



SAFETY IS PERSONAL

**Partnering with Patients and Families
for the Safest Care**



THE NATIONAL
PATIENT SAFETY
FOUNDATION'S
**LUCIAN
LEAPE**
INSTITUTE

**The National Patient Safety Foundation's
Lucian Leape Institute**

**Report of the Roundtable on Consumer Engagement
in Patient Safety**

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

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**Providing a strategic vision
for improving patient safety**

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INSTITUTE

The National Patient Safety Foundation's Lucian Leape Institute

The National Patient Safety Foundation's Lucian Leape Institute, established in 2007, is charged with defining strategic paths and calls to action for the field of patient safety, offering vision and context for the many efforts under way within health care, and providing the leverage necessary for system-level change. Its members comprise national thought leaders with a common interest in patient safety whose expertise and influence are brought to bear as the Institute calls for the innovation necessary to expedite the work and create significant, sustainable improvements in culture, process, and outcomes critical to safer health care.



National Patient Safety Foundation

The National Patient Safety Foundation's vision is to create a world where patients and those who care for them are free from harm. A central voice for patient safety since 1997, NPSF partners with patients and families, the health care community, and key stakeholders to advance patient safety and health care workforce safety and disseminate strategies to prevent harm. NPSF is an independent, not-for-profit 501(c)(3) organization. Information about the work of the National Patient Safety Foundation may be found at www.npsf.org.

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This report is dedicated to Betsy Lehman and her family.



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PREFACE

When I was 40 years old, I was diagnosed with an aggressive breast cancer that required immediate surgery and chemotherapy. When I heard the biopsy was positive, my first thought was, “I’ve been in training for this all my life.” Despite the frightening news, I felt prepared to manage the future because I had 20 years of experience with a chronic condition: rheumatoid arthritis. Dealing with the RA, it had taken me five years to find a physician who could help me achieve my goals, to understand how I wanted to be involved in decisions about my care, and to learn how to express my needs and concerns so that I was heard more often than not. I had a head start on making sure I would receive good care because of these hard-won experiences. Most people don’t have this preparation, however, and fortunately, many don’t need it.

I received excellent care for my breast cancer from a team of clinicians, including a surgeon, an oncologist, a team of chemotherapy infusion nurses, and a pharmacist. Although there were some “bumps in the road” with insensitive communications, I had no major adverse events. I had deep trust in my care team. I never worried that I had to be vigilant, which in fact would have been impossible as I was far too sick from the chemotherapy to do anything but concentrate on making it through each infusion.

Four years later, something happened that terrified me and reminded me that it is impossible to dodge bullets you can’t see. Betsy Lehman died from an accidental overdose of chemotherapy at the Dana-Farber Cancer Institute. A Boston Globe reporter who covered health issues, Betsy had knowledge of medicine that was about as sophisticated as a non-physician could have. I was devastated by this news and shocked at how naive I had been about the potential harm I had faced in my own care. I had had blind faith in the technical competence of my clinicians, and more importantly, about my ability to ensure my safety; however, vigilance over chemotherapy doses is beyond the realm of any cancer patient’s competence or purview. Equally devastating was the news that Betsy’s repeated attempts to alert her care

team to her discomfort and concerns were ignored, adding to the disrespect and loss of dignity she suffered, and ultimately contributing to the loss of her life.

This report is dedicated to Betsy Lehman and her family. No one should ever endure what they have. Despite years of work to create a patient- and family-centered health care system, I was motivated by her story to do everything possible to make sure that all people receive safe care and have their needs clearly heard and respected. In our clinical relationships, in the redesign of care delivery, and in our research and policy discussions, we must change our dialogue from “what is the matter?” to “what matters to you?”¹

I encourage all health care leaders and clinicians to partner with their patients and families to design or discover the best and safest care possible, and to acknowledge that when they fail to deliver on this goal, they are responsible for any harm that is inflicted. We have the knowledge and experience to do this, as well as the imagination and the will. All of us deserve nothing less.

— Susan Edgman-Levitan, PA
Roundtable Chair

Member, National Patient Safety Foundation’s Lucian Leape Institute
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EXECUTIVE SUMMARY

Receiving safe care is definitely a personal experience. The harm to patients resulting from medical errors at the most vulnerable moments of their lives is a profoundly intimate experience for everyone involved. Clinicians and staff are also deeply affected when they are involved in an adverse event and frequently suffer shame, guilt, fear, and long-lasting depression.

But ensuring safety can also be shared and rewarding. The insights and perspectives of both those who experience care at its best and those who experience it at its worst can help health care leaders, clinicians, and staff at every level make the improvements needed to create a safer and more patient-centered system.

Engaging patients and families in improving health care safety means creating effective partnerships between those who provide care and those who receive it—at every level, including individual clinical encounters, safety committees, executive suites, boardrooms, research teams, and national policy-setting bodies. Increasing engagement through effective partnerships can yield many benefits, both in the form of improved health and outcomes for individuals and in safer and more productive work environments for health care professionals.

Patients, families, and their advocates increasingly understand the wisdom of this partnership. Too often, standing in the way is the health care system itself—whether by intention or not—because of its fragmentation, paternalistic professional culture, abundance of poor process design, and lack of experience on the part of health care leaders and clinicians with practical methods of engaging patients in the safety enterprise.

While patients and families can play a critical role in preventing medical errors and reducing harm, the responsibility for safe care lies primarily with the leaders of health care organizations and the clinicians and staff who deliver care. Many of the barriers to engagement faced by patients and families—such as lack of access to their health records, intimidation, fear of retribution, and lack of easy-to-understand tools and checklists for

enhancing safe care—can only be overcome if leaders and clinicians support patients and families to become more confident and effective in their interactions with health care providers. Many of the tools necessary to do this already exist, but the system must also provide the education and training needed by professionals and patients alike to become more effective partners.

Recommendations

The Roundtable on Consumer Engagement in Patient Safety convened by the National Patient Safety Foundation’s Lucian Leape Institute offers the following recommendations for health care leaders, clinicians, patients, families, and policy makers aimed at advancing the patient safety mission through partnerships with patients and families:

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 the design and improvement of care across the organization and/or practice.
- Educate and train all clinicians and staff to be effective partners with patients and families.
- Partner with patient advocacy groups and other community resources to increase public awareness and engagement.

