Actionable Patient Safety Solutions (APSS):
Person & Family Engagement

How to use this guide
This guide gives actions and resources for creating and sustaining safe practices for person & family engagement. In it, you'll find:

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SAUDI PATIENT SAFETY CENTER

Patient Safety
MOVEMENT

Executive Summary

The Problem

Person-centered care (PCC) and patient and family engagement (PFE) have proven effective in improving patient outcomes, bolstering an organization's culture of safety, and enhancing the patient experience. PCC and PFE are clinical improvement strategies as well as ethical and moral standards. However, such an environment is often compromised due to a pervasive, clinician-centered culture of care in most healthcare organizations. In addition, it is difficult to assess a person-centered culture through quantitative, measurable outcomes, so leaders are often unaware that true involvement and engagement are not occurring.

The Cost

When hospitals fail to integrate the patient and family members fully into the care team, and fail to establish a person-centered care culture, gaps in communication occur. Since most preventable harm is due to miscommunication, the cost of a lack of PCC and PFE is reflected in most of the patient outcomes in an organization. Preventable medical error costs an average of $8,000 per hospital admission. Executives must understand the tremendous cost to an organization when patients and families are not engaged and involved as active care participants.

The Solution

Patients and family members should always be at the center of their own care and each clinical decision should be made either after discussion with the patient and family members or after thorough consideration of the implications the decision could have for their specific, individual circumstance. Authentic person-centeredness integrates both structural and cultural aspects into the performance improvement plan. Many healthcare organizations have successfully implemented and sustained improvements from person and family engagement. These organizations have **shown a commitment to transparency and a willingness to value and learn from the patient perspective. They have integrated the voice of the patient into operations and strategy and involved patients and families as true partners on the care team.**

This document provides a blueprint that outlines the actionable steps organizations should take to successfully improve person and family engagement and summarizes the available evidence-based practice protocols. This document is revised annually and is always available free of charge on our website. Hospitals who make a formal commitment to improve PFE share their successes on the PSMF website and have access to an additional level of consulting services.

Leadership Checklist

On a monthly basis, or more frequently if a problem exists, the executive team should review the outcomes of person and family engagement and person-centered care. Use this checklist as a guide to determine whether current evidence-based guidelines are being followed in your organization:

- ☐ Complete an organizational assessment of current state of PFE and PCC using IHI's Patient and Family Centered Care Organizational Self-assessment Tool, patient satisfaction scores, patient complaint data, and feedback from leader rounding. Elicit input from board and staff routinely.

- ☐ Measure and report person and family engagement efforts monthly. Note trends and routinely reassess.

- ☐ If person and family engagement rates indicate room for improvement, initiate a PI (performance improvement) project. If a problem is not indicated, routinely reassess to identify gaps, and ensure integrity of the data collected. Make improving PFE an organizational goal whether you can measure a problem or not.

- ☐ Ensure patients and families are represented in improvement activities at all levels of the organization, including board committees.

- ☐ Ensure frontline involvement in person and family engagement improvement activities and remove barriers to progress.

- ☐ If a PI plan is put in place, measure the associated process outcomes.

- ☐ Ensure adequate training and documentation of person and family engagement competencies and skills.

- ☐ Eliminate barriers to making rapid changes to documentation templates and order sets.

- ☐ Debrief on a regular basis to solicit team feedback about barriers to sustained compliance. Adjust the plan quickly and nimbly as needed.

- ☐ Hold staff accountable for providing the standard of care and reward success.

- ☐ Ensure that leaders have a simple process to oversee person and family engagement improvement work while also considering how it aligns with other initiatives across the organization.

- ☐ Ensure your organization has a clear, universal definition for person and family engagement and person-centered care (HPOE, 2013).

Strategies to Improve PFE

Person-centeredness in hospitals consists of person-centered care, patient and family centered care, and patient and family engagement. Person-centered care is everyone's right to be a part of their own decision making, both in and out of the hospital. Patient-centered care is necessary in the organizational culture and includes the patient and family members in their individualized plan of care while in the hospital. Patient engagement involves the active dialogue and partnership between the patient, family, and care team.

