structures

At the heart of the structure of the Patient- and Family-Centred Care Program at KHSC is the Patient and Family Advisory Council. The council consists of a minimum of 12 Patient Experience Advisors and 4 staff. The Patient and Family Advisory Council serves in an advisory capacity, providing input to and making recommendations on matters that impact the experience of patients and their families at KHSC. Information and requests flow into the Patient and Family Advisory Council through hospital-wide committees, councils or individuals seeking the perspective of patients.

Patient Experience Advisors also play an integral role beyond the Patient and Family Advisory Council. Patient Experience Advisors are typically former patients or family members of former patients who volunteer their time to be members of committees, councils and working groups and/or to partner on improvement teams across KHSC. Processes have been developed to increase and sustain the Patient Experience Advisors. With respect to recruitment, there are many approaches which have included Patient Relations, word of mouth, a recruitment pamphlet, staff referrals and self-referrals. Advisors are supported in becoming involved with work that aligns to their experience and interests.

The work with patient- and family-centred care and patient engagement began in 2009/10 at the Kingston General Hospital (KGH) site and in 2012/13 at the Hotel Dieu Hospital (HDH) site and has now grown to involve 63 Patient Experience Advisors across KHSC. Patient Experience Advisors participate as full members on all committees making decisions materially affecting the patient experience.

In fiscal year 2017/18 Patient Experience Advisors volunteered over 4478 hours of their time. We believe that this calculation is under-estimated given some of the challenges we have in receiving reported hours from our dedicated Advisors.

## Supporting Patient- and Family-Centred Care at Kingston Health Sciences Centre

The Patient and Family Advisory Council members from each of the legacy sites met in September 2017 to determine how best to support Patient- and Family-Centred Care in the newly formed KHSC. It was agreed that moving forward:

- Patient Experience Advisors would be referred to as Kingston Health Sciences Centre advisors (no longer HDH or KGH advisors)
- All Patient Experience Advisors from the legacy councils would become members of the newly formed KHSC Patient and Family Advisory Council. This brought the total number of advisors on the Council to 19.
- We would let attrition whittle the total number of advisors on the Council down to 12 advisors before recruiting to the Council.
- The inaugural Council would be co-chaired by an advisor from each of the legacy councils (Angela Morin and Adrian Storm) with support from the Lead for Patient- and Family-Centred Care and the Executive Sponsor.
- An advisor experience survey would be sent to all advisors in order to best determine how to support and encourage advisors.

## Patient Council Meetings



An annual work plan was developed that included regular reports on the following topics:

- Quality Improvement plan
- Terms of Reference
- Review of Patient Experience Advisor recruitment pamphlet
- Review of Patient Experience Advisor involvement on committees
- Patient relations report
- Patient satisfaction report
- Regular Accreditation Canada updates
- Compass patient satisfaction survey results
- Health literacy
- Hand Hygiene compliance rates
- Alternative level of care patients
- Patient- and Family-Centred Care Grants committee report
- Exceptional Healer Awards report.

## Patient and Family Advisory Council Agenda Items

Over the past year the monthly meetings of the Patient and Family Advisory Council have seen a variety of agenda items including

- 2018-19 QIP development process
- Accreditation
- Advertising guidelines
- After-hours hospital access
- Body worn cameras
- Butterfly Program (for patients in last hours of life and their families)
- Equity and Diversity
- Ethics at KHSC
- Exceptional Healer Award
- Falls Prevention Poster
- Health Literacy (Patient-oriented discharge summary)
- Innovation at KHSC
- Medication Reconciliation
- Mission, Vision, Values and Strategy Development, including draft strategic directions
- Nutrition Survey results
- Patient satisfaction/experience survey results
- Patient and Family Advisory Council term limits
- Patient Bill of Rights and Responsibilities
- Patient Experience Advisor Application Form and handbook
- Policies: Incident Reporting and Disclosure of Patient Safety Incidents
- Post-discharge phone calls
- Survey results
- The Patient's Voice
- What Now? Pamphlet revision

## Patient Experience Advisor satisfaction/experience survey

A survey was distributed to all advisors in the fall of 2017. This is the second time a survey has been completed by advisors (the first was in 2014 at the KGH site) and the first time advisors from both legacy sites have been included. The survey was created in partnership with Patient Experience Advisors to measure how well the program was meeting the needs of advisors through both their satisfaction and experience of being in the program. Results were very positive. The survey is included as an addendum to this report.

## Exceptional Healer Award

This award recognizes physicians who demonstrate in clinical practice the core concepts of patient and family-centred care: dignity and respect, information sharing, participation and collaboration.

A total of 34 nominations were received from patients, family members and staff. The second annual Exceptional Healer Award was presented to Dr. Shawna Johnston at a ceremony on January 29<sup>th</sup>, 2018.

