Person & Family Engagement

A Road Map to Person and Family Engagement

Recommended Policies & Practices for Hospitals

MHA Keystone Center
A Certified Patient Safety Organization

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Developed with guidance from the MHA Keystone Center Person and Family Engagement Council
Introduction: Person- and Family-centered Care

Person- and Family-centered Care (PFCC) focuses on putting the patient and their family at the center of all decision-making, planning and monitoring of care and by empowering them to be active partners in their care. Although there is no consistency among institutions in the use of patient vs. person, the term “patient” is often used in a medical and health context. However, we focus on “person” rather than “patient” because it reflects the whole individual and looks beyond the medical and physical condition, to consider his/her desires, values, lifestyles and social circumstances. It represents the multifaceted nature and core principles of PFCC efforts.

Defined by the Institute for Patient- and Family-Centered Care (IPFCC), PFCC is an approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers and patients and families through respect and dignity, information sharing, participation and collaboration. It is through person and family engagement (PFE) strategies, which are designed to foster collaboration between patients, families, and clinicians working together toward mutually agreed-upon goals, that one builds a person- and family-centered healthcare system.

PFE relies on four core concepts outlined below:

- **Respect and Dignity.** Healthcare practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

- **Information Sharing.** Healthcare practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information to effectively participate in care and decision-making.

- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

- **Collaboration.** Patients and families are also included on an institution-wide basis. Healthcare leaders collaborate with patients and families in policy and program development, implementation and evaluation; in healthcare facility design; and in professional education, as well as in the delivery of care.

A patient can be defined as anyone who is a consumer of the healthcare system, meaning that they receive care from any combination of healthcare professionals, including physicians, nurses, physical therapists and others. The IPFCC defines family as “two or more persons who are related in any way — biologically, legally or emotionally. Patients and families define their families.”

Prioritizing PFE improves patient care and numerous measures of hospital performance. PFE is an integral part of clinical units’ culture. Embracing the implementation of PFE protocols can improve both patient and provider satisfaction, foster better internal and external communication and ultimately lead to healthier people who receive care in a highly reliable system. Because PFE is one of the MHA Keystone Center’s foundational concepts, the MHA Keystone Center is committed to incorporating PFE efforts into all its activities and assisting Michigan hospitals with advancing and sustaining PFCC by leveraging existing resources, identifying best practices and building on existing networks.
The shift to PFCC can be traced to the 2001 Institute of Medicine report that identified the importance of patient-centered care as one of the six interrelated factors constituting high-quality care. Due to growing evidence and momentum, PFE efforts have been expanding globally in the past decade, contributing to new norms constituting today's rapidly changing healthcare landscape.

According to the AHRQ Guide to Patient and Family Engagement, PFE efforts can:

- Improve quality and safety (additional information below)
- Improve financial performance (additional information below)
- Improve Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospital Survey Scores
- Improve patient outcomes
- Enhance market share and competitiveness
- Increase employee satisfaction and retention
- Help meet The Joint Commission standards

**IMPROVED QUALITY AND SAFETY**

Data suggests that many adverse events in hospitals occur as the result of a breakdown in communication between healthcare team members and the patient and family. By emphasizing effective communication and collaborative decision-making processes, PFE can reduce the risks that lead to adverse events. Research shows that hospitals that implement patient-centered strategies perform better on core quality measures. For example, after implementing changes to its visitation policy with the goal of promoting patient and family engagement, Georgia Health Medical Center (GHMC) saw a 62 percent reduction in medical errors, a 40 percent reduction in falls and a 50 percent decrease in length of stay. Emory Healthcare, a large academic teaching system in Atlanta, partnered with patients and families to implement bedside change of shift reporting to ensure the full engagement and voice of patients and families. Not only did they see an increase in patient satisfaction, but quality outcomes also improved with a decrease in pressure ulcers from 8.15 to 2.5 percent, and a decrease in patient falls from 3.24 to 2.85 falls per patient days.
PFCC has been shown to improve financial performance through decreased litigation and malpractice claims and lower cost per case due to fewer complications and shorter length of stay.\textsuperscript{6}

According to a 2007 study\textsuperscript{7} on the Planetree model of patient-centered care, the hospital unit receiving the PFE intervention “consistently maintained a lower mean length of stay” versus the control unit. The lowering length of stay consequently lowers the cost per case accrued by the hospital. A 2013 study\textsuperscript{8} conducted in a large health system found that “patients with the lowest level of activation had costs that were 21 percent higher than patients with the highest level of activation,” proving the more direct financial benefit of PFE implementation in hospitals.

