Health Quality 5.0: What Does Co-Creation Have to Do With It?

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Abstract

In this latest article in Leslee Thompson's Health Quality 5.0 series, she discusses the slow progress of patient engagement in healthcare over the past two decades, emphasizing the need for co-creation where patients and providers collaborate equally. It explores the challenges of overcoming traditional power dynamics and integrating patient knowledge into healthcare systems. Highlighting examples from around the world, the article identifies five success factors for global impact and stresses the importance of a holistic, inclusive approach to healthcare transformation. Co-creation is presented as essential for building resilient, high-performing health systems centred on patients' needs and experiences.

Introduction to the Co-Creation Imperative

"Nothing about me without me" has been a call to action for over two decades (Delbanco et al. 2001: 144). While there has been meaningful progress, change has been too slow, too cautious and, in many ways, too superficial. Why? Turning the tide on long-standing traditions, especially in healthcare, takes time, and paradigm shifts can take generations. As Thomas Kuhn famously explained in his 1962 book *The Structure of Scientific Revolutions*, embracing new paradigms can, at first, feel like "wearing inverted lenses" (Kuhn 1962: 122). Every radical idea, including Copernicus' notion that the earth orbits the sun and not the other way around, is initially dismissed as crazy, improbable and impractical. Patient engagement is no different. Overcoming cynical objections and skeptical voices has not been easy over the years, but with a growing body of evidence and experience from around the world on the positive impacts of patient engagement, there is momentum that signals an irreversible trend.

As patient engagement moves into the mainstream, however, we need to ensure that it is not diluted or dismissed as *done*. Vested interests will continue to resist sharing power, and the "we know best" professional culture will prevail unless the fundamental shifts we are starting to see take hold are sustained and strengthened over the long term. In fact, the real work ahead is to ensure that current models of patient engagement mature to reflect the evolving needs of our rapidly changing healthcare systems. Co-creation of a shared vision of the future will be key to success.

The primary focus of co-creation is to bring together groups of people with diverse perspectives, knowledge and expertise to generate new ideas and solutions. It involves engaging people from the initial stages of design and development through to implementation and evaluation. It is broader and more inclusive than the approach of consulting or gathering input and advice from individuals or groups at the execution or delivery phase of a change. When practised with purpose and inclusivity, co-creation opens up new opportunities to resolve complicated problems, reach difficult decisions and introduce innovations that increase the quality of care, make services more people-centred, improve health and strengthen provider and system resiliency.

This series opened with the premise that it is time for Health Quality 5.0 (Thompson 2023). We are entering a new era of personalization where a more holistic, human-centric approach to improving quality and building resilient, high-performing, learning health systems is required. As we examine each of the big challenges ahead, including workforce, planetary health, and access to equitable, people-centred integrated care, it is clear that leaders cannot tackle these on their own. Co-production and co-creation of solutions with patients and communities are essential. There is no one-size-fits-all approach here, and this article will explore what it takes to foster meaningful engagement in different contexts and what the future of co-creation can look like.

Before we get started, it is worth noting that there is a tendency for people to get caught up in circular, messy conversations about language when it comes to discussing collaboration, engagement, co-design, co-production and co-creation. Every framework defines things a bit differently, and I have seen organizations lose valuable time and energy getting lost in the details of definitions. The key is to define what you mean, together with your patient partners, and then move on so you have the capacity to focus on action. Most of the time, the term patient in patient engagement includes patients, residents or clients and their families or others in their circle of care. On the terms collaboration, engagement, co-production and co-creation, I see these concepts on a partnership spectrum, with co-creation as the more mature state we should be aspiring to reach for health system transformation.

Patient Knowledge: Moving Beyond the *Lived Experience Expert*

Partnerships are built on trust. And trust comes from respect for the different types of knowledge, expertise and life experiences people are bringing to the table. The knowledge of professionals providing care, creating services, crafting policy and reforming the system is often deep but narrow and anchored in a deep-seated belief that "we know best." This creates a power dynamic that needs to be acknowledged and addressed. Often, we create stakeholder tables of multiple experts from different disciplines, professions and sectors, then add one or two patients to represent *the voice of patients* as if patients were a homogenous group with a single knowledge and experience base. This must change for a paradigm shift to take hold. Being intentional in including different types of patient knowledge is a good step in the right direction.

We need the participation of people with first-hand experience and understanding of what it is like to rely on life-saving care or deal with chronic conditions, how it feels when care is good or bad or when we must step up, again, to help a loved one because services are withdrawn or inaccessible. As a patient living with Parkinson's disease reminds us, "every year I spend 1 hour in healthcare, and, 8,765 hours in self-care" (Thompson 2015: 38).