In order to achieve the vision of person-centeredness, the organization must have **both** a clear, actionable structure and a person-centered culture infused in every step. The below outline captures the synergy between the structural and cultural components necessary for improvement throughout the organization (HPOE, 2013; AIR, 2014).

1 — GOVERNING BODY AND EXECUTIVE LEADERSHIP

a. **Establish person-centered care as an organizational priority.**
- Listen to feedback from patients, family members, and frontline staff to inform a shared definition and vision and to ensure person-centered care pursuits are aligned with outcomes.
- Establish infrastructure in your organization that creates pathways for patient and family member participation in safety improvement work.
  - Use the Carman framework or alternative to implement a PFE program at multiple levels.
  - Express appreciation for the distinguished value that patients and family members offer in organizational improvement.

b. **Allocate the proper resources.**
- Appoint patients or patient advocates to your governing body, advisory bodies, and board and genuinely encourage their participation and perspectives at every opportunity.
- Establish a functional area in your organization with the focus of building a sustainable, equal relationship with patients and family members and supporting their participation and growth in PFE improvement projects.
- Develop an active Patient and Family Advisory Council (PFAC) that brings the patient and family members' voices into all hospital care decisions to establish this perspective as valuable and fundamental in all care aspects.

2 — SENIOR LEADERS

a. **Understand the current state.**
- Commit to investigating and becoming familiar with the organization's person-centered care gap.
  - Use IHI's Patient and Family Centered Care Organizational Self-assessment Tool.
  - Identify clinician behaviors and organizational barriers that may hinder PFE and person-centered care.
  - Actively listen to the experiences of patients, family members, and frontline workers.
- Request participation from the board, staff, and representative patients and families about what your organization will look like if it's successfully engaging patients and families.
- Explore methods that capture current state of person-centered care in more detailed ways, like observations or videos.

b. **Allocate the proper resources.**
- Provide clearly defined goals, support staff as they work through improvement initiatives, indicate measurable outcomes, and include opportunities for thorough communication every step of the way.
- Assess policies, processes, position descriptions, and training programs to ensure PFE and person-centered care are included and aligned with vision and goals.
- Encourage patient advocate input into improvement committees or root cause analysis teams.
- Implement patient advocate or navigator programs that are flexible to meet the need of the individual patient on a case by case basis.
- Synthesize an online resource platform for. patients to be directed to during their care. Help patients understand how these resources might be used in their care.

c. **Incorporate continuous education.**
- Develop and integrate patient experience and patient safety education in new-hire orientation and regular staff training to ensure that expectations about person-centered care are clear and consistent.
  - Training should be held on an ongoing regular basis.
- Utilize patient stories.
  - The inspiring story of Michael Seres.
  - Videos from the Safe Care Campaign's Patient Perspective Series.

d. **Regularly measure for improvement.**
- CMS is currently driving PFE through its Hospital Improvement Innovation Network (HIIN) program using the following metrics. See measuring outcomes section for additional metrics.
  - Develop a preadmission planning checklist that is discussed with every patient who has a scheduled admission (point of care).
  - Establish shift change huddles or bedside reporting as the norm (point of care).
  - Designate an accountable PFE leader (policy and protocol).
- Request feedback about the organization's person-centered care efforts.
- Assess current patients' perspectives of the centeredness of the care they personally received.
- Compile results in a format that can be easily understood and monitored.

e. **Reward efforts.**
- Reflect safety culture and PFE performance in leadership compensation to enhance direct accountability.
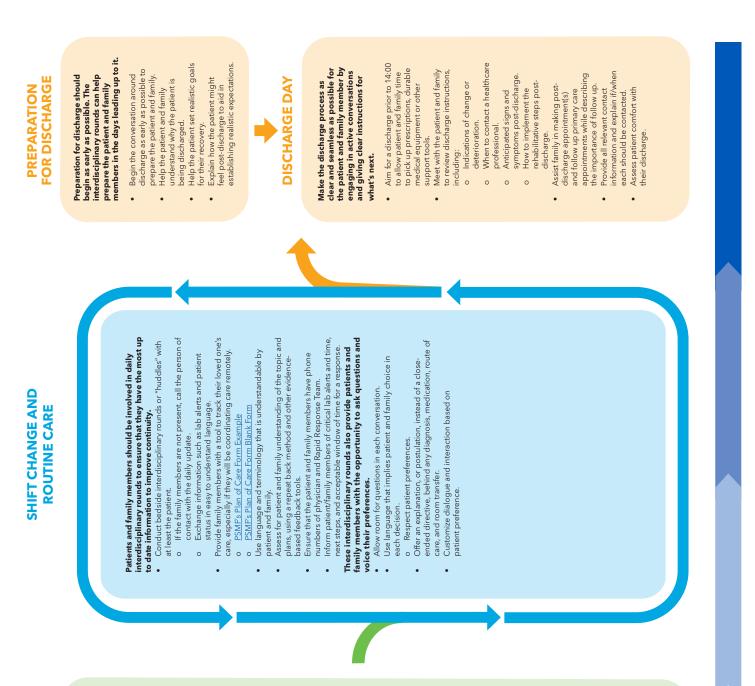- Praise healthcare professionals in situations of stellar person-centered care.