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.

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.

Patients, families, and the public

- 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.
- Always know why and how you take your medications, and their names.
- Be very sure you understand the plan of action for your care.
- Say 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.

Many of these recommendations are not new, nor are they the province of any particular interest group or organization; rather, they draw from the growing evidence about the power of engagement, and seek to build on what we know can work to reduce adverse events. Driven by a sense of urgency, the NPSF Lucian Leape Institute hopes this report serves as a call to action for leaders of health care organizations, health care professionals, patients and their families, and the public. This should not be seen simply as a new initiative or program; it is rather an effort to inspire a strategic alignment across the communities of health care consumers and advocates, policy makers, researchers, and health care leaders and clinicians to commit to increasing patient engagement in order to reduce harm.

We need to mobilize. We are all in this together. Let's get this work done now.



INTRODUCTION

The National Patient Safety Foundation’s Lucian Leape Institute convened two Roundtables* that brought together more than 40 individuals representing patient advocacy organizations, health systems, professional organizations, patient safety research initiatives, international safety organizations, and other groups to develop recommendations for engaging patients and families in improving patient safety. At the beginning of the first meeting, the participants were asked to reflect on an experience in which they or someone close to them had experienced harm at the hands of the health care system. They were also asked to reflect on the contributing factors and how they personally responded. Their perspectives exemplify what is often missing from formal root cause analyses—the personal and direct observation of an event from beginning to end from the patient or family perspective. Surprisingly, even these international experts have struggled to have voices in their care when something went wrong.

The stories collected from the Roundtable experts underscore the fallacy of assuming that patients can be expected to be responsible for the safety of their own care. While patient and family engagement in care can reduce the

Roundtable participants offered many poignant stories of safety gone wrong and how effective patient and family engagement could have made a critical difference in care outcomes. Here is one example. (A collection of other selected stories is provided in Appendix C.)

The mother said, “That doesn’t look like the chemo she has gotten previously, are you sure it’s right?” She asked again a bit later. And she asked a third time. She was right and her child—who had a curable cancer—died of a chemotherapy mixture error. The nurse confirmed each time that the label on the bag was accurate. And each time she assured the mother it was the right medication. And she was right—the label said the right thing. But that wasn’t what was in the bag.

I was responsible for the pharmacy and pharmacists who were the source of the error and resulting death of a lovely 7-year-old girl and the devastation of a mother who felt she didn’t do enough to protect her child. As an organization we were long in our safety journey and this horrific death showed us how far we had to go. Together with the pharmacy department team members, we faced the reality of what we had done and created a short list of terrible things never to be repeated.

— Roundtable Participant

*In April 2012 and February 2013

likelihood that adverse events will occur, these stories are powerful illustrations of why the balance of responsibility for safety falls primarily on the shoulders of health care leaders, clinicians, and their organizations.

Patient engagement, like patient- and family-centered care, has become a buzzword

What is meant by patient and family engagement and patient- and family-centered care?

Patient and family engagement and patient- and family-centered care are closely related concepts. Of the many thoughtful definitions of patient and family engagement that have been proposed, the one first published in *Engaging Patients and Families in the Medical Home* and later adapted by Carman and colleagues best highlights the need for an interactive partnership among communities, the health care system, and the patient and family at multiple levels, and illustrates how patients and families should move from a passive to a more active role in managing their own care and in partnering in the co-design of care delivery, policy making, and research.^{2,3} They define **patient and family engagement** as:

*patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care.*³

Patient- and family-centered care has also been the focus of carefully considered definitions over the years, stemming in large part from the early work of the Picker Institute and its identification of eight key dimensions of patient-centered care.⁴ We define **patient- and family-centered care** as:

a core value of an organization that guides its planning, delivery, and evaluation of health care and is grounded in mutually beneficial partnerships among health care providers, patients, and families.

Administrative and clinical leaders set the expectation for patient- and family-centered practice and authentic partnerships with patients and families at all levels of the organization.⁵

This report focuses on the patient and family role in fostering actions and interventions that are **directly related to reducing the potential for harm**.

whose meaning is often lost on the public and health care professionals. This report, targeted to health care leaders and practitioners, focuses on how engaging patients and families as respected partners can improve the safety of care and how this should drive an organization's mission and strategies for individual settings of care.

Patients can bring important contributions to their partnership role in helping to ensure the quality and safety of their own care. They are extra sets of eyes and ears that should be integrated into the safety processes of all health care organizations. For example:

- They know their symptoms and their responses to treatments better than anyone else.
- They are highly invested in their own well-being and outcomes.
- They are always “present” in their own care, unless impaired by factors beyond their control; they are the first to know when a symptom changes or about the impact of treatments, and can communicate this to their care team.
- Their courage and resilience can inspire and energize their care team.
- They often have insights into the processes of care that professionals lack because they are focusing on getting the job done.

For all these reasons, health care organizations should encourage patients to participate in their care and should create a climate where they are able to do so. If patients are truly members of the care team, they can more effectively protect themselves from errors and process failures that cause injuries.

In practice, however, too often health care organizations are unwelcoming or openly hostile to patients and families. As a result, patients are often reluctant to speak up when something does not seem right because they do not want to offend or anger

their care team or physician.⁶ They may feel vulnerable and worry that their care will be affected adversely if they are labeled as “difficult.”⁷

Patients and families also suffer at least as much as clinicians and staff from the same human factor issues that make one susceptible to error. These include circumstances such as unfamiliarity with the situation, inadequate or incomplete information, and ambiguity regarding next steps.^{8:142–45}

These factors also influence a person’s ability to remember and/or process information. Because patients are likely to experience at least one of these factors that increase the probability of error, it is unreasonable to expect them to manage unfamiliar tasks and the anxiety associated with potential failure.

