Vol.22 • Special Issue • July 2024

HealthcarePapers

New Models for the New Healthcare

> “Further exploration of community engagement may help illuminate these interdependencies to enhance engagement capabilities across health ecosystems.”
> (p. 22)

Nurturing Engagement-Capable Environments:

Strengthening Relationships With Partners and Communities

PM 40069375

www.healthcarepapers.com

HealthcarePapers New Models for the New Healthcare • Vol.22 • Special Issue • 2024

IN THIS ISSUE

INTRODUCTION

INVITED PAPER

COMMENTARIES

THE AUTHORS RESPOND

Vol.21 • No.4 • 2024

HealthcarePapers
New Models for the New Healthcare

Defining "Essential Digital Health for the Underserved"

Kendall Ho, Owen Adams, Ambreen Sayani and Gurleen Cheema

Commentary from Ibukun-Oluwa Omolade Abejirinde, Ewan Affleck, Terri Aldred, Clare L. Ardern, Joan Assali, Ron Beleno, Onil Bhattacharyya, Ann Chapman, Jennifer Cordeiro, Sonya Cressman, Mavis B. Dennis, Colleen Ferris, Anne Forsyth, Cassie Fraser, Dietrich Fürstenburg, Richard Golonka, Scott Graham, Carolyn Steele Gray, John Grogan, Alex Haagaard, Daniel Harper, Kendall Ho, Arianna Hogan, Alison James, Jason Jaswal, Bahar Kasaai, Helen Novak Lauscher, Anita Layton, Cliff Lindeman, John Mah, Jennifer Major, Meagan Mak, Shannon Malovec, Ray Markham, Mauree Aki Matsusaka, Alies Maybee, Megan McPherson, Tim Murphy, Jessica Nadigel, Nelly D. Oelke, Anita Palepu, John Pawlovich, Patricia Kay Pearce, Teri Price, Ambreen Sayani, Chad Kim Sing, Melissa Stewart, Jennifer Stinson, Michele Strom, Chantz Strong, Eric Sutherland, Michael Tatto, Dee Taylor, Paula Voorheis, Kim Williams, Tyler Williamson and Bob Woollard

PM 40069375

www.healthcarepapers.com

Vol.21 • No.3 • 2023

HealthcarePapers
New Models for the New Healthcare

Systemic Anti-Blackness in Healthcare:
What the COVID-19 Pandemic Revealed
about Anti-Black Racism in Canada

OmiSoore Dryden

Commentary from Sirry Alang, Jamiu O. Busari, Chelsey R. Carter, Alana Helberg-Proctor, Ayesha Jacub, Nkosinathi Maluleke, Allysha C. Maragh-Bass, Mantoa Mokhachane, Tonia C. Poteat, Nanky Rai and Annabel Sowemimo

PM 40069375

www.healthcarepapers.com

Healthcare*Papers*

Volume 22 • Special Issue • July 2024

Guest Editors *Maggie Keresteci and Amy Lang*
Editors-in-Chief *Audrey Laporte and Sara Allin*
Editorial Director *Dianne Foster-Kent*
Copy Editor *KnowledgeWorks Global Ltd.*
Proofreader *Nathalie Legros*
Publisher & CEO *Matthew Hart*
Publisher & COO *Rebecca Hart*
Associate Publisher, Careers & Web *Susan Hale*
Associate Publisher, Customer Service & Administration *Barbara Marshall*
Production Manager & Social Media Coordinator *Susmita Dey*
Design *Benedict Harris*
Creative *Eric Hart*

www.healthcarepapers.com

HOW TO REACH THE EDITORS AND PUBLISHER
Telephone: 416-864-9667
Fax: 416-368-4443

ADDRESSES
All mail should go to: Longwoods Publishing Corporation, 260 Adelaide Street East, No. 8, Toronto, Ontario M5A 1N1, Canada

For deliveries to our studio:
54 Berkeley St., Suite 305, Toronto, Ontario M5A 2W4, Canada

SUBSCRIBE ONLINE
Go to www.longwoods.com and click on "Subscribe."

SUBSCRIPTIONS
Individual subscription rates for one year are [C] $122 for online only and [C] $192 for print + online. Institutional subscription rates are [C] $519 for online only and [C] $718 for print + online. For subscriptions contact Barbara Marshall at 416-864-9667, ext. 100 or by e-mail at bmarshall@longwoods.com.

Subscriptions must be paid in advance. An additional tax (GST/HST) is payable on Canadian transactions. Rates outside of Canada are in US dollars. Our GST/HST number is R138513668.

REPRINTS
Reprints can be ordered in lots of 100 or more. For reprint information call Barbara Marshall at 416-864-9667 or fax 416-368-4443, or e-mail to bmarshall@longwoods.com.

Return undeliverable Canadian addresses to:
Circulation Department,
Longwoods Publishing Corporation,
260 Adelaide Street East, No. 8,
Toronto, Ontario
M5A 1N1, Canada

EDITORIAL
To talk to our editors please contact Dianne Foster-Kent at 416-864-9667, ext. 106 or by e-mail at dkent@longwoods.com.

ADVERTISING
For advertising rates and inquiries, please contact Matthew Hart at 416-864-9667, ext. 113 or by e-mail at mhart@longwoods.com.

PUBLISHING
To discuss supplements or other publishing issues contact Rebecca Hart at 416-864-9667, ext. 114 or by e-mail at rhart@longwoods.com.

Healthcare*Papers* was founded in 1999 by Editor Peggy Leatt (1940–2019) and Publisher Anton Hart (1946–2022). The journal is published four times per year by Longwoods Publishing Corporation, 260 Adelaide St. East, No. 8, Toronto, ON M5A 1N1, Canada. The views and opinions expressed are those of the individual contributors and do not necessarily represent an official opinion of Healthcare*Papers* or Longwoods Publishing Corporation. Readers are urged to consult their professional advisers prior to acting on the basis of material in this journal.

Healthcare*Papers* is indexed in the following: PubMed/Medline, CINAHL, Ulrich's, IndexCopernicus, Embase, Scopus, ProQuest, Ebsco Discovery Service and is a partner of HINARI.

ISSN No. 1488-917X.
eISSN No. 1929-6339
Publications Mail Agreement No. 40069375.

Longwoods.com

Fonds

Nurturing Engagement-Capable Environments

Instaurer des environnements propices à la participation

INTRODUCTION

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

Amy Lang,[1] PhD
Executive Director
Patient-Oriented Research
Canadian Institutes of Health Research
Toronto, ON

Introduction

We are honoured to bring this special edition to you and hope that it will resonate with and cause you to think and rethink what it means to engage people as they intersect with the healthcare system. Being co-editors of this special edition has provided us with a unique opportunity to learn from the lived and professional experiences of people actively working to develop and nurture engagement-capable environments (ECE). Individually, and in partnership as co-editors, we bring a profound belief in the importance of ECEs as they affect the lives, health and healthcare of individuals, families and communities.

Healthcare Excellence Canada, a keen proponent of ECEs, sought to deepen its understanding of building resilient engagement practices, particularly as these efforts waned for many organizations in the early days of the COVID-19 pandemic.

---

[1] The views expressed herein are solely those of the author and do not necessarily reflect those of the Canadian Institutes of Health Research.

Commissioned research by Kuluski et al. (2024a) explored engagement efforts across the country, and an analysis of these cases sheds light on key ingredients to enable engagement work in times of crisis. Authors in this special issue were invited to offer their insights on ECEs based on their experiences of engagement during the pandemic. The result is a unique collection of articles and interviews that seek to understand both fractures in engagement and new engagement practices that developed during these disruptive pandemic years. Building on their lived and professional experiences, these authors suggest constructive ways for us to expand and enrich our understanding of what healthcare environments need, in times of crisis and beyond, to strengthen and sustain effective engagement between patients, communities and health providers to improve healthcare.

Reimagining and Reconfiguring Relationships

At its foundation, engagement is about relationships, and the articles in this issue invite us to reimagine the relationships that underpin engagement focused on improving health and care. Where the ECE model specifies distinctions between the roles of leaders, staff and patient/caregiver partners, the realities described by our authors are more nuanced and complex. Without denying the power differences inherent in our health system, a number of the articles show how effective partnership – in crisis and in routine times – requires stepping outside of existing roles to connect at a deeper level and to share power in a more dynamic way. Rouly and Boivin's (2024) account of what happens when a patient partner offers care to a clinical partner, von Plessen and Batalden's (2024) description of the interplay of experiences involved in co-producing healthcare and Boozary and Keresteci's (2024) focus on the leadership exercised by peer workers and community members are all examples we can learn from.

Broadening Our Understanding of "Environments"

A critical insight of the ECE model is that relationships do not exist in a vacuum but are shaped and structured by the environments in which people work together to improve care. The articles in this volume invite us to think about "environments" beyond the organizational contexts that are often described in cases of ECEs. Environments in these articles include communities at all geographic levels, from neighbourhoods to national contexts, and can be usefully conceived as *ecosystems* involving and impacted by many different actors working inside and outside of healthcare organizations (Rouly and Boivin 2024). As authors from the First Nations Wellness Circle (FNWC) (Trott et al. 2024) and Boozary and Keresteci (2024) remind us, environments of engagement are also shaped by past and ongoing harms resulting from colonialism and social policies that perpetuate inequality. These articles provide a number of suggestions for how to work together within complex environments that are marked by systemic power differences and inequities, including the use of trauma-informed approaches eloquently described by Pomeroy (2024) and viewing communities as a source of strength, asset and solution as described in the FNWC (Trott et al. 2024), by Boozary and Keresteci (2024) and by Kuluski et al. (2024b) in their final commentary.

Broader Integration of Health and Social Care

Healthcare does not exist in a vacuum but rather is part of a broader ecosystem that encompasses the many components of a community. As such, it is imperative that health systems proactively and intentionally engage with the communities they interact with and serve.

The importance of community engagement was brought dramatically to the forefront during the pandemic. The pandemic did not cause inequities but rather exposed long-standing issues that advantage some communities while others are disadvantaged or ignored, leaving their healthcare needs unaddressed. Only when these communities were welcomed and included did we begin to see progress in developing and implementing programs that were able to address the needs of diverse communities. We learned that homogeneity in policy development did not serve individuals or communities well and, in many cases, caused harm when the latter were not engaged.

As these authors invite us to do, we see engagement efforts beyond traditional engagement with patients and caregivers within institutions, to encompass efforts within communities in order to advance a vision of healthcare that meets the needs of all peoples living in Canada.

Leadership and Culture

Leadership and culture are key to success if we are to realize the benefits of ECEs in healthcare. Persistent and bold leadership is required to see a new era of engagement become the norm, rather than the exception, particularly in times of crisis. Leadership has been shown to be an important component of developing and nurturing a culture of partnership that recognizes the need to co-design care delivery models and that builds the required infrastructure to sustain this culture.

Leadership must be willing to make decisions that are often at odds with the prevailing direction in the environment. Bravery in decision making leads to a culture where staff and those receiving care trust that their unique needs are recognized and supported by leaders who are willing to take a risk to support them. Boozary and Keresteci (2024) describe bold leadership within a large academic health centre that was willing to take risks, confident in their data and engagement practices to guide decision making and to co-produce solutions for care. Such bold leadership has been key to their success in implementing, then spreading and scaling transformative initiatives. During the pandemic, the leadership at the Holland Bloorview Kids Rehabilitation Hospital leaned into a culture they had nurtured for years and that allowed them to co-produce policies and practices that met the needs of those they serve (Baker et al. 2024). This was only possible because of the deep relationships that leaders and staff had with family leaders within their organization. Engagement is front and centre throughout the organization and is cited as "the heart of everything we do" (Baker et al. 2024: 33) Throughout this issue, a common thread woven through all the articles is a belief that organizational culture and bold leadership are key to sustainable and meaningful partnerships with patients and communities.

Conclusion

It is our hope that you will integrate what you learn from this special edition into your work in a way that advances the idea of ECEs. The lessons learned during the pandemic provide insights that lead us to partner with patients, caregivers and communities in different ways that will result in safe, high-quality and equitable care for all.

References

Baker, G.R., C. Fancott and A. Zarem. 2024. Creating a Sustaining Culture for Patient Engagement. *Healthcare Papers* 22(Special Issue): 28–36. doi:10.12927/hcpol.2024.27370.

Boozary, A. and M. Keresteci. 2024. The Power of Partnership Beyond Social Prescribing. *Healthcare Papers* 22(Special Issue): 37–43. doi:10.12927/hcpol.2024.27369.

Kuluski, K., C. Fancott, M. Keresteci and G.R. Baker. 2024a. Patient and Caregiver Engagement in an Era of COVID-19: What Did We Learn and How Do We Move Forward? *Healthcare Papers* 22(Special Issue): 9–26. doi:10.12927/hcpol.2024.27371.

Kuluski, K., C. Fancott, M. Keresteci, A. Lang and G.R. Baker. 2024b. Beyond the Crisis: Transforming Health Systems Through Community Engagement. *Healthcare Papers* 22(Special Issue): 72–77. doi:10.12927/hcpol.2024.27364.

Pomeroy, B.C. 2024. Resilience and Engagement in Crisis: Fostering Trauma-Informed Care and Patient Partnerships Into the Future. *Healthcare Papers* 22(Special Issue): 52–58. doi:10.12927/hcpol.2024.27367.

Rouly, G. and A. Boivin. 2024. Nurturing Resilient Health Ecosystems: What Can We Learn From Patient and Professional Experience? *Healthcare Papers* 22(Special Issue): 64–70. doi:10.12927/hcpol.2024.27365.

Trott, N., B. Carpenter, D. Papadopoulos and B. Restoule. 2024. First Peoples Wellness Circle and the Indigenous Mental Wellness and Trauma-Informed Specialist Workforce During COVID-19. *Healthcare Papers* 22(Special Issue): 44–51. doi:10.12927/hcpol.2024.27368.

von Plessen, C. and P. Batalden. 2024. Meaningful Engagement or Co-Production, or Both? *Healthcare Papers* 22(Special Issue): 59–63. doi:10.12927/hcpol.2024.27366.

INVITED PAPER

HealthcarePapers

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 healthcare 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 healthcare 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 *listening to* and *acting on* 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 healthcare 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?

Acknowledgment

The authors would like to thank the esteemed group of researchers based at the Institute for Better Health, Trillium Health Partners, for conducting the case studies featured in this paper: Michelle Marcinow, Jane Sandercock, Lauren Cadel, Harprit Singh, Penny Dowedoff and Aditi Desai. The authors thank Alies Maybee and Susan Law for their guidance as the case studies were conducted.

The full report on the case studies will be posted on the Institute for Better Health website (https://www.instituteforbetterhealth.com/) at a later date.

References

Baker, G.R., C. Fancott and A. Zarem. 2024. Creating a Sustaining Culture for Patient Engagement. *Healthcare Papers* 22(Special Issue): 28–36. doi:10.12927/hcpol.2024.27370.

Baker, G.R., M. Judd, C. Fancott and C. Maika. 2016. Creating “Engagement-Capable Environments” in Healthcare. In G.R. Baker, M. Judd and C. Maika, eds., *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare* (pp. 11–34). Longwoods Publishing.

Bammer, G. 2013. *Disciplining Interdisciplinarity: Integration and Implementation Sciences for Researching Complex Real-World Problems*. Australian National University Press.

Barello, S., G. Graffigna and E. Vegni. 2012. Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature. *Nursing Research and Practice* 2012: 905934. doi:10.1155/2012/905934.

BC Patient Safety and Quality Council and Patient Voices Network (BCPSQC and PVN). n.d. *What Matters to You: Unmasking Communication During the Pandemic*. Retrieved June 20, 2024. <https://bcpsqc.ca/wp-content/uploads/2020/11/WMTY_Pandemic-Pamplet_-FINAL.pdf>.

Boivin, A., V. Dumez, G. Castonguay and A. Berkesse. 2022. The Ecology of Engagement: Fostering Cooperative Efforts in Health With Patients and Communities. *Health Expectations* 25(5): 2314–27. doi:10.1111/hex.13571.

Bolden, R. 2011. Distributed Leadership in Organizations: A Review of Theory and Research. *International Journal of Management Reviews* 13(3): 251–69. doi:10.1111/j.1468-2370.2011.00306.x.

Bombard, Y., G.R. Baker, E. Orlando, C. Fancott, P. Bhatia, S. Casalino et al. 2018. Engaging Patients to Improve Quality of Care: A Systematic Review. *Implementation Science* 13(1): 98. doi:10.1186/s13012-018-0784-z.

Cadel, L., M. Marcinow, J. Sandercock, P. Dowedoff, S.J.T. Guilcher, A. Maybee et al. 2021. A Scoping Review of Patient Engagement Activities During COVID-19: More Consultation, Less Partnership. *PLOS One* 16(9): e0257880. doi:10.1371/journal.pone.0257880.

Carman, K.L., P. Dardess, M. Maurer, S. Sofaer, K. Adams, C. Bechtel et al. 2013. Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies. *Health Affairs* 32(2): 223–31. doi:10.1377/hlthaff.2012.1133.

Carter, A.J. 2022. The Role of Grassroots Community Organizations in Transforming Healthcare Systems to Achieve Health Equity. *Healthcare Management Forum* 35: 328–32. doi:10.1177/08404704221114723.

Forsythe, L.P., K.L. Carman, V. Szydlowski, L. Fayish, L. Davidson, D.H. Hickam et al. 2019. Patient Engagement in Research: Early Findings From the Patient-Centered Outcomes Research Institute. *Health Affairs* 38(3): 359–67. doi:10.1377/hlthaff.2018.05067.

