

# Patient and Care Partner Reflections

## WHITE PAPER

### *Experience Leader: A Critical Role At The Heart 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:

## 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.



## CULTURE & LEADERSHIP

### **The “Why”**

The foundation of any successful experience effort is set on who an organization is, its purpose and values, and how it is led.

### **The “Impact”**

When an organization’s culture is aligned in its purpose and values, patients and families feel that the entire organization was designed to provide them with best possible experience and find comfort and joy in every interaction across the organization.

**ABOUT THE AUTHOR:** Isabela Castro



I served 7 years in the Brazilian Airforce as a Specialized Dentist and 10 years at United Health Group as a Specialized Dentist and consultant for innovation and patient experience initiatives. When I entered into the Air Force as a pediatric dentist, I was told to see a patient with a very rare syndrome. It was this experience that moved me into action. To this day, I remember my feelings from the first contact with a patient and family in the NICU. The patient was afraid and vulnerable within their own healthcare system. I quickly realized that the healthcare system didn't offer specialized dentistry for people with disabilities. From there, I started knocking on the leaders doors to advocate for these patients. And after countless discussions, and some arguments, I transformed specialized dentistry to treat people with disabilities, geriatric dentistry, home care dentistry and hospital dentistry.

My experiences vary from public, private and military hospitals and home care to experience in healthcare operations and management. I have been involved with quality improvement and risk management and is well versed in working within new cultures, matrixed leadership teams and takes pride in not accepting the status quo.

I'm a global activist with the worldwide movement "What Matters to You?" (WMTY) and a patient advocate through my work as Co-Chair of The Beryl Institute's Global Patient and Family Advisory Board as well as the Planetree International and International Society for Quality (ISQua). I am a speaker on patient experience issues and consults in these roles.

## AUTHOR PERSPECTIVE

My personal motivation in reading this white paper is due to the fact that, as a user of the health system in my country I have not always had support on my journey. On the contrary, I will never forget the rainy Wednesday I was made fun of by a doctor on duty because I took my milk into the NICU to feed my premature daughter who was fighting for her life. Today, after 14 years, I still hear the noise of the monitor beeping, and I think of how many "Isabelas" are right now in intensive care units, all over the globe, needing support from local leadership to help them better understand what is happening. Let's make this better from today on and support next our generations' leaders in understanding the value of committing to understanding and improving the patient and family experience.

## GENERAL SUMMARY

This white paper aims to bring data revealing the trends in this field and the voices of the experience leaders to the forefront.

## KEY POINTS TO CONSIDER AS A PATIENT OR FAMILY CAREGIVER

When patients are receiving healthcare, they probably don't know if the organization has a Patient Experience leader with a well-defined process to improve the patient's journey. If a healthcare organization has invested in a patient experience professional, they have hired someone to be strategically committed to ensuring the best possible experience and outcomes for the patients they care for.

The role of the Patient Experience Professional reinforces how essential is to look at experience proactively and across the continuum of care. As the paper invites to reflect about this vital role, we see a growth in this field. The role of the experience leader is evolving because healthcare organizations are beginning to recognize the impact this role has overall. The focus for Experience Leaders has moved from beyond just focusing on scores into celebrating quality/process improvement and leadership development.

If a patient doesn't know about this specific role in the institution, the patient should feel empowered to ask their doctor or other available healthcare team member how that institution labels the Patient Experience discipline or leader and then express interest in connecting to that professional. In my observations, most patients are unaware of this role. So how could the patient experience improve during the visit if the patient knew about the various patient experience roles?

In some cases, organizations have a Patient and Family Advisory Council (PFAC) in which patients and families get together as a group, to advise the institution on how to deliver patient centered care. There are some Patient and Family Officers and leaders who embrace the PFAC and include them in decisions, helping the organization strategically move forward. While other PFAC's work within other areas such as communities and

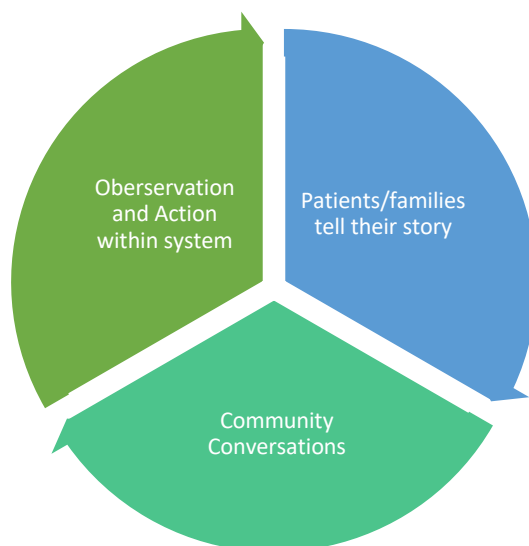
administrative areas. This is important for patients to be aware of since it's another resource for the patient to advocate for themselves or a loved one while supporting the organization in its attempt to respond to patient/family needs.

Being a patient or a care giver isn't easy. The Chief Experience Officer, or other similar role, examines all of the processes the patients are experiencing in their journey. Demands are different from patient to patient and it's the patients right to receive personalized care. If a patient needs guidance or would like to provide feedback regarding bedside care, contacting the patient experience professional dedicated to improving experience is one option for getting help and/or sharing important perspectives about the organization through the eyes of patients and families.

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

As an expanding role in healthcare, the experience leader is seen as critical to continuing the patient experience conversation. Key to this point is their ability to bridge and create personal connections by cultivating relationships with all, including leadership, decision makers, frontline workforce, patients and families.

Since relationship-building frames what they do, Experience Leaders often strive for the creation of partnerships through a fundamental belief that organizations must listen to the patients, families, staff and caregivers. The following 3 strategies are examples of how Experience Leaders "listen" before creating solutions for improvement. As a PFA, these are strategies you will want to explore within your organization, either to engage in existing programs or to explore creating a new program to expands the organization's ability to "listen".



# Patient and Care Partner Reflections

## WHITE PAPER

### *Experience Leader: A Critical Role At The Heart of Healthcare*

- 1) Patient Experience leaders should have the deep desire for improvement and connection to purpose, and so welcome patients to tell their story and speak about their experience. Doing so, they give the organization the chance to learn and improve.
- 2) Patient Experience Leaders can engage outside the walls of the organization in an effort to understand the communities' specific needs. By organizing periodic opportunities for conversation between community members and an Experience Leader, a common purpose and intention to improve can be established.
- 3) Patient Experience leaders identify key points in the system which needs to be fixed. They do this by observing, studying surveys and having conversations with those who deliver and receive care. When an Experience Leader identifies an area that needs improvement, they take action and design solutions for change.



Patient Experience Leaders are skilled in bridging connection, facilitating communication and breaking down "silos." It is good for a PFA to understand the work being done by Patient Experience Leaders and to partner with them, when or if possible.

## FINAL THOUGHTS

With a growing effort to engage in some form of patient improvement efforts aimed to deliver a better patient experience, leadership in healthcare organizations across the continuum vary in their approach. While roles and titles vary from one organization to the other, and each scope might look different from one institution to the other, there are some fundamental threads that make the role of Experience Leader important to patients and families.

The future of health care is filling up with patients who expect they will be treated as human beings. This is the opportunity for Experience leaders to embrace their responsibility for understanding the deep needs of patients and meet their needs.

Experience Leaders exist today to tackle the many parts of this puzzle. As an integrator, connector, someone who amplifies staff voices, and a champion of patient perspective, the experience leader will serve as an essential link that can align efforts and, in so doing, create successful ways to improve the human experience on healthcare.