

Patient and Care Partner Reflections

WHITE PAPER

Human Experience 2030: A Vision for the Future of Healthcare

Every individual sees the world through their own lens. In healthcare, the perspectives of patients and families are often different from those who deliver care. Anywhere you see the “eyeglass” icon, enjoy a companion resource written through the lens of patients and families.

INTENTION

The intention of reflecting on this white paper through the lens of patients and families is to support patients, families and PFAs by providing a more relatable entry point for The Beryl Institute’s resources. This accessibility through a peer voice enables patients, families and PFAs to be more effective and engaged members of the PX Community.

Each of these reflections fits within the Experience Framework. This reflection falls under the following Strategic Lens(s):

Policy & Measurement

The “Why”

Experience is driven and influenced by the external factors and systematic and financial realities and requires accepted and understood metrics to effectively measure outcomes and drive action.

The “Impact”

When the voices of patients and families are heard, their needs are considered in all aspects of policy design and reform. The lived experiences of those delivering and receiving care must be at the forefront of policies that affect clinical practice and patient interactions, at every-level. Determining the effectiveness of policies involves using metrics that are meaningful for patients and families



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I am a certified executive coach at Back Bay Leadership, and also serve on the coaches' cadre at Georgetown University McDonough School of Business. Before coaching, I began my 25+ year career at Marriott International in the Back Bay of Boston. While at Marriott and The Ritz-Carlton, I earned a reputation for leading high performing sales teams by creating internal cultures where my teams learned, grew and felt safe, which enabled my teams to perform at their best.

In 2018, I was diagnosed with stage IIB breast cancer. I was lucky I didn't skip my mammogram that year. I underwent a mastectomy and reconstruction surgeries the same day and, to avoid infection, my doctor with my input, let me return home that night to heal. After surgery I had a difficult time with insurance approvals for proton radiation versus traditional photon treatments. Ultimately, insurance approved these treatments, but only after three appeals and two denials, which delayed my cancer treatments. This unnecessary stress and complication inspired me to do more for patients and families and to pay it forward. Today, I volunteer as a proton champion with the Alliance for Proton Therapy Access. I also serve as Co-chair for the Global Patient Family Advisory Board at The Beryl Institute and Chair the Inova Schar Cancer Institute's Patient Family Advisory Council. In 2020, my close friend and fellow breast cancer survivor launched [breast.friends.dc](https://www.breast.friends.dc), a community on [Instagram](https://www.instagram.com/breast.friends.dc) and [Facebook](https://www.facebook.com/breast.friends.dc) where people can learn from from our lived experiences as breast cancer survivors.

AUTHOR'S PERSPECTIVE

I'm passionate about personalized service excellence, whether it's in hospitality or healthcare. I believe positive, meaningful and memorable human experiences affect all of us in unique and powerful ways. Because of my passion to serve others, I believe in order to move forward in healthcare, experience needs to be the focal point – for patients, care partners, the community and, equally if not more important, our healthcare workforce. Before the COVID-19 pandemic, I heard themes of dedicated, passionate healthcare providers who are burned out; they have since been catapulted into a healthcare crisis like no other. Early on as I watched the news, healthcare providers desperately wanted to safely help patients, and patients needed to be cared for in new and different ways. Suddenly, all of the tension, disparities and burnout took center stage. Equal access to healthcare for all became even more prominent.

I was drawn to this white paper because I believe in thinking differently, dreaming big, and learning from what's been done right and what hasn't been done right. HX 2030 demonstrates what can be done better in order to move healthcare forward and deliver excellence. We now know that after 2020, healthcare will never be the same, yet on the other side of the pandemic, there's hope that a better tomorrow exists. I believe these elements are captured in the Human Experience (HX) 2030 whitepaper when it states, "It is now up to all of us to begin laying the path forward together."