Together, the knowledge, skills and acumen of patients plus healthcare providers and other stakeholders can become a powerful force for change. If we can get everyone to listen, learn, discuss and decide together how to tackle difficult issues or seize opportunities to take steps in a shared direction, then there really is not a problem that cannot be solved.

Dumez and L'Espérance (2024) take our understanding of patient knowledge and ways it can be mobilized to a new level in their groundbreaking article recently published in *Social Theory & Health*. They challenge the way patient knowledge is typically cast and codify six types of patient knowledge that arise from learnings acquired through their personal health experience, their experience with the system and the broader interaction with professional and peer communities:

- *embodied:* sensory knowledge of one's bodily strengths and vulnerabilities;
- *monitoring:* personalized management and self-care strategies;
- *navigational:* knowledge from repeated use of health and services across settings;
- *medical:* technical information specific to condition;
- *relational:* explicit knowledge of who to turn to access care they need; and
- *cultural:* norms, values and world views that impact experience of life and illness.

The authors emphasize that the depth and breadth of patient knowledge reflects the patient's individual journey and grows over time, so it cannot be mobilized all at once. They also make the case for incorporating patient knowledge into both patient and professional education so that it can be used to help address the inherent biases and power imbalances that exist in most healthcare experiences.

These knowledge categories can be helpful in planning for various engagement activities. When you are looking at a problem to solve, take the time to consider what types of patient knowledge would be most relevant. Think of patients with these different knowledge bases as specialists and work with them to identify the right mix of knowledge and expertise to bring to the situation. For example, to co-create a patient pathway for people living with diabetes, patients with navigational and relational knowledge will be very helpful. For the design of a new pain management protocol, patients who have lived with chronic pain and can express embodied and monitoring knowledge may fit the initiative best. Asking what type of knowledge you and your patient partners see as most relevant to a given activity and labelling it as such will go a long way toward building awareness and respect for the depth and breadth of knowledge patients can bring. Moving beyond the generic notion of including people with *lived experience* to identifying and valuing the defined areas of knowledge and expertise patients bring will be another positive step forward.

Five Success Factors for Achieving Global Impact

People often ask whether patient partnerships will *work* across different healthcare settings, countries and cultures. The answer is a resounding yes. Here are five conditions for success that are enabling change around the world:

- Where well-organized (*and well-funded*) patient advocacy groups are active, they make positive impacts on the political process, which can lead to changes in regulation and legislation. We saw this with the AIDS movement worldwide and the work of the International Alliance of Patients' Organizations, EURORDIS (Rare Diseases European Patients Forum) and World Health Organization (WHO) Patients for Patient Safety. All are making significant, positive impacts and there is a lot to learn from how they bring about positive change. Patient advocacy played a big role in the WHO Patient Safety Rights Charter and the WHO first-ever global member state resolution that endorsed social participation in national health planning and implementation (WHO 2024a). Patient advocacy is the essential ingredient in fuelling system-level change and it should be embraced, not feared.
- Where international teams of patients, physicians and researchers work together to define outcomes that matter to patients, global sets of patient-centred outcomes are created. There are over 45 datasets co-created with patients through the International Consortium for Health Outcomes Measurement that have been adopted worldwide. We are also seeing increasing uptake on the use of patient-reported experience measures and patient-reported outcome measures in research and health system performance reporting, and this data-driven approach to change brings the patient voice to the table in new and powerful ways.
- When organizational leaders are deliberate in ensuring conditions for co-creation are in place, patients are more likely to be included as equal partners in decisions that affect their care. Purposeful, people-powered leadership at all levels brings about sustainable change. While it is essential to adapt to local conditions and cultures, our experience shows that fundamental conditions for co-creation transcend boundaries of geography, sectors and culture.
- Where patients and citizens participate in the development of standards and accreditation assessments, expectations of patient partnership are embedded and become a catalyst for change. Language in standards drives change as organizations strive to meet the criteria to earn and maintain their accreditation. Patients such as Heather Thiessen at Accreditation Canada are now included in accreditation survey teams, which is a game-changer because who better to assess if patient partnerships are contributing to quality improvement than patients?
- When you are not sure what to do, just get started. We know from the Carman framework (Carman et al. 2013) and other research that patient engagement lives on a continuum, moving from *light-touch* consultation to partnership and shared leadership. The path along the continuum is not linear – it is punctuated by starts and stops, ups and downs and unexpected detours. When there is an openness to learn and persevere, change starts to happen. When we first established the People Partnership Office and the Patient Surveyor Program at Health Standards Organization (HSO), I remember Heather Thiessen (personal communication, September, 2017) telling me, "Yes, it's new ground, but let's not overthink it – let's get started, we will find our way if we take this path together."

