

Actionable Patient Safety Solutions™ (APSS™): Person and Family Engagement

How to use this guide

This APSS provides evidence-based resources and recommendations for person and family engagement for executives, leaders, clinicians, and performance improvement specialists. This document is intended to be used as a guide for healthcare organizations to examine their own workflows, identify practice gaps, and implement improvements. In it, you will find:

Best Practice Summary: A high level summary of evidence-based, clinical best practices. (page 2)

Executive Summary: Executives should understand the breadth of the problem and its clinical and financial implications. (page 2)

Leadership Checklist: This section is for senior leaders to understand common patient safety problems and their implications related to person and family engagement. Most preventable medical harm occurs due to system defects rather than individual mistakes. Leaders can use this checklist to assess whether best practices are being followed and whether action is needed in their organization around person and family engagement. (page 3)

Clinical Workflow: This section includes more specific information around person and family engagement across the continuum of care. Leaders should include the people doing the work in improving the work. This section outlines what should be happening on the frontline. Clinicians can use this section to inform leaders whether there are gaps and variations in current processes. This is presented as an infographic that can be used for display in a clinical area. (page 4)

Education for Patients and Family Members: This section outlines what frontline healthcare professionals should be teaching patients and family members about engaging in their care. Clinicians can inform leaders whether there are gaps and variations in current educational processes. (page 6)

Performance Improvement Plan: If it has been determined that there are gaps in current processes, this section can be used by organizational teams to guide them through an improvement project. (page 7)

What We Know About Person and Family Engagement: This section provides additional detailed information about person and family engagement. (page 10)

Resources: This section includes helpful links to free resources from other groups working to improve patient safety. (page 13)

Endnotes: This section includes the conflict of interest statement, workgroup member list, and references. (page 15)

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Best Practice Summary

Admission:

- Ensure patients are prepared before their healthcare interaction.
- Understand the key family point of contact.
- Provide patients and family members with the tools needed to stay engaged in their care.
- Be aware of personal biases that may influence the ability to listen.

Routine Care:

- Inquire about patient preferences and patient routines that may impact health decision making.
- Maintain open and respective lines of communication with patients and family members across the continuum of care.
- Create an environment that promotes transparency and learn from patient and family member experiences after medical error.
- Use language that patients and family members can understand and provide visual aids for decision making.
- Address an limitations from patients that affect their active involvement in their care.

Discharge:

- Assess barriers to patient's ability to follow the care plan after discharge.
- Provide necessary information about how, when, and where to seek help if needed.
- Engage patients with tools for continued engagement, such as digital health technologies.

Executive Summary

The Problem

Person and family engagement (PFE) is a valuable tool for clinicians to use to advance clinical improvement strategy by improving the safety of care, advancing a culture of transparency, and achieving person-centered care. Leaders are unaware of PFE's proven effectiveness in reducing preventable harm events due to a non robust amount of quantitative measurements of its impact. Fear of transparency and accountability in many healthcare organizations further inhibits the progress that PEE can accomplish in improving patient outcomes.

The Cost

Failing to fully integrate patients and family members into the care team leads to miscommunication which results in medical error and preventable harm. The cost of a lack of PFE is reflected in negative patient outcomes linked to miscommunication or care coordination gaps. Preventable medical error costs an average of \$8,000 per hospital admission to an organization. Furthermore, uncompensated costs to patients and their families are far-reaching and often uncalculated (e.g., patient legal costs, time off of work, babysitters, etc.), costs to employers (e.g. absenteeism and increased employee healthcare costs), and costs to society (e.g unemployment, public assistance).

The Solution

The purpose of this guide is to increase person and family engagement to improve patient safety. This document provides a blueprint that outlines the actionable steps organizations can 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.

Leadership Checklist

Engage patients and family members at every level of the organization.