3 — FRONTLINE PROFESSIONALS

a. **Understand and employ person-centered care protocols in routine care.**
- Routinely discuss the preadmission planning checklist with every patient.
  - Engage in active listening and make every attempt to understand the individual reasons behind questions or concerns. Do not anticipate what you think the patient needs, but instead give them an opportunity to explain themselves.
- Allocate time for thorough shift change huddles or bedside reporting.
  - This time should include time for the patient to contribute and report.
- Direct patients to hospital or online networks or resources.
  - Explain the purpose behind said resources and how they may benefit the patient.
- Explain opportunities for patients to partner in the organizational structure.
  - Express genuine hope for their involvement and help them take the next steps.
- Conduct advanced care planning.
  - Listen to the cultural or religious concerns unique to that patient.

b. **Bring patients and families into the education and care process.**
- Assess patient understanding using the "teach back" method.
- Explain the "why" behind the "what" and the "how".
- Translate medical jargon into plain language.
- Reiterate information in a variety of ways.
- Identify barriers related to the patient's self-management and help overcome by setting realistic goals.
  - Make every attempt to understand the patient's physical, cognitive, and emotional circumstance.

c. **Welcome the patient voice.**
- Avoid a directive conversation style in favor of an open dialogue.
- Introduce yourself and understand the patient as an individual human being.
- Encourage questions and feedback during discussions.
  - Convey the value that patient feedback can have.
  - Patients and family members should understand that, although all clinicians in the hospital do their best, no one is ultimately coordinating their care. Patients and family members should understand that they are the managers of their care and as such, should demand to be an active part of the care team by participating in conversations and decisions.
- Understand what technologies are available to ease patient communication and involvement.
  - Help patients learn how to use any technologies available.

Clinical Workflow Infographic

ADMISSION

Build a relationship based on openness with the patient and family member. This time is crucial to set the tone for the rest of the patient's stay. Introductions, a hospital overview, open communication, and active discussions should take place immediately upon admission.

- Personally introduce yourself with your name, role, background, and a few personal facts.
- Allow patient and family time to ask you initial questions to orient them to the new surroundings and plan of care.
- Ensure patients and family members understand who's who in the hospital, what resources are available, reason for admission, and what to expect.

Understand and discuss how the patient and family members can be active in their care based on their current circumstances. It is important to collect information about their normal lives, routines, preferences, and health literacy to develop an involvement plan around their capacities.

- Collect family contact information and set a designated time for conversation, via phone if necessary, daily.
- Describe to the patient and family member how they can contribute to interdisciplinary rounds and why these rounds are helpful.
  o Discuss patient and family rights and responsibilities.

Guide patients and families in their understanding of the reasons behind their admission and the proposed route of care moving forward, including points of contact during their stay.

- Review physician orders and (re)educate family on the important role they can play in ensuring patient safety by asking questions and reporting changes in patient status.
- Review orders of admitting physician and advance care directive.
- Provide patient/family with phone numbers of admitting physician and Rapid Response Team in the event that the assigned nurse does not respond in a timely manner.
- Provide patient/family a written list of signs to watch out for during hospital stay and whom to notify of changes in patient status/signs of deterioration. (See PatientAider "Signs of a Rapidly Declining Patient").
- Keep family fully informed of any emerging complications and what they may mean for the patient/family members.

