## **Insights into Quality Improvement**

# **Engaging with Patients:**

Stories and Successes from the 2015/2016 Quality Improvement Plans

Let's make our health system healthier



About Us

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: **Better health for all Ontarians**.

#### Who We Are.

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province's complex health system.

#### What We Do.

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the voice of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large scale quality improvements by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

### Why It Matters.

We recognize that, as a system, we have much to be proud of, but also that it often falls short of being the best it can be. Plus, certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better has no limit.

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# Executive Summary

On April 1, 2015, more than 1,000 health care organizations from four sectors of the health system in Ontario (including hospitals, interprofessional team-based primary care organizations, community care access centres and long-term care homes) submitted Quality Improvement Plans (QIPs). Health Quality Ontario has reviewed all of these QIPs, and has released four reports to share the results of analyses for each sector (as part of the <u>Insights into Quality Improvement</u> series). This report is the fifth and final report in this series, and represents an analysis of the patient engagement activities described in the QIPs submitted by all four health sectors. The goal of this report is to share how health care organizations across Ontario are engaging with patients and families to improve the care they provide and enhance the health system as a whole.

A high-quality health system provides care that is safe, effective, patientcentred, efficient, timely and equitable.<sup>1</sup> Health Quality Ontario's plan to improve the quality of health care in Ontario is rooted in these six domains of quality,<sup>2</sup> and promoting patient-centred care by engaging patients in improving care is a specific <u>strategic priority</u><sup>3</sup> for Health Quality Ontario. A commitment to patient engagement on the part of health care organizations leads to better quality of care as patient engagement positively influences the development of programs and policies, ensuring that they reflect patients' lived experience.

Organizations can engage patients in countless ways, but which activities best suit them depend on the relationships they typically have with patients, the populations they need to engage with and the initiative they are working on. By describing their patient engagement efforts in their QIPs, organizations can demonstrate how and why their chosen activities are right for them.

To categorize the patient engagement activities reported in the 2015/16 QIPs, we used a framework that describes three levels of engagement (direct care, organizational and policy) and three categories (consultation, involvement, and partnership and shared leadership).<sup>4</sup> We explored activities at the direct care and organizational levels, as policy-level activities are not reported in QIPs.

Note: For simplicity, the term *patients* in this document refers to patients, residents of long-term care homes and clients receiving community care, as well as their family members and caregivers.

Patient engagement at the direct care level is about individual interactions: ensuring that patients understand their diagnosis, and that patients and providers work together to make decisions that take patient preferences into account. Many organizations reported initiatives at this level, from ensuring the availability of translation and interpretation services to patient education programs, shared decision-making initiatives and coordinated care plans.

Patient engagement at the level of the organization means incorporating patient priorities and experiences into how the organization is governed and run. This type of engagement took many forms in the QIPs, including patient surveys, patient advisory councils, experience-based co-design and patient leadership on quality improvement committees.

We also considered patient engagement using an equity lens by exploring how organizations were engaging with underrepresented patient populations, including new Canadians, Indigenous communities, and people with mental illnesses or addiction issues. Engaging with patients from these populations presents a number of challenges: patients may be more difficult to reach, and they may be less willing or less able to participate. Nevertheless, some organizations are finding ways to connect with these patients and overcome these barriers.

Patient engagement at any level demonstrates a commitment to patientcentred care, one of the six domains of quality care. As the owners and users of the health system, patients and families should be a driving force for improving quality in Ontario's health system. This year's QIPs have shown that organizations across the four sectors are finding new and innovative ways to engage with the communities they serve.

# **About This Report**

For the past five years, health care organizations across Ontario have developed and submitted Quality Improvement Plans (QIPs). A process that began with Ontario's hospitals has now extended to organized primary care organizations, community care access centres (CCACs) and long-term care homes.

The annual submission of QIPs demonstrates the ongoing commitment of more than 1,000 health care organizations to deliver higher quality care in Ontario. These plans allow organizations to articulate their quality objectives, formalize their improvement activities and pinpoint precise ways of achieving those goals.

Each QIP details an organization's work on a set of priority indicators. These indicators align with the *Common Quality Agenda*,<sup>5</sup> a set of more than 40 indicators developed collaboratively by Health Quality Ontario and other health system partners. The Common Quality Agenda is an effort to focus performance reporting, lend greater transparency and accountability to the health system, and promote integrated, patient-centred care. It forms the foundation of Health Quality Ontario's yearly report on how Ontario's health system is performing, *Measuring Up*.<sup>6</sup> Health care organizations can use the information available in *Measuring Up* and our *Insights Into Quality Improvement* series to gain a greater understanding of quality improvement from both an organizational and system-wide perspective. The preparation and detail that go into each QIP typically represent an impressive effort on the part of each health care organization to commit to and document their commitment to quality. Health Quality Ontario recognizes this work by carefully reading each QIP to examine and evaluate the data and the change ideas provided. Using QIPs to highlight progress and identify areas in need of improvement is one way in which Health Quality Ontario works with more than 1,000 health care organizations across four sectors to transform the quality of care throughout the health system.

Health Quality Ontario hopes that the findings in this report will help inform health care organizations about what methods are being used successfully to engage patients in the health system and, through that sharing, encourage uptake of innovations and help guide patient engagement planning efforts for the coming year. This report is part of Health Quality Ontario's ongoing *Insights into Quality Improvement* series, which analyzes and summarizes QIP submissions from across the province. As well as the sector-specific reports in this series, we also create reports that compare findings on a particular theme across all four health sectors. The focus of this report is how health care organizations have engaged patients in their quality improvement work by sharing some of the many stories, plans and change ideas from QIPs across health sectors and around the province.

We are aware that there are many other ways of engaging patients in quality improvement that have not been captured in this report. This report is intended to provide a snapshot in time of the work that has been reported by organizations when submitting their QIPs. While we occasionally gathered additional information and followed up with a few organizations to ask for more details on the examples they included in their QIPs, we chose not to include examples outside of those reported in the QIPs.

This report was reviewed by eight patient advisors, who participated in a focus group exercise led by the authors of the report and members of the Patient Engagement Team at Health Quality Ontario. Feedback from these patient advisors is presented throughout the report, and is marked by the icon shown to the left. Their comments are also summarized in the conclusion of this report. The feedback from these patient advisors provides an insightful perspective that goes beyond the findings from the QIPs.

# Introduction

To improve the quality of the health system in Ontario, we need to consult the people who use it. Patient engagement is an essential component of patientcentred care, and involves incorporating the voices of patients and families into decisions that will affect the care they receive at every level of the system. This can include anything from informal conversations and quick feedback surveys to putting patient representatives in leadership positions on committees and boards.

We produced this report to share how health care organizations across all four sectors of the system are actively working to engage with patients and families to improve the care they provide and enhance the health system as a whole, as reflected in their QIPs.

