Actionable Patient Safety Solutions™ (APSS™):

Person and Family Engagement

How to use this guide

This guide gives actions and resources for person and family engagement. In it, you'll find:

Executive Summary 2
Leadership Checklist 3
Clinical Workflow 4
Performance Improvement Plan 5
What We Know About Person and Family Engagement 7
Education for Patients and Family Members 11
Endnotes 11

Patient Safety MOVEMENT

3179A Care Coordination APSS

Executive Summary

The Problem

Person and family engagement (PFE) is an underutilized resource for improving the safety of care, advancing a culture of safety and transparency, and achieving person-centered care. In addition to its value as a clinical improvement strategy, PFE is an ethical and moral standard (e.g., "the right thing to do"). Although PFE has proven effective in reducing preventable harm events and improving patient outcomes, it is impeded by fear of transparency and accountability in many healthcare organizations. In addition, leaders are often unaware of the value of PFE because quantitative measurement of its impact has not been robust.

The Cost

When patients and family members are not fully integrated into the care team, gaps in communication and care coordination increase. Since most preventable medical error is due to miscommunication or care coordination gaps, the cost of a lack of PFE is reflected in patient outcomes. Preventable medical error costs an average of $8,000 per hospital admission to an organization, in addition to the costs borne by the patient and family, that are often uncompensated and 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). Failure to embrace PFE also contributes to liability exposure and damage to reputation.

The Solution

The purpose of this guide is to help all members of the healthcare team, including patients and family members, work more effectively together to improve patient safety. Many healthcare organizations have successfully implemented and sustained effective PFE programs. These organizations have

- Made a commitment to transparency and a willingness to value and learn from the patient perspective,
- Integrated the voice, experience and competencies/skills of patients 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 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. Hospitals and healthcare organizations that make a formal commitment to improve PFE and share their successes on the Patient Safety Movement Foundation (PSMF) website via the Shared Learning Network have access to an additional level of consulting services.

Leadership Checklist

IN GOVERNING BODY AND EXECUTIVE LEADERSHIP.	**Be intentional with person and family engagement planning and make plans known throughout the organization.**
	☐ Designate an individual at the Executive level to champion Person and Family Engagement initiatives.
	☐ Involve patients and family members in strategic planning and visioning.
	☐ Adopt a person and family engagement policy.
	☐ Implement patient and family advisory councils (PFACs) focused on safety and quality.
	☐ Establish infrastructure (e.g., Carman framework) that creates pathways for patient and family member participation in safety improvement work at the front line, improvement work and governance/leadership levels of the organization.
	☐ Involve patients and family members in root cause analyses, performance improvement initiatives, and communication and resolution conversations after an adverse event.
	☐ Allocate time for discussion about what the organization will look like if it's successfully engaging patients and families and to hear about successes and shortcomings.
	
	Support PFE with budget and staff.
	☐ Build a budget that overtly incorporates patient and family engagement initiatives.
	☐ Appoint a consistent person/group to oversee organization PFE.
	☐ Invest in the wellness of staff. Healthcare workers can't pour from an empty cup. See "Workplace Safety" APSS.
	
	Sustain progress and momentum.
	☐ Communicate the organization's PFE policy and opportunities for involvement to everyone in the organization and system.
	☐ Highlight the distinguished value that patients and family members offer in the organization, by routinely expressing appreciation to both:
	  ☐ Those encouraging patient and family involvement on the frontline and
	  ☐ Patients and families themselves.
	☐ Establish a sense of history and recognition of input but ensure all work will not be lost if the champion were to leave. See "Effective Model for Sustainment".

IN SENIOR LEADERSHIP.	**Make PFE easy for those on the frontline.**
	☐ Adopt and promote very clear definitions and expectations of PFE (HPOE, 2013).
	☐ Use multiple applied examples that are relevant to specific workflows to show the numerous ways PFE can be incorporated for everyone.
	☐ Internally market the organization's PFAC as a resource for all units of the organization to use in developing patient safety/QI intervention and obtaining feedback on policies, protocols or interventions.
	☐ Frequently encourage all to remain vigilant for opportunities to engage patients and family members within their own personal workflows.
	☐ Assess policies, processes, position descriptions, new hire training, and routine training programs to ensure PFE and person-centered care are included and aligned with vision and goals. See "6Ps of Clinical Practice".
	☐ Adopt tools (e.g., written, digital, etc) for a patient engagement experience for every step of a patient and family's care journey.
	  ☐ Communicate to those on the frontline the basics of this tool and how they can leverage it in their provision of care.
	☐ Showcase the connection between PFE and safety outcomes to frontline staff.
	