There are other reasons why patients and families should not be expected to assume primary responsibility for the safety of their own care. If clinicians believed that patients or their families were routinely double-checking medications, coordinating care, or taking on other important clinical duties, they might inappropriately step back from assuming responsibilities that are truly theirs. Health care professionals are ultimately responsible for assuring safe, high-quality care, and that responsibility cannot be shared. Finally, care delivery has become so complex that patients or families could quickly become overburdened with responsibilities that are well beyond their ability to manage.

This report seeks to illuminate both the power and the limitations of engaging patients and families in achieving safe care, and to galvanize the specific actions needed on the part of health care leaders and clinicians to foster meaningful partnerships with those whose care has been entrusted to them.

At its heart, the test of whether a health system is tackling the patient safety agenda will be reflected in the everyday experience of its patients, the practical ways in which frontline staff are supported to implement safer practices, and the extent to which organizational managers and leaders can establish patient safety as a genuine priority.⁹

— Phillip Carruthers

THE POWER OF ENGAGEMENT IN IMPROVING PATIENT SAFETY

What is the value of engaging patients and families in improving safe care? Both research and practice show that engagement leads to safer patient care by improving the outcomes of care, improving the experience of care for individual patients, improving the work experience for caregivers, and—by helping the organization change its processes—improving the outcomes for all patients.

Improving the outcomes of care

Patients and families can play a number of key roles to improve the safety and outcomes of their own care.¹⁰ These include accessing information that helps in determining the correct diagnosis, involving themselves in decisions about appropriate care, choosing an appropriate provider, following the agreed-upon treatment plan, and speaking up when something does not go as expected or appears possibly to be a medical error. Health care organizations and clinicians have a responsibility to encourage and enable patients and families to become proactively engaged in these activities.

An extensive literature demonstrates the association between active engagement of patients at all stages of care—from diagnosis to treatment—and a variety of important outcomes.^{11–14} Engagement can take various forms:

Participation in diagnosis. Accurate diagnosis requires that the patient and/or their representative provide the full story, which in turn requires skillful encouragement and support by the clinician. Clear communication greatly enhances the likelihood of a correct diagnosis.

Shared decision making. Appropriate decisions about treatment must be based on both clinical evidence and patient preferences, values, and circumstances. For

example, an appropriate course of treatment for a mother with young children may be entirely wrong for an older person near the end of life with no dependents. Patients tend to be more conservative than their doctors, often ready to watch, wait, and monitor. When patient preferences are ignored, interventions that seem clinically reasonable at the time may be deeply regretted later by both patients and their caregivers. Mulley and colleagues argue that misdiagnosing patients' preferences ("silent misdiagnosis") may be less obvious than misdiagnosing disease, but the consequences for the patient can be just as severe, especially around end-of-life decisions.¹⁵ A recent study in Washington State and northern Idaho found that giving decision aids to patients resulted in 26% fewer hip replacements, 38% fewer knee replacements, and a reduction in costs of 12% to 21% during a six-month period.¹⁶

Following the treatment plan. With even the best of treatment plans, it is the patient who decides whether or not to take a prescribed medication or follow a diet or an exercise plan. In talk of "compliance" and "adherence" caregivers often forget this critical fact. But evidence shows that if the patient has not been engaged and consulted, they are less likely to follow the treatment plan, which results in poor outcomes and waste of resources and time for patients and caregivers.

Another pair of eyes. Good clinicians are constantly on the alert for signs of deterioration in their patients and for problems and failings in the health care system. Patients and families can, and should, do the same. While this is important in the hospital setting, it is essential in the home and community when they are in charge of their own care. Patients often see flaws in the health care system that are invisible to clinicians. We need them to monitor, to inform, and to participate in patient safety. Weingart and colleagues examined whether patient participation influenced the incidence of adverse events and found that patients with greater participation were more likely to report high quality of care and, more importantly, were less likely to experience adverse events.¹⁷

What does patient and family engagement look like in practice?

There are many ways for patients and families to contribute to improving safety through their interactions with their providers and the health care system. Here are just a few examples:

- A patient identifies the wrong drug or dose at the pharmacy.
- A parent reports that his/her child "looks funny" days before a diagnosis of infection or cancer is made.
- A patient emails his/her provider about experiencing a medication side effect such as difficulty with vision or balance.
- A patient notifies hospital staff of a slippery area near the building entrance.

Even the smallest observation or comment, offered in a supportive way in a trusting relationship, can make the difference between a positive and a negative outcome.

Improving the experience of care

The experience of partnership. We can all remember doctors, nurses, and others who were “on our side” and who worked *with* us rather than working *on* us. This experience of trust and partnership is itself valuable, satisfying, and fulfilling to patients, families, clinicians, and staff alike.

Improved satisfaction with outcomes. Patients who make decisions based on their preferences and values are more satisfied with their outcomes. A 2011 analysis of 86 randomized clinical trials conducted by Cochrane Reviews concluded that decision aids make patients better informed, improve their communication with their doctors, and increase their participation in decisions about their care.¹⁸

The relationship between patient experience and a culture of safety. Organizations with strong leadership and shared values that provide the systems, training, and resources to support their clinicians and staff in providing patient- and family-

Patients who make decisions based on their preferences and values are more satisfied with their outcomes.

centered care also appear to be effective in engaging patients. Data from the Hospital Survey of Patient Safety Culture (SOPS) show that high patient experience scores correlate with a lower incidence of adverse events. Similarly, hospitals where staff have positive perceptions of a patient safety culture tend to receive more positive assessments of care from

patients. Sorra and colleagues found that higher Hospital SOPS composite scores are associated with higher overall Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospital Survey composite scores ($r = 0.41$, $P < 0.01$). Further research is needed to determine the generalizability of these results to hospital units and other settings of care, but these findings are encouraging.¹⁹

Improving the work experience for caregivers

Caregivers and patients as members of the same team. A critical component of high-performing health care systems is an emphasis on multidisciplinary teamwork. Organizations that have been most successful, such as Virginia Mason Medical Center and Cincinnati Children’s Hospital, have included patients as members of the teams, both for their own care and for planning new care processes. This new relationship with truly engaged patients has proved to be a key to successful improvement and thus a source of great job satisfaction for caregivers.²⁰

Improving outcomes of care for all patients

Spreading benefits system-wide. System changes that result from patient and family engagement in their care can potentially benefit all future patients. A patient-identified improvement to prevent a medication dosing error, for example, if implemented institution-wide, will prevent similar errors for subsequent patients.