#### **CURRENT CONTEXT**

Patient engagement is not new: organizations across Ontario have been involving patients in their quality improvement efforts for many years. However, a number of recent initiatives (both driven by Health Quality Ontario and the health system at large) have highlighted a commitment to a patient-centred approach across the system.

Health Quality Ontario's <u>Quality Matters</u> framework<sup>2</sup> adopts the Institute of Medicine's definition of a high-quality health system as one that is safe, effective, patient-centred, efficient, timely and equitable,<sup>1</sup> and points to patient engagement as one of the ways to achieve that vision. In addition, Health Quality Ontario's strategic plan, <u>Better Has No Limit: Partnering for a Quality Health</u> <u>System</u>,<sup>3</sup> specifically cites engaging patients in improving care as one of five key strategic priorities on which to focus to fulfill our vision of a just, patient-centred Note: For simplicity, the term *patients* in this document refers to patients, residents of long-term care homes and clients receiving community care, as well as their family members and caregivers.

health system committed to ongoing quality improvement. Health Quality Ontario has also produced a number of resources for both patients and health care organizations, providing reporting advice, tools, tips and resources to support patient engagement efforts (see box on Patient Engagement Resources).

The integration of patient engagement into Health Quality Ontario's driving framework and strategic plan is consistent with other changes occurring in the health sector in Ontario. In February 2015, the Ministry of Health and Long-Term Care released Patients First: Action Plan for Health Care,<sup>7</sup> a blueprint for health care transformation that puts patients at the centre of the health system and focuses on their needs first. According to this document, putting patients first will involve engaging patients in health care so that we can fully understand their needs and concerns, and making decisions that are informed by patients so that they play a major role in affecting system change. In addition, two new regulations under the Excellent Care for All Act, 2010<sup>8</sup> were enacted in September 2015, requiring hospitals to engage patients in developing their QIPs as well as their patient relations processes, respectively. Specifically, the regulation focusing on the QIPs (Ontario Regulation 187/15) requires that hospitals engage patients, former patients and their caregivers in the development of their QIPs; describe their patient engagement activities in their QIPs; and report on how patient engagement informs their quality improvement efforts.9

#### **Patient Engagement Resources**

#### **Resources from Health Quality Ontario**

- Guides on creating and sustaining patient and family advisory councils. Patient and family advisory councils are in operation in all long-term care homes and many hospitals, and are increasingly being implemented in primary care organizations and community care access centres. Health Quality Ontario has prepared a set of three guides to help organizations create and sustain patient and family advisory councils:
  - o Recruiting for Diversity
  - o <u>Creating an Effective Terms of Reference</u>
  - o Choosing Meaningful Projects

• Engaging with Patients and Caregivers about Patient Relations: A Guide for Hospitals. This guide was produced to help hospitals increase patient engagement in improving their patient relations process as they aim to fulfil the requirements of <u>Regulation 188/15</u> under the Excellent Care for All Act, 2010.

- <u>Striving for Excellence in Patient Relations Processes: A Guide for Hospitals</u>. This resource was produced to help hospitals understand what is expected with the new requirements of Regulation 188/15.
- A comprehensive list of <u>patient engagement tools and resources</u>. This list includes resources for patients, families and caregivers as well as resources for health care providers.

#### Resources from other organizations

There are many organizations in Ontario and across Canada that are doing important work to support patient engagement and patient-centred care. Here are a few examples:

- The Canadian Foundation for Healthcare Improvement
- <u>Cancer Care Ontario</u>
- Canadian Institutes of Health Research

#### DEFINITION

Patient engagement has been described in many different ways. At a direct care level, it is about patients improving the experience of their own care: "Actions individuals must take to obtain the greatest benefit from the health care services available to them."<sup>10</sup> At an organizational level, it is more about collaboration to improve practice: "Actions patients and providers take together to promote and support active patient and public involvement in health and health care and to strengthen their influence on health care decisions, at both the individual and collective levels."<sup>11</sup>

To take both of these perspectives into account, Health Quality Ontario has developed its own working definition aimed at describing organizational efforts for quality improvement. In this report, *patient engagement* will be defined as "Strengthening the role and partnership of patients, caregivers, and the public at all levels of the health system, in order to improve the delivery of care." As an example, patient advisors noted that efforts to incorporate patients' views on quality improvement need to be directed not only to medical staff but to all staff.

#### HOW DO ORGANIZATIONS ENGAGE PATIENTS?

Organizations can engage patients in countless ways. Simple efforts can include suggestion boxes, informal conversations and comment cards, while the most participatory models include committees co-led by patient representatives, or patient involvement in the design of programs and other initiatives.

Which activities will best suit each organization depend on a range of factors such as the type of interactions and relationships it typically has with patients, the infrastructure for engagement, the populations it needs to engage with and its own specific challenges and goals. By describing their patient engagement efforts in their QIPs, organizations can show how and why their chosen activities are right for them. Our review of the QIPs revealed a wide variety of approaches to patient engagement. The following stories describe two types of patient engagement and show how organizations can tailor their approach to meet the needs of their patients. For example, the Taddle Creek Family Health Team determined that it wanted to focus on reaching seniors, and designed its patient engagement efforts accordingly:

In Toronto, the **Taddle Creek Family Health Team** is undertaking a Seniors Advisory Volunteer Initiative. This initiative has led to a group of 10 seniors championing recommendations from the seniors' strategy report, *Living Longer, Living Well*,<sup>12</sup> and two seniors' health fairs, with an average of 300 participants representing diverse ethnic groups. In other methods cited, the team ensures patient representation on all working groups (including five patients serving on its health council and two patient co-chairs) and offers peer-to-peer outreach for patients in need.

Because of its extensive one-on-one contact with clients, Central East Community Care Access Centre (CCAC) was able to acquire recorded patient stories and is planning to host learning circles:

To better engage patients and improve overall client experience and satisfaction, the **Central East CCAC** (responsible for the Central East Local Health Integration Network [LHIN] catchment area) has begun to use patient stories to identify areas for potential quality improvement. The video-based stories are focused on individual experiences of care. Going forward, the Central East CCAC intends to host patient learning circles—groups of patients who provide specific feedback on an area of care—which they believe can drive future quality-improvement initiatives with specifics derived from real-world lessons.

There are many ways in which patients can be engaged, and different approaches will work best in different circumstances. It is important to share stories of successful patient engagement efforts to promote the spread of these approaches among more organizations, embedding them in the health care system.

#### A PATIENT ENGAGEMENT FRAMEWORK

To describe and categorize the patient engagement activities reported in the QIPs, we needed a framework. A number of published options are available, but we adapted one created by Carman et al (2013).<sup>4</sup> The framework describes three different levels of patient engagement (direct care [provider/ patient]), organizational, and policy) and three major categories (consultation, involvement, and partnership and shared leadership). The framework categories represent a continuum; they are not mutually exclusive, and organizations should use activities from more than one category.

For the purposes of this report, the most relevant levels of engagement to highlight were the direct care and organizational design and governance levels. Because organizations do not report activities at the policy level in their QIPs, we have not explored that level in this report.

