

Patient and Caregiver Engagement in an Era of COVID-19: What Did We Learn and How Do We Move Forward?

Mobilisation des patients et des proches
aidants à l'ère de la COVID-19 : qu'avons-nous
appris et comment aller de l'avant?



INVITED PAPER

Kerry Kuluski, MSW, PhD
Dr. Mathias Gysler Research Chair in
Patient and Family Centred Care
Institute for Better Health
Trillium Health Partners
Mississauga, ON
Associate Professor
Institute of Health Policy,
Management and Evaluation
University of Toronto
Toronto, ON

Carol Fancott, PT, PhD
Director
Patient Safety, Equity and Engagement
Healthcare Excellence Canada
Toronto, ON

Maggie Keresteci, MA, CHE
Patient Partner and Executive Director
Canadian Association for Health Services
and Policy Research
Toronto, ON

G. Ross Baker, PhD
Professor Emeritus
Institute of Health Policy, Management
and Evaluation
University of Toronto
Toronto, ON



ABSTRACT

Patient and caregiver engagement is a core component of high-quality healthcare systems. The COVID-19 pandemic revealed to us the fragility of patient and family engagement that was not as firmly rooted in the health system as expected. In this paper, we reflect on case examples from healthcare organizations across Canada where pivots and adaptations were made to patient engagement activities. We share core enablers of engagement in times of high system stress, drawing on illustrative examples. We then synthesize key learnings in relation to existing literature and conclude with reflective questions as we orient the work of engagement into the future.

RÉSUMÉ

La mobilisation des patients et des proches aidants est un élément indispensable des systèmes de santé de qualité. La pandémie de COVID-19 nous a ouvert les yeux sur la fragilité de l'engagement des patients et des familles, moins bien enraciné dans le système de santé que nous le pensions. Dans cet article, nous analysons des cas tirés d'organismes de santé partout au Canada, où les activités d'engagement des patients ont connu des virages et des adaptations. Nous présentons des facteurs clés de la mobilisation en période de stress systémique élevé en partant d'exemples et synthétisons les principales leçons tirées en les reliant à la littérature existante, avant de conclure par des questions de réflexion pour orienter le travail en matière de mobilisation.

Key Takeaways

- During COVID-19, patient engagement in many health and social care organizations stalled, while in other organizations engagement activities continued or restarted after a brief pause.
- Sustained patient engagement during times of crisis is enabled by leadership support, through an entrenched organizational philosophy in favour of person-centred care, by giving patient and caregiver partners the space to lead, by ensuring engagement activities are meaningful and by offering different modes of engagement.
- The Engagement-Capable Environments Framework can be used to guide organizations and their surrounding ecosystems in understanding (and building) their engagement capacity.

Overview

Engaging patients and care partners in the delivery, design and governance of health-care services is a critical component of high-quality healthcare systems (Barello et al. 2012; WHO 2016). While principles of person- and family-centred care (PFCC) have existed for decades, engagement with patients, care partners and communities has grown dramatically over the past number of years as a means through which to bring PFCC principles to life (Kuluski et al. 2019; Mead and Bower 2000; Santana et al. 2018). Momentum has been building as many health organizations

across Canada have begun to put dedicated resources and staff to patient engagement efforts, with increasing expectations to bring lived experience perspectives to all levels of the health system, in policy making and in research.

Emerging evidence demonstrates the impacts that engagement and partnership have on improving patient experiences, outcomes, quality and safety of care (Bombard et al. 2018). However, the COVID-19 pandemic revealed to us the fragility of some patient and family engagement that was not as firmly rooted in the

health system as expected and the apparent tensions that existed in creating safe care environments that adhered to PFCC principles. In this crisis, many healthcare organizations stalled or stopped patient engagement activities altogether (Tripp et al. 2022), particularly in the early days of the pandemic. Stopping or stalling patient engagement activities resulted in varying policies and practices that affected the quality, safety and experience of care for patients and care partners. Yet in some organizations, engagement efforts were sustained and even strengthened during this time.

In this paper, we reflect on patient engagement activities during the COVID-19 pandemic, drawing from various case examples from across Canada. From these cases, we consider the key enablers of engagement that emerged, and discuss what is required to build resilience in our health systems during times of crisis. Our goal is to reflect on what it takes for health systems to create and sustain capabilities for engagement with patients, care partners and broader communities that will respond to the needs and priorities of those who use the system. In our reflections, we consider how we may embed these principles of engagement and partnership to withstand crises in the future.

The paper is divided into several sections. We first set the context by describing what we mean by patient engagement and why it matters and review a framework that guided our work. We then move into core themes of enablers of engagement in times of high system stress, providing illustrative examples from several of the case studies that we conducted. We synthesize key learnings in relation to existing literature and conclude with reflective questions as we orient the work of engagement into the future.