<p>IN GOVERNING BODY AND EXECUTIVE LEADERSHIP.</p>	<p>Be intentional with person and family engagement planning and make it known that it is not optional.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Designate an individual at the Executive level to champion Person and Family Engagement initiatives. <input type="checkbox"/> Involve patients and family members in strategic planning and visioning. <input type="checkbox"/> Implement patient and family advisory councils (PFACs) focused on safety and quality. <input type="checkbox"/> Involve patients and their families in root cause analyses, performance improvement initiatives, and communication and resolution conversations after an adverse event. <input type="checkbox"/> Allocate time for discussion to share successes and shortcomings in engagement <input type="checkbox"/> Ensure diversity in improvement work from those of various backgrounds, socioeconomic statuses, cultures, education levels, and ethnicities. <p>Support PFE with Budget and Staff.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Build a budget that overtly incorporates patient and family engagement initiatives. <input type="checkbox"/> Appoint a consistent person/group to oversee organization PFE. <input type="checkbox"/> Invest in the wellness of Healthcare worker staff See "Workplace Safety" APSS. <p>Sustain progress and momentum.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Communicate the organization's PFE policy and opportunities for involvement to everyone in the organization and system. <input type="checkbox"/> Routinely expressing appreciation to both patients and family members to highlight their distinguished value in the organization
<p>IN SENIOR LEADERSHIP.</p>	<p>Make PFE easy for those on the frontline.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Adopt and promote very clear definitions and expectations of PFE (HPOE, 2013). <input type="checkbox"/> Internally market the organization's PFAC as a resource within the organization to develop patient safety/QI intervention and obtain feedback on current practices. <input type="checkbox"/> Assess policies, processes, position descriptions, and associated training practices to ensure PFE and person-centered care are prioritized. See "6Ps of Clinical Practice" <input type="checkbox"/> Adopt tools (e.g., written, digital, etc) for a patient engagement experience for all patients' and family's care journey to leverage it for their provision of care. <p>Make it easy and comfortable for patients and family members.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Design patient portals with the user in mind. Personalize navigation (e.g., content the user will need, not type of resource). Solicit patient input throughout the development process. <input type="checkbox"/> Accommodate language and other communication needs (e.g., poor hearing, cognitive disabilities, etc) and allow everyone in the committee to contribute to agenda setting. <ul style="list-style-type: none"> <input type="checkbox"/> Be prepared to explain in plain language when it cannot be avoided and avoid using medical jargon and acronyms when communicating with patients or family members. <input type="checkbox"/> Allow patients to 'comment' on their health record, whether electronic or paper, and provide a pathway for voice out any corrections when they find errors. <input type="checkbox"/> Be proactive in ensuring patients' and their families' are comfortable in healthcare settings and procedures by ensuring you have an independent number to personally listen to concerns and use organizational protocols such as codes to maintain boundaries and avoid any disruption or errors (e.g., partner being in the delivery room but not engaging with the obstetrician or staff working as this distraction can cause an error).

	<p>Incorporate continuous education.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Hold regular PFE trainings for all staff members in multimodality forms throughout the day <input type="checkbox"/> Use patient stories to inspire change and debrief frontline members of areas of improvement in their workflows to foster people-centered care and patient and family engagement. <p>Regularly measure for improvement.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Clearly define goals, support staff throughout improvement initiatives, indicate measurable outcomes, and include communication opportunities at all steps in order to easily display results to be reviewed by the public and staff. See Performance Improvement Plan. <p>Reward efforts.</p> <ul style="list-style-type: none"> <input type="checkbox"/> Reflect safety culture and PFE performance in compensation of staff responsible to enhance direct accountability and incorporate patients and families' input by using feedback forms.
IN DIRECT CARE.	See Clinical Workflow .

Clinical Workflow

ALWAYS

Show respect for everyone's background, wishes, and decisions.

- Allow time:
 - For patients and family members to ask questions in every discussion.
 - To engage in active listening (e.g., asking open ended questions, pausing to listen, etc)
 - To give them an opportunity to explain themselves.
- Provide:
 - Patients and family members with a tool to track their care, especially if they are coordinating care remotely
 - ◇ [PSMF's Plan of Care Form Example](#)
 - ◇ [PSMF's Plan of Care Form Blank Form](#)
 - All updates to patients and family members and what these updates mean for *their* care
 - An explanation behind any diagnosis, medication, route of care, and room transfer
 - Transparency
 - Definitions for every aspect of *their* care and what it means for *them*
 - Information on how to access *their* medical records (e.g., via the electronic patient portal, written documents, etc).
 - Feedback to leadership about why PFE matters to you
- Be aware of your own biases and understand how they impact your ability to listen and act.
- Speak in a way that patients and family members can understand. See [Healthcare Literacy](#) APSS.

1. ADMISSION/ENTRY

- Prepare patients to engage in their care before the interaction. See Care Coordination APSS.
- Explain (in verbal and written format):
 - Who you are
 - Who's who in the facility
 - Resources they should be aware of
 - What to expect in their care
 - Main points to ask healthcare professionals during their care
 - The importance of speaking up about any questions or concerns
 - Who to contact, how, and when.
- Determine:
 - Key family point of contact, and how, and when to contact them.
 - Wishes around advance care directives, goals, etc.