In addition to the shorter length of stay, PFCC can also lead to a decrease in litigation and malpractice claims. As research indicates, malpractice suits often are the result of differences in expectations between the patient and their caregivers as well as poor communication between the patient and family leading to misunderstanding of the patient views and perspective.\textsuperscript{9} By making PFCC “central to organizations’ values, strategic plan and personnel policies and practices,” healthcare organizations can greatly maximize their resources. This is evidenced by MCG Health System in Augusta, GA, which has become the most cost-efficient hospital in the University Health System Consortium, reporting a decrease in malpractice claims and litigation after the implementation of PFE “at all levels of care.”

“As research indicates, malpractice suits often are the result of differences in expectations between the patient and their caregivers as well as poor communication between the patient and family leading to misunderstanding of the patient views and perspective.”\textsuperscript{9}
Health equity is the “attainment of the highest level of health for all people.” Achieving health equity requires attending to health disparities, with particular attention to vulnerable populations. Health disparities refer to differences in health status and access to or availability of facilities and services based on social, economic and environmental conditions.

“Vulnerable populations” is a term that is used broadly to encompass racial and ethnic minorities; the economically disadvantaged; the elderly; rural residents; the homeless; the uninsured or under-insured; individuals with no or limited English proficiency; those with low health literacy; children and youth with special healthcare needs; individuals with chronic health conditions, poor health status, or mental health issues; disabled individuals; those at end-of-life; high-risk mothers and children; members of the LGBT community; incarcerated persons; and substance users.

Health equity must be strategically integrated into all aspects of quality improvement and PFE; it is not a separate agenda or area of focus. Because not all patients and families are alike, efforts to promote and support PFE must consider the values, preferences and needs to be reflected in diverse populations. The work of PFE requires co-designing more equitable systems by working with vulnerable populations to 1) develop organizational policies and practices that promote intentional diversity and inclusion; 2) engage persons and families who truly reflect the communities in which healthcare organizations are located; 3) use race, ethnicity, age and language (REAL) data to inform day-to-day operations and quality improvement work; and 4) direct systems changes and tailor other organizational change efforts and resources to groups that are most likely to face disparities in their health and healthcare.
The recommended policies and practices, which build upon the original Centers for Medicare & Medicaid Services (CMS) Partnership for Patients (PfP) PFE metrics, were developed with the guidance of the MHA Keystone Center PFE Council. These policies and practices are fundamental to improved quality of care for patients in hospitals. The MHA Keystone Center asks that each facility commits to implementing at least two practices a year from the list below, with the five CMS PfP metrics set as priority for implementation.

### CMS PfP PFE Metrics

1. Prior to admission, hospital staff provide and discuss a discharge planning checklist with every patient who has a scheduled admission, allowing for questions or comments from the patient or family (e.g., a planning checklist that is similar to CMS’s Discharge Planning Checklist).

2. Hospital conducts shift change huddles and bedside reporting with patients and family members in all feasible cases.

3. Hospital has a person or functional area, who may also operate within other roles in the hospital, that is dedicated and proactively responsible for PFE and systematically evaluates PFE activities (i.e., open chart policy, PFE training, establishment and dissemination of PFE goals).

4. Hospital has an active Patient & Family Engagement Committee (PFEC) OR at least one former patient that serves on a patient safety or quality improvement committee or team.

5. Hospital has at least one or more patients who serve on a governing and/or leadership board and serves as a patient representative.

For additional background and metric purpose, please see Purpose & Resource(s) section.