In using this framework to describe the patient engagement activities in the QIPs, the goal is not always to move toward activities at the far end of the continuum. The most participatory levels of engagement are not always better for every patient in every setting, and organizations cannot assume that patients are interested in partnership or that they share the organization's goals. The continuum is meant only to categorize a wide range of opportunities and help patients and organizations choose methods that are best suited to the topic and the best fit for the situation and the patients involved.<sup>4</sup> It should also be noted that while this report focuses on data from the QIPs, initiatives to engage patients and families go far beyond QIP reporting. These activities reflect only a portion of organizations' efforts to involve patients.

# Figure 1. A current framework for patient and family engagement in health and health care

Levels of Engagement	Consultation	Involvement	Partnership and shared leadership		
Direct Care	Patients receive information about a diagnosis	Patients are asked about their preferences in their treatment plan	Treatment decisions are made based on patients' preferences, medical evidence and clinical judgement		
Organizational design and governance	Organization surveys patients about their care experience	Organization involves patients as advisors or advisory council members	Patients co-lead safety and quality improvement committees		
Policy making	Public agency conducts focus groups with patients to ask opinions about a health care issue	Patients' recommendations about research priorities are used by public agency to make funding decisions	Patients have equal representation on agency committee that makes decisions about how to allocate resources to health programs		
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<ul> <li>Factors influencing engagement:</li> <li>Patient (beliefs about patient role, health literacy, education)</li> <li>Organization (policies and practices, culture)</li> </ul>					

Adapted with permission from Carman et al, 2013.4

Society (social norms, regulations, policy)

#### **GENERAL FINDINGS**

Overall, we found that organizations most often use surveys to gather information on areas of strength and opportunities for improvement. This practice is well established in the literature, and aligns well with expectations related to QIP priority indicators. Hospitals and long-term care homes are also required by law to survey their patients and residents.<sup>\*†</sup>

Organizations in all sectors described using surveys to capture patients' perceptions of care. Patient surveys have an important place in patient engagement, but they are a less participatory form of patient engagement.

Organizations should consider supplementing the use of satisfaction surveys with additional engagement techniques to ensure that they are collecting a full range of feedback. Organizations scoring highly on satisfaction surveys should continue to challenge themselves to improve. Figure 2 shows other common patient engagement methods that organizations have reported in their QIPs. All of the methods mentioned below span the *Consultation, Involvement* and *Partnership* columns of the framework. Each sector's choices of patient engagement activities are presented as the percentage of all of organizations that submitted QIPs in that sector (organizations could choose more than one type of patient engagement). The activities are increasingly participatory, from left to right.

Not surprisingly, sectors varied in how they engaged patients. For example, in the long-term care sector, patient and family advisory councils are legislated; 72% of long-term care homes reported using this method of engagement in their quality improvement activities (more than any other sector). In contrast, fewer interprofessional primary care organizations used advisory councils, but this sector reported greater use of focus groups and community meetings. CCAC narratives and workplans provided many examples of patient involvement, co-design and patient leadership. Hospitals showed a fairly evenly distributed approach across all methods.

\* From the Long-Term Care Homes Act, 2007:

#### Satisfaction survey

#### Action

(2) A licensee shall make every reasonable effort to act on the results of the survey and to improve the long-term care home and the care, services, programs and goods accordingly. 2007, c. 8, s. 85 (2).

#### <sup>†</sup> From the Excellent Care for All Act, 2010:

#### Surveys

5. (1) Every health care organization shall carry out surveys,

(a) at least once every fiscal year, of persons who have received services from the health care organization in the past 12 months and of caregivers of those persons who had contact with the organization in connection with those services;

#### Purpose of surveys

(2) The purpose,

(a) of a survey under clause (1) (a) is to collect information concerning satisfaction with the services provided by the health care organization.

<sup>85. (1)</sup> Every licensee of a long-term care home shall ensure that, at least once in every year, a survey is taken of the residents and their families to measure their satisfaction with the home and the care, services, programs and goods provided at the home. 2007, c. 8, s. 85 (1).

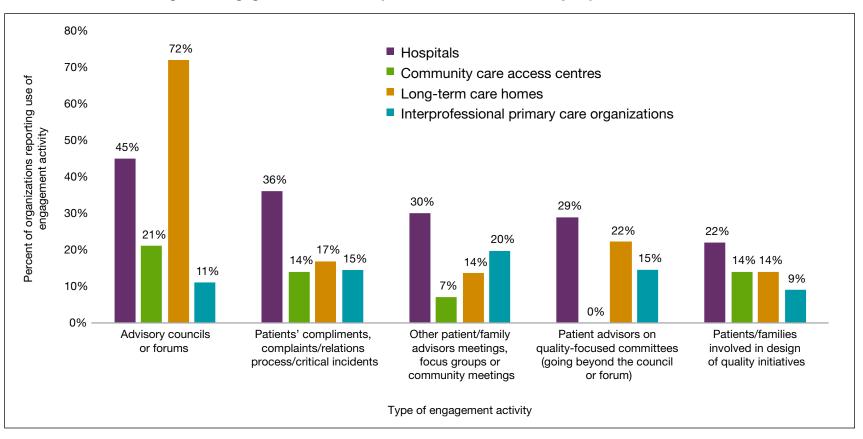


Figure 2. Engagement activities reported in the 2015/16 Quality Improvement Plans

The QIPs proved to be a rich source of stories, change ideas and examples of patient engagement across the four health care sectors. We discuss such examples at the direct care level (Chapter 1) and in organizational design and governance (Chapter 2). We also look at how organizations have sought to move beyond more common engagement activities to reach underrepresented patient populations (Chapter 3). We hope the findings described here will encourage organizations to reflect on their own progress and consider new opportunities for collaboration, shared learning, and creative ideas to enhance patient engagement and drive quality improvement. Chapter 1: Patient Engagement: Direct Care BS

Patient engagement at the direct care level is about individual interactions: ensuring that patients understand their diagnosis, and that patients and providers work together to make decisions that take patient preferences and needs into account. Many organizations reported initiatives at the direct care level in their QIPs.

### Continuum of engagement

Levels of Engagement	Consultation	Involvement	Partnership and shared leadership
Direct Care	Patients receive information about a diagnosis	Patients are asked about their preferences in their treatment plan	Treatment decisions are made based on patients' preferences, medical evidence and clinical judgement

#### CONSULTATION

Common consultation methods of patient engagement include probing questions, dialogue and "teach-back"<sup>13</sup> approaches to ensure patients have understood the conversation. Engagement at the direct care level is based on interaction with a care provider, who may require training in health literacy to ensure they know how to communicate clearly with patients who have different needs. Health literacy is "the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions."<sup>14</sup>

#### Social Media/Technology Enablers

Organizations from all four sectors are using social media and new technologies to communicate with patients and families about issues ranging from appointment setting to health prevention. Some organizations use self-managed, secure online portals or social media to announce activities and provide information. There are many opportunities to use social media and technology to engage patients at the direct care level, but dissemination requires institutional agility and responsiveness.<sup>15</sup> Moreover, it is important to note that the use of email and text is in many cases limited by privacy legislation and the recommendations of professional colleges.