SHIFT CHANGE AND ROUTINE CARE

Patients and family members should be involved in daily interdisciplinary rounds to ensure that they have the most up to date information to improve continuity.

- Conduct bedside interdisciplinary rounds or "huddles" with at least the patient.
  o If the family members are not present, call the person of contact with the daily update.
  o Exchange information such as lab alerts and patient status in easy to understand language.
- Provide family members with a tool to track their loved one's care, especially if they will be coordinating care remotely.
  o PSMF's Plan of Care Form Example
  o PSMF's Plan of Care Form Blank Form
- Use language and terminology that is understandable by patient and family.
- Assess for patient and family understanding of the topic and plans, using a repeat back method and other evidence-based feedback tools.
- Ensure that the patient and family members have phone numbers of physician and Rapid Response Team.
- Inform patient/family members of critical lab alerts and time, next steps, and acceptable window of time for a response.

These interdisciplinary rounds also provide patients and family members with the opportunity to ask questions and voice their preferences.

- Allow room for questions in each conversation.
- Use language that implies patient and family choice in each decision.
  o Respect patient preferences.
- Offer an explanation, or postulation, instead of a close-ended directive, behind any diagnosis, medication, route of care, and room transfer.
- Customize dialogue and interaction based on patient preference.

PREPARATION FOR DISCHARGE

Preparation for discharge should begin as early as possible. The interdisciplinary rounds can help prepare the patient and family members in the days leading up to it.

- Begin the conversation around discharge as early as possible to prepare the patient and family.
- Help the patient and family understand why the patient is being discharged.
- Help the patient set realistic goals for their recovery.
- Explain how the patient might feel post-discharge to aid in establishing realistic expectations.

DISCHARGE DAY

Make the discharge process as clear and seamless as possible for the patient and family member by engaging in active conversations and giving clear instructions for what's next.

- Aim for a discharge prior to 14:00 to allow patient and family time to pick up prescriptions, durable medical equipment or other support tools.
- Meet with the patient and family to review discharge instructions, including:
  o Indications of change or deterioration.
  o When to contact a healthcare professional.
  o Anticipated signs and symptoms post-discharge.
  o How to implement the rehabilitative steps post-discharge.
- Assist family in making post-discharge appointment(s) and follow up primary care appointments while describing the importance of follow up.
- Provide all relevant contact information and explain if/when each should be contacted.
- Assess patient comfort with their discharge.

Performance Improvement Plan

Follow this checklist if the leadership team has determined that a performance improvement project is necessary:

☐ **Gather the right project team.** Be sure to involve the right people on the team. You'll want two teams: an oversight team that is broad in scope, has 10-15 members, and includes the executive sponsor to validate outcomes, remove barriers, and facilitate spread. The actual project team consists of 5-7 representatives who are most impacted by the process. Whether a discipline should be on the advisory team or the project team depends upon the needs of the organization. Patients and family members should be involved in all improvement projects, as there are many ways they can contribute to safer care.

> **Complete this Lean Improvement Activity:** Conduct a SIPOC analysis to understand current state and scope of the problem. A SIPOC is a lean improvement tool that helps leaders to carefully consider everyone who may be touched by a process, and therefore, should have input on future process design.

RECOMMENDED PERSON AND FAMILY ENGAGEMENT IMPROVEMENT TEAM	
• Patients	• Admitting and registration staff
• Family members	• Allied health professionals (PT, OT, etc.)
• Physicians	• Ancillary service representatives (pharmacy, lab, etc.)
• Nurses	• Quality and safety specialists
• Social workers	

Table 1: Understanding the necessary disciplines for a person and family engagement improvement team

☐ **Understand what is currently happening and why.** Reviewing objective data and trends is a good place to start to understand the current state, and teams should spend a good amount of time analyzing data (and validating the sources), but the most important action here is to go to the point of care and observe. Even if team members work in the area daily, examining existing processes from every angle is generally an eye-opening experience. The team should ask questions of the frontline during the observations that allow them to understand each step in the process and identify the people, supplies, or other resources are needed to improve patient outcomes.

> Create a process map once the workflows are well understood that illustrates each step and the best practice gaps the team has identified (IHI, 2015). Brainstorm with the advisory team to understand why the gaps exist, using whichever root cause analysis tool your organization is accustomed to (IHI, 2019). Review the map with the advisory team and invite the frontline to validate accuracy.