GENERAL SUMMARY

HX 2030 represents an elevation of the human experience like no other. I enjoyed reading HX 2030 as it is evidence based and represents diversity in voices through an initial set of community conversations with 130 participants from 11 countries who shared their thoughts on the future of healthcare. In addition, the collection of feedback and data began before the COVID-19 pandemic and continued thereafter, wherein over 1000 people shared what *has* to be done in healthcare, not what *should* be done. I believe through the pandemic, the latter statement of what *has* to be done is an ironic twist of positive fate that quickly played out in healthcare, such as immediate access to telemedicine.

Key Points to Consider as a Patient or Family Caregiver

- **How can you elevate your own patient experience through actively participating in your care and advocating for yourself?**

One passage in HX 2030 calls for humans in healthcare to reframe our roles from "consumerism to patient and consumer partnership" as we see ourselves as consumers engaging in services. I gravitate to this passage because through my own lived experience in breast cancer, I've experienced co-creating my patient/consumer partnership through meaningful patient-centered care. Through my interactions with my healthcare providers, most in the Inova Health System, I'm viewed as a person and not just a patient, whether in the exam room, in a diagnostic procedure or on a telemedicine appointment. Simply put, what matters to me, matters to my team. I'm so grateful for their expertise, patience, advice and compassion, and most of all their ability to listen to me. I feel I have a relationship of trust versus a simple transaction at the doctor's office. I've also been with my primary care provider for 30 years in the Privia Health System. He's always made me feel like a person, not a patient; that matters to me, and he knows it.

We need more of this type of consumer experience across the healthcare landscape. Yet in some ways, my experiences could be better when transitions in care take place. Through more effective usage of electronic medical records (EMR) inside one system and outside to another, I feel my care could elevate and be even more efficient.

HX 2030 explains technology as an enabler, not a tool that will create more inequities. As a consumer of healthcare, I'm grateful for the instant access to telemedicine, yet I also want the flexibility to have an in-person appointment. I want relatively instant access to my medical records, notes and lab results. Paying a doctor's office to transfer my medical records seems archaic. These are simple illustrations of the work that needs to be done.

- **What can you do to become more involved in your community and within the healthcare system to elevate the patient and human experience?**

Perhaps consider volunteering or joining a local Patient and Family Advisory Council (PFAC) to share your insights as a patient or caregiver. Patients and family caregivers can also share recognition or feedback in the moment to show the healthcare workforce appreciation and help them feel informed about what's going well and what's not.

The only way to move forward beyond words and beliefs is through policies and incentives that encourage access to healthcare, especially in minority and underserved communities. Otherwise, the risk of staying in the dream state is real. This means providing feedback in the moment versus relying only on lagging indicators through patient experience surveys like the HCAHPS. If hoteliers can use technology to instantly connect with a guest about their stay upon check-in, why can't that same technology be applied in healthcare? Change like this requires policy changes that affect the entire system.

