Bruyère Reports

Issue No.

Patient engagement in Accreditation Required Organizational Practices (ROPs). A Bruyère Rapid Review

REPORT AUTHORS

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Key messages

Bruyère Continuing Care is preparing for accreditation and seeking evidence about how to further build patient engagement in the organization. Accreditation Canada recommends the principles of patient and family centred care which involves a true partnership between the health care providers and the patients and their family members, and now evaluates patient engagement as part of its accreditation process.

We assessed the experience of six health care organizations which have achieved a reputation as exemplar models of patient engagement. Characteristics of governance, accountability, communication, training, roles and responsibilities, and recognition were assessed for five of these organizations which used Patient and Family Advisory Councils (PFAC) and these were compared with Bruyère Continuing Care.

- This report serves as a self-evaluation tool that can be used by leadership at Bruyère Continuing Care and its
 PFAC to set priorities and develop standardized processes for governance, accountability, communication,
 training, roles and responsibilities, and recognition to meet its needs.
- There was little evidence available on how to initiate patient engagement in specific departments/clinics. However, some organizations are willing to share their experiences and provide guidance and support. Bruyère Continuing Care may consider partnering with such organizations.
- There is a need for more research and scholarly publication about lessons learned from efforts to enhance patient and family engagement in health care organizations.

Executive summary

Hospitals in Ontario are required to involve patients in developing quality improvement plans, and to meet accreditation requirements. Accreditation Canada standards have incorporated the principles of patient and family centred care which involves a true partnership between the health care providers and the patients and their family members.

Bruyère is committed to providing patient and family centred care and has engaged patients and families through a Patient and Family Advisory Council (PFAC). In preparation for an assessment by Accreditation Canada in 2019, Bruyère is seeking to engage patients and families at all levels of the organization as recommended by Accreditation Canada, the Canadian Foundation for Healthcare Improvement (CFHI), as well as Health Quality Ontario (HQO).

This rapid review was undertaken to assess exemplar models of patient engagement. We first reviewed frameworks for patient engagement such as the IAP2 (International Association for Public Participation) and the ICPM (Interprofessional Collaborative Practice Model). We then considered the following six organizations suggested by the clinical champions on the basis of achieving a reputation as exemplar models of patient engagement and with similar purpose and structure to Bruyère Continuing Care (e.g. multiple specialties and sites): Cleveland Clinic, Mayo Clinic, Virginia Mason, Kingston General Hospital, North York General Hospital and St Elizabeth Care.

We identified the following organizational factors, described by HQO and CFHI, to guide our assessment of the PFAC across the five organizations: 1) governance, 2) accountability, 3) communication, 4) training, 5) roles and responsibilities, and 6) recognition.

Comparisons of Bruyère Continuing Care to these five organizations across these characteristics are described in the report. For example, Bruyère Continuing Care is a leader amongst this group of organizations in recognizing the contributions of their PFAC members. The report also identifies areas which can be strength-

ened at Bruyère, such as accountability structures to implement and assess the impact of PFAC contributions.

Implications for practice

Based on the review of six successful hospital-based models of patient and family engagement:

This report serves as a self-evaluation tool that can be used by leadership at Bruyère Continuing Care and its PFAC to set priorities and develop standardized processes.

There was little evidence available on how to initiate patient engagement in specific departments/clinics. However, some organizations are willing to share their experiences and provide guidance and support such as Cleveland Clinic, Mayo Clinic, Virginia Mason, St Elizabeth Care. Bruyère Continuing Care may consider partnering with such organizations.

Implications for research

There is a need for more research and scholarly publication about lessons learned from efforts to enhance patient and family engagement in health care organizations.

Background

The issue

Hospitals in Ontario are required to involve patients in developing quality improvement plans, and to meet accreditation requirements [1]. Hospital accreditation programs are systematic assessment of hospitals against accepted standards [2]. Accreditation Canada standards have incorporated the principles of patient and family centred care which involves a true partnership between the health care providers and the patients and their family members [3]. The Accreditation Required Organizational Practices (ROPs) are evidence -informed essential practices that organizations must have in place to enhance patient safety and minimize risk. There are six patient safety areas, each with their own goal. Safety culture, communication, medication use, work life or workforce, infection control and risk assessment.