PROCESSES TO CONSIDER ASSESSING AND OPPORTUNITIES TO INTEGRATE PFE	
• Infection control, e.g. sepsis, CLABSI, CAUTI, COVID-19	• Patient personal health record accessibility
• Medication management	• Strategic planning
• Missed or delayed diagnoses	• Provider education
• Falls	• Patient safety rounding
• Admission	• Organizational ethics
• Shift changes	• Disparity in healthcare outcomes
• DVT/VTE	• Care for the caregiver
• Pressure ulcers	• Patient reported outcomes
• Delirium	• Research
• Telehealth	• Facilities design
• Root cause analysis processes	• Patient activation/confidence
• Discharge planning	• Health literacy
• End of life care	• Human Resources, e.g. employee recruiting, orientation, evaluation

Table 2: Consider assessing these processes to understand where the barriers contributing to a lack of person and family engagement may be in your organization

☐ **Prioritize the gaps to be addressed and develop an action plan.** Consider the cost effectiveness, time, potential outcomes, and realistic possibilities of each gap identified. Determine which are a priority for the organization to focus on. Be sure that the advisory team supports moving forward with the project plan so they can continue to remove barriers. Design an experiment to be trialed in one small area for a short period of time and create an action plan for implementation.

The action plan should include the following:
- Assess the ability of the culture to change and adopt appropriate strategies
- Revise policies and procedures
- Redesign forms and electronic record pages
- Clarify patient and family education sources and content
- Create a plan for changing documentation forms and systems
- Develop the communication plan
- Design the education plan
- Clarify how and when people will be held accountable

TYPICAL GAPS IDENTIFIED IN PERSON AND FAMILY ENGAGEMENT	
• Lack of adoption as an organizational priority • Provider bias • Hierarchy • Lack of patient/provider communication • Lack of accountability • Patient and family member health literacy • Inadequate involvement of all provider disciplines	• Perception that involving patients and family members takes valuable time • Uncertainty about what bedside hand-offs should look like • Varying levels of interpersonal skills • Language and cultural barriers • Disagreements of patient access to data • Patient apprehension in participation

Table 3: By identifying the gaps in person and family engagement, organizations can tailor their project improvement efforts more effectively

☐ **Evaluate outcomes, celebrate wins, and adjust the plan when necessary.** Measure both process and outcome metrics. Outcome metrics include the rates outlined in the leadership checklist. Process metrics will depend upon the workflow you are trying to improve and are generally expressed in terms of compliance with workflow changes. Compare your outcomes against other related metrics your organization is tracking.

Routinely review all metrics and trends with both the advisory and project teams and discuss what is going well and what is not. Identify barriers to completion of action plans, and adjust the plan if necessary. Once you have the desired outcomes in the trial area, consider spreading to other areas (IHI, 2006).

It is important to be nimble and move quickly to keep team momentum going, and so that people can see the results of their labor. At the same time, don't move so quickly that you don't consider the larger, organizational ramifications of a change in your plan. Be sure to have a good understanding of the other, similar improvement projects that are taking place so that your efforts are not duplicated or inefficient.

Read this paper **from the Institute for Healthcare Improvement to understand how small local steps can integrate into larger, system changes**

PERSON AND FAMILY ENGAGEMENT COMPARATIVE OUTCOMES
• Readmission rates • Patient satisfaction • Patient reported experience • Patient and family board involvement • Complications, adverse events, and escalations in care

Table 4: Consider evaluating related metrics to better understand person and family engagement presence and contributing factors

What We Know About Person and Family Engagement

Person and Family Engagement (PFE)

History: Historically, patients have been passive and treated objectively in their care. Clinicians, especially doctors, were always expected to be listened to without question, as they possessed education beyond that of a typical member of the general public. This hierarchical difference was embedded into the culture of medicine and still remains today.

> "Person and family engagement goes beyond informed consent. It is about proactive communication and partnered decision making between healthcare providers, patients, families, and caregivers. It is about building a care relationship that is based on trust and inclusion of individual values and beliefs" (CMS).

