

INTRODUCTION

Creating “Engagement-Capable Environments” in Healthcare

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This casebook is designed to provide compelling examples of healthcare organizations in Canada, the US and England that have advanced patient-centred care and patient engagement. These selected healthcare organizations have demonstrated that patient engagement contributes to improving care, outcomes and the experiences of patients and families. By detailing these organizations’ strategies, investments and experiences, we hope to illustrate pathways to increased engagement for innovation and improvement.

As these cases illustrate, there is no one strategy for engagement. However, there are important common themes and approaches to patient engagement that can be adapted for different types of organizations and environments. There are substantial challenges to successful engagement; yet, as these cases show, there are important benefits as well.

Why Focus on Patient Engagement?

Efforts to improve healthcare services' quality, safety, efficiency and to optimize the patient experience are presenting challenges for leaders across the globe. Many different strategies and ideas have been tested in search of solutions. These strategies appear to work in some contexts, but not in others. And, while some countries rank higher on comparative international assessments of healthcare systems, all countries continue to have substantial variations in performance among individual practitioners, organizations, clinics, regions and sectors.

Part of the challenge in designing successful healthcare systems arises from the obvious truth that effective healthcare at its heart relies on human interactions – the communications and trust between patients and providers. While new interventions – medications, diagnostic testing and treatments – offer fresh approaches to care, the human dimension of healthcare means that improvements in healthcare quality cannot rely on innovations and technology alone. In many countries, there is a growing recognition that high-quality care is possible only when patients are engaged in their own care. This engagement needs to happen at an individual level (What care works for you or me?); at a program, unit or organizational level (How should care be designed and delivered for all patients like you or me?); and at a system level (What services should be available, for whom and in what way?). At all levels of healthcare, high-quality care is possible only through co-design and co-production: patient preferences and patient insights need to be linked to professional knowledge and experience to produce better care (Batalden et al. 2015). No sustainable changes in system performance are possible without effective co-design: patients and family members working together with clinicians, leaders and staff.

Many new initiatives in healthcare services recognize this reality. Increased patient participation in decisions on their treatment options has been viewed as an important strategy for improving outcomes for some years (Joosten et al. 2008; Kaplan and Frosch 2005; O'Connor et al. 2007). Strategies to reduce unnecessary services that consume resources and may harm patients need to engage patients as well as providers (Cassel and Guest 2012). More broadly, patients must play a central role in efforts to create a "learning healthcare system" in which healthcare resources are used more effectively to deliver evidence-based care (Institute of Medicine 2011). A number of studies show that when patients and their families are actively engaged in their health and with their healthcare teams, patients' experiences of care and self-management improve (Rathert et al. 2013). Engaged patients may also experience better outcomes (Hibbard and Greene 2013; Kane et al. 2015; Stewart et al. 2000), and the costs of their care may be decreased (Charmel and Frampton 2008; Smith et al. 2013).

Healthcare systems in a number of countries are striving to integrate patient engagement, patient experience and patient-centredness into daily care and broader operations. In the US, the seminal report from the Institute of Medicine (2001), *Crossing the Quality Chasm*, included patient-centredness as one of six dimensions of quality. The US Centers for Medicare and Medicaid Services have introduced a Partnership for Patients initiative that enjoins healthcare systems to listen to patients and use the knowledge gained to improve systems and reduce unnecessary harm (McCannon and Berwick 2011). The passage in the US of the *Affordable Care Act* in 2010 introduced a series of reforms that emphasize the role of patients and patient-centred care in the development of a more effective delivery system (Kocher et al. 2010). In addition, several important organizations advancing patient-centred care and patient engagement are located in the US, notably the Institute for Patient- and Family-Centered Care (IPFCC), the Picker Foundation and Planetree. These organizations have helped healthcare leaders and staff to recognize the value of listening to and including patients in all aspects of healthcare, and they have provided tools and guidance to assist organizations in doing that.

In England, the Department of Health and the National Health Service (NHS) have placed an increasing priority on patient and public involvement in the health service (Baggott 2005). The *Health and Social Care Act 2012* requires involving patients, both in decisions about their own care and at the service delivery level. Service delivery decisions include those made by clinical commissioning groups regarding funding prevention, treatment and care for groups of patients. Patient choice has been an important feature in health service reforms in England’s NHS over the last 15 years (Department of Health [England] 2006), including initiatives such as Choose and Book, which helps general practitioners (GPs) and patients book outpatient appointments (Department of Health [England] 2004). Experience-based co-design methods, whereby patients and providers work together to redesign services, have also been used for over a decade in a number of health trusts (Bate and Robert 2006; Robert et al. 2015). Yet, despite this emphasis on patient involvement in England, there is still considerable resistance to some aspects of patient involvement (Greenhalgh et al. 2014) and limited evidence of its impact (Baggott 2005; Veronesi and Keasey 2015).

In Canada, organizations and governments in several provinces have launched initiatives to promote patient-centred care and support patients, family members and staff in mutual engagement. The Canadian Foundation for Healthcare Improvement (CFHI) programs and resources – including its quality improvement (QI) collaboratives, executive-training program (EXTRA) and patient engagement hub – have enabled health system leaders from across the country to improve patient and family involvement in care (re)design and to measure its impact. In British Columbia in 2008, the Ministry of Health developed the Patients as Partners program, which supports the identification and development of patients in a range of planning activities (Government of British Columbia n.d.; McQuillen et al. 2013). The Government of Saskatchewan (n.d.) has committed to patient- and family-centred care as a priority for the province’s healthcare system, the reform of surgical services, the lean

initiatives to improve service delivery across the province and daily care. Similarly, Ontario's Ministry of Health and Long-Term Care (2015) has identified "putting patients first" as a key priority. In addition, The Change Foundation (2014) in Ontario has interviewed patients, family members and staff to understand how to create effective patient and family advisory councils in hospitals, and has developed guidance for those creating such councils.

Yet, if patient engagement – by which we include the engagement of families and caregivers – has become a new buzzword, it is neither simple nor easy to do. Unlike industries that have a long history of tapping into their customers' experiences and needs to create value for services and products, healthcare has remained focused on providers. Healthcare has "missed out mainly because it has seen patient involvement in their own care as a moral rather than an economic issue" (KPMG International Cooperative 2014: 3), and because many healthcare providers remain wedded to the idea that professional knowledge trumps patient experience (Berwick 2009).

Pressure is growing, however, on healthcare leaders and staff to reconsider the current, limited levels of patient engagement. Part of the pressure is financial and regulatory. Despite recent budget constraints, many factors suggest healthcare costs will continue to increase. Partnering with patients may help to reduce unnecessary services and bolster patient understanding and commitment to improving their own health. As already noted, governments, responding to public pressures, have mandated increasing patient engagement in a number of areas, and accreditation agencies and regulators are specifying greater patient involvement. Accreditation Canada (2015), for example, has developed new standards on client- and family-centred care that include involving patients and families in advisory groups, collaborative care teams and initiatives to design or improve care processes.