The context

Bruyère is committed to providing patient and family centred care and has engaged patients and families in improving quality of care through the Patient and Family Advisory Council (PFAC). Bruyère has used the IAP2 (International Association for Public Participation) model to engage patients and their families. See Appendix 1 for details about the IAP2 model.

The current structure of the Bruyère PFAC has been developed in consultation with the patients and families.

In preparation for an assessment by Accreditation Canada in 2019, Bruyère is seeking to engage patients and families at all levels of the organization as recommended in the Accreditation ROPs and by the Canadian Foundation for Healthcare Improvement (CFHI) [4], as well as Health Quality Ontario (HQO) [1]. Some ways in which patients and families could be involved include [3, 5]:

- Monitor and evaluate services and quality with input from clients and families
- Co-design services with health care providers and clients
- Include client and family representatives on advisory and planning groups
- Include clients and families as part of a collaborative care team
- Partner with clients in planning, assessing, and delivering their care

This rapid review was undertaken to provide evidence of models of patient and family engagement in healthcare and their impact on the patients and organizations.

Objectives

To assess experiences of hospitals or health care settings with a reputation as exemplar models of patient engagement.

Methods

We defined the question in consultation with the clinical champions.

Eligibility and selection criteria

We included articles that described the experiences of hospitals or healthcare settings which have achieved a reputation as exemplar models of patient engagement.

Literature search

We used the following keywords in Google and Google scholar search engines to identify relevant articles on models of patient and family engagement of specific health organizations identified by the clinical champions which have achieved a reputation as exemplar models of patient engagement. These organizations also have a similar purpose and structure as Bruyère Continuing Care (e.g. multiple specialties and sites).

- Patient engagement survey
- Patient engagement case studies
- Patient engagement case reports
- Patient engagement report
- Patient engagement case studies Canada

We also searched websites of the specific health organizations identified by the clinical champions. These included Cleveland clinic, Kingston General Hospital, Mayo clinic, North York hospital, St Elizabeth Care, and Virginia Mason.

Critical appraisal

The case studies were not appraised for quality since the purpose is to assess different experiences with patient engagement.

Evidence review

Different guidelines are available for patient engagement in health care settings, such as HQO [1], CFHI [4], and AHRQ (Agency for Healthcare Research and Quality) [5]. We do not review those in detail here since the purpose of this review is to assess experiences of hospitals or health care settings which have achieved a reputation as exemplar models of patient engagement. We adapted our framework for as-

sessing the case studies from these guidelines, i.e. governance, communication, training, roles and responsibilities, and recognition. Details of the case studies are in Appendix 2.

Synthesis of findings

Five of the six health organizations we identified use patient and family advisory councils/committees (PFAC) as a method of patient engagement to promote patient and family centred care: Cleveland clinic, Virginia Mason, Mayo clinic, Kingston General Hospital, and North York hospital. St Elizabeth Care offers education workshops to all employees to promote patient and family centred care.

PFAC structure

The PFAC structure in these organizations operated at different levels, such as at the senior leadership level or at the level of individual departments.

1. Governance

Governance details are described in Table 1. Members had to be former patients or their family members. Recruitment was through surveys of discharged patients; or recommendations by staff. Former patients or family members could also apply directly by contacting

the Patient Experience Office or completing online application forms. Potential members are interviewed to determine which roles are appropriate for them and their willingness to participate.

The frequency of meetings varied across the five organizations from quarterly to monthly.

Some PFACs had shared leadership between staff and patient and family advisor (e.g. Kingston General, North York) whereas others were led by staff (Mayo clinic, Cleveland clinic).

Membership ranged between 10-20 per PFAC with more patient/family advisors than staff except for Mayo Clinic where there were 50% patients and 50% staff.

The PFACs had different reporting relationships. In KGH and Mayo clinic, the PFAC reported to a leader-ship committee whereas in North York and Cleveland Clinic, the PFAC reported to the Patient Experience Office.

