Institute for Healthcare Improvement

Middle East Forum

Engaging and Empowering Patients and Families in Safety – Lessons from the Lucian Leape Institute

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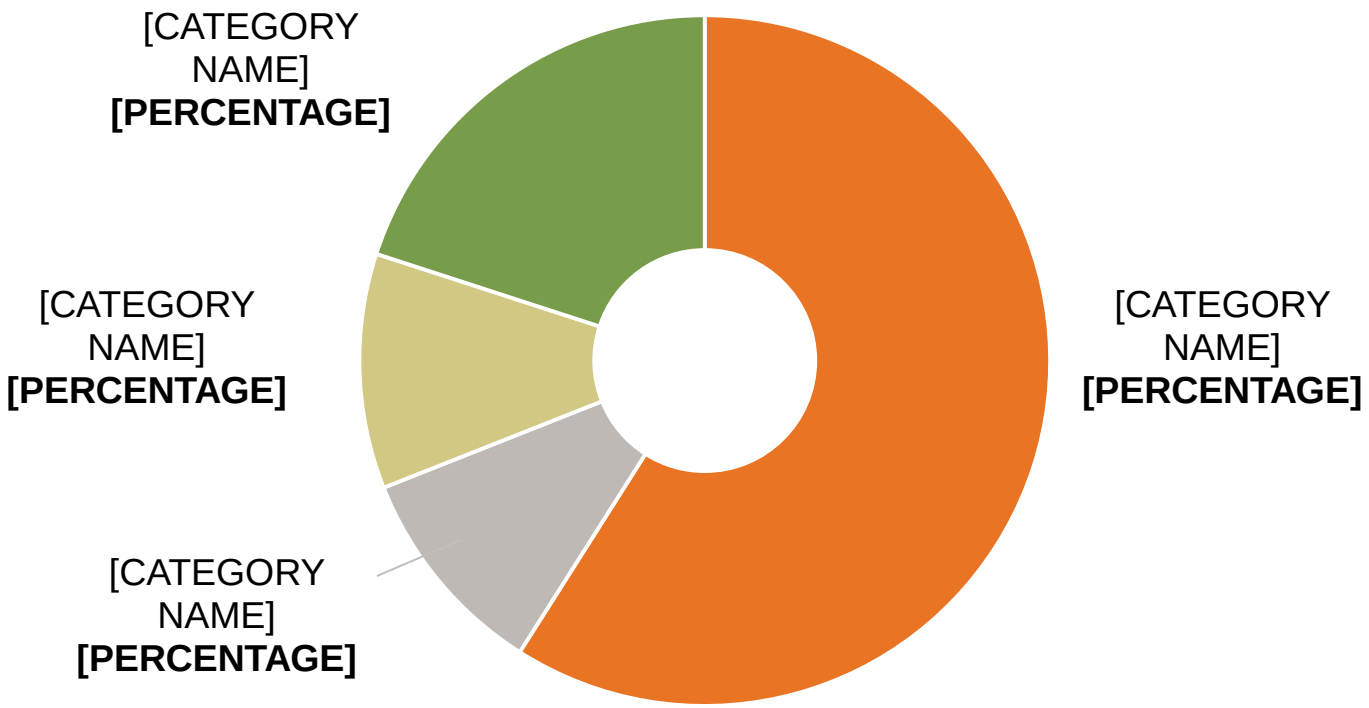
Learning Objectives

- Incorporate tactile ways to engage patients at all levels of healthcare
- Discuss the connection between patient engagement and patient safety
- Demonstrate proven techniques for implementing patient and family engagement tools into practice
- Develop a process to utilize and apply input from patients to improve the safety of care delivered

