Actionable Patient Safety Solutions (APSS) #16:

Person and family engagement

How to use this guide

This guide gives actions and resources for creating and sustaining practices for patient and family engagement. In it, you'll find:

Patient Safety MOVEMENT

Executive summary checklist

"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, n.d.)

An effective program to implement and sustain PFE should include the following actionable steps (HRET, n.d.). Use this checklist to help you prioritize your actions and measure your organization's progress in each area.

Create an action plan

- ☐ Include PFE as a priority in organization-wide patient safety strategies
  - ☐ Make PFE action items part of these strategic requirements to determine safe care and enhanced outcomes
- ☐ Develop and implement consistent internal communications about the importance of effective PFE—beginning with management—to ensure all staff see the connection between PFE and outcomes and safety
- ☐ Develop and integrate PFE education in new-hire orientation and regularly with staff to ensure that expectations are clear, engaging, and consistent
  - ☐ Training should be held on an ongoing regular scheduled basis

Engage staff and use data to find areas for improvement

- ☐ Ensure that all members of the care team understand the importance of listening to the patient and their family members' questions and concerns
- ☐ Assess strengths and gaps in your organization's PFE efforts by using this checklist:
  - ☐ Request feedback from your senior leadership team, staff, patients, and families about your organization's PFE efforts
  - ☐ Assess policies, processes, position descriptions, and training programs to determine whether PFE is included
  - ☐ Talk about findings and conclusions with leadership, staff, and patients to create awareness and lay the groundwork for improvement efforts
- ☐ Deploy a system to implement PFE and monitor progress on improving PFE using the following:
  - ☐ Develop an infrastructure that brings the patient and family's voice systemically into your patient safety improvement work, such as:
    - ☐ Appoint patients who identify as patients or patient advocates to your governing body
    - ☐ Establish patient and family advisory bodies that contribute to organizational safety initiatives
    - ☐ Include patient advocate input into improvement committees or root cause analysis teams
    - ☐ Establish a functional area in your organization whose role and accountability is to engage patients and families

- ☐ Select measures that will allow you to see whether processes and patient safety outcomes are changing
- ☐ Ensure systems are in place so that data can be collected and shared
- ☐ Compile results in a format that is easy-to-understand and monitor
- ☐ Share results with staff, senior leadership, board, community, and the public

☐ Use patient stories – in written and video form – to help teach and inspire change in your staff

What is person and family engagement?

Person and family engagement (PFE) is an underutilized resource for achieving the goal of zero patient harm. Definitions of PFE vary. Angela Coulter put it well when describing the intention of PFE to "promote and support active patient and public involvement in health and healthcare and to strengthen their influence on healthcare decisions, at both the individual and collective levels." (Coulter, 2011).

What we know about person and family engagement

The problems with patient safety and why they matter.

Despite widespread recognition of patient safety as a public health issue since 1999, preventable patient harm still happens. Estimates suggest that the number of people harmed is increasing, although arguably the larger and more alarming estimates now are a product of more effective measurement.

Studies show:

- Deaths due to medical errors in hospitals across the U.S. were estimated at 180,000 each year by the landmark Harvard Medical Practice Study in 1984 (Leape, 1995)
- A 2013 study by John James, a NASA toxicologist, estimates that the number of US deaths due to medical error are between 210,000 and 440,000 annually, making it the 3rd largest cause of preventable death (James, 2013).
- U.S. hospital deaths attributed to medical error are 250,000, reinforcing the finding of 3rd largest cause of preventable death (Makary, 2016).

Analyses of error in other U.S. healthcare settings underscore that unsafe care is prevalent and systemic. In a series of reports from 2008 to 2018, The Office of the Inspector General (OIG) of the US Department of Health and Human Services found that adverse events and temporary harm events are common, endanger patient health, and are costly to the Medicare program. In a 2010 study, OIG found that 27 percent of hospitalized Medicare beneficiaries experienced such events, costing Medicare approximately $4.4 billion a year. OIG then expanded on this work by examining post- acute-care settings, finding that 33 percent of Medicare beneficiaries in skilled nursing facilities, 29 percent of Medicare beneficiaries in rehabilitation hospitals and 46% of beneficiaries in long term care hospitals experienced harm.