	Make it easy and comfortable for patients and family members to participate.
	☐ Consider if a greater number of patients/family members to healthcare professionals in committees/groups may help patients/family members feel more comfortable voicing their feedback.
	☐ Design patient portals with the user in mind. Make navigation really easy (e.g., group resources by the content the user will need, not by the type of resource). Solicit patient input in the development and beta test modifications with patients before going live.
	☐ Allow everyone in the committee to contribute to setting the agenda for meetings.
	☐ Accommodate language and other communication needs (e.g., poor hearing, cognitive disabilities, etc).
	  ☐ Avoid the use of medical jargon and acronyms when communicating with patients or family members and be prepared to explain concepts in plain language.
	☐ Ensure patients/families are involved long enough to build relationships and to engage them with their historical feedback.
	☐ Consider having patients interview other patients to get their feedback.
	☐ Make sure to counter bias in participants by identifying social determinants that may hinder patient and family participation (e.g., transportation). See Social Determinants APSS.
	☐ Consider opportunities to create an environment that is conducive to patient and family member participation (e.g., instead of making patients/family members travel to the hospital, consider opportunities for their participation to meet them where they are).
	☐ Allow patients to 'comment' on their health record, whether electronic or paper, and provide a pathway for them to get corrections made when they find errors..
	☐ Have a number to call where they can reach a member of staff that is independent from the healthcare team that can listen to concerns and facilitate discussions as needed.
	☐ Have organizational protocols for when family member presence in emergency situations (e.g., codes). Make it clear what the boundaries are in care (e.g., you may be with your wife for the cesarean delivery but you cannot engage with the obstetrician or staff working as this distraction can cause an error).
	
	Incorporate continuous education.
	☐ Hold regular PFE trainings for all staff members.
	  ☐ Don't limit opportunities for PFE education to just formal trainings.
	☐ Infuse messages around PFE in multiple ways, multiple times throughout day to day activities.

	☐ Debrief with those on the frontline about how they've engaged patients and family members in their workflows and ask about their areas for improvement in the future. ☐ Ensure these debriefs are not punitive in nature, but a period for collective learning and support. ☐ Use patient stories to inspire change. ☐ Make it easy for everyone to submit suggestions (e.g., electronically, written, in huddles, etc). Focus on making it easy for patients to give feedback especially after they've exited the organization. ☐ Update patient education material to incorporate feedback from patients and family members. Frequently assess accuracy in educational handouts, such as phone numbers. **Regularly measure for improvement.** ☐ 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. ☐ Show the audit results in places that can be reviewed by the public and staff in an easily understood way. ☐ See Performance Improvement Plan. **Reward efforts.** ☐ Reflect safety culture and PFE performance in compensation of staff responsible to enhance direct accountability. Reward all involved, not just leaders. ☐ Call out specific examples of a 'job well done' as it is happening or shortly thereafter. ☐ Allow patients and families to give timely positive staff feedback using feedback forms and opportunities at healthcare rounds.
IN DIRECT CARE.	See Clinical Workflow.

Clinical Workflow

ALWAYS

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

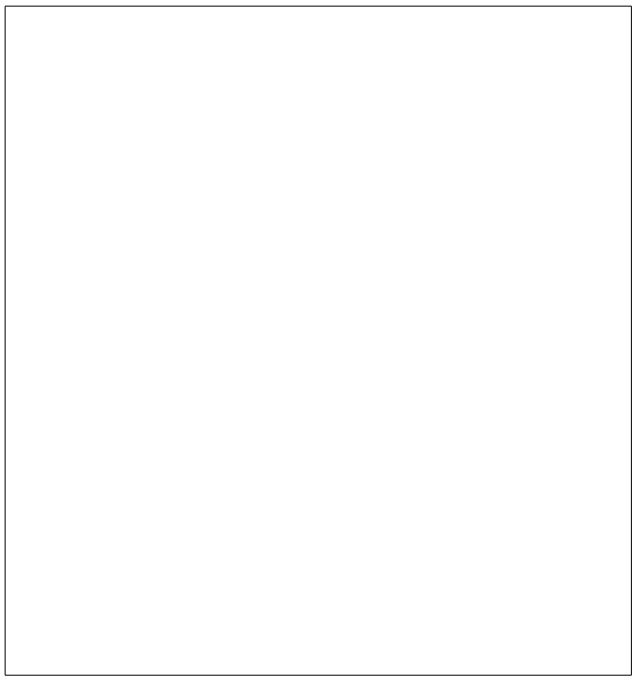
- Allow time:
  - For patients and family members to ask questions in every discussion.
  - To engage in active listening (e.g., asking open ended questions, pausing to listen, etc)
  - To give *them* an opportunity to explain *themselves*.
- Provide:
  - Patients and family members with a tool to track *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.
- 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 and feedback during discussions and convey the value that patient feedback can have.
  - Help patients and family members ask the best questions.

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.

ROUTINE CARE

- Ask about and/or evaluate:
  - Their normal lives/routines
  - Their preferences
  - 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. For example:
  - When/how patients and family members can contribute to their care (e.g., reporting changes in status beyond what's usual, providing oral are to prevent pneumonia, etc)
  - Discussion with patients and family members after an emergency
  - During shift change huddles/bedside reporting
- Explain:
  - How and when to use available technologies/tools and the purpose as it relates to the patient's individual circumstance
  - Information for management of their care



ROUTINE CARE CONT.

