

# The Leadership and Organizational Context Required to Support Patient Partnerships

## Le leadership et le contexte organisationnels nécessaires à l'épanouissement du partenariat avec le patient

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### **Abstract**

Healthcare providers and managers typically design programs based on what they believe patients need and want. Yet patients have knowledge and insight into how the system can be changed to better meet their needs, improve outcomes and reduce costs. We describe challenges in creating a culture of patient partnerships and the leadership actions and organizational context required now and in the future to support engagement-capable environments at the organizational and policy levels in Canada. Case examples illustrate the need for leaders to set clear expectations, develop the infrastructure to support patient partnerships and provide education to staff, physicians and patient partners.

### **Résumé**

Les prestataires et gestionnaires de soins de santé conçoivent généralement des programmes selon une conception théorique des besoins et des volontés du patient. Pourtant, le patient a des idées et des connaissances par rapport aux éléments du système qui gagneraient à être changés pour mieux répondre à ses besoins, améliorer ses résultats et réduire le coût des soins. Cet article décrit les défis liés à la création d'une culture de partenariat avec le patient pour aujourd'hui et demain, les actions que doivent prendre les dirigeants et le contexte organisationnel nécessaire pour instaurer des milieux propices à l'engagement aux niveaux organisationnel et politique au Canada. Les exemples de cas illustrent la nécessité pour les dirigeants d'établir des attentes claires, d'aménager l'infrastructure nécessaire pour soutenir le partenariat avec le patient et de former le personnel, les médecins et les patients partenaires.

## KEY MESSAGES

1. Leaders at all levels need to walk the talk by setting clear expectations, developing infrastructure and committing resources to support patient partnerships and person- and family-centred care.
2. Patients, families and caregivers need to be partners in the co-design of health system improvements as they have experiential knowledge and insight into how the system can be changed to better meet needs, improve outcomes and reduce costs.
3. Training and education of staff, physicians and patient partners in quality improvement and co-production creates a common language and a foundation for innovation.

## Background

Leading successful change in healthcare and sustaining the gains are challenging work. This work is influenced by many factors and involves recognizing the need for change and being able to mobilize the time, effort and expertise of others. Contextual factors known to be important to quality improvement (QI) success include leadership from top management, organizational culture, improvement initiatives that engage staff, resource allocation, data infrastructure and information systems and years involved in QI (Kaplan et al. 2010; VanDeusen Lukas et al. 2007). There is growing recognition that for true health system transformation to occur, those receiving care must be included in co-designing the needed improvements in care, service delivery and policy. This involves mobilizing the time, effort and expertise of patients, families and caregivers as partners working side by side with providers and managers. There is now substantial evidence that strategies to strengthen patient and public engagement are effective (Batalden et al. 2015; Bate et al. 2008; Boivin et al. 2014; Holmes et al. 2018; O'Connor et al. 2016; Verma et al. 2017) and lead to better health outcomes and lower costs (Anhang Price et al. 2014; Doyle et al. 2013; Manary et al. 2013).

Meaningful and effective partnership occurs when the trilogy of leadership support for person- and family-centred care is matched with staff skilled in delivering person-centred care and when patients and families are treated as necessary partners in care and QI (Baker and Denis 2011). Meaningful partnership involves a complex culture change in values and organizational transformation rooted in a long-term commitment and vision of what can be achieved through effective partnerships with patients, families and communities (Baker 2014; Baker et al. 2016). The Carman framework (Carman et al. 2013) serves as a useful guide in understanding the many ways in which patients and families can be meaningfully engaged at the direct care level, as well as in organizational design and governance and in policy making.