Harrison, J.D., A.D. Auerbach, W. Anderson, M. Fagan, M. Carnie, C. Hanson et al. 2019. Patient Stakeholder Engagement in Research: A Narrative Review to Describe Foundational Principles and Best Practice Activities. *Health Expectations* 22(3): 307–16. doi:10.1111/hex.12873.

Healthcare Excellence Canada (HEC). n.d. *Engagement-Capable Environments Organizational Self-Assessment Tool*. Retrieved June 20, 2024. <https://www.healthcareexcellence.ca/media/0n0hfkwj/20220321_ece_organizationalselfassessmenttool_en.pdf>.

Healthcare Excellence Canada (HEC). 2020, November. *Evidence Brief: Caregivers as Essential Care Partners*. Retrieved June 20, 2024. <https://www.healthcareexcellence.ca/media/rz0ihqa1/evidence-brief-en-final-ua.pdf>.

Healthcare Excellence Canada (HEC). 2021, August. *Evidence Brief Addendum: Essential Care Partners Emerging Evidence*. Retrieved June 20, 2024. <https://www.healthcareexcellence.ca/media/xjfdvtml/hec-10570-evidencebrief-addendum-care-partners_092421_1.pdf>.

Hodges, B., G. Paech and J. Bennett. 2020. *Without Compassion, There Is No Healthcare: Leading With Care in a Technological Age*. McGill-Queen's University Press.

Jeffs, L., K. Kuluski, V. Flintoft, A. MacLaurin, M. Asselbergs, R.L. Zeng et al. 2024. Reconceptualizing Patient Safety Beyond Harm: Insights From a Mixed-Methods Qualitative Inquiry. *Journal of Nursing Care Quality* 39(3): 226–31. doi:10.1097/NCQ.0000000000000757.

Jeffs, L., K. Kuluski, A. MacLauren, V. Flintoft, M. Asselbergs and G. Baker. 2022, January. *How Safe Is Your Care? Measurement and Monitoring of Safety Through the Eyes of Patients and Their Care Partners*. Healthcare Excellence Canada. Retrieved June 20, 2024. <https://www.healthcareexcellence.ca/media/dnrgw10m/20220525_howsafeisyourcare_final_en.pdf>.

Kholina, K., S.H.E. Harmon and J.E. Graham. 2022. An Equitable Vaccine Delivery System: Lessons From the COVID-19 Vaccine Rollout in Canada. *PLOS One* 17(12): e0279929. doi:10.1371/journal.pone.0279929.

Kuluski, K., A. Peckham, A. Gill, D. Gagnon, C. Wong-Cornall, A. McKillop et al. 2019. What Is Important to Older People With Multimorbidity and Their Caregivers? Identifying Attributes of Person Centered Care From the User Perspective. *International Journal of Integrated Care* 19(3): 4. doi:10.5334/ijic.4655.

Marcinow, M., J. Sandercock, L. Cadel, H. Singh, S.J.T. Guilcher, P. Dowedoff et al. 2023. A Qualitative Study Exploring How Patient Engagement Activities Were Sustained or Adapted in Canadian Healthcare Organizations During the COVID-19 Pandemic. *PLOS One* 18(3): e0282890. doi:10.1371/journal.pone.0282890.

Mead, N. and P. Bower. 2000. Patient-Centredness: A Conceptual Framework and Review of the Empirical Literature. *Social Science Medicine* 51(7): 1087–110. doi:10.1016/s0277-9536(00)00098-8.

Munshi, L., A. Odutayo, G.A. Evans, M. Keresteci, J. Drury, D. Kain et al. 2021. Impact of Hospital Visitor Restrictions During the COVID-19 Pandemic. *Science Briefs of the Ontario COVID-19 Science Advisory Table* 2(31). doi:10.47326/ocsat.2021.02.31.1.0.

Rowland, P. and J. Johannesen. 2020. Patient Engagement and Compassionate Care. In B.D. Hodges, G. Paech and J. Bennett, eds., *Without Compassion, There Is No Healthcare: Leading With Care in a Technological Age* (pp. 59–78). McGill-Queen's University Press.

Santana, M.J., K. Manalili, R.J. Jolley, S. Zelinsky, H. Quan and M. Lu. 2018. How to Practice Person-Centred Care: A Conceptual Framework. *Health Expectations* 21(2): 429–40. doi:10.1111/hex.12640.

Silvera, G., J. Wolf, A. Stanowski and Q. Studer. 2021. The Influence of COVID-19 Visitation Restrictions on Patient Experience and Safety Outcomes: A Critical Role for Subjective Advocates. *Patient Experience Journal* 8(1): 30–39. doi:10.35680/2372-0247.1596.

Tripp, L., M. Vanstone, C. Canfield, M. Leslie, M.A. Levasseur, J. Panday et al. 2022. The Impact of COVID-19 on Patient Engagement in the Health System: Results From a Pan-Canadian Survey of Patient, Family and Caregiver Partners. *Health Expectations* 25(2): 744–53. doi:10.1111/hex.13421.

Witteman, H.O., S. Chipenda Dansokho, H. Colquhoun, A. Fagerlin, A.M.C. Giguere, S. Glouberman et al. 2018. Twelve Lessons Learned for Effective Research Partnerships Between Patients, Caregivers, Clinicians, Academic Researchers, and Other Stakeholders. *Journal of General Internal Medicine* 33(4): 558–62. doi:10.1007/s11606-017-4269-6.

World Health Organization (WHO). 2016. *Patient Engagement: Technical Series on Safer Primary Care*. Retrieved June 20, 2024. <https://apps.who.int/iris/bitstream/handle/10665/252269/9789241511629-eng.pdf>.

COMMENTARIES

Healthcare*Papers*

Creating a Sustaining Culture for Patient Engagement

Créer une culture d'engagement des patients durable

COMMENTARY

G. Ross Baker, PhD
Professor Emeritus
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

Adrienne Zarem, DC
Patient Partner
Healthcare Excellence Canada
Former Co-Chair
Family Advisory Committee
Holland Bloorview Kids Rehabilitation Hospital
Toronto, ON

~

ABSTRACT

Engagement-capable environments enable strategies and processes supporting patient engagement. However, research using this framework has not fully explored how leaders can help to shape organizational cultures that sustain engagement over *time, even during crises such as the COVID-19 pandemic. Using interviews and documents from the Holland Bloorview Kids Rehabilitation Hospital in Toronto, ON, prior to and after the pandemic, we examine the maturation of their engagement practices and culture to illustrate how a supportive culture developed and shaped their responses to this crisis. Further exploration of such dynamics could inform leaders designing engagement strategies with greater impact and sustainment.*

RÉSUMÉ

Les environnements propices à la participation permettent la mise en œuvre de stratégies et de processus favorisant l'engagement des patients. Mais les recherches basées sur ce cadre n'ont pas examiné en détail la façon dont les leaders contribuent à façonner des structures organisationnelles qui pérennisent l'engagement à long terme, même en situation de crise telle que la pandémie de COVID-19. À partir d'entretiens et de documents prépandémiques et postpandémiques de l'Hôpital de réadaptation pour enfants Holland Bloorview à Toronto, en Ontario, nous examinons l'évolution des pratiques d'engagement et de la culture de l'organisme afin d'illustrer l'établissement d'une culture solidaire et la façon dont une telle culture a modelé les réactions à cette crise. Une analyse approfondie de ces dynamiques pourrait guider les leaders concevant des stratégies d'engagement aux retombées et au potentiel de pérennisation encore plus importants.

Key Takeaways

- Many healthcare organizations struggled to sustain patient engagement during the COVID-19 pandemic. Several studies suggest that organizational culture was key to sustaining a mature patient-engagement environment, but this analysis often lacks substantive detail.
- Our case study underlines the critical roles that leaders played in shaping Holland Bloorview's organizational culture, one that valued patient engagement, ensuring that staff were supported in co-designing and collaborating with families and patients, as well as embedding patients and family members into key roles and structures that reinforced the importance of this engagement.
- Leadership support (from both senior leaders and family leaders) for the continued engagement of patients and family during the COVID-19 pandemic succeeded at Holland Bloorview because of the widely accepted values and governing assumptions in their culture that developed over decades.

Introduction

Patient engagement has been identified as a major contributor to high-performing health systems (Carman et al. 2013; WHO 2016). Using a case study of Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) in Toronto, ON, we examine the maturation of their engagement practices and their culture, built over decades and nurtured by various leaders. The broad expectations for patient engagement that were created across the organization enabled them to expand and diversify *how* and *with whom* they engaged during the COVID-19 crisis. The insights gained from this case further amplify the work of Kuluski et al. (2024), highlighting the dynamics and linkages of the three pillars of "engagement-capable environments" (Baker et al. 2016: 19–23; Fancott et al. 2018). Specifically, we highlight the significant role for leaders in shifting organizational culture to support the ongoing engagement and impact of clients and families.

Data for this article were gathered from interviews with executives, senior leaders, family leaders and Holland Bloorview staff who supported the programs at the hospital. Data collection began prior to the COVID-19 pandemic, with additional interviews conducted in 2022–23 that focused on the impact that the pandemic had on their engagement practices. We also gathered data from published materials on the hospital- and family-engagement programs.

The Organization and Development of Family-Engagement Roles and Programs

Holland Bloorview provides in-patient and outpatient care to children and youth with a broad range of disabilities, who often require ongoing care for years, with close involvement of family and other informal caregivers. Holland Bloorview was an early adopter of engagement practices, creating one of the first family advisory committees in Canada in the 1980s that gave parents and caregivers a forum to discuss their children's care and offer ideas for improving these services. Holland Bloorview's structures to support child/youth/family engagement have expanded greatly since the first family council, now supported by a Family Leadership Program. This program became the hub for client and family engagement and partnership, with dedicated staff, including family leaders, to advance partnerships in care and across all levels of the organization.

One critical step that has reinforced a philosophy of care essential for engagement has been the addition of a half-day session about client-centred care in new staff orientation, which includes family leaders sharing their lived experiences with new employees and teaching principles of client and family-centred care. One former staff leader noted:

> I think we try to win hearts and minds [of staff] early, so it informs practice from the first moments you enter the door. So, I think that [initial orientation] is a milestone and an important educational practice that creates a baseline across the organization for folks.

Another staff leader underlined this point, saying:

> From the moment of onboarding, one of the first voices you engage with in the new staff orientation is a family leader, taking you through … the basics … and core concepts and practices of client-centred care and partnership, to interview processes where family leader presence is built into quality improvement, etc. So, I think that kind of steady exposure [to patient partnership] is important.

Clients and families are involved across all levels of the hospital: at the direct level of care with wide involvement of families in the care of their children and at organizational levels with the presence of family leaders on decision-making committees across the hospital, including the board and board committees. The Family Leadership Program is placed in the Programs and Services portfolio, resulting in a crucial linkage of engagement with service delivery and clinical care. As one senior leader explained:

> [Client- and family-integrated care] is a corporately embedded set of activities, structures, partnership, but its home is within clinical care. And so far, I think that that's become a really good way of investing in true partnership. So, we're co-designing solutions based on what we elicit and learn from kids and families and staff and have the means to, kind of, put change in action … partnered with operations. I think, here [that] has been very effective.

Holland Bloorview has also invested in family leaders through the Family as Faculty program that prepares family leaders to partner with staff to co-design, deliver and teach in a variety of initiatives across the organization (Ho et al. 2024), an initiative recognized as a leading practice by the Health Standards Organization. The Family Leadership Program continues to grow: in 2023, its 119 family leaders contributed close to 2,700 hours to engagement and partnership initiatives (Holland Bloorview Kids Rehabilitation Hospital 2023). Similarly, Holland Bloorview has also created and supports a Youth Engagement Strategy, with a Youth Advisory Council, Youth Mentorship Program and internal employment opportunities. The youth leaders offer insights from their own experiences to current clients, their families, staff and learners about their care experiences and about preparing for their transition to adult life (Holland Bloorview Kids Rehabilitation Hospital 2023).

In all these ways, Holland Bloorview has been actively building on the three pillars of engagement-capable environments, preparing and enabling partnerships among clients, families and staff. Leaders have demonstrated the value of such engagement efforts, providing the requisite structures and resources for meaningful engagement, and have set expectations for this work.

The COVID-19 Response

The emergence of the COVID-19 pandemic had a dramatic impact on operations at Holland Bloorview, where "family leadership receded dramatically and immediately … even with all of our strengths in family leadership," noted Julia Hanigsberg (Personal interview, October 12, 2023), president and the chief executive officer (CEO) of Holland Bloorview, a reaction paralleling the experience of many organizations across Canada (Tripp et al. 2022). However, this initial response quickly led to the realization that even during an emergency, the voices of family leaders continued to be essential. The near-absence of family leaders in the early days of the pandemic undermined the organization's commitment to client- and family-integrated care in the development of hospital policies and practices to address COVID-19. Hanigsberg described the situation this way:

> We [the members of the COVID-19 pandemic response committee] were … meeting on a probably twice-daily basis at that stage in an extended large committee across the organization, making incredibly important decisions very rapidly and we were making bad decisions [about family presence] because no family leaders were at the table. … I think the benefit we had … is we have deeply scaffolded foundational family leadership throughout our organization. And so, I think that's why we realized as quickly as we did that we were failing our clients and families because of the want for family leaders at our pandemic response leadership table.

Indeed, it was the *absence* of family leadership in the early weeks of the pandemic that was seen as aberrant. Senior leaders recognized and valued the experience and expertise that family leaders brought to decision-making processes, including those related to family presence and rapid changes made to ambulatory services.

In reaching out to family leaders, Holland Bloorview leaned on the strength of relationships and the trust already built with family leaders over the decades. As the CEO remembered it:

> We went to … family leaders with essentially two requests. One was we needed

> family leaders on this committee, this pandemic response committee. And the second [was that] we needed something that ended up being called "rapid response family leaders." And those were a rotating group of family leaders who would be able to give us feedback on new policies, processes, etc., in six hours, a very rapid turnaround.

How Holland Bloorview navigated through family presence policies is a telling example of the existing foundations for engagement, balancing views seen as risky by some staff who felt that family presence was "putting them in harm's way, and … putting them and their families at risk" at a time where other hospitals were adopting more restrictive policies. But as the CEO later noted, she could not recall any member of the staff who said anything critical about family engagement:

> For sure there were moments of balancing between what staff apprehended as the best approach and what our family leaders advised us. But it never felt like we had to make a choice, and it never felt to me like our staff were saying, "families don't know what they're talking about or we [staff] hold all the expertise." That was never what I was faced with. … I did hear nervousness from some staff saying our family caregiver presence policy [during COVID-19] needs to be built by … tomorrow or we have to pivot this program to become virtual in two weeks [but we were] understanding that family partnership at its best works on its own timeline. We're not going to rush anything, and sacrifice process or respect built into that process. And how do we reconcile that with what was a very rapid environment [required for the] COVID[-19] response?

Recognizing the impact of the COVID-19 pandemic on clients, families and staff, family leaders also volunteered to participate in "experiential rounding" where staff leaders and family leaders visited in-patient and outpatient areas to check in with families and to ask about their experiences. These conversations generated a list of improvements to care and in support of family members, including providing meals for bedside caregivers, creating a business centre so family members could work remotely at the hospital and a grocery-to-go section in the cafeteria to support caregivers in preparing meals and staff who were unable to get to the grocery store because of the work pressures during the early phase of the pandemic.

While their initial response was to dramatically decrease engagement efforts as they focused on the pandemic, as noted earlier, their efforts to quickly re-engage family leaders rebounded and, surprisingly, grew. As the family engagement staff lead noted:

> Ultimately … with certainly some hiccups at the very beginning … we were very proud that at the end of the first year of [the] pandemic, March [2020] to March [2021], there was a 30% increase in partnership initiatives that we were co-creating. [This was] not what we expected, but certainly a positive sign, … a year into the pandemic we [had been] able to rebound and not let some of those engagement structures and processes atrophy.

In addition, like many other organizations, Holland Bloorview transitioned many formerly face-to-face activities to virtual meetings, including the Family Advisory Committee and the Youth Advisory Council, which also signalled their importance to the organization. The transition to virtual engagement opportunities facilitated broader participation of family and youth leaders who had previously been unable to engage because of other commitments or travel time required to attend. New COVID-19 town halls for family leaders were added to keep them appraised of current actions in the pandemic response and to gather rapid feedback. Family leaders also joined the hospital's working groups to develop virtual care strategies and tools and co-facilitated resource navigation and funding assistance workshops. Concurrently, leaders were also conscious of the *digital divide* and sought solutions to support broader participation.

> *… leaders often struggle to identify the levers that promote desired long-lasting culture change, and these efforts are frequently hampered by the continuing impact of professional autonomy, performance pressures and inertia.*

Discussion

Kuluski et al. (2024) identified five themes that enabled the sustainment or resumption of patient engagement in the COVID-19 pandemic, but the nature of the context that enabled these organizations to be successful – when many others failed – remains to be specified. The case of Holland Bloorview helps to uncover *how* and *why* they succeeded in their ongoing engagement efforts, shining a light on their organizational culture, nurtured over decades by leaders, staff and family leaders to co-create an environment that was able to support continuing roles and ongoing impact by family and youth leaders, even during times of crisis.

The dominant culture at Holland Bloorview incorporated client and family engagement as "the heart of everything we do" (Holland Bloorview Kids Rehabilitation Hospital n.d.). Engagement occurred across the organization – in clinical settings and across a broad range of management and support functions. The norms, values, structures and processes of client and family engagement were well-developed when the COVID-19 pandemic struck in March 2020, along with long-standing relationships, trust and goodwill between hospital leaders and staff and family leaders. This maturation enabled leaders, staff and family leaders to revitalize and transform the role and impact of family leaders at Holland Bloorview early in the pandemic period. More fundamentally, the sustained experience and intentional efforts to foster client and family engagement had created a foundational culture that supported the roles of clients and families in a range of activities across the organization and spurred a quick reversal when their absence was noted in the early days of the pandemic.