Understanding Patient Engagement and Engagement-Capable Environments

Over the past several decades, health systems globally have made important strides in creating opportunities for patients and care partners (i.e., families, friends and neighbours who provide unpaid care) to be more actively engaged in different levels of the healthcare system. These different levels include the following: the *clinical level* (through shared decision making with care providers); the *organizational level* (through co-design and planning activities with care teams, researchers and health systems leaders); and the *policy level* (through participation in decision-making tables and governance activities) (Carman et al. 2013). Engaging patients and care partners in these various realms can lead to better care experiences, better-informed decisions, less waste (i.e., better value for dollars spent) and a greater likelihood that research, care and quality improvements will align with what matters most to patients and their care partners (Bombard et al. 2018; Forsythe et al. 2019). Engaging patients and care partners can also lead to safer care, particularly when opportunities are provided for them to voice needs and values without fear of reprisal, flag potential harms and participate in care and activities in ways that are meaningful to them (Jeffs et al. 2022, 2024). While health system leaders, scholars, policy makers and educators are far from reaching the full capabilities of “meaningful engagement” (i.e., engagement as fully integrated into how health systems function), progress has been made.

Meaningful engagement occurs when all parties (patients, care partners, providers, community members, decision makers, etc.) are invited and welcomed to share ideas, feel safe to speak and have their experiences and

perspectives acknowledged and considered when doing activities together (Harrison et al. 2019; Witteman et al. 2018). Engagement activities typically centre on problems that need to be solved and ideally involve stakeholders with aligned lived experience, as well as those in positions to implement required changes (Bammer 2013). The future requires a proactive approach where we co-produce a health system that meets the needs and priorities of those it serves, rather than taking a reactive stance as problems arise.

Engaging meaningfully can be challenging; compromises need to be made and roadblocks anticipated and addressed. Doing the “work” of engagement requires understanding the priorities, values and goals of all involved. Engagement is inherently about power and where power lies and how it is shared. Open dialogue, compromise and expectation management are required given the complexities of aligning priorities, addressing challenges and implementing solutions. There is a range of engagement approaches that are fit for purpose. For example, engagement can be meaningful at a consultative level (e.g., through focus groups) if expectations are clear from the outset and people understand how/why they are being engaged. Co-design efforts aim to draw on consensus with greater expectations for decision making for all involved. Importantly, when patients, care partners and community members are not engaged, vital perspectives are missed and we risk focusing on (and investing in) the wrong things. In the worst case, lack of engagement can lead to poor experiences, harmful outcomes and implementation of inelegant, knee-jerk policies or practices that do not lead to the desired outcomes for people, organizations and broader systems. Establishing the mechanisms for meaningful engagement within healthcare organizations takes time and ultimately

requires a culture shift where we value and prioritize multiple forms of evidence and expertise.

Mechanisms for engagement have been articulated by two of the co-authors (GRB and CF) through the Engagement-Capable Environments (ECE) Framework. Based on earlier learnings with healthcare organizations across Canada and beyond, the ECEs provide insights into key ingredients that support and sustain patient engagement at the meso level (e.g., within healthcare organizations) and the macro level of the health system to support changes in processes and systems of care. Three interrelated pillars are articulated in this framework and include the following: ensuring leadership support and strategic focus; engaging staff to involve patients; and enlisting and preparing patients (to become engaged).

Engagement is inherently about power and where power lies and how it is shared.

Leadership support requires embedding patient engagement practices within the strategic directions of the organization, making it *a must* rather than a *nice-to-have* and linking patient engagement to organizational accountabilities. Leaders understand that patient engagement requires a culture shift, with dedicated time and resources to create the conditions for change. Leaders role model engagement practices and demonstrate their own humility in interactions with others. They demonstrate lived experience perspectives as a valid and legitimate form of knowledge by actively seeking out patient and care partner perspectives to understand how the organization/system is functioning to meet the needs of those it serves. Leaders understand that meaningful engagement does not happen without the appropriate resources and

staff and put accountability mechanisms in place that demonstrate engagement as a priority for the organization/system. Leaders also provide opportunities for patients and care partners to be active members of leadership tables with decision-making authority, who understand that lived experience perspectives offer insights and knowledge that others around the table do not have. Leaders also seek to remove barriers to participation and value the contributions of patient partners through compensation or other forms of recognition.

Staff and healthcare teams require support at the front lines to embed patient engagement in their day-to-day activities and to understand how engaging with patients and care partners can extend beyond the direct level of care. The lived experience perspectives have bearing on improving processes and systems of care, which ultimately will impact patients' experiences and outcomes. Linking engagement work to an underlying philosophy of PFCC, providing training, resources and supports for staff and healthcare teams as they engage with patient partners and building in accountabilities through hiring practices and performance reviews helps to shift to a culture that understands and values experiential knowledge across the health system.