Table 1: Governance of PFACs

PFAC struc- ture	KGH	North York	Cleveland clinic	Mayo clinic	Virginia Ma- son	Bruyère
Method of recruitment of members	Application form and information available on the website.	Register to attend information session then apply. Information available on the website.	Internal nominations by staff or external sources through surveys.	Contact information available on the website.	Application form and information available on the website.	
Frequency of meetings	Many meetings are held regularly (i.e. once permonth). Some committees will function intensely over a short period of time (i.e. once perweek for a month).	The PFAC meets a minimum of eight times per year and at the call of the chair.	Meetings held monthly or quarterly each lasting 2 hours in length.	Six annual meetings, lasting 90 minutes each.	Monthly meetings of up to 1 ½ hours each.	Quarterly (will in- crease to monthly as of Septem- ber 2017)

PFAC struc- ture	KGH	North York	Cleveland clinic	Mayo clinic	Virginia Ma- son	Bruyère
Leadership	Chaired by a staff and co- chaired by PFAC member.	Chaired by a staff and co-chaired by PFAC member.	Led by Cleve- land clinic care- givers.	Physician leader		Co-chaired the Senior VP Clini- cal Programs, Chief Nursing Executive, and Chief of Allied Health and Pharmacy
Membership	Up to 12 former patient or family members, plus four KGH staff members and a physician.	A maximum of 12 patient/family advisors who must attend a minimum of 6 meetings annually and 8 staff members (others may be invited to attend on a rotating basis and depending on the topics for discussion). Staff members include the Vice President, People Services and Organizational Development, Chief Human Resources Officer, the Director of Patient Experience and Quality, and the Patient- and Family-Centred Care Coordinator.	10-12 members with up to 4 caregiver leader roles (staff).	12+ patient-family volunteer advisors, and a network of staff supporters (50% patients, 50% staff).		Patient and Family Members, Corporate members including the Project Lead for Patient Experience, Directors of Mission, Ethics, Compliance and the Office of the Patient Experience, Director of Therapeutic Support Services and the Director of Quality, Risk Management and Patient Safety, and a Physician member.
Reporting relationship	PFAC reports to the Patient Care and People Committee. Advisors are accountable to the Lead for PFAC.	PFAC reports to the Director, Patient Experience & Quality. Supported by the PFCC Office and Volunteer Services Department.	VPAC reports to the Office of Patient Experi- ence	Report to the Transcultural Patient Care Subcom- mittee		

PFAC struc- ture	KGH	North York	Cleveland clinic	Mayo clinic	Virginia Ma- son	Bruyère
Minutes distribution		Minutes are kept and distributed to all Patient and Family Advisors.	The co-facilitator distributes the minutes/report within 2 weeks of each VPAC meeting to all VPAC staff and patient members; as well as post attendance and minutes/report out through the online survey			

2. Accountability

For accountability, a report was shared with governance to ensure that the recommendations of the PFAC were implemented in Kingston General. In Cleveland clinic, the staff lead reported back to the PFAC on pro-

gress of implemented programs. In North York, Patient Experience specialists ensured that recommendations were implemented in the clinical programs (see Table 2).

Table 2: Accountability structures and processes

PFAC struc-	KGH	North York	Cleveland clinic	Mayo	Virginia	Bruyère
ture				clinic	Mason	
Accountabil-	Reports are	North York has 4 pa-	Caregiver provides a re-			The Project
ity	provided	tient experience spe-	port back to the VPAC on			Lead, Pa-
- How to fol-	regularly to	cialists (PES). Each PES	progress of ongoing pro-			tient Expe-
low up on	governance	works with their identi-	jects and any hospital			rience is
actions and	and opera-	fied clinical programs to	changes of interest to the			accounta-
recommenda-	tional com-	support patient experi-	group. Helps the VPAC			ble for the
tions from	mittees with	ence feedback, risk	achieve established goals			develop-
PFAC?	detail about	management concerns	by removing or minimizing			ment of the
	the design of	(e.g., legal claims), pa-	potential barriers and			agenda, the
	the service,	tient safety issues and	used leverage/influence			minutes,
	the involve-	quality improvement	to implement programs in			inviting
	ment of the	work. The PES also	the institute.			quests to
	advisors and	speaks with staff, physi-	Facilitator is responsible			provide
	the impact of	cians, patients and fam-	for communicating initia-			information
	their engage-	ilies regularly to remain	tives to ensure VPAC ideas			related to
	ment	aware of the range of	and activities are vetted			items of
		issues and opportuni-	for meaningful integration			interest to
		ties that present them-	within an institute, clinic,			the PFAC
		selves, and to be able	hospital or the enterprise.			and the
		to identify potential				follow up of
		quality improvement				recommen-
		projects.				dations
						made by
						the PFAC