Organizational scholars have explored the role of culture extensively, viewing organizational cultures as socially constructed and serving as "the great stabilizing force that cannot be manipulated with quick fixes" (Schein and Schein 2019: 53). Cultures are resistant to change, incrementally adaptive and continually in flux (Meyerson and Martin 1987), features that can slow desired changes. Many healthcare leaders aim to create and sustain a culture that enables safe and effective care, where patients, clients, care partners and families can fully participate and co-design their interactions with providers and the care environment. Yet leaders often struggle to identify the levers that promote desired long-lasting culture changes, and these efforts are frequently hampered by the continuing impact of professional autonomy, performance pressures and inertia.

Ed Schein, a leading scholar of organizational culture and leadership, argues that organizational culture incorporates three interrelated levels (Schein 1992: 16–27).The first level consists of the *governing assumptions* about the nature of the organization, its relationship to the environment and people's relationships with each other. These, largely invisible, governing assumptions guide everyday thinking and action in the organization. At a more conscious level are the *values and norms* that influence behaviour and can be taken for granted over time. Finally, at the most visible level are the *artifacts*, the physical, behavioural and verbal manifestations of values and norms. Governing assumptions shape the norms and values, which, in turn, influence behaviour and the visible artifacts. At the same time, new behaviours and new norms may shift governing assumptions (Alvesson and Sveningsson 2015; Schein 1984, 1990, 1992).

Over more than 20 years, Holland Bloorview's leaders integrated family leaders into operational, policy and governance roles across the organization, expanding and growing the level and impact of engagement. Staff increasingly saw that family leaders were important partners, both in daily work and in longer-term efforts to improve care experiences. Over time, the engagement of family leaders and the actions of the family and youth leadership programs shifted behaviours and influenced values, norms and the underlying governing assumptions across the organization.

In retrospect, Holland Bloorview's success in sustaining and growing client and family engagement against the pressures to focus solely on the COVID-19 priorities was not surprising. The pivot back to established practices and the incorporation of new practices was led by leaders who supported the continuing presence of family leaders as integral members of the Holland Bloorview team. Family leaders also recognized and voiced the need for their help, and they assumed new roles and responsibilities to support the ever-changing needs of the organization and its clients and families during the pandemic. Leadership support (from both senior leaders and family leaders) for this continued engagement succeeded because of the widely accepted values and governing assumptions developed over two decades that valued lived experience perspectives and expertise. Senior leaders role-modelled the norms and behaviours they expected of others by creating space for family leaders at decision-making tables, creating clear normative expectations across the organization to involve family and youth and creating "artifacts" in structures (e.g., youth and family leadership committees and governance positions) and resources (e.g., staffing, training and orientation) dedicated to engagement activities.

The concept of engagement-capable environments provides a framework for identifying the strategies and processes supporting the implementation of patient engagement. The framework consists of three interrelated key processes that facilitate the formation of authentic relationships between leaders, staff, patients and caregivers in a patient-centred environment (Baker et al. 2016; Fancott et al. 2018). However, not yet fully articulated in the current model of engagement-capable environments is the bedrock of organizational culture that shifts over time to reflect, and then support, the changing norms, values and governing assumptions. Leaders in organizations create structures and processes that bring engagement to life, but continued engagement relies on the transformation of the organizational culture in microsystems and leadership structures to sustain and develop these practices.

The data on the diminished role of patient and caregiver partners in many healthcare organizations during the COVID-19 pandemic suggest that the failure of these organizations to sustain engagement stems from the fragility of their patient engagement efforts and their nascent, underlying organizational engagement cultures (Tripp et al. 2022). Moreover, in times of crisis, organizations may "snap back," reverting to previous ways of working (Kania 2021; Zimmerman 2015). Holland Bloorview illustrates an alternative path where leadership creates new processes and supports new roles and relationships between clients, families and organizational staff. These actions reinforced the tangible value of lived experience perspectives in the work of the organization. In turn, the new roles, relationships and activities influenced new values and new ways of working. At Holland Bloorview, organizational leaders placed family leaders into key roles and helped staff to understand the value of their roles and contributions. As Schein and Schein (2019) note, as an organization ages, "it develops strong beliefs … about what kinds of talent are needed and then recruits only those people. Talent management ... then becomes a subtle process of the culture just re-creating itself" (p. 56). The organizational culture at Holland Bloorview matured over more than 20 years, supporting patient engagement as a fundamental ingredient in excellent client care and experiences and enabling new levels of partnership in care and at organizational and policy levels.

Conclusion

Organizational culture is key to sustainable patient engagement. Creating an organizational culture that is committed to patient engagement in organizational, system or network settings requires persistent leadership and broad involvement by staff, leaders, patients and caregivers learning how to work effectively together. Disruption and disequilibrium can upset established routines and expectations if the leaders, staff and patients are not fully committed to these norms and routines. However, the culture in mature engagement-capable environments enables leaders to formulate strategies and practices that adapt engagement to meet these challenges. Further research to identify how the practices of leaders and staff develop organizational structures and practices that influence the values and norms of organizational culture in different settings will advance knowledge of how to create resilient patient-engagement cultures.

References

Alvesson, M. and S. Sveningsson. 2015. *Changing Organizational Culture: Cultural Change Work in Progress (2nd ed.)*. Routledge.

Baker, G.R., M. Judd, C. Fancott and C. Maika. 2016. Creating "Engagement-Capable Environments" in Healthcare. In G.R. Baker, M. Judd and C. Maika, eds. *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare* (pp. 11–34). Longwoods Publishing.

Carman, K.L., P. Dardess, M. Maurer, S. Sofaer, K. Adams, C. Bechtel et al. 2013. Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies. *Health Affairs* 32(2): 223–31. doi:10.1377/hlthaff.2012.1133.

Fancott, C., G.R. Baker, M. Judd, A. Humphrey and A. Morin. 2018. Supporting Patient and Family Engagement for Healthcare Improvement: Reflections on "Engagement-Capable Environments" Pan-Canadian Learning Collaboratives. *Healthcare Quarterly* 21(Special Issue): 12–30. doi:10.12927/hcq.2018.25642.

Ho, C, A. Goulden, D. Hubley, K. Adamson, J. Hammond and A. Zarem. 2024. Teaching and Facilitation Course for Family as Faculty: Preparing Families to Be Faculty Partners in Healthcare Education. *Clinical Social Work Journal* 52: 23–36. doi:10.1007/s10615-023-00886-y.

Holland Bloorview Kids Rehabilitation Hospital. n.d. Client and Family Engagement. Retrieved June 20, 2024. <https://hollandbloorview.ca/client-and-family-engagement>.

Holland Bloorview Kids Rehabilitation Hospital. 2023. *Imagination Innovation Inclusion: Impact Report 2022*–23. Retrieved June 20, 2024. <https://hollandbloorview.ca/stories-news-events/news/impact-report-2023-imagination-innovation-inclusion>.

Kania, J. 2021, June 15. Preventing System "Snap Back." *Stanford Social Innovation Review*. Retrieved June 20, 2024. <https://ssir.org/articles/entry/preventing_system_snap_back#>.

Kuluski, K., C. Fancott, M. Keresteci and G.R. Baker. 2024. Patient and Caregiver Engagement in an Era of COVID-19: What Did We Learn and How Do We Move Forward? *Healthcare Papers* 22 (Special Issue): 9–26. doi:10.12927/hcpol.2024.27371.

Meyerson, D. and J. Martin. 1987. Cultural Change: An Integration of Three Different Views. *Journal* of *Management Studies* 24(6): 623–47. doi:10.1111/j.1467-6486.1987.tb00466.x.

Schein, E.H. 1984. Coming to a New Awareness of Organizational Culture. *MIT Sloan Management Review* 25(2): 3–16.

Schein, E.H. 1990. Organizational Culture. *American Psychologist* 45(2): 109–19. doi:10.1037/0003-066X.45.2.109.

Schein, E.H. 1992. *Organizational Culture and Leadership (2nd ed.)*. Jossey-Bass.

Schein, E.H. and P.A. Schein. 2019. A New Era for Culture, Change and Leadership. *MIT Sloan Manaagement Review* 60(4): 52–58.

Tripp, L., M. Vanstone, C. Canfield, M. Leslie, M.A. Levasseur, J. Panday et al. 2022. The Impact of COVID-19 on Patient Engagement in the Health System: Results From a Pan-Canadian Survey of Patient, Family and Caregiver Partners. *Health Expectations* 25(2): 744–53. doi:10.1111/hex.13421.

World Health Organization (WHO). 2016. *Patient Engagement: Technical Series on Safer Primary Care*. Retrieved January 10, 2024. <https://ore.exeter.ac.uk/repository/bitstream/handle/10871/25108/WHO%20report%20on%20patient%20engagement%20for%20patient%20safety%20PUBLISHED.pdf?sequence=1>.

Zimmerman, B. 2015, January 5. *Preventing "Snap Back: The Challenge* of *Resilient Systems* [Youtube video]. The Tamarack Institute. Retrieved December 15, 2023. <https://www.youtube.com/watch?v=cnXRX0Y9io8>.

The Power of Partnership Beyond Social Prescribing

Le pouvoir du partenariat au-delà de la prescription sociale

COMMENTARY

Andrew Boozary, MD, MPP, MS, CCFP
Founding Executive Director
Gattuso Centre for Social Medicine
University Health Network
Toronto, ON

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

ABSTRACT

This commentary focuses on the social determinants of health and how they may be more fully integrated into engagement-capable environments. In this commentary, the authors provide excerpts from their in-depth discussion that explored how the foundational principles of the Gattuso Centre for Social Medicine emphasize the importance of prioritizing care for populations that are marginalized and engaging communities to improve health outcomes. The article delves into some of the historic and current issues facing communities and individuals that are marginalized and describes how a large academic centre has leveraged its structures and resources to build partnerships with communities and community organizations to address these challenges.

RÉSUMÉ

Ce commentaire porte sur les déterminants sociaux de la santé et sur la façon dont ils pourraient être mieux intégrés aux environnements propices à la participation. Dans cet article, les auteurs citent des extraits de leur analyse approfondie des façons dont les principes fondateurs du Centre Gattuso pour la médecine sociale insistent sur l'importance de prioriser les soins pour les populations marginalisées et de mobiliser les communautés pour améliorer les résultats cliniques. L'article explore certains enjeux historiques et actuels pour les communautés et les personnes marginalisées et décrit comment un grand centre universitaire a répondu à ces enjeux en tirant parti de son infrastructure et de ses ressources pour établir des partenariats avec les communautés et leurs organismes.

Key Takeaways

- We must prioritize lived experience and leverage population health data to meaningfully address inequities in healthcare. For meaningful change to happen, we must be willing to confront the chronically unconscionable health outcomes facing marginalized communities.
- Partnership with communities during COVID-19 demonstrated that we can deliver innovations in the public system and we need to implement these lessons to ensure better health access and outcomes for all.
- The power of partnership beyond *social prescribing* demonstrates what health and social care integration can look like beyond the walls of the hospital.

Introduction

While the concept of social determinants of health is not new, increasing efforts to better link health and social care are emerging, with innovations seen in public and community health sectors, with increased focus on integrated care and in the design of systems and policies that support active connections between these previously isolated sectors. The recent COVID-19 pandemic revealed the stark realities of inequities in health and in care and has propelled efforts to bring together health and social care in more meaningful and relevant ways.

Prior to the COVID-19 pandemic, Canada's largest academic health sciences centre – the University Health Network (UHN) in Toronto, ON – created the Gattuso Centre for Social Medicine. This novel program, set within the traditional hospital sector, focuses on integrating social determinants of health (e.g., housing, food) into care delivery and supports better partnering with community organizations to improve access to care and improving the quality of care for structurally disadvantaged populations. Driven by a commitment to health equity, the centre underscores the need for policy changes to support integrated health and social care, advocating for a more universal and effective healthcare system. Underpinning this work are foundational efforts to improve population health. Collaborative work and partnership have been central to advancing the work of the centre, recognizing the importance of lived experience of those in diverse communities served by UHN.

This commentary provides excerpts of a discussion that one of the co-guest editors of this special edition, Maggie Keresteci (MK), and Andrew Boozary (AB), founding executive director of the Gattuso Centre for Social Medicine, had about engagement-capable environments. Throughout our discussion, the "leadership" pillar of the engagement-capable environments model stands out – leaders who not only value and seek out other forms of experience and expertise but also centre these lived experiences in the work; leaders who understand the strengths of community wisdom and knowledge; leaders who seek to collaborate, listen to understand and act with humility; and leaders who make space for others to enable them to lead and set direction. Lessons embedded throughout this interview point us to areas where engagement-capable environments need to be more attentive moving from individual to community engagement and enabling others to lead.

MK: Why is the bringing together of health and social care so important?
AB: The idea behind social medicine has a solid foundation in Canada, rooted in the work of Minister Marc Lalonde, with the 1974 report entitled, *A New Perspective on the Health of Canadians* (Lalonde 1974). The report clearly outlined the need to address social factors and the social determinants of health if the health of all people in Canada was to be improved. The report meant that Canada became known as a leader in developing and then disseminating theory about the social determinants of health; however, upon reflection of the past almost 50 years since the Lalonde Report, we have not been a leader in putting the theories and principles into practice for patients and communities.

Prioritizing care for structurally disadvantaged and marginalized populations is of paramount importance if we are to truly claim a universal health system. The lack of awareness about these inequities in healthcare access and delivery became clear at the outset of the pandemic when the highest public health authority in the province stated that we do not need to collect health equity data because we have a universal healthcare system (Boyd 2020). I find it highly problematic that the highest levels of public health fall into the mirage of universality when it comes to healthcare in Canada. The mistaken belief that Canada has universally accessible healthcare and the neglect of long-standing health disparities in Canada have hindered reconsiderations of the root causes, the barriers and the potential solutions.

MK: What has been the impetus for engaging with communities in your work?
AB: One of the things reiterated early in the pandemic, in the COVID-19 vaccine response, is that rightfully, many communities have deeply rooted mistrust of hospitals and the healthcare system. There are plenty of good reasons for this mistrust as we consider the history of the healthcare system relating to violations and experimentation of Black and Indigenous populations and of how refugee newcomer populations have not been able to access healthcare. For a long time, hospitals and healthcare academia have held the view that only we hold the answers with all the basic science and therapeutic advances. This historical way of thinking and working relied on a unidirectional dynamic that did not invite or welcome the input and insights of the communities we serve. The COVID-19 community vaccine response underscored the need for a bidirectional approach to innovation, especially when it comes to healthcare delivery – and that is going to demand humility from those of us in hospital and clinical sectors.

MK: Can you provide examples of work you have done with and for communities that are underserved?
AB: We saw examples of how community coalesced to support each other and how we, at the Centre for Social Medicine, could support them in their efforts. There are many examples of innovations such as mobile clinics providing vaccines or testing in community spaces – community health ambassadors going door to door to answer questions and build trust. Vaccine clinics were set up and run on public basketball courts right beside apartment buildings to improve access for people

who did not have transportation or people who could not afford a day without paid sick leave. These issues continue to be barriers to healthcare for people today. We still do not have consistent paid sick leave for people in Ontario, and we do not consider or account for the broader indirect costs such as transportation or childcare imposed on people to see a physician or nurse in a clinic. All these factors must be reconsidered and integrated in how we deliver care as we reimagine a more equitable and effective approach to healthcare.

At the outset of the pandemic, there was a drastic shift that began in Toronto whereby within a matter of weeks, we saw Toronto Public Health ensure the collection of health equity and race-based data to better understand the needs and the disparities that were at play during this pandemic. This was really a result of strong community leadership and advocacy. It became clear, but not unsurprising to individuals working in health equity spaces, that racialized populations were three to five times more likely to be infected with COVID-19 with far worse health outcomes.

This health equity lens that was now better informed by data helped lay out the need for better policy protections for certain communities and neighbourhoods. Early on, it was also clear that unhoused individuals were facing dire risks and impossible situations when it came to physical distancing in shelters. This led to the creation of the first COVID-19 recovery hotel in Canada – an interim housing response in partnership with the City of Toronto, UHN, Parkdale Queen West Community Health Centre, Inner City Health Associates and The Neighbourhood Group (UHN 2020). The inclusion of peer support workers as part of the COVID-19 recovery hotel healthcare team really helped shape my own perspective on the need to see such a trauma-informed response in our own emergency departments at UHN.

The COVID-19 recovery hotel was created in recognition of the fact that there was a distinct gap in care for those with COVID-19 or for those at risk because they did not have access to housing as a human right. The data showed serious disparities and much worse outcomes for marginalized and structurally disadvantaged populations. The COVID-19 recovery hotel was an initiative put in place as a direct response to help mitigate these disparities. The hotel provided access to a hotel room that gave people the ability to physically distance and recover. From a care perspective, the secret sauce of the COVID-19 recovery hotel was truly the peer support workers. These are people with lived experience – many who either have used drugs or have survived homelessness – who were able to check in, provide supports for people, build trust and help in terms of navigation and provide accompaniment in the journey. Because of what we learned during this experience, the Gattuso Centre for Social Medicine worked to embed peer support workers as permanent, *bona fide* members of the UHN emergency department healthcare team. This means that people with lived experience, working as equal partners in the team alongside physicians, nurses and social workers, could help UHN bring a trauma-informed approach to care for people who have historically been stigmatized in healthcare settings.