2. ROUTINE CARE

- Ask about and/or evaluate:
 - Their normal lives/routines
 - Their preferences

- Use language that implies that they have a choice. For example, state when there are options to consider, be prepared to explain the potential benefits and risks of each option, and inquire about what is needed to make a decision given the options presented. Encourage questions.
- Encourage questions and feedback during discussions and convey the value that patient feedback can have.
 - [Help patients and family members ask the best questions.](#)

- Their baseline health literacy levels
- Their capacity to be involved in their care
- Who will be involved in their care.
- Any limitations they have and resources that could be engaged.
- Remain watchful for PFE opportunities:
 - Like when/how patients and family members can contribute to their care (e.g., reporting changes in status beyond what's usual, providing oral care, etc)
 - For discussion with patients and family members after an emergency
 - In shift change huddles/bedside reporting
 - Such as open ended questions and teach back
- Explain:
 - How and when to use available technologies/ tools and their purpose as it relates to the patient's individual circumstance
 - Information for management of their care
 - Any risks in their care, how to detect these risks, and what to do
- Prepare the patient and family members for:
 - Their participation prior to a shift change huddles/bedside reporting (e.g., prioritizing questions, taking notes, etc)
 - Discharge as early as possible by explaining instructions and next steps.



3. DISCHARGE/EXIT

- Assess
 - Patient comfort with their discharge by asking open ended questions at multiple times
 - Barriers related to the patient's self-management and help overcome by setting realistic goals.
- Express:
 - Opportunities for patients to partner in organizational structure
 - Genuine hope for their involvement. Help them take the next steps for their involvement.

See [Care Coordination](#) APSS for more information.

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.

Frontline professionals should explain:

- Why patient and family involvement in care is important.
- That they are the only ones present at all times they are receiving care. Emphasize that they know what has already happened in their care.
- That it is okay to feel overwhelmed in the healthcare system but that they are supported by all staff.
- What they can do to help in their care and where to go if they have questions.
- How to [ask the best questions](#).
- That their care team is doing everything they can to deliver excellent care AND it is important that the patient and family members are fully aware of and participate in their own care plan.
- How to participate in the creation of their care plan.
- That the purpose of interdisciplinary rounds/bedside rounds are to discuss the care plan with all healthcare worker team members present and what to ask for if the family members are not able to physically be there.
- What a health record is, how to access their health record, and how to raise any concerns or questions.
- That patients and family members are equals with the healthcare professionals and that their care should center around them.
- What expectations patients and family members should have in their care.
- What bedside alarms mean, what to do if the alarm rings and staff do not arrive, and which alarms are emergencies
- That providers may not have full access to the patient's record.
- How the feedback from patients and family members is considered routinely in organizational processes.
- What 'tasks' patients and family members have to keep themselves safe in the organization. Examples include:
 - Applying compression socks and monitoring their use to prevent blood clots
 - Making sure the bed is elevated during and after meals to prevent the patient from inhaling anything other than air (e.g., food)
 - Ensuring the patient is wearing non slip socks to prevent falls
 - Double checking all medications for dosage, timing, and potential interactions
 - Responding to bedside alarms
 - Inquiring about deep breathing exercises.
 - Helping the patient wash their hands and ensuring all providers wash their hands.
 - Speaking up if they have questions or concerns about their care and treatment.
- Opportunities for patient and family member involvement on quality improvement projects.

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 the 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

- | | |
|--|--|
| <ul style="list-style-type: none">• Patients• Family members• Patient advocates• Patient and Family Advisory Council (PFAC) members• Physicians• Nurses, including APRNs, APPs, etc• Patient Safety and QI staff• Patient Experience staff• Environmental services• Dietary staff | <ul style="list-style-type: none">• Pharmacists• Social workers• Admitting and registration staff• Allied health professionals (PT, OT, etc.)• Ancillary service representatives (radiology, lab, etc.)• Hospital Volunteers• Spiritual care• Community partners• Community healthcare organizations |
|--|--|

Table 1: Understanding the necessary disciplines for a person and family engagement improvement team. Ensure diversity in participation from those of various backgrounds, socioeconomic statuses, cultures, education levels, and ethnicities.