System changes that result from patient and family engagement in their care can potentially benefit all future patients.

Guiding the organization. As well as engaging in their own health care, patients can play a major role in supporting the care of other patients by supporting health care organizations. Health care provider organizations that are leading the way in this area have patients on all important hospital committees—to highlight and communicate the patient experience, to be a critical friend to the clinicians, and to link the hospital with the wider community. Patients support each other in countless associations, discussion groups and forums, and in providing advocacy for better care and safer systems.

In summary, evidence indicates that high-quality, safe clinical care and positive patient experience are correlated, and that high-performing organizations that take patient and staff engagement seriously are perceived more favorably by patients, clinicians, and staff.

THE CURRENT LANDSCAPE OF ENGAGEMENT

There is an exceptional amount of activity under way nationally and internationally to promote patient- and family-centered care and patient engagement. The evidence is strong and growing regarding the importance of engaging patients and families in actions at all three levels described in the patient engagement definition cited above (page 2): direct care, organizational design and governance, and policy making.

While not all of this activity relates directly to patient safety, these efforts create the opportunity to align and integrate safety-focused initiatives with the larger community of interests and organizations committed to patient engagement.

Patient engagement efforts are most common in direct care, aimed at enhancing the efficacy of individuals managing their own health and medical care. Examples include informed medical decision making, programs designed to improve health literacy (such as the National Patient Safety Foundation's Ask Me 3[®] initiative), medication reconciliation with the patient and family that includes counseling to prevent adverse drug events, and nurse reporting at the bedside.^{21–23}

Partnering with patients and families at the clinical organization and governance levels is also becoming more commonplace. Many health care systems, hospitals, and practices routinely involve patients on organization committees and as partners in redesigning clinical operations and improving the patient care experience. Massachusetts has enacted a law that requires all hospitals to create patient and family advisory councils and to report on their work annually.

A number of institutions, including Dartmouth-Hitchcock Medical Center, the University of Wisconsin Hospitals and Clinics, the University of Michigan Hospitals and Health Centers, Vidant Medical Center, Georgia Regents Health Center, Cincinnati Children's Hospital, Emory Healthcare, and Kaiser Permanente, have multiple patient/family advisory councils, and include patients and family members on quality

and safety committees, as judges for patient safety awards, and as participants in executive walk rounds.

At the policy-making level, patients are increasingly being recruited to serve on local, regional, state, and federal committees charged with making policy decisions and designing and funding research initiatives. For example, the Patient-Centered Outcomes Research Institute, funded by the Affordable Care Act (ACA), requires that patients be involved in all aspects of the research activities it funds, including establishing study aims, design, and methodology, and puts more focus on outcomes that matter to patients.^{24,25}

Foundation support for patient engagement research and implementation has been increasing. The Gordon and Betty Moore Foundation has committed \$500 million to fund its new Patient Care Program to support patient engagement. As part of this initiative, the Foundation funded the American Hospital Association–Health Research & Educational Trust (AHA-HRET) survey of hospitals on patient engagement strategies, a *Health Affairs* issue on patient engagement, and a National Committee for Quality Assurance (NCQA) study on the impact of technology on patient engagement. It also funded the Armstrong Institute for Patient Safety and Quality at Johns Hopkins with an \$8.9 million, 10-year grant to eliminate all preventable harms that patients experience in the hospital. The Johns Hopkins grant focuses on hospital intensive care units and has the goal of preventing harms by better engaging patients—and their families—in their own care, thus making them an integral part of the health care team.

Patients are increasingly being recruited to serve on local, regional, state, and federal committees charged with making policy decisions and designing and funding research initiatives.

The Commonwealth Fund has supported extensive efforts to engage patients in patient-centered medical homes, and the Robert Wood Johnson Foundation supports patient engagement in communities through its Aligning Forces for Quality initiative. Internationally, the World Innovation Summit for Health (WISH), led by the Imperial College of London and the Qatar Foundation, selected patient engagement as one of the eight themes for the 2013 WISH meeting in Doha, Qatar. More than 70 health ministers and 60 finance ministers from around the world left this meeting in December 2013 with concrete patient engagement recommendations to implement in their own countries and a commitment to an international “Declaration on Engagement for Global Health” (see Appendix B).

The guidelines for Accountable Care Organizations (ACOs) and the guidelines for recognition of a patient-centered medical home (PCMH) both create incentives that

are designed to enhance patient engagement and the patient's experience of care. The ACA mandates that all Pioneer and Shared Savings ACOs collect feedback from patients about their experiences of care using the CAHPS Clinician & Group ACO survey. This instrument collects information about aspects of care that have important safety ramifications, including getting timely appointments and information, clinician communication, and patient involvement in decision making. NCQA has embedded a variety of practices that enhance patient safety into its new PCMH and Patient-Centered Specialty Practice Recognition Programs. The Centers for Medicare & Medicaid Services (CMS) mandates use of the CAHPS Hospital Survey, which collects feedback about important aspects of safety such as doctor and nurse communication, responsiveness of staff, education about medications, cleanliness of the hospital, and preparation for discharge.



BARRIERS TO ENGAGEMENT

Despite the growing evidence about the value of engaging patients and families in improving health care safety, a number of formidable barriers remain. These include barriers imposed both directly and indirectly by the health care system, as well as limitations that patients and families themselves bring to their interactions with health care organizations and clinicians. These two sets of obstacles interact with each other, since the structure of the health care system and the behavior of health care professionals can either impede or enhance the engagement behavior of patients and families.

Patient and Family Barriers

Some barriers arise out of the physical impact of illness and significant socioeconomic and cultural factors that influence the degree to which patients and families are able or motivated to engage in their health care. In identifying these factors, care must be taken to avoid blaming the patient for being unable to act, as patient inaction most often derives from the context created by the structure and culture of health care. Thus, primary responsibility for addressing these barriers lies directly in the hands of health care leaders and policy makers.