The third pillar within ECEs is how best to *support patients and care partners* to use their lived experience perspectives to support health system change by inviting and welcoming their input. Engagement opportunities are provided across the continuum of engagement approaches, providing opportunities for them to share their experiences and perspectives in a safe space. In these spaces, they require clarity in their role and expectations, shared purpose in the work and opportunities to continue to grow in their capacity as a patient partner through mentorship and other learning opportunities (Baker et al. 2016). Previous case study work led by Baker et al. (2016)

articulated that organizations that had the capabilities for patient engagement were engaging patient partners across the spectrum of engagement, addressing the three pillars of the ECE model simultaneously. Recently, Healthcare Excellence Canada developed an organizational self-assessment tool to enable health organizations to reflect upon their current practices related to these three pillars required to support engagement capability (HEC n.d.).

Ultimately, the work of engagement is a human endeavour. It is built on relationships that exist among the pillars of leaders, staff and healthcare teams and patient and caregiver partners. There is inherent power that shapes how these relationships form and evolve. The ECE Framework articulates key practices required to enable and sustain engagement as a cultural transformation, beyond patient engagement processes and structures alone. An extensive structure without deep commitment to the people within these organizations and the enabling roles and relationships that need to be built will challenge engagement efforts when “shocks” to the healthcare system (such as the COVID-19 pandemic) occur.

Patient Engagement Momentum Stalled: COVID-19

The COVID-19 pandemic disrupted the progress made in engagement activities with patient and care partners in the health-care system not only in Canada but globally (Cadel et al. 2021). Many organizations assumed that patient and care partners would not have the time or willingness to be involved in organizational activities and hence, in some cases, they were not even asked to be involved. Many assumed that engaging patients and care partners would take too long and not be possible given constrained timelines for rapid decision making based on the ever-changing understanding of COVID-19. After a brief

pause, some organizations found their way back to engagement efforts, by implementing and restarting or pivoting activities with patient partners. Those organizations with a more mature context for engagement, with solid structures in place and a longer history of embedding a PFCC culture, lost little momentum, pivoted as needed and built on the strength of relationships to continue engagement activities.

A pan-Canadian survey of over 500 patient partners revealed that the majority of respondents (62.5%) experienced at least a temporary or partial reduction in their patient engagement activities during the COVID-19 pandemic. Frustration was expressed at not being included in COVID-19-related activities. Using virtual methods for engagement had mixed reviews (Tripp et al. 2022). What became apparent throughout the pandemic was the loss of vital perspectives of patients and care partners to inform policies, practices and protocols that directly impact them.

Perhaps the most obvious example of unintended harms that resulted when creating and implementing policy without engagement of patients, residents and care partners were the blanket restrictions placed on all “visitors” from health and care facilities. This policy directive – implemented quickly in the early stages of the pandemic – restricted the physical presence of all visitors, including essential care partners, within health and care settings from supporting the care of loved ones. It was a blunt policy instrument that, in hindsight, required a more nuanced solution to consider other forms of risk. In a survey of 32 hospitals in the US, hospitals that had banned “visitors” outright had poorer performance by way of negative patient satisfaction, poor staff responsiveness, increased fall rates and infections (Silvera et al. 2021). Those hospitals with partial or no restrictions saw similar outcomes as pre-pandemic levels and even

marginal improvements in some cases (Silvera et al. 2021). Similar evidence in Canada and worldwide demonstrate the many harms that resulted from these restrictive policies, including poorer patient outcomes, decreased patient safety, poorer patient experience and quality of life and increases in anxiety, depression and dementia-related behaviours (HEC 2020, 2021). There were increases in mental health issues and anxiety for care partners, as well as moral distress for care partners and healthcare staff. A lack of presence of care partners also exacerbated the already high levels of staff burnout and increased job dissatisfaction among staff (HEC 2020, 2021). There was an already growing body of evidence that demonstrated the benefits of essential care partners in the care and support of their loved ones, which became even more clear in their absence. Consistent with other emerging evidence, Ontario’s COVID Science Advisory Table found no supporting evidence that essential caregivers (e.g., family and friends who provide direct care support to patients/residents in health and care settings) played a substantial role in the spread of COVID-19 (Munshi et al. 2021).

Organizations with a more mature context for engagement (more robust and embedded partnerships with patients and care partners in decision-making roles), including a longer history of patient engagement, worked together with residents, patients and care partners to modify and create more nuanced approaches that ultimately resulted in more inclusive policies for essential care partners. These organizations understood the essential role that care partners play to support the physical, emotional, spiritual and social well-being of their loved ones and were able to differentiate *visitor* from *essential care partner*. Ontario’s COVID-19 Science Advisory Table, as well as notable

organizations such as Healthcare Excellence Canada and the Ontario Caregiver Organization, articulate the clear differentiation of roles of visitor from that of an essential care partner as fundamental to creating person-centred policies to support PFCC practices in care.

Patient engagement through the COVID-19 pandemic

Many patient partners across Canada and those working to support engagement efforts expressed frustration with rapid changes being implemented throughout the pandemic, with seemingly little or no involvement of patients, care partners or communities. Yet, anecdotal reports of ongoing engagement and, in some cases, strengthened patient engagement efforts were also emerging. We set out to learn about some of these organizations through a series of case studies in 10 health organizations across Canada. We examined how they approached patient engagement activities, with specific attention to the early waves of the pandemic when health systems and organizations were rapidly making and implementing changes that impacted all involved in providing and receiving care.

