

# Patient and Family Engagement in Hospital Planning and Improvement

## A Casebook

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**A compilation of 40 accounts of patient and family engagement in hospital planning and improvement gathered from patient/family advisors, patient engagement managers, clinicians and corporate executives at hospitals of different types and sizes in Ontario.**

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# TABLE OF CONTENTS

3	Acknowledgements
4	Introduction
4	Purpose
4	Content
4	How to use this casebook
5	Background
5	Patient engagement
5	Organizational capacity for patient engagement
5	Research objectives
6	Knowledge translation
6	Casebook development
6	Research design
7	Interview sampling and recruitment
7	Data collection and analysis
7	Case preparation
8	References
10	Case representatives
10	Types of cases included
13	Summary of key findings
13	Patient engagement was embedded throughout organization
13	Patient engagement structures
13	Patient engagement approaches
14	Strategies to optimize patient engagement
15	Challenges and solutions
15	Essential elements of hospital capacity for patient engagement
16	Impacts of patient engagement
18	Integrated findings
19-58	Cases
	<b>Tables</b>
10	1 Characteristics of representatives of included cases
11	2 Case characteristics
14	3 Strategies employed to promote and support patient engagement
15	4 Elements of patient engagement capacity considered essential
16	5 Impacts on hospital, patient/family and clinician/staff capacity for patient engagement
17	6 Impacts of patient engagement on hospital, patient/family and clinician/staff outcomes
	<b>Figures</b>
18	1 Impacts of Patient/Family Engagement in Hospital Planning and Improvement

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# Introduction

## Purpose

This casebook shares real-world accounts of patient (and family) engagement (henceforth, PE) in hospital planning and improvement gathered from patient/family advisors, patient engagement managers, clinicians and corporate executives at hospitals of different types and sizes featuring a high level of PE.

By sharing experiential knowledge, casebooks supplement evidence-informed knowledge or address gaps in such knowledge, enabling users to learn from a plethora of diverse initiatives, and choose and tailor those strategies to their own context.

## Content

This casebook includes 40 cases:

Organized primarily by type of initiative: Develop or renew organizational policies/strategies, Evaluate strategies/programs, Develop strategies/programs, Plan or improve facilities/amenities, and Develop resources for patients/families

Each case offers detail on:

- Hospital type (<100 beds, 100+ beds, teaching)
- Participant type (Patient/Family Advisors, PE Managers, Clinicians, Corporate Executives)
- Engagement type (consultation, collaboration, blended approach)
- Initiative topic, goal and timeline
- Patient engagement strategies
- Challenges, success factors and impact

Cases are preceded by an overall summary of key findings across all cases including PE structures, PE approaches, strategies to optimize PE, challenges to PE and corresponding solutions, essential elements of hospital capacity for PE, and impacts of PE.

## How to Use this Casebook

Review content:

- Refer to the overall summary of key findings rather than specific cases
- Identify cases by type that match what you wish to improve in your hospital
- Scan all cases to learn about different approaches used to engage patients/families

Apply content:

- Integrate into education on and orientation to PE for both Patient/Family Advisors and staff
- Use as a basis to develop or evaluate PE in your hospital

**We hope that you find this casebook useful in enhancing hospital patient/family engagement!**

# Background

## Patient Engagement

Patient (and family) engagement (PE) is defined as patients, families or their representatives, and health professionals working in active partnership at various levels across the healthcare system – individual care, organizational design and governance, and system-level policy-making – to improve health and health care.<sup>1</sup> PE in healthcare organization planning and improvement (henceforth, hospital PE) is a growing practice that can lead to a range of beneficial impacts such as educational tools for patients, programs and services tailored to patient needs and preferences, enhanced patient experiences and better clinical outcomes such as reduced hospital admissions.<sup>2,3</sup> However, several systematic reviews of published research revealed that many barriers can result in token PE, and little or no service improvement.<sup>4-6</sup>

## Organizational Capacity for Patient Engagement

By synthesizing research to date, these reviews identified gaps in knowledge about how to optimize PE in hospital planning and improvement. For example:

- It is not clear whether: more active engagement approaches involving collaboration (patients and providers working together to create solutions) are necessary for all planning and improvement decisions; collaboration always leads to improved programs or services, patient experiences or clinical outcomes compared with less active engagement approaches such as consultation (patient opinions or ideas sought via survey, interview or focus group);<sup>2</sup> or a “mosaic” of engagement approaches is best.<sup>7,8</sup>
- Prior research on what constitutes an “engagement-capable” environment provided valuable insight, but studies differed in recommended resources and processes, signaling the need for more knowledge on the essential ingredients of organizational capacity for PE.<sup>9-10</sup>
- Prior research was largely conducted in primary care settings rather than hospitals, which account for the largest share of health spending in many countries.<sup>1,2,11</sup>
- In a scoping review, we identified only 10 studies published in 2016 or earlier that focused on PE for planning and improvement specifically in hospitals.<sup>3</sup> Included studies provided little detail about precisely how patients were engaged. For example, a survey of quality managers found that 50% of hospitals engaged patients, largely as quality committee members, but the study did not report mode or frequency of PE, how their contribution was used, and with what impact.<sup>12</sup>

## Research Objectives

Given the little evidence-based guidance on how to best translate patient and family voices in improving hospital facilities, services, experiences, and outcomes, we conducted a multi-year study to generate insight on how to optimize PE in hospital planning and improvement:

- Surveyed Ontario hospitals about PE capacity and processes, which identified high-PE hospitals
- Interviewed representatives of high-PE hospitals to gather best practices
- Generated evidence-informed consensus on capacity and processes essential to PE in hospital planning and improvement.

# Knowledge Translation

A review of the knowledge management and organizational learning literatures identified three processes required to adopt quality improvement practices: transfer of knowledge about practices between organizations, copying best practices, and translating them into a new context.<sup>13</sup> Another review revealed that tacit knowledge increases in relevance as organizational complexity increases. Tacit knowledge refers to dynamically-created context-specific learning acquired through one's own personal experience or that of others.<sup>14</sup>

One way to share tacit knowledge about quality improvement is through “collaboratives,” which bring together groups of healthcare workers from different organizations to systematically improve one aspect of the quality of their services through joint learning and sharing of experiences.<sup>15</sup> In a systematic review of 64 studies of such collaboratives, 83% reported improvements in measured outcomes; however, studies varied in settings, topics and populations, and many did not provide descriptions of the collaboratives to enable replication.<sup>16</sup> In-person or virtual coaching has also been used to transfer tacit knowledge in support of quality improvement with a positive impact on knowledge, self-efficacy, decision-making, staff satisfaction and quality of clinical care.<sup>17,18</sup> However, evidence is sparse on the optimal characteristics and roles of coaches, also referred to as knowledge brokers, opinion leaders, facilitators, or change agents, and their effectiveness.<sup>19,20</sup>

An alternative approach for sharing tacit knowledge is the casebook, which may be easier to develop, and less costly and complex to implement compared with collaboratives or coaches. Casebooks refer to compilations of narrative accounts of quality improvement experiences. To prepare for developing this resource, we conducted a scoping review of casebooks.<sup>21</sup> In all included studies, casebook development was a multistep, iterative, interdisciplinary process that engaged stakeholders in identifying, creating and reviewing content. While casebooks differed in topic, level of application and scope, cases featured common elements: a description of setting or context, quality improvement strategy details, impacts achieved, and additional tips for implementing strategies.

We derived cases that include these elements based on aforementioned qualitative interviews with patient/family advisors, PE managers, clinicians and corporate executives with experience in PE for hospital planning and improvement.

## Casebook Development

### Research Design

We employed a multiple-methods research design. The University Health Network Research Ethics Board approved the study. First, we conducted a cross-sectional survey of hospitals in Ontario, Canada to collect descriptive information about years of PE experience, number and type of corporate and clinical departments featuring PE, organizational capacity for PE (28 items) and mode of engagement (inform, consult, involve, partner) across three categories of activities: planning (13 items), service delivery (14 items) and evaluation/quality improvement (17 items).<sup>22</sup> The survey concluded on September 30, 2018. In total, 91 (66.4%) hospitals responded. Detailed findings are published elsewhere.<sup>22</sup>

# Casebook Development

Of note, we created an index measure of hospital capacity for PE and used Multiple Correspondence Analysis,<sup>23</sup> a form of multivariate analysis, to reveal that capacity was not associated with hospital type. Variance in capacity was largely due to number of departments featuring PE and use of active engagement modes (e.g. involve, partner). As a result of this analysis, we identified hospitals of all types (<100 beds, 100+ beds, teaching hospitals) with high PE capacity.

Next, we conducted descriptive qualitative interviews with representatives of high-PE capacity hospitals to gather detailed information about how patients/family were engaged, key elements of hospital capacity for PE, PE enablers and barriers, and impacts of PE for a range of initiatives. Interviews concluded on July 16, 2020. Detailed findings are reported elsewhere.<sup>24-26</sup> Based on the findings, and in collaboration with interview participants, we prepared and refined case descriptions.

## Interview Sampling and Recruitment

We used purposive sampling to recruit individuals from high-PE capacity hospitals whose PE experiences might vary by: role (patient/family advisors, managers responsible for PE, clinicians and corporate executives involved in at least one PE project), type of hospital (<100 beds, 100+ beds, teaching) and geographic setting (urban, rural). We first conducted interviews with PE managers, who then referred us to patient/family advisors, clinicians and corporate executives in their hospital. As is common for qualitative research, we sought in-depth information from a small number of representative participants; thus, we aimed to recruit one PE manager, two patient/family advisors and two corporate executives or clinicians from each of two hospitals for each type (<100 beds, 100+ beds, teaching) for a minimum total of 30 interviews. We sampled and recruited participants until no further unique themes emerged with successive interviews, known as thematic saturation. This was determined by discussion among the research team.

## Data Collection and Analysis

During the interview, participants were asked to provide an example of a planning or improvement activity that engaged patient/family advisors, and to answer subsequent questions based on that example: How were patient/family advisors engaged; why was that engagement approach chosen; what was done to optimize engagement and ensure patient/family input was used; what key challenges did you encounter and what was done to solve those problems; what was the impact of the engagement project; and what key conditions led to successful engagement?

A Masters-trained Research Associate (NNA) and Senior Scientist/Professor (ARG) jointly conducted the first two interviews, independently reviewed transcripts, met to discuss their analyses, refined the wording of the interview guide and established an initial coding scheme of themes and exemplar quotes. NNA conducted and analyzed remaining interviews, with periodic review by ARG, and together they conducted a deeper analysis of the data to finalize the coding scheme and summarize findings. The research team reviewed and interpreted all findings and assisted in preparing reports.

## Case Preparation

We used an iterative approach to ensure that case descriptions accurately and fully captured participant project details. At the outset of interviews, all participants agreed to subsequently assist in reviewing their case description. NNA and ARG created a preliminary case description template reflecting topics discussed during interviews. Research team members reviewed and improved the template. NNA and ARG jointly developed a case description based on the transcript of the first two interviews, and through discussion, further refined the template. Within two weeks of receiving an interview transcript, NNA created a case description and shared it with the participant for review. NNA incorporated participant feedback, and ARG reviewed cases to enhance clarity.



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# Case Representatives

We included 40 cases (Table 1). Representatives who contributed those cases included 20 patient/family advisors, 8 PE managers, 10 clinicians and 2 corporate executives affiliated with hospitals that varied by type (<100 beds, 100+ beds, teaching) and region (urban, suburban, rural).

**Table 1. Characteristics of representatives of included cases**

Role	Affiliation by hospital type			Sub-total
	<100 beds	100+ beds	Teaching	
Patient/family advisors	4	10	6	20
PE managers	2	4	2	8
Clinicians	2	6	2	10
Corporate executives	0	1	1	2
Sub-total	8	21	11	40

## Types of Cases Included

Cases were categorized and organized by aim or output of the initiative described in each case (Table 2). Following is a list of the types of cases, examples of those initiatives, and the number of each type of case included in this casebook.