Co-creation requires bringing together people with diverse sets of knowledge and experience as equal partners. Sharing power and decision making is not easy – especially in situations where there are lots of politics at play. And enabling patients or communities to lead on their own is even harder but there are some great examples of that happening already. Leaders need to learn and unlearn behaviours that will help set the conditions for co-creation to happen and ensure resources are in place to help build the capacity and capabilities of all players involved so that everyone is able to participate fully in the process.

Winds of Change: From First Nations in British Columbia to Primary Care in Qatar

Standards are designed to reflect the voice of those they are intended to serve and HSO has been including people with lived experience into the development process since 2017. However, when the First Nations Health Authority in British Columbia and HSO came together to co-lead the creation of a new cultural safety and humility standard, we found that traditional approaches to engagement were inadequate. It took years to travel the journey of transformation in thinking, knowing and doing at individual, departmental and organizational levels to shape the new standard. We needed to take a big step back from a Eurocentric development process. The standard evolved over three intense years under the leadership of a 16-person, Indigenous-led technical committee. This approach challenged traditional engagement models and standards' development norms, and it involved rewriting ways to integrate Indigenous traditional knowledge while adhering to traditional data knowledge processes: ownership, control, access and possession (OCAP). The impact of this journey, which took traditional notions of patient engagement to a whole new level, has brought deep and profound learnings for us at HSO that are influencing the ways we approach engagement in other areas. The British Columbia Cultural Safety and Humility Standard is a first for Canada and the world, and it simply would not have the same impact had it been developed using old models (HSO n.d.).

In another part of the world, the team at Primary Health Care Corporation in Qatar (PHCC Qatar) was taking deliberate steps to introduce patient engagement to improve patient experience and outcomes. After attending a conference in British Columbia, leaders at PHCC Qatar realized co-production was key to achieving their vision of transforming their model of care. When I interviewed Mariam Abdul Malik, Managing Director of PHCC Qatar, she shared that patient engagement in the Middle East is a journey that is challenging traditional cultural norms. When they started in 2015, there was concern and criticism from both patients and staff on how engagement would work in multiple and mixed environments. Reluctance, she added, often comes from a place of fear – fear that "patients won't accept this" or that it will be too much work for the staff. The process had to be given time and staff had to work patiently in phases, establishing trust, raising awareness and helping patients see the value of engagement.

Over the course of two years, a formal framework for patient engagement was implemented, and the impact of their strategies was measured in part from direct feedback from patients. The results were published in a paper (Khattabi et al. 2023) and the organization earned the first Patient-Centred Care Commitment Award from Accreditation Canada. At its core, the principle of patient-centred care is universal, but it is even more valuable to primary care because working with patients over time, providing continuity and comprehensive care, builds unique trust and relationships. The focus on prevention, active listening and patient-centred care across the system can drive toward the bigger goal of people-centred, integrated care.

There are many other examples around the world of where new models of patient partnerships are emerging, and the challenge for healthcare leaders is to ensure conditions are in place for these to grow and thrive over the long term. It takes courage, patience and perseverance to make this *stick*. We all have seen examples where there is a great flurry of activity putting patient councils in place, celebrating having *representatives* at the table, but little change where it matters the most, which is at the point of care. Policy levers are critical, leadership must be bold and deliberate, and front-line environments of care need to reflect the commitments and charters in daily practice. That is why we introduced patients as surveyors at Accreditation Canada, to bring the patient lens and voice directly into the assessment of how well organizational philosophies and commitments are translated into reality for patients and families. While the inclusion of patients on survey teams is still growing, the feedback on this approach has been overwhelmingly positive. At the end of the day, who better to help determine whether people-centred care is *real* than patients themselves?

Ushering in Our Copernicus Moment

"Nothing about me without me" can and should still be our north star when it comes to shaping the future of quality (Delbanco et al. 2001: 144). It is good to see the different models of engagement happening across the health ecosystem, and outcomes are improving as a result at individual patient, organizational and system levels. It is hard to keep up these days with new evidence, new approaches and new ideas that are shaping the ways patient partnerships can create value that helps save and improve lives. Recently, one of the most significant milestones is the World Health Assembly's endorsement of the first-ever resolution on social participation in health (WHO 2024b). It sets out expectations for people, community and civil society to have a stronger voice influencing decisions that affect their lives and well-being. The opportunity is there for leaders to show that social participation in health is the path to health and I, for one, am excited to see this new chapter in the patient engagement story.

