

Patient and Care Partner Reflections

WHITE PAPER

A Global Inquiry on Excellence in the Diagnostic Journey

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:

PATIENT, FAMILY AND COMMUNITY ENGAGEMENT

The “Why”

Central to any experience effort are the voices of, contributions from and partnerships with those receiving care and the community served.

The “Impact”

When the experience of patients and families are included in all of the organizations’ processes and executive leadership strategies, patients and families feel respected and valued as both integral part of their healthcare team and change agents for the organization.

ABOUT THE AUTHOR: Rosie Bartel



I am a wife, mother, grandmother and educator. In August of 2009, I underwent a total right knee replacement that developed into a MRSA staph infection. This healthcare-acquired infection has led to 58 surgeries, over 200 hospitalizations, 100 blood transfusions, a right leg amputation six inches above the knee, and, eventually, a total hip amputation with the removal of part of her pelvic bone. I have also experienced sepsis and septic shock twelve times.

As I continue to battle this infection in my body, I am driven to share my story of survival. Every day, I use the story of my journey to advise or advocate for others. I believe in helping patients and caregivers find their voice. As an educator, I used stories to teach children and adults. Today, I use my own story to co-design with medical professionals and researchers and to advise and advocate for patients and their caregivers.

AUTHOR PERSPECTIVE

My personal story has been shaped by my diagnostic journey over most of the last several years. When I was diagnosed with MRSA in 2009, I didn't realize my journey would be changed forever. It not only changed my healthcare journey, it also changed my whole focus in life. Because I wasn't able to continue with my career in education, I started using my new journey to improve the human experience for others.

In June, 2020, my world was turned upside down in completely different way. I didn't think anything could change my world anymore because my experience with diagnosis had taken many different roads along my healthcare journey. Little did I know that the diagnosis my husband, David, received following an MRI for a backache would shake our family to the core. This MRI led to more tests, which resulted in a diagnosis of multiple organ terminal cancer. One month later, on July 28, 2020, David lost his battle with cancer. The diagnostic journey was hard to take at the time, but the way the diagnosis was shared, with me and with David, was important.

GENERAL SUMMARY

This paper explores - through the voices of healthcare leaders, clinicians, staff, patients and family members - the actions and efforts that lead to excellence in the diagnostic journey. People seek to be heard, understood, and communicated with compassionately. They expect quality and support from the healthcare system during

some of life's most tenuous moments. In this time, more than ever, elevating humanity in healthcare is essential.

Understand that each patient comes with a story that informs and guides their perspective. Their actions, their ability to engage, and what matters to them needs to be understood. The diagnostic experience is about the advancement of care. It's about a journey, about relationships and communication.

In this white paper, data was collected through focus groups and surveys. The data showed that how people were engaged in the diagnostic experience was as important or more important than the way the diagnosis itself was processed by healthcare.

KEY POINTS TO CONSIDER AS A PATIENT OR FAMILY CAREGIVER

The elements of a positive diagnostic journey uncovered in this white paper included having a care team that communicated well with one another and acted compassionately to address patient fears and concerns. Communicating the reasons for any delays was important, as well as a commitment to quality and safety.

The diagnostic journey was also improved when the patient and family were actively included as part of the care team and engaged in the development of their care plan. Managing transitions effectively was another key component of a positive diagnostic experience.

Each patient comes with a story that informs and guides their perspective, their actions, their ability to engage, and what matters to them. This is what needs to be understood by healthcare professionals. The stories ultimately broaden the view that must be taken during the diagnostic experience.

While the efficiency of the process including managing waiting and scheduling and the environments of the experience play an important role; they are only part of the equation. The human experience provides a broader range of information and emotions and it points to what people truly want from healthcare. It is not only about "what is the matter" but also about "what matters" to the patient and their care partners.

Patients and families/care partners can be active participants by:

- Being engaged as members of the care team
- Participating in the development of the care plan
- Developing how and when test results will be shared with patient
- Ensuring that the patient is treated with compassion
- Sharing the patient's story

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

Data was collected from healthcare administrators, care teams and staff, and patients and families through focus groups and surveys. The results were essentially the same for all three groups.

The top 25% of the key factors in a positive diagnostic experience, from both focus groups and surveys, were:

- Communication/Engagement
- Process
- Results/Planning
- Scheduling/Timing

The initial analysis of the data shows that how people were engaged in the diagnostic experience was as important or more important than the mechanisms of the diagnostic process itself. There are strong themes around communication, compassion and partnership across all the groups. In addition, what was also found is that across all respondents, people were seeking and ultimately expecting a commitment to quality and safety while the flow through the journey was well-managed for the patient and their care partners.

It is important to understand that patient health and well-being were their primary drivers, followed closely by how they were treated as a person. This reveals something important for healthcare organizations looking to reflect on quality and compassion. They also need to ensure loyalty and a lasting engagement from their community because the experience they provide matters significantly.

PFA's can help the diagnostic experience at their healthcare facility be patient-friendly by:

- Understanding that how care teams communicate diagnoses
- Ensuring that their institution provides time for care teams to be present with the patient
- Reinforcing a focus on outcomes
- Understanding and enforcing their institution's commitment to efficiency
- Providing time for the patient to share their story

FINAL THOUGHTS

This white paper reveals that the experience healthcare systems provide matters significantly. The key considerations in excelling at the diagnostic experience include: how care teams communicate matters, taking time to be present for patients is important, focus on outcomes need to be reinforced, care teams establish a foundational commitment to efficiency and care teams provide opportunities for partnership.

When care teams ensure these results are as equally important to the healthcare organization as they are to those it serves, great things can and will happen. Excellence in experience - the true human experience - will be achieved.