Societal pressures for patient engagement are also important forces for change. Patients increasingly expect to be involved in their own care, and new technologies, including digital health records and smart phones, coupled with growing public impatience about the slow pace of change in healthcare, have pushed providers to rethink barriers to patient engagement. Organizations, such as Patients Canada and Patients for Patient Safety, are aiding this momentum for greater patient participation in decision-making, both as individuals and as groups.

Still, many healthcare organizations have been reluctant to engage patients or to alter long-standing policies, such as limitations on visiting hours or family participation in bedside rounds, and other rules designed to ensure efficient operations or to promote patient safety. Results of a recent survey of hospitals in the US showed that many hospitals were focused on different priorities, or did not have the resources to support increased patient engagement (Herrin et al. 2015). A recent survey by the CFHI found that only 30 of 114 Canadian acute-care hospitals that were surveyed scored high on visiting policies that promote family presence and patient-centred care, despite

growing evidence of the benefits of family-friendly policies (Farmanova et al. 2015). In many healthcare organizations, there is still insufficient awareness that increasing efforts on patient-centred care and patient engagement, and allocating resources to support engagement and the adoption of patient-friendly policies will yield results.

In the face of multiple priorities and limited funding, more evidence that demonstrates the value of patient-centred care and patient engagement is needed to increase the urgency accorded these issues, and to win over the hearts and minds of clinicians and decision-makers. First, however, there needs to be a clearer understanding of what is meant by patient-centredness and patient engagement, and how these efforts connect to broader improvements in care and care systems.

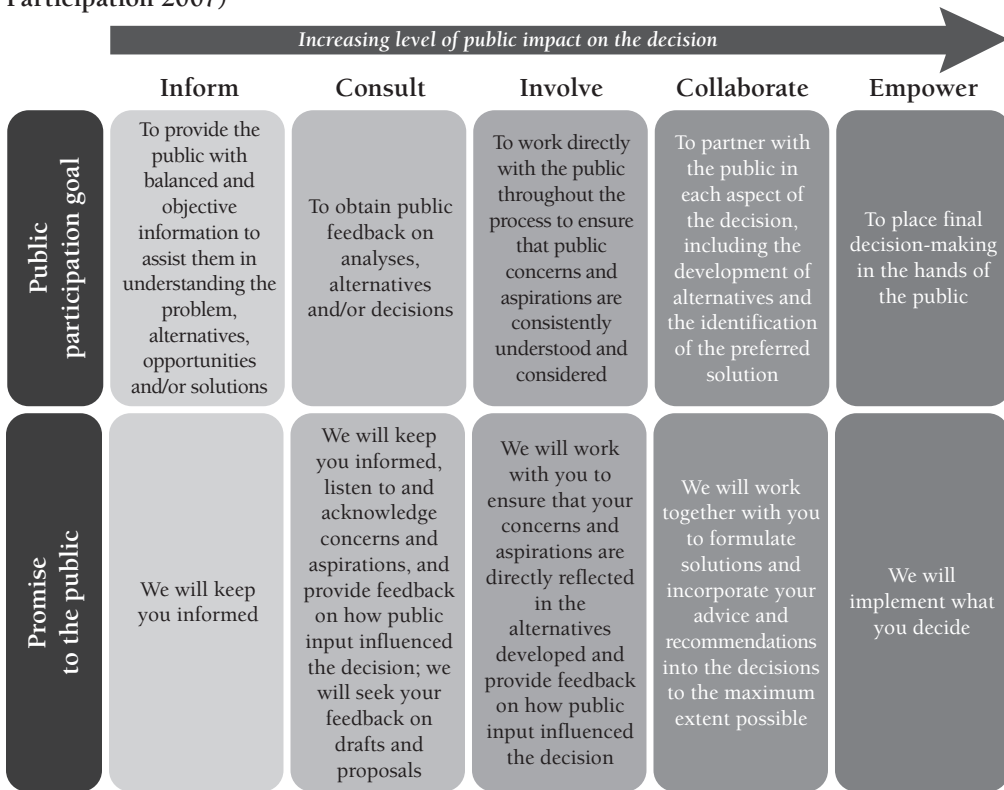
Definitions of Patient-Centredness and Patient Engagement

Patient-centred care has been defined as “care that is respectful of and responsive to individual patient preferences, needs and values, and [that ensures] that patient values guide all clinical decisions” (Institute of Medicine 2001: 40). This philosophy of care has been extended to include families, recognizing the role of caregivers as integral participants in the delivery of care. Effective patient- and family-centred care (PFCC) relies on the beliefs and behaviours of healthcare providers who care for patients. The IPFCC (2010) identifies four core principles for PFCC that extend to and guide patient engagement: respect and dignity, information sharing, collaboration and partnership.

Patient-centred care requires involving patients. There is a burgeoning literature on patient engagement, but no consistency on how this term is defined. For our purposes, we have developed a definition based on the work of Tambuyzer et al. (2011: 142) and others. We define patient engagement as “the involvement of patients and/or family members in decision-making and active participation in a range of activities (e.g., planning, evaluation, care, research, training, and recruitment). Starting from the premise of expertise by experience, patient engagement involves collaboration and partnership with professionals.” Much of the discussion on patient-centred care and patient engagement has focused on engagement at the clinical level and shared decision-making about treatment (rightly so, as these are important dimensions of engagement). But patients also need to be involved more broadly. The cases detailed in this book focus on patient engagement at a program, unit or organizational level, and on initiatives that cross organizations. Such engagement reinforces and spreads shared decision-making at multiple levels of the health system.

If patient engagement incorporates a broad range of activities and differing levels of involvement, it also ranges in the degree of contribution by patients and family members. The International Association for Public Participation (2007) maps out a spectrum of participation (or engagement) activities, ranging from “informing” to “empowering.” While this spectrum was developed for describing public participation, it is also useful in defining levels of patient engagement (Figure 1).

Figure 1: Spectrum of public participation (International Association for Public Participation 2007)