6. Hospital communicates PFE vision and values, supports PFE in all policy programs and surfaces, and has dedicated resources for these efforts.

7. The principles of person- and family-centered care, including active PFE, are taught or shared as part of hiring, performance evaluation, orientation and continuing education.

8. There are systems in place to encourage partnerships among patients, families and care providers (chart, a patient portal in EMR, email, bulletin/whiteboards in patient’s room, pagers, telephone contact). Patients receive guidance and counsel on decision aids to improve patient-provider shared decision-making.

9. Patients and families are informed at admission of family-initiated rapid response teams (RRT), with a verbal review of guidelines. Patients and families are encouraged to call for RRT if the patient’s health changes notably.

10. Patients and families are advised of physician/multidisciplinary rounds and are invited and encouraged to participate to the degree in which they wish to be involved.

11. Family and/or personal representatives, as determined by the patient, are respected as essential members of patient’s healthcare team, sharing information and providing support. They are not viewed as visitors, and their presence and participation are welcomed 24/7 providing safety can be maintained.

12. A process has been developed to gather the voice(s) of the patient, family and/or caregiver in the root cause analysis of an adverse or near miss event and to engage patient-family advisors in serious safety event reviews.
1. Prior to admission, hospital staff provide and discuss a discharge planning checklist with every patient who has a scheduled admission, allowing for questions or comments from the patient or family (e.g., a planning checklist that is similar to CMS’s Discharge Planning Checklist).

**Purpose:** The intent of this practice is to ensure organizations are creating a mechanism and procedure so that patients and families scheduled for admissions are sent a checklist and have an opportunity to talk with hospital staff at admissions. The ‘checklist’ can serve as a list of items and topics for conversation that patients/families can address related to what patients should expect, concerns and preferences for their care, potential safety issues (pre-admission medicines, history of infections, etc.), and any relevant home issues, such as needs for additional support, transportation and care coordination. ([Addendum-to-PFERoadmap_PfPPFEDefinitions](#))

**Resource(s):**
- CMS: “Your Discharge Planning Checklist”
- Robert Wood Johnson Foundation: “Care About Your Care”

2. Hospital conducts shift change huddles and bedside reporting with patients and family members in all feasible cases.

**Purpose:** As an evidence-based best practice, bedside shift report is a tangible way to ensure that complete and accurate information is shared and that there is a mutual understanding between the care provider, patients and families of the care plan and priorities. The patient and/or family member is able to hear, question, correct or confirm, and/or learn more about the next steps in their care as it is discussed between nurses changing shifts or clinicians making rounds.

Patients and/or family members should be present during these meetings. They should be encouraged and prompted by the clinical staff to be active participants to whatever degree they desire and add to the information being shared between the nurses or other clinicians discussing their care. Clinical staff should make an effort to adjust their use of medical jargon, acronyms, and other technical language to ensure that the patient and family member can easily follow the conversation. If necessary due to language barriers, an interpreter should be present. The patient/family member should be part of the entire conversation concerning their care, and not just select parts. ([Addendum-to-PFE Roadmap_PfPPFEDefinitions](#))

**Resource(s):**
- AHRQ: “Nurse Bedside Shift Report”
3. Hospital has a person or functional area, who may also operate within other roles in the hospital, that is dedicated and proactively responsible for PFE and systematically evaluates PFE activities (i.e., open chart policy, PFE training, establishment and dissemination of PFE goals).

**Purpose:** It is critical for the organization to ensure that PFE efforts are built into the management of hospital operations and given the attention and resources needed to be successful and sustained over time. The hospital should identify at least one staff member to be responsible and accountable for overseeing the implementation and evaluation of the PFE efforts at the hospital. Hospitals may create a role or department (that may have many names such as Patient/Person and Family Engagement, Patient Experience, or Quality Improvement) or identity that focuses on PFE. The person responsible for PFE at the hospital does not need to have a special title or position or be 100 percent focused on PFE, but all hospital staff should be aware that this person manages the hospital's PFE plans and activities. The PFE leader should, at a minimum, identify, implement, monitor and evaluate PFE activities, and is most likely coordinating the Patient and Family Advisory Council (PFAC). ([Addendum-to-PFE Roadmap_FpPFEDefinitions](#))

**Resource(s):**

4. Hospital has an active PFEC OR at least one former patient that serves on a patient safety or quality improvement committee or team.