The mix of organizations we chose to study spanned Canada (British Columbia, Saskatchewan, Ontario, Quebec and Nova Scotia) and included both health and care service delivery organizations at local, regional and provincial levels, as well as health organizations that support improvements in care and patient engagement at the organizational and system levels. These organizations emerged through key informant interviews with patient engagement leaders across the country. The organizations selected as cases had reputations for their commitment to patient engagement and had processes and structures in place to support their patient

engagement efforts. Importantly, these organizations also had their share of struggles in sustaining and continuing patient engagement during the pandemic.

Health and care delivery organizations included the following: a large urban hospital network (Kingston Health Sciences Centre [KHSC]); a children's rehabilitation hospital (Holland Bloorview Kids Rehabilitation Hospital [Holland Bloorview]); a community services organization (Bellwoods Centres for Community Living [Bellwoods]); an Ontario Health Team (North York Toronto Health Partners [NYTHP]); a care delivery model in Ontario that aims to integrate care providers and services for local populations; and two provincial health authorities (Saskatchewan Health Authority and Nova Scotia Health Authority [NSHA]) that oversee and deliver health services in their respective provinces. Other health organizations included BC Patient Safety and Quality Council/Patient Voices Network (BCPSQC/PVN) (a provincial entity that provides direction for enhanced health system quality and connects patient partners to quality improvement activities in the healthcare system); BC Renal (a province-wide organization that plans and coordinates services for people with kidney disease); and two communities of practice/centres of excellence based in Quebec that are building capacity, supports and resources for patient engagement – the Centre of Excellence on Partnership with Patients and the Public (CEPPP) and the Community of Practice on the Experience and Partnership of Care and Services.

In-depth individual interviews were conducted with a range of individuals within each of these organizations (a mix of patient and care partners, quality improvement and patient engagement organizational leaders and members of senior leadership teams). In

our interviews, we explored patient engagement activities prior to the pandemic; activities during the pandemic, including what was stalled and what was sustained or introduced; barriers and facilitators to patient engagement activities; and overall lessons learned. A fulsome report on each of these cases, including the methodology and detailed results, will be available later. A paper featuring qualitative insights from a subset of these case studies has been published elsewhere (Marcinow et al. 2023).

Maintaining Momentum for Engagement: Key Enablers

From our case study work, we share our reflections on five core themes that emerged as key enablers of patient engagement during times of crisis: (1) strong connections between organizational leaders and patient and care partners; (2) maturation of context, including entrenched philosophy of PFCC; (3) giving patient and care partners the space to lead, build and sustain relationships; (4) willing partnerships through meaningful activities; and (5) creating new mechanisms for engagement. For each of these themes, we provide illustrative examples from our cases. These five sections/themes represent “what worked” regarding patient engagement during the COVID-19 pandemic. Please see Table 1 for examples of noted practices from cases to enable engagement activities during times of health system stress. Examples have been organized by the three components of the ECE Framework.

Strong connection between organizational leaders and patient and care partners

Our case studies reinforced the importance of organizational leaders creating the space for engagement and fostering a culture that enabled the respect for and incorporation of

the views of patient and care partners into health system planning. Sustaining engagement activities was supported through direct lines of *operational* and *relational* connections between senior leaders and patient and care partners. At KHSC, a key operational enabler is the Office of Patient and Family Centred Care that runs separately from the patient relations department. An experienced patient partner holds a staff position as PFCC lead and leads this office with resource support (including staff) and is accountable to the vice-president (VP) of Mission and Strategy Integration and Support Services. In this staff role, the PFCC lead serves as the liaison between leadership and the approximately 60 patient experience advisors who work across the organization. This role was protected throughout the pandemic (no redeployment occurred) and the PFCC lead liaised between patient and family advisors and leadership to provide updates from daily incident command tables and facilitated communications and activities between the two groups. The fact that a patient partner was hired into this lead role highlights the commitment that KHSC has made to patient leadership.

One of the VPs also had a well-established “Balzac’s group,” named after the coffee shop where periodic meetings took place with patient partners. Due to the strength of relationships with this Balzac’s group, the VP was able to hold a meeting to brainstorm how they could work together during the pandemic, acknowledge the uncertainties that stood before them and demonstrate a commitment to partnership with patient partners even before the pandemic took hold. The leadership approach used by this VP provides a concrete example of what it looks like to not only value patient and care partner input but to create a process to actively seek it out. Another example of strong connections

between leadership and patient and care partners comes from the CEPPP in Quebec. The CEPPP has been a foundational leader in the mobilization of experiential knowledge across the health system, including in care, health system improvement, research and education. A well-respected patient partner leader at the centre was approached by the Ministry of Health and Social Services to join a tactical committee focused on ethics and COVID-19. To support this committee in developing pandemic-related policies, he, along with other leaders at CEPPP, assembled a group of 12 patient partners to support the efforts of this committee. Leaning into the strength of their relationships and trust built over time, more fulsome patient and care partner engagement and a diversity of perspectives to support the COVID-19 response at a provincial level were possible.