MK: How have lived experience perspectives been embedded into the work of your program?
AB: Lived experience is core to everything that we do. My belief is that lived experience, coupled with other forms of data analysis, is the way to move more equitable and effective programs forward. So first, we interviewed people who survived homelessness as to what they wanted from the Social Medicine Housing Initiative (Bozikovic 2024). For

example, this was integral in helping inform the need for a community kitchen and inclusive pet policies. We also have a Social Medicine Lived Advisory Council that remunerates people for their time to help overcome any barriers in engagement. They are actively engaged in everything from strategic priority setting to program delivery with governance that helps keep us accountable. This is a crucial component to true co-design, and committing to this process informs all current and future interventions or initiatives taken together.

Diverse communities, especially those that are marginalized or disadvantaged, have, in fact, already established innovations in healthcare delivery that are needed to improve outcomes and to improve the system writ large. If we are to co-create a truly person-centred healthcare system, the system must approach communities with humility and respect. The pandemic lesson was clear: the healthcare sector needs to better acknowledge the wealth of knowledge and innovation that already exists within communities if we are serious about bridging and addressing long-standing health disparities. The delivery and implementation gaps across Canada have really kept us back.

MK: How does a large academic centre such as the UHN leverage any lessons or resources to advance this work?

AB: The lessons we have learned over the past four years continue to drive the strategy for the Centre for Social Medicine. We continue to gain a better understanding of the importance of the integration of social policy and health policy and believe this is desperately needed to improve population health. Integration needs to be happening on the ground for people and not just in the theoretical spaces of academic medicine. As we enter this new era, it is key that hospitals and other system leaders recognize we are not experts in everything. We must foster partnerships over prescribing. One example at UHN is the Food Rx program that the Centre for Social Medicine launched in Toronto. This initiative was launched in partnership with Food Share Toronto, an organization with deep understanding of food security and of the kind of community response that is needed to be successful. This resulted in significant improvements in health and well-being for over 200 people and families over the past two years of the pandemic (Kennedy 2022).

Another example is the housing initiative whereby UHN, in partnership with the City of Toronto and United Way Greater Toronto, has repurposed a former UHN parking lot to build 51 housing units with embedded health and social supports that will open this summer (Boozary et al. 2024). We also know that nobody wants a hospital as their "landlord." So part of the partnership includes a non-profit supportive housing operator, Fred Victor, that has deep expertise in this work (https://www.fredvictor.org/). The reality is that we need new coalitions to respond to long-standing disparities if we are serious about improving health for everyone. This is what I hope is the next evolution in health and social care integration. It requires co-design with patients and communities that have long been shut out of system decisions, and we are seeing concrete steps toward this aim.

MK: How can policy shape the care that is provided?

AB: Currently there are misaligned incentives and a siloed, fragmented system where you have various ministries, departments and organizations that are ostensibly responsible for the outcomes of that same one patient or one family. The same siloed approach at the policy level then plays out at the delivery level. The reality is that numerous providers or ministries must collaborate for high-quality care delivery or to help create lower-risk conditions for patients and families. That is just not happening currently, and the price we pay is in how challenging it is for patients and health workers to navigate both health and social care systems.

From a public spending perspective, Canada spends fewer public dollars on health and social care than other OECD [Organisation for Economic Co-operation and Development] countries. Seeing these innovations in social medicine within the public system over the past few years, especially throughout the pandemic, gives us reason for hope. Where Canada has failed is in ensuring that such successful pilots are scaled up across the country. If we do not ensure the policy bandwidth and focus to see more delivery innovations, we are at serious risk of seeing medicare coming undone. This is a major health policy nightmare that doesn't need to happen.

MK: What is your hope for the future? Where are you seeing the bright lights now?
AB: Healthcare specifically, and society more broadly, has felt bleak recently. There is widespread despair, including significant moral distress among healthcare workers. But there are also some pockets where we can galvanize hope. Just a few years ago, the notion of what large academic health sciences networks in Canada should and could be doing in areas of poverty, systemic racism and marginalization was altogether new and untested. Yet, we are now seeing a clear articulation of the rationale for these kinds of partnerships and, more importantly, we are seeing them come into practice, changing the way care is provided. There remain very real challenges to this work, but my hope is that there are too many people working in healthcare who are unwilling to give up on progress and the moral arc of health equity.

What we were able to do in partnership with community health centres around the COVID-19 vaccine response is a source of hope. The experience of the vaccine response shows that we can deliver things differently in the public system with improved outcomes for people who have not been on the health system's radar for far too long.

The idea of re-imagining a parking lot in downtown Toronto and turning it into housing seemed impossible. Now, seeing true housing in place of a parking lot is a testament to the power of thinking differently and of acknowledging inequities head on. It has demonstrated the power of collective commitment over many years. What started as a dream in 2019 will now provide real housing options for people – not just transitional housing, but real homes for people. This is the power of partnership beyond prescribing. These 51 housing units are not going to end the homelessness crisis, but they do demonstrate, in very real terms, what is possible when we partner with communities and when we think about care in a way that extends beyond the walls of the hospital or clinic.

What gives me hope is the belief that these sorts of partnerships can hopefully be scaled elsewhere or used as a playbook of where other public institutions can mobilize these sorts of innovations in the public health system. The friendships and partnerships that went through a pressure cooker over the past few years now give me hope, given how dire and dark things feel right now.

MK: What advice do you have for others to ensure that all of us are putting lived experience perspectives at the centre?
AB: The work is never done. There are areas every day in our healthcare system where, I know, we are letting patients and families

down. But this is why I feel it is so important to build on the learned lessons of the pandemic – the first to me being the importance of prioritization. We have to be willing to confront the chronically devastating health outcomes of marginalized populations. Otherwise, nothing will change.

We cannot continue to buy into the mirage that a *universal health system* means that there is universal access. If we believe in improving the health of all in Canada, now 50 years after the call from Minister Marc Lalonde (Picard 2024), we have to centre the lived experience of people who have been pushed to the sidelines. This will mean hearing hard truths. It will also require new structures in the way we make decisions – from lived advisory councils to health equity data collection, something we do not do all that well in the Canadian system.

But there is hope here. It was not long ago that a chief medical officer of health essentially said that we did not need to collect health equity data because we had a universal health system. But within a matter of months, various public health agencies and healthcare organizations mandated the collection of this data. We still have lots to learn from communities as to how to do this well and how to ensure that we follow the best practices on data governance. And, maybe most importantly, when we identify that a patient is not taking their medications because they cannot afford it or do not know where they are going to sleep that night, we do something to help. We need to move beyond data collection exercises alone to meaningfully improve population health.

Many of us working in healthcare have the privilege of hope. Things may feel bleak, but there is strong evidence that as partners we can bend or will the system to a fairer place. In our experience, truly engagement-capable environments extend beyond the hospital or clinic walls. The partnerships we describe can be used as a guide to scale similar partnerships elsewhere so that the public health system can make meaningful strides in creating a universally accessible health system in Canada.

References

Boozary, A., C. Varner and A. Laupacis. 2024. Homelessness Is a Health Crisis: Why Hospitals Are Resorting to Building Housing. *CMAJ* 196(19): E666–67. doi:10.1503/cmaj.240649.

Boyd, A. 2020, April 10. Race-Based Coronavirus Data Not Needed in Canada yet, Health Officials Say. *Toronto Star.* Retrieved June 27, 2024. <https://www.thestar.com/news/canada/race-based-coronavirus-data-not-needed-in-canada-yet-health-officials-say/article_0ccacf74-43a3-569c-95bf-47c58b7518f2.html>.

Bozikovic, A. 2024, June 16. Toronto's University Health Network Aims to Treat Homelessness as a Health Issue. *The Globe and Mail.* Retrieved June 27, 2024. <https://www.theglobeandmail.com/canada/article-torontos-university-health-network-aims-to-treat-homelessness-as-a/>.

Kennedy, B. 2022, June 5. A Prescription for Healthy Food? Food Rx Program Gives People Access to Fresh Fruit and Vegetables on Doctor's Orders. *Toronto Star.* Retrieved June 27, 2024. <https://www.thestar.com/news/gta/a-prescription-for-healthy-food-food-rx-program-gives-people-access-to-fresh-fruit-and/article_8fae3e01-6f6b-5ed2-bde4-ed649de79d57.html>.

Lalonde, M. 1974. *A New Perspective on the Health* of *Canadians*. Minister of Supply and Services Canada. Retrieved June 27, 2024. <https://www.phac-aspc.gc.ca/ph-sp/pdf/perspect-eng.pdf>.

Picard, A. 2024, June 25. Some Sensible Advice on Health Spending, Still Ignored 50 Years Later. Retrieved June 27, 2024. *The Globe and Mail.* <https://www.theglobeandmail.com/opinion/article-some-sensible-advice-on-health-spending-still-ignored-50-years-later/>.

University Health Network (UHN). 2020, July 22. Hotels Offer 'Health and Human Dignity' Along With a Place to Recover. Retrieved June 27, 2024. <https://www.uhn.ca/corporate/News/Pages/Hotels_offer_health_and_human_dignity_along_with_a_place_to_recover.aspx>.

First Peoples Wellness Circle and the Indigenous Mental Wellness and Trauma-Informed Specialist Workforce During COVID-19

Collaboration du First Peoples Wellness Circle et du personnel spécialisé en bien-être mental des Autochtones et en prise en compte des traumatismes pendant la pandémie de COVID-19

COMMENTARY

Naomi Trott, MSc
Research, Evaluation and Policy Officer
First Peoples Wellness Circle
Montreal, QC

Becky Carpenter, MSc, MPIA
Policy Analyst
First Peoples Wellness Circle
Red Deer, AB

Despina Papadopoulos, MEd
Director
Strategic Initiatives and Programs
First Peoples Wellness Circle
Ottawa, ON

Brenda Restoule, PhD, CPsych
Chief Executive Officer
First Peoples Wellness Circle
North Bay, ON

* * *

ABSTRACT

Members of the Indigenous mental wellness and trauma-informed specialist workforce – including Mental Wellness Teams (MWTs), Crisis Support Teams (CSTs), the Indian Residential Schools Resolution Health Support Program workforce, and other community-based cultural support workers – are often the primary and urgent care providers for individuals and families in need of culturally safe supports. While fulfilling a critical role, these teams contend with distinct challenges stemming from colonial impacts and health systems that continue to undermine Indigenous mental wellness and cultural traditions of healing. During the COVID-19 pandemic, increasing rates of mental illness and substance use among Indigenous populations strained the already overworked and under-resourced mental wellness workforce. First Peoples Wellness Circle sought out and embraced new approaches for meaningful virtual engagement to sustain and enhance workforce wellness and capacity by facilitating culturally relevant and culturally led connections from coast to coast to coast.

RÉSUMÉ

Les membres du personnel spécialisé en bien-être mental des Autochtones et en prise en compte des traumatismes, dont les équipes de mieux-être mental (EMEM), les équipes de soutien en cas de crise, le personnel du Programme de soutien en santé – résolution des questions des pensionnats indiens (PSS-RQPI) et d'autres intervenants de soutien culturel, assurent souvent les soins primaires et d'urgence des personnes et des familles qui ont besoin de soutiens respectueux de la culture. Si leur rôle est fondamental, ces équipes rencontrent des défis particuliers découlant des séquelles du colonialisme et des systèmes de santé qui nuisent encore au bien-être mental et aux traditions culturelles de guérison des Autochtones. Pendant la pandémie de COVID-19, les taux accrus de maladie mentale et d'usage de substances psychoactives chez les populations autochtones ont essoufflé le personnel de bien-être mental, qui était déjà débordé et sous-financé. Le First Peoples Wellness Circle (FPWC) a recherché et adopté de nouvelles approches concrètes de mobilisation virtuelle afin d'améliorer et de préserver le bien-être et les capacités du personnel en encourageant des liens culturellement adaptés et fondés sur la culture dans tout le pays.

Key Takeaways

- Meaningful engagement with Indigenous communities – including the Indigenous mental wellness and trauma-informed specialist workforce – empowers culturally safe, relevant and responsive practices of care and healing rooted in Indigenous knowledge and culture.
- Occupying the dual role of both community members and care practitioners, engaging the Indigenous mental wellness workforce advances community-defined health priorities, improves quality and conditions of care, supports worker wellness and promotes equity within systems of care.
- First Peoples Wellness Circle shares best practices for engagement with the workforce that centre Indigenous ways of knowing and being, are community-led, build upon cultural strengths and are grounded in reciprocal relationships.

Introduction

It is well-documented that Indigenous communities and individuals experience disproportionately high rates of mental wellness challenges compared to their non-Indigenous counterparts (Kirmayer et al. 2000) and have inequitable access to culturally safe healthcare and related services (McIntyre et al. 2017). These inequities stem from colonial policies that have displaced Indigenous ways of being and doing (Nelson and Wilson 2017). They persist as Western colonial healthcare systems continue to underservice Indigenous communities and undermine Indigenous knowledge and cultural approaches to healing. In this context, recent and ongoing efforts within mainstream healthcare systems and institutions to improve quality of care through patient, family and community engagement often exclude Indigenous experiences and perpetuate culturally unsafe care environments. This article provides insights into strategies for meaningful engagement that empower Indigenous leaders, practitioners and communities to reclaim systems and practices of care that are relevant, responsive and informed by Indigenous knowledge and culture.

There is increasing recognition of the success and need for strength-based, holistic, community-led approaches to care, healing and recovery that are firmly rooted in Indigenous culture, communities and knowledge. The Indigenous mental wellness and trauma-informed specialist workforce – including Mental Wellness Teams (MWTs), Crisis Support Teams (CSTs), members of the Indian Residential Schools Resolution Health Support Program (IRS RHSP) workforce and other community-based cultural support workers – are a key resource in providing critical services to address crises and promote intergenerational healing. Unlike mainstream approaches to addressing mental health, these teams incorporate both Western and Indigenous methods informed by knowledge, language and culture. Often occupying a dual role of community member and care provider, this workforce is well-positioned to navigate and provide culturally safe and trauma-informed care. However, teams frequently contend with high rates of burnout, compassion fatigue, stress and staff turnover, and are at higher risk of experiencing lateral violence and secondary trauma (FPWC 2019). Despite ongoing and significant need for their care, the workforce struggles against issues of wage parity and inequitable government funding, which results in inadequate workplace conditions, a lack of capacity to support workforce wellness and challenges with recruitment and retention of a qualified workforce (Sutherland et al. 2019).

Many of these issues were compounded and exacerbated with the onset of the COVID-19 pandemic, which disproportionately impacted Indigenous Peoples and put unprecedented pressure on the workforce. In 2020, Indigenous Peoples reported poorer mental health than their non-Indigenous counterparts, with 60% indicating that their mental health had worsened since physical distancing came into effect (Arriagada et al. 2020). A recent survey found that 10% of First Nations adults and 6% of First Nations youth started using substances during the pandemic (TPF and ISC 2023). In the context of the ongoing drug crisis, frequency and severity of substance use among Indigenous communities also increased, contributing to high rates of drug poisonings and related hospitalizations and deaths (Task Group on Mental Wellness 2021). At the same time, many social determinants of health (i.e., poverty, food insecurity, housing) became increasingly unstable, contributing to negative mental health outcomes.

First Peoples Wellness Circle and the Indigenous Mental Wellness Workforce

First Peoples Wellness Circle (FPWC) is an Indigenous-led national not-for-profit dedicated to enhancing the lives of First Peoples from coast to coast to coast by supporting and promoting strong, holistic mental wellness of Indigenous Peoples, families and communities. We target our services to supporting the mental wellness and trauma-informed specialist workforce to ensure coordinated, competent and culturally safe programs and services that are, above all, responsive to community needs and firmly rooted in culture. Our work is guided by the implementation of the First Nations Mental Wellness Continuum Framework (AFN and Health Canada 2015). At the system level, FPWC advocates for collaborative and transformative policy and system change that fully embraces the strengths of culturally based approaches to healing embedded in Indigenous cultural lenses and knowledges. At the community level, we strive to elevate and address the identified needs of the workforce by developing and delivering culturally safe, respectful and relevant resources and trainings that build capacity, promote workforce wellness and advance pay and funding equity.

During the pandemic, this became even more important as the workforce continued to support communities despite the challenges they faced. The COVID-19 pandemic resulted in higher levels of stress, burnout and fatigue, compounded with an increasing workload and lack of supports (FPWC 2019; Task Group on Mental Wellness 2022). We heard from the workforce the need to develop skills and strategies built on Indigenous knowledge and cultural practices to foster worker wellness and well-being in communities (FPWC 2022). In response to these needs, FPWC created and introduced initiatives to support the existing work of the workforce as they navigated their way through the pandemic (FPWC 2021, 2022).

FPWC engagement during COVID-19

From the onset of the COVID-19 pandemic, FPWC engaged members of the workforce, Elders, community leaders and knowledge holders to identify and discuss how to address areas of support. Together, we developed and implemented virtual methods to connect members of the workforce with resources, each other and cultural supports. For example, early in the pandemic, FPWC made culturally relevant information sheets available online for Elders, parents, health providers and communities to assist in coping and managing the challenges they were experiencing. As community needs increased, FPWC introduced national, virtual support calls with participants working in and for communities across the country to sustain and enhance workforce wellness. FPWC hosted 23 weekly/biweekly sessions with nearly 600 participants in 2020–21 to facilitate sharing of wise practices; identify tools, resources and training needed to adequately respond during the pandemic; and highlight promising approaches to supporting wellness. Over time, these calls expanded to learning series consisting of workshops and virtual gatherings designed to specifically address the needs identified by the workforce in the support calls. From 2020 to 2022, FPWC held five learning series that focused on skills to promote worker wellness, Indigenous methodologies to support well-being, decolonizing healthcare, as well as (re)connecting with traditional knowledge.