The future of healthcare relies on a strong learning health system, patient and provider engagement and co-creation of a shared vision of the future. I dream of a day when patient partnerships and co-creation become the norm throughout our health and social care systems. While progress feels slow some days, I see examples of new ideas, perspectives and informed input from people with diverse experiences and insights come together to co-produce solutions that can be put into practice and sustained over time. This may be our Copernicus moment – the time when we have the best chance of building widespread acceptance that healthcare will not and cannot be about patients circling the provider-oriented system looking in from afar, but patients being at the centre and the system orbiting around them.

A CONVERSATION WITH HEATHER THIESSEN

Leslee J. Thompson (LT) talks with Heather Thiessen (HT), patient partner lead in the Patient Partnership Office, a volunteer role created in 2018 at Health Standards Organization (HSO) and Accreditation Canada (AC). Thiessen is based in Saskatoon, SK, and spoke with us in June 2024 (the following has been edited for length and clarity).

LT: What motivated you to raise awareness of the value of patient partnership?

HT: As a chronically ill patient in the healthcare system, I have encountered many challenges first-hand. The Patient First Review of Saskatchewan in 2009 was life-changing for me and many patients and families (Duncan 2015). It was a landmark document, marking for the first time in Saskatchewan and Canadian history, a move away from a system-centred approach in healthcare to one that was more patient- and family-centred. It represented a shift in thinking and the creation of authentic partnerships between healthcare providers and patients and families. This was a massive culture change and one that opened the door to patients and families being more actively involved in how care was delivered and administrated. I have not had the easiest journey in healthcare, I have experienced my care being compromised and harmed. I vowed when I started to partner with health systems that I would represent others more, not just myself, and create a culture where everyone feels safe and can be an integral part of their care experience. I have met many strong leaders who have found ways to help me elevate my messages and bring me in to support the work we do at HSO and AC. I do not want to be defined by my illness; being a patient partner gives me purpose, drive and joy.

LT: What qualities do organizations that successfully engage in patient partnerships have in common, based on your observations as a patient surveyor?

HT: Successful organizations show passion and joy in partnering with those with lived experience. They eagerly share stories from both their own and the patient partners' perspectives. They now include patient partners in decision-making tables once reserved only for senior leaders. They have dedicated staff to educate and support both internal teams and patient partners, emphasizing the value of these voices. Some organizations elevate patient partners to roles across various areas, integrating their insights to drive changes at the direct care, organizational and policy levels. For example, I have seen some health organizations say they will not undertake any major project unless a patient partner is at the table. It really sets the tone.

LT: What has been the hardest part of creating a culture for meaningful engagement with patients and making it stick?

HT: To connect with those who have had the most difficult experiences in healthcare; remember that trust has been broken, and you have one opportunity to create a better relationship. Rebuilding trust takes continuous effort, and it does not happen overnight. Consistently engaging with patient partners, thanking them and acknowledging their contributions will be a game changer. These relationships will aid in the healing process and create champions for your work. The same applies to staff – they have also endured a lot and are often overlooked. By involving staff and adopting a bedside-to-boardroom approach, everyone will understand their role in people-centred care, realizing they are stronger together.

LT: What gives you hope for the future?

HT: Over the past 16 years as a patient partner, I have seen an incredible shift in our role within healthcare improvement. Initially, I had to ask for a spot on agendas and at conferences, often being the only patient present. Now, patients are integral to meetings, events and research papers. At AC and HSO, we have evolved our thinking and relationships with patient partners, dedicating seats at standards tables and including those with lived experience in surveyor roles. As an "in-house" patient partner, I have built trusting relationships and seen other organizations replicate this role. I spend a lot of my time in the education of health sciences students because they are our future leaders in healthcare. By making sure they know the importance of authentic relationships and creating an engaging, capable environment, we will see changes for the better. This cannot be done without tapping into the most underutilized voices in healthcare – the people who are patients, clients, residents, families and essential care partners.

LT: What advice do you have for healthcare leaders?

HT: Keep pushing for what is possible and do not settle for the status quo. Focus on creating an environment that welcomes patient engagement. Celebrate successes when partnering with those with lived experience, staff and the whole organization. Recognize and acknowledge the change agents who bravely contribute to these efforts. Empower and embed the voices of those with lived experience in your daily work. Maintain open communication with patients and families, meeting them where they are – tour your organizations, attend advisory meetings, visit emergency departments and go into the community. Include patient partners in staff orientations, hiring committees and senior leadership tables and involve them in other projects, such as implementing the Lean methodology (Lawal et al. 2014). As leaders, be role models and consider being mentored by someone with lived experience to gain their perspective and become better leaders through this acknowledgment. HQ

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