Develop or renew organizational policies/strategies (7 cases)

Examples: strategic plan, patient declaration of values, quality improvement objectives

Evaluate strategies/programs (4 cases)

Examples: Evaluate post-discharge follow-up, patient transfer model

Develop strategies/programs (11 cases)

Examples: Integrate internal medicine, daily experience rounding, bundled joint replacement program, staff identification badges

Plan or improve facilities/amenities (7 cases)

Examples: Personalized meal plans, communication boards, way-finding system

Develop resources for patients/families (11 cases)

Examples: research consent form template, COVID-19 protocol information, patient admission handbook, palliative care information booklet

# Types of Cases Included

**Table 2. Case characteristics**

Case type	Initiative	Hospital type	Representative type	Engagement type	Case #	Page #
<b>Develop or renew organizational policies/strategies (n=7)</b>	Develop and launch a new organizational strategic plan	Teaching	Patient Engagement Manager	Blended	1	19
	Develop and launch a new organizational strategic plan	Teaching	Patient/Family Advisor	Blended	2	20
	Develop a new Patient Declaration of Values	Teaching	Patient/Family Advisor	Blended	3	21
	Develop a new Patient Declaration of Values	Teaching	Patient Engagement Manager	Blended	4	22
	Develop a new Patient Declaration of Values	100+ beds	Patient Engagement Manager	Blended	5	23
	Establish priorities for quality improvement objectives	100+ beds	Patient/Family Advisor	Collaboration	6	24
	Develop a hospital quality improvement plan	100+ beds	Corporate Executive	Blended	7	25
<b>Evaluate strategies/programs (4 cases)</b>	Evaluate post-discharge telephone calls for high-risk patients	100+ beds	Clinician	Consultation	8	26
	Evaluate daily post-discharge telephone follow-up	100+ beds	Patient/Family Advisor	Consultation	9	27
	Evaluate daily post-discharge telephone follow-up	<100 beds	Clinician	Consultation	10	28
	Evaluate a team-based patient transfer approach	100+ beds	Patient/Family Advisor	Consultation	11	29
<b>Develop strategies/programs (11 cases)</b>	Design a hospital-wide program to improve timeliness of care	100+ beds	Patient Engagement Manager	Blended	12	30
	Integrate internal medicine staff in multiple hospital units	Teaching	Patient/Family Advisor	Blended	13	31
	Develop and implement daily patient experience rounding	100+ beds	Patient Engagement Manager	Blended	14	32
	Develop a bundled care program for hip/knee replacement	100+ beds	Clinician	Collaboration	15	33
	Plan COVID-19 screening communication and processes	100+ beds	Patient Engagement Manager	Blended	16	34
	Re-design staff/volunteer identification badges	<100 beds	Patient/Family Advisor	Consultation	17	35
	Provide access to care plans in online patient profiles	100+ beds	Patient/Family Advisor	Consultation	18	36
	Develop policy and processes for a new stroke unit	Teaching	Patient/Family Advisor	Collaboration	19	37
	Develop a proposal for an Ontario Health Team system	100+ beds	Clinician	Blended	20	38

# Types of Cases Included

**Table 2. Case characteristics cont'd.**

Case type	Initiative	Hospital type	Representative type	Engagement type	Case #	Page #
	Implement mental health care pathways for oncology patients	Teaching	Corporate Executive	Collaboration	21	39
	Design and implement staff introduction/interaction protocol	<100 beds	Clinician	Consultation	22	40
<b>Plan or improve facilities/ amenities (7 cases)</b>	Design and implement personalized meal plans	<100 beds	Patient/Family Advisor	Collaboration	23	41
	Develop and launch a healthier food initiative	Teaching	Patient/Family Advisor	Collaboration	24	42
	Design neonatal intensive care unit communication boards	Teaching	Clinician	Consultation	25	43
	Design and implement communication boards in medicine rooms	Teaching	Clinician	Blended	26	44
	Design and implement communication boards in patient rooms	<100 beds	Clinician	Blended	27	45
	Design a new way-finding system	100+ beds	Patient/Family Advisor	Collaboration	28	46
	Design a new way-finding system	100+ beds	Patient/Family Advisor	Blended	29	47
<b>Evaluate strategies/ programs (4 cases)</b>	Develop an aging-well online tool for seniors	100+ beds	Patient/Family Advisor	Collaboration	30	48
	Develop a research consent form template for patients	100+ beds	Patient/Family Advisor	Collaboration	31	49
	Develop COVID-19 protocol information for patient/family	Teaching	Patient/Family Advisor	Collaboration	32	50
	Develop post-discharge integrated care pathway and patient educational material	100+ beds	Clinician	Collaboration	33	51
	Develop family information on neonatal intensive care	100+ beds	Clinician	Collaboration	34	52
	Develop a patient admission handbook	100+ beds	Patient/Family Advisor	Collaboration	35	53
	Update patient discharge information sheets	<100 beds	Patient Engagement Manager	Collaboration	36	54
	Develop information material for intensive care unit patients	100+ beds	Patient/Family Advisor	Collaboration	37	55
	Develop mental health educational material for waiting room	100+ beds	Clinician	Collaboration	38	56
	Develop a palliative care information brochure	<100 beds	Patient/Family Advisor	Collaboration	39	57
	Develop a palliative care information brochure	<100 beds	Patient/Family Advisor	Collaboration	40	58

# Summary of Key Findings

## **PE was embedded throughout organizations**

PE had become the norm throughout the hospital and for all activities.

We always have a patient or two involved in everything that we do (038 exec teaching)

Being able to see our system through their eyes is very informative and leads to better patient experiences, which also leads to better outcomes (025 clinician 100+)

To have patient-family centred care, you can't just pay lip service to it, you absolutely have to engage patients (039 patient/family teaching)

## **PE structures**

Participants said they employed a variety of structures including general and department-specific patient and family advisory councils, standing committees and project teams at all levels of the hospital including executive governance.

There is a patient on the General Medicine Quality Committee and the Quality Committee...both of those committees had input into what was on the Board agenda (012 clinician teaching)

## **PE approaches**

Participants chose engagement approaches to match initiatives including the project topic, availability of patient/family advisors and staff, and project timeframe.

**Collaboration** approaches (involve/partner through standing committees or project teams) were preferred for three reasons:

- To ensure that patient perspectives were heard and integrated in decision-making
- This approach was perceived to be evidence-based, referring to their own past experience or successful use in other hospitals, and
- This approach was expected by hospital leaders

Collaboration was used to engage patient/family advisors in creating, reviewing or editing documents or resources such as patient information handouts or videos, online educational tools, web sites or research consent forms; and to discuss and evaluate issues pertaining to planning or improving services or programs, brainstorm or develop solutions for those issues, and to inform the development of innovative new programs.

**Consultation** approaches (gather ideas or input via surveys, interviews or focus groups) were preferred for three reasons:

- This approach was best for reaching many patients/family members
- Doing so would capture the full range of perspectives from diverse individuals
- It was an efficient way to rapidly gather feedback to quickly solve problems or make improvements as issues arose

# Summary of Key Findings

Consultation was used to gather feedback on existing or newly-implemented programs, or ideas about how to plan or improve services.

**Blended** approaches (collaboration and consultation for the same initiative) were preferred when there was a need to gather a wide range of perspectives through consultation, and then gather deeper insight on those ideas, prioritize those that could lead to the biggest improvements, and design or plan implementation through collaboration with patient/family advisors on project teams or standing committees.

A blended approach was used to develop patient tools (e.g. communication boards) and new programs or models of care (e.g. daily rounding, post-discharge follow-up).

## Strategies to optimize PE

Participants said that hospitals employed a range of strategies to prepare and engage patient/family advisors, and ensure that patient/family voices informed planning and improvement (Table 3).

**Table 3. Strategies employed to promote and support patient engagement**

Category	Strategies
<b>Engage diverse patients</b>	<ul style="list-style-type: none"> <li>• Aim for diversity in characteristics</li> <li>• Employ various recruitment strategies to achieve diversity</li> <li>• Patient/family advisors were largely retired persons</li> </ul>
<b>Prioritize what benefits many</b>	<ul style="list-style-type: none"> <li>• Chose projects that benefit the majority</li> <li>• Used perspectives expressed by the majority</li> <li>• Blended approach of consultation then collaboration</li> </ul>
<b>Match patients to projects</b>	<ul style="list-style-type: none"> <li>• Deploy those with PE experience/skill</li> <li>• Match patient/family experience or characteristics to PE project</li> </ul>
<b>Train participants</b>	<ul style="list-style-type: none"> <li>• Train patient/family for role of advisors</li> <li>• Train healthcare workers on how to collaborate with patient/family advisors</li> </ul>
<b>Ensure patient perspectives inform decisions</b>	<ul style="list-style-type: none"> <li>• Include a critical volume of patient/family advisors</li> <li>• Quorum requires at least one patient/family advisor</li> <li>• Patient and family Advisory Committee (PFAC) review of standing committee or project team work</li> <li>• Patient/family advisor feedback loop</li> <li>• Philosophical commitment to respect/value patient perspective</li> </ul>
<b>Staff champions</b>	<ul style="list-style-type: none"> <li>• Skilled PE managers/staff</li> <li>• Proactive standing committee/project team Chairs</li> </ul>
<b>Links with Board of Directors</b>	<ul style="list-style-type: none"> <li>• Board member on PFAC</li> <li>• Patients on Board/Board Committees</li> <li>• Accountable to Board</li> </ul>

# Summary of Key Findings

## Challenges and Solutions

Participants uniformly identified three types of challenges they faced:

1. Given that PE was pervasive and routine, leading to an ever-increasing number of planning or improvement initiatives, participants emphasized the need to continuously recruit patient/family advisors to maintain a large pool.
2. When recruiting patient/family advisors, participants underscored the need to include individuals with a range of characteristics and experiences to ensure a diversity of perspectives that represented the hospital's community, and better match patient/family advisors to initiatives.
3. To ensure that decisions reflected patient/family advisor perspectives, participants also stressed the need to engage patient/family advisors earlier in planning or improvement activities using collaborative approaches instead of asking for input on decisions already made by staff.

## Essential elements of hospital capacity for PE

Participants identified elements of hospital capacity that they considered essential to successful PE (Table 4).

**Table 4. Elements of PE capacity considered essential**

Category	Elements of PE capacity
<b>Resources</b>	<ul style="list-style-type: none"> <li>• Operational funding dedicated to PE activities</li> <li>• Compensation for patients and release time for staff</li> <li>• Staff who are responsible for and enable PE (dedicated manager and staff, and staff champions)</li> <li>• Technology to support PE</li> </ul>
<b>Training for patients and staff</b>	<ul style="list-style-type: none"> <li>• Background information for patients</li> <li>• Establish roles and responsibilities for all involved</li> <li>• Orientation for existing and new staff</li> </ul>
<b>Organizational commitment to PE</b>	<ul style="list-style-type: none"> <li>• Endorsed and modeled by CEO and Board</li> <li>• All staff support PE</li> <li>• PE is evaluated and improved</li> </ul>
<b>Staff behaviour conveys value for patient and family advisors</b>	<ul style="list-style-type: none"> <li>• Staff accommodate and are receptive to patient input</li> </ul>

## Participants highlighted the need for sufficient resources to support PE:

The only person in the room not being paid to be there is the patient, whose voice is apparently critical to the work. The advisors I know at my hospital essentially pay to volunteer at the hospital. They pay their mileage or their time; they take time off work, they may pay for babysitters. I think the next step is put your money where your talk is and compensate people so they're not sacrificing overly much to take part (029 patient/family 100+)



# Summary of Key Findings

We do it mostly by paper unless we bring in our own tablets...the Board has secure emails, we are using our personal ones...the hospital does not have a Zoom account and we were using one of the member's Zoom accounts...we're printing the materials on our own printers (036 patient/family <100)

They may need more staff because I think as this grows they're busier than ever. I think having enough staff to be able to implement a patient program that is vital and useful and valid, I think this is probably most important (015 patient/family teaching)

## Impacts of PE

Participants identified 23 impacts of PE. Table 5 identifies 9 impacts of PE on hospital capacity for PE and the capacity of those involved to participate in PE. Table 6 identifies 14 impacts of PE on hospital, patient/family and clinician/staff outcomes.