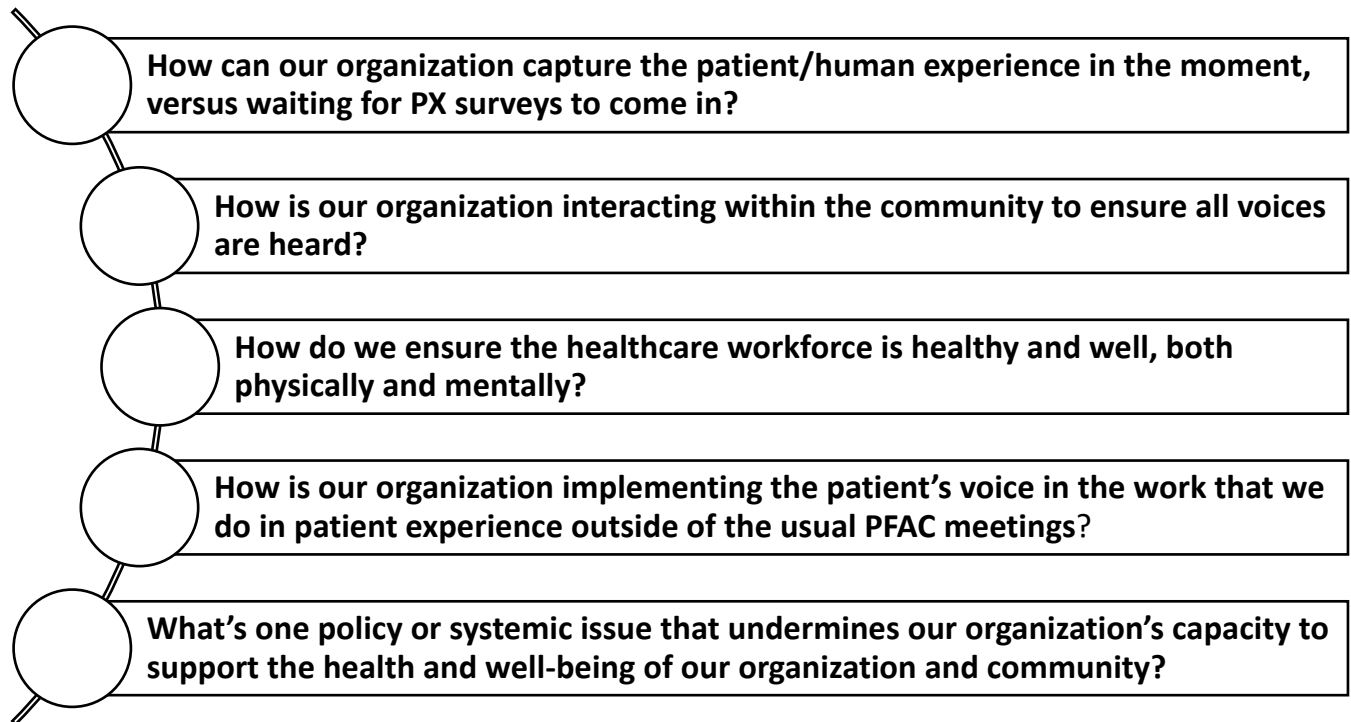
I recently visited my doctor's office and there was a simple poster board sign displayed in the reception area asking patients, "Tell us how we're doing." Patients are encouraged in the moment to write on the poster board about their own patient experience. This is full transparency. As a breast cancer survivor, it feels great to be able to tell a short story of positivity for patients to see as they arrive. Little things mean a lot and sometimes they don't cost a lot to implement.

- **We're all humans experiencing life in our own ways. Reach out to a neighbor, friend or family to check-in. Sometimes a phone call can make a person's day, especially as we continue through this pandemic and beyond.**

A commitment to a proactive approach to health and wellbeing, including mental health, is necessary. According to the CDC, 6 in 10 adults have a chronic disease in the United States. To move forward toward a healthy community and nation, it is vital that a proactive approach to well-being through permanently closing gaps in resources and education is required.

CONCEPTS, IDEAS OR PRACTICES WORTH SHARING WITH YOUR ORGANIZATION AS A PFA

As PFAs. We may be able to help our organizations think about things differently or more deeply. Based on the ideas in HX2030, here are some questions you might consider bringing to your PFAC for deeper exploration:



FINAL THOUGHTS

In order to improve systemic issues affecting the human experience, leaders need to implement policies and measurement that are aimed at permanently closing inequities of access and care. To get there, leaders must be willing to ask the hard questions, be vulnerable and open to sustainable change. The insurance companies also need a place at the table within these policy changes, or we will be in the exact same place five years from now.

A quote from HX 2030 that captured my attention was the passage, "The future of healthcare will have to turn itself inside out." HX 2030 illustrates that the path forward is for all – patients, care partners, the workforce and the community. Looking at healthcare from this ecosystem is necessary in order to transform. Healthcare can no longer be separated into the medical team and the patient and community; we need to be viewed together so we can move forward as one.