- 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 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 HELP YOU UNDERSTAND YOUR ORGANIZATION'S CURRENT STATE OF PFE

- Organizational strategic planning
- Organizational prioritization and decision making (e.g., hiring, budgeting, training, etc)
- Healthcare professional behaviors and attitudes that encourage and discourage PFE in both direct care and organizational improvement efforts
- Design of patient portals, apps, educational material, etc
- When and how PFAC members are leveraged
- Design, implementation, and sustained improvements to telemedicine and digital health initiatives
- Which patient populations are being engaged and which are not as engaged and why (e.g., ethnicity, diagnosis, cherry picking only patients who will have positive feedback, etc)
- How patient satisfaction reports and complaint data are used, to whom the data is reported, and how frequently
- The role of the patient during transitions of care, hand-offs, and shift changes
- Communication and resolution discussions after an adverse event
- The role of the patient and family members in population-specific performance improvement initiatives, such as, but not limited to:
- Infection control (e.g. sepsis, CLABSI, CAUTI, COVID-19, etc)
 - o Medication management
 - o Falls
 - o DVT/VTE
 - o Pressure Ulcers
 - o Delirium

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. Consider [IHI's Patient and Family Centered Care Organizational Self-Assessment Tool](#).

- 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

- **Gap:** Organizations do not have the most accurate picture of PFE.
- **Gap:** Person and family engagement is advertised as an organizational priority, but may not be meaningfully incorporated everywhere in the organization.
 - o **Possible root causes:** Those making the organizational decisions are not present during patient and family engagement conversations. There is no body (e.g., PFAC) focused on PFE improvement.

- **Gap:** Not everyone understands their role in PFE.
 - Possible root causes: There is a poor ratio of healthcare professionals to patients/family members in organizational improvement groups. Patients don't understand their role in shared decision making conversations.
- **Gap:** There is a perception of a lack of need to engage patients and family members beyond what the organization is already doing.
 - Possible root cause: Organizations do not have the most accurate picture of PFE.
- **Gap:** PFE is perceived as a time intensive investment with little payoff.
 - Possible root cause: There is a lack of meaningful data capture and reporting to those doing the work.
- **Gap:** Those on the frontline don't know what they can do to improve PFE.
 - Possible root cause: Tools for those on the frontline to use are not readily accessible (e.g., structure for bedside hand-offs, etc).
- **Gap:** Patients are not well-equipped to be involved in their care.
 - Possible root cause: Patients don't have access to their data or portal.
- **Gap:** It is difficult for patients and family members to participate.
 - Possible root cause: PFE engagement discussions are scheduled during the work day. Patients do not have a family member or advocate present during discussions.

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



PERSON AND FAMILY ENGAGEMENT METRICS TO CONSIDER ASSESSING

- Preadmission Planning Checklist
 - Organization has a physical planning checklist that is discussed with every patient who has a scheduled admission.

- Shift Change Huddles or Bedside Reporting
 - o Organization conducts shift change huddles or bedside reporting with patients and family members in all feasible cases.
- Designated PFE Leader
 - o Organization has a designated individual (or individuals) with leadership responsibility and accountability for PFE.
- PFAC or Representative(s) on Hospital Committee
 - o Organization 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
 - o Organization has one or more patient(s) who serve on a governing and/or leadership board as a patient representative.
- Support for patient and family voices
 - o Are there policies, procedures, and actions taken to support patient and family participation in governance or operational decision-making of the practice (Patient and Family Advisory Councils, Practice Improvement Teams, Board Representatives, etc.)?
- Shared decision-making
 - o Does the practice support shared-decision making by training and ensuring clinical teams integrate patient-identified goals, preferences, concerns, and desired outcomes into the treatment plan (e.g. those based on the individual's culture, language, spiritual, social determinants, etc.)?
- Patient activation
 - o Does the practice utilize a tool to assess and measure patient activation to understand how to work with or alongside the patient in supporting decision making and self management?
- Active e-Tool
 - o Does the practice use an e-tool (patient portal or other E- Connectivity technology) that is accessible to both patients and clinicians and that shares information such as test results, medication lists, vitals and other information and patient record data?
- Health literacy survey
 - o Is a health literacy patient survey being used by the practice (e.g. CAHPS Health Literacy Item Set)?
- Medication management
 - o Does the clinical team work with the patient and family to support their patient/caregiver management of medications?
- Other metrics for measuring engagement can include ([HPOE, 2013](#)):
 - o Number of patient and family advisors involved in the hospital
 - o Number of patient and family advisors on committees or quality improvement teams
 - o Number of staff trained in partnering with and enhancing engagement from patients and families
 - o Patient ratings of hospital care
 - o Readmission rates
 - o Patient satisfaction
 - o Patient reported experience measures (e.g., 'Net Promoter Score', etc)

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)

The Ideal: Optimal person and family engagement would look like:

- Engaging patients and family members at every level across the organization
- Making PFE opportunities easily accessible to all (e.g., considering those with

disabilities, etc)

- Designing incentives around incorporating PFE in all interactions
- Removing existing burdens on the frontline so they can better understand their patients and family members
- Ensuring all across the organization understand how they can incorporate PFE into their role
- Prioritizing patients and family members as partners in their care
- Continuously improving to be better than yesterday.