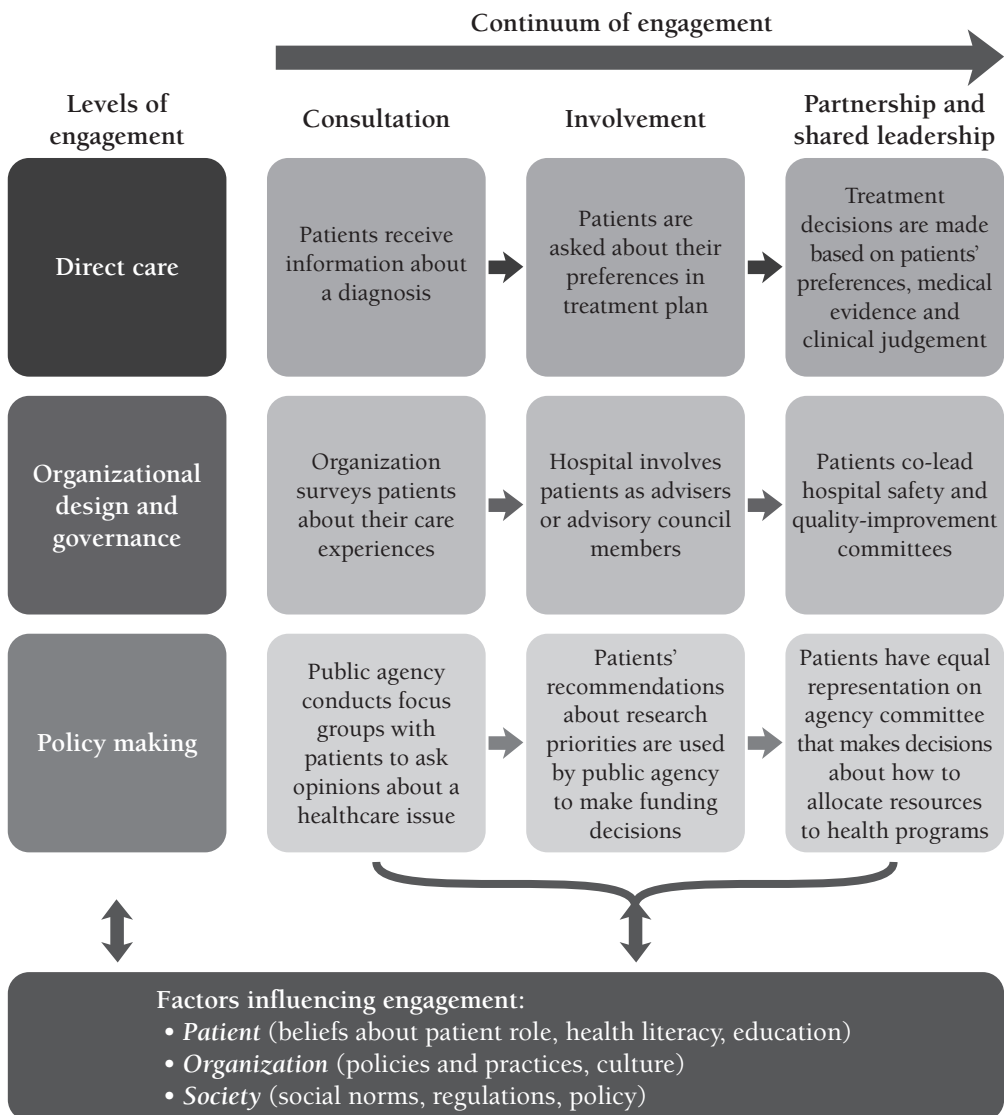


Carman et al. (2013) have developed a helpful framework that links the spectrum of participation activities with levels and types of engagement (Figure 2). They identify three levels of engagement – direct care; organizational design and governance; and policy making – and portray a continuum of engagement for each of these levels. Although there are no arrows linking activities between each level of engagement, the authors note that patient beliefs, health literacy and education; organizational policies, practices and culture; along with societal norms, regulations and policies, influence engagement at all levels. Moreover, the experience in several countries suggests that actions at each level have ramifications at other levels. For example, government policies encouraging patient engagement along with accreditation standards have influenced organizational design and governance in Canada, the US and the UK. And, engagement of individual patients and family members in QI – building on these patients’ experiences taking active roles in their own care – has influenced the design of care. For example, Sabadosa and Batalden (2014) discuss how engaging patients with cystic fibrosis and their families in reviewing the care they received helped to identify opportunities to improve care and to make it more patient-centred for all patients with cystic fibrosis.

As the examples cited above illustrate, the need for both a more patient-centred healthcare system and greater engagement of patients and families in decision-making at all levels of

care is increasingly recognized; nevertheless, healthcare organizations are not all developing and adopting patient engagement strategies at the same pace or achieving the same degrees of success. Patients and families bring a unique lens and important insights to the healthcare setting, but in many organizations their involvement in care remains notably absent (Coulter and Elwyn 2002). In a UK report, Cottam and Leadbeater (2004: 16) argue, “[t]he biggest untapped resources in the health system are not doctors but users (of the service) ... We need systems that allow people and patients to be recognized as producers and participants, not just receivers of services.” To achieve this partnership, patients and families will have to be given and to take on much larger roles in partnership with clinicians: identifying needs, proposing solutions, testing them out and implementing them together.

Figure 2: A multi-dimensional model for patient and family engagement in health and healthcare (Carman et al. 2013)



Including patients has added value for unblocking the barriers to change in organizations and systems. For example, in the Institute for Healthcare Improvement (IHI) report, *Seven Leadership Leverage Points for Organization-Level Improvement of Health Care*, Reinertsen et al. (2008) note that putting patients in positions of real power and influence, and using their wisdom and experience to identify issues and to inform and redesign care to improve processes and systems, provides the most important force for driving change and has the greatest potential for achieving long-term transformation of the healthcare system.

So, while excellent examples of engagement strategies exist in Canada and internationally, these strategies are not widely implemented. And, even when they are implemented, they are often not systematically evaluated, which limits their application elsewhere. Moreover, the findings from those strategies that are evaluated are often not shared broadly and, because they frequently are part of QI efforts, not seen as evidence to inform organizational practice. This state of affairs recalls the observation attributed to novelist William Gibson: “The future is already here – it’s just not evenly distributed.” Closer examination of successful patient engagement strategies is needed to understand the investments, decisions and contexts for successful patient engagement.

Methods

The case studies in this book were developed over a five-year period as part of two connected projects. Five of the cases were initially developed as part of research funded by the CFHI, carried out by G. Ross Baker and a team of co-investigators from Toronto, Montreal and London, England (the team comprised Jean-Louis Denis, Marie-Pascale Pomey, Carol Fancott, Yvonne Bombard, Anu MacIntosh-Murray and Jocelyn Cornwell). These cases, conducted between 2012 and 2013, include detailed studies of five organizations in three countries: Canada, the US and England. Of these five original case studies, four were identified through interviews with experts on patient engagement as organizations that were leaders in these strategies. One case deals with an organization that participated in the CFHI Patient Engagement Project and whose patient engagement efforts demonstrated important achievements. Data for these cases were collected via interviews during field visits and supplemented with information from publications, grey literature and relevant websites. The initial cases were very detailed; shorter versions of these cases are included in this book.

The five additional case studies featured in this casebook were developed in 2014 and 2015 as part of a report released in summer 2015, commissioned by the Federal Advisory Panel on Healthcare Innovation, chaired by Dr. David Naylor. The panel’s mandate was to identify “promising areas of innovation . . . that have the potential to sustainably reduce growth in health spending while leading to improvements in the quality and accessibility of care” (Advisory Panel on Healthcare Innovation 2015: para 6). The report to the Naylor panel – *Patient Engagement: Catalyzing Improvement and Innovation in Canadian Healthcare* – included a review of relevant literature, short versions of the case studies developed for the earlier project as well as five new case studies of Canadian and US organizations and networks. Information for these case studies was derived from interviews and other materials. These new case studies were selected based on the authors’

experiences and knowledge of leading practices in patient engagement and involvement and included Canadian organizational case studies; a provincial network for recruiting, training and supporting patient and family advisors; and two network collaborations – one that links senior caregivers and their healthcare providers in a Canadian community, and one composed of patients, family members and clinicians across a number of pediatric hospitals in the US. These case studies describe engagement activities taking place at the time of research. Over time, there have been many changes to these organizations (e.g., personnel, structures, processes) to varying degrees. Organizational efforts detailed in these cases are worth highlighting to share common elements and lessons learned in the pursuit of improvement, in partnership with patients and families.