This article describes challenges in creating a culture of patient partnerships and the leadership actions and organizational context required now and in the future to support engagement-capable environments at the organizational and governance levels and at the policy level. This article reflects the authors' collective experiences and common vision in

leading patient partnership initiatives within Canada. Di Carlo is a patient partner with extensive experience in leading improvements at the local, provincial and national levels (a patient surveyor with Accreditation Canada) and a master trainer in chronic illness self-care management; O'Connor is a nurse leader who has led co-design transformations at the organizational level and supported over 100 pan-Canadian teams in co-leading QI initiatives with patient partners; and Rouleau, a physician and former dean of medicine, was the key leader in supporting the creation of a new centre at the University of Montreal for patient partnerships in the undergraduate education of all healthcare disciplines and in identifying the advancement of patient partnership research as one of the five core objectives of the Strategy for Patient-Oriented Research (SPOR) of the Canadian Institutes of Health Research (CIHR). We hope to provide actionable guidance on a set of leadership actions that people working on health system improvements, including patients, families and caregivers, can use.

## Challenges in Creating a Culture of Patient Partnerships

Many of the barriers to effective partnerships at the organizational level are cultural in nature. Although patient involvement is advocated, healthcare providers and managers typically design programs based on what they believe patients need and want. Unlike other industries that have a long history of tapping into their customers' experiences and objectives to create value for services, healthcare has largely remained focused on the experiences and objectives of providers. With true patient engagement, solutions are designed and delivered with patients rather than to or for them. Theories on shared or distributed leadership propose that a multi-level, dispersed but integrated system of leadership holds many of the keys to a whole systems approach to quality (Bate et al. 2008; Denis et al. 2001; Nelson et al. 2002). Deliberation theory further suggests that patient involvement can foster mutual influence and increased agreement between patients and professionals, resulting in collective decisions about healthcare services and policies that are more acceptable by those affected (Abelson et al. 2003). Patient involvement on healthcare boards of directors is still a relatively new phenomenon in many Canadian

provinces, with the exception of Quebec, which mandated this in 1991 with the *Act Respecting Health Services and Social Services* (Province of Quebec 1991). Evidence of multi-level involvement of patient partners in QI initiatives, although growing rapidly, is recent, and the degree to which this is consistently in place throughout all levels of a service delivery organization is still highly variable.

Reflecting broader changes in society, patients and caregivers are increasingly more vocal about their challenges with the care delivery system. Finding ways in which they can address these concerns in meaningful and constructive ways to help co-design improvements with those running the health-care system is a new developmental course for most persons. Feedback from many patient partners underscores their perception of how long it takes for decisions to be made and change to occur.

### **Leadership Actions to Support Partnerships and Co-Design**

The ultimate aim of successful patient engagement is accelerating healthcare improvement and better health outcomes, with patients and staff having collective ownership of efforts to improve their shared healthcare service. Power resides not within any one stakeholder group but within the process of co-production or co-design (Robert 2016). Borrowing from design thinking, we identified two core design elements underlying effective partnerships and co-design to guide leaders in their work. The first element is to understand the experiences, needs and expertise of patients and families (care as seen through their eyes) before moving to solutions. There are many ways of capturing the voice of patients (Alberta Health Services 2014), and their stories can serve to motivate and inspire providers to consider how experiences shared by patients may be improved. The second core element is the premise “nothing about me, without me.” In this instance, patients, families and caregivers are part of the co-design team in generating a range of ideas to solve problems in service or care delivery that matter to them and then testing and evaluating the solutions. Described below are leadership actions and case examples of how Canadian and other organizations are embedding these design principles into the building of engagement-capable environments. This list is far from exhaustive.

#### **Set clear expectations, develop infrastructure and commit resources to support patient partnerships and person- and family-centred care**

As a starting point, executive leaders enable the transformation of an organization’s culture by building a common vision, articulating the expectations and helping embed person-centred values as a strategic focus. It is their job to communicate to staff and physicians the need for change and explain

how they will benefit from having patients as partners, for example, answering the “what’s in it for me” to various stakeholder groups, showing the link between their own priorities and those of patient partners. Engagement of a wide range of stakeholders is important, and leaders at all levels play an important role in identifying champions to move priorities forward. Although co-design methods provide ideal opportunities for addressing complex change, organizations should be using a wide range of partnership activities.