Getting There: While this situation is the ideal and may seem nearly impossible, PFE is a cultural change that is intentional, intensive, and low cost and can be implemented by healthcare organizations without capital investment, usually with existing personnel.

“Person and family engagement goes beyond informed consent. It is about proactive communication and partnered decisionmaking between healthcare providers and patients, families, and caregivers. It is about building a care relationship that is based on trust and inclusion of individual values and beliefs” ([CMS](#))

Existing research still lacks the ability to reliably estimate preventable harm due to missed, delayed, or miscommunicated diagnoses.

Organizations that have engaged their patients in improvement work report significant changes in building a culture of safety. See the “[Creating a Foundation for Safe and Reliable Care](#)” APSS for more information.

The Evidence for PFE

While it is difficult to measure improved patient outcomes based on increase 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. For example, there is a strong correlation with family involvement and a reduced rate of in-hospital falls. This led CMS to incorporate PFE into its overall Quality Strategy in 2016.

Guided by the Carman framework and other common PFE frameworks noted in the “[Resources](#)” section of this document, in 2013 the U.S. CMS developed and deployed 5 PFE metrics in a nationwide effort to reduce 10 Hospital Acquired Conditions (HACs) and readmissions as an integral part of its Partnership for Patients (PfP) campaign. The 5 hospital-based PFE metrics are expanded upon in the Action plan of this Actionable Patient Safety Solutions (APSS). Verified results show that hospitals with robust PFE accomplished a greater reduction in HAC frequency and did so at a faster rate. Based on these initial results, in 2015, 6 PFE metrics were deployed by CMS in the ambulatory care sector as part of its Transforming Clinical Practice Initiative (TCPI). The 6 ambulatory care-based metrics are explained in detail in the Action plan of this APSS. Research and evidence continues to demonstrate the impacts of PFE on achieving zero patient harm. For example, there is a strong correlation with family involvement and a reduced rate of in-hospital falls. This led CMS to incorporate PFE into its overall Quality Strategy in

2016. Many hospitals and healthcare systems that have prioritized patient safety are building patient and family advisory councils (PFACs) or other infrastructure that embed PFE strategies. However, some hospitals and clinical practices have yet to incorporate robust PFE into their patient safety programs.

PFE Education

Educational efforts should address the needs of all populations, including, but certainly not limited to, 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
 - PatientAider mobile app
 - [Safety4Me](#) mobile app
- 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 are also an international movement to 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, such as with referrals from their regular provider, if the patient 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. When seeking patient engagement via portals or feedback systems, be sure to:

- Make sure patients and family members know its purpose and how and when to access it.
- Design the platform so it's easy for patients and family members to access and use.
- Have a mechanism for closed loop communication once feedback is submitted.

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

For Person and Family Engagement Improvement

- [NHS: Framework for Involving Patients in Patient Safety](#)
- [Patient Recommendations to Improve the Implementation of and Engagement with Portals in Acute Care](#)
- [Covenant Health: Patient/Resident and Family Partner Program](#)
- [CMS: Person and Family Engagement Toolkit](#)
- [Engaging patients in patient safety: A Canadian guide](#)
- [Engaging patients to improve quality of care: A systematic review](#)
- [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](#)
- [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](#)
- [Health Information and Management Systems Society: Patient Engagement](#)
- [American Hospital Association, Engaging Health Care Users: A Framework for Healthy Individuals and Communities](#)
- [The Guiding Framework on Patient and Family Engaged Care from the National Academy of Medicine](#)
- [Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families](#)

For General Improvement:

- [An Empowered Patient](#)
- [CampaignZERO: Families for Patient Safety](#)
- [Minnesota Alliance for Patient Safety, You: Your Own Best Medicine](#)
- [AHRQ Question Builder tool for patients](#)
- [OpenNotes movement](#)
- [PfP Strategic Vision Roadmap for Patient and Family Engagement](#)
- [Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care \(National Academy of Medicine\)](#)
- [Getting the most out of the clinical encounter: the four habits model](#)
- [American Hospital Association's Health Research and Educational Trust \(AHA HRET\) Patient and Family Engagement Resource Compendium](#)
- [The Empowered Patient Coalition](#)
- [PatientAider](#)

- [Engaged Patients](#)
- [FasterCures Patient Perspective Value Framework](#)

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](#)

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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