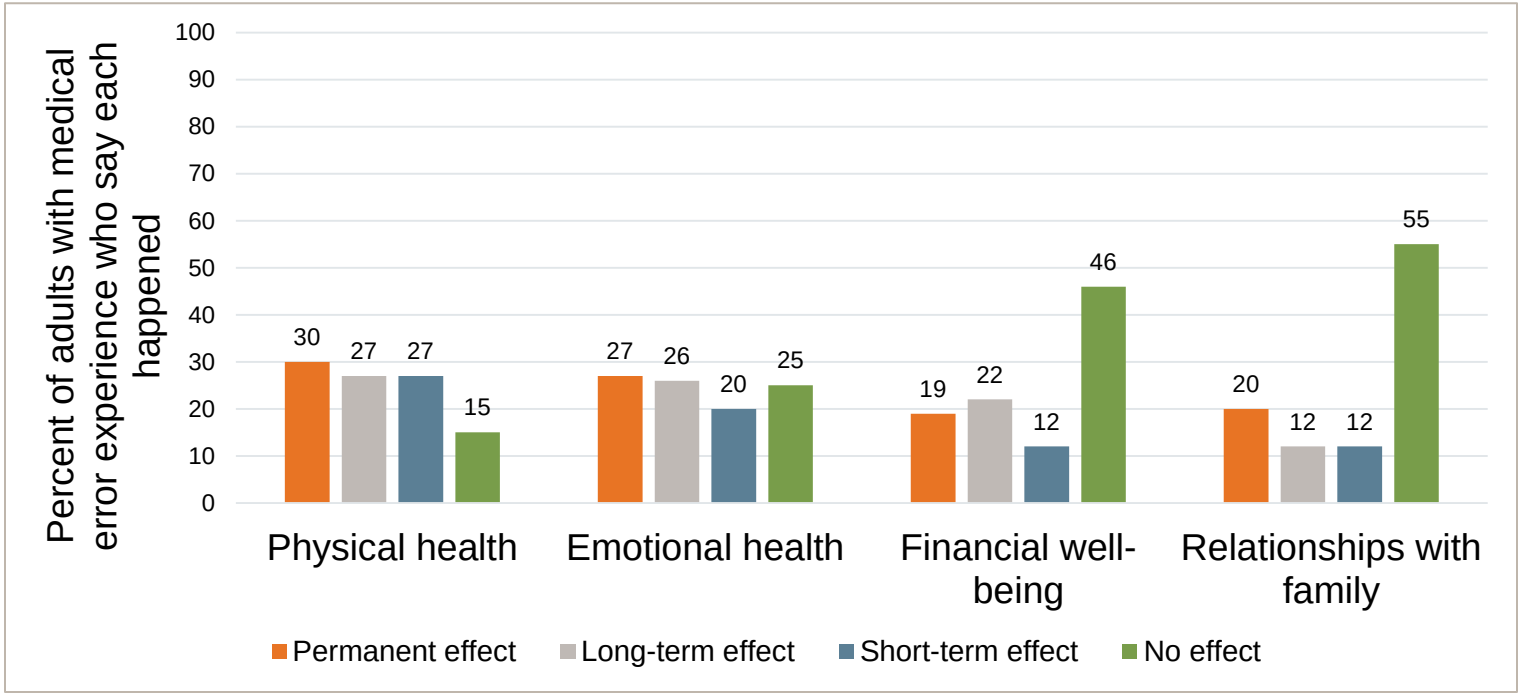
Patient Safety Is a Public Health Issue

- Despite progress, preventable harm remains unacceptably frequent
  - Significant mortality and morbidity
  - Quality of life implications
  - Adversely affects patients in every care setting

Prevalence of Patient-Perceived Errors

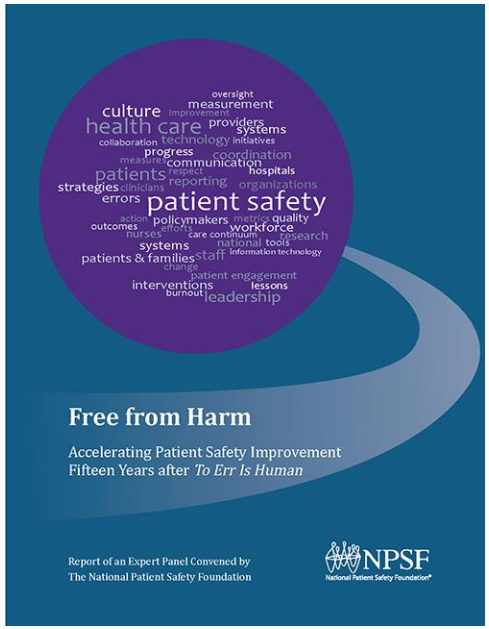


Patient-Perceived Harm, Continued



Question: Did the error have a short-term effect that lasted less than one month, a long-term effect that lasted more than one month, a permanent effect, or did it have no effect on [your/the person close to you's]…?