**Table 5. Impacts of PE on hospital, patient/family and clinician/staff capacity for PE**

Category	Theme	Exemplar quotes
<b>PE Capacity</b>	New PE approaches or processes developed and widely replicated	And then it was decided that the PE activity process was a success that we'd start to look at doing it for other units (027 PE manager <100)
<b>Patient/Family Advisors</b>	Satisfaction with contributions that help others	You could see the sense of pride for them as true patient partners because they knew the impact that it was going to have on the families (022 clinician 100+)
	Feeling valued when perspectives heard/used	I have always felt that my contribution is valued and listened to. And taken into account when it comes to decision-making (030 patient/family 100+)
	Learning about the complexity of healthcare	[Patient/family advisors] always comment on how much more they appreciate the complexity of the healthcare system having been engaged in trying to solve some of these gaps (038 corporate executive teaching)
	Feeling empowered leading to greater engagement	[Patient/family advisors] felt empowered to be able to speak up and provide their feedback. They became more and more engaged as time went on (040 clinicians 100+)
<b>Clinicians or staff involved in PE</b>	Reminder of importance of listening to patients	It reinforces what really matters when it comes to healthcare and the importance of listening to patients (015 patient/family teaching)
	Reminder of why they chose a healthcare career	It reminds clinicians and staff to really think about why they came to work in healthcare (028 PE manager teaching)
	Greater appreciation of PE for planning and improvement	I think its increased awareness around patient engagement in staff. We believe strongly enough in this process that we take the feedback that they give us which is very valuable and staff can see that. So I think it increased awareness of how important it really is (027 PE manager <100)
	Increased openness or willingness to engage patients	Now, everybody's mad if the patient isn't at the committee. They're, like, where's the patient? Can we have the meeting without them? (001 PE manager <100)

# Summary of Key Findings

**Table 6. Impacts of PE on hospital, patient/family and clinician/staff outcomes**

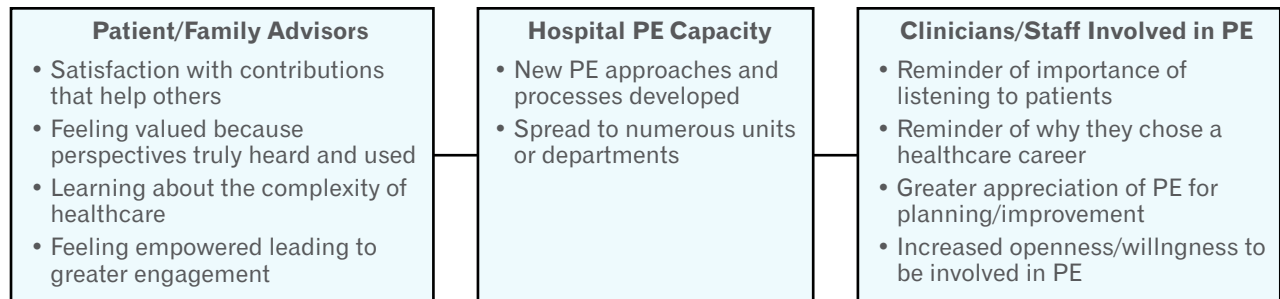
Category	Theme	Exemplar quotes
<b>Hospital structures and resources</b>	New or improved hospital policies and strategic plans	We've also engaged patient and family feedback...to build our quality improvement plan every year (032 corporate executive 100+)
	New or improved facilities, programs and services	I think the impact was that people actually did get healthier food (003 patient/family teaching) For sure there was a lot more consistency in terms of the services that were provided and the level of service as well as the kind of service provided (021 clinician 100+)
	Resources for patients/family	We have seen a significant improvement in the clarity of the consent letters that our patients are being asked to sign to be part of a research project (017 patient/family 100+)
<b>Clinician or staff functions and processes</b>	Greater work enjoyment	We found that charge nurses and nursing staff were able to achieve a bit more joy in their work (024 PE manager 100+)
	Satisfaction with new or improved facilities, programs or services	Increased [staff] satisfaction that patients are having somebody to engage with versus just in their rooms when they're attending with other patients (037 clinician <100)
	Greater ease in fulfilling job requirements	It makes their [staff] job easier (013 patient/family 100+)
	Greater efficiency in healthcare delivery	So the staff would say that it's a more efficient way to do their care and that they are getting just as good outcomes with this change in model (025 clinician 100+)
	Greater confidence in information for patients	They [staff] also feel more confident in the information that they're giving to patients and families, and there would be an increased understanding (027 PE manager <100)
	Improved patient-staff communication	We also surveyed both doctors and nurses. There was a substantial improvement in the efficiency and quality of communication with patients (012 clinician teaching)
<b>Patient experience</b>	Reassurance that hospital addresses what matters to patients	Patients knew that staff at the hospital were listening to what really mattered to them (015 patient/family teaching)
	Increased satisfaction with facilities, programs and services	So the patient satisfaction increased greatly from this [post-discharge follow-up program] (031 clinician 100+)
	Improved healthcare experience	Patients would say that their experiences are better following the changes that were made (025 clinician 100+)
	Greater understanding of hospital instructions (due to new/improved resources)	So I think it [patient admission handbook] had a significant impact on patient admission as far as preparation and simplifying the process somewhat for the hospital (023 patient/family 100+)
<b>Patient outcomes</b>	Decreased wait times	There's been a significant reduction in the number of wait time hours between the Emergency Department to in-patient units (011 PE manager 100+)
	Decreased falls	We did see a decrease in falls (037 clinician <100)
	Decreased readmissions	We also saw a reduction in patient readmission rates (021 clinician 100+)
	Increased quality and safety of care	They're rolling out elements of the model of care unit by unit and improving quality, safety, patient experience (011 PE manager 100+)

# Summary of Key Findings

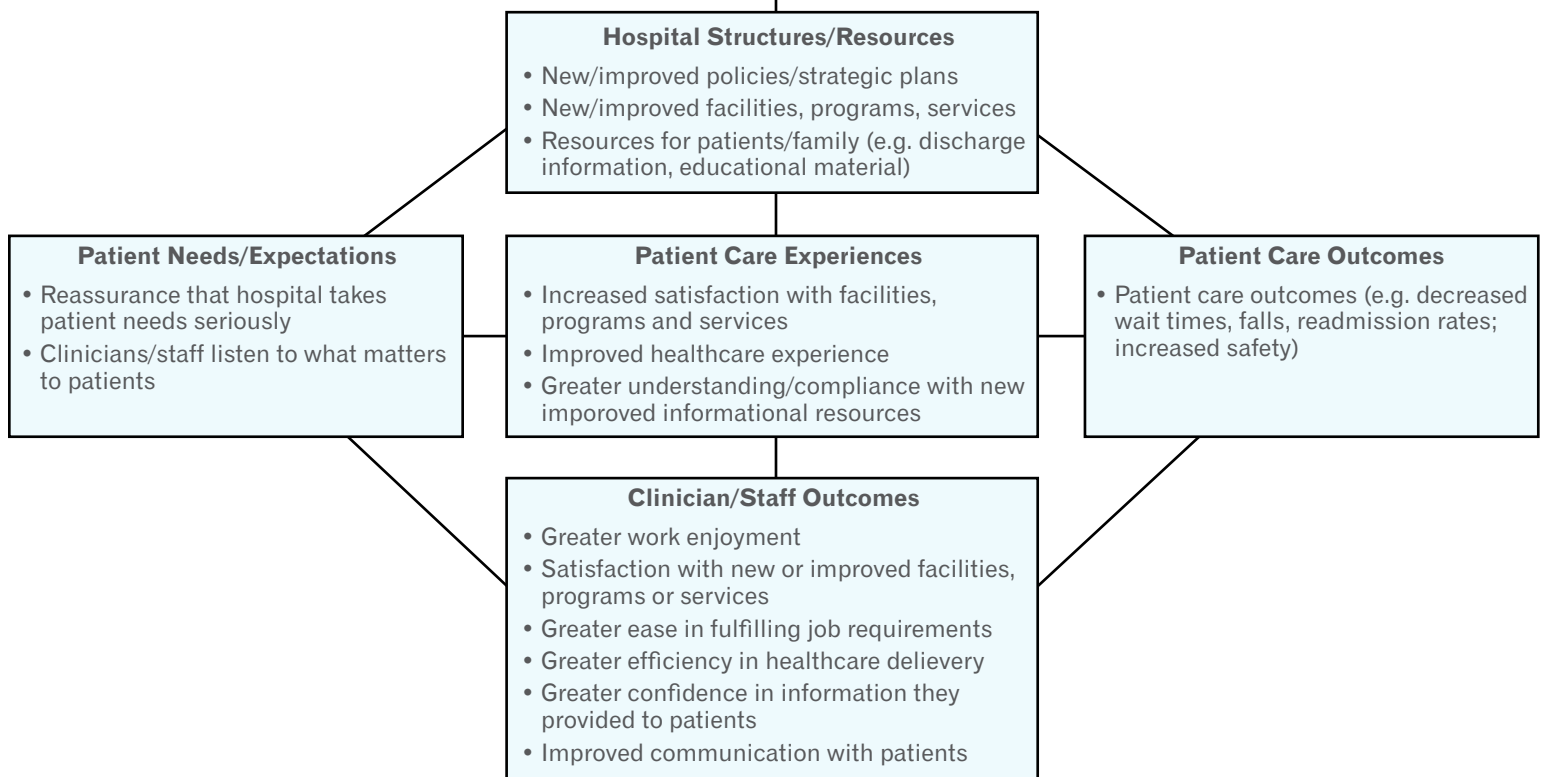
## Integrated findings

We compiled findings to create a Framework of Impacts of Patient/Family Engagement in Hospital Planning and Improvement (Figure 1). This framework can be used to assess and allocate resources to hospital PE, and can be used as the basis for ongoing research on the impacts of hospital PE and how to measure it.