In Toronto, Access Alliance Multicultural Health and Community Services focused its change ideas on translation and health literacy and pointed out that its engagement activities make full use of interpretation and the translation of written materials and resources, as well as the literacy levels of patients in both English and language spoken at home.

#### INVOLVEMENT

Patient involvement is at the heart of patient-centred care. <u>Patients First:</u> <u>Action Plan for Health Care</u><sup>7</sup> encourages patients and providers to be involved in joint decision-making, and the examples below demonstrate how some organizations are ensuring patient involvement in their own care.

**London Family Health Team** is conducting education workshops on health literacy, and has taken health literacy to a new level by giving iPads loaded with appropriate apps to allied health professionals, which they can use to help patients understand their course of treatment or disease. **BlueWater Health**, located in Sarnia, has implemented the *2012 Registered Nurses' Association of Ontario Facilitating Client Centred Learning Best Practice Guideline (Teach Back)*<sup>13</sup> to help ensure that patients are aware of danger signals, regardless of their condition. One goal for this change idea was that 65% of patients would be able to describe danger signals to emergency department staff by March 31, 2016.

**Grey Bruce Health Services**, located in Owen Sound, has instituted the Teach Back methodology as a way of supporting patient understanding of health education and discharge plans—using training and audiovisual methods—and is using unit-based champions to help providers practice their skills. This training will also be provided to CCAC and emergency medical service partners.

**Prescott Family Health Team** has kept its emphasis on self-managed care as a way of involving patients in care decisions. Clinicians report that they encourage patients to ask questions, call, or book follow-up appointments to address any further issues. Other strategies have included Teach Back methods, graphical displays, written instructions and handouts generated from patients' electronic medical records.

#### **Spotlight: Gateway Community Health Centre**

In Tweed, Gateway Community Health Centre—the lead organization in the Rural Hastings Health Link—stands out as a notable example of a primary care provider that is directly engaging patients in their care and showing strong results in doing so. Gateway has been an earlier adopter of a new role they call the System Navigator in primary care, and has found the role helpful when managing care coordination plans.

The results below are from an initial test of change conducted by Gateway over a one-year period (between November 2013 and December 2014) involving a group of 158 complex patients who were identified through the Health Links initiative.

Gateway monitored what happened to the patients who had the support of the System Navigator. The patients being followed demonstrated an 87% reduction in emergency department visits, an 85% reduction in hospital admissions, a 71% reduction in length of stay and 100% implementation of a medicine reconciliation post-care plan. These results may indicate that navigator support is helping to improve care, although further evaluation is required before the use of system navigators can be widely recommended. The Health Links initiative is compiling data about initiatives like this across the province.

More recently, Gateway Community Health Centre has found that patients with care coordination plans who are admitted to hospital demonstrated a shorter length of stay. It is worth noting, however, that other factors may also contribute to explain the difference in length of stay between the two groups

The executive director of the Gateway Community Health Centre described the care coordination plans as a way of capturing patients' voices and guiding providers' care. They help patients to be engaged in their care and improve providers' experiences as well, because providers can see that their patients' goals have been met. The executive director stated that "This is change we have been waiting for".

A single point of contact to coordinate care is a great help to patients as they navigate the health care system.

**Bramalea Community Health Centre** has initiated a trial of "<u>Ask Me 3</u>®<sup>‡</sup>," a practical tool that creates awareness of the importance of clear health communication and encourages patients to be involved in their care (self-management). It prompts patients to ask their health care provider three questions at every visit:

- *What is my main problem*? (focus on diagnosis or major presenting problem)
- What do I need to do? (discussion of health care provider's instructions)
- *Why is it important for me to do this?* (provide context for instructions and follow-up)

Shared decision-making changes the distribution of power between providers and patients by supporting joint decisions based on an understanding of the benefits and harms of all health care options and on patients' preferences. Decision aids are commonly used with shared decision-making to improve patients' involvement in decision-making.<sup>16</sup>

#### The University Health Network Toronto Western Family Health Team

has used evidence-based shared decision-making tools to enhance interactions between patients and their providers. As an example, the University Health Network is piloting a statin tool and incorporating shared decision-making tools into electronic medical records. The University Health Network is also educating residents and staff physicians on the shared decision-making process and partnering in a multicenter study on shared decision-making for goal-setting in people with diabetes.<sup>§</sup> At the **Fort Frances Family Health Team**, all patients over 50 years of age will discuss the advantages of an advance care plan with their interprofessional health care provider during a regularly scheduled appointment. This will be enabled by a shareable electronic advance care plan for use with the local hospital and long-term care home. The team sees this as a chance to discuss quality of life with families and caregivers and to share information across health care sectors in Fort Frances. The family health team is testing the idea that shareable advance care plans will improve the integration of care when a patient is admitted to the hospital or a long-term care home.

**Carefirst Family Health Team** in Richmond Hill has undertaken an advance care planning initiative to ensure that it can initiate, monitor and achieve patient engagement on thinking about future health and personal care preferences, along with the completion of important documents. Change ideas included ensuring physician buy-in and advising patients about advance care planning using a toolkit. The family health team has reported great progress with this initiative, as physicians continue to communicate and hand out the toolkit and materials. Distribution of toolkits is documented in the electronic medical record to track and assess how this initiative is working.

A shared or coordinated care plan is a written or electronic plan created and retained by the patient and family, the health care team and, when necessary, community services. It is designed to help patients with their daily health care requirements and outlines their short- and long-term needs, rehabilitation goals, coordination requirements and who is responsible for each part of the plan (e.g., the physician, care team, patient, etc.). Coordinated care plans were mentioned more frequently in the QIPs of organizations that were participating in <u>Health Links</u>, whose focus is on providing coordinated, shared, interprofessional, cross-sectoral care to complex patients.

<sup>&</sup>lt;sup>‡</sup> Ask Me 3<sup>®</sup> is an educational program of the National Patient Safety Foundation<sup>®</sup> (NPSF) that encourages patients to ask specific questions of their care providers to better understand their health conditions and what they need to do to stay healthy. NPSF<sup>®</sup> provides licensees materials and resources. Visit <u>their website</u> to learn more.

<sup>&</sup>lt;sup>§</sup> For example, The Ottawa Hospital Research Institute offers a number of shared decision-making tools. <u>https://decisionaid.ohri.ca/index.html</u>

The **London InterCommunity Health Centre** is undertaking a pilot project that involves developing coordinated care plans for a test population of clients. Outcome measures include the number of staff trained in coordinated care planning and motivational interviewing, and the number of clients involved in development of a client-centred care plan. Objectives include improvement in client satisfaction rates; the top 5% of complex clients with a coordinated care plan that involves client participation; and 80% of clients seen between January and March 2016 to be met with motivational interviewing.