Research from other countries confirms that the problem is international. Using data from the 2016 Global Burden of Disease study in 137 low and middle income countries, researchers estimated that 5 million deaths were attributable to poor quality care, significantly more than the 3.6 deaths caused by lack of access to care. (Kruk et al., 2018)

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

Whatever the estimates, the challenge before us is huge and touches millions of people worldwide. Collaborative efforts among healthcare provider organizations, thought leaders and policymakers, payors, innovators and researchers, educators, nonprofit/non-governmental advocacy groups, product makers, and people who use healthcare can make a difference.

Through focused attention and aligned efforts in the U.S. driven by the Centers for Medicare

and Medicaid Services (CMS), measurable patient harm was reduced by 21% between 2010 and 2015, which led to:

- 125,000 fewer deaths
- 3 million fewer injuries
- $28 billion in saved costs

At the local level, collaboration between the public health sector, hospitals, and outcome improvement experts reduced hospital readmissions by 7,000 in Minnesota between 2011 and 2013, enabling patients in Minnesota to spend 28,120 nights sleeping in their own beds instead of the hospital, and helped reduce healthcare costs by more than $55 million (AHRQ, 2016)

Person and family engagement

PFE is an underutilized 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. 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."*

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. Moreover, healthcare users or those who help loved ones are typically highly motivated to partner with their healthcare providers to improve safety. Their experiences bring an urgency to the patient safety movement that propels action by generating empathy—they engage our hearts as well as our minds and hands. In 2006, the World Health Organization captured this urgent offer to partner in the London Declaration of its Patients for Patient Safety group, a core component of its Global Patient Safety Programme (WHO, 2006).

Growing excitement over the potential for PFE strategies and tactics to measurably reduce harm and improve outcomes has generated many white papers, frameworks, and toolkits designed to engage healthcare users as partners in care—notably, as subject matter experts in safety and quality improvement initiatives, organizational governance, and the development of policies and procedures. Hospitals, healthcare systems, and ambulatory clinics that have engaged their users of care in improvement work and at the governance level report significant change in growing and sustaining a culture of safety.

A culture of safety is simply defined as the result of 3 things:

- 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

The leading framework for PFE was published by Carman and colleagues in 2013 (go to **Figure 1**), and outlines opportunities for engagement at 3 levels:

- Direct care
- Organizational design and governance
  - Applies to healthcare providers
- Policymaking
  - Applies to government agencies, research bodies, and non-profit organization