To further support capacity building within the workforce, FPWC shifted to virtual delivery of our training services and offered new, relevant training opportunities, toolkits and learning resources to enhance the efficacy of teams. In 2021, we held a virtual

National Gathering, titled, *Caring for Our Bundles: Healing and Resilience During and After the Pandemic*. The gathering included 10 expert guest speakers and was attended by over 200 participants who shared stories and experiences of strength and resiliency. In addition to highlighting holistic wellness in prevention, healing and self-care within the workforce, this gathering was also a meaningful opportunity for participants from the workforce, knowledge keepers, community helpers and partners and allies to connect with one another and support their well-being.

> *We learned that shifting to delivering activities and programs virtually can better accommodate the needs of an overworked, under-resourced workforce …*

Successes and enablers of engagement

Workforce-Centred Relationship Building and Partnership

FPWC is founded on values and beliefs in community-driven, Indigenous-led, culturally based holistic mental wellness care and services. At the core of this work is a commitment to meaningful engagement that centres the knowledge and experience of the workforce in discussions, planning and policies related to supporting Indigenous mental wellness. The FPWC executive leadership, as well as the chief executive officer and staff members, have lived and/or worked in communities, with experience in frontline and Indigenous mental wellness healing. FPWC has teams of staff dedicated to addressing the needs and supporting MWTs and the IRS RHSP workforce, with direct engagement to identify challenges and opportunities for support. During the COVID-19 pandemic, the workforce maintained a strong willingness and desire for FPWC to continue to deliver specialized and tailored programs and resources. As such, FPWC and the workforce worked alongside each other, sharing knowledge, insight and feedback throughout the development and delivery of pandemic resources, training and online gatherings. FPWC's strong commitment to engage with and centre the needs of the workforce during the design and development of programs and policies by building upon existing organizational structures and relationships ensured the delivery of relevant activities and initiatives during the pandemic.

New Approaches for Accessible Engagement

The primary way in which FPWC was able to reach and engage with the workforce during the pandemic was by quickly transitioning and embracing technology as a means for connecting. While technical difficulties are inevitable, FPWC remained flexible, willing and open to learn and made changes when suggested by the workforce. Importantly, members of the workforce, keynote speakers, workshop leaders, Elders, knowledge keepers and partners who participated in the online sessions and gatherings also demonstrated patience and flexibility to adapt and learn new tools.

We learned that shifting to delivering activities and programs virtually can better accommodate the needs of an overworked, under-resourced workforce and improve the accessibility of resources. By providing workshops and training remotely, participants were not required to expend travel time to attend events in person, and the same could be offered to a larger audience. However, while more accessible to some, shifting to virtual connections also highlighted the need for equitable access to stable and reliable Internet and hardware in remote and northern communities.

Creating and Supporting Ethical Spaces for the Mental Wellness Workforce to Lead, Build and Sustain Relationships

The online training, resources and gatherings that FPWC hosted responded to the needs and priorities expressed by the workforce. Their lived experiences led the direction and development of activities. For example, areas of support identified during the biweekly support calls held in 2021 informed the topic areas and discussion for the subsequent learning series to directly address and share strategies to cope with the challenges of the pandemic. Creating spaces and opportunities to come together with the intention to listen and learn from the workforce promotes a strengths-based approach for nurturing and maintaining meaningful and respectful engagement grounded in reciprocity.

In addition to tangible professional outcomes of online sessions (i.e., coping skills, tools, resources), workshops, trainings and gatherings created a space and enhanced opportunities for members of the workforce to connect and build relationships with each other across and within regions. Rather than being limited to one community, workshops included participants from various communities across a region, who could share, validate and learn from their own and others' experiences of navigating the pandemic. While physical distancing and travel restrictions were in effect, virtual offerings reduced the sense of isolation many felt by connecting them with a network of like-minded people who were all working toward supporting their communities, thereby promoting wellness and capacity building from within.

Culture as Foundation

The success of many of the learning series and gatherings that FPWC hosted during the pandemic was facilitated by a focus on strengths-based approaches that are firmly rooted in culture – the foundation of promoting and supporting Indigenous mental wellness. During the pandemic, many members of the workforce were disconnected and displaced from the communities they worked with, and physical distancing and isolation made it difficult to carry out traditional and cultural practices. For instance, ceremonies and rituals that connect people with family, community and culture, such as those during funerals and burials, could not be held. While recognizing that virtual spaces cannot replace in-person gatherings, they offered an alternative way to share traditional knowledge and cultural practices, and to connect with Elders, cultural practitioners and cultural supports.

In 2021, FPWC held a three-day learning series, titled, *Connecting to Our Traditional Knowledge to Support Wellness*. This event included a panel discussion about the role of language revitalization in upholding Indigenous wellness, land-based teachings and workshops with Elders and other leaders. The National Gathering in 2021 celebrated how land-based programs and connecting with Indigenous culture, language and knowledge contribute to wellness, and also highlighted the strengths of the workforce to lead this work, especially given the challenges of the pandemic. The significant message that resonated throughout this event emphasized that Indigenous ways of being and doing are practices that had immeasurable benefits to support wellness within communities and the workforce during the pandemic. Members of our team shared that these and other events that brought culture to the foreground were some of the most powerful and meaningful moments of connection.

Conclusion

During the pandemic, FPWC saw our organizational reach and engagement extend and increase as participants in online training, learning series and gatherings invited colleagues and members of their networks to attend, and barriers to access were reduced. Rather than witnessing diminished connection, a new form of connection was fostered among teams within and across regions. Although challenges persist, many barriers in accessing personal and professional resources and supports were reduced. Despite high stress, workload and burden, members of the Indigenous mental wellness and trauma-informed specialist workforce reported many positive outcomes from participating in FPWC activities during the COVID-19 pandemic, including feeling validated and supported, building relationships with others and cultural connection.

The pandemic also highlighted some challenges and considerations while operating in a new virtual reality. Inequitable and unreliable Internet access, especially among northern and remote communities, must be addressed to share resources to build capacity and resilience and promote wellness. Questions also arose about the blending of technology and teachings, uncovering the need to identify wise practices related to sharing ceremonial, ritual and cultural practices virtually in ways that honour and respect their intentions and sacredness.

FPWC's commitment to building relationships facilitated the design and development of resources and initiatives that directly respond to workforce-identified areas of support. During the pandemic, relationships within and across regions among members of the workforce could be strengthened and sustained virtually, cultivating a network of support for navigating the pandemic. Meaningful engagement emerged from a foundation of culture that supports workforce wellness by building on cultural knowledge, teachings, ceremonies and practices. Given the multiple benefits to the workforce of offering online and virtual tools, resources and training, FPWC continues to maximize this approach to engagement, which better accommodates the needs of the workforce while building on Indigenous knowledge and cultural practices.

For FPWC, meaningful community engagement encompasses the Indigenous mental wellness and trauma-informed specialist workforce that often occupies the entangled role of community member and care provider. Importantly, engagement-capable environments, be it with patients, communities or community workers, are always situated within western worldviews and colonial ways of knowing and doing that are upheld by health education, systems and institutions. The Indigenous mental wellness and trauma-informed specialist workforce faces double exclusion from these systems that do not prioritize the health and wellness of Indigenous communities and individuals *and* undermine non-western approaches to care, including cultural models of care and healing. In order to respectfully and effectively address Indigenous wellness needs and priorities, healthcare systems and services must fundamentally shift their orientation of care to centre engagement with and for Indigenous communities, which involves empowering the wise practices and knowledge held by communities and the workforce. Such a shift rests on a commitment to reciprocal relationship-building and exchange at all levels of engagement and across the health system more broadly to recognize and enhance the strengths of cultural and traditional knowledge and healing practices. During the pandemic and beyond, FPWC has striven to model this approach and motivate structural and policy shifts by amplifying the voice of the workforce and promoting their needs through meaningful and respectful engagement grounded in reciprocity, in the hopes of creating a more balanced and equitable decision-making system that fosters resilience to withstand future shocks, wherein a well-supported workforce, families and communities can thrive.

References

Arriagada, P., T. Hahmann and V. O'Donnell. 2020, June 23. *Indigenous People and Mental Health During the COVID-19 Pandemic.* Statistics Canada. Retrieved June 21, 2024. <https://www150.statcan.gc.ca/n1/en/pub/45-28-0001/2020001/article/00035-eng.pdf?st=9kx4CzFt>.

Assembly of First Nations (AFN) and Health Canada. 2015, January. *First Nations Mental Wellness Continuum Framework*. Retrieved June 21, 2024. <https://thunderbirdpf.org/wp-content/uploads/2015/01/24-14-1273-FN-Mental-Wellness-Framework-EN05_low.pdf>.

First Peoples Wellness Circle (FPWC). 2019, November 14. *Briefing Note: Post-Traumatic Stress Disorder.* Retrieved June 21, 2024. <https://fpwc.ca/wp-content/uploads/2021/11/PTSD-FN-Briefing-Note.pdf>.

First Peoples Wellness Circle (FPWC). 2021. *Annual Report 2020/2021: Adaptation, Meaning & Connections.* Retrieved June 21, 2024. <https://fpwc.ca/wp-content/uploads/2021/10/FPWC_annual_report_2020_2021.pdf>.

First Peoples Wellness Circle (FPWC). 2022. *Annual Report 2021/22: Meaning and Transition.* Retrieved June 21, 2024. <https://fpwc.ca/wp-content/uploads/2023/01/FPWC-AnnualReport-21_22-low-res.pdf>.

Kirmayer, L.J., G.M. Brass and C.L. Tait. 2000. The Mental Health of Aboriginal Peoples: Transformations of Identity and Community. *Canadian Journal of Psychiatry* 45(7): 607–16. doi:10.1177/070674370004500702.

McIntyre, C., M.G. Harris, A.J. Baxter, S. Leske, S. Diminic, J.P. Gone et al. 2017. Assessing Service Use for Mental Health by Indigenous Populations in Australia, Canada, New Zealand and the United States of America: A Rapid Review of Population Surveys. *Health Research Policy and Systems* 15: 67. doi:10.1186/s12961-017-0233-5.

Nelson, S.E. and K. Wilson. 2017. The Mental Health of Indigenous Peoples in Canada: A Critical Review of Research. *Social Science and Medicine* 176: 93–112. doi:10.1016/j.socscimed.2017.01.021.

Sutherland, M., M. Maar and A. Fyffe. 2019, June. *Mental Wellness Teams Comprehensive Needs Assessment: Validation of Findings Based on Key Informant Interviews and Focus Groups: Final Report.* Retrieved June 21, 2024. <https://fpwc.ca/wp-content/uploads/2021/11/MW-Teams-Comprehensive-Needs-Assessment.pdf>.

Task Group on Mental Wellness. 2021, July. *Substance Use Treatment and Land-Based Healing.* Thunderbird Partnership Foundation. Retrieved June 21, 2024. <https://thunderbirdpf.org/?resources=substance-use-treatment-and-land-based-healing-task-group-on-mental-wellness>.

Task Group on Mental Wellness. 2022, September 21. Workforce Wellness July 2022 Task Group On Mental Wellness. Thunderbird Partnership Foundation. Retrieved June 21, 2024. <https://thunderbirdpf.org/workforce-wellness-july-2022-task-group-on-mental-wellness/>.

Thunderbird Partnership Foundation (TPF) and Indigenous Services Canada (ISC). 2023. *Addictions Management Information System: Fiscal Year 2016*–2023 [In press].

Resilience and Engagement in Crisis: Fostering Trauma-Informed Care and Patient Partnerships Into the Future

Résilience et mobilisation en situation de crise : favoriser les soins tenant compte des traumatismes et les partenariats patients pour l'avenir

COMMENTARY

B.C. Pomeroy, MPsych
Director
Medical Assistance in Dying
Provincial Health Services Association
Vancouver, BC

ABSTRACT

The COVID-19 pandemic has significantly disrupted patient engagement and exposed long-standing inequities within Canada's healthcare system. As a patient partner and caregiver, the author reflects on the exacerbated challenges during the pandemic, particularly for hardly reached communities and those managing chronic conditions. The crisis highlighted the absence of opportunities for patient partnership, with healthcare organizations halting engagement activities despite an increased need for communication and community involvement. The pandemic underlined the necessity of trauma-informed care and engagement-capable environments (ECE). To address these challenges, the author advocates for integrating trauma-informed practices with ECEs, thereby promoting a healthcare model that is both structurally supportive and *responsive to individual trauma and resilience. By focusing on compassion, recognizing trauma and fostering engagement, such an approach could enhance patient outcomes and create a more adaptive, inclusive healthcare environment.*

RÉSUMÉ

La pandémie de COVID-19 a bouleversé l'engagement des patients et exposé des iniquités anciennes au sein du système de santé canadien. Personne patiente partenaire et proche aidante, l'auteurice revient sur les défis exacerbés au cours de la pandémie, en particulier pour les communautés difficiles à atteindre et les personnes atteintes de maladies chroniques. La crise a mis en exergue l'absence d'occasions de partenariats avec les patients, puisque les organismes de santé ont suspendu les activités de mobilisation malgré le besoin accru de communication et de participation de la communauté. La pandémie a fait ressortir le besoin de soins tenant compte des traumatismes et d'environnements propices à la participation. Pour répondre à ces défis, l'auteurice prône l'intégration des pratiques tenant compte des traumatismes aux environnements propices à la participation pour un modèle de soins de santé à la structure solidaire et sensible à la résilience et aux traumatismes individuels. Cette approche privilégiant la compassion, reconnaissant les traumatismes et favorisant la mobilisation pourrait améliorer les résultats cliniques et mener à un environnement de santé plus adaptatif et inclusif.

Key Takeaways

- The COVID-19 pandemic disrupted patient engagement efforts, revealing existing tensions in healthcare systems.
- Healthcare disparities worsened during the pandemic, affecting marginalized communities disproportionately.
- Integrating trauma-informed and resilience-activating practices is crucial for fostering effective patient engagement and partnerships.

Introduction

The COVID-19 pandemic has had a significant impact on patient-engagement efforts, as healthcare organizations were forced to adapt quickly to the crisis and prioritize urgent patient care needs. The pandemic challenged the culture of patient engagement efforts, exposing tensions that exist in creating person-centred policies and practices during times of crisis (Genuis et al. 2022). However, these tensions were not new to patients and caregivers. The COVID-19 pandemic merely emphasized with a big yellow highlighter what most of us already have experienced and continue to experience as patients and caregivers in Canada's healthcare system: a lack of trust, transparency and collaborative decision making, be it at the bedside, the board room and, dare I say, the legislative floor.

Discussion

When I reflect on my own experience as an activated patient partner and caregiver during COVID-19 along with the communities around me and consider the lessons noted by Kuluski et al. (2024), a few things became true: the pandemic exposed and, sometimes exacerbated, inequities in healthcare access and outcomes. These disparities were seen and experienced in various dimensions, including access to care, outcomes and the broader social determinants of health. Equity-seeking and equity-deserving groups and underserved communities often faced greater barriers to healthcare access and higher rates of COVID-19 infection and mortality. The pandemic had a disproportionate impact on racial and ethnic minority groups, as well as economically disadvantaged populations. We experienced higher rates of infection, hospitalization and mortality.

Patients and caregivers like me with chronic conditions or caring for those with chronic conditions – often more prevalent in equity-deserving communities – faced significant challenges. Disruptions in routine care, fear of accessing healthcare facilities and resource reallocation away from non-COVID-19 care adversely affected the management of conditions such as diabetes, hypertension and cardiovascular diseases.

As a patient partner, my existing partnerships came to an abrupt halt. New opportunities were noticeably absent. In the realm of patient partnerships, we often discuss the importance of having a seat at the table to inform and influence programs, services and systems; however, during the COVID-19 public health crisis, we were not even allowed in the building. Healthcare organizations – some previously recognized as advocates and leaders in patient partnership and engagement – appeared to suspend all partnership activities, both internally and externally. Yet, there was a paradoxical surge in the need for public and community communication. This dichotomy was clear to those of us working and partnering in healthcare. Patients, families, healthcare staff, leaders and the system itself were, and perhaps still are, experiencing and responding to trauma.

Patient partnerships, like many social change initiatives, originated at the grassroots, the community level. Despite the progress made over the past two decades, we – patient partners and caregivers – found ourselves returning to these grassroots to advocate for ourselves and our loved ones. Four to six weeks into the pandemic, a group of us from across Canada, all involved as patient partners and advocates in healthcare and research, self-organized to meet via Zoom. We aimed to connect and check-in, but also to brainstorm ways to underscore the increasing importance of patient and family partnerships during the pandemic. Along with another patient partner active in patient-oriented research, I started a podcast called SPORcast[1]. The series discusses the standard for patient-oriented research and strives to inspire patients, families, clinicians, academics and decision makers to get involved and create their own impact through patient-oriented research, thereby making healthcare research more relevant and meaningful.

As we reflect on how to support the system to engage with populations, we must acknowledge two current realities with respect to trauma[2]. The impact trauma has had on the populations that we want to engage with and that have also experienced the most health inequities, and the impact trauma has had on the healthcare workforce during COVID-19. If we do not acknowledge and address this trauma, we risk creating relationships and environments where people may be re-traumatized and feel unsafe.

When I consider this initial experience of exclusion, isolation and lack of opportunities as an activated patient public partner during the COVID-19 pandemic, I am inclined to explore the relationship between the principles of trauma-informed care, as explicated by Sandra Bloom (Bloom 2005), and the concept of engagement-capable environments (ECE) (Baker et al. 2016), articulated by Baker et al. (2024), particularly with respect to their implications for patient and public engagement during the COVID-19 pandemic. The current health crisis has exacerbated the need for a resilient healthcare system that can adequately respond to traumatic stress and ensure effective public engagement. This exploration reveals points of convergence and divergence between these two frameworks and discusses strategies to promote and activate resilience in healthcare.