At Kingston General Hospital in Ontario, strong and courageous leadership from the executive team over several years led to the deliberate integration of patients into every layer of the organizational structure, including in the hiring of all clinical staff, sending a clear message about accountability and “a new way of doing business” within the organization. A bundle of practice changes specifically aimed at improving communication with patients and families were also implemented with all staff. Similarly, at McGill University Health Centre in Quebec (MUHC), the “Transforming Care at the Bedside” initiative, with initial funding from the Canadian Foundation for Healthcare Improvement (CFHI), rolled out over five years extensive practice changes across six acute care hospitals. Building on a strong foundation of person- and family-centred care at MUHC, patients and caregivers were partnered with front-line clinical teams to identify the problems in care delivery, generate and test new ideas and then evaluate the outcomes. Grants totalling \$1M and \$1.6M of in-kind resources were critical in enabling both significant innovations in care and staff capacity to co-lead QI with patients. Ultimately, infrastructure and resources were created at the corporate level to support patient partnership opportunities in a more systematic way across all clinical programs. Co-leadership of quality committees became the new expectation, along with patient membership at many decision-making tables. Accreditation Canada acknowledged this work with two leading practice awards. Commitments to building the capacity of patients to self-manage their health conditions was supported over many years through funding the My Toolbox program, based on Stanford University’s Chronic Disease Self-Management Program. MUHC’s multi-year journey reflects the relationship between the maturation of context and the sophistication of engagement methods used.

Since 2010, CFHI has provided funding and support to hundreds of teams through its learning collaboratives, with an explicit focus on building capacity to partner with patients in QI. One organization, Huron Perth Healthcare Alliance in Ontario, was supported in its multi-year journey in person-centred care and patient partnerships, providing an excellent example of how leadership with a clear vision and strategic

focus has transformed its organization. Unit action councils were created in 2011 with patient partners as members, followed in 2012 by the change to open visitation across all their sites and the use of bedside whiteboards to improve communication with families. In 2013, the alliance created a patient experience committee, followed in 2015 by the introduction of standardized uniforms when patients indicated that they could not tell who was who among the staff; and in 2016, they implemented bedside change-of-shift reporting including families, again in response to families' requests for better information about what was happening with their loved ones. Improvements in the patient and family experience of care were matched by better efficiencies and greater staff satisfaction.

Creating the infrastructure support includes recruitment of patient partners who reflect diversity, as well as the proper match of patients and projects. Recruitment tailored to the specific illness-related quality teams allows professionals to draw upon the lived expertise of patients. Many organizations have struggled with overuse of specific patient partners, contributing to burnout. Online resources regarding recruitment and training of patient partners are available from many provinces and jurisdictions, such as British Columbia, where they recruit and train a large pool of patients and caregivers from which organizations can draw. In a Quebec study, Boivin and colleagues conducted the first cluster randomized controlled trial of public involvement in collective healthcare decisions at the population level, comparing priority setting in two different regions, one with and one without public (patient) involvement (Boivin et al. 2014). In addition to their findings of the positive influence of patient involvement in shifting priorities at the regional level, their study was notable for recruitment methods of a diversified pool of patients, which ensures a balanced representation of age, gender, socio-economic condition and health status.

Compensation of patient partners is an important issue that needs to be addressed by organizations. There is considerable variation in practices, with some organizations not even compensating patients, families or caregivers for basic out-of-pocket expenses. In Saskatchewan, policy guidelines exist where patient and family advisors are eligible to receive an honorarium, in recognition of their contributions. The Change Foundation (2017), Ontario's independent health policy think tank, has provided a decision tool developed and used internally by the organization to determine the conditions under which patient engagement participants should be paid.