**Purpose:** The hospital should have a formal relationship with patient and family advisors from the local community who provide input and guidance from the patient perspective on hospital operations, policies, procedures and quality improvement efforts. The relationship may be via a mechanism such as a PFEC, which often combines hospital staff with a range of patient and family representatives, or a patient and family advisory council (PFAC) which is comprised mostly of patients and family members.

An alternative to forming a PFEC or PFAC is the inclusion of patients and family advisors on one or more existing hospital committees. These patient representatives should have all the same rights and privileges of all other committee members, and efforts should be made to enable these representatives to share their unique perspective as patients or family members at meetings. The PFAC or other committees should be formal mechanisms that seek advice, input, and active involvement from patients and family advisors on a regular basis. ([Addendum-to-PFE Roadmap_FpPFEDefinitions](#))

**Resource(s):**
- IPFCC: “Creating Patient and Family Advisory Councils”
- IPFCC: “Tools to Foster Collaboration with Patient and Family Advisors”
- AHRQ: “Strategy 1: Working With Patients and Families as Advisors”
5. **Hospital has at least one or more patients who serve on a governing and/or leadership board and serves as a patient representative.**

**Purpose:** The intent of this recommendation is to ensure that at least one board member, with full voting rights and privileges, provides the patient and family perspective on all matters before the board, similar to other board members who represent specific interests in the community. Ideally, at least one board member with full voting rights would specifically be appointed for this purpose and with a written role definition as a patient representative. The ultimate goal of this activity is to ensure that the board works with patient and family perspectives when making governance decisions at the hospital.

While designating at least one patient representative on the board is the preferred mechanism to ensure co-governance, there may be barriers that do not allow the formation of a patient or family representative seat on the board. Until such barriers are removed, the hospital should strive to:

- Ask for PFEC/PFAC input on matters before the board and incorporate a PFEC/PFAC report into the board agenda.
- Identify elected or appointed board members to serve in a specific role, with a written role definition, as representing the patient and family voice on all matters before the board.
- Require all board members to conduct activities that connect them with patients and families, such as visiting actual patient units in the hospital two times per year and/or attending two PFEC meetings per year. ([Addendum-to-PFE Roadmap_PfPPFEDefinitions](#))

**Resource(s):**
- IHI: “How-to Guide: Governance Leadership (Get Boards on Board)”
- IHI: “Guidelines for Using Patient Stories with Boards of Directors”

6. **Hospital communicates PFE vision and values, supports PFE in all policy programs and surfaces, and provides the necessary infrastructure and resources for these effort.**

**Purpose:** Aligning the hospital’s mission and vision statements to support PFE helps ensure that everyone recognizes the importance of these efforts in improving safety and quality of healthcare. Organizations should work to incorporate person and family centered care into hospital’s strategic planning, which ensures a clear vision of how PFE fits into organizational processes on a daily, operational basis.13

In addition to setting a clear vision of how the organization will work to engage patients and families, hospitals must also define how it will measure and evaluate these efforts, identifying organizational strengths and weakness. Begin by reviewing policies and procedures to ensure they related to PFE efforts, ensure there are mechanisms for employees, patients and families to report concerns and failure in engaging patients and families, incorporate processes for acknowledging and correcting engagement failures, and define ways to review and improve PFE processes over time.17 Involve patient and family advisors in the review and development of hospital policies and procedures to ensure the guiding principles and values of PFCC are incorporated. Providing a sound infrastructure and dedicated resources for PFE efforts are also critical aspects in ensuring suitability of a PFCC
culture. Staff will need time to develop, implement, integrate and coordinate various initiatives, such as recruiting, selecting and training patient and family advisors or establishing patient and family advisory councils.13

Resource(s):
• AHA and IPFCC: “Patient- and Family-Centered Care: A Hospital Self-Assessment Inventory”
• AHRQ: “Supporting Patient and Family Engagement: Best Practices for Hospital Leaders”

7. The principles of PFCC, including active PFE, are taught or shared as part of hiring, performance evaluation, orientation and continuing education.

