

Patient and Care Partner Reflections

WHITE PAPER

Caring for our Children: A Look at Patient Experience in a Pediatric Setting

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

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My experiences as an educational psychologist, a patient with chronic illness, a patient advocate, and the parent of a child with complex healthcare needs led to my involvement with pediatric patient and family councils. In addition to a graduate certificate in Patient Advocacy, for which my research was focused on increasing the capacity of parents of medically fragile children, I have a master's degree in Educational Psychology with thesis research on improving the critical thinking and engagement skills of parents of children with disabilities. As the Executive Director of MAdvocator Educational and Healthcare Advocacy Training, I create programs and curricula to change the way families and health care professionals think and act, with a focus on improving equity, critical thinking, and engagement. I currently serve on the Board of Directors for University Hospitals Rainbow Babies & Children's Hospital and on the Global Patient and Family Advisory Board for The Beryl Institute, along with my role as project coordinator for the Patient Experience Policy Forum.

AUTHOR'S PERSPECTIVE

I was drawn to this white paper because, as the caregiver to my medically complex son, most of my healthcare experiences have occurred in the pediatric setting. Pediatrics has led the way in patient and family engagement. By necessity, caregivers must be involved in the care of the patient, both in and outside of the hospital setting. The entirety of experience goes beyond the bedside to include leadership, mission, environment, participation, quality and measurement.

Simple concepts like allowing a caregiver to be present, including caregivers in care planning, and ensuring that both the patient and caregiver feel welcomed, included, connected and cared for are essential concepts in pediatric care that can and should be applied to every patient population. In fact, patient experience would probably vastly improve if these principles of engagement were universally accepted in adult care.

GENERAL SUMMARY

Caring for our Children: A Look at Patient Experience in a Pediatric Setting examines patient experience in pediatric settings. Pediatric healthcare leaders featured in the white paper discuss leadership principles involved in patient experience and the challenges they face in measuring experience effectively. The paper explores patient experience through conversations with pediatric hospital leaders from The Beryl

Institute's Pediatric Council and surveys of members of The Beryl Institute's larger pediatric community. Seventy percent of survey respondents considered patient engagement a high organizational priority. Themes of care, compassion and connection to mission stood out, as well as practical ways to implement and institutionalize experience improvements.

Key Points to Consider as a Patient or Family Caregiver



Hospitals want patients and families to be involved in making the patient experience better. Consider ways to offer feedback on your personal experiences, like reaching out to leaders, joining an advisory or partnership council, and building positive relationships with the healthcare team.

Making decisions together with the healthcare team creates a better experience. Patients and families can assert their preferences, concerns and needs during the care planning process to participate in decision making.



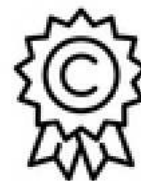
Many hospitals offer family supports like parking, food, laundry and other comforts. Patients and families can ask about the family support services available at their institutions.

Patients and families can find out about the experience scores of their institution as they make decisions about where to receive care.



Participating as part of the decision making team improves both the patient and family experience. Caregivers and patients should ask questions, and ask professionals to clarify when they don't understand a word, acronym or idea.

If patients have an excellent experience, they can find out how their institution recognizes and rewards excellent staff members and submit a recognition.



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



PFAs should understand how patient experience is embedded into the mission and values of their institution. They should also be aware of the patient experience leaders and staff members at their institutions. Do patient experience professionals have a consistent process to present to or meet with the council at least annually? Understanding the roles and responsibilities of the staff members, and the size of the team, can help PFAs know where and how to contribute their knowledge to patient experience improvement efforts.

PFAs can learn what types of measures their institution uses to understand experience. Is the institution using real time measures, lagging measures or both? Does your council know about the institution's experience scores and what is being done to improve them?



Families and PFAs can be involved in onboarding or training of staff at an institution so they can learn from one another at the bedside and beyond. PFAs can also participate in staff recognition programs and learn about how their institutions support staff and prevent burnout.

This white paper has a section on creating "above and beyond" moments for patients and families. Free parking, free meals and wayfinding apps were a few of the ways institutions created "above and beyond" experiences. Does your institution use any of these methods to improve patient and family experience? Which ones might work at your institution?



Families and PFAs take part in safety in many institutions, including serving on safety committees and Root Cause Analysis teams. If your institution does not have PFAs on these committees, talk to experience leaders about how to make that a reality.

The primary ways patient and family advisors were engaged were on committees and improvement teams. Institutions may want to consider whether their committee processes and schedules create structural barriers based on class, race, ethnicity and language. New means of engaging diverse populations can create opportunities for inclusion and equity.



FINAL THOUGHTS

Patient experience has many parts and pieces, from policy and measurement to community engagement. This white paper provides a wide lens on the pediatric approach to patient experience and how to make improvements in measurable ways. The healthcare system as a whole can benefit from seeing patient experience from the pediatric perspective, where caregivers and patients alike are included, considered and engaged in unique and personal ways.