The Roundtable identified six patient and family barriers that need to be addressed: understanding the terms of engagement and safety, health literacy problems, limited social support for vulnerable patients, fear of retribution from health care providers, other performance-shaping factors, and absence of nationally representative advocacy groups.

1. Understanding the terms of engagement and safety

In spite of the pervasive reference to consumer and patient engagement among health care professionals and advocates, the vast majority of Americans remain relatively uninformed and passive recipients of health care services and thus lack

the confidence and skills needed to fully engage in their health care.²⁶ At the same time, the range of engagement behaviors increasingly required of people to maintain their health and benefit from their health care has expanded greatly.²⁷ The lack of understanding and preparedness, particularly among those older and most vulnerable, regarding the meaning and requirements of engagement presents a major barrier.

Another challenge is the fairly limited understanding most consumers have of what patient safety means. Consumers sometimes misinterpret “patient safety” as a reference to their personal security in a clinical environment. Studies show that people typically associate lack of safety only with medical errors and lack a more comprehensive understanding of safety issues as the result of system failures.²⁸ National polls have shown that most Americans are unfamiliar even with the term “medical errors” and generally perceive that care is safe.²⁹ When errors do occur, patients tend to think they are the result of individual provider mistakes, not because of the underlying flaws in the systems in which the providers work.³⁰

2. Health literacy problems

Health literacy and numeracy problems are widespread in all segments of the U.S. population. Only 12% of English-speaking adults in the United States have proficient health literacy skills.³¹ Although the impact of limited health literacy disproportionately affects lower socioeconomic and minority groups, people of all ages, races, incomes, and education levels are affected by it. Patients with poor literacy skills receive less preventive care, have less knowledge about chronic conditions, perform more poorly at self-care, use health care services at a higher rate, and have worse outcomes on a variety of measures than do patients with better literacy.³²

3. Limited social support for vulnerable patients

The infrastructure for supporting human needs for health and social services beyond acute care episodes is notoriously inadequate in the United States. For those who are socioeconomically disadvantaged, finding and paying for care-giving support at home can be especially difficult. Getting someone to accompany patients to and from visits to health care providers can also be a challenge. These limitations can have a major impact on the ability of vulnerable patients to obtain safe care, not only when interacting with doctors and hospitals, but also when attempting to follow medical advice at home.

4. Fear of retribution from health care providers

Even when patients have the advantages of high health literacy and a working knowledge of the health care system, many are too intimidated to ask questions or probe into treatment alternatives. The paternalistic behavior of health care professionals, combined with the prevailing social norm that patients should not challenge the advice of their providers, leads many individuals to adopt a deferential position.

They fear being viewed as “difficult patients” if they ask too many questions or disagree with treatment recommendations.⁷ Some patients fear that speaking up might have a negative influence on the quality of care they receive. Vulnerable hospitalized patients, for example, have expressed the fear that speaking up about safety concerns might lead to neglect or even abuse by staff in charge of their care.⁶ This absence of “psychological safety” in health care settings poses a major barrier to the willingness of patients to engage in their health care, and therefore to their physical well-being.³³

5. Other performance-shaping factors

Factors such as the quality of the physical environment, and stressors such as the severity of illness, fatigue, pain, discomfort, hunger or thirst, and lack of physical exercise, as well as personality, intelligence, motivation, and emotional state, may present significant barriers to patient or family contributions to error reduction. These factors also influence a person’s ability to remember and/or process information. For example, one study found that following a laparoscopy for acute abdominal pain 20% of patients responded incorrectly to questions of whether anything had been removed during the surgery, yet 91.4% said they were satisfied with the information received during their hospital stay. This illustrates the limitations of patients as a source of information about their own clinical histories.³⁴

6. Absence of nationally representative advocacy groups

A large number of patient advocacy groups exist in the United States, and the federal commitment to supporting patient advocacy through the Affordable Care Act promises further expansion of these groups at the state and community levels.³⁵ While these groups are well intentioned, most are focused on specific diseases, and some are funded by large medical or pharmaceutical companies that have vested interests in promoting specific drugs and therapies. Some, such as cancer advocacy organizations, even compete with each other for funds. Although the diversity of the patient advocacy movement is in some respects its strength, the lack of a central organization with unconflicted sources of revenue that can unite like-minded groups in a common cause for patient safety and quality is a significant limitation. It contributes to fragmentation of effort and may dilute the leverage potential of a concerted strategy such as exists in several European nations that favor a more centralized, government-funded approach such as the United Kingdom’s National Voices. The World Health Organization’s Patients for Patient Safety initiative is an excellent example of an organizational structure that could be effective in the United States.

What do patients and families need in order to participate effectively in their care?

- We must know it’s **important** (i.e., the why behind the what).
- We must know it’s **possible** (i.e., the ways or avenues we can take that are within our ability).
- We must know it’s **safe** (i.e., we can’t be punished, ignored, or made more fearful).

— Jessie Gruman
Patient, and President of the
Center for Advancing Health

Health System Barriers

While patient-sourced barriers are formidable, as we have emphasized, the most significant barriers to patient engagement are those imposed by the health care system itself. Until these are addressed, even the most advantaged, motivated, and informed patients and families will find it difficult to engage in full partnerships across the continuum of direct care, organizational leadership, and policy making. The Roundtable identified five major system barriers that must be addressed to enable patients to be truly engaged in their care. These are: a fragmented health care system, a dysfunctional professional culture, organizational leadership deficits, workflow design flaws, and lack of effective engagement tools and training.

