

Patient and Care Partner Reflections

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 lenses of patients and families.



INTENTION

The intention of reflecting on this PX paper through the lenses 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 the organizations’ processes and executive leadership strategies, patients and families feel respected and valued as both integral part of their care experience.

ABOUT THE AUTHOR:



Scott Ballard-Ridley works for an organization in the U.K. called Bridges Self-Management where he uses his lived experience as a stroke survivor to help healthcare professionals grow more collaboratively with their patients. Through interactive training, they look to shift the power in the healthcare relationship from sitting with the professional to sitting with the professional, the patient, and the people who care for them. Through his involvement with NHS England, he seeks to embed these principles into healthcare systems, not as one-off interactions. Ballard-Ridley is also a member of The Beryl Institute Global and Patient Family Advisory Board.

AUTHORS' PERSPECTIVE

My perspective on this paper is that of a patient but also as somebody who has been running healthcare services. I also have a small degree of learned experience, as prior to my stroke, I had just finished my training as a physiotherapist.

GENERAL SUMMARY

Prior to the COVID-19 pandemic, organizations felt that they were doing well at patient and family involvement. But it should also be noted that patients and families didn't feel as if they had an equal role in enabling change. We also know that when the pandemic hit, pretty much all involvement stopped and is still yet to be fully resumed.

Interestingly, and maybe understandably, organizations didn't involve people at the beginning of the pandemic, but as the pandemic continued, organizations continued not to involve people. This lack of involvement has affected people's view on healthcare and the morale of people who are running healthcare. The lack of involvement has been quite damaging, and healthcare will struggle to get that goodwill back.

We can see from the paper that the organizations that did involve people, both from the early stages and slightly later, had better outcomes. So, involving people is key to having better outcomes in many different metrics.

There's an interesting point made in the paper that involvement for a long time has not been very diverse. And a key to resolving this could be how we look to involve people in different ways, whether that be in person, online or over email, and going to where people are rather than expecting them to come to us, which is a key distinction to make.

Another interesting point is that patients and families need to feel supported to be involved, especially in an environment which is often quite intimidating and foreign to them. Many people aren't familiar with the healthcare environment. It often uses language not familiar to them. It's often a scary place where people feel like they aren't qualified to be in it. People need to be supported, to feel like they deserve to be in that environment and that their views matter.

KEY POINTS TO CONSIDER AS A PATIENT OR FAMILY CAREGIVER

As a patient and family care partner, I suggest you advocate for these actions in the organizations you're engaged with. The first point is to start asking patients and families deliberately and with intention what's important to them. And it's not just what is important to them from the point of view around their medical condition, but also what's important to them from a wider perspective: *what's important to them in their*

life. Organizations can begin to understand them as people and take those things into consideration, and organization can then begin to understand how to help people on a wider basis.

The second point is to engage patient, patient and family advisors at the start of a project. Bringing people in at the beginning of a project right at that conception point can make such a big difference. There are many projects where I have been involved, at the very beginning or even before the start of the project, where I've been able to make recommendations and suggestions about how that project has been set up or how people should be involved. Whereas there are other projects where I've been brought in after key decisions have been already been made, and those decisions can't be reversed. Bringing people in at the earliest possible moment can make a big difference and to all people on that project.

The third point is to see PFAs as people who are informing healthcare and not just helping healthcare. This is key. Patient and family advisors are people who have huge amounts of knowledge about their conditions and how the healthcare system works and operates. They have information that can help to improve the system.

The next point is recognizing that it's so much more than people's lived experience, but it's people's lived *expertise*. Patients and families spend countless hours in healthcare organizations, and they are the ones who understand how organizations are working. It would be remiss not to bring them into our organizations and get their feedback about how to improve.

The next point is to bring leaders into contact with patient and family advisors. It's great that people at the point of care are working with patient and family advisors, but we also need to get leaders and the decision-makers working with the patient and family advisors as well, because they are the ones who are furthest away from the point of care, yet they are the ones who make the most impactful decisions.

Also, organizations need to be diligent in asking for feedback and make it part of the standard operating procedure. When asking for feedback, do something with that feedback, because it can be demoralizing to patients and families to provide feedback and then it doesn't go anywhere. Organizations need to show that feedback is being used and being used well.

The next point is to try to remove hierarchies in patient and family advisory programs so that patient and family advisors are seen as equals to staff. Patient and family advisors have as much knowledge and expertise, and organizations need to try and recognize that.

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

Work with your patient and family advisors to integrate them into community partnerships. Also integrate patient and family advisors into research. Patient and family advisors have so much to offer in terms of how healthcare can improve, not just how services are run but also how treatments are delivered.

Consider how your PFA reimbursement and compensation program is being run. If PFA's aren't being compensated or reimbursed, consider how valuable their feedback is to your organization? Your organization then needs to prioritize that in terms of the budgetary consideration.

Avoid patient and family advisor tokenism. Never underestimate the value of the patient and family voice. They have much to offer your organization in so many ways.

See your PFAs as teachers of your organization. A patient and family advisor story is always an opportunity for your organization to learn.

Finally, always give patient and family advisors a choice in how they participate with your organization.

FINAL THOUGHTS

My final thought on this PX paper and this topic, in general, is that healthcare leaders must consider how to more effectively involve their patients and family advisors into their organizations, not as a “nice to have” but as a standard part of their strategic planning.