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## In divided times, a focus on human experience connects us

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### Abstract

The realities of the time in which we find ourselves, not only in healthcare, but in society overall, have exposed so much of what was simmering beneath the surface of our humanity. Issues of equity and inclusion, of stress and burnout, of division and misconception and even the existence of alternative “truths” have caused rifts in our connection, weakened our societal foundations and pulled on the seams of the healthcare system itself. We close our eighth volume of Patient Experience Journal (PXJ) under this veil, yet I believe we have an opportunity to use this moment as a place from which to build. I do not suggest this work will be easy, but a conversation on experience is a clear and common ground. It challenges those who seek to dismantle versus build. It provides a space to look and act above the noise and does not let us overlook that it needs to be challenged and addressed. When we focus on the human experience found underneath all the rhetoric, we find opportunity and inspiration. A focus on human experience connects us.

### Keywords

Human experience, patient experience, future of healthcare, health equity, social justice, workforce engagement

### A Commitment to Action

The Declaration for Human Experience opens with these words, “*Our shared experience over the past year has shifted the foundation of healthcare forever, exposing systemic weaknesses and wounds that can no longer go untreated.*”<sup>1</sup> This statement captures so much of what we have experienced over almost two years of the pandemic. The realities of the time in which we find ourselves, not only in healthcare, but in society overall, have exposed so much of what was simmering beneath the surface of our humanity. Issues of equity and inclusion, of stress and burnout, of division and misconception and even the existence of alternative “truths” have caused rifts in our connection, weakened our societal foundations and pulled on the seams of the healthcare system itself.

We close our eighth volume of Patient Experience Journal (PXJ) under this veil, yet I believe we have an opportunity to use this moment as a place from which to build. For far too long, the issues we have been unwilling to fully address have lingered, eroding what connects us as people. The work of healthcare and the incredible mix of the science and art of medicine, of caring and compassion on which it has been built, is grounded in a broader idea – that we are human beings caring for human beings. And even with our deepest differences, this idea provides us a foundation on which to stand.

In the work of healthcare, all are engaged to care, to heal or to help others live the days that remain with dignity and respect. Those who seek healthcare as patients or engage in it as family caregivers or care partners do so for the

same reason. This basic human need addressed in the healthcare experience is a common ground. For while in a world of a billion stories and experiences, our basic and common needs do not waver.

Regardless of our differences, we, as human beings, still seek the same things from our healthcare experience, from the human experience itself – to be listened to, to be communicated to in a way we can understand, to be treated with dignity and respect – and in healthcare encounters to know our health and well-being are a priority.<sup>2</sup> In these moments, we are not our beliefs or perspectives; we are our needs, hopes and dreams. Yet, even in these most delicate moments, we see too how people look or are perceived still leads to inequitable care, differences in access and clear and measurable disparities. A commitment to the human experience is a common ground on which I believe we cannot just declare things are important. We must finally move to action on the very things that can connect us.

The Declaration for Human Experience calls on us to not only consider but to act on four core commitments:

1. ***Acknowledge and dismantle systemic racism and prejudice, tackle disparities and provide the highest-quality, most equitable care possible.*** The evidence is indisputable that outcomes vary because of who you are and, yes, how you look. The reality of a focus on human experience means we cannot let this system of disparity continue. Our entire special issue from August 2021<sup>3</sup> raised critical issues and insights on both the impact and opportunity we have here.

2. ***Understand and act on the needs and vulnerabilities of the healthcare workforce to honor their commitment and reaffirm and reenergize their purpose.*** The future of healthcare as a global system today stands on weakened ground, for as the number of people we care for grows, those who choose caring as their path is being diminished. Burnout, stress, anger and depression are all words people are using about their experience of working in healthcare today.<sup>4</sup> (CITE POST) A breaking of trust and the opportunity to rebuild it is fundamental. In this issue's opening commentary *Rebuilding a foundation of trust: A call to action in creating a safe environment for everyone*,<sup>5</sup> Rushton et al. offer a framework for rebuilding trust as a means to rebuild connection to self, to one another and to the work of healthcare. There is also the opportunity to contribute your own thoughts, practices and research to this conversation in the 2022 Special Issue of PXJ: Elevating the human experience through caring for the healthcare workforce (<https://pxjournal.org/journal/vol8/iss2/14/>).<sup>6</sup>
3. ***Recognize and maintain a focus on what matters most to patients, their family members and care partners to ensure unparalleled care and a commitment to health and well-being.*** "What matters to you" is not just a simple phrase; it is an intricate and thought-provoking question that gets to the heart of our being as individuals. In our willingness to ask this both collectively and individually, we learn what motivates people, what moves them and what scares them. This is the essence of our common humanity beneath the divisiveness we feel all too often today. In the narrative *How to address fear: A patient's perspective of seeking care during COVID-19* by Bartel et al.,<sup>7</sup> the authors write, "It is up to all of us to acknowledge the shared fears that affect us all," suggesting that in our failure to do so, we miss the chance to provide the best in care, let alone care for one another.
4. ***Collaborate through shared learning within and between organizations, systems and the broader healthcare continuum to forge a bold new path to a more human-centered, equitable and effective healthcare system.*** This fourth commitment is a statement of how we must move forward. It is how a commitment to human experience can serve as a binding to our human connection. We have lived through a pandemic that stirred fear of the unknown, created uncertainty on how to act and elevated our basic instincts of survival. Our very human nature to care for ourselves and our families turned many inward, but in the shrinking often

caused by fear and the very gaps this exposed also revealed the great potential we have. It was through collaboration and connection that solutions to the pandemic were discovered; it was through community effort that waves in the pandemic either rose or fell. We experienced first-hand how our commitment to connection and collaboration can lead to positive outcomes.