The Free From Harm Report



Download the full PDF report for free at:

www.npsf.org/free-from-harm

Thank you to AIG for their generous support of this project.

Current State of Patient Safety

- Evidence mixed but panel overall felt that health care is safer
- More work to be done
- While limited, progress notable
  - Young field
  - Still developing scientific foundations
  - Received limited investment
- Improving patient safety is a complex problem
  - Requires work by diverse disciplines to solve

Total Systems Approach Needed

- Advancing patient safety requires an overarching shift from reactive, piecemeal interventions to a total systems approach
- Need to embrace wider approach beyond specific, circumscribed initiatives to generate change
- Fundamental finding: Initiatives can advance only with a key focus on teamwork, culture and patient engagement

Recommendations

Eight Recommendations for Achieving Total Systems Safety

1. ENSURE THAT LEADERS ESTABLISH AND SUSTAIN A SAFETY CULTURE

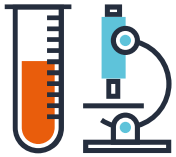
Improving safety requires an organizational culture that enables and prioritizes safety. The importance of culture change needs to be brought to the forefront, rather than taking a backseat to other safety activities.

2. CREATE CENTRALIZED AND COORDINATED OVERSIGHT OF PATIENT SAFETY

Optimization of patient safety efforts requires the involvement, coordination, and oversight of national governing bodies and other safety organizations.

3. CREATE A COMMON SET OF SAFETY METRICS THAT REFLECT MEANINGFUL OUTCOMES

Measurement is foundational to advancing improvement. To advance safety, we need to establish standard metrics across the care continuum and create ways to identify and measure risks and hazards proactively.



4. INCREASE FUNDING FOR RESEARCH IN PATIENT SAFETY AND IMPLEMENTATION SCIENCE

To make substantial advances in patient safety, both safety science and implementation science should be advanced, to more completely understand safety hazards and the best ways to prevent them.

Eight Recommendations for Achieving Total Systems Safety

5. ADDRESS SAFETY ACROSS THE ENTIRE CARE CONTINUUM

Patients deserve safe care in and across every setting. Health care organizations need better tools, processes, and structures to deliver care safely and to evaluate the safety of care in various settings.

6. SUPPORT THE HEALTH CARE WORKFORCE

Workforce safety, morale, and wellness are absolutely necessary to providing safe care. Nurses, physicians, medical assistants, pharmacists, technicians, and others need support to fulfill their highest potential as healers.

7. PARTNER WITH PATIENTS AND FAMILIES FOR THE SAFEST CARE

Patients and families need to be actively engaged at all levels of health care. At its core, patient engagement is about the free flow of information to and from the patient.

8. ENSURE THAT TECHNOLOGY IS SAFE AND OPTIMIZED TO IMPROVE PATIENT SAFETY

Optimizing the safety benefits and minimizing the unintended consequences of health IT is critical.

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7. Partner with patients and families for the safest care

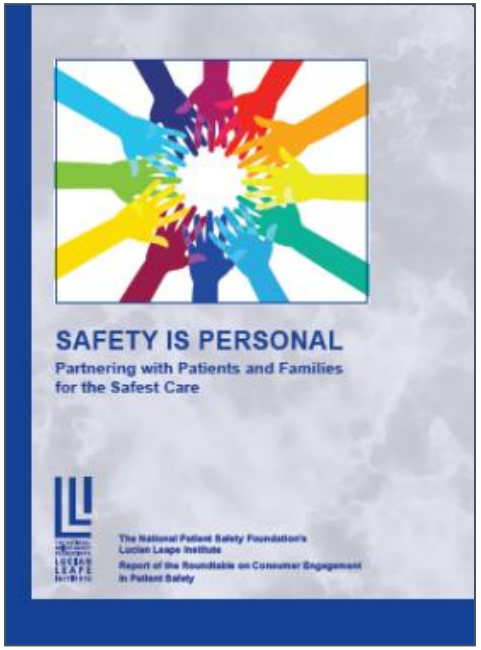
- Patients and families need to be actively engaged at all levels of health care
  - Patient engagement: Free flow of information to and from the patient
  - Foundation: Environment where patients and families are always treated with respect and personal dignity honored
- Patient involvement needs to be authentic

