PARTNERING WITH PATIENTS

A Compass for Our Care: Leadership that Enables a Culture of People-Centred Care

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Abstract
The healthcare system has undergone a transformational shift toward people-centred care (PCC), and healthcare leaders are accountable for enabling this culture change. This paper describes the University Health Network’s journey of using a person-centred approach for cultural transformation, reflecting on (a) the leadership elements required to build and sustain a culture of PCC; (b) the importance of establishing a Patient Declaration of Values, which is a framework for patient care; and (c) how this culture led our approach during the COVID-19 pandemic.

Introduction
The healthcare system can be difficult to navigate alone, and it is important to know [that] every smile, every interaction holds meaning. Every moment, every exchange is an opportunity for us to improve healthcare. When we empathize, we empower. (J. O’Connor, Patient Partner, personal communication, 2019)

Jermaine O’Connor, a University Health Network (UHN) Patient Partner (quoted above), eloquently described what is most important to him when it comes to partnering with his care team. Over the past five years, UHN has focused on building and sustaining a culture that aligns with O’Connor’s vision of a compassionate and collaborative healthcare environment. An intentional change management approach was used to shift to a culture where partnership drives shared decision making among healthcare providers, healthcare leaders, patients and families.

This paper uses UHN’s Patient Declaration of Values (PDoV) as a key example of shared decision making and demonstrates the change that has occurred as a result of patient engagement (PE) prioritization.

A significant shift occurred in health system priorities with the introduction of Ontario’s Excellent Care for All Act (2010). This act established several patient-centred provincial accountabilities, including the requirement for each hospital to develop a PDoV that is reflective of the needs of patients. However, without a leadership commitment, a PDoV can be reduced to simply being a document on a website or a plaque on a wall. In order to make these values a priority, an actionable plan is needed so that these values are demonstrated in every care encounter.

UHN’s primary organizational value is “The needs of patients come first.” This has become an embedded mantra that is aligned with the deeper vision of UHN’s PDoV. As Peter Kyriakides, a UHN Patient Partner, shared:

During very challenging times, there are opportunities, and through collaboration we reach solutions. UHN’s PDoV has been successful because of its collaborative...
Knowing that new initiatives tend to fail due to change fatigue (Beaudan 2006), it was decided that the PDoV would become UHN’s commitment to exceptional patient care and be used as an accountability framework to patients and families. In this article, we share the experience of our quest to build and sustain a truly people-centred, compassionate healthcare environment by answering a few key questions:

- How do healthcare leaders ensure that rich knowledge, such as O’Connor’s, becomes part of the fabric of the organization?
- What do leaders need to do to shift the culture of an organization to one that meaningfully values collaboration and partnership with patients, both in their individual care and in organizational decision making?
- How can organizational change management approaches help leaders ensure that a foundational guide, such as UHN’s PDoV, is reflective of the population a hospital serves and can be used to drive quality improvement even through challenging times?
- With this change in culture, what is different at UHN?

Key Leadership Elements Required to Foster a Culture of People-Centred Care

Leadership commitment and public endorsement
It speaks volumes when a healthcare CEO intentionally starts his weekly all-user e-mail update with “What [have] we learned from Chris Channon, UHN Patient Partner, at the Quality and Safety Committee of the Board meeting?” A culture of patient prioritization must be actively and consistently demonstrated by all levels of leadership. UHN’s CEO continuously reminds TeamUHN that “it is a privilege to serve our patients” and has strategically placed patients at the top of the UHN Organizational Chart (UHN 2020) to remind the organization that “the needs of patients come first” (UHN 2016). UHN’s Patient Partners are included on the senior leadership team’s organizational chart with a clear statement that they will be involved in all major decisions at UHN. It has become the expectation that all key decision-making committees or new hiring panels have Patient Partners as full participants, and the CEO asks for evidence of this on a regular basis. This change has resulted in very different discussions at hiring tables. Patient Partners are posing new questions and challenging leaders to think broadly about who joins the organization and how. For example, questions about diversity – both in who is being hired and who is doing the hiring – are being broached both in the moment and in broader tables by Patient Partners. They are prioritizing human-centred competencies along with skill competencies. While these questions are an organizational and individual accountability, Patient Partners are helping to ensure that we are actively keeping these important considerations at the top of our minds.