3. Communication

Open and unbiased communication is encouraged between the patients/family and staff across all five organizations. Different channels are used such as forums, calls, emails, online tools, and social media as shown in Table 3.

Table 3: Communication

PFAC structure	KGH	North York	Cleveland clin- ic	Mayo clinic	Virginia Mason	Bruyère
Communication	Patient and Family Feedback forums offer the opportunity for patients to share hospital experiences with staff and physicians.	Minutes are kept and distributed to all Patient and Family Advisors.	Administrative Support (co- facilitator) serves as point of contact for patient/family members (calls/emails)	Vibrant virtual communities encourage new connections among patients, staff, students and the public. Individuals can connect and share their experiences through: Sharing Mayo Clinic blog, Facebook, Twitter, Mayo Clinic YouTube channel, and for Spanish-speakers, Twitter and Facebook		Presentations, agendas, and information for the next meeting is provided to all members by email, regular mail and in person to PFAC members.
Minute distri- bution		Minutes are kept and distributed to all Pa- tient and Family Advi- sors.	The co- facilitator pub- lishes meeting minutes and assists with communi- cating VPAC activities; com- pletes VPAC online re- porting tool within 2 weeks after each VPAC meeting.			Minutes are distributed and reviewed and adopted by members of the PFAC.

4. Training

Different training sessions were organized for staff and for PFAC members using various formats such as faceto-face and online training modules.

Orientation sessions were held for council/committee members before their meetings.

Training programs on Patient- and Family-Centred Care standards for staff and volunteers.

Training in communication tools for staff to provide the skill set and re-enforcement to better engage patients, families and each other (e.g. the H.E.A.R.T. [Hear, Empathize, Apologize, Respond, Thank] communication tool created by Cleveland Clinic, also used by Kingston General).

Resources for training can be obtained from different organizations, such as St Elizabeth which was one of our selected case studies because it is a leader in providing training to health care organizations (including staff and patients) about how to strengthen patient engagement in organizational practices (resources available described below).

Table 4: Training for PFAC members and healthcare staff

PFAC	KGH	North York	Cleveland clinic	Mayo clinic	Virginia	Bruyère
structure					Mason	
Training for PFAC members	Advisors will receive orientation to their committee.	A training program for volunteers to become Patientand Family-Centred Care Champions. An orientation day for council members where they review hospital policies, procedures, communication skills and how to be successful in their new role.	45-60 minutes for volunteer orientation which covers Cleveland clinic safety, security and confidentiality policies. Online training modules for patient representatives.		Orienta- tion ses- sion for council members	Volunteer orienta- tion for PFAC members.
Training for staff	Orientation and ongoing education on Patient- and Family-Centred Care standards. Online and face-to-face training in H.E.A.R.T. (Hear, Empathize, Apologize, Respond, Thank) communication tool created by Cleveland Clinic which provides the skill set and reenforcement to better engage patients, families and each other.	A training program for staff and physicians to become Patient- and Family-Centred Care Champions.	Online training modules for staff			

5. Roles and responsibilities

There were similar roles and responsibilities across the organizations such as:

- To partner with staff to promote patient and family -centered care
- Share their experiences and insights to help improve patient services and programs
- Evaluate policies, programs and practices to help

identify opportunities to improve patient and family satisfaction

Review or help create educational or informational materials

Table 5: Roles and responsibilities

PFAC	KGH	North York	Cleveland	Mayo clinic	Virginia Ma-	Bruyère
structure			clinic		son	
Roles and responsibilities	-To partner with staff to ensure patient and family centered care is provided in a fully accessible environment that promotes healing, ensures dignity and instills trust. -To keep the patient and family as the focal point of our health system. -to be viewed as a positive reinforcement of the patient family centered care concept. -to build partnerships with health care professionals based on mutual respect and open communication -to participate in facility design, quality improvement and program developmentto support the hospital and clinics in their process improvement projectsShare your story -participate in committee work -review or help create educational or informational materials -work on short-term projects e.g. helping to plan and design a family resource centre.	Corporate, Strategic, Program Committees and/or Focus Groups: Patient and Family Advisors work with teams on various projects, to enhance patient- and family- centred care throughout the hospital. Patient and Family Advisors can join committees and working groups that best match their particular interest or relevant ex- perience.	Members share their experiences and insights to help im- prove pa- tient services and pro- grams across institutes in the Cleve- land clinic.	to promote patient and family-centered care by: Collaborating with staff to improve the quality of service provided. Assisting in the identification of opportunities that will improve patient and family satisfaction. Offering input to leadership in the planning and evaluation of services. Serving as a vital link between the medical center and the community	-Collaborate with staff to improve the quality of service provided -Evaluate policies, programs and practices to help identify opportunities to improve patient and family satisfaction -Share best practices across the organization -Generate new ideas to drive initiatives -Serve as a vital link between Virginia Mason Memorial and the community	PFAC developed with an approved Terms of Reference for the Committee. The mandate and roles and responsibilities are clearly defined.

PFAC	KGH	North York	Cleveland clinic	Mayo clinic	Virginia Ma-	Bruyère
structure					son	
Some examples of com- mittees advisors partici- pate in	Accessibility Patient Experience Advisory Committee, Cancer Centre Resource Education, Medication Safety Committee, etc.	Quality of Care Committee, E- Health Steer- ing Com- mittee, Access to Care Steer- ing Com- mittee, Rede- sign Working Group, and Senior Staff Recruitment Panel.	VPACs have reviewed several hospital policies, including patient visitation and discharge information, helped define the expected service behaviors of all employees, renovated family areas, and developed educational materials for different nursing units.	Improving accessibility for wheelchair users, health care literacy challenges, evaluation of health history forms and developing a script for appointment staff to use with new patients to explain required paperwork.		

6. Recognition

Coverage of parking and/or meals was often used as a token of appreciation for PFAC members. In addition, Bruyère is planning to recognize the commitment and contribution of a PFAC member and a team/individual

towards enhancing and improving patient and family care experience as part of the Partner in excellence awards.

Table 6: Recognition

PFAC structure	KGH	North York	Cleveland clinic	Mayo clinic	Virginia	Bruyère
					Mason	
Recognition	The cost of parking is covered for KGH advisors.		A meal (lunch or dinner) is provided before the start of the meetings and complimentary parking as well	A meal is provided and during the meetings		Parking vouchers provided to PFAC members. Light snacks at meetings. Planning to add two partners in excellence awards

Resources for training

St Elizabeth provides PFCC education through workshops to all employees both regulated and unregulated, as well as support staff, management, supervisors of direct care providers and care coordinators in the health care organization. St Elizabeth has developed a tool kit for implementing PFCC education across health care organizations in which they describe their experience [6].

All stakeholders were involved in the planning and implementation phases and included representatives from senior leadership team, middle management (supervisors of direct care providers and support staff

and clinical educators), direct care providers (e.g. nurses, rehabilitation professionals, personal support workers, health care aides) and support staff (e.g. housekeeping, food services, custodial, office workers) as well as patients and family members.

Different versions of workshop education content and format were developed for target audiences (leadership team, regulated care providers, unregulated care providers and support staff) and a generic version for interdisciplinary groups of employees. It was found that additional versions were needed for physicians, volunteers and care coordinators.