### Hospital, patient/family and clinician/ staff capacity for PE capacity



### Hospital, patient/family and clinician/ staff outcomes



**Figure 1. Impacts of Patient/Family Engagement in Hospital Planning and Improvement**

## Develop and launch a new organizational strategic plan

### Representative

Patient Engagement Manager

### Engagement type

Blended

### Hospital type

Teaching

#### Engagement strategies

- A working group that included one patient/family advisor planned the design and launch of the new strategic plan
- The working group acquired feedback from hospital users by participating in several community-based festivals where users ranked healthcare priorities and shared hospital experience stories
- A third party hired by the hospital summarized findings and shared results with the working group
- The working group synthesized and interpreted feedback from the community, resulting in four broad goals/themes: improve access for vulnerable populations; use technology to improve health care; community partnerships to improve health in the region; and holistic care for the mind, body and soul
- The four themes were developed further, and initiatives were established to operationalize each theme
- The Patient/Family Advisor on the working group was involved in all levels of decision-making

#### Goal

Create and implement a corporate strategic plan

#### Timeline

12 months

#### Success Factors

- Long-standing Patient and Family Advisory Committee members were knowledgeable in their roles
- Corporate representatives established the expectation that patients/families must be included, and their voices considered in all hospital activities
- The Board requires regular updates from staff on how they are fostering patient/family-centred care and partnering with patients and families
- Dedicated staff, resources and infrastructure in place to recruit, orient, and retain Patient/Family Advisors

#### Impact

- Developed and launched a new strategic plan informed by community priorities
- New strategic plan reinforces the priorities of the hospital for patients and staff
- New strategic plan inspires staff to refresh and advance quality of work
- Initiative set a precedent and now all new clinical initiatives are designed with patient/family advisors

#### Challenges

- Staff ambassadors representing units and programs communicated with hospital staff but not Patient/Family Advisors about strategic plan launch activities
- Few Patient/Family Advisors were involved in activities to launch the strategic plan

## Develop and launch a new organizational strategic plan

### Representative

Patient/Family Advisor

### Engagement type

Blended

### Hospital type

Teaching

#### Engagement strategies

- Patient/Family Advisors were members of a strategic planning group that collaborated with staff (e.g. Vice President, Public Relations)
- A Patient/Family Advisor worked directly with four strategic plan champions who oversaw the strategy's four directions: leading, learning, building and caring
- The hospital set up booths in the main lobby to ask patients and family members for their input to help guide the contents of the new strategic plan
- The strategic planning group combined and interpreted responses from patient/family on demographics, priorities for healthcare services and research, and definitions of compassionate care
- Staff, Patient/Family Advisors and champions offered feedback to refine the strategic plan at a large group session where the draft plan was presented
- Patient/Family Advisors collaborated with managers to teach staff ambassadors about the new strategic plan through educational sessions

#### Goal

Create and implement a corporate strategic plan

#### Timeline

17 months

#### Success Factors

- Patient/Family Advisors are welcomed and encouraged to contact the quality department for assistance
- New Patient/Family Advisors were paired with seasoned Advisors for mentoring and support
- Senior staff ensured the availability of resources for community consultation activities
- Staff are committed to working with patients as partners

#### Impact

- Developed and launched a new strategic plan informed by patient and community input
- Programs throughout the hospital are now creating their own goals linked to the strategic plan
- Future policies and processes involving the strategic plan will engage patients

#### Challenges

- Limited number of Patient/Family Advisors involved in each activity associated with the new strategic plan because of their involvement in other ongoing activities
- Ensuring Patient/Family Advisors and champions kept draft plan confidential to avoid staff confusion as the plan evolved
- Keeping Patient/Family Advisors involved and engaged over a long period of time
- Staff turnover delayed the planning and launch of the new strategic plan

## Develop a new Patient Declaration of Values

### Representative

Patient/Family Advisor

### Engagement type

Blended

### Hospital type

Teaching

#### Engagement strategies

- A steering committee of 20 members, including two Patient/Family Advisors, was formed to update the Patient Declaration of Values
- The committee worked on defining patient values and describing behaviours that were associated with each value through large- and small-group discussions
- A virtual focus group was conducted with patients who described their thoughts about a preliminary draft of the Declaration. Results were then incorporated into an updated Declaration by the committee
- The committee visited multiple areas of the hospital with the updated Declaration to gather further feedback from patients and family members
- The committee summarized all feedback and made final revisions to the Declaration

#### Goal

Update the hospital's Patient Declarations of Values

#### Timeline

6 months

#### Challenges

- Meeting project deadlines
- Confidentiality when visiting patients and family members to gather feedback
- Some patients were not comfortable conversing with committee members
- Determining how to widely share the document across all areas of the hospital and incorporate diverse feedback

#### Success Factors

- Multiple strategies were employed to engage patients and family, and incorporate their views
- Staff throughout the hospital were engaged to speak with patients/family about the Declaration if they were not comfortable speaking with committee members
- Clinicians from various departments participated on the committee, and contributed considerable time and attention to the project
- The PE Manager and team organized meetings in a professional manner and dedicated an immense level of effort to the project (e.g. worked evenings and weekends to ensure success)

#### Impact

- Patient input is reflected in the new Patient Declaration of Values, providing clear guidance on what is important to patients/family, and reinforcing the hospital's commitment to excellence in patient care
- The patients who were involved in the virtual focus group and conversations with committee members felt that their needs were being taken seriously and that their input was important to the hospital
- The Declaration serves as a reference for a Patient/Family Advisor role on the Quality of Care Committee, providing a basis for the ideas and concerns brought forward

## Develop a new Patient Declaration of Values

### Representative

Patient Engagement Manager

### Engagement type

Blended

### Hospital type

Teaching

#### Engagement strategies

- Two Patient/Family Advisors sponsored the Declaration along with Vice President sponsors, acting as final decision-makers for the document
- Two Patient/Family Advisors sat on a multidisciplinary working group that developed the Declaration
- A team of 10 Patient/Family Advisors provided feedback on the Declaration throughout the development process
- A virtual focus group and a survey gathered feedback from patients on the Declaration
- Patient/Family Advisors and staff conducted one-on-one interviews with inpatients to collect information about what patients wanted from the hospital, and discuss Declaration values, behaviours, and definitions
- All groups collectively established the Declaration's values, wording and associated behaviours of care teams that would support the values

#### Goal

Develop a new Patient Declaration of Values that reflected the needs patients and families

#### Timeline

4 months

#### Challenges

- Adhering to the short timeline of the project
- Deciding how to implement the Declaration to ensure that it was appropriately supported

#### Success Factors

- The virtual patient focus group allowed for broad engagement and scope of feedback
- Working group members had key skills in deep listening and reflective listening
- The hospital has a comprehensive engagement program, a large pool of Patient/Family Advisors and sufficient resources for engagement activities
- Board- and CEO-level encouragement and culture of embracing patient engagement

#### Impact

- Patient voices are represented in the final Declaration
- The Declaration is being used as the foundation for different projects and discussions within the Quality and Safety Committee
- COVID-19 responses are informed by the Declaration (e.g. policies related to visitors, ventilator decisions)



## Develop a new Patient Declaration of Values

### Representative

Patient Engagement Manager

### Engagement type

Blended

### Hospital type

100+ beds

#### Engagement strategies

- Fifty Patient/Family Advisors worked with hospital staff and community members to plan the Declaration (e.g. Director of Quality, Safety and Patient Experience; Manager of Patient Relations, social workers, Youth and Community Advisory Council)
- Patient/Family Advisors were included on a steering committee that conducted an environmental scan of publicly available Patient Declaration of Values and contacted other hospitals to learn about Declaration methodology
- Patient and family perspectives about receiving care were captured at a World Café involving breakout discussions and post-it note activities
- Approaches such as affinity diagrams were used to establish Declaration themes, which were then refined by Patient/Family Advisors
- Declaration statements were iteratively reviewed by Patient/Family Advisors at each stage of the process

#### Goal

Develop a new Patient Declaration of Values to guide care delivery

#### Timeline

12 months

#### Challenges

- Fulfilling the hospital's commitment to ensuring that any committee, project, steering committee, new policy, procedure or protocol is done in authentic partnership with patients and family
- Iterative process required a lot of rigor contributing to a lengthy timeline

#### Success Factors

- Multiple instances of engagement in project
- Hospital has a commitment and philosophy around engaging patients and families in everything that impacts patients and families
- Patient/Family Advisors select projects to work on
- Open recruitment of Patient/Family Advisors that ensures marginalized individuals are represented
- Long-standing Patient and Family Advisory Committee members

#### Impact

- Staff and Patient/Family Advisors involved in the process felt that their voices and perspectives were heard
- The Declaration is incorporated into family guides and employee orientations
- This activity set a precedent for engaging patients/family in the development of future policies, programs or processes

## Establish priorities for quality improvement objectives

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

100+ beds

#### Engagement strategies

- A committee of 3 Patient/Family Advisors, the Chief of Staff, Vice President of Clinical Services, departmental program directors, frontline care providers and unit managers was struck to prioritize quality improvement objectives
- Patient/Family Advisors reviewed background materials prior to meetings, and posed questions and offered suggestions through discussion at meetings
- Patient/Family Advisors were responsible for reflecting on what was said by the healthcare professionals during meetings to identify whether it resonated as true and reasonable from the patient perspective
- Patient/Family Advisors assessed minutes and materials following committee meetings to determine whether the patient perspective was accurately reflected

#### Goal

Set objectives that align with the hospital's strategic direction

#### Timeline

3 months

#### Challenges

- Committee meetings were scheduled during weekdays in accordance with leadership availability, which made it difficult for Patient/Family Advisors to attend
- No reimbursement to Patient/Family Advisors for costs related to attending meetings (e.g. time off work, mileage)

#### Success Factors

- Patient/Family Advisors were recruited for the project based on familiarity and comfort with type of activity
- The hospital used best practices around engaging patients in committee work
- Committee members thoroughly introduced themselves at the table, providing information such as what their roles were and why they were there
- Executive sponsors continuously checked in with Patient/Family Advisors during meetings to see if they had any questions
- Staff received training on how to effectively engage with Patient/Family Advisors

#### Impact

- Patient/Family Advisors felt that their voices were heard in the committee, as they had equal footing with the healthcare practitioners and leaders
- Patient/Family Advisor input was reflected in final strategic direction documents
- Patient/Family Advisors felt valued and that the activity, process and product were worth their contribution

## Develop a hospital quality improvement plan

### Representative

Corporate Executive

### Engagement type

Blended

### Hospital type

100+ beds

#### Engagement strategies

- Two Patient/Family Advisors sat on a steering committee with staff (e.g. Directors, Vice President of Clinical Services) that was struck to guide the development of the quality improvement plan
- Patient/Family Advisors gathered information and feedback from Patient/Family Advisors on various corporate and program committees
- Patient/Family Advisors informally interviewed patients and family representing various hospital areas to elicit ideas on where improvements could be made
- Patient/Family Advisors presented the findings to the steering committee and participated in prioritizing quality improvement recommendations

#### Goal

Create and implement a new hospital quality improvement plan

#### Timeline

4 months

#### Challenges

- Patient/Family Advisors were passionate about a variety of areas which sometimes required bringing them back into scope of steering committee aims
- Quality improvement plan implementation was halted due to COVID-19

#### Success Factors

- Patient/Family Advisors provided strong insight based on corporate- and program-level strategies
- Patient/Family Advisors were voting members of the steering committee
- Robust engagement process and active committees
- The roles and responsibilities of Patient/Family Advisors were clearly outlined at the outset of their participation
- Hospital staff acknowledged and expressed how much they valued Patient/Family Advisor members
- Hospital engages Patient/Family Advisors as early as possible in activities

#### Impact

- Patient/Family Advisor voices were represented in the final quality improvement plan recommendations
- Patient/Family Advisors felt valued, resulting in the desire to continue seeking engagement opportunities

## Evaluate post-discharge telephone calls for high-risk patients

## Representative

Clinician

## Engagement type

Consultation

## Hospital type

100+ beds

**Engagement strategies**

- A nurse conducts post-discharge telephone calls with all patients who were admitted with a high-risk diagnosis (e.g. pneumonia, hip fracture, surgery)
- During the telephone call, patients are asked about their hospital stay, how they are feeling after discharge, knowledge of post-discharge plans, and ability to integrate at home or in the community
- Positive and negative feedback is collated and shared monthly with the medicine and surgical programs so that they can refine inpatient care and discharge processes

**Goal**

Carry out post-discharge contact program to gather feedback that can be used to improve inpatient care and discharge processes

**Timeline**

Ongoing (as of August 2021)

**Challenges**

- Language barriers during calls, which were overcome by using live interpreters
- Blinded hospital numbers resulted in a low proportion of patients answering calls, but as a solution the hospital installed a separate phone line that identified the hospital when calling
- Recognizing the emotional effort demanded of patients when asked for feedback about hospital experiences

**Success Factors**

- Empathetic, non-judgmental and intuitive staff who welcome patients sharing their experiences, making patients feel heard and supported
- Alternative survey scripts were developed for sensitive situations (e.g. palliative status)
- Hospital created a position dedicated to conducting the post-discharge contact program
- The nurse who conducted the calls was able to connect patients with various services throughout the healthcare system to support post-discharge well-being

**Impact**

- Decreased patient readmissions and enhanced patient recovery
- Perceived increase in patient satisfaction with discharge process and subsequent support
- Success of post-discharge contact program established a precedent, and the hospital now plans to spread the post-discharge follow-up program to additional patient groups