Resource allocation and people-led change management approach
A strategy cannot be fulfilled without proper resources along with a clear vision for why and how this is important. To ensure that we meet this mandate, UHN has aligned and directed resources for a PE team that is values driven. The six programs within this portfolio demonstrate how UHN supports this partnership (UHN 2019b) using collaborative, compassionate and motivational leadership that aims to sustain an exceptional patient experience. These programs include the following: Patient Relations; Patient Partnerships; Patient Education and Engagement, Interpretation and Translation Services; Patient and Family Libraries; and myUHN Patient Portal. The positioning of these teams together has created a synergy where patient voices significantly influence how we provide care at UHN. The teams have individual and shared goals, but all follow the same change management approach: a leadership framework with top-down accountabilities that prioritize a people-led approach to ensure that patients, families and team members are central (Hussain et al. 2018). This gives rise to diverse and differentiated opportunities to embed the PE strategy in a meaningful way and has created a culture where the value of PE has grown over time through thousands of meaningful partnership experiences. The team, including Patient Partners, shares leadership, and this drives deeper and more meaningful and complex discussions. This means that it is not only PE team members who are driving people-centred change but all staff and patient partners who are engaged in shared decision making. This people-led approach removes assumptions and creates space for individuals to speak up.

Accountability and capabilities
As described by Rowland et al. (2018), in an “engagement-capable environment,” the roles of Patient Partners in an organization are clearly recognized. This requires a leader’s strong commitment to people-centred care (PCC), an understanding of what quality PE looks like and ongoing modelling of partnership with patients.

Led by the Patient Partnerships team, 144 Patient Partners have been oriented to their role and are matched to quality improvement initiatives and governance committees across the UHN. In order to ensure that this mandate has accountability, leaders at UHN are building PE plans for their work (e.g., strategy development, facility redevelopment, model of care changes) to directly engage with Patient Partners. When making decisions, they consider the following: “Does this align...
with what we hear from patients who share concerns about their care?” and “Are we using methods, such as patient journey mapping, that can be helpful in better understanding the experience of the patients we serve?” For example, the vision statement for UHN’s outpatient care strategy is “Compassionate care coordinated with patients and their essential care partners,” and the strategy includes equitable access, seamless transitions and patient empowerment as key foci. These came directly from journey mapping activities with Patient Partners. With these priorities in place, and a team of Patient Partners who are partnering to see this through, outpatient care will be developed with patient experiences at the forefront.

Establishing a Foundational Guide for PCC

With the key leadership elements for a PCC culture as described earlier being practised by leaders at UHN, the time was right and the decision was made to use the PDoV – named “A Compass for Our Care” – as the foundational guide for delivery of patient care and the framework for patient experience across the organization. Like all buildings, projects need a keystone, and the PDoV – in alignment with the organizational values – is that vital component.

What Is UHN’s Compass for Our Care?

“Whenever you lose your way, your compass and, in this case, our values point us in the right direction,” says Peter Kyriakides, Patient Partner (P. Kyriakides, personal communication, May 2019). These values are written from the perspective of patients and serve as a foundation for providing care that is reflective of patient needs and priorities (Figure 1).

UHN’s PDoV – “A Compass for Our Care” (UHN 2019a) – is intentionally aligned with UHN’s “Purpose, Values & Principles” (UHN 2016) and the Ontario Ministry of Health’s PDoV (Minister’s PFAC 2019) to support its visibility, consistency and longevity. “A Compass for Our Care” is illustrated by five values that help staff understand what patients, and families, trust will occur when they are partnering in care at UHN (Figure 2).

Collaborative Development Approach

The collaborative change management approach used to develop the PDoV made its implementation successful, fostering confidence and deepening commitment across the organization. This initiative was based on collaboration, appreciative inquiry, generative dialogue and an openness for what was emerging in the experience (Hodges et al. 2020; Whitney and Trosten-Bloom 2010). Leadership was shared with two Patient Partners being identified as executive sponsors alongside a hospital executive and operational sponsor, all of whom committed to developing the PDoV with integrity and a strong PE strategy before endorsing its approval.

The working group included Patient Partners along with operational and clinical staff across UHN. A shared goal and commitment – coupled with differing perspectives – enabled dynamic, respectful and inspiring discussions that honoured the patient and clinical voices in the discovery of what values were most important.

Multiple engagement methods were used, and 1,100 points of data emerged to inform the PDoV. The analysis revealed what patients appreciated in their care and what they trusted UHN would provide. The working group continued to refine the definitions and behaviours that related to the following five values:

- respect and dignity;
- empathy and compassion;
- transparency;
- accountability; and
- equity and partnership.

The Patient Partner Executive Sponsors presented the refreshed PDoV to UHN’s Board’s Quality and Safety Committee, which ensures alignment with priority decision making.

What Is Different?