Understanding the Key Elements of Patient Engagement

Improved understanding of what effective patient engagement looks like, what strategies and investments are needed and how leaders throughout an organization can advance these efforts must be considered in detail. This casebook aims to provide a fine-grained description of such efforts in different settings.

The following 10 case studies offer a number of common lessons. First, successful patient engagement is not a short-term project or tactic. Many organizations have created patient and family advisory councils or have recruited patients to join committees in response to external pressures to demonstrate patient involvement. In order for these efforts to be meaningful and sustained, they must be linked to an explicit, longer-term strategy, one that is rooted in a clear vision of what can be achieved through partnership with patients; explicitly and genuinely supported by leaders; and continually reviewed and renewed to address the logistical and cultural challenges inherent to such fundamental changes.

Second, meaningful patient engagement is a complex organizational transformation. Organizations are not easily altered, and effective change is both bottom-up and top-down. Therefore, the key to successful patient engagement lies not in proclamations of a new focus on patient-centredness or patient engagement. Instead, organizations need to change long-standing practices and the underlying norms and values that reinforce those practices. New practices and new values emerge from new experiences and the continued reinforcement of their significance. Leaders’ enunciation and enactment of these practices and values is critical, and must occur throughout the organization – not just at the top. Moreover, these statements and initial efforts must be accompanied by corresponding and reinforcing actions. Effective patient engagement requires more than slogans; sustainable efforts rely on broader organization-wide efforts to engage patients in improving care to create a better care environment and better-quality outcomes of care.

Better understanding of what effective patient engagement looks like, what strategies and investments are needed, and how leaders throughout the organization can advance these efforts must be considered in detail. This casebook aims to provide a detailed description of such efforts in different settings. Our third, and most fundamental lesson, is that

organizations that are successful in making substantive commitments to creating, learning and sustaining successful patient engagement are *different* from those that have made only limited changes to imitate these efforts or to respond to external mandates. Successful organizations have developed what we term *engagement-capable environments*. These engagement-capable environments may exist in organizations, or in networks or communities of multiple organizations. These environments provide the context for developing a range of structures and behaviours that support patient engagement and patient-centred care.

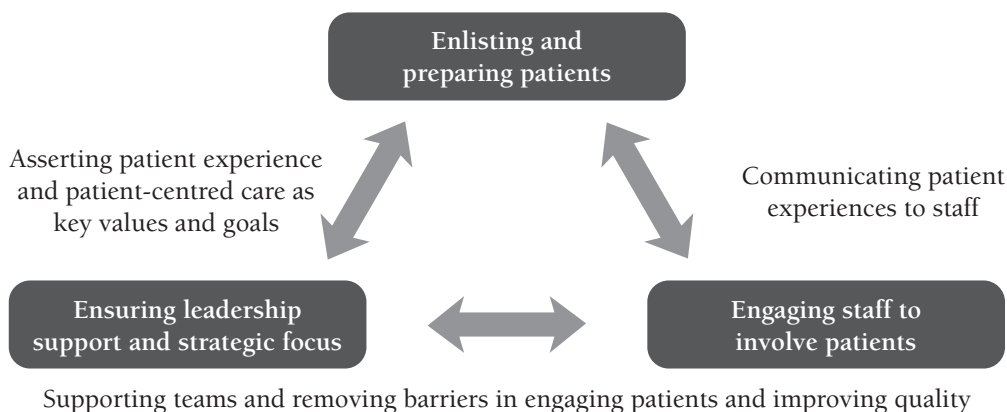
Engagement-Capable Environments

Based on our case studies from Canada, the US and England; our interviews with key informants; and our analysis of relevant literature, we believe engagement-capable environments are organizations or networks that respond to the needs and desires of patients and populations, and that create and foster a culture of patient-centredness and engagement. Engagement-capable environments are created by organizations and networks that build the necessary infrastructure and support the underlying values that encourage an active, ongoing and meaningful engagement of patients and families/caregivers with staff and leaders to collaborate in delivering high-quality care and a respectful and dignified patient experience. An engagement-capable environment promotes engagement and partnerships at all levels of care and is built around three key processes (Figure 3):

1. **Enlisting and preparing patients:** Effective engagement requires the ongoing recruitment and preparation of, as well as support for, patients and family members in their roles as patient and family advisors, and as members of various committees. It also requires support for patient and family engagement structures and initiatives across an organization or community. Initially, these support measures are often ad hoc; however, in engagement-capable environments there are clearly defined roles, policies and procedures to ensure development of a broad base of representative and effective patients who take part in a wide range of organizational activities, including improvement work.
2. **Engaging staff to involve patients:** To enable patients to influence policies, decisions and workflow, staff must value patient input, reshape their relationships with patients and family members and recognize the usefulness of their views and experiences. Staff must also be open to revising current ways of making decisions and providing care, and engage with patients using new methods. Several published tool kits provide guidance to support both patients and staff in patient engagement activities. Engagement-capable environments empower both patients and staff to work together to develop and implement sustainable improvements.
3. **Ensuring leadership support and strategic focus:** Empowering patients and staff to work in different ways requires strong leadership at senior levels and throughout an organization. Leaders enable the transformation of an organization's culture; articulate and help to embed patient-centred values and strategic focus; provide resources and support; and offer ongoing role-modelling of the behaviours that demonstrate and reinforce the necessary changes. Leaders create an expectation and accountability of staff to partner with patients, involving them not only on decisions on their care, but on issues across the

organization that influence policy and practice more broadly. Without strong leadership supporting the development of patient-centred care and patient engagement activities, the impact of these efforts will be limited. Governance also plays an important role in developing patient engagement. Organizational and system level boards set policies and create expectations that help to shape leadership actions and broader organizational strategies.

Figure 3: The three core processes of engagement-capable environments (Baker and Denis 2011)



These three core processes of engagement-capable environments reinforce each other and contribute to new values, relationships and ways of working. The organizational cultures of healthcare organizations characterized by successful long-term patient engagement embrace patient involvement as an essential element of all major activities and decisions. Of course, similar to other efforts to change organizational cultures, leaders need to recognize that the pace of change may be slow, and the rationale and benefits of the change need to be grasped by the full workforce. Cultural change is not easy; it requires long time frames, realistic aims and links to the experiences of staff and patients and families (Alvesson and Sverningsson 2015).

Many healthcare organizations, including several represented in this casebook, began their journeys toward patient engagement by enlisting small numbers of patients and family members who participated as advisors or team members in selected programs or activities. The Augusta University Health System (Augusta University Health) in Augusta, Georgia – formerly known as the Medical College of Georgia and Georgia Regents Health System – is widely recognized as one of the pioneers of patient and family engagement efforts. Similar to many other healthcare organizations, patient engagement at Augusta University Health began in pediatrics. Hospital staff started by involving family members in the design of a new children’s hospital in 1993, then spread the role of patient and family advisors to its adult hospital and outpatient clinics. Augusta University Health developed systematic recruitment, orientation and support resources that helped to integrate patients and families into its hospital and health system activities, and it now has more than 230 advisors across the system. Other hospitals, including Kingston General Hospital (KGH) in Kingston, Ontario, which was mentored by Augusta University Health

leaders, have followed a similar path, focusing on the careful selection and preparation of patients and family members to play meaningful roles as advisors and experts on the patient experience as a critical first step to improving care experiences and outcomes.

