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## Elevating the discourse on experience in healthcare's uncertain times

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### Abstract

Over the last five years, we have been inspired by the breadth of contributions that have helped shape the experience landscape through PXJ as well as the reach that the conversation on patient experience has had. Both the authors and readers of PXJ reinforce that the conversation on patient experience and the human experience in healthcare is not one dominated by national intent or even policy. While for some motivation has come in some part from mandated action, for most tackling this idea in healthcare is it grounded in two core realities. The first, in healthcare at its core we remain committed to ensuring the best for those we serve as active and engaged people, not simply as passive participants in care. This requires a different way of thinking and doing than a simple model for throughput or a checklist mentality. The complexity of the humanity at the heart of healthcare perhaps is also its greatest strength. In acknowledging the humanity of healthcare, we breathe life into our organizations, we excavate lost purpose in burned out and fatigued practitioners and we give permission to connect with others. This connection is not simply in the buildings we find ourselves, but it is our humanity that links us across communities and countries, continents and oceans. This connection and the conversation that supports it will forever be the grounds on which healthcare will ultimately succeed, it is the foundation on which we can and must elevate the discourse on experience.

### Keywords

Healthcare, patient experience, humanity, caring, well-being, consumerism, culture

### Healthcare is an action with evolving expectations

Welcome to Issue 3 and the close of our 5<sup>th</sup> volume of *Patient Experience Journal* (PXJ). Over the last five years, we have been inspired by the breadth of contributions that have helped shape the experience landscape through PXJ as well as the reach that the conversation on patient experience has had. Both the authors and readers of PXJ reinforce that the conversation on patient experience and the human experience in healthcare is not one dominated by national intent or even policy. While for some, motivation has come in some part from mandated action, for most tackling this idea in healthcare is it grounded in two core realities. The first, in healthcare at its core we remain committed to ensuring the best for those we serve as active and engaged people, not simply as passive participants in care. This requires a different way of thinking and doing than a simple model for throughput or a checklist mentality. The complexity of the humanity at the heart of healthcare perhaps is also its greatest strength.

It is this humanity that has elevated the second reality. That in healthcare today more than ever there is a growing realization that those seeking care approach healthcare with a consumer mindset. One framed by experiences they have outside the realm of health itself. One that shapes what people expect from healthcare at its best. In acknowledging that not all healthcare is about choice, we

do not set out to choose an illness or disease, when we do find ourselves in that place, the expectations that people bring now exceed just a “fix me” mentality. Bodies are not simply the machines we drive in through each day of our lives, rather they represent the container that houses our soul and spirit, our hopes and dreams, and with that we look to healthcare with very different lenses today.

This reality represents an expansive shift in the discourse of healthcare in what many feel are less certain times and a reset of expectations that people bring with them to the own healthcare encounter. This reality was reinforced through the insights of those seeking healthcare and those working in it. Through two major studies in the last year, one on Consumer Perspectives on Patient Experience and a soon to be released study on the Influence Factors of Patient Experience core ideas have been brought to light and reinforced across the contributing perspectives. A fundamental shift is taking place that in many ways may be returning us to the roots of healthcare itself. The word is comprised first of the idea of *health*, which the World Health Organization defines in its constitution as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”<sup>1</sup> It is then complemented by the concept of *care*, which in its duality as a noun and verb elevates the idea of a concern or more so to feel interest or concern for. These ideas together frame healthcare not as a static concept, but rather an

active and living idea driven in the interest of others and ourselves.

At the core of healthcare, of this concern for well-being, is our capacity to provide safe, quality, effective and comforting care and in doing so acknowledge the human in the experience, their needs, their concerns and their perspectives. As these concepts in total frame the experience one has in healthcare today, it too reinforces the importance of experience as an integrated whole at the heart of healthcare. It is for this reason we continue to encourage the exploration of this idea and was central to the two studies I will briefly share here.

### Consumer Perspectives on Patient Experience

In the recent study, *Consumer Perspectives in Patient Experience*<sup>2</sup>, the question was posed if patient experience was important, why it was important, what factors were most important to those experiencing healthcare and the impact of experience on healthcare decision-making. The key findings revealed that in the sample of 2000 consumers surveyed across five countries, 60% saw experience as extremely important.

Consumers offered that the reasons why experience was important was that first and foremost it was about their health. In support of that, 69% of respondents shared they believe a positive experience actually contributes to healing and good health outcomes. They followed that with offering is was about the way they were treated that was important, with 68% responding “I want/deserve to be treated with respect” and 65% identifying it is important they are addressed as a person not as an illness, symptom or disease. Lastly, they offered that it was to some extent

about the customer aspects of healthcare as well with 45% identifying that their time matters as central to healthcare experience. This last item was interesting and a cause for further exploration as the question this raises is has the current experience in healthcare and its challenges with efficiency and timeliness set the level of expectations people have or believe they have?

In asking respondents a series of questions identifying various factors potentially impacting experience and their importance to the respondent, overwhelmingly across both national and generational boundaries the top items were aligned and connected very closely to the why shared above. The top items people identified where: listen to me, communicate in a way I can understand and treat me with courtesy and respect. These were followed closely by give me confidence in what you do and take my pain seriously. (Table 1 shares the top 10 items) These items again reinforce the personal nature of caring for health and the experience that people expect in their care encounters.