Table 7: Resources for training

workshops	
Objectives	-promote interactive discussions and allow two-way flow and transfer of information between participants and facilitators -be flexible to meet the needs of organizations and trainers -support reflective learning
Content	-key concepts of PFCC -questions for discussion and reflection -case studies -role play scenarios -videos
Format	-videos -slides -handouts -small and large group discussions -flip-charting -self-reflection
Sessions	-series of three workshops, each 60-90 minutes and offered 4-6 weeks apart for direct care providers and support staff -series of two workshops, each two-hours long and offered 4-6 weeks apart

An evaluation was done after each workshop to understand if the education was useful, how well the workshop was implemented, its impact on participants and any challenges that were or could be encountered.

Discussion

Application of evidence/implementation

Health care organizations are engaging patients and their family more and more in healthcare quality improvement strategies through PFACs [7, 8]. However, many organizations are struggling with how best to fully engage patients and their family [7-9] as there is a variety of patient engagement models and guidance. Various factors can also influence the extent to which patients and their family engage such as fear, uncertainty, low health literacy, and provider reactions or support; and finding the right people who are committed and able to contribute meaningfully could be challenging [5, 10]. Investments in patient engagement efforts varied with the size and commitment of the organizations [8]. Some organizations have a committed budget for running the PFAC while others do not. The top five resources organizations invested in are: survey and feedback tools, interpreter services, parking, training and patient education.

Some success factors and lessons learned in the implementation process have been shared [8, 11] and include the following:

Patient and family engagement practices should be used across the organization and include everyone in every department and service. The leadership and other stakeholders across the organization should support patient engagement and patient and family centered care.

Staff should be committed and accountable across the organization.

Having and maintaining a patient experience department or team.

Focus on measuring, achieving and reporting on results and having a reporting structure.

Patient and family advisors should have a clear de-

scription of their role from the start and they should receive training to be able to share their experience and meaningful ideas for quality improvement.

Start the council by working on issues they have identified as important to them and by seeking their advice on hospital initiatives. Have the council work on concrete projects with measurable outcomes within a short period (e.g. one year); such as developing a policy.

Use evaluations after every meeting to assess its effectiveness and ensure open communication with the council and explain why their recommendations may not have been implemented.

Strengthening communication connections within and outside the organization.

It is helpful for organizations interested in forming a council to connect with hospitals with exemplar models to understand the commitment, purpose and usefulness of such a resource.

Strength and limitations

We used the patient engagement models and guidance to develop a systematic approach to summarize the details on patient engagement structures and processes in six exemplar organizations.

We limited our assessment to the six healthcare organizations suggested by the clinical champions. We limited our search for information about these organizations to their organizational websites and Google and Google scholar search engines, and may have missed additional information.

Implications

Implications for practice

- This report serves as a self-evaluation tool that can be used by leadership at Bruyère Continuing Care and its PFAC to set priorities and develop standardized processes for governance, accountability, communication, training, roles and responsibilities and recognition to meet its needs.
- There was little evidence available on how to initiate patient engagement in specific departments/
 clinics. However, some organizations are willing to share their experiences and provide guidance and support. Bruyère Continuing Care may consider partnering with such organizations.

Implications for research

There is a need for more research and scholarly publication about lessons

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Appendices

Appendix 1: Models of patient engagement

IAP2 (International Association of Public Participation) model

https://www.iap2.org/

The IAP2 model includes five levels of involvement (inform, consult, involve, collaborate and empower) with different tested methods of engagement under each level [12].

Table 8: Methods of engagement for each level across IAP2 model

Level of en-	Inform	Consult	Involve	Collaborate	Empower
Methods of engagement	Mass media (commercials, advertise- ments, mail- ings)	Focus group	Forums for debate	Patient advisory councils/ committees	Citizen jury
	Website	Patient surveys	Health panels	Expert pa- tients	Consumer managed project/
	Press release	Feedback and complaints	Shadow pa- tients	Charrette	Consensus con- ference
	Mail outs	Story-telling	Workshops	Constituent assembly	Deliberative polling
	Fact sheets	Social media (e.g. Facebook,	Public meetings	Delphi pro- cess	Search conference
	Hotline	Planning		Retreats	Study circles
	Displays and exhibitions	Suggestion boxes		Round ta- bles	Study groups
	Presentations	Patient diaries		Impact as- sessments	Sustainable community
		Mystery shop- ping		Ethics com- mittees	Think tanks
				World cafes	
				Town hall	
				Revolving conversa-	

KGH ICPM model of patient engagement

The Interprofessional collaborative practice model of care offers collaborative partnerships between healthcare providers, patients and their family in all aspects of care delivery [13]. This framework involves four interactive levers: People, Technology, Information and Process that are enabled by collaboration and coordination across the continuum, effective communication, on-going education, and committed and supportive leadership.