In other healthcare organizations, the significant transformational step was the integration of patients and family members into QI initiatives and teams. The McGill University Health Centre (MUHC) in Montreal, Quebec, engaged a group of former and current patients in its Transforming Care at the Bedside pilot program. Under the aegis of this program, patients joined with staff in learning new QI methods in the redesign of care. The presence of patients in this redesign also helped the pilot team to concentrate on several patient-focused changes, including the expanded use of whiteboards in patient rooms to communicate with patients and families and to improve staff communication and shift hand-offs. At Whittington Health in London, England, staff engaged patients in efforts to create an integrated focus on improved care for patients with chronic obstructive pulmonary disease – both in the hospital and the community. The patients helped to identify ways to manage their disease better and to improve communications between hospital-based consultants and GPs. Working together, patients and staff identified key supports and resources in the community that could contribute to sustaining patients outside the hospital.

Supporting staff to learn the value of and to participate meaningfully in patient engagement in improvement teams, unit councils and other working groups/committees is the second critical process necessary for meaningful patient engagement. KGH has developed education programs for staff that offer principles and practices of PFCC, helping to ensure that staff throughout the hospital support PFCC efforts. Facilitators assist in these initiatives, working to help both staff and patients contribute to councils and teams. New technologies also assist communication and engagement. In the Collaborative Chronic Care Network (C3N), patients, parents, clinicians and researchers from a large group of US pediatric hospitals focused on improving care for patients with inflammatory bowel disease (IBD). They developed a web-based platform that enables patients and parents across the country to share ideas and to interact with physicians, researchers and other staff in designing and providing better care for patients.

Leadership is critical to ensuring these efforts are developed and sustained. Senior leaders, such as Jim Mackay at Northumbria Healthcare Trust in northern England; Patty O'Connor at the MUHC; and Leslee Thompson, the former CEO at KGH, are visible symbols and champions of patient-centred care and patient engagement. Other leaders, including clinicians and those responsible for organizing patient- and family centred-care at the front line, help to maintain momentum, linking patient engagement efforts to other organizational strategies and ensuring commitment to working in new ways. At Augusta University Health, Bernard Roberson, the administrative director for PFCC, reinforces the strategic and operational focus on PFCC, noting, “People come, people go, but PFCC endures. It’s our foundation.”

Governance has also played an important role in efforts to create engagement-capable organizations. Boards that place a strategic focus on patient engagement help to ensure that these efforts

are sustained. And, as Jim Conway notes, in organizations where there is little support for patient engagement from the board, “leaders can lay low and outlive the initiative” (Conway 2016).

These examples of the key processes that underpin the development of PFCC and patient engagement processes illustrate some of the experiences of early and successful innovators. Other examples of strategies for creating engagement-capable environments are provided in Appendix 1, and a more detailed description of the implementation of these strategies is a major focus of the case studies in this book.

The benefits of greater patient engagement are widely shared by patients, staff, the organization and the broader community. Thompson, from KGH, summed up the impact of six years of integrating patients into many different activities this way: “Patients have stronger, more influential, real-time voices . . . which helps KGH staff think in new ways and improve.” The benefits are not only better experiences for patients and families, but also better outcomes. The C3N for IBD now engages staff and patients from more than 70 hospital clinics across the US in improving care for pediatric IBD patients. Along the way, the network has tested numerous innovations, creating new, simplified medication regimens that allow pediatric patients to manage their conditions more effectively. Many small changes have resulted in significant improvements for these patients. Over a period of five years, patient experience scores have increased and remission rates have moved from 55% to 79%.

Patient engagement may be the “blockbuster drug,” the “disruptive innovation” that transforms the delivery and impact of healthcare (Dentzer 2013; Kish 2012). The evidence of the impact of patient engagement is tantalizing, but most of the research focuses on engagement at a clinical level between providers and patients, not on the impact of creating organizations that have instilled new values and integrated new practices into daily work. Creating engagement-capable environments requires strong leadership and an understanding of the experiences of organizations – both those whose experiences are detailed here, as well as many others not covered in this book – so that the broader healthcare community can learn how to integrate patient engagement and patient-centred care into organizational practice. The cases that follow offer a rich array of experiences to inform leaders, staff, patients and families about improving care, care experiences and outcomes. A summary of the strategies for creating engagement-capable environments and an overview of the key attributes of the cases are included in Appendix 1 (p. 26).

The future of healthcare will be shaped by the structures, processes and resources that enable co-production. In 20 years, many observers may wonder why these changes took so long.

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APPENDIX 1

Table 1: Strategies for creating engagement-capable environments

Organization	Supporting patients/family for patient engagement	Supporting staff for patient engagement	Leadership for patient engagement
<i>McGill University Health Centre, Montreal, Quebec, Canada</i>	<ul style="list-style-type: none"> • Patients and staff supported to learn QI and engagement skills together “on the job” • Focused projects with specific goals • Clear roles and expectations • Seasoned patient representatives mentor less-experienced patient representatives 	<ul style="list-style-type: none"> • Patients and staff supported to learn QI and engagement skills together “on the job” • Ensure staff have protected time to engage in QI activities • Use facilitators to help teams build skills to implement changes and measures 	<ul style="list-style-type: none"> • Role model engagement behaviours • Senior leaders set expectations for managers about the value and importance of engagement and local QI activities • Ensure teams have the resources required to conduct QI and engagement activities • Ensure robust measurement plan in place (process and outcome measures)
<i>Kingston General Hospital, Kingston, Ontario, Canada</i>	<ul style="list-style-type: none"> • Establish recruitment processes for advisors • Provide resources for orientation, education and integration into their role • Provide education on QI, PFCC, organizational strategy and performance • Provide opportunities for advisors to showcase their roles and the value of their perspectives • Recruit strong patient advisors early on to develop their role and terms of reference for the PFAC 	<ul style="list-style-type: none"> • Provide education on QI, PFCC, organizational strategy and performance • Establish clear accountabilities for and auditing of expected practice standards for PFCC • Staff engagement in-step with patient engagement 	<ul style="list-style-type: none"> • Senior leaders practise patient-centred leadership • Leaders set clear expectations for the value of the patient voice and model behaviours expected of staff • Develop clear road map to achieve strategic directions • Develop resources, structures and processes to enable patient involvement • Clear expectations and accountabilities developed for improvement and engagement • Organizational champions of PFCC within an interprofessional care model • Mentorship from other PFCC organizations
<i>Augusta University Health System, Augusta, Georgia, USA</i>	<ul style="list-style-type: none"> • Establish recruitment processes for PFAs • Provide resources for orientation, education and integration into their role • Establish peer-support network and mentoring for PFAs • Provide PFCC education • Provide opportunities for PFAs to showcase their roles • Engagement breadth and depth determined by each PFA 	<ul style="list-style-type: none"> • Embed PFCC into new staff orientation • Offer refresher courses for staff/units through PFCC learning labs • Embed expected PFCC behaviours in job descriptions and performance reviews • Make ongoing coaching on PFCC available to staff and students 	<ul style="list-style-type: none"> • Role model and set expectations for PFCC behaviours • Consistent support for the patient voice at all levels of the organization • Dedicate structures, processes and resources for PFCC • Offer ongoing leadership development for PFCC, particularly with new senior leaders • Make explicit links between patient experience and quality and safety structures • Capture and share patient experience measures with patients and unit staff accountable for their performance