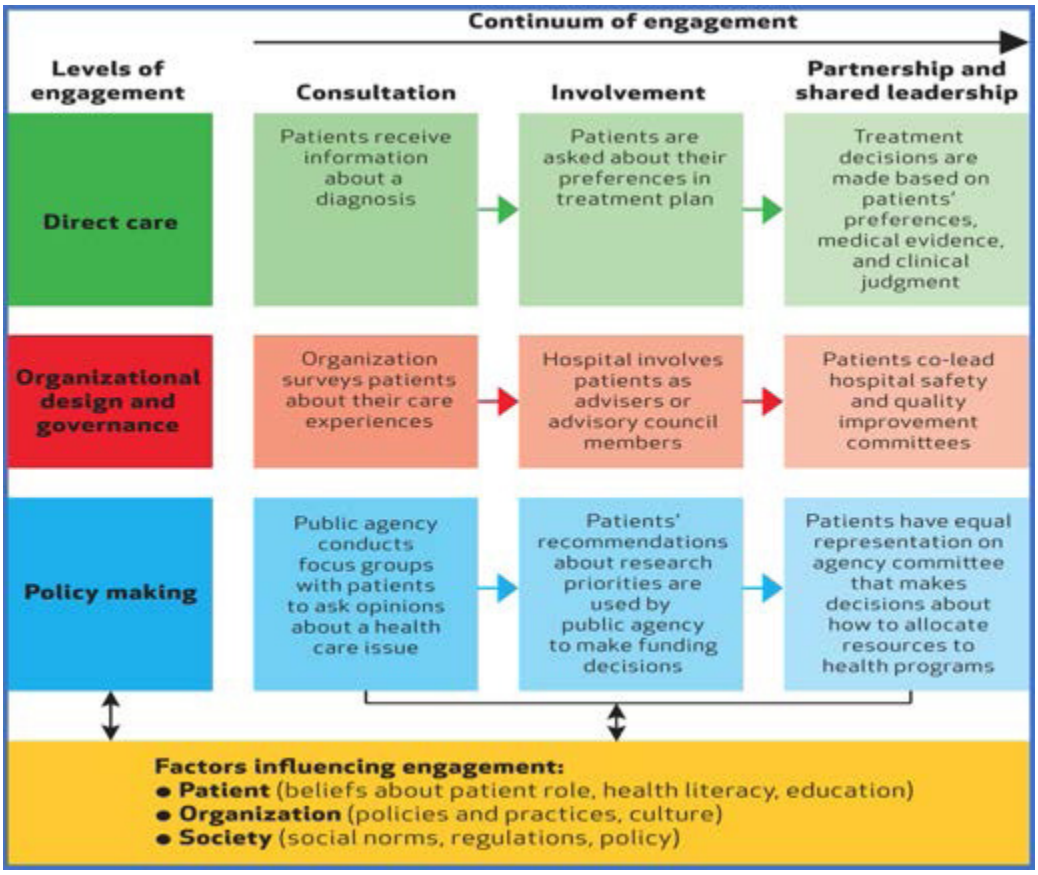

Figure 1: Framework for Patient and Family Engagement (Carman et al., 2013)

Other common PFE frameworks include:

- Health Information and Management Systems Society, Patient Engagement Framework
- American Hospital Association, Engaging Health Care Users: A Framework for Healthy Individuals and Communities
- FasterCures Patient Perspective Value Framework
- The Guiding Framework on Patient and Family Engaged Care from the National Academy of Medicine (Appendix A)

Guided by the Carman framework, 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.

Education about PFE

System improvement and patient advocates also emphasize the importance of education about PFE in multiple settings, including professional education in medicine, nursing, pharmacy, and other healthcare fields. General education about using healthcare safely should also be prioritized, in primary or secondary school curricula as well as libraries, online forums, or other venues for adult education.

All educational efforts should address the needs of vulnerable 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

Leadership plan

It's important that your healthcare organization commit to, and invest in, a culture of safety and transparency. This starts with, and is dependent upon, governance and executive leadership that is actively engaged and committed to achieving zero harm. A robust PFE program can help organizational leaders both build and sustain the culture of safety.

To successfully engage patients and families in safety at the point of care and in safety improvement work, leaders must take these key actions. The leadership plan for PFE incorporates and builds on the Culture of Safety Leadership Plan created in APSS #1.

Show leadership's commitment to PFE

- Hospital governance and senior administrative leadership must commit to investigating and become familiar with this major performance gap in their own organizations. Senior leaders cannot merely be "on board" with patient safety—they must own it.
- Your hospital boards must focus on safety and quality, not just on finances and strategy. Research demonstrates that patient outcomes suffer when boards do not make safety a top priority (Jha and Epstein, 2010).
- Hospital governance, senior administrative leadership, and clinical/safety leadership must close their own performance gap by implementing a proactive, comprehensive safety culture action plan
- Healthcare leadership (clinical/safety) must reinforce their commitment by taking an active role, such as to:

    - Champion process improvement
    - Give their time, attention, and focus to remove barriers
    - Remove barriers
    - Provide necessary resources
- Healthcare leadership must support your organization's action plan, such as to:
    - Shape a vision of the future
        - Provide clearly defined goals
        - Support staff as they work through improvement initiatives
        - Measure results
        - Communicate progress towards your goals
- There are many types of leaders within a healthcare organization, and for PFE process improvements to truly be successful, leadership commitment and action are required at all levels. The board, senior leadership, physicians, pharmacy and nurse directors, managers, unit leaders, and patient advocates all have important roles and need to be engaged in specific behaviors that support staff to provide safer care.
- Safety culture and PFE performance must be valued and reflected in compensation plans so that leaders have direct personal accountability for results