**Patient partners have a wealth of experience beyond their lived experiences in the healthcare system.**

### **Provide training/education to staff, physicians and patient partners in QI and co-production**

Engagement-capable environments not only value partnerships with patients; they also focus equally on staff engagement, encouraging local innovation. They realize that a top-down and a bottom-up approach are required for real transformation. Staff satisfaction (or lack thereof) is a key driver of patient experience. Mandating that clinical QI teams must include patient partners does not guarantee that real partnerships will be developed. Clear role descriptions for all team members and patient advisors must be provided, as well as guiding principles for partnerships and the evidence that supports person- and family-centred care practices. Also, someone should be designated to facilitate active listening, shared decision-making and collaboration to gradually build trust. Fundamentally, this process involves professionals learning to share control of the decision-making processes.

Co-education of patient partners, staff and physicians on QI and change management creates a common language. Most organizations now systematically survey patients on their experience of care. But if front-line care teams have not been provided with the time and support to learn QI methods, little change will occur (Coulter et al. 2014; Robert and Cornwall 2013; Sheard et al. 2017). Feedback from patients who have been invited to work as co-design partners on QI initiatives (versus a single consultation process) is unequivocal that their involvement needs to be from the very beginning of the initiative. Tip sheets on how to successfully engage patient partners in QI initiatives, designed by patient partners, have been developed by CFHI (2018a, 2018b, 2018c). Mentoring of patient partners, preferably from experienced partners, provides them with an important peer support network.

Patient partners have a wealth of experience beyond their lived experiences in the healthcare system. In the case of Huron Perth, patient partner Cathy Bachner directed her vast skills and creativity as an elementary schoolteacher into designing and providing the training for nurses on how to conduct meaningful and effective bedside shift reports. Her multiple hospitalizations gave her invaluable insights into how care and communication "could be better if ...". A further example of patient partners lending their expertise was evident in a recent CFHI collaborative focused on improving access to specialist consultations for persons living in rural and remote areas (the Connected Medicine program). During a workshop, a group of patient partners from different teams jointly developed a survey tool to measure the effectiveness of the new consultation process based on what mattered most to them. As a global pioneer in the science of patient partnership, the Centre of Excellence on Partnership with Patients and the Public (CEPPP) at the University of Montreal prepares healthcare students from all disciplines to understand patients as partners in care (CEPPP

2018). Built on a laboratory, a school and a network of partnership experts, the centre is developing new practices that focus on dialogue and sharing knowledge to improve the patient experience and the effectiveness of healthcare.

At a more macro-system and policy level, programs aimed at strengthening chronic illness self-management skills are a strategic decision and investment with far-reaching positive impacts and return on investments. The Stanford model and the Centre ÉPIC at the Montreal Cardiology Institute are just two examples. As well, a vast amount of information is now available, from diagnostic tools to side effect profiles, which people are acting on. There is an urgent need in Canada to harness the power of “big data” through practical information-sharing electronic platforms and to optimize its use by patients and their families in self-managing their health. The CIHR Strategy for Patient-Oriented Research (SPOR) is another example of strategic leadership leveraging its resources to ensure better alignment with what matters most to patients and communities.

### **Walk the talk**

Strong, inspired and highly persistent leadership is necessary to overcome barriers to engagement and to demonstrate what it looks like in practice. This needs to come from organizational leaders, clinicians and patient partner leaders. It involves clearly articulating the organization’s goals related to partnerships, being visible as a leader, asking how the partnerships are going, ensuring that patients or caregivers are present at all levels of decision-making, conducting regular rounds to support teams, ensuring robust measurement and evaluation, celebrating progress and communicating the results extensively within and outside the organization or network. Organizations recognized for having achieved significant culture change have been highly focused, directing resources to ongoing learning of all staff and physicians and toward the development of real-time data platforms that provide continuous feedback on patient experience of care and clinical outcomes. They then hold their staff accountable for using that data to drive the next stages of improvement, in partnership with patients, families and caregivers.