#### PARTNERSHIP AND SHARED LEADERSHIP

Partnership in patient engagement at the direct care level can lead to increased agreement on common priorities between providers and patients.<sup>17</sup>

Experience-based co-design is one example of shared leadership that involves capturing patients' experiences in the form of narratives or stories, and then working with them to understand and improve their care.

The **Kingston Family Health Team's** depression initiative has engaged patients in a number of ways, including "storyboarding," a patient-centred method of experience-based design, to guide the creation of a care pathway for patients with depression. At the individual patient level, storyboarding provides valuable information about the patient's experience. The aim of the project is to ensure that patients with depression have access to optimal, seamless care.

Involving patients in the co-design of initiatives that affect them is the focus of partnering and sharing leadership.

North Simcoe Muskoka CCAC is collaborating with patients and caregivers on an in-home falls safety checklist and a web-based resource site on how to create and maintain a safe home environment. The checklist, a tool to be used with the patient/caregiver to involve them in establishing their own safety goals, is currently being tested by one of the community teams. Two patients and a caregiver have been contacted directly and have provided feedback on development of the webpage. Others are being engaged to provide feedback on the community newsletter as an outreach tool that uses patient stories/experiences.

Other organizations have found a range of ways to partner with patients to improve the quality of care.

The **Algoma Nurse Practitioner–Led Clinic** in Sault Ste. Marie has an interdisciplinary team designing opportunities for patients to participate in the development of patient literacy tools, and to respond to patient satisfaction data, including a policy to guide patient participation.

Ontario has increased its emphasis on improving palliative and end-of-life care, assuming that patients and families should have a say in choosing the options they consider to be best for their future care. A number of organizations have followed this direction and have reflected this in their QIPs.

West Durham Family Health Team in Pickering is partnering with different stakeholders to support families and caregivers in the area of palliative care. Its initiative aims at improving health care providers' capacity to respond to the needs of patients and families using evidence-informed best practice. The team has also been working with the Central East CCAC, Palliative Pain Symptom Management Consultative Service Durham, "Speak Up", the Government of Ontario and the Association of Family Health Teams of Ontario to establish an advance care planning process that emphasizes patient-centred care and supports families and caregivers.

#### **GOING FORWARD**

Patient engagement at the direct care level requires that health care providers understand each patient's needs, abilities and preferences. Shared decisionmaking tools and coordinated care plans represent simple ways of ensuring that patient perspectives are included. Providers should be careful to respect the fact that different patients will have different levels of interest in engaging with health care providers, and even in engaging in their own care.

An opportunity for improvement could be a greater emphasis on shared decision-making for major health care decisions such as whether a patient should undergo joint replacement surgery or heart surgery, or the decision to live in a LTC facility.

Patient engagement in quality improvement could be improved by incorporating a number of strategies. Examples include ensuring proactive follow-up by medical staff, providing access to electronic medical records, and providing staff training in communication for patient engagement. It is also important to consider not only patients, but also families and caregivers when reaching out. Chapter 2: Patient Engagement: Organizational Design and Governance

#### Continuum of engagement Levels of Partnership and Consultation shared leadership Engagement Involvement Organization Organization Patients co-lead Organizational involves patients surveys patients safety and quality design and as advisors or about their care improvement advisory council governance experience committees members

Patient engagement at the level of the organization means incorporating patient priorities and experiences into how the organization is governed and run. This type of engagement can take many forms, including patient surveys, patient advisory councils and patient leadership on quality improvement committees.

#### CONSULTATION

Surveys and interviews are the most common way for organizations to consult with patients and families to learn more about their experience of care.

In Toronto, **Providence Healthcare**'s patient care managers and the Patient Experience Committee use the results of patient satisfaction surveys (completed 48 hours before discharge and during outpatient visits) to inform projects and initiatives.

Patients and caregivers are also often engaged at the bedside via informal interviews/surveys to obtain valuable information and insights. For example, comments over several months indicated that noise at night was interfering with patients' sleep. The quality improvement manager interviewed patients at the bedside and asked for ideas about how to improve the nighttime experience for patients. As a result, the centre has begun a pilot project to address this problem. This pilot project has helped to identify what made sleeping difficult for patients, including staff speaking too loudly, malfunctioning door hinges and bright overnight lights. Once the problems were identified, Providence Healthcare started implementing solutions such as training staff to speak quietly, changing and greasing hinges, and scheduling announcements of quiet time. According to the quality improvement lead at Providence, the preliminary results of this pilot project have been positive, and the initiative will likely be implemented in the palliative care unit. For example, regarding the change idea to improve the night experience, between June and December 2015, the program reported a 32% relative improvement.\*\*

Patients also complained that they did not know staff names. The quality improvement lead asked patients, family and staff about the staff ID badges and how they could be improved for visibility. The patient and family advisory council was also consulted. Based on feedback, three suggested ID badge templates were developed and approximately 200 patients, family and staff voted on the most visible and appealing format. These new ID badges will be rolled out soon.

<sup>\*\*</sup> Relative improvement is the difference between current and past performance divided by past performance (denominator).

**Spotlight: Mississauga Halton CCAC's Share Care Council** Mississauga Halton CCAC (covering the Mississauga Halton LHIN) has instituted a new <u>Share Care Council</u>. The 15-member council represents a partnership that is meant to ensure a direct voice for patients and families with regard to the development of programs and services at the CCAC.

The Share Care Council is a membership-based forum where patients and caregivers are given a direct voice to inform new programs and services. It also includes two staff to support the council. So far, the 15-member council has worked with improvement teams to improve care and has also developed several products.

Products that the Council has created include a patient and caregiver bill of rights, and information sheets to support patients to get the most value before and after a visit with a family doctor.

As well, the Council provided direct recommendations to hospital improvement teams, such as improving seamless transitions from hospital to home (The <u>Seamless Transitions, Hospital to Home</u> Initiative).

Pamela was motivated to become involved in the Share Care Council because she is a "success story" and wants people to know that the system *can* work and did work for her. Pamela has multiple sclerosis and has received home care for 13½ years without any major problems.

Jatinder is a caregiver to his 96-year-old mother and uses the knowledge he has gained seeing his mother through two hospital stays and ongoing home care to inform the development of CCAC and hospital services.

The Mississauga Halton CCAC and Trillium Health Partners (located in Mississauga) have a formal partnership to improve the way patients are cared for in the region, and *Seamless Transitions: Hospital to Home* is their

first initiative. Pamela and Jatinder were both consulted at multiple stages of its design. "[Trillium Health Partners] did a flow chart of processes that covered the wall," Jatinder explained. "And they went through each step and asked us for feedback. At times we were saying 'You are forgetting some of the basic stuff here because you are still in the old ways.'"

"When I was talking to Trillium, I said the most important thing you can do is have connection with the people—listen to what they've got to say," Pamela explained. The *Seamless Transitions: Hospital to Home* initiative has now been designed and tested, has shown promising results, and is spreading throughout the hospital system. Patient feedback has been very positive. Other hospitals and regions are also expressing interest in adopting the new approach.