Discussion around the award has included an expansion of the process in 2018/19 to include an award for nursing. Recognizing the optic of the award being hierarchical (first physicians and then nurses) the Patient and Family Advisory Council is also looking at ways to work with People Services and Organizational Effectiveness to include all disciplines and departments in an award which celebrates staff who exemplify the tenets of patient- and family-centred care.

## Patient- and Family-Centred Care Grants (HDH Site)

Through designated donations to the University Hospitals Kingston Foundation, up to \$2000 was available to support projects that will enhance patient and family-centred care at HDH (Note: the terms of the original donations were specified to the HDH site only. Further discussion can be undertaken in future with existing donors to explore options to expand this across both sites of KHSC, but this will require donor input). The Patient- and Family-Centred Care Grants Committee chaired by Patient Experience Advisor Don Mann and which included four KHSC advisors as the voting members distributed the \$2000 in funding in June 2018. (Previously the award had been granted twice per year but due to funding restraints it was determined to support one grant per year moving forward.)

The grants were provided to the following Programs/Clinics:

- Ophthalmology: The program received \$728.14 to help produce information material for patients receiving treatment for macular degeneration and diabetic retinopathy. The funding will support medical writing; photography/graphic design/copyediting; e-publishing; and printing costs. By providing helpful treatment information this project aims to enhance information sharing with patients and families and so reduce post-procedure anxiety and unnecessary hospital visits.
- Cancer Program: The program received \$399.50 to purchase a wall mounted display rack to house materials and resources for cancer patients and families seen in either the

Jeanne Mance 4 or Jeanne Mance 5 clinic. The display will be designed as a hub of safe, reliable information for patients and families, which in turn can help to improve their overall care experience.

- Infection & Immunology Clinic: The HDH-site clinic received \$872.36 to purchase an order entry printer that will help to speed up the adoption of order entry, which will help to support better patient flow and encourage ongoing collaboration between patients and caregivers.

## Accreditation Canada

In announcing the results of the 2018 survey, Accreditation Canada praised KHSC's "unique model of patient and family-centred care" and how patients and families are more than engaged they are "fully activated". Surveyors also commended KHSC in their briefings about the manner through which Patient Advisors have been embedded in the organization and members of all measure of decision-making bodies. Advisors actively participated in survey activities.

### Organizations approaching KHSC since April 2017

Alberta Health Services,  
Australian Government,  
Baycrest Health Sciences,  
Bluewater Health,  
Brockville General Hospital,  
Campbellford Hospital,  
Central Health NFDL,  
Children's Hospital of Eastern Ontario,  
Cornwall General,  
Dublin Midland Hospital Group, Ireland,  
Eastern Health NFDL,  
Gander NFDL,  
Guelph General Hospital,  
Hamilton Health Sciences,  
Health Quality Ontario,  
Horizon Health, Fredericton,  
Kemptville District Hospital,  
KFL&A Public Health,  
Lakeridge Health,  
Mayo General Hospital, Castlebar, Ireland,  
Montfort Hospital,  
Napanee Hospital,  
North York General,  
Northumberland Hills,  
Perth & Smiths Falls District,  
Peterborough Regional,  
Providence Care Hospital,  
Quinte Health Care,  
Rouge Valley Health System,  
Saskatoon Health,  
Sault Area Hospital,  
St. Joseph's Health Care London,  
Sunnybrook Hospital,  
Windsor Hospital,

## Education

To support the orientation and ongoing educational needs of our staff, in-house patient- and family-centred care education is provided at each new hire orientation. The number of staff who have formally completed the introduction to patient- and family-centred care now totals over 3500.

An online education module instructing on the 5 patient- and family-centred care standards is required of each staff member.

In support of the Communication standard there has been on-going training in H.E.A.R.T. (Hear, Empathize, Apologize, Respond, Thank). H.E.A.R.T. is a communication tool which provides staff and physicians the skill set and the re-enforcement to better engage patients, families and each other. The training has evolved over time and now consists of an on-line learning module.

In October, 2017 KHSC sponsored ten Patient Experience Advisors along with Patient- and Family-Centred Care Executive Sponsor Elizabeth Bardon and Lead for Patient- and Family-Centred Care Daryl Bell to attend the Health Quality Transformation Conference in Toronto. This provided both rich learning and an opportunity for advisors to get to know one another better.

## External Recognition and Involvement

KHSC continues to be looked to as a resource at an international level for patient- and family-centred care. Since April 2017 we have been approached 55 times by organizations for teleconferences, video-conferences or site visits raising our total since we began to 356 external requests for support. This year we hosted a site visit from Australia and one from Ireland. This has created a rich network from which we also learn.

