Harnessing the Evidence for Patient and Family Engaged Care

What is Patient and family engaged care (PFEC)?

“Patient and family engaged care (PFEC) is care planned, delivered, managed, and continuously improved in active partnership with patients and their families (or care partners as defined by the patient) to ensure integration of their health and health care goals, preferences, and values. It includes explicit and partnered determination of goals and care options, and it requires ongoing assessment of the care match with patient goals.”

Recently, the National Academy of Medicine asked a scientific advisory panel of experts to collect and summarize the evidence for patient and family engaged care (PFEC). As a result, a discussion paper is now publicly available with all of the information to support PFEC in one place (https://www.nam.edu/pfec). The paper includes a framework for PFEC, which describes specific changes and steps that healthcare organizations need for PFEC to truly flourish in process and practice. The purpose of this document is to summarize the 38-page paper for busy healthcare professionals.

Until now, patient-and family-centered care (PFCC) has focused on changing patients’ behaviors – patients are seen as the “problem” to be fixed. PFEC recognizes that health care leaders have to drive a “patient-centered culture of care that continuously integrates patient and family perspectives and involvement—at the point of care, in health care system design, and in defining outcomes that matter most.”

Here’s a quick summary of what we know about PFEC & Why It Works:

- We know what organizations have to do to make it work. It means creating a different culture in healthcare organizations. The research shows that to do this, you have to develop a workplace where all staff members share the same feelings and values about the importance of partnering with patients in everything related to their healthcare. This influences day-to-day behaviors in the workplace and bigger policy and practice decisions.

- PFEC starts at the top of the organization. To make it happen, leaders need to be committed and transparent.

- It takes teamwork. It requires the support of leadership to build open governance, to have people work in teams, to build skills and encourage communication among and between staff and patients.

- It depends on everyone, at every level. It requires training for everyone to build skills in empathy, listening, and respect.

- It requires communication in all directions. There have to be systems of continuous feedback from patients to providers and decision-makers to ensure that changes make a good difference. Patients have to be really encouraged to participate, and told how they make a difference.

- PFEC leads to better outcomes and experiences for patients and families.

- Healthcare staff are happier when patients and families are engaged with them.

- One lesson for all of us is that every concern and complaint is an opportunity. An opportunity to problem solve, improve, grow, and develop better relationships.

- There is more to learn.
WHAT NEXT?
Use the framework for PFEC to figure out where your organization does well and where you need more work.