Family leaders co-created resources for other patients, families and community members on how to engage virtually in care.

Maturation of context, including entrenched philosophy of PFCC

Some of the organizations (cases), in particular Holland Bloorview, have a long history of PFCC, and engagement with patients and families that dates back to the 1980s, initially through the development of a Patient and Family Advisory Council (PFAC) of dedicated parents. While the PFAC was one approach to support PFCC principles in care, Holland Bloorview actively sought to strengthen its engagement practices. Approximately 10 years ago, they began to implement engagement activities that spanned the organization in all areas of care to support accreditation, program development and

education. They supported the capacity development of family leaders (parents who work closely with leadership and other family care partners across the organization) by providing opportunities for learning, both internal and external, to the organization. When the pandemic hit, Holland Bloorview already had a strong ethos for engagement that was well-established within the organization. This culture of engagement, combined with a strong, articulated commitment from the chief executive officer created expectation for ongoing partnership with patients and family leaders and was a powerful enabler for continued engagement activities. While restrictions on family visitors (through provincial directives) created some constraints in the earlier stages of the pandemic, they were able to create policies that enabled ongoing essential care partner presence. The organization stayed in close contact with patients, families and the broader community through town halls and webinars. Having already implemented communication platforms such as Zoom for family leaders, it was easier to conduct technology-enabled engagement activities. In fact, for some families with children with complex needs at home, virtual engagement made it easier to participate and replaced the previous long commutes to in-person meetings. Family leaders co-created resources for other patients, families and community members on how to engage virtually in care. Some of the family leaders have been brought on as paid staff who lead initiatives and coordinate family leader and educational activities, thus putting these patient/family partners in positions of leadership and decision making. The evolution of their engagement efforts with ongoing leadership support – from a PFAC to a more entrenched Family Leadership Program – has shifted the culture and expectations within their organization that embody the values of

PFCC. The role of culture and leadership is explored further in this special issue in a paper by Baker et al. (2024).

Giving patient and care partners the space to lead, build and sustain relationships

In many organizations across Canada, leadership and managerial roles for patient engagement and experience within an organization were treated as “nice to haves” instead of essential components during the pandemic. For example, many patient engagement staff and leaders were redeployed, thereby reducing the organization’s capacity for continued and sustained engagement activities. However, when patient engagement activities stalled, in many areas across the country, we saw the emergence of patient and care partners as leaders stepping up and saying: “Hey, we’re here, don’t forget about us!”

Within the NSHA, as patient engagement leads were redeployed and engagement activities were put on hold, patient and care partners came together to check in with each other and provide mutual support. After a pause in activity, patient engagement leads at NSHA conducted a survey of patient and care partner needs and, shortly thereafter, engagement activities were partially reinstated. Wellness coffee chats were implemented, with topics suggested by patient and care partners, leading to interactive webinars led by and for patient and care partners. In this case, we see how patient partners led efforts to support each other, particularly in the early days of the pandemic, with patient engagement leaders being responsive and supportive of their needs and giving them the space to lead.

Similarly, at the NYTHP, patient and care partners were supported by an organizational leader who was not redeployed during the pandemic. They provided support and space for patient and care partners to share ideas and lead initiatives. Weekly unstructured

wellness checks among partners eventually created the mechanism for more formalized engagement activities, including a co-design project that focused on improving access to a 24-hour hotline to support people with mental health and addictions challenges during the pandemic.

The ongoing connections with patient partners, whether formal or informal, particularly in the early days of the pandemic, were instrumental for organizational leaders to maintain and sustain relationships. Wellness checks and other forms of ongoing communications were simple ways to let patient partners know that their health and well being mattered. Similar to NSHA and NYTHP, many other organizations such as CEPPP, KHSC and Holland Bloorview also put into place mechanisms to check in with patient partners, demonstrating the importance of these relationships that need to be nurtured, especially in times of crisis. Check-ins allowed for two-way communication that helped to deepen relationships and enable the opening of space for patient partners to lead and co-lead engagement work. Importantly, patient and care partners actively sought each other out, supported each other and stood up for each other, highlighting the importance of peer support in advancing patient engagement. While space can be given to patients and care partners (by way of inclusion and support in engagement activities), sometimes they have to “fight” for that space. Our case examples demonstrate a strong sense of community among patient partners, which created important momentum during the pandemic.

Willing partnerships through meaningful activities

Some staff and leaders assumed that patient and care partners would not have time for (or would be burdened by) engagement activities

throughout the pandemic. Yet among the patient and care partners interviewed in our work, they noted a willingness and strong desire for continued involvement. Willingness of patient and care partners to be engaged was amplified when the work was perceived as meaningful. Indeed, giving back and providing input during a time of high system stress and crisis was important for many patient and care partners. Several organizations, including the NSHA, Saskatchewan Health Authority, KHSC and Holland Bloorview and others, implemented “fast feedback” groups, which required quick input from patient and care partners into policies, processes and practices to support the pandemic response. Despite the tight turnaround times, sometimes within hours of the request, these rapid response groups proved to be an effective and meaningful way to engage patient and care partners. Patient and care partners saw quick responses to the fruits of their labour, a welcome change from usual process improvements, which could take months and even years to reach fruition.