## Evaluate daily post-discharge telephone follow-up

## Representative

Patient/Family Advisor

## Engagement type

Consultation

## Hospital type

100+ beds

**Engagement strategies**

- A small working group developed the interview questions regarding quality of care (i.e., length of time before admission, meal ratings, care received from hospital staff) (working group did not have patient representatives)
- The Patient and Family Advisory Committee (PFAC) was consulted about the interview questions for scope and appropriateness, and offered feedback to the working group
- Four to five Patient/Family Advisors conducted the interviews within 72 hours of discharge and recorded patient responses verbatim on a survey form
- Patient/Family Advisors are included in hospital quarterly meetings where patient satisfaction is addressed based on collected survey forms

**Goal**

Gauge patient satisfaction with hospital experience

**Timeline**

8 months

**Challenges**

- Acquiring post-discharge telephone interview participation from patients who had upsetting or tough hospital experiences

**Success Factors**

- The phone surveys provided a quick and easy way to gather patient feedback
- Patients were offered alternative times/dates to complete their post-discharge telephone interviews to suit their schedules
- Patient/Family Advisors conducting interviews were flexible and skilled in ability to ask questions in alternative ways to ensure rich feedback

**Impact**

- Patients/families were better equipped to provide feedback from home on the phone after discharge rather than in-hospital
- The post-discharge interviews made patients/families feel heard by their hospital
- The hospital staff who were mentioned in post-discharge interviews received individualized feedback which created an opportunity for them to learn and validated their efforts
- The post-discharge interviews are being expanded and modified for different units that cover sensitive and intimate matters (i.e., mental health units)
- Interview results offered the hospital important information about what needs to be improved upon

## Implement and evaluate an elder-life program

## Representative

Clinician

## Engagement type

Consultation

## Hospital type

&lt;100 beds

**Engagement strategies**

- Nurse manager, Staff Development Coordinator, Patient and Family Centred Care Committee and Patient and Family Advisory Committee (PFAC) worked together to implement and evaluate the hospital's elder-life program
- Select Patient/Family Advisors assisted in planning how to implement the program, and gathered feedback from the entire PFAC to refine that plan
- Nearly 100 patient/family users of the program were surveyed by the Patient and Family Centred Care Committee about their satisfaction with the program's activities and impact
- Survey results were shared with the PFAC and the hospital Board to monitor the elder-life program's implementation, effectiveness and impact

**Goal**

Improve the quality of care for elder patients on multiple units (e.g. medical, surgical, therapy-intensive)

**Timeline**

3 months (evaluation ongoing)

**Challenges**

- Abiding by and having patience with the length of time required for the project
- Staff and volunteers involved in patient engagement activities work on a part-time basis, which limits the amount of time available to carry out activities

**Success Factors**

- High response rate on elder program patient/family user survey
- The roles and responsibilities of all committee members and collaborating staff were well-established prior to engagement
- The policies and procedures relating to the project were well-defined prior to engagement
- Staff members involved in the project had highly-developed communication skills

**Impact**

- Perceived increase in patient satisfaction with their hospital stay
- Perceived increase in staff satisfaction with patient care
- Patient/Family Advisors and patient/family participants wanted to be engaged again in the same program or future activities

## Evaluate a team-based patient transfer approach

## Representative

Patient/Family Advisor

## Engagement type

Consultation

## Hospital type

100+ beds

**Engagement strategies**

- The hospital reorganized a team-based patient transfer approach to reduce the time between patient admission and ultimate destination
- A Patient/Family Advisor conducted nearly 100 telephone surveys with recently discharged patients, and successfully advocated for allowing family members to complete the survey if the patient was unable to do so
- The Patient/Family Advisor recorded survey responses and submitted forms to unit managers and quality improvement staff who were leading the initiative
- The Patient/Family Advisor also shared comments made by patients/family during survey telephone calls with project leads

**Goal**

Assess patient/family perspectives on a new team-based transfer approach that aimed to reduce wait time from patient admission to final destination

**Timeline**

12 months

**Challenges**

- Resources (e.g. survey forms) for the Patient/Family Advisor were not always available due to communication errors between staff and project leads
- Ensuring patient privacy while conducting telephone surveys
- The Patient/Family Advisor was not made aware of whether/how survey data was used to refine the new transfer approach

**Success Factors**

- The telephone surveys offered immediate feedback to allow just-in-time improvement to the transfer approach
- Good communication between the Patient/Family Advisor and patient/family survey respondents, who were receptive to answering the survey questions
- Patient confidentiality was secure as the Patient/Family Advisor completed the telephone surveys instead of staff who could potentially identify the respondent

**Impact**

- Given successful conduct of telephone surveys by a Patient/Family Advisor, the same approach is being used in the next step of the hospital's improvement plan
- Survey responses helped monitor the value and impact of the new team-based patient transfer approach
- Patient/family survey respondents appreciated being asked for input about their experiences



## Design a hospital-wide program to improve timeliness of care

### Representative

Patient Engagement Manager

### Engagement type

Blended

### Hospital type

100+ beds

#### Engagement strategies

- Patient/Family Advisors sat on a steering committee that coordinated program design and launch
- The Patient and Family Advisory Committee (PFAC) worked on various parts of the program such as creating discharge summaries, and advising on a collaborative care model and rounding changes
- Patient Relations cases related to the new program were reviewed by the steering committee and used to enhance program design
- The CEO, Chief Communications Officer and program champion, met with the PFAC and a community advisory panel on several occasions to present program data, discuss concerns, and incorporate their feedback in program design and launch plans
- A nursing executive and Patient/Family Advisors conducted monthly rounds on units where the new program was rolled out to ask inpatients about the timeliness of their care, and further refined the program

#### Goal

Move patients through the hospital in a timely, safe and patient-centered way

#### Timeline

17 months

#### Challenges

- Patient/Family Advisor pace slowed down program progress
- Hospital's ability to offer adequate time and resources to effectively recruit and form relationships with Patient/Family Advisors

#### Success Factors

- Patient/Family Advisors could choose which program activity to work on based on interests and suitability
- The hospital's strategic plan mandates partnering with patients and families in each phase of a project or initiative
- Hospital staff who typically lead or participate in patient engagement activities were invited to an event to learn about being an effective leader in patient engagement
- Good working relationships between Patient/Family Advisors, the PE manager and other staff

#### Impact

- New model of care reflects patient/family input, preferences and decisions
- Significant reductions in patient wait times in the emergency department
- Perceived increase in Patient/Family Advisors feeling valued by the hospital

## Integrate internal medicine staff in multiple hospital units

### Representative

Patient/Family Advisor

### Engagement type

Blended

### Hospital type

Teaching

#### Engagement strategies

- The General Internal Medicine (GIM) program developed the program; the GIM Quality Council refined and implemented the program
- A patient representative was a member of the GIM Quality Council and played a key role in designing and implementing the program
- The patient representative relayed information from Council meetings to the Patient and Family Advisory Committee (PFAC) and elicited PFAC feedback
- The patient representative conversed with patients/families from various hospital units to gather additional input on the program
- The patient representative evaluated the program by interviewing 10 to 12 patients from different units about how comfortable they felt with the new staff and whether they were being listened to

#### Goal

Place teams from the General Internal Medicine program into specific units to become more accessible to patients/families

#### Timeline

24 months

#### Challenges

- Maintenance of a good working relationship between patients and staff while patients voiced problems they encountered
- Staff were initially nervous about including a patient on the Quality Council marked by perceived initial tension between staff and the patient

#### Success Factors

- Management and staff were committed to working with patients as partners
- Project progress and patient input were discussed at each PFAC and Quality Council meeting to ensure patient feedback was being used
- No perceived sense of hierarchy existed between staff and patient representatives
- The hospital strives to be a leader in patient engagement and co-design

#### Impact

- Enhanced communication between medical staff and allied health professionals, leading to improved working relationships
- Increase in patient access to medical staff and allied health professionals
- Staff are spending less time traveling between patients, increasing the time and resources spent on patients
- Perceived reduction in staff frustration because they became more familiar with the units in which they were integrated

## Develop and implement daily patient experience rounding

### Representative

Patient Engagement Manager

### Engagement type

Blended

### Hospital type

100+ beds

#### Engagement strategies

- The initiative was driven by Patient and Family Advisory Council (PFAC)
- The PFAC analyzed patient experience feedback from surveys and post-discharge telephone calls to develop a quality improvement plan
- The themes the PFAC uncovered were focused on improving communication with patients and families
- The PFAC identified best practices for patient communication to develop daily patient experience rounding questions
- The PFAC created a survey to gather feedback from patients/families involved in rounding to refine the rounding questions and process
- Changes made to rounding questions in specific units were brought back to the PFAC for further input and approval

#### Goal

Gather information on inpatient care experiences

#### Timeline

3 months

#### Challenges

- Daily rounding had big implications for managers' and charge nurses' daily work-flow
- Recruiting system-level thinkers to be a part of steering committee-level work

#### Success Factors

- Data from patient surveys and post-discharge telephone calls helped guide the development of rounding questions
- PFAC involvement validated and elaborated on findings with the greatest potential to improve rounding
- Unit-level surveys identified rounding issues that could immediately be addressed and improved
- Detailed corporate and unit-level patient feedback results were shared with managers and charge nurses who would be impacted by change to create buy-in
- Staff were given latitude regarding when they could complete the rounding to best suit their schedules

#### Impact

- Rounding was implemented on five inpatient units, increasing two-way conversations and shared decision-making between clinicians and patients/family
- By directly asking rounding questions, issues are identified and flagged well before becoming problematic
- Perceived increase in staff satisfaction due to positive feedback and enhanced inpatient experiences

## Develop a bundled care program for hip/knee replacement

### Representative

Clinician

### Engagement type

Collaboration

### Hospital type

100+ beds

#### Engagement strategies

- A steering committee including Patient/Family Advisors was established to identify gaps and best practices, and oversee program development
- Patient/Family Advisors were active participants in meetings where program components were discussed and decisions were made
- To inform the program, a nurse followed six patients and family across their continuum of care journey to observe the current pathway, during which patients documented their experiences, identified issues that could be improved and noted strategies that worked well
- Those findings were used to create a patient experience map, which was shared with the six patients/family to ensure details were accurately captured
- The patient experience map was further analyzed at steering committee meetings to guide discussion and refine the program

#### Goal

To improve the continuum of care for patients undergoing hip or knee replacement

#### Timeline

6 months

#### Challenges

- Little funding in hospital budget to support patient engagement in hospital planning and improvement
- No resources available to conduct a post-implementation evaluation of the program

#### Success Factors

- Use of resources in creative ways compensated for lack of funding (e.g. nurse on modified duties enabled pilot prioritization and ability to carry out process in depth)
- Nurse did not influence patient/family responses
- Support in principle from executives to incorporate patient experiences in all hospital activities
- Hospital appointed a coordinator of patient engagement

#### Impact

- Implementation of a bundled care program improved continuity of care for patients and family
- Perceived increase in patient satisfaction and in efficiency of care delivery by staff
- The six patients/family who were followed felt valued because the hospital cared about their experiences

## Plan COVID-19 screening communication and processes

### Representative

Patient Engagement Manager

### Engagement type

Blended

### Hospital type

100+ beds

#### Engagement strategies

- A hospital Director championed the initiative and created a task force action group that include two Patient/Family Advisors and diverse staff
- Patient/Family Advisors helped make decisions on communication about screening, the no-visitor policy, space layout and patient flow
- Patient/Family Advisors provided feedback virtually about their experiences with the new screening communication and processes
- Pop-up patient experience surveys were conducted with visitors who were allowed into the building to elicit feedback about the screening strategy

#### Goal

Plan how to screen people for COVID-19 when entering the hospital

#### Timeline

18 months

#### Challenges

- Achieving patient/family engagement in rapidly-evolving circumstances
- Given the need for virtual meetings, Patient/Family Advisors must be familiar with technology (e.g. Microsoft Teams)
- Given need for familiarity with technology, ensuring equity and diversity of the participating Patient/Family Advisors