1. A fragmented health care system

One of the overarching barriers to engaging patients in safety is the fragmented nature of the U.S. health care system, in which health care providers caring for the same patients often work independently from each other. This “non-system” leaves patients and families to navigate on their own within and across multiple care settings with no map of the terrain, thus contributing to poor quality of care, frustrating experiences, and an increased potential for medical errors.³⁶ This lack of coordination also makes it difficult to hold providers accountable for quality and safety outcomes. Engaging patients in a system as disjointed as ours will continue to be a monumental challenge until the health care system is restructured to create transparent care pathways and improve communication, care coordination, and accountability.³⁷

2. A dysfunctional professional culture

The second overarching barrier to engaging patients and families involves the deep-seated cultural norms and traditions in medicine, nursing, and other health care professions. For example, Leape and colleagues have described a “culture of disrespect” in medicine that fosters individual privilege and autonomy instead of

The connection between disrespectful behavior to patient safety should be made explicit in our efforts, since this is a rallying point that everyone can agree on. Medical staff members should absolutely be holding ourselves to the highest bar of professional and respectful conduct. We have no excuses for anything less. But beyond this, the medical system needs to re-evaluate itself and the way it respects—or disrespects—its own workers, and by extension, its patients.⁴⁰

— Danielle Ofri, MD

the attitude of teamwork, collaboration, and inclusiveness that is needed.³⁸ If professionals have difficulty cooperating with and showing respect for each other, it is difficult to imagine how they can willingly embrace the engagement of patients and families to share in treatment decisions, monitor medications to prevent errors, or plan for self-

management after leaving the hospital or office.³⁹ The culture of disrespect in medicine imposes a significant barrier to achieving many health care reform goals, but it is

especially detrimental to the aim of weaving patients and families into a collaborative process for improving patient safety.

Physicians and nurses commonly perceive that involving patients and families will be burdensome. Several studies have documented providers' perceptions that engaging families in rounding, encouraging patients to tell stories, and educating patients about their treatment plans and medications takes too much time.²⁸ However, there is increasing evidence that the time invested in such activities actually leads to greater efficiencies in patient care by reducing unnecessary and costly readmissions and "getting it right" the first time.⁴¹

Other attitudinal barriers include fears that involving patients and families will lead to unreasonable demands on clinicians, expose their deficiencies, and compromise patient confidentiality.^{32,42} Clinicians are sometimes also skeptical that engagement efforts will lead to any real change.⁴²

3. Organizational leadership deficits

The central role of leadership in improving quality and safety in health care organizations has been well established through numerous theoretical and empirical studies.⁴³ Health care organizations that are reliably safe are characterized by a "culture of safety" fostered through strong senior executive and board leadership.⁴⁴ According to the "complicity" concept suggested by David Lawrence, former Chief Executive Officer of Kaiser Foundation Health Plan, health care leaders are implicated in every aspect of the organization they lead that can influence an outcome. In other words, they are as responsible as (i.e., complicit with) every individual clinician or staff member who touches a process affecting safe care.⁴⁵

Knowledgeable leaders recognize that patient safety is achieved through the design of systems and processes that consistently produce desired results rather than through simply reminding individual staff members to "be more careful."⁴⁴ When board and executive leadership is lacking, thoughts of a systems approach to safety are often overtaken by a culture of blame that discourages transparency and makes work-arounds and quick fixes the dominant response to errors.⁴⁶ The absence of informed leadership may also lead to a "top-down" approach to initiating partnerships with patients and families, with insufficient focus on building staff understanding and support.³²

4. Workflow design flaws

Faulty system design not only produces serious safety vulnerabilities, it can also contribute to process deficiencies that compromise the ability of clinicians and staff to effectively engage with patients and families. For example, the standard 15-minute patient visit appointment in most medical practices constrains patient-provider

communication and often creates long waiting times and frustration. Change-of-shift processes in hospitals that do not include the patient or family can also lead to confusion and errors in care management.⁴⁷ Further, the pressures of seemingly endless paperwork and bureaucratic red tape can lead to fatigue and disillusionment in all care settings. Inefficient workflow design undermines even the most simple, basic steps to engaging patients and families. When patients are not involved as co-designers to improve system design and workflow, the best solutions are less likely to be identified, and the dysfunctional status quo is perpetuated.

5. Lack of effective engagement tools and training

If clinicians are to actively engage patients in improving safety, they need not only supportive leadership and improved system design and workflow, but also access to well-designed engagement tools and resources and the training necessary to use them effectively. Unfortunately, patient education materials are often designed without adequate patient input and attention to literacy levels and cultural appropriateness.⁴⁸ Patient and family safety tips and recommendations have multiplied rapidly, but many of these lists are too lengthy to be meaningful or memorable, or they contain difficult-to-perform, non-evidence-based recommendations. Even when decision aids of proven value are available to clinicians, they are often not used, in large part because of lack of comprehensive training.^{49,50} While cultural and organizational barriers contribute to the modest use of engagement strategies, the ability of many physicians to understand and accurately explain scientific evidence and make informed judgments themselves is often overestimated. Contrary to popular belief, even some health care professionals lack the skills to accurately assess the evidence for or against a medical treatment.⁵¹

Equipping leaders and clinicians with the vision, knowledge, and skills to foster a culture of inclusion that enhances patient safety should start early in their education and be reinforced during subsequent training. Few medical schools or health administration schools, however, are offering education on patient and family engagement.²⁸



RECOMMENDATIONS

The primary responsibility for safe care lies with the leadership of health care systems and organizations and with the clinicians and staff who deliver care. Increasing patient and family engagement in the design and delivery of care as well as in research initiatives can leverage the work of health care professionals and organizations and serve as a strategic compass for these efforts.

In the words of Robert Johnstone from National Voices and the International Alliance of Patients' Organizations, "Clinicians will need to step off their pedestals and patients will need to get off their knees."⁵² For this to happen, health care organizations, clinicians, and patient advocates will need to help patients and families become more confident and effective in their interactions with health care providers and the system. Clinicians should reinforce these capabilities by serving as positive "receptor sites" for partnering effectively with patients and families.

To help transform these aspirations into tangible, concrete realities, the following recommendations are grouped by the three key audiences responsible for their implementation: leaders of health care systems, health care clinicians and staff, and health care policy makers. These three groups correspond to the three levels of patient and family engagement included in the definition presented at the outset of this paper. Specific strategies associated with each recommendation are provided in the form of a checklist in Appendix A.

For recommendations from Roundtable participants regarding specific actions that patients can take to help make care safe, see "What Should Patients Do to Help Make Care Safe? A Roundtable Poll" below (page 20).