Southcentral Foundation (SCF), an Alaska Native-owned non-profit healthcare organization serving Alaska Natives and Native Americans, is a prime example of leadership “walking the talk.” A winner of the 2011 and 2017 Malcolm Baldrige National Quality Award, SCF is recognized as one of the world’s leading models of healthcare redesign, built upon the simple yet revolutionary belief that the relationship between the primary care team and the patient (known as the customer-owner) is the single most important tool in managing chronic disease, controlling healthcare costs and improving the overall wellness of a population. The focus on relationships extends beyond healthcare delivery. To ensure whole-system transformation, each key work system was redesigned – including workforce

development, compliance, human resources and finance – to ingrain an organization-wide focus on relationship building and shared decision-making. Patient satisfaction/experience ratings are 95%, whereas employee satisfaction is 95%, and SCF has been pursuing these improvements since 1998. SCF serves as an outstanding example of the relationship between maturation of context and use of sophisticated, multi-level engagement behaviours over time.

On a smaller scale, Bruyère Continuing Care in Ontario serves as a case example of how organizational commitment to improving transitions in care by better understanding care through the eyes of patients can lead to multi-level practice changes. A CFHI-funded team between 2014 and 2015, Bruyère implemented Always Practices – aspects of the patient experience that are so important to patients and families that healthcare providers must perform them consistently for every patient, every time. Bruyère heard from its advisory committee that patients and families wanted to be more included in their plan of care, so staff began conducting bedside handovers using patient-co-designed care boards. Patients indicated that they wanted to see their nurses more, so Bruyère instituted hourly rounding. Clinical teams told leaders they wanted better communication, so priority huddles and lists became part of the intervention bundle. In addition, Bruyère developed a volunteer ambassador program, established a patient and family advisory committee and partnered with CCAC and the Champlain LHIN to open its Path to Home Resource Lounge. In 2016, these changes were recognized as Leading Practices by Accreditation Canada.

At the macro-system level, several examples are noteworthy. Patients, families and caregivers are mobilizing to accelerate change through the creation of forums such as Patients Canada, the Patient Advisory Network, the Patients Critical Co-op and a plethora of illness-specific associations, all aimed at advocating for a stronger role in shaping health policy, service delivery, research or education in Canada. In both Saskatchewan and Prince Edward Island, leaders walked the talk by implementing policy changes to support open visitation by families and loved ones across the province, recognizing their role as partners in care, not just visitors. CFHI has been a powerful leader in stimulating transformative change within organizations through its funding priorities, its learning collaboratives with skilled coaching to interprofessional teams and patient partners and the hiring of a patient partner in 2017. The Canadian Patient Safety Institute (2016) also strongly promotes patients as partners in all of their work promoting safer healthcare environments. Accreditation Canada and Health Standards Organization have leveraged their influence by setting new standards related to person- and family-centred care and by including patient surveyors as part of the accreditation review team.

## Reflections on the Future

There has been considerable progress in Canada in developing knowledge and leading practices related to partnering with patients, families and caregivers. Although there are encouraging signs that the culture is starting to shift, we are still a way off from being able to demonstrate that patient partnerships have become culturally embedded in the norms and values in “the way we do business” – where patients and staff have collective ownership to improve their shared healthcare service. Increased awareness of the value of partnering with patients to improve care, service delivery and health outcomes needs to be matched with long-term strategy from leaders in developing more comprehensive and systematic approaches to engaging patients, families and caregivers as true partners in transforming our healthcare system. Ministries of health could leverage their influence by prioritizing measurement of patient experience as a key performance indicator across sectors and by mandating patient-partnership involvement (e.g., patient membership on boards, quality committees and other decision-making fora). Upstream interventions include changing university curricula for healthcare disciplines and, at a policy level, investing to increase patient capacity for self-management as this improves patient activation and lowers healthcare expenditures. One thing is clear: patients and their loved ones want to be co-leading this change. It is time for leaders at all levels of care and service delivery to recognize the potential and expertise of patients in co-leading system improvements to better respond to what matters most. **HQ**

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