Purpose: Integrating PFCC principles and active PFE into personnel policies and practices transforms PFE from something that is “nice to do” to something that is expected. The PFCC principles and expectations should be included as part of hiring, training, evaluation and compensation. Ensure that job descriptions include emphasis on engaging patients and families and specify standards for incorporating PFCC in job performance for staff both directly and indirectly involved in patient care, set expectations during the hiring and orientation process and educate new staff on PFCC principles, include PFE in annual performance reviews, and tie compensation to PFE. Involve patient and family advisors in new hire interviews and make them part of new employee orientations to set a clear message upfront on the importance of these principles. By using the human resource infrastructure, the organization can further embed PFCC values and principles in the workforce.13

Resource:
• AHRQ: “Supporting Patient and Family Engagement: Best Practices for Hospital Leaders”

8. There are systems in place to encourage partnerships among patients, families and care providers (chart, a patient portal in EMR, email, bulletin/whiteboards in patient’s room, pagers, telephone contact). Patients receive guidance and counsel on decision aids to improve patient-provider shared decision-making.

Purpose: This recommendation ensures organizations are building and strengthening partnerships among patients, families and care providers in all decision-making. Partnerships are the cornerstone of PFCC. To encourage patients and families to become active participants, they must be engaged in their care and well-informed to take part in decision making. The goal of this recommendation is to ensure hospitals develop systems that encourage and facilitate communication between patients, families and care providers and provide patients the tools they need to partner with their healthcare providers. Examples include the following:

• Work with patients and families to design unit-specific whiteboards, adding space for patients and families to communicate with their care team, inviting them to share information, goals and write down questions they may have.
• Provide and educate patients on the use of patient portals.
• Ensure culturally diverse patient population has access to interpreter services. Develop peer mentoring programs to support critically ill patients.
• Provide and educate patients and families on decision aids that help them become more involved in decision making.

Four elements should be part of all shared decision making: information, support, discussion and follow-through. These informational health materials should be evidence-based, balanced, understandable and targeted. They should include information that makes explicit the decisions that need to be made, provide information on treatment options and outcomes, and help patients clarify personal preferences and values.

Resource(s):
• AHA and IPFCC: “Patient- and Family-Centered Care: A Hospital Self-Assessment Inventory”
• Families USA: Shared Decision Making” Engaging Patients to Improve Health Care

9. Patients and families are informed at admission of family-initiated RRTs with a verbal review of guidelines and are encouraged to call for RRT if patient’s health changes notably.

Purpose: Family-initiated RRTs give families a powerful tool to quickly call for help when their loved one’s condition is rapidly worsening or a serious new health concern has developed. A “Rapid Response Team” is a group of specialized and trained individuals, also known as a medical emergency team, who are called to action to provide immediate assistance when early signs of clinical deterioration are seen in a patient’s condition. Allowing patients and families to call a RRT is a significant way hospitals can make patients and families equal partners in safety. Hospitals must ensure these family-initiated RRTs are easy to activate and that patients and families receive educational information and verbal guidelines on when to call the RRT during the admission process. Information about the program should be included in the patient/family handbook, and hospitals can also create a poster listing the phone number to summon the RRT. Giving families and patients the ability to call for help provides a safety net and ensures they are an active member of the care team.

Resource:
• SCCM: Patient and Family Activation of Rapid Response Teams

10. Patients and families are advised of physician/multidisciplinary rounds and are invited and encouraged to participate to the degree in which they wish to be involved.

Purpose: Engaging patients and families in multidisciplinary rounds conducted at the bedside creates a vehicle for improvement in quality and safety of patient care. Patients and their families best know their needs and can provide valuable insight into the care planning process. It’s important that patients and families are prepared and receive information about rounds, such as their purpose and structure, time they are conducted, who will be present and how they can participate.