In the case of BC Renal, patient partners were involved in a committee focused on resource allocation for patients with kidney disease. The patient partners, who were also recipients of transplants, felt deeply committed to this work given their lived experiences. They felt comforted that thoughtful planning was occurring in preparation for a potential shortage of treatments and equipment resulting from the pandemic.

In the Saskatchewan Health Authority, patient and care partners were involved in revising visitor policies, a particularly contentious issue across the country as blanket visitor restrictions prevented families and caregiver partners from being involved in the care of their loved ones to the extent that they were accustomed to before the pandemic.

The Community of Practice on the Experience and Partnership of Care and Services based in Quebec (established in 2016 with 206 members and 30 patient partners, led by Marie-Pascale Pomey), developed eight webinars and a white paper on specific ways that patient and care partners can be engaged during the pandemic. Their work includes topics such as how to maintain the presence of a loved one during the pandemic, how to revive patient partnership committees and how to engage in pandemic solutions, among others. This collection of resources produced by this community of practice is an example of the practical solutions and strategies that can be borne by engaging directly with patients and care partners.

Creating new mechanisms for engagement

Times of crisis may also be a time that creates new opportunities and ways of doing out of necessity. In many cases that we studied, new mechanisms for engagement were developed, including both the adaptation and creation of new policies and procedures, as well as the implementation of new tools and approaches. For example, at Bellwoods, senior leadership conducted a needs assessment of their residents to learn what types of supports they would require during the pandemic. In confirming that the needs of residents exceeded their capacity, they implemented a Caregiver Presence Policy that allowed caregiver partners (typically family and friends of the residents) to be identified as “essential,” thereby allowing them to support the care of their loved one once a week in three-hour blocks. A care plan and schedule were created with each caregiver, and information was shared with front-door screening teams to allow seamless access. This policy, particularly when blanket visitor restrictions were in place across the country, was important in

recognizing the essential role that caregivers play and how they can support system capacity.

Patient partners noted that they really wanted connection and a working group was struck to develop a plan and identify the resources needed.

The work of the PVN, supported by Health Quality BC, provides another example of changing forms and foci of engagement as a result of the pandemic. Health Quality BC (formerly known as the BC Patient Safety and Quality Council) is a government-funded organization that focuses on supporting quality and safety of care in British Columbia and is not a direct healthcare provider. Health Quality BC provides training and support for patient engagement work with health system partners and patient and care partners. Patient and care partners who are members of PVN are linked to health sector quality improvement opportunities. These engagement opportunities were reduced drastically in the early days of COVID-19, but as the pandemic progressed, organizations across the health system began looking for patient partners to support COVID-19-specific initiatives. This prompted Health Quality BC and PVN to accelerate their processes for linking patient partners with health system partners. The pandemic also provided an opportunity for the PVN to look inward to see what could be done to support their own patient and care partners and organizational capabilities. PVN and Health Quality BC staff did this by reaching out to PVN patient partners and asking, “What do you need from us right now?” and “What’s the most important thing for you?” Patient partners noted that they really wanted connection and a working group was struck to develop a plan and identify the resources needed. Health Quality BC and PVN had an

opportunity to take stock of what was working well as well as explore opportunities for improvement. PVN went on to create many new resources during this time to support their work with health system partners, including guides on how to communicate during the pandemic (including verbal and non-verbal communication best practices and how to make digital solutions more accessible) (BCPSQC and PVN n.d.).

Similar to many elements of care that shifted quickly to virtual delivery during the pandemic, a key accelerator to continue or resume engagement activities was connecting using virtual platforms such as Zoom. Organizations that were able to eventually restart or sustain engagement activities typically leveraged virtual technology to stay connected with patient and care partners and the broader community. In some cases, the Zoom calls did not have a specific purpose or agenda other than staying connected during a very isolating time. These weekly touchpoints were quickly instituted by patient partners at NYTHP, mostly to stay socially connected and eventually became the touchpoints for more specific activities such as reviewing and co-designing various initiatives. In the NSHA, the Zoom chats were about connecting “as Nova Scotians,” with its main purpose to create such points of connection. Similar to NYTHP, these Zoom touchpoints later enabled more focused discussion, planning, education and co-design, many led by patient partners. Using virtual means to connect was a way to sustain and, in some cases, build relationships to enable engagement of specific activities. As noted earlier, Health Quality BC and PVN created resources to make virtual engagement more meaningful and accessible. As described by KHSC, it was critical to also use non-virtual forms of engagement (phone calls, mail-outs, etc.) to honour the preferences and capabilities of all partners.