Table 1: Continued

Organization	Supporting patients/family for patient engagement	Supporting staff for patient engagement	Leadership for patient engagement
<i>Cincinnati Children’s Hospital Medical Center, Cincinnati, Ohio, USA</i>	<ul style="list-style-type: none"> • Establish regular (monthly) meeting FAC • Establish Patient and Family Experience Council to support patient experience summits every two weeks • Establish additional councils at organizational and unit levels 	<ul style="list-style-type: none"> • Participate in regular patient experience summits every two weeks (involving cross-disciplinary personnel, including patients) • Engage staff in user-centred design work 	<ul style="list-style-type: none"> • Develop a framework for operational excellence linking employee and staff experience through seven points of focus • Senior leadership establish Patient and Family Experience Council and appoint a physician as patient and family experience officer • Institute organization-wide brief to identify and address items critical to patient experience
<i>Whittington Health Respiratory Service, London, UK</i>	<ul style="list-style-type: none"> • Provide with self-management education and information • Offer financial support and cover expenses for service planning meeting attendance • Obtain feedback via surveys and interviews • Encourage patients to share experiences and perspectives 	<ul style="list-style-type: none"> • Support staff in their learning of new skills to encourage and facilitate patient self-management • Use small tests of change to make improvements and receive real-time patient feedback • Openness to learning from others (patients and various health professions) 	<ul style="list-style-type: none"> • Physician leaders supported by local service manager and local trust to make dramatic changes in new program • Model fine-tuned over 10 years to respond to needs/lessons learned from patients within their local context • Team-based initiative across care continuum • Funding model to support physicians working across care settings and incentivize early diagnosis and care
<i>Northumbria Healthcare Trust, North East England, UK</i>	<ul style="list-style-type: none"> • Establish peer-support program for patients with stroke • Membership on executive group for stroke improvement (and associated working groups) • Partnership with external charity (Age UK) provides real-time feedback to unit staff 	<ul style="list-style-type: none"> • Empower staff to recognize when caregivers seem stressed • Provide information on benefits, services and local caregiver’s centre • Provide near real-time data to unit staff within 24 hours of collection by patient experience team • Individual consultants receive individual data, which is fed into appraisal system • Offer training and support when performance falls below targets 	<ul style="list-style-type: none"> • Appoint a DPE, reporting to the CEO, whose role is defined in terms of QI • Allocate small budget for DPE to support ideas for improving the patient experience • Develop strategy whereby all QI efforts incorporate the patient experience in partnership with patients
<i>Patients as Partners, Ministry of Health, British Columbia, Canada</i>	<ul style="list-style-type: none"> • Provided with online orientation • Offered coaching, skill-building opportunities and information support 	<ul style="list-style-type: none"> • Matching process (of patients to providers/initiatives) facilitated by Patients as Partners • Consolidate engagement resources, knowledge and expertise 	<ul style="list-style-type: none"> • Establish infrastructure to support Patients as Partners philosophy • Assume collaborative approach and distributed leadership across sectors • Anchor engagement within Triple Aim QI framework

Table 1: Continued

Organization	Supporting patients/family for patient engagement	Supporting staff for patient engagement	Leadership for patient engagement
<p><i>Northumberland Community Partnership, Cobourg, Ontario, Canada</i></p>	<ul style="list-style-type: none"> • Structured one-on-one recruitment strategy • Develop a sense of teamwork by learning EBCD together with staff and caregivers • External facilitation to ensure patient supported and encouraged through sessions • Learn together through the entire project process • Developed RISE team to support patient representatives throughout engagement processes • Focus on community mobilization and tapping into the skills and expertise of seniors 	<ul style="list-style-type: none"> • Learn together to support staff and patients to learn EBCD methods and to share perspectives to enhance understanding of each others' experiences • External facilitators ensure mutual respect and openness • Focus on relationship-building between patients and providers 	<ul style="list-style-type: none"> • Leaders across the continuum showed explicit support for PATH, making connections with other leaders/organizations • Establish strong governance structure when working with broad stakeholder group • Develop roles, responsibilities and terms of reference • Assume a flexible approach to learning and supported changes to project plans as teams evolved and learned together • Ensure appropriate measures in place for evaluation • Strong history with community engagement efforts supported ongoing engagement throughout PATH • Focus on developing relationships with all partners
<p><i>Collaborative Chronic Care Network (C3N), Cincinnati, Ohio, USA</i></p>	<ul style="list-style-type: none"> • Families made aware of the network • Engagement breadth and depth determined by each patient • Broad range of initiatives for patients and families to be involved in • Flat hierarchy enables patients' participation and feeling they are valued • Common goal drives input from all • Parents coach other parents how to form a mentoring group and incorporate parents into QI teams • Patients educated to learn new skills through automated self-management tools • Infrastructure supports: job descriptions for Patient Advisory Council members, matching of patients with innovation teams 	<ul style="list-style-type: none"> • Establish a common understanding of co-design potential and value of the patient voice • Technology, processes and tools make collaboration easier and facilitate engagement beyond traditional meetings • Flattened hierarchy supports engagement from all stakeholders • Standard progress measures established and understood 	<ul style="list-style-type: none"> • Leaders support an integrated system to mobilize patients, family and community members in the delivery and improvement of care • C3N supported by strong existing engagement culture based out of Cincinnati Children's Hospital Medical Center in collaboration with ImproveCareNow Network • Strong adherence to a flattened hierarchy across the network • Transparency related to regular sharing of outcome data, examples of successful care centres and personal narratives • Electronic medical record helps to capture patient information and upload into registry • Support for communication strategies to share knowledge and coordinate effort across all sites • Support for the development of technological platforms that allows the networking of 70+ sites across the US to share information and knowledge, and to encourage others to join

Table 1: Continued

Organization	Supporting patients/family for patient engagement	Supporting staff for patient engagement	Leadership for patient engagement
<i>Saskatchewan Health Quality Council and Saskatoon Health Region, Saskatchewan, Canada</i>	<ul style="list-style-type: none"> • Targeted recruitment and defined role for patients/ caregivers • All patients/caregivers provided orientation and onboarding support • Ongoing training offered throughout • Standardized education materials developed • Robust network (165 advisors) 	<ul style="list-style-type: none"> • All staff trained in Lean methodology 	<ul style="list-style-type: none"> • Requirement to have patient representatives on every RPIW team • Role-modelling of expected behaviour • Clear strategic directions

CEO = chief executive officer; DPE = director of patient experience; EBCD = experience-based co-design; FAC = Family Advisory Council; PATH = Partners Advancing Transitions in Healthcare; PFACs = Patient and Family Advisory Councils; PFAs = patient and family advisors; PFCC = patient- and family-centred care; QI = quality improvement; RISE = Respect Inform Support Empower; RPIW = rapid process improvement workshop.