Oftentimes patients and families are intimidated by the healthcare team, who can encourage participation by encouraging them to write down questions in advance to prepare for rounds. Invite patients and families to fully participate, understanding that choice is important and not all will have the desire to participate. It’s critical that each member of the team is identified and their
role and responsibilities explained. Setting the scene occurs daily upon entering the patient room and involves one designated participant introducing key members of the team and encouraging the family to take an active role in clarifying information and contributing to the plan for care. Be sure to also prepare the team to be sensitive when using technical language that may not be understood by the patient and family, and also encouraging patients to ask questions if there is something that is not completely clear to them.

Resource(s):
- Cincinnati Children’s Hospital Medical Center: “Navigating Patent- and Family-Centered Care Rounds”
- IPFCC: Applying Patient- and Family-Centered Concepts into Bedside Rounds”

11. Family and/or personal representatives, as determined by the patient, are respected as essential members of patient’s healthcare team, sharing information and providing support. They are not viewed as visitors, and their presence and participation is welcomed 24/7 providing safety can be maintained.

Purpose: Engaging families as partners in care can only be achieved if they are present, yet many hospitals continue to have restrictive visitation policies. Evidence shows that the unrestricted presence and participation of family and friends – as partners in care – improves the safety of care, provides cost savings, enhances patient and family experience of care, improves management of chronic and acute illnesses, enhances continuity of care and prevents hospital readmissions. Not only is it essential that restrictive visitation policies and practices that view “families care” as visitors are changed, but that hospitals develop policies that support patients’ right to identify the individual they view as “family” and chose to be “partners in their care”. Patients need to have the right to define their family and who can visit them, how they will be involved in their care planning and in decision-making. Engage in the process to change “visiting” policies to guidelines which support the presence and participation of family and other “partners in care,” ensuring the choice to identify these individuals and preferences are left to the patient, yet still ensuring support for frontline staff in providing care safely and efficiently with their presence.

Resource:
- IPFCC: “Better Together – Partnering with Families”

12. A process has been developed to gather the voices of the patient, family and/or caregiver in the root cause analysis (RCA) of an adverse or near miss event and to engage patient-family advisors in serious safety event reviews.

Purpose: Patients, families and patient advocates can play a critical role in the process of change. By partnering with them in the adverse event review process, hospitals increase transparency, improve their organization’s systems analysis process and empower patients and families to be part of the solution.
Hospitals should welcome patients and families to provide their perspective to help better understand what led to an adverse and/or near miss event. The choice to engage in this process needs to be left to the patients and family members. Prior to involvement, patients and families must be prepared for the experience, supported during and after the formal process is concluded by opening the lines of communication and making them aware of the positive changes that have resulted from their input. Start the RCA process by inviting the patient or family member to tell their story. Inform them of the results and process changes and ask for their input and involvement in finding additional necessary changes.

Hospitals nationally have also partnered with their patient/family advisors as members of the RCA team, providing a critical voice yet having less emotional connection to the event. Having patient/family advisors serve in this role ensures the perspective from the patient/family side, leading to a deeper understanding of the root cause, bringing diversity to the team and bringing a perspective that no one else on the safety review team can bring. Patient advisors as members of the RCA committee can serve many roles, including:

- Working to identify pieces of the process missing from the patient’s perspective
- Participating in information/data gathering
- Presenting at all patient/family meetings before and after the RCA
- Analyzing findings
- Assisting in the development of action plans and recommendations
- Acting as an advisor

**Resource(s):**
- [Journal of Healthcare Risk Management: Including patients in root cause and system failure analysis](#)
- [Communication and Optimal Resolution (CANDOR) Toolkit](#)

For additional resources, please visit the Person & Family Engagement (PFE) – Foundational Concepts folder on the MHA Community, a secure online networking website that allows MHA-member hospital staff and volunteers to collaborate, share information and facilitate quality and safety activities.
References

Thanks to Our Contributors

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