- Any risks in their care, how to detect these risks, and what to do if a risk is detected
- 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.

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.

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	• Pharmacists
• Family members	• Social workers
• Patient advocates	• Admitting and registration staff
• Patient and Family Advisory Council (PFAC) members	• Allied health professionals (PT, OT, etc.)
• Physicians	• Ancillary service representatives (radiology, lab, etc.)
• Nurses	• Organizational volunteers
• Patient safety and quality improvement staff	• Spiritual care
• Patient experience staff	• Community partners
• Environmental services	• Community healthcare organizations
• Dietary staff	

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

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.

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.

PROCESSES TO CONSIDER ASSESSING TO UNDERSTAND 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: o 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. o Possible root cause: Example fishbone diagram • **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. o 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. o 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. o 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. o 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. o Possible root cause: Patients don't have access to their data or portal. • **Gap:** It is difficult for patients and family members to participate. o 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 can integrate into larger, system changes**

PERSON AND FAMILY ENGAGEMENT METRICS TO CONSIDER ASSESSING	

• Preadmission Planning Checklist
  o 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 Organizational 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 There are policies, procedures, and actions taken to support patient and family participation in governance or operational decision-making (Patient and Family Advisory Councils, Practice Improvement Teams, Board Representatives, etc.).
• Shared decision-making
  o The organization supports 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 The organization utilizes 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 The organization uses an e-tool (patient portal of 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 The health literacy patient survey is being used patient survey being used by the practice (e.g. CAHPS Health Literacy Item Set).
	• Medication management
	  o The clinical team works 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.

"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)

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 usually with existing personnel.

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.

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."

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. 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. 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, these PFE metrics were deployed by CMS in the ambulatory care sector as part of its Transforming Clinical Practice Initiative (TCPI). 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

The following resources have been identified as useful for organizational PFE performance 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 Communitie
- 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 patients and family members:

- 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 organizational 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.

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.
- How family members can participate in interdisciplinary rounds/bedside rounds if they are unable to be there physically.
- 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

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.

Workgroup

Leadership

Martin Hatlie	MedStar Institute for Quality and Safety
Vonda Vaden Bates	10th Dot
Daria Terrell	St. Bernard's Hospital
Krista Hughes	Hughes Advocacy

Current Workgroup Members

Bill Adams	Patient Advisor
Jill Arnold	Maternal Safety Foundation
Steve Barker	Patient Safety Movement Foundation; Masimo
Karen Curtiss	Campaign ZERO; Families for Patient Safety
Kirsten Hinsdale	Boston Medical Center
Kellie Goodson	Vizient

Danielle Jennings	Healthcare Technology Company
Sherri Loeb	Advocate
Edwin Loftin	Parrish Medical Center
Ariana Longley	Patient Safety Movement Foundation
Olivia Lounsbury	Patient Safety Movement Foundation
Kaelie Marquez	Patient Safety Movement; Chapman University
Patricia Morrill	PM Healthcare Consulting, LLC
Donna Prosser	Patient Safety Movement Foundation
Mari Miceli	Patient Safety Movement Foundation
Nancy Yamauchi	Patient Centricity Consulting
Neesha Nair	Aster DM Healthcare
Salvador Gullo Neto	SAFETY4ME
Vivien Overall	Covenant Health, Alberta Medications Safety Consultant
Doner Gadsden	Family member and caregiver
Wray Ryback	Pomona Valley Hospital Medical Center
Sarah Knowles	University Hospitals Cleveland Medical Center

Past Members

This list represents all contributors to this document since inception of the Actionable Patient Safety Solutions

Victoria Baskett	Baskett Patient Safety Foundation
Michel Bennett	Patient Safety Movement Foundation
Cindy Cassity	Baylor Scott & White Health
Aline Chibana	Brazilian Patient Safety Foundation
Amy Cohen	The University of Vermont Health Network
Victor Grazette	Virginia Hospital Center
Kari Hamlin	Hackensack Medical Center
Diane Hopkins	Patient Safety Movement Foundation
Kori Jew	Patient Safety Movement Foundation
Arthur Kanowitz	Secrurisyn
Audrey Kennedy	Children's Mercy Kansas City
Jacob Lopez	Patient Safety Movement Foundation
Brenda Ludens	Patient Advocate
Charles Micheli	The University of Vermont Health Network
Kenneth Rothfield	Medical City Healthcare
Allison Sandera	Florida Hospital Association
Deeba Siddiqui	Hackensack Medical Center
Caroline Stade	University Children's Hospital Basel
Jonathan Stewart	Beta Healthcare Group
Kristen Terlizzi	Maternal Safety Foundation
Cheryl Thomas	Credence/87th Medical Group
Robert Van Boven	Brain & Body Health Institute

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