

# A COMMITMENT TO PATIENT & FAMILY ADVISORS (PFAS) IN IMPROVING THE HUMAN EXPERIENCE IN HEALTHCARE

## The value of patient and family partnerships

***The Beryl Institute community calls on health system leaders and organizations to commit to the industry standard of ensuring formal, intentional, and continuous partnerships with patients, families, and care partners.***

Such partnerships can be effectively designed and enhanced during a range of organizational activities including strategic planning, space and program design, operations, quality and safety improvement, and policymaking.

Patients, families, care partners, and community members bring unique and important perspectives to the barriers, gaps, and challenges faced by healthcare systems, and their lived experience of an organization's culture is an essential source for input, feedback, and lasting solutions. Leadership commitment and organizational strategies to partner meaningfully with patients, families, and care partners elevate efforts to deliver safe, high-quality care and reflect tangible evidence of an organization's commitment to person-centered care and the patient experience.

The more than 60,000 members of The Beryl Institute community, representing the voices of patients, families, care partners, and patient experience practitioners, endorse a holistic approach to partnering with patients, families, and community members through formal Patient and Family Advisor (PFA) programs including councils, focus groups, ad hoc advisors, and co-designers. Beyond their contributions to improvement and co-design, patient and family advisors provide depth and perspective to patient feedback beyond survey results.

"All too often, the metrics collected from patient experience surveys are the only data considered in measuring experience. This is a narrow view of experience that leaves organizations at great risk of missing all that ultimately influences the experience they provide and the richness of other means of feedback."<sup>1</sup> It is in recognizing this risk that we call on organizations to think more comprehensively and lead with intention in engaging and acting on the voices of patients, families, care partners, and community members.

While there are many ways organizations may describe groups and individual patient and family advisors comprised of patients, families, care partners, and community members, in this value statement, we refer to them as PFAs.

## What is a PFA?

***A PFA is a patient, care partner, or family member who partners with the healthcare system to provide insights based on their lived experiences.***

It is an essential role that helps narrow the perception gap between patients, clinicians, and organizations overall on the experience of care provided. The success of PFAs depends on the true embrace of patients, families, and care partners as co-designers and integrated resources throughout the system. Examples of ways to engage the voices of PFAs are via Patient and Family Advisory Councils (PFACs), focus groups, improvement teams, root cause analysis, surveys, e-panels, observation, capturing stories, committee membership, and more at all levels and across all segments of an organization.

Ways that PFAs and PFACs add value include:

- Ensuring priorities, policies, and strategies are informed by what matters most to patients, families, care partners, and staff.
- Including diverse voices and expertise of those with lived experience in co-leading, influencing, and informing ongoing improvements in the care provided.
- Providing transparency and visibility about what patients, families, care partners, and staff are experiencing and what matters to them across the continuum of care.
- Building trust and partnership between those receiving and providing care.
- Helping guide and proactively co-design healthcare experiences, including wayfinding, patient education, and more.
- Improving quality, safety, experience, and equity of care.

## Evidence of Impact

There is ample evidence (2,3,4,5) that formally and proactively inviting PFAs to guide and co-design healthcare experiences is essential in tackling some of healthcare's most difficult challenges including but not limited to those listed below. Quantifiable outcomes are reported in the attached resources.

Partnerships with PFAs result in:

- Improved safety, access, and overall quality of experience.
- Reduced disparities through engagement with diverse populations.
- Increased trust through community engagement.
- Reduced rework and increased program effectiveness.
- Improvements in staff and patient satisfaction scores, as well as reductions in patient complaints.
- Physical space that is better designed for healing and recovery.
- Reduction of stigma associated with mental health.

## Recommendations for leaders

Building and sustaining a PFA/PFAC program takes organizational commitment and dedication. Taking action only to check a box will not lead to the gains that come with a developed, respected, and engaged program. Successful partnerships and meaningful engagement with PFAs require implementation of the following strategies:

1. Clear executive commitment and support, including active participation in PFA/PFAC meetings.
2. Senior staff member(s) to provide oversight and support for all PFA/PFAC strategies and activities.
3. A formal operating structure with a guiding charter or bylaws.
4. A defined budget for PFA/PFAC engagement such as training, parking, honoraria, food, childcare, interpretation services, and staff support.
5. Recruitment of qualified PFAs to match the diverse population being served.
6. Robust, staff supported PFA/PFAC onboarding and training programs.
7. A policy ensuring that board-level, organizational, and department-specific initiatives include input from PFAs.
8. Identification of staff champions to help reinforce the importance of PFAs and their impact.
9. PFA representation on working and leadership committees including the Board of Trustees.
10. PFAs positioned as co-chairs of PFAC meetings supported by a staff liaison.
11. A workforce and culture that embraces and implements co-design and other engagement methodologies with PFAs/PFACs.
12. A process to measure the impact of PFA engagement and a commitment to share stories of success.

Patients are the heart of healthcare, and their voices must be included in every conversation about improving experience. Building trust with those you care for and about – patients, families, care partners, community members, and the healthcare workforce – is enhanced when these same stakeholders understand, inform, and co-create their own care experiences and care environments. A commitment to PFA engagement is a clear path to realizing all the outcomes healthcare organizations seek to achieve.

## References

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