Current State: While the movement surrounding the importance of PFE and person-centered care has increased in recent years, the patterns of the past continue to influence hospital culture significantly. Therefore, PFE improvement efforts are continually hindered by physician hierarchy, perceptions of inferiority, lack of cultural awareness, and organizational design and incentives that do not place priority on PFE.

The Ideal: An organization with ideal PFE embodies person-centered care in all of its efforts and PFE is embedded as a priority from the executive leadership level to the bedside care level. This organization would focus its design and incentives around comprehensively incorporating person-centered care into all interactions. With the newly-allocated time for PFE, staff would engage patients and families in active dialogue and would carve out tasks that family members and the patient can be responsible for. Additionally, its structure would shift to provide opportunities for patient and family representatives at the board level or on project improvement teams.

Getting There: While this situation is the ideal and may seem nearly impossible, PFE is a low cost intervention that can be implemented by healthcare organizations without capital investment, usually with existing personnel. Achieving the ideal requires only reprioritization of resources and a current and future state analysis.

PFE is an underutilized and incredibly pivotal natural resource for improving the safety of care. Healthcare users and their family members play significant roles in managing care and often encounter aspects of care that providers and researchers miss. If their observations, insights, and lessons learned are overlooked in safety improvement, an organization loses important opportunities to prevent harm. There is ample evidence demonstrating that patients who are actively engaged as partners in managing their own long-lasting healthcare conditions achieve measurably better outcomes.

> In a 2013 editorial, then Health Affairs Editor Susan Dentzer recognized the value of PFE in describing it as the "blockbuster drug" of the 21st Century, observing:
> "Even in an age of hype, calling something 'the blockbuster drug of the century' grabs our attention. In this case, the 'drug' is actually a concept–patient activation and engagement–that should have formed the heart of health care all along."

Hospitals that have engaged their patients in improvement work report significant changes in building a culture of safety, which consists of (APSS #1: Culture of Safety):

- Behaviors that create safe outcomes and are used even when people in authority are not present
- The deeply held convictions of "how things are done around here" that drive the use of safety behaviors
- The workplace experiences, created by leadership, that drive those convictions

The Evidence for PFE

While it is difficult to measure improved patient outcomes based on increased person and family engagement, it has been found that comprehensive family discharge education was associated with lower presence of cough two weeks post-discharge, lower medication error rates at 12 days post-discharge, lower medication non-adherence rates, increased return to baseline health status at four weeks post-discharge, and higher rate of follow up visits at four weeks post-discharge (NCBI, 2015). Furthermore, researchers observed a significant increase in the patient knowledge of the follow up plan and in patient satisfaction post-discharge after engaging the patient and family members in conversations leading up to discharge (NCBI, 2015).

Research and evidence continues to demonstrate the impacts of PFE on achieving zero patient harm. This plethora of compelling evidence led CMS to incorporate PFE into its overall Quality Strategy in 2016.

PFE Education

All educational efforts should adapt to and meet the needs of all populations, including those with:
- Low literacy
- Low health literacy
- Disabilities
- Cognitive or mental health challenges
- Limited access to or inability to afford healthcare services
- Limited access to or inability to use information technology
- Language and cultural barriers

Virtual PFE and Technologies

Although the above human and organizational components should be thoroughly established in the hearts and minds of healthcare workers before incorporating extra digital features, technologies currently available are being used more frequently to bridge the gap between patients and providers and to improve PFE culture.

There are some circumstances in which family members must be involved in their loved one's care virtually. These situations might include distance or visitor restrictions. An example of a circumstance which required virtual PFE is in the case of the 2019 coronavirus pandemic, during which visitors were completely restricted from visiting hospitalized loved ones.

Information Technologies

The use of information and communication technology is a particularly fertile area of innovation that is being used to engage patients and family members, both while in the hospital and virtually. Examples include:

- Electronic patient portals
- Smartphone apps
- Email
- Texting pathways
- OpenNotes
    - OpenNotes is an international movement advocating patient access to all aspects of their electronic health records—including physician notes and diagnostic tests.
    - Supporters believe that providing access to notes is transformative in empowering patients, families, and caregivers to feel more in control of their healthcare decisions and improve the quality and safety of care.