#### Success Factors

- The pop-up patient experience surveys allowed for immediate feedback, which enabled rapid improvement in screening communication and processes
- Patient/Family Advisors were recognized as team partners, and their input and feedback was prioritized at the same level as other task force members
- Staff were willing to participate in the patient engagement activity in addition to their regular work responsibilities

#### Impact

- Patient/family input is reflected in COVID-19 screening communication and processes
- Patient feedback encouraged staff to ramp up virtual visits as a solution to the no-visitor policy
- Feedback from patients has helped screeners to understand the diverse needs of hospital users, enhancing their patience and empathy in managing issues related to screening individuals
- Patient input has helped staff understand what is expected of them, while also preparing them to better understand the needs of people coming into the hospital

## Re-design staff/volunteer identification badges

## Representative

Patient/Family Advisor

## Engagement type

Consultation

## Hospital type

&lt;100 beds

**Engagement strategies**

- Patient/Family Advisor experienced visual challenges reading names on identification badges due to font size and badge location; as a result, they conceived the plan to improve badges
- The Patient/Family Advisor raised the issue at a Patient and Family Advisory Committee (PFAC) meeting and proposed a solution: reducing the size of the staff/volunteer photo to allow increasing font size of their name
- The Vice President of Patient Relations shared the proposal with the Board, which gathered input from staff on the proposed badge changes
- The Board proceeded to oversee modification of identification badges

**Goal**

Support better visibility and identification of staff and volunteers by patients

**Timeline**

3 months

**Challenges**

- Budget concerns regarding the cost of updating the badges
- Staff and volunteers had time constraints for badge photos and pick-up due to competing priorities

**Success Factors**

- The PFAC and staff are committed to continually identifying areas where improvements can be made
- PFAC meeting minutes are shared with staff by posting on information boards throughout the hospital
- PFAC members receive agendas outlining activities taking place throughout the hospital
- PFAC members are dedicated to being on the committee, and are willing to speak up or raise concerns

**Impact**

- As a result of suggestions by the Patient/Family Advisor, the hospital designed and implemented new staff/volunteer identification badges
- Patients are better able to read the names on badges, and address staff and volunteers using their names
- Perceived improvement in patient experiences and satisfaction

## Provide access to care plans in online patient profiles

### Representative

Patient Engagement Manager

### Engagement type

Consultation

### Hospital type

100+ beds

#### Engagement strategies

- A patient experience specialist, charge nurse, patient flow representative and information technology employee championed the initiative
- A Patient/Family Advisor conducted a formal presentation to departmental supervisors on the importance of accessible care plans
- The Patient/Family Advisor worked with the patient experience specialist to develop and practice their speech for the presentation
- The Patient/Family Advisor discussed the project with other Advisors during a Patient and Family Advisory Committee meeting
- Following the Patient/Family Advisor presentation, departmental supervisors discussed how the information system could be changed
- Following the meeting of departmental supervisors, a committee was formed to develop a strategy for making care plans available to patients

#### Goal

Enhance healthcare provider decision-making and improve patient care

#### Timeline

2 months

#### Challenges

- Technical difficulties moving the patient care plans onto the online patient profile system
- Patient/Family Advisor was not a member of the committee formed to plan the initiative, limiting ability to continue providing input

#### Success Factors

- Patient/Family Advisors are very invested in seeing their hospital improve
- Staff are committed to engaging patients, and are very welcoming and respectful
- Staff welcome new activities that will help make the hospital better

#### Impact

- Patient care plans were moved to the online patient profiles for easier access by staff and patients
- The Patient/Family Advisor recognized how important patient storytelling can be for motivating staff to improve care
- Perceived increase in staff efficiency when managing patients with care plans



## Develop policy and processes for a new stroke unit

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

Teaching

#### Engagement strategies

- The hospital established a working group including a Patient/Family Advisor, clinicians and managers to develop policy for a new stroke unit
- The Patient/Family Advisor participated in the working group's monthly meetings
- The Patient/Family Advisor was regularly asked questions about policy and processes, and their feedback was integrated in decisions made at meetings
- The working group created materials for the new stroke unit, and asked the Patient/Family Advisor to review and draw attention to sections that were unclear or contained medical terminology that might confuse patients

#### Goal

Develop policy for a new stroke unit

#### Timeline

12 months

#### Challenges

- Patient/Family Advisor needed to get up to speed with medical terminology quickly to avoid slowing down the process
- Making decisions about the allocation of resources for the new stroke unit while being cautious of the hospital's overall limited resources (e.g. beds, personnel)

#### Success Factors

- The Patient/Family Advisor's prior experience was a benefit to the working group
- Working group members took time to explain medical terms and procedures to the Patient/Family Advisor
- All members of the working group were accepting of the Patient/Family Advisor's input and perspectives
- Clinicians were willing to join the working group and train for roles within the unit once implemented

#### Impact

- Resources were redistributed to implement the new stroke unit, establishing a high level of expertise and fostering a sense of ownership within the unit
- Treatment protocols and patient-oriented discharge summaries were developed
- Since implementation, the length of stay for acute stroke patients has been reduced and patient satisfaction has improved

## Develop a proposal for an Ontario Health Team system

### Representative

Clinician

### Engagement type

Blended

### Hospital type

100+ beds

#### Engagement strategies

- Six working groups were struck to identify what constitutes an ideal Ontario Health Team system
- One of the six working group committees specifically focused on community engagement to obtain patient/family ideas of what constitutes a good system
- 30 Patient/Family Advisors were invited to working group meetings to collaborate in planning with diverse hospital staff
- A Patient/Family Advisor co-chaired the community engagement working group, working closely with the chief nursing executive to develop a terms of reference, organize meetings by setting agendas and taking minutes, and assemble information between meetings
- Documents were created based on feedback from working groups, and were shared with Patient/Family Advisors for review and approval
- Patient/Family Advisors provided information about Ontario Health Teams that was included on forms submitted to the Ministry of Health
- Community members were surveyed about the characteristics of an ideal Ontario Health Team system

#### Goal

Develop a proposal for an Ontario Health Team system

#### Timeline

12 months

#### Challenges

- Considerable time commitment was required from Patient/Family Advisors for many meetings
- Transportation needs for Patient/Family Advisors to attend meetings

#### Success Factors

- Patient/Family Advisors reviewed the final application before submission to the Ministry of Health to ensure their perspectives were integrated
- Working group activities and materials were shared by email with Patient/Family Advisors who could not attend meetings, and they were able to participate in meetings by teleconference
- Sense of trust between staff and Patient/Family Advisors

#### Impact

- Patient/Family Advisors better understand the healthcare system, what they want from it and their roles as Advisors in the hospital
- Patient/Family Advisors and community members who were engaged felt empowered
- Patient/Family Advisors became more engaged as they continued participating in working groups because they became comfortable in working with staff

## Implement mental health care pathways for oncology patients

### Representative

Corporate Executive

### Engagement type

Collaboration

### Hospital type

Teaching

#### Engagement strategies

- The regional program director championed the project to improve the oncology outpatient mental health care pathway and acted as the executive sponsor
- A working group was struck to including a project manager, a clinical manager and social workers
- The working group partnered with the Patient and Family Advisory Committee (PFAC) to recruit two Patient/Family Advisors
- During working group meetings, the Patient/Family Advisors helped to formulate terms of reference, identify the limitations of existing oncology services, establish optimal wait times, and develop patient-facing tools and surveys
- The Patient/Family Advisors functioned as equal partners to working group members and took part in all decisions

#### Goal

Develop pathways to link patients with mental health practitioners outside of the regional cancer program

#### Timeline

36 months

#### Challenges

- Project time-constraints limited the hospital's ability to evaluate project outcomes and share findings with patients who were involved in the process
- Recruiting diverse Patient/Family Advisors to represent a range of experiences and preferences

#### Success Factors

- Patient/Family Advisors actively participated and shared their experiences to raise staff/clinician awareness of limitations in current services
- Patient/Family Advisors were involved from the outset of the project
- The program director ensured that the Patient/Family Advisors actively participated during meetings and that their voices were heard by working group members
- Patient/Family Advisors undergo training to prepare them to contribute to patient engagement activities

#### Impact

- The new oncology outpatient mental health care pathways are partially implemented in the hospital
- Patient/Family Advisors learned about and developed an appreciation for the complexity of the healthcare system after being engaged in this activity

## Design and implement a staff introduction/interaction protocol

### Representative

Clinician

### Engagement type

Consultation

### Hospital type

<100 beds

#### Engagement strategies

- Staff, patients/family and Patient/Family Advisors prioritized staff identification as a desired patient-/family-centered approach
- Patients from various units offered input on what the staff introductions and interactions should consist of through surveys and bedside conversations
- The lead nurse of the initiative synthesized and interpreted patient feedback, resulting in an introduction/interaction protocol and instructional video
- Patients volunteered to be actors in the video alongside staff
- The video was shared with staff and patients in the hospital cafeteria and on the hospital web site

#### Goal

Enhance communication and establish trusting relationships between staff, patients and family members

#### Timeline

24 months

#### Challenges

- Competing responsibilities among staff limited buy-in for this initiative
- Focus on standard procedures can overlook the long-term benefits of engaging patients in initiatives like this

#### Success Factors

- Patients are eager to provide input about what goes on in their hospital
- Patient input is encouraged by staff and management
- Best practice champions for person- and family-centered care support ongoing patient engagement activities
- Efforts are made to disseminate information about patient engagement initiatives to all hospital staff

#### Impact

- Staff introduction and interaction protocol reflected patient input and preferences
- Staff have adopted the introduction/interaction strategy into daily routines
- A positive shift in the culture and atmosphere of the hospital as a whole, resulting in greater sense of collaboration and cooperation between patients and staff
- This initiative set a precedent for engaging patients in policy and process planning throughout the hospital

## Design and implement personalized meal plans

## Representative

Patient/Family Advisor

## Engagement type

Collaboration

## Hospital type

&lt;100 beds

**Engagement strategies**

- A recreologist consulted with inpatients on the hospital's continuing care unit over a four-month period of time to review existing meal plans and generate recommendations for an improved menu
- The hospital inpatients council and the Patient and Family Advisory Committee (PFAC) reviewed recommendations and created an implementation plan
- A nurse manager worked with continuing care inpatients and the PFAC to implement personalized meal plans

**Goal**

Reduce late-night hunger and personalize meals to individual preferences

**Timeline**

18 months

**Challenges**

- Staff turnover delayed implementation of new meal plans
- Additional resources and staff were required to execute desired change

**Success Factors**

- Executive-level support to make changes that will address patient/family needs and benefit the greatest number of patients
- Motivated management and healthcare workers who promote open communication, and consider all views and preferences

**Impact**

- The design of the personalized meal plan reflects patient input and preferences
- The new meal plans included options for smaller lunches and larger dinners, and dinners could be delivered at a later time to prevent late-night hunger
- Daily interaction between patients and dietary staff to jointly personalize meal plans
- Perceived increase in patient satisfaction with new meal plan options

## Develop and launch a healthier food initiative

## Representative

Patient/Family Advisor

## Engagement type

Collaboration

## Hospital type

Teaching

**Engagement strategies**

- A healthy eating committee was established including two Patient/Family Advisors, dietitians and other staff
- During meetings, the two Patient/Family Advisors were asked to provide feedback on healthy eating policies, how to implement them, and plans for a launch event
- The two Patient/Family Advisors responded to emails in between meetings to provide further feedback and help make decisions about the content and format of informational materials associated with the initiative
- The healthy eating committee presented the healthy eating initiative to the Patient and Family Advisory Committee and elicited their feedback

**Goal**

Provide patients, visitors and staff with healthier food options

**Timeline**

6 months

**Challenges**

- The two Patient/Family Advisors were required to learn about hospital processes (e.g. how the cafeteria worked)
- Acceptance of new food options, and associated patient, visitor and staff impressions of convenience and price
- The initiative had not been attempted before so there were no supporting documents or policies upon which to base the strategy