Table 1: Engagement-capable environments: Examples of noted practices from cases to enable engagement activities during times of health system stress

Ensuring leadership support and strategic focus	Continuous leadership buy-in
	Distributed leadership (patient and caregiver partners situated across the organization, with at least one partner having a direct line to organizational leaders)
	Having an adaptive mindset (accepting imperfection as the norm)
	Having embedded practices within the organization to facilitate ongoing patient engagement activities
	Leadership <i>listening to</i> and <i>acting on</i> the requests of staff related to patient and family needs
	Having enough staff available to continue to support patient engagement activities in the event of redeployments
Engaging staff to involve patients	Creating spaces and venues for check-ins (such as virtual weekly meetings)
	Openly valuing patient and caregiver partners and asking for their help
	Reaching out to patient partners to check in, see what they need and seek their advice on how to move forward
	Closing the loop (following up and explaining how feedback was used)
	Not excluding patient and caregiver partners just because feedback is needed quickly
	Trusting patient and caregiver partners as leaders (not pushing back when they take the lead and providing opportunities to lead)
Enlisting and preparing patients	Proactive planning and expectation management (sharing early on that the situation is changing and work styles and activities will shift)
	Wellness checks/ongoing communication (immediately when the pandemic hits and then ongoing)
	Keeping patient partners informed and checking in on what they needed
	Involving patient partners in meaningful activities
	Providing the tools to engage (tailoring communication and engagement approaches to suit different needs and learning styles via virtual platforms, phone calls, mail-outs, etc.)
	Having patient partners mentor other (new) patient partners
	Having dedicated patient partners (i.e., patient leaders) who can keep other patient partners in the loop/engaged

The Path Forward: Building Resilience for Engagement

In this paper, we reflected on five core themes, presented as enablers to sustain (or restart) and strengthen patient engagement activities during times of crisis: (1) strong connection between organizational leaders and patient and family partners; (2) maturation of context, including entrenched philosophy of PFCC; (3) giving patient and care partners the space to lead, build and sustain relationships;

(4) willing partnerships through meaningful activities; and (5) creating new mechanisms for engagement.

While these themes were identified from cases that we studied from across the country, we know that the work of engagement occurs in a broader health ecosystem, influenced by cultures of care that have instilled compassion and kindness at their core and often with leaders who view their roles in ways that engender more distributive and shared

leadership styles. We further reflect on these findings by situating them within these broader literatures, to consider how we may deepen our understanding of ECEs during times of high health system stress. We then pose some questions for health organizations, health systems and communities for reflection as we seek to build resiliency for patient, caregiver and community engagement and partnership into the future.

Ecosystems of Engagement: Moving Into Community

Boivin et al. (2022) position the work of engagement in the context of ecosystems. Ecological models identify the interdependencies between different systems and the people within those systems. In the context of their paper, which is focused on engagement among people in health and social care systems, Boivin et al. (2022) note that ecosystems include all people who are engaged in health-related activities (such as care delivery, research, governance, education, etc.) not just healthcare professionals. An ecosystem includes patients, families, community and environment – as equal contributors to health at the individual and population levels. During times of high health systems stress, such as COVID-19, weaknesses in these ecosystems come to light and point us to areas where resources and attention have been neglected and are required. What we saw through this pandemic is that the health ecosystem favours more traditional, medical models of care and hierarchies of evidence that do not fully account for insights, perspectives and lived experiences of patients and caregivers. We learned that we need to create a more balanced approach to decision making that will allow us to strengthen health ecosystems to withstand critical shocks, such as COVID-19, going forward. While the ECE Framework aims to

highlight interdependencies and interconnections between key stakeholders – particularly, leaders, patient and care partners and health-care providers – embedding the ECEs more broadly into a model of health ecosystems and further articulating the interconnectedness with broader communities outside the walls of organizations is also required to shape engagement capabilities. As we saw in our cases, policies and directives from the broader policy community had a direct impact on the engagement capability *within* organizations. We also saw that strong relationships between individuals that were situated within organizations with community partners and policy stakeholders enabled meaningful engagement opportunities throughout the course of the pandemic (as we saw through patient leadership at the CEPPP in Quebec). Furthermore, and not highlighted in our cases studies, is the power of local communities and neighbourhoods that mobilized through grassroots initiatives to support community members, including equity-deserving populations that were at risk of isolation and illness and had compromised access to vaccines and other supports (Carter 2022; Kholina et al. 2022). Further exploration of community engagement may help illuminate these interdependencies to enhance engagement capabilities across health ecosystems.