Patient Experience Advisors and staff also respond to various requests for speakers and external Board and Committee membership including the following:

- Accreditation Canada as a Member of the Client and Family Advisory council
- Beryl Institute as a presenter
- Canadian Foundation for Healthcare Improvement (CFHI) as a Coach and Faculty Member
- Cancer Care Ontario Provincial Patient and Family Advisory Council
- CFHI Design Committee
- Health Quality Ontario (HQO) as a Board member
- Health Quality Transformation Conference
- HQO Governance Committee
- HQO Quality Standards Committee
- Institute for Patient- And Family Centred Care International Conference as a presenter
- Kingston Chapter, Kidney Foundation of Canada, Board of Directors
- Member of Ontario Patient Ombudsman Interview Panel
- Ontario Hospital Association Advisory Council
- Ontario Palliative Care Network
- Ontario Renal Network(ORN) Patient and Family Advisory Council
- ORN Advance Care Planning and Goals of Care Working Group
- ORN Comprehensive Conservative Renal Care Task Group
- ORN Palliative Care Priority Panel
- Orientation for first year nursing students
- Orientation for first year medical residents
- Patient Advisor Network

## Partnering



Patient Experience Advisors partner with staff and physicians in innumerable ways across KHSC. In fiscal year 2017/18 Patient Experience Advisors have participated in over 100 hiring interviews. They currently have 215 active positions on 119 long and short term committees.

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. Thirteen Patient Experience Advisors 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

The Renal Program has a Patient and Family Advisory Council which was formed in September of 2015 and which meets monthly to advise on the local and regional Renal Program. It is co-chaired by Patient Experience Advisor Vivian Bethell and Lori Van Manen, Program Operational Director of the Renal Program.

## Quality Improvement

This year, the Quality Improvement Indicator is to achieve a 98% compliance rate for the 5 patient- and family-centred care standards developed and put in place four years ago. The 5 standards include:

- ID badges being worn at chest level so they are easily read
- Inpatients being intentionally seen by a staff member at least once per hour
- Staff introducing themselves at every encounter with a patient/family and explaining what they are there to do
- Patient whiteboards being up-dated at every shift change
- Each program completing two Patient-Led Feedback Forums per year

These standards were developed to provide consistency across the organization with some being applicable to support/service areas and all being applicable to inpatient units. In the fall of 2018 the standard regarding ID badges will begin being audited at the HDH site. Orientation has also been rolled out to leaders about the patient-led feedback forums to support expanding this across both sites of KHSC.

## Challenges & Opportunities

As can be expected with any transformational change, there can be many challenges, and with those come great opportunities to innovate and lead. Challenges that have presented since the launch of work focusing on patient- and family-centred care have included the following:

- Ensuring everyone has a basic understanding of, and a commitment to patient- and family-centred care.
- Skepticism and resistance to change
- Preventing overextension and burnout of voluntary Patient Experience Advisors
- Focusing on and supporting our need to continuously learn & improve as we go forward

- Ensuring availability of funds to cover the need and cost of educational events for Patient Experience Advisors and staff
- Intentionally supporting staff in engaging patients and families at the frontline.
- Working with physician schedules and communication methodologies to enable their engagement and understanding of patient- and family-centred care and patient engagement
- Minimizing strain on corporate resources as the program grows
- Sharing our learning with other organizations

To address these challenges, we will continue with deliberate focus to put in place and sustain drivers that contribute to this cultural transformation. As examples:

- Ensuring senior leadership commitment and support
- Having clear accountability for processes that enable patient and family engagement
- Identifying unit/program/service based patient- and family-centred care champions
- Ensuring education and training of health care professionals and service providers including in-house orientation and continuing educational sessions for Patient Experience Advisors, staff and physicians and sustaining educational and networking opportunities within the broader health care system
- Continuing to recruit and support Patient Experience Advisors
- Ensuring that as corporate policies are developed, reviewed and revised to integrate the language and reflect responsibilities that align with patient- and family-centred care philosophy
- Creating a workplace that supports patient- and family-centred care adoption and monitoring the application and adherence to patient- and family-centred care standards
- Continuing to support and facilitate the voice and experience of the patient/family being heard and embedded in improvement processes,

## Summary

Without a doubt the success of the Patient- and Family-Centred Care Program at KHSC has been dependent on the many passionate and dedicated advisors who are willing to give of their time in order to improve the patient experience. In the past year with their guidance, we have been successful at incorporating the two legacy Patient and Family Advisory Councils. To the credit of all advisors and staff KHSC is internationally recognized as a system leader in patient engagement and practices that support patient- and family-centred care. Moving forward KHSC must continue to challenge itself and look for further opportunities and innovations to partner with patients and families to ensure the patients' perspective and participation are fully integrated at every level of the organization.