From an implications standpoint the story was equally clear, people share stories about their healthcare experiences regardless of how good or bad they are. In either case – good or bad – the top thing people do as a result is to tell others. After their experience is shared they then make a choice about what they will do. For good experiences they are likely to stay with the same healthcare provider or organization 73% of the time while for bad experiences they are likely to leave and find another provider or healthcare organization in around 40% of the cases. The impact is clear, experience drives the story people tell, the decisions people make and the path they choose to take. With that consumers shared that experience was extremely significant to 55% of them and a

**Table 1. Top Rated Items of Importance to Healthcare Consumers**

	Extremely Important	Very + Extremely Important
Listen to you	71%	95%
Communicate clearly in a way you can understand	67%	95%
Treat you with courtesy and respect	65%	95%
Give you confidence in their abilities	64%	94%
Take your pain seriously	63%	93%
A healthcare environment that is clean and comfortable	62%	94%
Provide a clear plan of care and why they are doing it	59%	93%
Ask questions and try to understand your needs and preferences	56%	92%
The ability to schedule an appointment or procedure within a reasonable time period	52%	93%
A discharge/check out process in which your treatment plan and/or next steps in care are clearly explained	52%	92%

total of 91% offered it was somewhat or extremely significant to the healthcare choices they would make.

The final insight on the impact of experience revealed by consumers was the implications of experience on healthcare decision-making overall. When asking consumers what would drive their decision-making what topped the list was the recommendation of family or friends in 72% of the responses. This was followed closely by referrals at 70%. This reinforces the relational nature of care and underscores the priorities consumers revealed that healthcare is about health and how people are treated. And they are sharing these stories with friends, loved ones and others every day. In only one in four of the respondents did we see ratings, rankings and other items listed as important to decision making. This doesn't mean they don't refer to them in large percentages, but rather reflects the impact they have on the ultimate healthcare decisions people make.

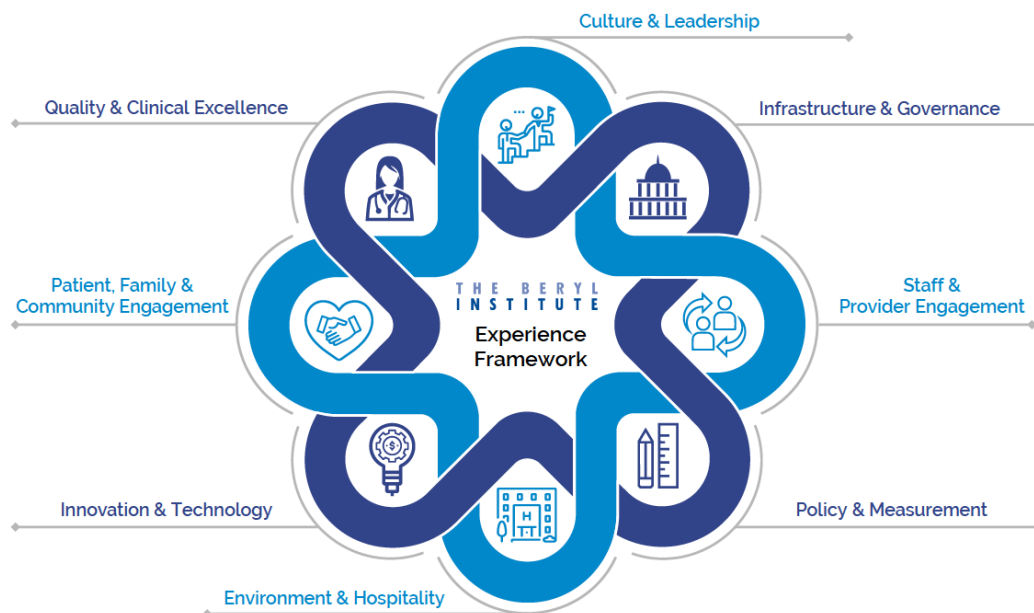
The story here brings us back to the changing discourse and expectations of healthcare itself. The voices of consumers suggest that the very issues that face individuals as people in healthcare more than just patients will influence how choices are made and therefore how healthcare will have to act now and into the future. This was further reinforced in a study to be released soon exploring the influence factors on patient experience as well.

## Influence Factors on Patient Experience

The study on Influence Factors on Patient Experience<sup>3</sup> (pending publication in 2018) continues to support this trend that we must elevate a focus on experience. The study surveyed two groups of people, a general healthcare population of over 1400 respondents and a group of 294 high performing healthcare units representing 175 distinct healthcare organizations across the United States. The inquiry framed on The Beryl Institute's Experience Framework<sup>4</sup> (Figure 1) looked at the extent of influence that a defined list of factors had on patient experience.