The creation of a Patient and Caregiver Bill of Rights is another major area of contribution for the Share Care Council. "It's important because too many people—I see this with people with disabilities all the time — they're afraid to speak up when they have bad care because they think that care will be taken away from them. That's wrong. It has to stop. And the only way to do that is to make sure they know what their rights are," explains Pamela.

Jatinder adds, "It is rights for everybody who is involved. It's recognizing what [personal support workers] can expect from us. It's rights for what the patient or the caregiver can expect from them. You want to see [the patient] smiling when [the care provider] comes in, and [the care provider] should be leaving happily after providing the service. That's the ideal."

"It's a safe place," confirms Pamela. "We've come together very well as a community."

#### INVOLVEMENT

Organizations can encourage patients and families to get involved by showing that patient participation and leadership can help organizations achieve their improvement goal<sup>18</sup> and by responding positively to patients' efforts.<sup>19</sup> Involvement activities described in organizations' QIPs include interviews, patient focus groups and advisory councils.

McCormick Home in London includes members of its residents' council and family council on its performance improvement team. The team is accountable to the quality committee of the board, and its purpose is to ensure internal, ongoing assessment of all risks related to safety, human resources and physical resources. The committee reviews data from Canadian Institute for Health Information reports and benchmarks the organization's performance against provincial and historical comparators. McCormick Home implemented a very useful system that includes a heat map and a chart that are used to monitor and measure performance on the indicators. Through discussion, the team determines desirable, achievable and measurable quality indicators (for example, "Percentage of residents who were physically restrained daily") and compares them to the actual operations of the home.

South West CCAC (covering the South West LHIN) is conducting "Always Event" interviews to inform quality improvement activities and meet patient needs. Always Events are aspects of the patient experience that are so important to patients and families that health care providers must perform them consistently for every patient, every time.<sup>20</sup> The objective of the interviews is to facilitate a discussion with patients and caregivers to help the CCAC define what Always Events might be, providing a roadmap to rapidly meeting long-standing patient needs. With consent, these interviews will be videotaped and transcribed. Experiences will be shared with staff to provide opportunities for quality improvement. Patients will be asked what they might see as solutions.

The Always Event work mentioned above grew from the Never Event safety movement, a quality initiative familiar to hospitals. According to work produced by the Canadian Patient Safety Institute in collaboration with Health Quality Ontario, Never Events are "patient safety incidents that result in serious patient harm or death, and are preventable using organizational checks and balances".21

It's important to consider Never Events in addition to Always Events. Organizations should involve patients in the process of responding to a complaint, critical incident or "near miss".

#### Langs Farm Village Association Community Health Centre in

Cambridge involves patients in various committees throughout the organization, including Community Services, the North Dumfries Advisory Committee and, most importantly, the Langs Board of Directors. This involvement ensures the voices of patients are heard and that patients are involved in making decisions. Patients are also involved in hiring, as part of group interviews.



Involving patients in hiring decisions is a great example of

#### FRENCH-SPEAKING COMMUNITIES

It is important to reach out to engage French speakers in health care in order to fully understand their needs and concerns. Organizations such as Carlington Community Health Centre and Pinecrest-Queensway Community Health Centre, both located in Ottawa, are using surveys in French to collect information about patient experiences in their Francophone populations. However, QIP findings show that few organizations have gone beyond surveys in engaging with this particular group of patients. Still, some are taking proactive measures to facilitate access for Francophone populations in their region and to improve the provision of support and services in French.

**Hotel Dieu Hospital** in Kingston aims to advance a French Language Services Implementation Plan via a number of initiatives. The hospital noted that its focus in 2015–2016 would be to offer language training for interested staff; develop linguistic profiles for key clinical positions; develop bilingual recruitment materials (e.g. job postings, job descriptions) for clinical positions and begin to recruit bilingual staff for clinical positions; boost bilingual signage to help Francophone [patients] know which departments house French-speaking staff; and launch French-language functionality on the hospital website.

#### PARTNERSHIP AND SHARED LEADERSHIP

Working with patients as active partners means sharing opportunities to make decisions, valuing patient contributions and working together to create a plan for their care. Engaging patients in co-design is different than consulting or involving patients as it requires deliberate processes that originate from participatory action research, user-centred design, learning theory and narrative-based approaches to change.<sup>22</sup>

**Northumberland Hills Hospital**, located in Cobourg, is including patients and caregivers as active members of its quality and practice committees, reflecting its growing cultural commitment to experience-based co-design. Taking learnings from the Northumberland <u>PATH project</u>, the hospital is achieving its strategic priority of commitment to person-centred care. Experience-based co-design—a philosophy at the root of PATH and its unique involvement of patients and caregivers—is now being woven into the culture of the hospital. Patients and caregivers are also being invited to attend program-planning days to engage with care providers and set priorities for the upcoming year. They are also helping with patient satisfaction surveys in the emergency department. **Bridgepoint Hospital** in Toronto (now part of the Sinai Health System) has adopted the National Health Service's experience-based co-design methodology, which brings patients, families and staff together to redesign services and improve the patient experience of care. So far, the hospital has undertaken two projects using this approach. Patient and family experience in these projects was captured to identify change opportunities, and some patients and families were recruited as advisors on the redesign teams. This year, six patient and family advisors who participated in the hospital's co-design quality improvement work were also recruited to review the QIP—in particular the change ideas for patient satisfaction and the opportunities to provide insight into how to best engage future patients and families in other priority areas.

At **Rouge Valley Health System**, with two sites, in Ajax and Pickering, and in Toronto, a community advisory group is involved in discussions at the organizational level to improve the quality of end-of-life care. Group members have played an active role in quality improvement, facilitating nine focus groups with community members, staff, physicians and board members to understand how stakeholders currently experience end-of-life care. The findings were reported to the quality and risk committee. To support this focus, the organization's QIP includes a new indicator that looks at the percentage of palliative care patients discharged from hospital with home support.

It is important to relay findings resulting from engaging patients at the organizational level to the frontline staff who provide palliative care at the point-of-care level. Strategies such as training, outreach and the use of powerful stories are useful approaches to do this.

#### **GOING FORWARD**

Engaging patients at the organizational level can lead to a wide range of benefits for everyone involved. Organizations can better understand how to improve care by accessing the unique perspective of those with lived experience, and can incorporate patient priorities into their decision-making. Patients who serve on committees or advisory councils talk of feeling empowered and listened to, and of having a greater sense of community. When organizations and patients work together, the needs of the community can be addressed in a meaningful and impactful way.

It is important to spread effective care coordination to support all complex patients. Addressing this issue is key to improving quality of care for complex patients.

These issues may be rooted in some of the challenges reported in the QIPs with regard to issues that have an impact on patient integration. For example, the **Erie St. Clair CCAC** identified "access to timely, meaningful data and how this data is used in decision-making and improving the services and care we provide" as a consistent challenge. Similarly, **Brighton Quinte West Family Health Team** reported that "the migration of clinical information, especially historical data, has been a challenge", as filling in patient histories and risks takes a substantial effort.