Create the infrastructure needed to make changes

- Ensure your organization has a clear definition of PFE
- Discuss PFE with your senior leadership team so that they understand that it matters to you and the organization
- Request participation from your board, your staff, and representative patients and families about what your organization will look like if it's successfully engaging patients and families
- Make improving PFE an organizational goal
- Establish infrastructure in your organization that creates pathways for PFE participation in safety improvement work
    - For example, Imperial College London has outlined their clear method for Patient and Public Involvement programs within the NHS in their five-year patient and public involvement found here: **http://patient.sm/Tzp6ds**
- Establish a shared vision and goals between safety and patient experience leaders so that PFE pursuits are aligned with outcomes and actions are transparent
- Allocate time in meetings with senior leadership, staff, and the board to hear and tell stories about engagement success and shortcomings
- Utilize patient stories – in written and video format – to help teach and inspire change in your staff:
    - One example of an inspiring story is that of Michael Seres.
        - It was filmed by the Patient Safety Movement Foundation and can be viewed for free here: **http://patient.sm/VULt2F**
        - Video from Safe Care Campaign's Patient Perspective Series: **http://patient.sm/LEZjr9**

Action plan

Embed PFE in governance and operations

Healthcare organizations should use the Carman framework or an alternative framework to implement a PFE program that engages patients or their family members at multiple levels, including point of care, policy and governance, CMS currently is driving PFE through its Hospital Improvement Innovation Network (HIIN) program, using 5 metrics to track progress:

1. Preadmission Planning Checklist [point of care]: Hospital has a physical planning checklist that is discussed with every patient who has a scheduled admission
2. 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
3. Designated PFE Leader [policy & protocol]: Hospital has a designated individual (or individuals) with leadership responsibility and accountability for PFE
4. 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
5. 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

Hospitals and multi-site systems should consider using the same program and metrics. In non-acute care clinics or other ambulatory care delivery sites, a 6 part PFE practice plan should be considered.

1. **Support for patient and family voices** [point of care]: 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.)?
2. **Shared decision-making** [point of care]: 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.)?
3. **Patient activation** [point of care]: Does the practice utilize a tool to assess and measure patient activation?
4. **Active e-Tool** [policy & procedure]: Does the practice use 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?
5. **Health literacy survey** [policy & procedure]: Is a health literacy patient survey being used by the practice (e.g. CAHPS Health Literacy Item Set]?
6. **Medication management** [governance]: Does the clinical team work with the patient and family to support their patient/caregiver management of medications?

At the organizational design and governance level, healthcare organizations should consider engaging healthcare users in improvement efforts and measure progress in the following areas (you may choose one or more):

- Preventing Adverse Drug Events
- Preventing Catheter-Associated Urinary Tract Infections (CAUTI)

- Preventing Central Line Associated Bloodstream Infections (CLABSI)
- Preventing Falls and Falls out of Bed
- Preventing Obstetrical Adverse Events
- Preventing Pressure Ulcers
- Preventing Surgical Site Infections
- Preventing Venous Thromboembolism (VTE)
- Reducing Hospital Readmissions
- Preventing Clostridium difficile (c-diff)
- Ensuring Airway Safety
- Preventing Sepsis and Septic Shock
- Preventing Hospital Acquired Acute Renal Failure
- Preventing Ventilator-Associated Pneumonia (VAP)
- Teaching Practical Skills for Managing Critical Test Results
- Preventing Iatrogenic Delirium
- Preventing Procedural Harm
- Preventing Undue Exposure to Radiation
- Monitoring for Opioid-induced Respiratory Depression
- Advancing Hospital Culture of Safety
- Preventing Methicillin-resistant Staphylococcus aureus (MRSA)
- Teaching Effective Pain Management Practices and Behaviors and Addressing the Opioid Crisis
- Define and Advance Child-Friendly Care Practices
- Ensuring and/or Advancing Antibiotic Stewardship
- Preventing Diagnostic Error
- Reducing Health Care Disparities
- Preventing Malnutrition
- Preventing Multi-Drug Resistant Organisms

Technology plan

These suggested practices and technologies have shown proven benefit or, in some cases, are the only known technologies for certain tasks. If you know of other options not listed here, please complete the form for the PSMF Technology Vetting Workgroup to consider: **https://patient.sm/ydmHKI**

Information and communication technologies

The use of information and communication technology is a particularly fertile area of innovation that is being used to engage patients. Examples include:

- Electronic patient portals
- Smartphone apps
  - PatientAider mobile app **http://patient.sm/f6MnWH**
  - Patient Safety Advisor (English) and Dr. Rafael (Portuguese) mobile app **http://patient.sm/BIAlR5**
- Email
- Texting pathways

OpenNotes and personal health records

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

Researchers in the OpenNotes community are collaborating closely with health systems, healthcare professionals, and millions of patients around the world to understand the effects of fully transparent medical care on communication, engagement, safety, costs, and the overall quality of care

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 placethat 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

Many companies are producing technological solutions designed to advance PFE. Healthcare organizations can use the HIMSS PFE framework displayed below to track innovation in this space (Figure 2). 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.