The bottom line discovery revealed a significant similarity to the very things consumers identified as important. In fact, both groups of respondents revealed the most influential items impacting patient experience were “how patients and families were personally treated” and “effective communication with patients and families”. While not a surprising discovery, the fact that how we treat people and communicate with them was seen as important to those delivering care as it was to those receiving care provides a cross study validation of what is important. In addition, and of significance, is the next alignment between the two respondent groups near the top of both lists was that of “teamwork among the care team”, and “engagement level of employees”. These were seen by both respondent groups as significant factors influencing experience. This reinforces an idea that rests at the heart of the definition of patient experience<sup>5</sup>; that experience is

Figure 1. Experience Framework



“the sum of all interactions, shaped by an organization’s culture...” And that culture is manifested in how engaged people are and how they work together.

This discovery brings the experience conversation full circle. Providers of care have acknowledged who they are and how they work as organizations enables their capacity to deliver on experience and that experience is grounded in how they treat people and communicate. Consumers of care want to be communicated to effectively and treated with respect. And both groups in that alignment expect safe, coordinated and quality care. With that it is possible we identified the challenge in achieving experience excellence is not due to lack of understanding of what to do, but rather in the capacity and commitment to do it?

In a time where healthcare is rapidly changing, systems are shifting and policies are in flux, dollars are compressing and workforces shrinking, the pressures on healthcare are immense. But in all of this what is evident is a clear and aligned knowledge of what healthcare is expected to deliver and what it has the capacity to do. That is why the discourse on experience must be elevated through community dialogue and collaborative action, through shared practices and lessons learned, through grounded evidence and boundless innovation. The experience conversation is a place where healthcare can emerge and grow, and it is in places like PXJ that we hope to continue to catalyze and inspire exploration and action to ensure that happens.

### **Expanding the Conversation in Issue 3**

This issue continues that commitment through elevating a range of topics and weaving them together to underscore the true integrated nature of care. In our opening commentary, “Patient partner compensation in research and health care: the patient perspective on why and how”<sup>6</sup> the authors push readers to engage in a thoughtful reflection on what engaging patient and family voice can look like as it is further extended, formalized and as a result potentially provided compensation. This evolving conversation on how healthcare thoughtfully incorporates the voices of those it serves in the improvement of its work will continue to push the boundaries of opportunity in healthcare overall.

The issue also delves into topics delving into measurement and technology, two other key factors of the Experience Framework, represented by great articles including a look at engaging Patient Reported Experience Measures (PREMS)<sup>7</sup> and an exploration of efforts in Canada to develop a nationwide survey on acute care patient experience<sup>8</sup> which reveals both the opportunities and challenges found in just such an endeavor. This is interesting as globally more and more organizations and national systems are trying to determine the best ways in

which to measure experience performance and success. Technology is an emerging point of discussion in the experience space and represented in this issue by two great pieces on the use of handheld technology to transform care<sup>9</sup> and lessons gleaned from the effective use of patient portals.<sup>10</sup> (As a reminder PXJ currently has an open call for submissions for a July 2019 Special Issue on the role of technology and innovation in patient experience.)<sup>11</sup>

This issue expands the conversation as well to mental health and psychosocial issues. It also provides considerations for healthcare impacting veterans. And returning to some of the core ideas introduced to start this piece, two cases close the issue getting back to the topic of engaging and educating those providing care themselves. An exploration of the C.O.N.N.E.C.T. model employed at Northwell Health<sup>12</sup> (and a recipient of a 2016 Patient Experience Grant from The Beryl Institute) provides practical insights into the very top priority issues revealed in the study on influence factors, that of engaging healthcare teams. The issue closes with a topic that continues to grow in conversations on experience, that of changing the nature of education for those entering healthcare,<sup>13</sup> in this case medical students, to provide the skills and perspectives necessary to thrive in the new healthcare world.

While this summary only touches the surface of all that follows, I encourage you to dive into Volume 5, issue 3 voraciously. It represents the true breadth and depth that must and will frame the experience conversation in healthcare. It reflects the reality that healthcare is evolving and in elevating the discourse through evidence we create stronger foundations on which to grow into the future.

### **Elevating the discourse on experience**

To end with the beginning in mind, we return to the opportunity found in the words that comprise healthcare. In elevating a concern for wellness and a caring for one another through this work, we frame a universal language of connection, care and possibility in times that can sometimes feel uncertain, divisive and daunting. The knowledge shared on the pages of this issue complements the insights gathered in the studies I shared above and when all this is woven together, we begin to create the sweet scents of a recipe for success in healthcare.

In our conversations here, we will never diminish the critical application of the medical practice of healthcare, that is the critical framework on which this work builds the capacity for healthcare to heal. But what we have learned is that healing is no longer just physical and may well be inspired by and even catalyzed by those things that reach from the clinical space to well beyond. In acknowledging the humanity of healthcare, we breathe life into our organizations, we excavate lost purpose in burned

out and fatigued practitioners and we give permission to connect with others. This connection is not simply in the buildings we find ourselves, but it is our humanity that links us across communities and countries, continents and oceans. This connection and the conversation that supports it will forever be the grounds on which healthcare will ultimately succeed, it is the foundation on which we can and must elevate the discourse on experience. We will all ultimately be the better for it.

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