Chapter 3: Engaging Underrepresented Populations Health Quality Ontario considers *health equity* to be one of the six essential components of high-quality care. According to Health Quality Ontario's working definition, health equity is achieved when everyone in Ontario can reach their full health potential and receive high-quality care that is fair and appropriate to them and their needs, no matter where they live, who they are, or what they have.<sup>23</sup> An equitable health system will ensure that the same high-quality care is provided to everyone in Ontario, regardless of social determinants such as economic or social status, language, culture, gender, housing or food security.

As the provincial advisor on health quality, Health Quality Ontario is also committed to better health for everyone in Ontario, ensuring that improvements made to the health system extend to everyone. Our <u>2016–2019 Strategic Plan</u><sup>3</sup> highlights the importance of both health equity and patient engagement in improving the quality of health care.

And yet, one of the challenges of patient engagement is finding ways to connect with populations who face health equity barriers and who, as a result, are less able to advocate for their own care. While there are no simple solutions to this problem, some organizations are finding innovative ways to partner with patients and other groups to engage with underrepresented populations and improve their care.

#### UNDERSERVED POPULATIONS (INCLUDING NEW CANADIANS)

The review of the QIPs showed that although health equity approaches are becoming increasingly important for health care organizations across the province, there were differences between sectors.

Analysis of the QIP data revealed that references to health equity were more likely to be found in QIPs from the primary care sector.<sup>++</sup> Initiatives in primary

care also took different forms and focused not only on patients' medical needs, but also on related needs such as food security and housing. Some primary care organizations have encouraged partnerships with community stakeholders, patients and families. This clearly aligns with the direction proposed by the Association of Ontario Health Centres, which states: "We advocate for increased focus, healthier public policy and a more effective, equitable and comprehensive primary health care system that addresses the determinants of health".<sup>24</sup>

**Upper Canada Family Health Team**, located in Brockville, has promoted the formation of a "Community Table" that provides a space for patients and families to partner and share leadership at the organizational level. Membership consists of community stakeholders/partners and patient and/ or family representatives who meet on an ongoing basis. The goal is to provide a way of reviewing anonymous patient cases to provide feedback and improve patient flow through the health and social service system. This can include referral processes to specialists, community services (including the Ontario Disability Support Program) and housing, hospitals, CCACs, addictions and mental health, children's mental health, [public] health units, long-term care and general system navigation. This will provide a way for Upper Canada Family Health Team providers to share the experiences of their patients and determine ways to improve their experiences.

Other organizations have paid particular attention to language services as a way of addressing the health concerns of new Canadians and refugees.

At Access Alliance Multicultural Health and Community Services in Toronto, all engagement activities make full use of interpretation and the translation of written materials and resources, and take into account the literacy levels of the patients in English and in their home language. Results are also used to inform the change ideas, the methods used to implement the change ideas, the measures used and the goals set.

<sup>&</sup>lt;sup>++</sup> To perform this analysis, we searched the following four keywords: "income" (as it related to equity), "homeless", "poverty" and "refugee" in the Narratives, Workplans and Progress Reports. We found that 52 organizations mentioned at least one of these four keywords. The breakdown of the counts showed that these keywords were mentioned by one CCAC, five hospitals and 46 primary care organizations.

Encouragingly, hospitals are also showing a growing interest in ensuring that the voices of underrepresented populations are heard.

St Michael's Hospital and its Centre for Research on Inner City Health, located in Toronto, has become an international model for best practice; it relies on several community advisory panels (CAPs) to involve patients and improve the overall quality of care of underserved populations. For example, there are four inner city health panels: Aboriginal health; women and children at risk; homeless and under-housed; and mental health and addictions. Made up of patients, family members, community agency representatives, and hospital staff and physicians, the CAPs meet regularly to improve the overall quality of care for these populations and by extension all patients of the hospital. The CAPs have contributed to more than 60 innovations in patient care, research and education. Some of the innovations drawn from the Aboriginal CAP include the Aboriginal Stroke Care Guide (which has been incorporated into an Aboriginal health curriculum at the University of Toronto); Aboriginal cultural safety training for members of all St Michael's CAPs; and the creation of Well Living House, an Aboriginal infant, child and family health and well-being research centre.<sup>25</sup> Engaging patients and empowering them in their own care is also at the centre of the hospital's new corporate strategic plan.

#### **INDIGENOUS COMMUNITIES**

Organizations that serve Indigenous individuals are also looking for ways to better meet the needs of populations that are often marginalized and may have difficulty connecting with the health system.

**Georgian Bay General Hospital** in Midland has taken proactive steps to incorporate historically marginalized populations. This hospital encourages its staff to receive training to better understand the culture of the populations they serve. Partnering with patients, families and the community, the change idea currently being tested is implementation of an "Aboriginal Patient Navigator" role. This role will help the hospital meet the needs of its community and facilitate an improved experience for First Nations, Metis and Inuit patients. It is entirely funded via a partnership with a First Nations women's organization. To support this work, staff have been encouraged to participate in a certificate program for cultural awareness, and a cultural awareness day is planned on site for all staff to ensure a foundational understanding of the unique views and beliefs on health and health care delivery of the First Nations, Metis and Inuit community.

**Maamwesying North Shore Community Health Services Inc.** (which includes the N'Mninoeyaa Aboriginal Health Access Centre and the Baawaating Family Health Team), located in Cutler, works with partners to focus on the design of a community-driven and evidence-informed holistic Primary Healthcare Services Delivery Model. Their client engagement is fulfilled through quarterly community conversations.

The engagement activities are focused on three major questions:

- 1. What's working in our service delivery model?
- 2. What's not working in our service delivery model?
- 3. What do we need to improve on?

From these conversations, the senior management team looks to implement changes to the current model of care.

#### MENTAL ILLNESS AND ADDICTION

People with mental health and addictions issues are particularly vulnerable, and it is important to proactively engage with these populations. People living with mental health and addictions issues often face discrimination, difficulty accessing services and poverty. Recent documents such as Health Quality Ontario's <u>Taking Stock: A Report on the Quality of Mental Health and</u> <u>Addictions Services in Ontario</u>,<sup>26</sup> <u>Changing Directions, Changing Lives</u><sup>27</sup> and <u>Better Mental Health Means Better Health</u><sup>28</sup> have touched on the challenges faced by people living with mental illness and addition. Nevertheless, many organizations that serve these populations are finding ways to proactively engage with patients and families.

The **Centre for Addiction and Mental Health** (CAMH), which is located in Toronto and has regional offices across Ontario, has developed a program (Employment Works!) to hire former or current patients as peer support workers and members of care teams. By doing so, CAMH has made a commitment to engaging patients in partnerships and leadership initiatives. They actively seek out patient input on quality activities, using the lens of recovery and patient-centredness. The Quality, Patient Safety and Risk team hires people with lived experience of mental illness and addiction to administer the annual Client Experience Survey, deliver peer-based safety education to in- and outpatients at community meetings, and to participate in small change initiatives such as using the Plan-Do-Study-Act method to increase post-restraint incident debriefs.