The COVID-19 pandemic has highlighted the critical need for trauma-informed approaches in healthcare systems. Bloom's (2005) trauma-organized systems theory emphasizes understanding the impact of trauma on individuals and institutions. Simultaneously, patient public engagement has emerged as a crucial strategy to foster trust, transparency and collaborative decision making during the pandemic. However, trust is fragile – it is created slowly, and once it is lost, it takes a long time to rebuild (Slovic 1999).

The COVID-19 pandemic has highlighted the critical need for trauma-informed approaches in healthcare systems.

The healthcare sector's ability, even inability as noted earlier, to engage the public effectively during public health emergencies, such as the COVID-19 pandemic, is pivotal in ensuring community resilience. Bloom's (2005) trauma-organized systems and the concept of ECEs (Baker et al. 2016) may provide critical insights into this engagement process. Bloom's (2005) work focuses on the detrimental impacts of trauma on organizations, arguing for trauma-informed care as an essential element of system resilience. Meanwhile, ECEs aim at facilitating active patient and public involvement in healthcare decisions. ECEs "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" (Baker et al. 2016: 20).

Bloom's (2005) work on trauma-organized systems emphasizes the detrimental impacts of chronic, unresolved traumatic stress on both individuals and institutions. COVID-19, with its significant implications for health and life, fits these criteria, with potential for widespread traumatic impacts. The uncertainty, fear and loss associated with the pandemic can lead to what Bloom describes as a "parallel process" (Bloom 2010: 140), where the trauma experienced by individuals is mirrored in the health institutions tasked with addressing the crisis, thereby leading to systems that may inadvertently perpetuate trauma. The lack of family presence policies and practices during the initial wave of the pandemic is a perfect example.

ECEs, on the other hand, are founded on the notion of fostering robust patient-public interactions and enabling individuals to take an active role in their healthcare. The COVID-19 pandemic has highlighted the importance of these environments, as misinformation and fear have frequently impeded public health measures.

Both frameworks recognize the importance of trust, safety and communication in shaping effective healthcare responses. However, while Bloom's (2005) model emphasizes the systemic recognition and healing of trauma, the ECE Framework focuses on enabling engagement/partnerships at all levels of care, along with creating the structure to support said engagement. This can create potential tension when patients and public members, affected by the trauma of COVID-19, struggle to actively engage in their care or public health measures due to heightened stress and anxiety.

Taking a deeper look into my experiences over the past several decades as an active caregiver and patient partner, tension could occur for a variety of reasons: (1) expectation versus reality – engagement structures often rely on the assumptions that individuals are ready and able to participate. For those affected by trauma, there is a gap between the expected level of engagement and what some may realistically be able to offer; (2) one-size-fits-all approach – structures that do not account for individual differences in the ability to engage can feel alienating to those who are struggling, making them feel as though their experiences and difficulties are not acknowledged; (3) overlooked emotional states – systems that emphasize engagement may inadvertently prioritize operational efficiency or measurable outcomes over the emotional and psychological well-being of individuals, which can exacerbate feelings of stress and detachment; and (4) barrier to access – when engagement is a prerequisite for receiving full benefits from healthcare, those who are unable to engage may not receive the care they need, thus widening health disparities.

To alleviate such tensions, I am suggesting an alternative approach that could focus on trauma-informed practices that are sensitive to the barriers faced by those struggling to engage. This approach would weave trauma awareness into the fabric of engagement structures and ECEs, beginning with recognizing that trauma affects how individuals perceive and interact with healthcare systems. This understanding could inform all aspects of care and engagement efforts, promoting psychological safety by creating an environment where individuals feel safe to express their concerns and participate to the extent that they are able. This may involve facilitating different levels of participation and offering various modes of engagement. Imagine if we trained healthcare workers to approach patients with empathy and self-compassion, recognize the signs of trauma in both themselves and their patients and respond in ways that prioritize wellness and connection.

By focusing on practices rather than rigid structures, healthcare systems can create more adaptive and responsive engagement strategies. This approach acknowledges the reality of trauma's impact on engagement and seeks to build a bridge between the healthcare system and the individuals it serves, fostering a more inclusive and effective healthcare environment.

Healthcare systems worldwide are facing unprecedented challenges, ranging from the impact of infectious diseases to the rising burden of chronic conditions. The concept of resiliency has gained traction in healthcare as an essential factor in managing these challenges effectively. Patient-public engagement plays a pivotal role in building resilient healthcare systems. Engaging patients in the development and evaluation of healthcare policies, programs and services ensures that their unique needs and perspectives are considered. This process also fosters a sense of ownership and trust between patients and healthcare providers, leading to a more patient-centred and resilient healthcare system.

Resilience, in the context of healthcare, refers to the capacity of individuals, healthcare providers and systems to adapt positively to adversity and maintain their well-being. Resiliency is critical to the success of healthcare organizations and the provision of high-quality and safe patient care. I believe there are two distinct approaches to resiliency in healthcare: (1) building resiliency and (2) activating resiliency.

Building resiliency refers to the proactive steps healthcare organizations take to create a culture and environment that supports resiliency. This approach focuses on developing the skills and resources needed to cope with adversity before it occurs. Building resiliency involves fostering a supportive environment that empowers individuals to cope effectively with stressors, uncertainties and adverse events.

Activating resiliency is a strengths-based approach that focuses on identifying and leveraging individuals' inner resources to enhance their ability to cope with challenges and promote well-being. By recognizing and activating their inherent strengths, individuals can better navigate stressful situations and enhance their resilience (Brown et al. 2010; Werner 2005).

The convergence of activating and building resiliency in healthcare, inspired by the works of Joel Brown and Emma Werner, I believe, represents a transformative approach to healthcare delivery and partnership (Brown et al. 2010; Werner 2005). By integrating and activating resiliency techniques and promoting patient-public engagement, healthcare providers, healthcare leaders and decision makers can enhance patient outcomes, strengthen community well-being and build resilient healthcare systems capable of withstanding future challenges. As the healthcare landscape continues to evolve, the pursuit of resiliency remains a fundamental aspect of ensuring the health and well-being of individuals and populations worldwide.

This brings me back to today and this commentary. I am here as a patient partner – a patient partner who has been navigating our Canadian healthcare system for decades in the pursuit of providing my daughter, Sophia, with compassionate care. Sophia, ultimately and sadly, lost her life to the rare disease that encompassed her little body. In the years that have passed, patient and family partnerships and engagement have evolved. Our understanding and acknowledgment of trauma and resiliency have deepened.

My hope and experience suggest combining ECEs with trauma- and resiliency-informed practices represents a holistic approach to enhancing patient engagement and partnerships within healthcare systems. ECEs prioritize the creation of structures that facilitate active collaboration across various levels of care and partnerships, promoting a culture whereby patients, families and healthcare professionals work in concert. By integrating trauma- and resiliency-informed practices, these environments become attuned to the psychological and emotional needs of individuals, recognizing the pervasive impact of trauma on a person's ability to engage and participate. My hope is this synergistic approach acknowledges that the capacity for engagement is contingent upon a sense of safety, empowerment and trust, which I believe are the core principles of trauma-informed care.

Moreover, resiliency-informed practices contribute to this model by fostering an individual's ability to recover and adapt in the face of adversity, built through supportive, reliable and responsive healthcare relationships and community connections. I know that when I perceive my environment as capable of supporting my engagement and resilient growth, I will be more likely to partake actively and benefit from partnerships aimed at improving those partnerships and, ultimately, health outcomes.

Conclusion

I am encouraged when I consider an integrated model that combines ECEs with trauma- and resiliency-informed practices and how it ensures that healthcare systems are not only structurally prepared to support engagement but are also responsive to complex and nuanced human experiences of trauma and resiliency. I believe such an approach promotes a more inclusive, adaptive and supportive healthcare framework, one that is capable of meeting patients where they are and supporting us in moving toward where we need and wish to be in our healthcare journey. The COVID-19 pandemic was and still is many things to patients and caregivers – I would like to consider the experiences of the past few years both a wake-up call and permission to not just consider but to embody approaches that have the potential to serve patients and families in compassionate and just ways.

Notes

[1] www.sporcast.ca.

[2] Trauma is a term used to describe the challenging emotional consequences that living through a distressing event, series of events or set of life circumstances can have for an individual, group or community. In simple terms, trauma is any experience that overwhelms a person's or community's capacity to cope (https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/trauma).

References

Baker, G.R., C. Fancott and A. Zarem. 2024. Creating a Sustaining Culture for Patient Engagement. *Healthcare Papers* 22(Special Issue): 28–36. doi:10.12927/hcpol.2024.27370.

Baker, G.R., M. Judd, C. Fancott and C. Maika. 2016. Creating "Engagement-Capable Environments" in Healthcare. In G.R. Baker, M. Judd and C. Maika, eds., *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare* (pp. 11–34). Longwoods Publishing.

Bloom, S.L. 2005. The Sanctuary Model of Organizational Change for Children's Residential Treatment. *Therapeutic Community: The International Journal for Therapeutic and Supportive Organizations* 26(1): 65–81.

Bloom, S.L. 2010. Trauma-Organised Systems and Parallel Process. In Tehrani, N. ed., *Managing Trauma in the Workplace: Supporting Workers and Organisations*, (pp. 139–53). Taylor & Francis Group.

Brown, J.H., G. Jean-Marie and J. Beck. 2010. Resilience and Risk Competence in Schools: Theory/Knowledge and International Application in Project REBOUND. *Journal of Drug Education: Substance Use Research and Prevention* 40(4): 331–59. doi:10.2190/DE.40.4.b.

Genuis, S.K., W. Luth, T. Bubela and W.S. Johnston. 2022. COVID-19 Threat and Coping: Application of Protection Motivation Theory to the Pandemic Experiences of People Affected by Amyotrophic Lateral Sclerosis. *BMC Neurology* 22: 140. doi:10.1186/s12883-022-02662-w.

Kuluski, K., C. Fancott, M. Keresteci and G.R. Baker. 2024. Patient and Caregiver Engagement in an Era of COVID-19: What Did We Learn and How Do We Move Forward? *Healthcare Papers* 22(Special Issue): 9–26. doi:10.12927/hcpol.2024.27371.

Slovic, P. 1999. Trust, Emotion, Sex, Politics, and Science: Surveying the Risk-Assessment Battlefield. *Risk Analysis 19*(4): 689–701. doi:10.1023/a:1007041821623.

Werner, E.E. 2005. What Can We Learn About Resilience From Large-Scale Longitudinal Studies? In S. Goldstein and R.B. Brooks, eds., *Handbook of Resilience in Children* (pp. 91–105). Springer.

Meaningful Engagement or Co-Production, or Both?

Mobilisation authentique, coproduction, ou les deux?

COMMENTARY

Christian von Plessen, MD, PhD
Senior Lecturer
University Center for Primary Care and Public Health (Unisanté)
University of Lausanne
Lausanne, Switzerland

Paul Batalden, MD
Professor Emeritus of Pediatrics
Geisel School of Medicine
Dartmouth College
New Hampshire, US
Guest Professor
Quality Improvement and Leadership
Jönköping University
Jönköping, Sweden

ABSTRACT

The COVID-19 pandemic magnified the cracks in healthcare performance. Dysfunctionalities and exhaustion appeared, but so did resilience and innovation. Examination of these cracks offers opportunities for learning and potential for new developments just as in the Japanese art of kintsugi, *which is about building new objects from pieces of broken ceramic and mending the cracks. Engagement and partnership activities came under strain in Canada, as well – a pioneer in the field.*

Some were put on hold; others proved resilient and contributed to surmounting the challenges of the pandemic. Applying their Engagement-Capable Environments Framework, Kuluski and colleagues (2024) studied kintsugi in partnership activities in Canada during the pandemic. The resulting case studies exemplify the factors facilitating engagement and partnership during crisis. Through a lens of co-production that we see as a precondition for understanding and improving healthcare during a crisis and beyond, we challenge the results of the study, hoping to open new perspectives and advance engagement and partnership.

RÉSUMÉ

La pandémie de COVID-19 a amplifié les failles dans les soins de santé. On a observé des dysfonctionnements et de l'épuisement, mais aussi de la résilience et de l'innovation. L'examen de ces failles peut apporter des connaissances et des innovations, à la manière du kintsugi, *art japonais consistant à façonner une nouvelle poterie à partir des éclats et des fissures d'un objet cassé. Les activités de mobilisation et de partenariat ont été fragilisées au Canada, pourtant pionnier en la matière. Certaines activités ont été suspendues, mais d'autres ont perduré et contribué à surmonter les défis de la pandémie. En appliquant leur cadre d'environnement propice à la participation, Kuluski et son équipe (2024) ont étudié le kintsugi dans les activités de partenariat au Canada menées pendant la pandémie. Les études de cas obtenues illustrent des facteurs facilitant la mobilisation et le partenariat en situation de crise. Dans une optique de coproduction, condition préalable selon nous pour comprendre et améliorer les soins de santé pendant une crise et dans d'autres contextes, nous remettons en question les résultats de l'étude dans l'espoir d'ouvrir de nouvelles perspectives et de faire avancer la mobilisation et le partenariat.*

Key Takeaways

- The language of engagement and co-production connects with different epistemologies. By using both, we can enhance our shared efforts to improve how healthcare service is created and experienced.
- The descriptive language used also depends on the perspective of the user: observer, participant, policy maker, researcher or assessor?
- Using multiple languages to understand the amazingly human work of helping and supporting one another in the pursuit of better health can also invite inquiry into the limits and benefits of any one epistemology.

Introduction: Applying the Art of *Kintsugi*

The COVID-19 pandemic made visible the cracks in the organization and the performance of healthcare systems around the world. Fragile and vulnerable things often crack first. Engagement and partnership activities were among such vulnerable innovations in healthcare that cracked. Many were put on hold because they were considered less crucial. Others, however, rapidly got back up on their feet again, demonstrated resilience and agility and made new and critical contributions to health during the pandemic. Learning from these cracks for the future reminds us of the Japanese art of *kintsugi* (Wikipedia 2024). The kintsugi master carefully examines the crack lines of broken ceramics, then gilds them and finally recreates objects of stunning beauty.

Many consider Canada the world leader in patient involvement. The Montreal model (Pomey et al. 2015) is famous for good reasons. It has inspired colleagues around the world to develop partnerships between patients and healthcare professionals, policy makers and researchers. To hear from such a mature player what facilitated and inhibited these activities during the disruption of the COVID-19 pandemic holds important messages for others.

The Canadian frame is ambitious. Meaningful engagement, as Kuluski et al. (2024) define it, should involve all stakeholders from patients to policy makers and happen everywhere in clinical care and on the organizational and the policy levels. It means proactively co-producing a health system where power is shared. This takes time and resources and requires will, understanding and a culture shift valuing the expertise from lived and professional experience.

The authors propose a framework for what it takes to implement system-wide partnership. This Engagement-Capable Environments Framework (Baker et al. 2016; Kuluski et al. 2024) includes leadership support and strategic focus, engagement of staff to involve patients and enlisting and preparation of patients so they can act as partners. Stakeholders can self-assess the presence of these facilitators in their organizational setting with a self-assessment tool recently published by Healthcare Excellence Canada (HEC n.d.).

After the pandemic, the authors studied examples of kintsugi in their system. Patients and care partners, leaders of quality improvement and patient involvement and senior managers participated in in-depth interviews that were summarized as case studies. These include hospitals, community services, health authorities, regional quality improvement agencies and coordination agencies, a knowledge centre for patient and public engagement and a community of practice for patient experience and partnership.

The results of the study are five core themes that are exemplified with short vignettes from the case studies: "(1) strong connections between organizational leaders and patient and family partners; (2) maturation of context, including entrenched philosophy of PFCC [patient and family-centred care]; (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" (Kuluski et al. 2024: 16). These echo Bannear's suggestion that we need to "design for the conditions that enable the emergence of many solutions" (Bannear 2023).

It means proactively co-producing a health system where power is shared.

Through the Lens of Co-Production

We come to this commentary with a lens of co-production of healthcare service that we have been living with and developing. The lens of healthcare service co-production has helped us see that, like other services, making a healthcare service involves two parties: one who is an expert in the lived reality of the person whose health it is and one who has studied the multiple types of knowledge and applications of it as others with similar situations have seen or experienced. These two parties work interdependently to *make the service*. Each party has access to supportive resources – information that they bring to the task. Their interaction is key to the logic of service making. Since it is common to refer to people by the name of the role they are playing such as "patient" or "professional," this has sometimes obscured the truth that both people are "kin" to one another and that, as people, they are working together.

We have come to see that work systems as well as policies can make it easier or harder to do that shared work by the way we frame, assess and improve. So, we have come to understand that co-production is a logical precondition – not just a priority – for how we understand and improve a healthcare service. This logic is a fundamental enabler of the practice of meaningful engagement that Kuluski et al. (2024) present. Furthermore, we have come to understand that this frame carries multiple knowledge systems, which are created with different methods. The biology of the condition, the experience of having it and the design of interventions that work and that help minimize the undesired burdens of the condition and its treatment are all different streams of knowledge. The architecture of the systems of co-production offers the opportunity to explore ways by which structures can contribute to the design and the performance of the parties as the work is done.

Our Questions

These *ways of seeing* have made us curious as we approached the article by Kuluski et al. (2024), and it is from those ways and habits that our questions and reflections have emerged:

1. **How would a patient and a clinician working together view meaningful engagement in designing and delivering a healthcare service?**

"Meaningful engagement" for two parties actively working together is not a matter of ticking a box or of applying some measure of "engagement meaningfulness." The core work of co-creating service invites attention to that work – not the strength of one or more attributes of their interaction. Meaningful engagement, trust, mutual respect, willingness to be vulnerable, shared power, integrity and mutual accountability are all illustrative of attributes seen in good co-production.