Personal Health Records

Personal health records give each consumer a complete, consumer-controlled, consumer-centered, unified, lifetime electronic health record. Supporters believe that each consumer should have a complete electronic health record in one place that is updated automatically after every encounter with a provider. The complete record is then available if the patient ever needs to see a new provider, changes insurance, or relocates to another city or country.

With personal health records, family members and caregivers can have access as representatives to the patient's unified health record—so they can advocate and care for the patient when necessary.

- Personal health records can store patient-generated health data (PGHD) including the patient's goals and preferences for healthcare.
- Personal health records promote safer care when they are available to telehealth providers seeing the patient for the first time over a video connection.
- If the patient is unable to give consent, emergency providers can access the patient's unified record when giving life-saving treatment.
- All providers should be sure that their electronic health record systems automatically send a copy to the patient's personal health record whenever new information is generated.

Patient Feedback

When possible, healthcare organizations should consider integrating patient complaints, the narrative portions of patient satisfaction surveys, or other mechanisms that patients and families use to communicate concerns about patient safety events.

Inclusivity

However, patient advocates also cite the digital divide and urge that PFE implementers be aware that many people are not proficient using information technology or don't have access to it, and should take steps to ensure that these patients are not left behind.

Resources

- CMS: Person and Family Engagement Toolkit
- The Empowered Patient Coalition
- PatientAider
- CampaignZERO, Families for Patient Safety: Checklists
- Engaged Patients
- You: Your Own Best Medicine
- AHRQ: Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families
- AHRQ: Guide to Patient and Family Engagement in Hospital Quality and Safety
- OpenNotes
- American Institutes for Research: PfP Strategic Vision Roadmap for Patient and Family Engagement
- National Academy of Medicine: Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care
- American Hospital Association: Engaging Health Care Users: A Framework for Healthy Individuals and Communities
- FasterCures: Patient Perspective Value Framework
- IHI: When Things Go Wrong: Responding to Adverse Events
- The Joint Commission: Busting the Myths About Engaging Patients and Family Members in Patient Safety
- AHRQ: Guide to Patient and Family Engagement in Hospital Quality and Safety
- Medstar Institute for Quality and Safety, Center for Engaging Patients as Partners
- Healthcare Patient Partnership Institute
- Consumers Advancing Patient Safety
- Institute for Patient and Family Centered Care
- Planetree International
- A Leadership Resource for Patient and Family Engagement Strategies
- PfP strategic vision roadmap for patient and family engagement (PFE): achieving the PFE metrics to improve patient safety and health equity
- Imperial College London: Five-year Patient and Public Involvement Strategy

For hospital project improvement teams for general improvement:

- CMS: Hospital Improvement Innovation Networks
- IHI: A Framework for the Spread of Innovation
- The Joint Commission: Leaders Facilitating Change Workshop
- IHI: Quality Improvement Essentials Toolkit
- SIPOC Example and Template for Download
- SIPOC Description and Example

Education for Patients and Family Members

The outline below illustrates all of the information that should be conveyed to the patient and family members by someone on the care team in a consistent and understandable manner.

Explain why person-centered care is a priority. All members of the healthcare team should consistently reinforce that person-centered care and PFE are not only organizational priorities, but personal priorities for each clinician. This can be both explicitly said or implied through dialogue, preference consideration, active listening, and inclusion in healthcare team procedures. These strategies, and all mentioned through this document, can be employed for any clinical condition or disease state and should be carried throughout the full care continuum, including post-discharge. Therefore, it should be explained to patients and families that their input and involvement are valued through every step of the process.

It should also be conveyed to patients and family members that there exists not one sole person responsible for coordinating care, and while all members of the healthcare team do their best, it is ultimately up to the patient and family members to manage their care and demand inclusion.

Illustrate for patients where the healthcare system "touches" the patient and family members to fortify PFE efforts in these pivotal areas. By identifying the areas in which patients and family members are most impacted by the healthcare system, during transfers, for example, the full care team can collaborate at each stage to:

- Establish a horizontal relationship with the patient and family member to bolster their collaboration with the care team.
  - Make sure the patient and family members understand that they are equals with the healthcare professionals in their care team and that their care should center around them.
- Establish expectations for healthcare provider response time.
  - Patients and family members should have expectations of their care team and be responsible for certain "tasks" in their care.
  - The patient should firmly understand that their care centers around their needs and preferences.
- Anticipate questions that patients and family members may have at each stage.
  - While anticipation is helpful to prepare resources and material, each question should be considered and addressed on a case by case, individualized basis. Healthcare providers should model active listening and should encourage dialogue with their patients.
- At each stage, continuously reemphasize the person-centeredness of their care.
  - Ask for feedback about how confident and supported the patient and family members feel in engaging in their care.