Nuances of Relationships and Compassionate Care

Throughout our cases, we have noted how relationships form the core of engagement capabilities. A book called *Without Compassion, There Is No Healthcare*, edited by Hodges et al. (2020), explores the notion of compassionate care and engagement with patients in a more nuanced way. In a chapter of this book, Rowland and Johannesen point out that patient engagement is typically instrumental in nature, which they describe as

action focused, including committee work or co-design activities that strives for a tangible outcome (Rowland and Johannesen 2020). They help to broaden our thinking to see how engagement can also be democratic in form (as patients and caregivers *have the right* to influence healthcare), as well as narrative in form (referring to dialogic communication, sharing, learning, re-learning and influencing one another) (Rowland and Johannesen 2020). During the pandemic, all of these types of engagement were impacted. Instrumental patient engagement activities typically stalled and resurfaced over time as patient and care partners were “invited back into the circle” to provide pandemic advice and support the design of processes and strategies. When these activities were stalled, combined with physical distancing and visitor restrictions, patients and care partners lost their right to influence healthcare processes and strategies (democratic and narrative forms of engagement). The opportunity to share and learn from patient and care partners was lost, their contributions and value were not recognized and relationships became strained or broken. Organizations like Bellwoods, the Saskatchewan Health Authority, KHSC and Holland Bloorview made adaptations to the blanket visitor restrictions, ensuring that they engaged with patients, residents and care partners that enabled the physical presence of care partners and, in some cases, co-developed policies that would meet the needs of those receiving care. We see how patient and care partners found their voice to remind those in authority that they were still there, as they did in Nova Scotia and Saskatchewan – willing and able to contribute to the immediate work needed throughout the pandemic, exerting democratic forms of engagement. In shifts to virtual engagement necessitated by the pandemic, many organizations continued to demonstrate narrative forms of engagement

and dialogic learning – creating open spaces for discussion and dialogue of learning and unlearning in decision-making processes. In our cases, we saw this when virtual wellness checks morphed into spaces for deeper discussion and co-building of new strategies to address pandemic-related needs of the system. In order to build resiliency and more engagement capabilities into the system, Rowland and Johannesen (2020) help us think about engagement at a deeper, more nuanced level. We can draw out elements of the ECE Framework to include instrumental, democratic and narrative forms of engagement. This deeper and more nuanced understanding of engagement in health organizations and systems is indicative of a deeper commitment to patient engagement that is supportive of and aligned with a culture that enables partnership in care.

Walking the Talk of Engagement: Power and Distributed Leadership

A supportive culture and the power shift required for patient engagement can also be seen in the form of distributed leadership. “Distributed leadership is not something ‘done’ by an individual ‘to’ others, or a set of individual actions through which people contribute to a group or organization ... [it] is a group activity that works *through and within relationships*, rather than individual action (Bennett et al. 2003: 3, as cited in, Bolden et al. 2011: 251–52). The tenets of distributed leadership align with the ECE Framework by emphasizing the *interconnectivity* between different groups (patients, families, staff and leadership). A core tenet of distributed leadership is that the whole is greater than the sum of its parts. The whole, when it comes to health ecosystems and the optimal functioning of these ecosystems, requires input as well as support for many actors, including patients, families, care partners, staff, people

in formal leadership positions and members of the broader community. Distributed leadership brings new voices to bear on key issues. In our cases, we uncovered many examples of leadership among patient and care partners, including NSHA whose core group of patient and care partners formed an alliance and pushed themselves onto the radar of organizational leaders to continue patient engagement activities, thereby exerting power by which they could ensure they continued to have a voice. When leaders started to reengage with these partners, momentum in patient engagement activities was reignited, demonstrating the importance of this bi-directional synergy in achieving a common goal. Distributed leadership was also evident in KHSC with a staff role to lead PFCC activities and the intentional hiring of a person with lived experience of the health system into this lead role – an act of power sharing. The PFCC lead was protected from redeployment in their role and acted as a bridge with firm connections to organizational leadership and the other patient and care partners. When the hospital VP rallied patient partners to discuss the impending pandemic and made space for patient and care partners on incident command tables, it demonstrated an understanding that problem solving during the pandemic required the collective effort and insight of various partners.

Conclusion

Over the past decade, patient engagement efforts have been gaining momentum in Canada and worldwide, with increasing expectations for the involvement of those with lived and living experiences in all domains of the health system. Understanding what creates a positive environment for engagement has emerged through examination of numerous care environments that exhibited ways to support meaningful and

authentic engagement with those they serve. Meaningful engagement is noted in the ECE Framework, where environments foster relationships among patient partners, staff and healthcare teams and leaders, within a culture that values and seeks out perspectives of those using the system. The COVID-19 pandemic challenged the culture that patient engagement efforts require to thrive and revealed the tensions that exist in creating person-centred policies and practices during times of crisis. We have learned from many organizations where engagement practices and philosophies not only survived but thrived. Moving forward, in closely examining cases where organizations have shifted their engagement practices, we can consider engagement capabilities in the broader ecosystems of health where engagement needs to grow. We can seek to understand the instrumentality of engagement efforts but also the democratic forces of engagement and dialogic understanding brought about through opportunities for learning and unlearning.

In this special edition of *Healthcare Papers*, our hope is to continue to grow our understanding of ECEs to make them more resilient now and into the future. By asking authors to reflect on the following questions, our learning will continue:

- What did engagement efforts look like in your work through the pandemic?
- What is required to build resiliency in engagement efforts moving forward?
- How do organizations and health systems build a foundation for engagement that can withstand the next health crisis?

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