**Success Factors**

- Staff recognize the importance of engaging Patient/Family Advisors throughout the hospital, and respecting and listening to their ideas
- Patient/Family Advisors are given background information and supporting materials prior to meetings so that they can understand project topics and contribute to decision-making
- Staff update Patient/Family Advisors of any changes or improvements resulting from projects, validating their time and contributions

**Impact**

- Improved policies and services in hospital (e.g. healthier food options)
- Patient/Family Advisors better understand the complexity of the healthcare system and became advocates of the hospital in their communities

## Design neonatal intensive care unit communication boards

### Representative

Clinician

### Engagement type

Consultation

### Hospital type

Teaching

#### Engagement strategies

- The Quality Council initiated the idea of communication boards
- Managers, physicians and an educator led the initiative to design the communication board
- Parents of babies in the neonatal intensive care unit were consulted in-person and by email for ideas about what should go on the board and how parents should be involved in adding information to the board

#### Goal

Enhance communication between parents and hospital staff

#### Timeline

6 months

#### Challenges

- Recruiting parents with babies in the special care unit had competing priorities
- Staff time constraints to consults with parents and design the board

#### Success Factors

- Flexible communication styles between staff and parents
- The Board mandates patient engagement in all improvement work within the hospital
- Healthcare workers are committed to working with patients as partners

#### Impact

- Communication board design reflects patient/family input and preferences
- Perceived increase in staff appreciation of the importance of engaging patients in improvement activities

## Design and implement communication boards in medicine units

## Representative

Clinician

## Engagement type

Blended

## Hospital type

Teaching

**Engagement strategies**

- Patient/Family Advisors identified the need for enhanced communication and recommended the use of communication boards
- Staff engaged patients on the Patient and Family Advisory Committee (PFAC) and on the General Medicine Quality Committee in determining what information should go on the boards and how it should be organized so that boards were user-friendly for both patients and family members
- A prototype board was created and pilot-tested on a General Internal Medicine unit where patients and family members provided feedback to a unit clerk, who compiled and shared feedback with the PFAC and Quality Committee
- The PFAC and Quality Committee members also gathered input from physicians, nurses and other staff to further refine board design

**Goal**

Create an open channel of communication between patients and their families with hospital staff

**Timeline**

6 months

**Challenges**

- Allocating sufficient resources to collect data/ feedback (e.g. staff, time and money)
- Securing adequate representation of frontline nurses throughout board design and implementation phases

**Success Factors**

- Patient/Family Advisors were extremely committed throughout the process
- The hospital prioritizes patient engagement in all planning and improvement activities
- Patients who sit on committees are made to feel that they are valued and that their opinions will be heard
- Clinicians believed that better communication leads to better outcomes and patient flow, and recognized that patients want to hear from their doctors
- 200 diverse patients and families provided feedback on the prototype board

**Impact**

- Final product reflected patient and family member input, and was implemented on all medicine wards
- Perceived improved patient satisfaction
- Surveys of physicians and nurses identified increased efficiency and quality of communication
- Clinicians gained a better sense of what patients and family members want to know about their health



## Design and implement communication boards in patient rooms

### Representative

Clinician

### Engagement type

Blended

### Hospital type

<100 beds

#### Engagement strategies

- Nurse champions drafted a preliminary communication board template
- The Patient and Family Advisory Committee refined board format design
- The nurse manager coordinating the project consulted inpatients with diverse characteristics about communication board format and content, optimal placement in the room, and how it could support communication between patients/family and staff
- Family members provided feedback if patients were unable to do so due to cognitive limitations

#### Goal

Improve communication between patients/family and staff

#### Timeline

12 months

#### Challenges

- Physical space limitations in some inpatient rooms for boards
- Not possible to accommodate all preferences of the large number of inpatients/family members who were consulted (instead, an area of the board was left blank for tailored communication)

#### Success Factors

- Support from senior management for the project
- Financial support to purchase and mount boards
- Many nurse champions volunteered to participate in the project
- Physicians were also involved and supportive
- Enthusiastic staff who conducted planning outside of working hours to achieve goals

#### Impact

- Communication board design reflected patient/family preferences and was implemented throughout the hospital
- Relationships between involved staff were strengthened
- Perceived increase in patient satisfaction and confidence as a result of being better informed and feeling engaged in their care
- Perceived increase in collaboration for care between patients/family and staff
- Perceived reduction in patient bell-ringing, enabling more efficient use of time by staff

## Design a new way-finding system

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

100+ beds

#### Engagement strategies

- The Patient and Family Advisory Committee (PFAC) collaborated with a consulting firm and patient engagement manager to develop a preliminary way-finding design
- The consulting firm attended two PFAC virtual meetings and presented way-finding approaches and the preliminary model
- At the initial meeting, 25 PFAC members formed small groups to identify way-finding challenges in the hospital based on their own experiences
- PFAC members also reviewed photos of current directional signs to identify flaws and inconsistencies, and offered solutions
- At the second meeting, PFAC members reviewed the way-finding design based on the input they provided at the first meeting, and suggested further refinements

#### Goal

Reduce stress and improve the patient/family experience when navigating through the hospital

#### Timeline

2 months

#### Challenges

- PFAC members were required to learn how to use applications to participate in virtual meetings, which was difficult for some
- PFAC attendance at meetings could sometimes be limited due to competing priorities (e.g. family, jobs)

#### Success Factors

- The PFAC was composed of individuals with a range of experiences in diverse hospital units and programs, allowing for thorough insight on navigation
- The roles and responsibilities of the PFAC members were understood by everyone involved
- The PE manager was skilled in facilitating patient engagement virtually
- Patient/Family Advisors had an open and trusting relationship with the PE manager

#### Impact

- Patient/Family Advisors learned from one another in meetings about healthcare challenges, fostering empathy and a good working relationship based on those stories of lived experiences
- Patient/Family Advisors gained a better understanding of the hospital, hospital programs, staff, and how to help improve the system
- Patient/Family Advisors gained skills on how to optimize communication when engaging in projects

## Design a new way-finding system

### Representative

Patient/Family Advisor

### Engagement type

Blended

### Hospital type

100+ beds

#### Engagement strategies

- A steering committee was formed including directors, clinicians from various departments and two Patient/Family Advisors
- A consulting company with previous experience in similar initiatives worked with the steering committee via monthly meetings
- The consulting company walked the committee through the hospital to learn about the current way-finding system, during which committee members flagged problem areas on floor-by-floor diagrams with stickers
- The consulting company surveyed and interviewed a larger group of hospital patients to gather additional information on way-finding problems, and shared that information with the committee
- The consulting group presented a range of solutions to the committee, who discussed the options and finalized decisions

#### Goal

Help patients and families easily navigate through the hospital

#### Timeline

6 months

#### Challenges

- Ensuring Patient/Family Advisors provide input based on their patient/family experiences and perspectives
- Achieving diverse representation from Patient/Family Advisors, staff and clinicians

#### Success Factors

- Patient/Family Advisors choose which activities to work on based on interests and suitability
- Steering committee directors and clinicians actively elicited Patient/Family Advisors opinions and ideas
- The steering committee designated a project lead who clearly defined objectives, scheduled meetings, and outlined timelines and responsibilities
- Passionate Patient/Family Advisors who are dedicated to their roles and bettering their hospital
- Recruitment of a consulting company with considerable expertise to guide the initiative

#### Impact

- Perceived increase in staff recognition of the importance of engaging patients in improvement activities
- Perceived enhanced reputation of Patient/Family Advisors
- Perceived reduction in the amount of time it takes patient/family to navigate through the hospital

## Develop an aging-well online tool for seniors

## Representative

Patient/Family Advisor

## Engagement type

Collaboration

## Hospital type

100+ beds

**Engagement strategies**

- A researcher presented the idea for an aging-well online tool to the Patient and Family Advisory Committee, and recruited six Patient/Family Advisors to work on the project
- The Patient/Family Advisors met regularly with the researcher to establish desirable content for the online tool (e.g. information, questions, visuals, voice prompts)
- Patient/Family Advisors reviewed and refined content with the researcher and research assistant during bi-weekly meetings
- Patient/Family Advisors contributed to decisions by conveying opinions and expressing concerns

**Goal**

Aid seniors in maintaining good physical and mental health

**Timeline**

3 months

**Challenges**

- Patient/Family Advisors formed a strong-willed, articulate group that raised concerns, occasionally leading to disagreements
- Ensuring diverse representation from Patient/Family Advisors

**Success Factors**

- Committed Patient/Family Advisors who had high meeting attendance rates, and worked together to listen to all voices at the table and reach a consensus
- Some of the Patient/Family Advisors were seniors, offering direct insight on age-specific needs
- The researcher independently gathered input from medical personnel on suggested tool content to avoid influencing the Patient/Family Advisors
- The researcher showed appreciation towards Patient/Family Advisors for their time and effort

**Impact**

- The aging-well tool reflects patient/family input, preferences and decisions
- Perceived high validity of the tool by Patient/Family Advisors because they were involved in its creation
- Precedent set for Patient/Family Advisors to work with researchers in future activities

## Develop a research consent form template for patients

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

100+ beds

#### Engagement strategies

- Patient/Family Advisors sit on the hospital's Research Ethics Board (REB) with other clinicians and staff
- Patient/Family Advisors are full voting members of the REB and review REB applications at monthly meetings
- REB members discussed expectations, concerns and ideas for human subjects research participant consent form content
- The REB coordinator developed a consent form template based on REB members' opinions and shared it with the REB to gather additional feedback and finalize the template

#### Goal

Ensure that language and information in research participant consent forms are appropriate and comprehensible for patients

#### Timeline

4 months

#### Challenges

- It took time for the Patient/Family Advisors to build credibility with the clinicians and staff on the REB
- REB members' ability to balance information that Patient/Family Advisors thought should be in consent form with clinical, privacy or legal obligations

#### Success Factors

- The REB is required to include Patient/Family Advisors
- REB champions consistently asked the Patient/Family Advisors questions to elicit information and ensure patient perspectives were accounted for
- The Patient/Family Advisors feel comfortable speaking up and sharing their opinions during REB meetings
- Patient/Family Advisors sign up for a 2-year commitment on the REB, which allows for an appropriate amount of time to learn about the role and be effective in the role

#### Impact

- Considerable improvements in the clarity of patient consent forms submitted to the REB
- Patients are receiving concise and sensitive consent forms that are much easier to understand
- Enhanced efficiency when REB staff review consent forms that accompany studies submitted for approval

## Develop COVID-19 protocol information for patients/family

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

Teaching

#### Engagement strategies

- A Patient/Family Advisor worked with the PE Manager and Medical Director to develop information materials for patients/family on COVID-19 protocols including COVID-19 triage process, ICU treatment for COVID-19, reduced visiting hours, and COVID-19 testing
- The Patient/Family Advisor voiced concerns and opinions about how best to support patients/family; for example, strategies for lowering anxiety and providing alternative supports when visitors were not allowed
- The PE Manager and Medical Director consulted with the Patient/Family Advisor by email and video-chat
- The Patient/Family Advisor reviewed and edited draft information materials

#### Goal

Inform patients and family about COVID-19 protocols

#### Timeline

3 months

#### Challenges

- Difficulty recruiting Patient/Family Advisors to aid in COVID-19 triage responses due to comfort-level with required actions
- Coordination of different programs due to size of organization

#### Success Factors

- The Patient/Family Advisor was recruited by the PE Manager based on specific skills that would be conducive to this project
- The PE Manager and Medical Director were very clear about project goals, roles and deadlines
- The Patient/Family Advisor was given background information and examples to aid in individual tasks
- The Patient/Family Advisor conducted own research on relevant COVID-19 information to help with role

#### Impact

- Information materials (e.g. COVID-19 testing centre, hospital visiting hours) were implemented
- Information materials on COVID-19 triage protocols are prepared and are ready for dissemination
- The Patient/Family Advisor's input and decisions were reflected in the information materials
- Perceived enhancement in staff's ability to respond to the pandemic due to information materials