Using the PDoV as a framework to deepen PCC culture and foster system change

Leaders: Consider using [the PDoV] to celebrate what you’re doing well with your teams and for creating a safe space to discuss room for improvement. (K. Smith, personal communication, February 8, 2021)
FIGURE 2. Declaration of Patient Values: Handouts

**A Compass for Our Care**

**UHN Patient Declaration of Values**

- **Respect and dignity**
  - We trust that you recognize and acknowledge our lived experience, individual identities, values, preferences and beliefs.
  - We trust that we are asked what is important to us.
  - We trust that we are valued as partners in our care teams.

- **Empathy and compassion**
  - We trust that you care about us and treat each of us as a whole person, without labels and assumptions.
  - We trust that together, we can build a relationship based on kindness, understanding and mutual respect.

- **Accountability**
  - We trust that we receive safe, high quality care that is coordinated by all members of our care team at every step of our journey here at UHN and beyond.
  - We trust that you are open and honest when mistakes happen and that we know the plan to make sure it doesn’t happen again.
  - We trust that our voices are heard, and our questions or concerns are welcomed and acknowledged.

- **Transparency**
  - We trust that we meet and maintain safe spaces to support our cultural health practices and traditions.
  - We trust that you support our diverse identities including age, ancestry, Indigenous culture, abilities, gender expression, gender identity, race, religion, sexual orientation and socioeconomic status.
  - We trust that we are considered partners in our care, and included in hospital program design, policy development and governance decisions.

- **Equity and partnership**
  - **Empower me**
    - Keep me up to date about my care and what to expect next.
    - Respect and support my right to make informed choices about my care.
    - Honour my right to privacy.

**Accountability**

- **Show me you are accountable by...**
  - **Providing high quality care**
    - Use your skills, knowledge and the most up-to-date position to give the best care possible.
    - Tell me if things go wrong, and include me in the process of finding out what happened with honesty and compassion.

- **Coordinating my care**
  - Share important information with me and my entire care team.
  - Ask me if I need something to be explained or clarified.
  - Help me prepare for any transfers to other care settings, providers or to home.

- **Listening and responding**
  - Hear my concerns and work with me to address them.
  - Keep your word to me. If you told me you will follow up on something, please do so.
  - Answer any questions using language I can understand.
  - Get back to me about my questions as soon as you can.

**Empathy and compassion**

- **Show me you value empathy and partnership by...**
  - **Building a relationship with me**
    - Ask me questions that go beyond my condition or treatment plan.
    - Notice my emotions and offer me support.
    - Try to take your time with me and be fully present, even if you are in a rush.

- **Helping me**
  - Find out what I need or want.
  - Offer options for my care that take my needs and preferences into account.

- **Sharing my kindness**
  - Smile, say hello, and be friendly to me.
  - Listen more and do your best to understand my concerns.
  - Ask me “What else can I do for you?”

**Transparency**

- **Show me that you value transparency by...**
  - **Communicating clearly, in a way I can understand**
    - Ask me what questions or concerns you have heard.
    - Use words that I can understand when I have medical jargon, be sure to re-explain if your wording is unclear.
    - Tell me if I have any new programs and medical standards to explain my health or treatment to me.
    - Tell me if there are important decisions to make that affect me.
    - Be honest with me, and give me all the information you have available.

- **Sharing resources and services I may need**
  - Tell me about hospital resources and services that can support my care, such as Patient Navigators, the Patient and Family Advisory, Inpatient Services, Birthcenter, Spiritual Care, myUHN Patient Portal, Patient Partnerships and research opportunities.

- **Keeping me aware**
  - Tell me what to expect next and how I can best prepare.
  - Check with me to understand the steps and next steps, or ask questions when I have medical jargon.
  - Continue to work with me and check back.

- **Giving me access to my health records**
  - Ask me if I have any questions or concerns about my care.
  - Help me to register if I have not yet registered.
  - Ask me if I want access to my health records and why.
  - Let me know if I have signed up for my health records, and help me to register if I have not yet registered.
Through strategic nudges such as this quotation from communication from UHN’s CEO to his leaders, and through the philosophy of collaborative change leadership (Hodges et al. 2020) and “going where the positive energy is,” leaders have been able to organically embed the values into core areas of the organization. Without the collaborative model and engagement methods used to develop the PDoV, the adoption of the values in the organization would not have been realized by leaders and staff. The process provided a sense of confidence in its meaning. A few examples of how the values have been embedded in the organization are mentioned in the following sections.