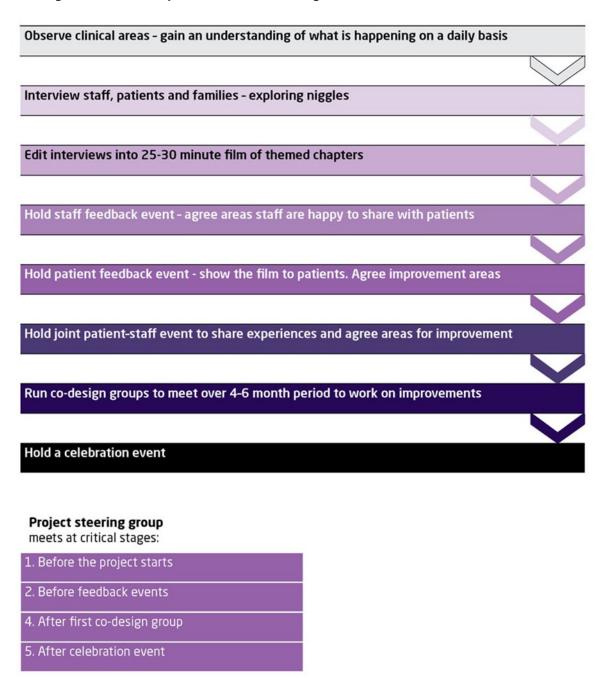
ICPM conceptual framework **Patients** Respectful, Compassionate, High Quality Care People Working in a Collaborative Interprofessional Team with Clear Consistent, Appropriate Roles Enabled by Accessible Technology Accessing Timely, Accurate Information Collaboration & to Support Decision Making Coordination cross the Continue Effective Communication eraging Efficient, Effective Education **Processes** Leadership

Figure 1: ICPM model of patient engagement

Experience Based Design or Co-design model

This model uses patient and staff experiences to identify quality improvement opportunities. The experiences are shared individually to staff and patients and all participants work together in small groups to identify and implement activities to improve services as well as patient and staff experiences [14, 15]. See Figure 2 for the stages involved in Experience Based Co-design [16].

Figure 2: Stages involved in Experience Based Co-design



Appendix 2: Case studies

Kingston General Hospital

http://www.kqh.on.ca/about-kqh/patient-and-family-advisory-council/patient-experience-advisors

Kingston General Hospital (KGH) is a 440 inpatient bed facility providing complex-acute and specialty care. It has the Hotel Dieu Hospital site and Kingston General Hospital site, as well as the Cancer Centre of Southeastern Ontario, two research institutes, and 24 satellites across southeastern Ontario.

KGH uses the interprofessional collaborative practice model of care (ICPM) to deliver patient and family centred care [11, 13] (See Appendix 1 for details about the ICPM framework). This framework was created in 2009 and implemented starting with two showcase units then with the help of the Patient and Family Advisory Council (PFAC), the framework was implemented in other units throughout the organization.

The KGH Patient and Family Advisory Council (PFAC) was formed in February 2010 and is composed of up to twelve former patients or family members of patients plus four KGH staff members and a physician. The patient or family members include individuals who have received care at KGH in the medicine, emergency, surgery, cardiology, oncology, obstetrics/gynecology, critical care and pediatric programs. They work in partnership with executive leadership and staff in every initiative that can influence their care and service. The Council is co-chaired by a Patient Experience Advisor and a staff member.

Today KGH has more than 180 patient experience advisors on 88 long and short term committees working with staff at all levels of the organization. The advisors are members of key service-based and corporate committees, such as steering committees, taskforces, working groups, accessibility committees, education committees, and patient care program councils. They are part of job interview panels for all levels of staff including directors and health care providers. They also welcome new staff and physicians at orientation. Patient and Family Feedback forums offer the opportunity for patients to share hospital experiences with staff and physicians.