LEADERS OF HEALTH CARE SYSTEMS

Supporting patients and families to become meaningfully engaged in their care will require a major culture change for most health care organizations. While efforts are needed at all levels, the most important must take place at the top: the CEO and the board must lead the change. The following action steps are essential:

1. Establish patient and family engagement as a core value for the organization.

Institutions that have succeeded in patient engagement place a high priority on creating a learning culture that incorporates patient partnering as a core value, along with transparency, collaboration, and accountability. They create standards of dignity and respect for all and implement policies that facilitate patient engagement, such as providing open access to clinical records, establishing open visitation policies, and including patients and families on improvement and safety committees.

2. Involve patients and families as equal partners in all organizational activities.

Patients and family members should be part of everything the organization does. In addition to participating on patient and family advisory councils for major clinical services, patients should be incorporated into the governance process and be active members of quality and safety committees, quality improvement and process design groups, and personnel review committees.

3. Educate and train all personnel to be effective partners.

Education and training of health care leaders, clinicians, and staff is essential to achieving the organizational commitment that is needed to effectively engage patients and families in the provision of safe care. Training in patient partnering is needed at all levels and across all disciplines—from management to medicine to nursing to allied health to pharmacy to other professional and support groups. The purpose of training is to enable everyone in the organization to understand and commit to meaningful involvement of patients and families. Patients and families have an important role in educating clinicians about the experience of illness, as well as working with them on developing communication skills that are specific to patient/family partnerships, shared decision making, and disclosure and apology.

4. Partner with patient advocacy groups and other community resources.

Health care systems should partner with patient safety advocacy groups, schools, churches, community organizations, and public health agencies to enhance public education and awareness of safety issues and the importance of active patient engagement in assuring safe care practices.

HEALTH CARE CLINICIANS AND STAFF

Doctors, nurses, and other health professionals have been trained to provide care that is patient-centered, but most do not regard patients as true partners in all of the activities and decisions related to their care. While there is a wide range of specific actions that clinicians and staff can take, priority engagement strategies include the following:

1. Support patients and families to engage effectively in their own care.

The concept that “safety is personal” may find its most powerful expression in the ways that patients and families manage and experience their own care. Although individuals will differ in the extent to which they want and are able to be engaged in their care, all patients should be actively supported to make their values and preferences explicit and to receive the information, training, and tools they need to manage their health conditions according to their expressed wishes. This is particularly important in decision making about tests and treatments, end-of-life care, and when patients are harmed by treatment or errors.

2. Engage patients as partners in safety improvements and care design.

Patients and families bring to the planning process ideas, perspectives, and values that often differ from those of providers who are “locked in” to traditional methods and practices. Engaging patients and family members as active partners in planning, implementing, and evaluating the care experience will identify safety problems that might otherwise go undetected and will permit development of potential solutions that health system leaders and clinicians might not have thought of otherwise.

3. Support patients and families when things go wrong.

In addition to developing improved methods for disclosure of incidents and apology for errors, doctors and nurses need better training and resources for providing emotional support to patients and their families when things go wrong.

HEALTH CARE POLICY MAKERS

For patient engagement to become the norm, leaders in health care, government, academia, and research need to establish patient engagement as a fundamental policy objective. Critical action steps to make this happen include:

1. Involve patients in all policy-making committees and programs.

The perspectives of patients and families are vital to informing local, state, federal, and international agency policy and program development related to patient safety. Accordingly, patients should be recruited to serve as full partners on committees charged with setting policy and with designing and funding research initiatives.

Involving patients in setting policy related to payment reform, accreditation, certification, and licensure can add important relevant perspectives to patient safety improvement initiatives by giving voice to the very individuals whom the system should be designed to protect from harm.

2. Develop and implement safety metrics.

Systematic patient safety measurement and feedback are important not only for monitoring and guiding improvement within organizations, but also for holding organizations accountable. Evidence suggests that public reporting of performance results creates strong incentives for organizations to improve their performance. Patient safety metrics should be based on the best available scientific evidence and standardized to enable fair and accurate comparisons within and across organizations and practitioners.

3. Engage patients in setting and implementing the research agenda.

Patient and family perspectives can greatly enhance the relevance and focus of research in patient safety by defining key research topics, such as the effectiveness of interventions to prevent and mitigate errors, integration of patient preferences in decision making, improving communication, relationships between the patient experience and patient safety, and the contributions of family caregivers.

What Should Patients Do to Help Make Care Safe? A Roundtable Poll

Patient and family engagement is a two-way street. Although the Roundtable focused on what health care leaders and practitioners, rather than patients and families, can do to help make care safe, Roundtable participants were asked to answer the following question:

What is the one thing that you do routinely, either for yourself or for your loved one, that you think helps to make your/their care safer?

Responses were recorded, and participants were asked to vote on which three actions they would rank as most important. The following seven actions were identified as most essential:

- 1. Ask questions about the risks and benefits of recommendations until you understand the answers.**
- 2. Don't go alone to the hospital or to doctor visits.**
- 3. Always know why and how you take your medications, and their names.**
- 4. Be very sure you understand the plan of action for your care.**
- 5. Say back to clinicians in your own words what you think they have told you.**
- 6. Arrange to get any recommended lab tests done before a visit.**
- 7. Determine who is in charge of your care.**

CONCLUSION

In order to design and provide the safest care possible, health care leaders and clinicians must recognize and embrace the power of engaging patients and families as integral partners in the care delivery process. The recommendations in this report seek to create a sense of urgency among health care organizations and clinicians to take the actions needed to effectively engage patients and families in the quest for the safest possible care.



APPENDIX A

CHECKLIST FOR ENGAGING PATIENTS AND FAMILIES IN THE SAFEST CARE

Priority Actions for Health Care Leaders, Clinicians, and Policy Makers

LEADERS OF HEALTH CARE SYSTEMS

1. Establish patient and family engagement as a core value for the organization.

- ✓ Create written behavioral values and standards for all clinical and non-clinical staff that speak to: treating the patient and family member with dignity and respect, information sharing, participation in care, and collaboration in improving care.
- ✓ Make unlimited visitation policies the standard for all inpatient units, ICUs, and emergency departments.
- ✓ Give patients and their proxies full access to their clinical records and personal health information through patient portals, written materials, and options such as OpenNotes[®] and the U.S. Department of Health and Human Services Blue Button[®].
- ✓ Sign the World Innovation Summit for Health “Declaration on Engagement for Global Health” (see Appendix B).