Using the values in quality and patient safety
In alignment with the Canadian Patient Safety Institute’s guide to engaging patients (Patient Engagement Action Team 2017), there are 24 Patient Partners who sit as full members on UHN’s Quality and Safety Councils, from the board to program-based councils. Patient Partners do not only bring their own experiences and insights as a patient or caregiver; they have also been oriented to how safety and quality are monitored, measured and evaluated at UHN and they are well-versed in the PDoV. This exemplifies authentic shared leadership models. A Patient Partner on one of the councils reflected on how she feels empowered to reference the values at meetings when discussing serious safety events. In particular, she focuses on transparency and accountability:

It is so important to be honest and truthful when disclosing safety events to patients and families and to keep them informed during the review process. It helps to build trust and reassures families that UHN is committed to reducing preventable errors, improving practices and providing excellent care. (“UHN Safety Culture Change” 2020)

Prior to this, a discussion about disclosure and why it is important may likely not have occurred. With a Patient Partner at the table and the PDoV as a foundational guide, UHN’s chief patient safety officer reflected, “[T]he patient perspective keeps us focused on what is most important and ensures that decisions made to mitigate future safety risks are the most impactful ones” (E. Musing, personal communication, December 14, 2020).

Framework for discussing critical incidents
One of the most difficult accountabilities for an organization is the disclosure of critical incidents to patients and families who have been harmed through error. Transparency in this process demonstrates authentic leadership accountability. When a patient is affected by a critical incident (http://www.health.gov.on.ca/en/pro/programs/ecfa/legislation/criticalincident/update.aspx), Ontario hospitals have a legislated obligation (Quality of Care Information Protection Act 2016) to disclose the facts of what happened and the recommendations that have come from the Quality of Care review, to prevent similar
incidents from happening in the future. How deeply and authentically this occurs comes right from leadership.

At UHN, we have started overlaying the values in interviews with patients affected by a critical incident by asking, “Based on what you saw, heard and experienced, how could we have done better? Where and how did we not live up to the PDoV?” Using the PDoV allows us to create a framework when sharing their questions, concerns and perspectives with the Quality of Care review team. The PDoV is also providing a framework for UHN to begin discussing non-physical harm as a critical incident.

Learning from patient stories of quality and safety
Patient Partners have been leading the way as influencers of change at UHN and began attending board meetings to share their experiences of care. As Fancott (2016) suggested, we should use “patient stories to better understand patients’ experiences of illness and of care, and to inspire leaders and staff for quality and safety within healthcare.” Leaders are often far removed from the care experience. For UHN, it has given leadership the opportunity to hear first-hand from patients their recommendations for how care can be improved and where the values were practised in their care and where they were not. We cannot underestimate the opportunities this provides for action to be taken by leaders to implement change so that care can be more reflective of patient values.

Patient Partners have asked board members to consider what healing truly means and how to change our measurement to reflect what is important to patients, which may look different than our standard metrics. Being seen and heard, in an authentic way, is of critical importance, and UHN’s patient experience measurement tools have been updated to reflect this. A Patient Partner shared his priorities with the board:

One key tool that assisted [us] in our journey was [the] myUHN Patient Portal. Having lab results in real time kept me informed and gave me confidence when meeting with my healthcare providers. I was better prepared to discuss my results. Having direct access to surgery notes, clinic notes and medical test results is the epitome of transparency. (S. Overholt, personal communication, September 28, 2020)

Scott Overholt (quoted above) and so many other Patient Partners have emphasized the importance of patient portals. In order to make sure that we meet patients’ needs, Patient Partners are embedded across working groups for the implementation of a new health information system. Access to health information needs to be a priority, and their voices are advocating to ensure that a clinical transformation includes them. Hearing where the values fall short provides leaders with the opportunity to invoke change in the system. Although Karen Hanna believes that her mother’s overall care was positive, when it came to her transition out of UHN, she said:

Both my brother and I were at work at the time of the call and could not make it to the hospital in time to comfort my mother and prepare her for this sudden transition of care. As a result, she was transferred without a family member with her. (K. Hanna, personal communication, October 26, 2020)

By hearing this feedback and tying it to the PDoV of accountability, empathy and compassion, leaders were able to identify new processes to support change and accountability. This experience reminded the team of the need to include patient perspectives in the transfer of the accountability process. This process was adjusted and included as important context during the pandemic when patients needed to be transferred to other hospitals to meet volume demands.