#### **GOING FORWARD**

Engaging with populations that are underserved presents a number of challenges: it is more difficult to reach patients from these groups, and patients and families may be less able to participate in engagement activities. Health care professionals may also feel uncomfortable seeking feedback from patients who have health equity barriers. Still, applying a health equity lens to quality improvement shows how important it is to bring underserved populations to the table. Organizations may need to implement training and look beyond traditional approaches to find ways of engaging with these groups of patients.

# Conclusion

Patient engagement at any level demonstrates a commitment to the kind of patient-centred care described in *Quality Matters*,<sup>2</sup> and in the findings from the QIPs. Making that commitment at the direct care and organizational levels leads to better health quality because patients can positively influence the development of programs and policies, ensuring that they reflect their lived experience.

Health care organizations across Ontario have shown their active engagement with patients and caregivers across the continuum of engagement (consultation, involvement and partnerships). At present, the majority of patient engagement activities use consultation and involvement methods; fewer have taken steps to engage patients in partnership and shared leadership. Finding ways to engage with French speakers and underserved populations such as newcomers to Canada, Indigenous communities, and those with mental illness or addictions also continues to be a challenge. Nevertheless, this year's QIPs show that organizations across the four sectors are finding new and innovative ways to engage with the communities they serve.

#### INPUT FROM PATIENT ADVISORS

The authors of this report were pleased to have the opportunity to engage with patient advisors and hear their perspectives on the examples of engagement described in the 2015/16 QIPs. Their insightful comments are presented throughout this report, marked by the icon to the left. The advisors highlighted particularly valuable engagement activities as well as opportunities for future improvement, and proposed approaches to more firmly embed patient engagement as a fundamental part of the health care system.

# Here are some of the key comments that patient advisors had while reviewing this report:

- It is important to consider the connection between the two levels of engagement (direct care and organizational) when determining which change initiatives to choose. Stories and examples at a direct-care level can catalyze change at the organizational and system levels. Reciprocally, change initiatives at an organizational level need to be relayed to frontline providers in a way that is meaningful to them so that these changes can impact the direct-care level.
- Supporting staff in developing effective communication strategies is a key approach to supporting patient engagement, particularly when dealing with patients who have been harmed or have raised complaints.
- The stories that come from a direct-care level are a powerful way to share patient experience and should be captured in a way that can provide a useful illustration when communicating about a change initiative. Organizations should strive to learn the art of *stories as data*<sup>29</sup> and use those stories to relay an empathetic perspective on the topic. By doing so, organizations reinforce the data and the outcomes, and other patient advisors engaged in quality improvement can understand and apply lessons from these examples.
  - o A speaker's corner format is a potential product to consider. Imagine searching a speaker's corner to learn directly from a patient advisor how the work resulting from a quality initiative impacted a patient and demonstrated progress.
- Key enablers to engagement include allowing patients to access their own electronic health records, and supporting cultural competency for staff to embrace the principles of "the voice of the customer".

- It is important to describe approaches that were not successful as well as potentially sensitive issues (e.g., work on patient safety through investigation of Never Events) in the QIPs.
- Social determinants of health are a key component of equity. Issues related to these determinants should be considered, reported and embedded into quality improvement initiatives.

Overall, the information gleaned about patient engagement from the QIP reports submitted by organizations across all four sectors as well as from patients themselves were hugely revealing and encouraging. We look forward to working with organizations and patients to move the health system toward more participatory modes of engagement, and to helping organizations share best practices across the province.

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### **Committed to Quality Improvement**

We promote ongoing quality improvement aimed at substantial and sustainable positive change in health care, fully leveraging emerging evidence and public reporting to help identify improvement opportunities. We then help build the health system's capacity for quality improvement by supporting the collection and use of data for improvement, sharing insights into innovations that are working to make improvement and promoting skills development in quality improvement. We actively support the development of a culture of quality and aim to connect the quality improvement community to learn from one another.

## **Quality Matters**

<u>Quality Matters</u> is an effort at Health Quality Ontario designed to bring everyone in the health system to a shared understanding of quality health care and a shared commitment to act on common goals.

*Quality Matters* takes a two-pronged approach. One involves a patient engagement process, called *Quality Is...* that allows patients, caregivers, and the public to provide their insights on what quality is from their perspective. A second involves a deep dive by an expert panel into understanding health quality, delivering system-wide quality, and developing a culture of quality. The panel's first report, *Realizing Excellent Care For All*, provides a provincial quality framework and lays out key factors to consider. Our hope is that it will serve as a touchstone for organizations as they undertake quality improvement efforts, such as those identified in their quality improvement plans, and support an ever-improving health system.

This is just the start. In the months ahead, we will continue to engage with patients, experts, and those across the system. *Quality Matters* will result in a road map, informed by patients and the public, to help policy makers, clinicians, and health system leaders build a quality-first health system in Ontario.

Learn more about Quality Matters by visiting www.hqontario.ca.

## The Common Quality Agenda

The Common Quality Agenda is the name for a set of measures or indicators selected by Health Quality Ontario in collaboration with health system partners to focus performance reporting. Health Quality Ontario uses the Common Quality Agenda to focus improvement efforts and to track long-term progress in meeting health system goals to make the health system more transparent and accountable. The indicators promote integrated, patient-centred care and form the foundation of our yearly report, *Measuring Up*. As we grow our public reporting on health system performance, the Common Quality Agenda will evolve and serve as a cornerstone for all of our public reporting products. Health Quality Ontario is the operational name for the Ontario Health Quality Council, an agency of the Ministry of Health and Long-Term Care.

### Methods

For this report, we did a narrative review: we gathered and examined organizations' stories, rather than compiling a set of statistics. We used key words to search the QIPs and find common themes related to patient engagement. We then chose examples of patient engagement initiatives to illustrate the many different activities being carried out by organizations across the province. To learn more, we conducted follow-up interviews and group discussions with selected organizations. Then, we reviewed and classified the examples to make sure they reflected a wide range of initiatives across the province and within each of the four sectors. Occasionally, when some examples required further clarification, we followed up with the organizations through emails and phone calls. Finally, we performed Internet searches to gather additional resources and information when necessary.

### Acknowledgements

This report could not have been put together without the help of Health Quality Ontario's sectoral partners, the 14 Local Health Integration Networks, Health Quality Ontario's Cross-Sector QIP Advisory Group, and the generous review from Health Quality Ontario's patient advisors and patient engagement department. We hope the findings in this report will spur further testing of innovations and help inform decisions about patient engagement for the public of Ontario.

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ISBN 978-1-4606-8325-5 (Print) ISSN 2369-9116 (Print) ISBN 978-1-4606-8326-2 (PDF) ISSN 2369-9124 (Online)