2. **What is the model behind the reasoning of enabling factors and environments?**

Bannear (2023) identifies the shared voices of intent, experience, capability and design that together create an ecosystem for change and improvement. According to Uhl-Bien and Arena (2017: 12), enabling factors for such an ecosystem include "space" in time, human interaction, generative exploration and inquiry, some boundary setting and "local rules of interaction" (Hazy 2012), active community building, the use of data to learn from the work and the exploration of information from the experience of others. Southcentral Foundation's Nuka System of Care, based in Anchorage, Alaska, may serve as an example of meaningful engagement and kinship in a community. Through native customer ownership and relationships, the Nuka System of Care evolved from a centrally managed, bureaucratic system to an integrated, high-performing and comprehensive healthcare service (Gottlieb 2013). April Kyle and Doug Eby describe the journey in a podcast in the "The Power of Coproduction" series (Kaplan et al. 2019).

3. **Might co-production invite a more explicit understanding of the relevant "action" and its interconnection with "relationship"?**

The work of healthcare service making involves both relationship and action. Meaningful engagement offers an important invitation to authentic, helpful relationships. The case in Box 1 may illustrate the development of a co-produced decision, care plan and action.

Box 1. An example of meaningful engagement

A 70-year-old man was told he had borderline vascular hypertension. He was offered treatment, but declined. A while later, he decided to obtain a method for recording his own blood pressure. He began to see the data that confirmed borderline hypertension. On the next visit with his primary care professional, he told the physician that he agreed with the doctor's earlier assertion. The doctor asked if he wanted treatment. He said that he wanted to lose weight, reduce the alcohol he was drinking and exercise more in addition to getting a very low dose of an established antihypertensive medication. He lost about 20 pounds, reduced the number of glasses of wine with meals, and started regularly walking regularly. His blood pressure moved into the normal range. The action required agreement between the professional and the patient. Data helped the patient share the doctor's opinion. The patient actively co-designed the intervention. The relationship between the professional and the patient was based on trust and data. Both were proud of the result.

4. What is required for an epistemology for the work of co-production and engagement in healthcare?

A sociologist (engagement) and an economist (co-production) describe this work differently. In healthcare, we borrow their terms, which can be confusing. Developing an epistemology for healthcare might help advance both.

So, enabling co-production, or "engagement," as Kuluski et al. (2024: 10) call it, requires at least two parties who develop a clear sense that both are "kin" to each other and who cultivate an open spirit for the use of multiple knowledge systems to make it work and put in unceasing efforts to challenge our individual and organizational habits that have often made this hard to accomplish. We hope that our questions will stimulate further curiosity and understanding about meaningful actions and relationships in healthcare.

References

Baker, G.R., M. Judd, C. Fancott and C. Maika. 2016. Creating "Engagement-Capable Environments" in Healthcare. In G.R. Baker, M. Judd, C. Maika, eds., *Patient Engagement: Catalyzing Improvement and Innovation in Healthcare* (pp. 11–34). Longwoods Publishing.

Bannear, B. 2023, March 8. The New Zeitgeist: Relationships and Emergence. *Medium.* Retrieved August 15, 2023. <https://medium.com/@bill.bannear/the-new-zeitgeist-relationships-and-emergence-e8359b934e0>.

Gottlieb, K. 2013. The Nuka System of Care: Improving Health Through Ownership and Relationships. *International Journal of Circumpolar Health* 72: 21118. doi:10.3402/ijch.v72i0.21118.

Hazy J.K. 2012. The Unifying Function of Leadership: Shaping Identity, Ethics and the Local Rules of Interaction. *International Journal of Society Systems Science* 4(3).

Healthcare Excellence Canada. n.d. *Engagement-Capable Environments: Organizational Self-Assessment Tool.* Retrieved August 15, 2023. <https://www.healthcareexcellence.ca/media/0n0hfkwj/20220321_ece_organizationalselfassessmenttool_en.pdf>.

Kaplan, M., P. Batalden, A. Kyle, D. Eby, T. Bovaird and E. Loeffler [Speakers]. 2019, May 30. Episode 12: Coproduction and Macrosystems of Health Care [Podcast]. *The Power of Coproduction*. <https://ju.se/center/icohn/podcasts/the-power-of-coproduction/episodes/episode-12.html>.

Kuluski, K., C. Fancott, M. Keresteci and G.R. Baker. 2024. Patient and Caregiver Engagement in an Era of COVID-19: What Did We Learn and How Do We Move Forward? *Healthcare Papers* 22 (Special Issue): 9-26. doi:10.12927/hcpol.2024.27371.

Pomey, M.-P., L. Flora, P. Karazivan, V. Dumez, P. Lebel, M.-C. Vanier et al. 2015. Le "Montreal model": enjeux du partenariat relationnel entre patients et professionnels de la santé. *Santé Publique* 27(1_Suppl): 41–50.

Uhl-Bien, M., and M. Arena. 2017. Complexity Leadership: Enabling People and Organizations for Adaptability. *Organizational Dynamics* 46(1): 9–20. doi:10.1016/j.orgdyn.2016.12.001.

Wikipedia. 2024. Kintsugi. Retrieved June 21, 2024. <https://en.wikipedia.org/wiki/Kintsugi>.

Nurturing Resilient Health Ecosystems: What Can We Learn From Patient and Professional Experience?

Cultiver des écosystèmes de santé résilients : que peut-on apprendre de l'expérience des patients et des professionnels?

COMMENTARY

Ghislaine Rouly
Canada Research Chair in Partnership with Patients and Communities
Centre de recherche du CHUM
Université de Montréal
Montreal, QC

Antoine Boivin, MD, PhD
Canada Research Chair in Partnership with Patients and Communities
Centre de recherche du CHUM
Université de Montréal
Montreal, QC

~

ABSTRACT

Patients and professionals face important crises through their "normal" experiences of illness and care, which can either prepare them or make them more vulnerable to global crises. What can we learn from these experiences to nurture more resilient health ecosystems? In this commentary, we reflect on resilience in times of crisis, *based on our lived experience as patient and physician. We learned that identifying "who is strong" and "who is vulnerable" can be surprising and unexpected, that patients and professionals can lean on one another at different stages of crises and that resilient health ecosystems require reciprocal, caring relationships at the individual and collective levels.*

RÉSUMÉ

Au cours des expériences « normales » de la maladie et des soins, patients comme professionnels font face à des crises majeures qui peuvent les préparer aux crises mondiales… ou les rendre plus vulnérables. Que pouvons-nous apprendre de ces expériences pour cultiver des écosystèmes de santé plus résilients? Dans ce commentaire, nous nous penchons sur la résilience en temps de crise, à partir de notre vécu expérientiel en tant que patiente et médecin. Nous avons appris que la catégorisation des personnes comme étant « fortes » et « vulnérables » s'avère parfois surprenante et inattendue; que les patients et les professionnels peuvent s'épauler mutuellement à différentes étapes des crises; et que les écosystèmes de santé résilients demandent des relations bienveillantes et réciproques, aussi bien à l'échelle individuelle que collective.

Key Takeaways

- While often perceived as "vulnerable," patients often build strong resilience through their experience of health and life challenges.
- While often perceived as "strong," health professionals can be particularly vulnerable to crises, which disturbs their sense of control and puts at the forefront the need to also care for oneself.
- Patients, health professionals and system leaders are all individually vulnerable to crises. A key lever of health ecosystem resilience is our collective capacity to lean on one another, recognize each other's strengths and care with one another, especially when the sea is rough.

Introduction

The COVID-19 pandemic was a "cluster of crises" that disrupted our personal lives, health systems and communities. Although the crises were unprecedented in many ways, they were not entirely unfamiliar for some of us. Indeed, patients and professionals face important crises through their "normal" experiences of illness and care. These events can either prepare them or make them more vulnerable to global crises. What can we learn from these experiences to build more resilient health ecosystems?

In this commentary, we reflect on resilience in times of crisis, based on our lived experience as patient and physician. We learned that identifying "who is strong" and "who is vulnerable" to crises can be surprising and unexpected and that lived experiences of crises can provide important lessons for nurturing resilient health ecosystems. Our stories illustrate many of the key concepts introduced by Kuluski et al. (2024) in this special issue: the critical importance of relationships as a foundation of health and care; the interconnectedness of patients, health professionals, system leaders and community members; and the importance of learning from a crisis from an asset-based perspective (what helped us survive and foster resilience?), rather than a deficit perspective (what was lacking?).

Building Resilience Through Personal Life Crisis: A Patient's Journey

March, 1980, in the emergency room of one of the biggest hospitals in Montreal, QC

> *Are you divorced?*
>
> Excuse-me?
>
> *Answer the question, please.*
>
> Well, yes, but …
>
> *I knew it! You women are all the same. You cannot handle stress so you need to blame it on someone or something. What happened is that you probably had heavy menstruation. You should be ashamed of yourself to come to the ER, fake pain and take the place of a real patient in need of my care! Go home. Now!*

May, 1980, in a trauma centre in the US

I just got remarried and was happy.

I was transported unconscious by helicopter to the centre for the exact same reasons I came to the emergency room (ER) in March. During urgent surgery, they discovered double cancer: ovaries and uterus with metastasis, during which time I had a cardiac arrest. It was followed by months of palliative sedation.

Then the nightmares really started. Who was I? From speaking numerous languages, I went to understanding only one. I did not recognize my own daughter nor anyone. It took me two years of re-education, rehabilitation and re-adaptation to come back to what I am now, more or less.

Why? Because one person, who was supposed to care for me, put his own disrespect for and hatred of women before his oath. That day, my entire life changed forever. Even now I still suffer the consequences of his action, or lack thereof.

I thought often of the other doctor present with me that day. A young resident in the ER in Montreal who was in partnership with me, long before the patient partnership started. He knew and saw the cancer, he wanted me to go to another hospital, he wanted to denounce his boss, but I made him promise me he would not. That man would have destroyed him. I am sure that this resident is a wonderful doctor now, because he was an incredible human being from the start.

This event had an impact on the way I envisioned health professionals for many years to come. I realized then that what makes a "good" doctor is definitely not the years of studies but who he is as a human being: his humility, his respect for others regardless of gender, religion and race and his empathy. In fact, it is his humanity doubled by his scientific knowledge. Without humanity, this doctor became an impostor, a dangerous one for that matter. My trust was shattered. I became more assertive, more demanding as I realized that caring and curing are not a gift but a right. As such I made sure that patients' voices can be heard, especially women's voices.

As a child, I promised myself that I will never be a victim. Never will I behave as such. Instead, I will try to understand what is happening, knowing that from every negative event, positive sprouts. All you need to know is that you have a choice in everything in life. Logically, you cannot accept illness since you cannot refuse it, but you can tame it, learn about it, grow from it and decide once and for all how you are going to live with it. The illness should not dictate how you live. You should choose how you live with it.

I am alone with it, even surrounded by staff, family and friends. No one knows truly what it is that I feel, what my pain is. It belongs to me. It is sacred and it demands respect. If we want to survive and live a decent, healthier life, we need to give ourselves the right to take care of ourselves, before thinking of others around us. Healthy selfishness is a must. Attitude in life is everything. The perception of an event triggers the outcome. If one behaves like a victim, one becomes a victim. I chose not to and made sure to help my peers ever since. I have this strong personality that helps me deal with life's surprises. But not everyone is the same. I have a huge intellectual curiosity, a huge appetite for life and an enormous love for my fellow human beings. When combining these three ingredients, one becomes so much alive even when we are dying inside a little bit at a time.

Every day, everywhere, people suffer tremendous events, traumas, illnesses, aggressions, and so on. We are truly alone with them. They belong to us and to us only. They are intimate. But if you are lucky like I was, you meet people who will change your path. For that, you have to be open to changes, curious about the unknown and believe in your own destiny. Before "finding" myself, instinctively, I listened to the power of my broken mind and spirit. Later, I believed in faith, that attitude and openness of the mind will bring you to a new path in the acceptance of things you have no power to change. Attitude and recognition of one's limits are key factors in your survival. I had the great privilege to encounter and trust some incredible persons who took the time to rebuild me, to truly care and to teach me how to be a human being again. It took two long years.

Having learned from previous life experiences, refusing as always to be a victim, when the COVID-19 pandemic halted the world, I was somehow prepared mentally and emotionally; no panic, no anxiety and no fear. I had no power in controlling it, but I had the power to be part of the solution by following what was required of me, of each one of us. I immersed myself into survival mode – action, reflection, respect and learning about it from the right people, not making it a political theme, nor a treaty on liberty. It was about coming to terms with what you cannot change while at the same time, participating in a solution for yourself first and society, second. The COVID-19 pandemic gave me another powerful opportunity of experiencing what resilience is all about: making and living your best life in spite of traumatic experiences and embracing whatever outcomes show.

My approach is one of humility and respect, trying to learn one day at a time what life brings, good or bad; riding the wave of life, not fighting it but truly surfing with it; enjoying the good and learning from the rough moments; and accepting that with every new wave comes great knowledge, satisfaction, pride and joy, until that one day when your final ride will come making you realize that you have done everything with such love and hunger for this wonderful journey that you cannot regret anything. Life, per se, is an incredible gift that we should cherish during and until our last breath.

Attitude and recognition of one's limits are key factors in your survival.

Building resilience through professional crisis: A physician's journey

Ghislaine's contribution to this written dialogue is a humbling story of resilience and survival in the face of struggles and illness, of facing injustice with grace, of turning anger into gifts for others, of focusing on what can become, rather than what has been lost, of hope rather than despair and of resilience in times of crisis. For me, Ghislaine's life is an invitation to flip our professional care narrative on its head, to recognize patients and citizens as the first caregivers in society, as people with power, knowledge and strengths, and to reframe our roles as facilitators rather than saviours.

This cultural shift is easier to write on paper than to enact in daily life. In this second part, I share my personal physician's perspective on resilience during the pandemic crisis.

When crisis disrupts caring relationships

Throughout my medical training, I was taught that I was "in charge" of patient care: responsible for identifying the problem and finding the solution. I often feel alone in front of "my" patients, projecting a strong outlook on the outside, stethoscope around my neck, "MD" at the end of my name, with the power to prescribe, refer and advise. On the inside, however, I often feel clueless, powerless and uncertain of the nature of the problem and the appropriate course of action.

These feelings of uncertainty are acutely exacerbated in times of personal and global crisis, as they were during the pandemic. Our clinic was shut down and then reopened with everyone isolated, compartmentalized and fragmented. We lost support and contact with each other as we moved to teleconsultation behind closed doors – no more corridor conversation to discuss complex cases, no more chats at the coffee machine to debrief about the emotional toll of care and no more team lunches to laugh, relieve stress and share stories.

Oh yes, we did "replace" all of those interactions with Zoom meetings and an incalculable number of e-mails about changing protocols and guidelines. The *information flow* surged as the *relationship flow* dwindled. Caring relationships were hampered by face masks and team relationships were constrained by social distancing, each eating alone while scrolling on our phones, maintaining two metres of distance between our speechless bodies.

The crisis weakened the social fabric of care at the same time as the pressure for care increased. Patients were scared, isolated at home, uncertain of where to find a trusting ally in an ever-changing system and worried that clinical consultation might carry more harm than good. How can we build trust over the phone? Where is the caring gaze and the reassuring presence on the answering machine and the government website? Crisis not only transformed the *service supply chain*, but affected the *trust supply chain*.

Finally, crises not only affect the *professional* caregiver but the *personal* caregiver as well. When COVID-19 hit, my partner took a full-time job in public health, working over 12 hours a day, for months. Vacations were forbidden by the same policy makers who hailed us as "guardian angels" a few months earlier. Our four children were at home for weeks: no schools, no friends and no parents available because we were too busy caring for others. Our families and friends were scared. Caring for ourselves, caring for our children, caring for our families, caring for our patients and caring for our communities became an unsustainable burden. I was on a high-speed train, *productively* and *effectively* racing into a wall.

Caring for One Another in Times of Crisis

Faced with overwhelming responsibilities, I switched my own paradigm and *let the patient care for the physician*. Ghislaine and I had been working together as colleagues for a few years (Boivin and Rouly 2020): a patient and a physician joining forces to care for others, building a partnership that was strong enough to disclose my own vulnerabilities as a caregiver with her. Ghislaine became the compassionate voice who reminded me that it was okay to draw limits in my own care practice, that I could take a break during weekends, catch my breath, focus on myself and my family and then offer help to others within the limits of my own energy and abilities.

Ghislaine suggested that the first step toward resilience was to become a good caregiver for myself, to put the oxygen mask on me before trying to save others. This is difficult when your whole life and professional identity is built on the idea of caring rather than being cared for. In my personal life, I started opening my door to the help of others. Our neighbour offered to cook a few meals for our family. Grandparents started offering bedtime stories and daily presence to their grandchildren through videoconference. I started singing and playing the guitar again.

Around the same time, a small group within our clinical team transformed itself into a "mutual support team" through weekly interprofessional meetings to discuss complex cases. Facilitated by our psychologist, these meetings became a *lifeboat*, where we rediscovered the power of caring for one another, of caring with each other. Ghislaine's presence in these meetings was a catalyst for opening up about our own challenges and vulnerabilities as caregivers.