Table 2: Overview of case studies’ patient-engagement settings, strategies and impacts

Organization	Setting	Patient-engagement strategies used	Examples of impacts of patient engagement
<i>McGill University Health Centre, Montreal, Quebec, Canada</i>	<ul style="list-style-type: none"> • Organization-based: Large urban academic health sciences centre offering acute and post-acute care for adult and pediatric populations across six hospitals • Serves population of 1.7 million people 	<ul style="list-style-type: none"> • Long-standing history with user committees across the organization (as a result of Quebec legislation) and patient representatives on many prominent organizational committees, as well as on the board of directors • Since 2010, has embedded patient representatives onto teams with staff for QI by leveraging work done with TCAB, initially piloted on five units 	<p>Education/Tool development</p> <ul style="list-style-type: none"> • Standardized patient education materials <p>Improved care or service delivery</p> <ul style="list-style-type: none"> • TCAB has spread to 19 units with new grants and investments being made to accelerate and spread co-design activities • In the five pilot units, many newly developed or redesigned processes and materials, such as admission processes, communication strategies (e.g., use of whiteboards, hand-off and documentation processes, visual triggers to shorten bed turnover time), quiet zone for nurses while administering medications, physical space redesign <p>Outcomes (results from first five TCAB units)</p> <ul style="list-style-type: none"> • 50% decrease in medication interruptions, 60% decrease in medication errors, 8% increase in registered nurse direct time in care, increased patient satisfaction, cost savings in equipment, decreased infection rates (25% for <i>Clostridium difficile</i> and 26% for VRE), improved team effectiveness, statistically significant reduction in nurse voluntary turnover and overtime

Table 2: Continued

Organization	Setting	Patient-engagement strategies used	Examples of impacts of patient engagement
<p><i>Kingston General Hospital, Kingston, Ontario, Canada</i></p>	<ul style="list-style-type: none"> Organization-based: Academic hospital, including complex-acute and specialty care, cancer centre and 24 regional satellites Serves population of 500,000 in urban areas and outlying regions 	<ul style="list-style-type: none"> Developed a working definition of PFCC – “Respect me. Hear me. Work with me” – to guide patient-centred activities across the organization Since 2010, developed and implemented role of patient-experience advisors who work in partnership and collaboration with staff and leaders in areas requiring decisions that have patient impact (e.g., organization-wide and program specific committees, working groups, interview panels, strategic planning) Currently has an active PFAC and 60+ advisors that have contributed 5,000+ volunteer hours per year Visible presence of advisors throughout organization and in external forums promoting PFCC and patient engagement 	<p>Education/Tool development</p> <ul style="list-style-type: none"> Development of patient education materials Informed Policy or Planning Initiative Development of new policies and procedures (most notably Family Presence Policy) <p>Improved care or service delivery</p> <ul style="list-style-type: none"> Numerous service and process redesigns throughout hospital for quality and safety, and advancing core concepts of PFCC through five basic standards (i.e., identification badges, purposeful hourly rounding, effective and empathetic communication, bedside communication/whiteboard, patient-led feedback forums) <p>Outcomes</p> <ul style="list-style-type: none"> Improved hand hygiene compliance (from 34% to 98%) Decreased hospital-acquired infections
<p><i>Augusta University Health System, Augusta, Georgia, USA</i></p>	<ul style="list-style-type: none"> Organization-based: Academic health centre offering acute-care services to adult and pediatric populations, cancer care centre, outpatient clinics and satellite practices throughout Georgia 	<ul style="list-style-type: none"> Early pioneer in development of organizational design supporting PFCC since 1993 Development and implementation of the role of PFAs who serve on numerous organization-wide, program-specific committees (45 committees in 2013), working groups, interview panels, PFACs, with over 230+ advisors across the organization Developed role of Patient and Family Faculty (advisors) to educate students in health professions and staff regarding principles of PFCC and related behaviours Patient advisors also prominent in external presentations for organization and as mentors 	<p>Education/Tool development</p> <ul style="list-style-type: none"> Development of numerous education materials for patients Informed Policy or Planning Initiative Review of all policy and procedures based on PFCC principles (most notably the development of the Family Presence Policy) <p>Improved care or service delivery</p> <ul style="list-style-type: none"> Numerous hospital-wide efforts (e.g., design of new children’s hospital) and program-specific changes (e.g., design of new stroke services unit) implemented to processes and systems of care <p>Outcomes</p> <ul style="list-style-type: none"> Cost savings in design and construction costs Lower liability costs related to patient claims Improved patient experience scores (as measured by Hospital Consumer Assessment of Healthcare Providers and Systems) Decreased medication errors and falls; shorter lengths of stay; decreased readmissions, decreased staff turnover Positive feedback from patients regarding their involvement

Table 2: Continued

Organization	Setting	Patient-engagement strategies used	Examples of impacts of patient engagement
<p><i>Cincinnati Children’s Medical Center, Cincinnati, Ohio, USA</i></p>	<ul style="list-style-type: none"> • Organization-based: Non-profit academic medical centre, one of the leading pediatric hospitals in the US • 600-bed hospital providing acute care services to children 	<ul style="list-style-type: none"> • Creation of PAC, FAC, Patient and Family Experience Council and appointment of a physician as the patient and family experience officer • Strong integration of patients into quality and safety improvement work across the hospital and clinics • Creation and support of several networks of pediatric hospitals and specialty groups to promote safer care and to design more effective care for patients with chronic diseases 	<p>Education/Tool development</p> <ul style="list-style-type: none"> • PAC’s creation of a list of helpful strategies for employees to use while working with kids and developed communication tools for patients who are unable to speak <p>Improved care or service delivery</p> <ul style="list-style-type: none"> • Creation of a one-stop shop and a true hub model where patients and families are at the centre • FAC’s influence on campus design and building of medical centre <p>Outcomes</p> <ul style="list-style-type: none"> • Improved patient outcomes and family experiences, dramatic reduction in in-hospital-acquired infections, more reliable systems for delivering care safely, greater efficiency and timeliness, better management of hospital resources, significant savings to the healthcare delivery system
<p><i>Whittington Health respiratory service, London, UK</i></p>	<ul style="list-style-type: none"> • Integrated services across acute-care and community health services serving an ethnically diverse population of 460,000 with high levels of need • Program-specific initiative with COPD patients across the care continuum 	<ul style="list-style-type: none"> • Patient input in development of program through all phases; feedback via surveys (monthly) and interviews; patient co-design (with staff) of education materials • Shift from providing care to working with patients 	<p>Education/Tool development</p> <ul style="list-style-type: none"> • Development of patient education materials <p>Improved care or service delivery</p> <ul style="list-style-type: none"> • Development of an award-winning integrated, team-based program considered best practice for COPD patients across the continuum, influencing implementation of similar programs across the UK • Development of a number of new programs that focus on exercise, self-management, smoking cessation, end-of-life decision-making and palliative care, and psychosocial support encompassed within overall program <p>Outcomes</p> <ul style="list-style-type: none"> • Significant improvements in clinical outcomes (decreased COPD mortality and 90-day mortality), patient experience, costs