I do not suggest this work will be easy. The fissures of society are real and are being stoked by those who either find value in their existence or comfort in their presence. I believe we are stronger when we acknowledge that those differences have permeated the surface, and rather than giving them nourishment by looking back or down, we stand up and look forward. These ideas are laid out in the foundational agreements of *The New Existence*, an effort driven by thousands of members of *The Beryl Institute* global community to define what the future of health and healthcare can and must look like; what it will call on us to do in practice, process and policy; and what it will ask of us as people moving healthcare forward.<sup>8</sup> They offer:

- This work is born from our common experience in this moment
- We are all humans in healthcare and must recognize and act together on what impacts us
- We insist on equity in healthcare
- We commit to working better together, through and beyond this moment
- We will come out of this crisis as better human beings, organizations and systems

What underlines this idea is our shared experience, that we must act, that we insist, that we commit, and we are clear what will result. When we focus on the human experience found underneath all the rhetoric, we find opportunity and inspiration, connection and cause. It is not the answer to all that ails us, but a path on which we can and must walk. There is work to do to address hate; there are minds that will never be changed, but we cannot and must not let that which seeks to divide us break us down.

Human experience is about honoring all voices, but we too must set our boundaries and stand firm that voices of hate or harm are not aligned with these values. That efforts to diminish people or ideas because you do not like or respect them, tears the very fabric of society on which we build. These are not the ideals that bind us. Rather, it is in our commitment to human experience through which we can begin to reconnect.

A conversation on experience is a clear and common ground. It challenges those who seek to dismantle versus build. It provides a space to look and act above the noise and does not let us overlook that it needs to be challenged and addressed. A focus on human experience connects us.

The ask here is to get clear for yourself what matters and to be willing to ask what matters to others to arrive in a place for constructive discourse and expanding and sharing knowledge. That is what we hope to bring through the pages of Patient Experience Journal. That is what we foster in the broader Institute community. The ask now is what can each of us do and who and what can we influence to ensure a conversation on human experience leads us forward. In doing so, we can ask ourselves:

- What is my experience, what matters and what is important?
- How do I understand and appreciate what matters to others?
- How do we move past division to find what binds us? And how do we deprive oxygen to the flames of hate?
- What can we do to transform the human experience in healthcare as individuals, organizations and society?

I do not suggest one path or one solution but rather encourage an environment of inquiry, of asking with a commitment to action. In doing so, we can pave a path to a brighter future for ourselves, our families and loved ones and our world. Yes, some may say this is my greatest inner idealist shining through, but why, after so much grey, confusion and fear, should we not now build on hope? I reaffirm a focus on human experience connects us, and that is a focus I ask all to commit to with vigor.

## Our Issue

This issue closes our eighth volume, and this month we will hit the 900,000<sup>th</sup> article download from PXJ. With almost 400 published articles since we launched in April 2014 and readership from a documented 225 countries and territories, the work of PXJ underlines all I suggest above. There is a common ground on which to stand and build when we focus on experience and a global conversation to be had on how we move forward.

This issue continues to reflect the diversity and range of the experience conversation bringing together global voices across four continents and from academics to patient voices to applied practice. Following the powerful commentary on trust I noted above, a set of rich narratives help reflect the human elements of experience from the patient, care partner and care provider perspective. The issue also extends the conversation on innovation through design and co-production and challenges us to look deeper at the concepts of partnership in our experience efforts as well. It pushes us to look at how we measure and understand the best way to understand patient, family and care partner's perceptions and how we do this across settings. We wrap up with two powerful cases on the application of experience in primary care and then a

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perspective on operationalizing the Experience Framework from The Beryl Institute.

In the concluding piece, *Using a multidisciplinary data approach to operationalize an experience framework*,<sup>9</sup> the authors offer a significant insight into what has both created a perception of the “sometimes-glacial pace of experience improvement” and, I believe, what may actually help us begin to move on the very issues I address above. They wrote:

After four decades of research, Daniel Pink...concluded that true motivation comes from autonomy, mastery, and purpose. Extrinsic rewards or "Carrot and Stick" methods deployed in healthcare do not drive motivation. These three elements – autonomy, mastery, and purpose – are fundamental in creating ambition in humans. Psychological safety creates an atmosphere in which everyone seeks out new ways (autonomy) to improve, become experts (mastery), and speak up or push for change to achieve a shared goal (purpose). This human drive is critical to creating and sustaining high performance.

Perhaps as we return to the opportunity we have in a commitment to human experience and the connection it provides, we must individually seek new ways, work to expand our expertise and align ourselves around shared purpose. That, in fact, may be all we are asking for in the Declaration for Human Experience itself and the realization that a focus on human experience can connect us. As we seek to move forward with greater insight and a commitment to one another around shared purpose, perhaps we can move forward with greater intent. This means we must do the hard work, continue to push the boundaries of research, challenge the societal ills that exist, act with intent to ensure equity and call out moments when systems, organizations or even we, ourselves, are in the way of that progress.

That is our opportunity, and in looking at the evolution of eight years of contributions from authors around the world, I see great hope. While the pandemic years have revealed some of the worst in humanity, I believe more so it has unleashed our best. It has exposed clear opportunities and purpose; it has raised critical questions; it has awakened far too long dormant issues that must now be addressed together. We must and we will. The experience community is poised to act, and we know the power of its intent. I hope you all will join with your words, practices and action as we build the future of human experience together.

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