Explain what is expected of them during their care. By giving patients and family members a "job" while they are in the hospital, they can be immersed fully in the routine care, can hold other team members accountable, can feel more confident voicing their concerns or opinions, and can serve as an extra set of informed and vigilant eyes. This team involvement can also reduce their anxiety by transforming concern into proactive action. Examples of "jobs" include:
- Applying compression socks and monitoring their use (APSS #12A: Venous Thromboembolism).
- Checking the endotracheal tube for securement and for patient secretions (APSS #8B: Unplanned Extubation).
- Making sure the patient's bed is elevated during and after meals (APSS #2G: Non-ventilator Hospital-acquired Pneumonia).
- Ensuring the patient is wearing non-slip socks to prevent falls (APSS #14: Falls and Fall Prevention).
- Asking the nurse to double check medications for dosage, timing, and potential interactions (APSS #3: Medication Safety).
- Inquiring about deep breathing exercises (APSS #2G: Non-ventilator Hospital-acquired Pneumonia).

In general, patients and family members should:
- Speak up with any questions or concerns.
- Watch for signs of patient deterioration and notify nurse immediately (see Patient Aider "Signs of a Declining Patient").
- Sanitize hands before entering into the patient room.
- Ask about patient mobility.
- Perform or ensure nurse performs good oral hygiene on the patient.

All members of the healthcare team should genuinely express their hope for the patient and family involvement in the care team. A member of the care team should articulate why their involvement is beneficial in the care process and should articulate clearly what can be expected of them during their stay as it relates to their own circumstance. The patient and family member should be reassured that their care is individualized and their perspectives and involvement will be treated as such.

Provide opportunities for involvement on quality improvement projects.
Patients and family members should understand that the hope for their involvement does not end with discharge. Members of the healthcare team should frequently encourage their involvement in the organization via quality improvement projects, board participation, or the development of resources for future patients and families.

Some examples of opportunities for involvement include, but are certainly not limited to, board involvement, root cause analysis participation, and development of educational resources.

While these opportunities for patient and family involvement will vary by organization, members of the healthcare team should ensure that they are familiar with these opportunities and should communicate them to each patient and family member, along with an explanation of why their participation would be valuable, what can be expected, and who to contact if interested.

Measuring Outcomes

In hospitals and multi-site systems, 5 PFE metrics have been developed to ensure that hospitals have structures and practices that enable active patient and family partnership at 3 levels of the hospital setting, including: point of care, policy, and governance.

- Preadmission Planning Checklist [point of care]: Hospital has a physical planning checklist that is discussed with every patient who has a scheduled admission
- Shift Change Huddles OR Bedside Reporting [point of care]: Hospital conducts shift change huddles or bedside reporting with patients and family members in all feasible cases
- Designated PFE Leader [policy & protocol]: Hospital has a designated individual (or individuals) with leadership responsibility and accountability for PFE
- PFAC or Representative on Hospital Committee [policy & protocol]: Hospital has an active Patient and Family Advisory Council (PFAC) OR at least one patient who serves on a patient safety or quality improvement committee or team
- Patient Representative(s) on the Board of Directors [governance]: Hospital has one or more patient(s) who serve on a governing and/or leadership board as a patient representative

Other metrics for measuring engagement can include (HPOE, 2013):

- Number of patient and family advisors involved in the hospital
- Number of patient and family advisors on committees or quality improvement teams
- Number of staff trained in partnering with and enhancing engagement from patients and families
- Patient ratings of hospital care

Endnotes

Conflicts of Interest Disclosure

The Patient Safety Movement Foundation partners with as many stakeholders as possible to focus on how to address patient safety challenges. The recommendations in the APSS are developed by workgroups that may include patient safety experts, healthcare technology professionals, hospital leaders, patient advocates, and medical technology industry volunteers. Workgroup members are required to disclose any potential conflicts of interest.

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