- Healthcare organization should also consider using their Serious Safety Event reporting system, or any alternative or complementary reporting systems used to track patient safety outcomes
- 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

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Measuring outcomes

Hospitals and health systems should consider using the PFE metrics outlined above in the Action Plan section.

Referenced resources

1. PFE resources are easy to find online but it's important to incorporate them along the continuum of care
    - o You can encourage PFE by providing updated resources and conversing with patients and family members about how they may utilize the information
    - o The following resources have been identified as useful by patients and/or their family members to be used by the hospital:
        - An Empowered Patient
          http://patient.sm/41kUFL

          Engaged Patients is a national campaign under the guidance of the Empowered Patient Coalition nonprofit with the vision that all patients and their loved ones have free access to the tools and the resources they need to be fully informed and participating members of their health care teams
        - CampaignZERO: Families for Patient Safety
          http://patient.sm/dw789V
          CampaignZERO is a national non-profit organization that offers resources to patients, families and providers to advance PFE for patient safety through 4 main PFE initiatives:

          a. Free checklists for patients' families to help them support their loved ones' medical care in partnership with all care providers. CampaignZERO's checklists, written in simple terms (AMA recommended 6th grade literacy level/below), provide simple "how-to's" to: Prevent the most common hospital acquired conditions: infections, falls, medication errors, blood clots and more.

          b. Participate in shared decision-making for recommended surgery and other treatment plans

c. Participate in discharge planning and post-discharge support to prevent readmissions.

- Community-based patient safety education through its national speaker network of professional patient advocates, see PatientSafetySpeakers.org.
- Provider PFE training workshops based on CampaignZERO's Safe & Sound Tools for Family Engagement in Patient Centered Care, endorsed by QSEN and offered free of charge through the Medline Innovation Institute

- In-Patient PFE Education Tools (electronic and print) to inform and activate patients' family members to help prevent HACs and readmissions,

  http://patient.sm/dw789V
- Minnesota Alliance for Patient Safety, You: Your Own Best Medicine:

  http://patient.sm/tt4JIW
- Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families

  http://patient.sm/2G3fCz

  Content last reviewed April 2018. Agency for Healthcare Research and Quality, Rockville, MD
- Guide to Patient and Family Engagement in Hospital Quality and Safety.

  http://patient.sm/UkABMj Content last reviewed February 2017. Agency for Healthcare Research and Quality, Rockville, MD
- AHRQ Question Builder tool for patients

  http://patient.sm/ZjZC3r
- Motivational interviewing tools.

  http://patient.sm/esNJp1
- Access requires registration, but it is grant supported so there is no cost to users
- OpenNotes movement

  http://patient.sm/0luwWP
- PfP Strategic Vision Roadmap for Patient and Family Engagement

  http://patient.sm/Bszlah
- Harnessing Evidence and Experience to Change Culture: A Guiding Framework for Patient and Family Engaged Care (National Academy of Medicine)

  http://patient.sm/rfiTNv
- Four Habits

  http://patient.sm/U8elwM
- American Hospital Association's Health Research and Educational Trust (AHA HRET) Patient and Family Engagement Resource Compendium

  http://patient.sm/byTD4S

2. Education: everyone from youth to the most experienced clinician has an opportunity to improve healthcare safety through increased PFE:
   - You can contribute by educating others within your area of influence:
     - Educating future leaders in patient safety
       http://patient.sm/0FypVX

- The WHO Multi-Professional Patient Safety Curriculum Guide
  http://patient.sm/D8J6qD
- Academy for Emerging Leaders in Patient Safety
  http://patient.sm/csqw8m
- Canadian Patient Safety Institute, Patient Safety Education Program Core Curriculum
  http://patient.sm/uSqVrt

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. Some of the APSSs recommend technologies that are offered by companies involved in the Patient Safety Movement Foundation. The workgroups have concluded, based on available evidence, that these technologies work to address APSS patient safety issues. Workgroup members are required to disclose any potential conflicts of interest.

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