Importance of patient and family engagement

- Studies link patient engagement with
  - Patient satisfaction
  - Safer care
  - Improved work experience for caregivers
  - Better health outcomes

Safety Is Personal: Partnering with Patients and Families for the Safest Care

THE NATIONAL PATIENT SAFETY FOUNDATION'S LUCIAN LEAPE INSTITUTE



From NPSF's Lucian Leape Institute Roundtable on Consumer Engagement

Available for Download at http://www.npsf.org/lli-safety-is-personal/

Observations from the LLI Roundtable

- Move the system from asking patients "What's the matter?" to "What matters to you?"
- It is very hard to speak up, even for the most empowered
- Burden cannot be off-loaded to patients
- Engagement is a shared responsibility
- Patients who are alone are at highest risk
- Don't scare the patient – they need to feel they are safe and do not have to be constantly vigilant

Barriers to Patient & Family Engagement

- Historically paternalistic culture in health care
- Lack of understanding/ knowledge/ commitment on the part of health care leaders to embrace patient and family engagement and partnerships as an essential part of their mission
- Logistical and administrative barriers
- Lack of effective engagement tools and training
- Lack of trust among patients and families
- Problems with health literacy, limited social support, or fear of speaking up on the part of patients

Activity: Think, Pair, Share

Instructions:

1. ***Think*** about these questions (2 minutes)
2. ***Pair*** with your neighbor and discuss. (5 minutes)
3. ***Share*** with the larger group (5 minutes)

- **Where are you on your journey?**
- **What are some barriers to patient and family engagement that you've encountered?**

Whitepaper Recommendations

Based on evidence that patient engagement improves patient safety

For Leaders of Health Care Systems

- Establish patient and family engagement as a core value for the organization
- Involve patients and families as equal partners in all organizational improvement and redesign activities
- Educate and train all personnel to be effective partners with patients and families
- Partner with patient advocacy groups and other community resources

Whitepaper Recommendations

For Health Care Clinicians and Staff

- Provide information and tools that support patients and families to engage effectively in their own care
- Engage patients as equal partners in safety improvement and care design activities
- Provide clear information, apologies, and support to patients and families when things go wrong

For Health Care Policy Makers

- Involve patients in all policy-making committees and programs
- Develop, implement, and report safety metrics that foster transparency, accountability, and improvement
- Require that patients be involved in setting and implementing the research agenda

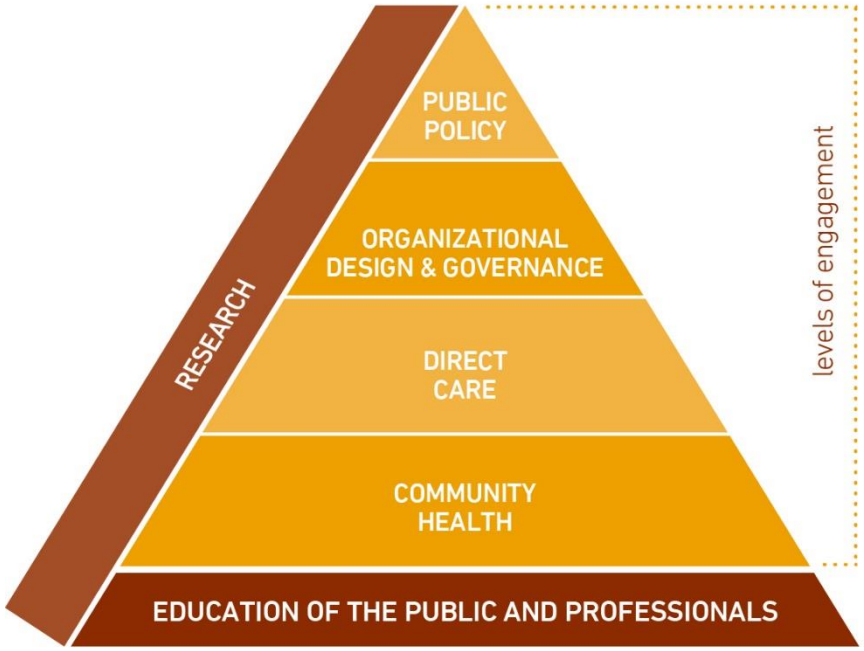
Whitepaper Recommendations

For Patients, Families, and the Public

While placing the responsibility for patient safety on health care providers and organizations, the report also urges patients, families, and the public to view themselves as full and active members of the health care system and recommends the following:

- Ask questions about the risks and benefits of recommendations until you understand the answers
- Don’t go alone to the hospital or to doctor visits
- Document and share your medications, including names, why, how, and dose with all providers
- Be very sure you understand the plan of action for your care
- Repeat back to clinicians in your own words what you think they have told you
- Arrange to get any recommended lab tests done before a visit
- Determine who is in charge of your care

Four Levels of Engagement



The framework/declaration was originally developed for the World Innovation Summit for Health (WISH) 2013, an initiative of Qatar Foundation. See WISH Patient Engagement Report (available at www.wish-qatar.org/reports/2013-reports).

Tools for Health Systems

- Patient family advisory councils
- Shared decision making tools
- Clear health communication tools
- Patient- and family-centered bedside rounds
- Patient activated rapid response systems
- Patient reporting systems
- Patients on root cause analyses and action
- Simulation-based training

Shared decision making

The **SHARE** Approach

Essential Steps of Shared Decision making

Step 1: **S**eek your patient's participation

Step 2: **H**elp your patient explore and compare treatment options

Step 3: **A**ssess your patient's values and preferences

Step 4: **R**each a decision with your patient

Step 5: **E**valuate your patient's decision

The SHARE Approach—Putting Shared Decisionmaking Into Practice: A User's Guide for Clinical Teams

https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/education/curriculum-tools/shareddecisionmaking/tools/tool-8/share-tool8.pdf

Clear Health Communication Tools

- Health Literacy
- Cultural Competency
- Language Proficiency

To learn more, visit ihi.org/AskMe3

Patient- and Family-Centered Rounds

Harmful medical errors decreased by 38% and family experience and communication processes improved after implementation of a structured communication intervention for **family centered rounds coproduced by families, nurses, and physicians** *Khan et al. BMJ 2018*

- Structured, high reliability communication on bedside rounds emphasizing health literacy, family engagement, and bidirectional communication
- Structured, written real-time summaries of rounds
- Formal training program for healthcare providers
- Strategies to support teamwork, implementation, and process improvement.

Patient Activated Rapid Response Systems

- Example: Condition H
- Opportunity for patients & families to voice concerns or note immediate threats to patients health
- Structured process for the care team to respond
- Organizational learning
- Enhanced communication

Patient & Family Advisory Councils

Characteristics of Excellent Patient/ Family Partners

- The ability to share personal experiences in ways that others will listen and learn from them
- The ability to see the “big picture”
- Interested in more than one issue
- Interested in improving health care or research
- The ability to ask tough questions constructively
- The ability to connect with people
- A sense of humor
- Representative of the relevant patients/ families/ conditions

Progress in Patient & Family Engagement

- Increasing use of decision aids, patient portals, OpenNotes, and care engagement plans
- Spread of Patient and Family Advisory Councils (PFACs)
- Internationally observed ‘What Matters to You? Day’

Simulation-Based Training

- Encourage engagement of patients and families in development of simulation scenarios for patient-and family-centered learning
- Develop and improve communication skills
- Practice!

Bedside Rounding

https://www.cincinnatichildrens.org/professional/referrals/patient-family-rounds/videos

At your table, consider the following

1. What did you notice about the different roles each individual serves in bedside rounds?
2. What opportunities for learning does the clinical team have from including the patient and family in the bedside rounds?
3. What opportunities for learning do the patient and family have from meeting the entire team?
4. What would you need to put into place to do this when you go home?

What can you do tomorrow?

- Establish PFAC's for all major clinical services
- Require patient and family input on all educational materials, brochures, posters
- Synthesize all of your input from patients to identify trends and set priorities: survey data, patient advocacy reports, letters, etc.
- Incorporate evidence-based decision aids into your patient portal and clinical care
- Implement Open Notes
- Incorporate patient-and family-centered rounds
- Implement simulation-based training for staff

Conclusion

- Much has improved but too much remains the same
  - Failure to make substantial, measurable, system-wide strides in improving patient safety
- Safety must be a top priority as a public health issue
- ***Patient engagement is key to acceleration of safety efforts***