North York

http://www.nygh.on.ca/home.aspx?lang=1

North York General is a community academic hospital in Toronto with three sites including the General Site (acute care services), the Branson Ambulatory Care Centre and a 192-bed long-term care home.

North York has a Patient Experience Office that promotes patient and family centred care by providing opportunities for patients and families to share experiences and feedback including compliments, concerns, questions and suggestions.

At North York, the PFAC works in partnership with the staff to promote patient and family centred care and improve patient experience of care by providing their perspectives in hospital initiatives, programs, services and policies.

Cleveland Clinic

https://my.clevelandclinic.org/about/overview/who-we-are/facts-figures https://my.clevelandclinic.org/departments/cancer/patient-education/voice-patient-advisory-council

Cleveland Clinic is a multi-specialty academic medical center with more than 1,400 beds on the main campus and 4,435 beds system-wide.

Cleveland Clinic has an Office of Patient Experience that is responsible for conducting and analyzing patient surveys, interpreting patients' complaints, administering "voice of the patient" advisory councils, training employees, and working with units to identify and fix problems.

The Voice of the Patient Advisory Council was created in 2009 and its members share their experiences and insights to help improve patient services and programs across institutes in the Cleveland clinic. They have reviewed several hospital policies, including patient visitation and discharge information, helped define the expected service behaviors of all employees, renovated family areas, and developed educational materials for different nursing units.

Mayo Clinic

http://www.mayoclinic.org

http://www.mayoclinic.org/about-mayo-clinic/office-diversity-inclusion/our-patients

http://mayoclinichealthsystem.org/locations/menomonie/patients-and-visitors/patient-and-family-advisory-council

Mayo Clinic has major campuses in Arizona, Florida, Minnesota and many locations in several states in the US.

The medical center's Patient and Family Advisory Council was started in 2004 to promote patient and family centered care. It collaborates with staff to improve service quality, provides input in the planning and evaluation of services, assists in the identification of opportunities to improve patient and family satisfaction. The council also serves as a link between the center and the community.

The PFAC has been involved in projects such as improving accessibility for wheelchair users, health care literacy challenges, evaluation of health history forms and developing a script for appointment staff to use with new patients to explain required paperwork.

Virginia Mason

https://www.virginiamason.org

https://www.virginiamason.org/volunteerservices

Virginia Mason is a 336 bed acute care hospital in Seattle with a network of 9 regional clinics, an AIDS care facility with 35 private rooms, a research centre as well as a training facility and a 226-bed community hospital serving the Yakima Valley in Central Washington.

Virginia Mason used the Experience Based Design or Co-design model to promote patient and family centred care improvement. See Appendix 1 for details about this model.

The Patient-Family Partner Program at Virginia Mason engages patients and family in process improvement workshops, focus groups and panels, as reviewers for patient/family educational and/or marketing communication materials for readability, simplicity and understandability. They could also serve as members of the family faculty to share

their personal stories and experiences, or as peer partners to support patients with a similar care experience in the Orthopedic and laryngectomy departments. They could be committee members sharing patient/family perspectives to help in planning services, for example: safety, quality, or guiding teams planning Kaizen improvement work within a specialty area throughout Virginia Mason.

St Elizabeth Health Care

https://www.saintelizabeth.com/About-Saint-Elizabeth.aspx

St Elizabeth is a national charitable organization with offices in Ontario, Alberta, British Columbia and Quebec. It provides a variety of health care services to people in long-term care facilities, clients' homes, hospitals, supportive housing, correctional facilities, hospices, retirement homes, schools and clinics across Canada. Their team includes registered nurses, personal support workers, community health workers and rehabilitation therapists. It also has a Foundation, Health Career College, Research Centre, and a Family and Patient Centred Care Institute.

The St Elizabeth Research Centre in collaboration with the Education Services has developed resources as well as education and consulting services to assist health organizations to implement patient and family centred care.

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