Slowly, this spirit of *caring for one another* extended to other teams in our community. The idea of a patient and a physician joining forces to care with each other gained traction. Ghislaine and I were approached to support a local community health centre in the integration of a peer with lived experience of homelessness (Panaite et al. 2024). Daniel, a wonderful human being with lived experience of homelessness and a strong ability to care for others *and* himself, started working in partnership with the medical director of the clinic. He brought this same spirit of "taking care of each other" as Ghislaine did in our clinic. Shelters were closed – the damages of the virus were compounded by a curfew leaving the homeless without a roof. Daniel landed in a care team that was exhausted. But, like Ghislaine, he had learned the value of caring for himself and to support each other. Rather than throwing himself into the fire, he kept his balance, started cross-country skiing and encouraged his teammates to take a weekend off to sustain their energy throughout this marathon of care.

Finally, we slowly built relationships with a broader ecosystem of community care, nurturing reciprocal relationships with diverse caregivers in our community: Indigenous navigators, harm-reduction peer-support workers, migrants, informal caregivers, community workers and their allies. Ghislaine – slowly and respectfully – brought us together through a circle of care, where we support and learn from each other.

I realized that those of us who appeared the most "vulnerable" – like Ghislaine and Daniel – were in fact the most resilient to this global crisis. Meanwhile, the "strong" healthcare professionals were struggling to maintain personal and professional balance.

Nurturing Resilient Health Ecosystems Through Relationships and Engagement

In reflecting on how to nurture a resilient ecosystem of care, we learned a few things together.

First, we will always feel overwhelmed by crises if we frame healthcare providers as the first, only, "strong" and "invulnerable" caregivers in society. What we have learned from caring together over many years is that patients are not only "vulnerable people in need of care" but also resourceful caregivers who have built knowledge and resilience through personal life crises. Similarly, experienced family members, informal caregivers and community members are not only "visitors" but also "essential care partners" who we can join forces with. As pointed out by Kuluski et al. (2024), engagement is a human endeavour built on relationships among all actors in the healthcare ecosystem. None of us have all the answers. Nobody is invulnerable. We all have good and bad days, and we are much stronger and resilient when we care together.

Second, we need to recognize our own vulnerabilities as healthcare professionals. The heroic figure of healthcare professionals and "high-performing" institutions is an illusion that masks our inherent fragilities and interdependencies. Resilience also requires spaces to share those vulnerabilities and support each other. Sometimes, it is patients who can support health professionals and system leaders. This is one of the reasons why we need to create space and moments for patient partners to take the lead and share power with them.

Finally, resilient ecosystems have a broad perspective on health that goes beyond service delivery. Caring is relating, trusting and being present for one another. Our personal lives are not detached from our professional lives. Health is intimately connected to the living conditions and social fabric of our communities. Fostering partnership and distributed leadership among patients, community leaders, health professionals and system decision makers are needed. And we need to balance the inherent power that shapes how these relationships evolve.

Resilient ecosystems are caring ecosystems; they are living systems that do not see people as machines and numbers; in these living systems we recognize our mutual strengths and need to care for one another. These strengths, knowledge and relationships are already there. What is most needed is a shift in culture that allows us to see beyond the surface and care with each other.

Acknowledgment

Genevieve Castonguay provided comments on different versions of the manuscript.

Funding

Antoine Boivin is supported by the University of Montreal's Department of Family Medicine, Centre de recherche du CHUM and the Canada Research Chair in Partnership with Patients and Communities. Ghislaine Rouly is funded by the Canada Research Chair in Partnership with Patients and Communities.

References

Boivin, A. and G. Rouly. 2020, February 28. Community Initiative Co-Led With Patients Could Improve Care for People With Complex Health and Social Needs. *The BMJ Opinion*. Retrieved June 21, 2024. <https://blogs.bmj.com/bmj/2020/02/28/community-initiative-co-led-with-patients-could-improve-care-for-people-with-complex-health-and-social-needs/>.

Kuluski, K., C. Fancott, M. Keresteci and G.R. Baker. 2024. Patient and Caregiver Engagement in an Era of COVID-19: What Did We Learn and How Do We Move Forward? *Healthcare Papers* 22(Special Issue): 9–26. doi:10.12927/hcpol.2024.27371.

Panaite, A.C., O.A. Desroches, D. Turgeon, M. Isabel and A. Boivin. 2024. Partnering With Peers in Homelessness to Face Systemic Crises: Experiences and Lessons Learned. In R. Schiff, A. Wilkinson, S. Cullingham and K. Buccieri, eds., *Pandemic Preparedness and Homelessness: International Lessons from COVID-19*. Canadian Observatory on Homelessness Press.

THE AUTHORS RESPOND

Healthcare*Papers*

Beyond the Crisis: Transforming Health Systems Through Community Engagement

Au-delà de la crise : l'engagement communautaire pour transformer les systèmes de santé

THE AUTHORS RESPOND

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

Amy Lang,[1] PhD
Executive Director
Patient-Oriented Research
Canadian Institutes of Health Research
Toronto, ON

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

~

---

[1] The views expressed herein are solely those of the author and do not necessarily reflect those of the Canadian Institutes of Health Research.

ABSTRACT

How can we effectively partner during crises? How can partnership with communities, patients, caregivers, providers and leaders be sustained and even evolve during difficult times? The opening paper of this special issue (Kuluski et al. 2024) probed these questions. The six response papers in this issue emphasized engagement that moves from partnership with individuals and communities to efforts that are led by communities; trauma-informed approaches at an individual and organizational level; and shed light on the interdependency of culture and leadership. By broadening our engagement efforts with communities, we are more apt to co-produce improvements in care that also address the social determinants of health.

RÉSUMÉ

Comment collaborer efficacement lors d'une crise? Comment maintenir, voire faire progresser les partenariats avec les communautés, les patients, les proches aidants, les prestataires et les leaders pendant les périodes difficiles? Le premier article de ce numéro spécial soulève ces questions (Kuluski et al. 2024). Les six articles de réponse nous encouragent à aller plus loin en soulignant le besoin d'un engagement où les partenariats avec les personnes et les communautés sont remplacés par des efforts menés par ces dernières; en employant des approches tenant compte des traumatismes à l'échelle individuelle et organisationnelle; et en reconnaissant l'interdépendance de la culture et du leadership. Élargir nos efforts d'engagement des communautés, c'est accroître notre capacité à coproduire des améliorations des soins tout en tenant compte des déterminants sociaux de la santé.

Background

Kintsugi, the Japanese art of repairing broken pottery using lacquer, is offered as a metaphor by von Plessen and Batalden (2024) for fragility, setbacks and rebuilding. The COVID-19 pandemic revealed the fragility of our health and social care systems as well as the vulnerability of patient-, caregiver- and community-engagement practices. The insights and experiences shared in this special issue showed us that sustaining and growing engagement practices were possible in some settings by harnessing the collective wisdom of leaders, care providers, healers, patients, families, caregivers and community members, including people experiencing structural marginalization. This was accomplished through bold and consistent leadership to protect and sustain a culture of partnership and reciprocity and by co-designing care delivery models and building new infrastructure. The COVID-19 pandemic exposed personal and system vulnerabilities and propelled us to think, learn and act in different ways. In this closing paper, we offer reflections on the wealth of insights offered by authors in this special edition, which we have distilled in four key takeaways: (1) relationships and partnerships are the precursors for change; (2) trauma- and resiliency-informed practices are the foundation for engagement; (3) community engagement and community leadership are necessary for social change; and (4) culture and leadership are interdependent. To carry through the kintsugi metaphor, we suggest that these takeaways represent the lacquer (the adhesive) to make a system whole.

Relationships and Partnerships Are the Precursors for Change

Principles of engagement, co-design and leadership underline the importance of relationships, building connections with others so that they feel heard, valued and respected. Rouly and Boivin (2024) provide a beautiful example of the deepening and evolution of relationships that dispel tropes that perpetuate patients as *weak and helpless* and physicians as *strong and saviours*. As noted by Boivin, vulnerability and uncertainty lie behind a mask of heroism that we place on providers and healthcare systems (Rouly and Boivin 2024). In their descriptions of roles that they took on for each other through the COVID-19 crisis, we see lived experience as expertise, and vulnerability as strength. The modelling of their relationship extended into their team, encouraging deepening relationships among their team members, who came together to support one another, including those with lived experience.

Similarly, von Plessen and Batalden (2024) draw from new models of quality (Lachman et al. 2021) to emphasize that co-production happens when people come together as "kin" (p. 61) to draw on multiple knowledge systems and challenge themselves and the systems in which they work.

Trauma- and Resiliency-Informed Practices Are the Foundation for Engagement

While Rouly and Boivin (2024) implicitly approach their relationship in ways that are trauma-informed, Pomeroy's (2024) article makes explicit links between trauma- and resiliency-informed practices as foundational to engagement-capable environments, noting the need to understand people – their histories, traumas, triggers and personal needs – to create psychologically safe spaces for engagement. These efforts also require attention to the setting in which engagement takes place and the ways these structures and processes may perpetuate trauma. Pomeroy (2024) cites psychologist Sandra Bloom who defines these "parallel process[es]" (p. 55) as the legacy of trauma and dysfunctional processes within and between organizations that parallel the trauma of people who are seeking care or service (Bloom and Farragher 2010). Bloom (2012) offers the Sanctuary Model to provide practical guidance on how individuals and organizations can deal with difficult situations, understand the depths of trauma and adversity, design a way to communicate about trauma and enhance psychological safety. Parallel processes and the Sanctuary Model signal the importance of workforce wellness, which became heightened through the COVID-19 pandemic.

Trott et al. (2024) from the First Peoples Wellness Circle (FPWC) draw on trauma-informed practices as central to their work as a national, Indigenous-led organization focused on Indigenous wellness priorities and needs across Canada. In their article, Trott et al. (2024) help us to recognize the blurred lines that exist between pillars that are described as "patients" and "healthcare teams" in the Engagement-Capable Environments Framework (Kuluski et al. 2024). As they point out, in Indigenous communities, community members may also be the healthcare providers, and the distinctions between these groups are not well defined. Harnessing the knowledge of communities and Indigenous ways of knowing and being lies at the core of how FPWC does its work, drawing from the collective wisdom of communities to create healthier spaces to live and work – for everyone. Notably, reciprocity is central to how they engage, ensuring that their work is community-led, anti-colonial and trauma-informed, meeting the needs of those who are served.

Without an enabling context and culture, individual efforts for engagement will be difficult, may lose momentum or disappear altogether over time.

Community Engagement and Community Leadership Are Necessary for Social Change

Expanding our thinking into engagement beyond individuals to communities is a consistent theme across these commentaries. Boozary and Keresteci (2024) speak eloquently of the need to centre lived experience perspectives to lead social change and address inequities in care. Boozary describes how a large academic teaching hospital centrally located in a large urban environment has been able to move beyond its walls to develop relationships with communities and community organizations to support the social determinants of health (Boozary and Keresteci 2024). Similar to Rouly and Boivin (2024) (and their work with "caring communities"), Boozary draws attention to those with lived experience in core team roles as peer support workers in the emergency department. This approach offers a supportive model of care to meet people's needs, often diverting people from the emergency room to community supports. Boozary goes on to describe additional initiatives that move beyond traditional medical models to meet the needs of those being served (including food delivery programs and affordable housing built on hospital property). These changes were made in partnership with the community, placing people with lived expertise directly into models of care delivery and redefining how we think about interdisciplinary teams and team membership. Boozary's examples remind us that different types of partnerships, outside the walls of the clinic/hospital, will be needed to address so many drivers of health (Boozary and Keresteci 2024).

Culture and Leadership Are Interdependent

At its core, engagement with patients, caregivers and communities is a fundamental culture change to how decisions are made, how power is shared and how knowledge is recognized and valued. Across all of these commentaries, we see these changes articulated – at the individual level with providers and patients, within communities and across organizations and systems. Baker et al. (2024), in their detailed case of the Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview), demonstrate how culture and leadership are inextricably intertwined. Over decades of intentional work, Holland Bloorview has built organizational structures and processes (i.e., the visible artifacts) that have become the "fabric" of how they work. While engagement-capable environments articulate the essence of leadership required to embed engagement practices, further work is required to more fully articulate the cultures that enable engagement-capable environments to flourish over time. Leadership and culture provide the enabling environment for other aspects of engagement across health and social care teams, patients, communities and caregiver partners. Without an enabling context and culture, individual efforts for engagement will be difficult, may lose momentum or disappear altogether over time.

The Way Forward

Over the past decade, engagement practices have grown, evolved and been challenged. COVID-19 revealed the fragility of many environments and their engagement practices, and simultaneously shone a light on other engagement practices that we need to continue to grow and nurture. The concept of engagement-capable environments was borne at a time when healthcare organizations were moving from *doing to* and *doing for* to begin *doing with*. While there is continued need to reinforce and strengthen engagement practices across the continuum, what these authors have helped us see is the ongoing movement required for *doing by*, where individuals and communities can lead the way (Russell and McKnight 2022). The case studies analyzed by Kuluski et al. (2024) provide ongoing insights into elements of engagement-capable environments that need to be considered. The reflections of authors in this series help us advance our thinking and our understanding that the core of engagement is relational work – one that is trauma-informed, resilient and equitable.

As we continue to move beyond the pandemic, it is important to reflect on lessons learned and evolve our practices within the broader environments where we live, work and play, as we are all part of intersecting, complex ecosystems. Cormac Russell's Asset Based Community Development (ABCD) approach (Russell and McKnight 2022) provides an example of how we may deepen our understanding of communities and begin building relationships. The ABCD approach moves us away from a deficit-focused, problem-based orientation to a strengths-based approach that recognizes, celebrates and illuminates local assets within communities. This shift requires deep reflection on how we show up for others in our engagement activities and how this is influenced by our social positions. In addition to strengthening engagement within organizational walls, healthcare organizations need to look to their communities to identify priorities as well as solutions, drawing on the strengths of diverse perspectives. As we advance our thinking on engagement-capable environments beyond organizational walls to ecosystems – perhaps we consider a fourth pillar that points to community and its assets.

As we move toward harnessing the power of communities in our engagement efforts, we share a quote by Indigenous Elder Lilla Watson on allyship, recently referenced in a paper by Nixon (Nixon 2019: 11):

> If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together.

This quote perfectly encapsulates the growing frontiers of engagement, though arguably, in many contexts, this is not new at all; it aligns with strengths-based approaches in social work practice, community-based participatory methods, equity and anti-oppression frameworks, Indigenous ways of knowing and being and other cultural practices. Moving beyond a traditional medical heuristic, a *new* era of engagement will also challenge our typically narrow view of leadership as being organizationally based. While organizational leadership is critically important in shifting a culture toward engagement, we must ask ourselves: "How do we also shift power to community to advance health and care for all?" We hope this special issue on lessons learned in engagement throughout the pandemic provides ideas, inspiration and perspectives on how we can continue to evolve and grow engagement-capable environments.

References

Baker, G.R., C. Fancott and A. Zarem. 2024. Creating a Sustaining Culture for Patient Engagement. *Healthcare Papers* 22(Special Issue): 28–36. doi:10.12927/hcpol.2024.27370.

Bloom, S.L. 2012. The Sanctuary Model. In C.R. Figley, ed., *Encyclopedia of Trauma: An Interdisciplinary Guide* (pp. 579–82). Sage Publications.

Bloom, S.L. and B. Farragher. 2010. Parallel Processes and Trauma-Organized Systems. In S. Bloom and B. Farragher, eds., *Destroying Sanctuary: The Crisis in Human Service Delivery Systems* (pp. 130–54). Oxford University Press.

Boozary, A. and M. Keresteci. 2024. The Power of Partnership Beyond Social Prescribing. *Healthcare Papers* 22(Special Issue): 37–43. doi:10.12927/hcpol.2024.27369.

Kuluski, K., C. Fancott, M. Keresteci and G.R. Baker. 2024. Patient and Caregiver Engagement in an Era of COVID-19: What Did We Learn and How Do We Move Forward? *Healthcare Papers* 22(Special Issue): 9–26. doi:10.12927/hcpol.2024.27371.

Lachman, P., P. Batalden and K. Vanhaecht. 2021. A Multidimensional Quality Model: An Opportunity for Patients, Their Kin, Healthcare Providers and Professionals to Coproduce Health. *F1000Research* 9: 1140. doi:10.12688/f1000research.26368.3.

Nixon, S.A. 2019. The Coin Model of Privilege and Critical Allyship: Implications for Health. *BMC Public Health* 19(1): 1637. doi:10.1186/s12889-019-7884-9.

Pomeroy, B.C. 2024. Resilience and Engagement in Crisis: Fostering Trauma-Informed Care and Patient Partnerships Into the Future. *Healthcare Papers* 22(Special Issue): 52–58. doi:10.12927/hcpol.2024.27367.

Rouly, G. and A. Boivin. 2024. Nurturing Resilient Health Ecosystems: What Can We Learn From Patient and Professional Experience? *Healthcare Papers* 22(Special Issue): 64–70. doi:10.12927/hcpol.2024.27365.

Russell, C. and J. McKnight. 2022. *The Connected Community: Discovering the Health, Wealth, and Power of Neighborhoods*. Berrett-Koehler Publishers.

Trott, N., B. Carpenter, D. Papadopoulos and B. Restoule. 2024. First Peoples Wellness Circle and the Indigenous Mental Wellness and Trauma-Informed Specialist Workforce During COVID-19. *Healthcare Papers* 22(Special Issue): 44–51. doi:10.12927/hcpol.2024.27368.

von Plessen, C. and P. Batalden. 2024. Meaningful Engagement or Co-Production, or Both? *Healthcare Papers* 22(SP): 59–63. doi:10.12927/hcpol.2024.27366.

This issue of *HealthcarePapers*
was made possible
through the support of:

Healthcare
Excellence
Canada

Excellence
en santé
Canada

Longwoods.com
Better Care | Health Services Publishing, Education & Recruitment