Table 2: Continued

Organization	Setting	Patient-engagement strategies used	Examples of impacts of patient engagement
<p><i>Northumbria Healthcare Trust, North East England, UK</i></p>	<ul style="list-style-type: none"> Acute and community health services and adult social services 	<ul style="list-style-type: none"> Public consultation process early in engagement work: built public confidence and helped trust refine original proposal QI strategy grounded in patient engagement to improve patient experience Patients integrated into QI working groups and executive committee Peer support program established in stroke services, 24 patients trained to provide peer support and communicate with staff Partnership with charity group to provide feedback to unit staff on patient experience 	<p>Education/Tool development</p> <ul style="list-style-type: none"> Informed Policy or Planning Initiative All QI initiatives grounded in patient experience <p>Improved care or service delivery</p> <ul style="list-style-type: none"> Peer support program established; near real-time patient feedback data provided to units by patient experience team Governance Engagement activities altered senior management composition Creation of DPE position that shares director of quality position with a physician <p>Outcomes</p> <ul style="list-style-type: none"> Statistically significant changes in coordination of care measures and patient experience Majority of staff recommending trust as a place to work or receive care 94% of staff feel their work makes a real difference
<p><i>Patients as Partners, Ministry of Health, British Columbia, Canada</i></p>	<ul style="list-style-type: none"> Province-wide initiative led by BC Ministry of Health in partnership with healthcare providers, universities, healthcare not-for-profits and NGOs 	<ul style="list-style-type: none"> Infrastructure supports provided from top-down to facilitate bottom-up operationalization of patients as partners philosophy Centralized knowledge and resources to facilitate matching of patient to healthcare providers seeking to partner with patients for QI Provision of engagement training for staff and patients together Partnering with community to engage patients through established community networks 	<p>Education/Tool development</p> <ul style="list-style-type: none"> Curriculum developed to orient patients to patient engagement and prepare patients for their role as partners Education and training provided to healthcare staff and patient partners to ensure meaningful engagement <p>Improved care or service delivery</p> <ul style="list-style-type: none"> Patients members of provincial surgical executive committee <p>Outcomes</p> <ul style="list-style-type: none"> 1,400 Patient Voices Network members 406 patient partners placed in 114 engagement opportunities Establishment of Patients as Partners recommended in New Brunswick Primary Healthcare Framework Statistically significant change in patient activation levels 75% of self-management workshop attendees expressed intention to make a positive health behaviour change as a result of attending an iCON event

Table 2: Continued

Organization	Setting	Patient-engagement strategies used	Examples of impacts of patient engagement
<p><i>Northumberland Community Partnership, Cobourg, Ontario, Canada</i></p>	<ul style="list-style-type: none"> • Inter-organizational network supporting seniors and complex patients in acute care, community care, primary care and community services brought together to form the PATH project 	<ul style="list-style-type: none"> • EBCD prime method of involvement for patients and families in all initiatives associated with PATH • Numerous patients and caregivers involved in working groups, committees and storytelling from inception to completion of their projects • Created multiple opportunities for patients and caregivers to be involved, at different levels, for different time frames, for different tasks/projects • Development and use of mobile technology platform to support self-care and communication with providers 	<p>Education/Tool development</p> <ul style="list-style-type: none"> • Developed and co-designed website as community resource for aging well at home <p>Improved care or service delivery</p> <ul style="list-style-type: none"> • Strong technological component co-designed with patients and staff to monitor symptoms/indicators at home, provide communication strategy with providers from home, provide input by patients into their needs/preferences/concerns that can be shared with care providers, all of which enable self-management strategies and partnerships between patients and providers • Implementation of transition coaches • Positive feedback from patients and their caregivers, providers and leaders on co-design processes <p>Outcomes</p> <ul style="list-style-type: none"> • Patients developing sense of empowerment over their health and self-management
<p><i>Collaborative Chronic Care Network (C3N), Cincinnati, Ohio, USA</i></p>	<ul style="list-style-type: none"> • Inter-organizational network focused on chronic conditions in pediatric populations • Initial focus on IBD in children • 70+ sites across country in ImproveCareNow Network (approximately one-third of all children with IBD in the US) 	<ul style="list-style-type: none"> • Patients and families encouraged to participate and share experiences in areas most meaningful to them and to the level they are able • Technology platform enables all stakeholders (patients, parents, providers, researchers, leaders) to work and learn together from current care delivery patterns and care experiences • Fundamental shift from a hierarchical, expert-driven approach to a flattened hierarchy that reflects a common purpose and encourages the co-production of information and knowledge across patients, families, clinicians and researchers 	<p>Education/Tool development</p> <ul style="list-style-type: none"> • Developed series of self-management support tools currently being tested in ImproveCareNow study • Parents collaborated on research teams in planning to identify research questions and to develop new innovations • Parents and clinicians co-teach modules at learning sessions <p>Improved care or service delivery</p> <ul style="list-style-type: none"> • Development of applications on mobile devices to collect and monitor patient health data, track symptoms and outcomes, identify important issues • Developed Facebook application that matches children with other children who have similar issues and interests <p>Outcomes</p> <ul style="list-style-type: none"> • Improved medication adherence and reduction in medication dosages • Increased patient satisfaction and overall happiness level, and increased remission level (from 55% to 79%)

Table 2: Continued

Organization	Setting	Patient-engagement strategies used	Examples of impacts of patient engagement
<p><i>Saskatchewan Health Quality Council and Saskatoon Health Region, Saskatchewan, Canada</i></p>	<ul style="list-style-type: none"> • Provincial quality council and health region 	<p>Saskatchewan Health Quality Council</p> <ul style="list-style-type: none"> • Accountability at the provincial level through oversight provided by quality council • Formalized governance structure in place through PFCC Guiding Coalition • Lean training for all participants <p>Saskatoon Health Region</p> <ul style="list-style-type: none"> • Robust network of advisors • CFCC steering committee • Formalized recruitment and application process • Orientation and ongoing education/training for advisors • Formal linkages between QI and patient engagement • At every RPIW, there must be a patient voice present • Facilitators brought in to facilitate workshops 	<p>Education/Tool development</p> <ul style="list-style-type: none"> • Standardized education modules developed for patients, families, staff on PFCC principles and on patient and family engagement <p>Improved care or service delivery</p> <ul style="list-style-type: none"> • Patients and families involved in RPIWs <p>Outcomes</p> <ul style="list-style-type: none"> • Improved response time for patient satisfaction/experience surveys • Governance • PFCC steering committee established

CFCC = client- and family-centred care; COPD = chronic obstructive pulmonary disease; DPE = director of patient experience; EBCD = experience-based co-design; FAC = Family Advisory Council; IBD = irritable bowel disease; iCON = interCultural Online Health Network; NGO = non-governmental organization; PAC = Patient Advisory Council; PATH = Partners Advancing Transitions in Healthcare; PFAC = Patient and Family Advisory Council; PFAs = patient and family advisors; PFCC = patient- and family-centred care; QI = quality improvement; RPIW = rapid process improvement workshop; TCAB = Transforming Care at the Bedside; VRE = vancomycin-resistant *Enterococcus*.