## Develop post-discharge integrated care pathway and patient educational material

### Representative

Clinician

### Engagement type

Collaboration

### Hospital type

100+ beds

#### Engagement strategies

- Hospital secured funding to develop and implement an integrated funding model that follows patients after discharge, and ensures that they have proper access to clinical care and supports
- Two Patient/Family Advisors with lived experience of family with chronic obstructive pulmonary disease or congestive heart failure were members of a steering committee and sub-committee working groups to assist in developing care pathways and patient education materials
- The Patient/Family Advisors reviewed all project data, and participated in committee meetings by raising concerns or identifying gaps
- Working group met monthly to develop the care pathways for the program, followed by bi-monthly meetings to evaluate performance metrics, and based on that data, refine the pathways

#### Goal

Ensure discharged patients with chronic obstructive pulmonary disease or congestive heart failure receive community-based follow-up care

#### Timeline

24 months

#### Challenges

- Engaging patients who are unwell, particularly when the time commitment or frequency of activity is high
- Encouraging constructive feedback from patients instead of focusing on frustrations

#### Success Factors

- Patient engagement is a focus of hospital's strategy
- Buy-in at every level from the CEO down to frontline staff for patient engagement
- All patient engagement activities are coordinated by one PE manager, which streamlines activities

#### Impact

- Increased consistency of services provided to patients (e.g. level and type of service)
- Standardized educational materials provided to all patients and family
- Reduction in readmission rates for patients with chronic obstructive pulmonary disease and congestive heart failure
- Subsequent integrated care models developed at the hospital for other conditions were informed by what was learned from this project
- Patient/Family Advisors used what they learned in this project to help with subsequent projects

## Develop family information on neonatal intensive care

## Representative

Clinician

## Engagement type

Collaboration

## Hospital type

100+ beds

**Engagement strategies**

- Parent Advisors and clinician project leads defined the project, and developed a print information booklet and online tool for families
- Parent Advisors contributed to decisions about content for the booklet and online tool including clinical care coordination, developmental milestones and discharge planning based on their experiences and needs
- Parent Advisors planned the structure of the booklet and online tool
- Parent Advisors were responsible for developing content for specific sections of the booklet and online tool, and worked with an assigned clinician to prepare that content and jointly review drafts
- Parent Advisors reviewed all content with project leads and flagged areas of concern (e.g. medical jargon)

**Goal**

Provide parents/families with information to prepare them for care in the neonatal intensive care unit

**Timeline**

6 months

**Challenges**

- Adhering to project timelines
- Determining how to translate English-language information
- Monitoring impacts of informational material on parents and staff

**Success Factors**

- Parent Advisors recruited for activity had neonatal intensive care unit experience, and were able to share the booklet and online tool with families at the bedside in a volunteer capacity
- An established Parent Advisory Council with terms of reference, regular meetings, minutes, and consistent leadership at the table
- Parent Advisors chose sections of the booklet and online tool to work on that met their interests
- Parent Advisors were paired with clinicians

**Impact**

- Parent Advisors were proud of being a part of the process and contributing to the materials
- Perceived strengthened relationship between Parent Advisors and clinicians
- Perceived increase in staff satisfaction with the information booklet and online tool



## Develop a patient admission handbook

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

100+ beds

#### Engagement strategies

- Hospital secured funding to develop and implement an integrated funding model that follows patients after discharge, and ensures that they have proper access to clinical care and supports
- Two Patient/Family Advisors with lived experience of family with chronic obstructive pulmonary disease or congestive heart failure were members of a steering committee and sub-committee working groups to assist in developing care pathways and patient education materials
- The Patient/Family Advisors reviewed all project data, and participated in committee meetings by raising concerns or identifying gaps
- Working group met monthly to develop the care pathways for the program, followed by bi-monthly meetings to evaluate performance metrics, and based on that data, refine the pathways

#### Goal

Help patients and family prepare for care before admission

#### Timeline

8 months

#### Challenges

- Patient/Family Advisors' personal experiences drive different priorities (both a value and a challenge to decision-making)
- Generating consensus in the face of diverging views to achieve a balance

#### Success Factors

- Patient/Family Advisors did not hesitate to share their input and opinions
- Patient/Family Advisors were committed to this project and to creating a handbook
- The manager and vice president champions were very receptive to Patient/Family Advisors' input, and kept all participants informed of progress and next steps
- Staff embraced this patient engagement activity despite time constraints

#### Impact

- The final patient admission handbook reflects Patient/Family Advisor recommendations and feedback
- Perceived increase in patient satisfaction with being prepared to enter the healthcare system
- Enhanced efficiency of hospital admission process as patients and families are better informed and prepared

## Update patient discharge information sheets

### Representative

Patient Engagement Manager

### Engagement type

Collaboration

### Hospital type

<100 beds

#### Engagement strategies

- Eight Patient/Family Advisors reviewed patient discharge information sheets, and offered comments and suggestions relating to language used, questions that arose and clarity of instructions
- Patient/Family Advisors started with reviewing 5 to 10 sheets at a time from the emergency department, as it is the biggest outpatient unit and would see the most benefit from updated discharge sheets
- Patient/Family Advisors subsequently reviewed discharge patient discharge information sheets for other hospital departments
- Department managers updated information sheets based on Patient/Family Advisor input, and Patient/Family Advisors further reviewed and refined information sheets

#### Goal

Ensure discharge information sheets are appropriate so that patient/family access proper supports outside of hospital

#### Timeline

6 months

#### Challenges

- Making decisions about language better suited for patients/family
- The project was time consuming

#### Success Factors

- Patient engagement is embedded within the hospital's strategic plan
- Patient/Family Advisors participate in staff meetings and are members of the Board
- Staff are highly aware of Patient/Family Advisors' roles within the hospital
- Patient/Family Advisors feel supported by their hospital

#### Impact

- Patient discharge information sheets reflect Patient/Family Advisors' input and decisions
- Perceived enhancement in clarity and comprehensibility of patient discharge information sheets
- Implementation was successful within the emergency department and patient/family understanding of what to expect is perceived to have improved
- Perceived increase in staff confidence in providing information to patients and family members regarding discharge

## Develop information material for intensive care unit patients

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

100+ beds

#### Engagement strategies

- A Patient/Family Advisor was interviewed about their experience in the intensive care unit, and recruited to join intensive care unit committee and work with physicians, nurses, respirologists, social workers, etc.
- The Patient/Family Advisor shared their personal story with committee members and made suggestions for how the unit could be improved
- Committee members brainstormed with the Patient/Family Advisor about how to improve communication in the unit
- Staff iteratively launched improvements, reported back to the committee, and elicited further Patient/Family Advisor feedback

#### Goal

Enhance communication between staff and patients/family

#### Timeline

24 months

#### Challenges

- Acquiring funds for communication material (e.g. brochures)
- Scheduling meetings at times when all committee members could attend
- Completing project goals within designated timeline

#### Success Factors

- PE manager scheduled committee meetings at times that worked for the Patient/Family Advisor
- Funding to provide release time for staff to participate in committee meetings
- Committee members explained medical jargon to the Patient/Family Advisor
- The Patient/Family Advisor was chosen based on their experience in the intensive care unit

#### Impact

- Patient/Family Advisor's input was reflected in communication materials that were developed
- Perceived improvement in hospital's intensive care unit services
- Perceived increase in patient satisfaction due to improved communication and smoother transitions
- Smoother transitions out of intensive care results in space for new patients requiring intensive care
- Staff more aware of the communication needs of patients/family in the intensive care unit

## Develop mental health educational material for waiting room

## Representative

Clinician

## Engagement type

Collaboration

## Hospital type

100+ beds

**Engagement strategies**

- Patient/Family Advisors participated the monthly meetings to develop mental health educational material for outpatient waiting rooms
- Department staff and social workers led the project, consulting with Patient/Family Advisors for suggestions and feedback
- Two Patient/Family Advisors prioritized the type of educational material offer in waiting rooms (e.g. breathing activities, thought records)
- The department continuously monitors use of educational material, which is reported to hospital leadership team and discussed in monthly meetings with Patient/Family Advisors

**Goal**

Promote mental health self-management and awareness of mental health programs offered by the hospital

**Timeline**

1 month

**Challenges**

- Maintaining sufficient supply of educational material in waiting rooms/replenishing
- Patient/Family Advisors sometimes regress in their own mental health, and may need to step back from participating on the committee for periods of time

**Success Factors**

- Long-standing Patient/Family Advisors
- Patient/Family Advisors are treated with respect and their ideas are welcomed without judgement by department staff and social workers
- Patient/Family Advisors included patients and family members to represent both viewpoints

**Impact**

- Patient/Family Advisors' input is reflected in the material that was developed
- The materials are being used by patient/family in waiting rooms
- Social workers gathered feedback from patients/family who said they appreciated the availability of the material, and provided positive feedback on material content and format
- Patients who had used resources were perceived to be better prepared for program sessions
- Sessions between social workers and patients perceived to be more productive

## Develop a palliative care information booklet

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

<100 beds

#### Engagement strategies

- The palliative care group lead who had developed a guideline for the palliative care unit determined that a palliative care information booklet for patients and family would be advantageous
- The lead proposed the idea in a Patient and Family Advisory Committee meeting and shared a palliative care booklet developed elsewhere that they could adapt
- Patient/Family Advisors assisted in adapting the booklet by suggesting edits to language and content, and reviewing and refining the booklet over several meetings

#### Goal

Prepare patients/families for palliative care

#### Timeline

3 months

#### Challenges

- Making a group decision about inclusion of verses or poems in sections pertaining to death
- Raising awareness about the initiative throughout the hospital

#### Success Factors

- The group worked towards reaching consensus on decisions through discussion and a voting system
- A palliative care nurse joined the Patient and Family Advisory Committee meetings to give the Patient/Family Advisors insight on palliative care
- The project lead continually expressed appreciation to the Patient/Family Advisors
- The number of individuals on the Patient and Family Advisory Committee was advantageous to making decisions (9 members)

#### Impact

- Patient/Family Advisors were impressed with the final version of the booklet and recognized that their input was reflected in the product
- The final booklet was printed and distributed to patients and family members in the palliative care unit
- Patient/Family Advisors felt that the booklet helped patients/family better cope with palliative care

## Develop a palliative care information brochure

### Representative

Patient/Family Advisor

### Engagement type

Collaboration

### Hospital type

<100 beds

#### Engagement strategies

- The Patient and Family Advisory Committee specifically asked senior management to work on projects for the palliative care unit
- A palliative care nurse initiated and championed the palliative care brochure project and presented the project to Patient/Family Advisors at a Patient and Family Advisory Committee meeting
- Several Patient/Family Advisors volunteered to work on the project, and edited content, and presented changes at meetings for group discussion
- The Patient and Family Advisory Committee reviewed brochure drafts, and suggested changes to wording and content over several meetings

#### Goal

Prepare patients/families for palliative care

#### Timeline

3 months

#### Challenges

- Patient/Family Advisors were required to use their own resources to participate in and contribute to the project (e.g. print material using own printers, use own tablets during meetings)
- Limitations in rural Internet connectivity hindered ability to work on project

#### Success Factors

- Patient/Family Advisors with palliative care experience volunteered to work on the brochure
- Staff were very attentive to Patient/Family Advisors when interacting with them during the project
- Effective communication between Patient/Family Advisors and staff
- The Patient and Family Advisory Committee worked to achieve consensus on all brochure decisions

#### Impact

- The final palliative care information brochure was based on Patient/Family Advisor input
- The brochure was made available to patients/family in the palliative care unit
- Perceived increase in staff appreciation and awareness of the value of Patient/Family Advisors
- Perceived increase in staff's willingness to collaborate with Patient/Family Advisors on future projects
- Patient/Family Advisors are equipped to develop information brochures for other departments