Patient Partners are also making recommendations to the board on what can be done to help foster a more PCC environment. A recent presentation to the board by Chris Channon, a Patient Partner, included these recommendations (C. Channon, personal communication, January 28, 2021):

1. Could it be made clear to UHN staff to always ask the following question: What do I need to know about you so that we can help prepare you for your appointment?
2. Could UHN employees be given the autonomy to make changes and help patients to the greatest extent possible?
3. Could you ensure that the needs of patients include an understanding of both seeing and hearing patients?

Once again, this shared leadership model created space for a Patient Partner to lead us in a direction of needed change.
Representing Patient Relations data through the PDoV

Patient Relations has collected patient feedback for many years. These data include compliments about the care received, as well as the concerns or complaints patients and families have about their care. The data are tracked, trended and shared with leadership for quality improvement purposes at the individual and system levels. A “refresh” of how patient feedback is quantified is currently under way, which has included the reframing of compliments provided by patients toward hospital staff using the PDoV and the five core values. When a compliment is received, staff are recognized and awarded a “compass pin” (Figure 3). This recognizes them for providing care that is reflective of patient needs and priorities and for truly “walking the talk” when it comes to living the values. Leadership is now asking for and using these data and the values as a framework for understanding how and where the patient experience is not aligning with our commitment to PCC so that quality improvement initiatives are developed and implemented. This signals to staff that the values are important and must serve as a guide.

How the PCC Culture Thrived at UHN throughout the COVID-19 Pandemic

The COVID-19 pandemic has served to emphasize health discrepancies to a much greater degree. The areas that an organization values became more apparent as departments and programs shifted to meet the needs of the urgent challenges. With our leaders already practising key elements to foster a PCC culture, our PDoV endorsed and embedded in the system and a PE portfolio collaboratively working to advocate for compassionate, equitable and safe care, UHN leadership immediately recognized that PE was critical to ensure that we heard from patients and families first-hand about their needs and priorities throughout the COVID-19 pandemic.

The Patient Partnerships team within the PE portfolio had already built strong relationships with our Patient Partner community, and the transition to virtual engagement with them was purposeful and mostly seamless. Patient Partners continued to be on-boarded and requests from teams across UHN for engagement with Patient Partners increased. Examples of this engagement included the following:

- The development of a COVID-19 Patient Partner Rapid Response Review Team. This group of 20 Patient Partners agreed to be contacted at any time of day or night to review patient-facing educational materials, communications and policy documents (e.g., COVID-19 screening information, essential care partner visiting policies and scripts for appointment delays).
- The Clinical Activity Recovery Team and COVID Operations Committee. These included Patient Partners who advocated in these settings for the PDoV and an ethical framework to serve as foundational guides for decision making, including the shift to provision of virtual care. They also ensured that communication channels were a priority between care teams and patients and families – specifically that they were open, strong and consistent as COVID-19 changes occurred.

A number of Patient Partners who are living with chronic conditions continued to receive care throughout the pandemic. With a relationship already fostered with this community as a whole and individually, they felt empowered to tap into their own experiences of care through the COVID-19 pandemic and reached out directly to the PE team to share their questions and concerns. Many opportunities for improvement were identified for virtual care, consent processes and infection control protocols, among others.

Opportunities for Reflection

As UHN had to shift focus to pandemic-related priorities, there was an unfortunate pause on many projects, committees and other important initiatives. A Patient Partner described his disappointment and frustration with a peer support program being shut down completely, noting that a virtual model could have been introduced in spite of concerns about privacy implications with virtual technology. It will be necessary to think about when and how to reintroduce these important and needed initiatives as we begin to function in our “new normal.”

Going forward, we will continue to reflect on the important issues raised by patients, families and Patient Partners to determine what the future of healthcare will look like – including improved communication channels, highly digitized healthcare impacting human connections and the health and social inequities that the COVID-19 pandemic shed a light on.

Conclusion

UHN’s senior director of Patient Experience shared her thoughts on this journey:

Witnessing a culture where leadership is shared with patients is a personal and professional transformation experience, connecting us with why we chose helping professions in the first place. There will always be more to do, but we have our compass to tell us which direction to follow. (L. Williams, personal communication, February 26, 2021)

If the key leadership qualities described in this paper are practised meaningfully, they will translate into building and sustaining a culture of trust and humanizing the care we provide to the patients we serve, guiding us toward our True North.
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References


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**Pam Breese** is a Patient Partner at UHN in Toronto, ON. Pam has been an active participant in the Patient Partner program at UHN for the past four years after having retired after 25 years working in administration with the Toronto District School Board. Based on her experience as caregiver for her daughter, she is committed to accountability and transparency and the importance of the patient voice in healthcare improvement.

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