2. Involve patients and families as equal partners in all organizational activities.

- ✓ Establish patient and family advisory councils for all major clinical services and large ambulatory practices.
- ✓ Incorporate patient and family advisors into governance board roles, quality and safety committees, and other relevant safety- and research-oriented committees and teams.
- ✓ Have patients and family members routinely review all patient-oriented written materials and educational brochures for content, relevance, and clarity.

3. Educate and train all personnel to be effective partners.

- ✓ Place high priority on creating a learning culture that emphasizes patient safety, models professionalism, enhances collaborative behavior, encourages transparency, and values the individual learner.
- ✓ Establish patient/family faculty programs to educate clinicians, staff, and health professional students about the experience of illness and perceptions of safe care.
- ✓ Incorporate into all programs training in communication skills that focuses on patient and family partnerships, shared decision making, and disclosure and apology.
- ✓ Launch a broad effort to emphasize and promote the development and use of interpersonal skills, leadership, teamwork, and collaboration among faculty and staff.

4. Partner with patient advocacy groups and other community resources.

- √ Participate in the design and implementation of programs that involve the broader community—churches, schools, community organizations, public health entities—to help inform adults and young adults about how to get the care they need, how to use patient safety checklists, and how to choose the right health care system and health care professional.
- √ Partner with patient advocacy groups to develop community education campaigns to inform people that it is important to understand the purpose of medications, to always question unusual or unexpected tests or medications, and that it is okay to speak up with questions and concerns about anything that happens in the course of receiving care.

HEALTH CARE CLINICIANS AND STAFF**1. Support patients and families to engage effectively in their own care.**

- √ Routinely involve patients in informed decision making about all diagnostic tests and treatment options, including medications.
- √ Use strategies such as Ask Me 3[®] and teach-back to overcome health literacy barriers and to ensure that patients truly do understand their condition, what they need to do next, and why it is important to do so.

2. Engage patients as partners in safety and care design.

- √ Invite patients and family members to partner with clinical and administrative staff in quality improvement activities.
- √ Involve patients and family members as full partners in the design and redesign of clinical workflows and care delivery.

3. Support patients and families when things go wrong.

- √ Create healing environments that include a physical setting and an organizational culture that support patients and families through the stresses imposed by illness, hospitalization, medical visits, healing, and bereavement.

HEALTH CARE POLICY MAKERS**1. Involve patients in all policy-making committees and programs.**

- √ Include patients and family members in safety-related policy-setting groups and committees at all governmental levels and within relevant bodies (e.g., accreditation, certification) in the private sector.
- √ Train patients and families through initiatives such as the National Breast Cancer Coalition's Project LEAD[®] to prepare them to fully participate in these activities and to advocate on behalf of other patients.

2. Develop and implement safety metrics.

- √ Implement and improve CAHPS (Consumer Assessment of Healthcare Providers and Systems) scores. This measure of patient experience now encompasses the continuum of care and includes many dimensions of the care experience related to improving safety, such as communication, responsiveness of staff to patient concerns, coordination of care, hand hygiene, and shared decision making.
- √ Implement and improve SOPS (Hospital and Medical Office Surveys of Patient Safety Culture) scores, which measure important attributes of organization culture contributing to patient safety. In many cases, it correlates closely with CAHPS measures.
- √ Participate in state and federal medical error reporting including measures such as falls, readmission rates, infections, adverse drug events, employee injury rates, and worker's compensation payments.
- √ Create new measures of patient safety related to diagnostic error, medication reconciliation, care inconsistent with patient preferences, and other key safety issues.

3. Engage patients in setting and implementing the research agenda.

- √ Engage patients and family members as partners to identify effective safe practices, create checklists and practice bundles, and test these innovations.
- √ Build patient and family input into defining key research questions and into strengthening the evaluations of relationships between patient experience and patient safety across the continuum of care. Suggested research topics for advancing the role of patients and families in ensuring safe care include:
 - Clinical studies that seek to understand the nature and extent of medical errors and the clinical effectiveness of interventions that can prevent or mitigate the extent of harm
 - Research on tools for optimizing the integration of patient preferences into clinical decision making
 - Studies that seek to examine and enhance patient adherence to recommended therapies
 - Research on how to improve communication between patients and their caregivers in ways that enhance the safety and effectiveness of care
 - Research on how to evaluate and support the critical contributions of family caregivers



APPENDIX B

DECLARATION ON ENGAGEMENT FOR GLOBAL HEALTH

I/We believe that the solutions to the health challenges of today and tomorrow will depend on building effective partnerships and harnessing the underutilized power of ordinary people who care about improving their health and, therefore, I/we support engagement at all six levels of the Global Health Partnership Framework.

I/We pledge to implement and/or support one or more of the following engagement strategies and to continue building the knowledge base on engagement by sharing my/our experiences with the global community.

1. EDUCATION

Education of Patients and Families:

- Develop and implement programs to improve the health literacy of the population, including enhancing primary and secondary education curricula to incorporate content related to physical and mental wellbeing, health literacy, statistical and risk literacy, self-care, and skills to enhance partnering with healthcare professionals.

Education of Healthcare Professionals:

- Create patient and family faculty programs to educate healthcare professionals about the experience of illness and the patient and family perspective on what constitutes high quality care.

2. COMMUNITY HEALTH

- Offer evidence-based sources of health information and decision support tools to people through effective dissemination strategies such as electronic portals, cell phones, and alternative low-tech tools (paper-based, for instance).
- Partner with community organizations to improve health literacy, raise awareness of common health threats, and to enhance access to necessary health services.

3. DIRECT CARE

- Set public expectations that every healthcare professional will routinely invite them to participate in informed decision-making, and will partner with patients and families to support their goals, as they define them.
- Promote self-management of medical conditions, through the use of effective materials and through coaching, support, and connections to community resources.

4. ORGANIZATIONAL DESIGN AND GOVERNANCE

- Engage patients and family members in developing and reviewing all communication and educational materials designed for patients and families, to ensure that they are relevant and clear.
- Mandate that all healthcare organizations will engage patients/families as partners in quality improvement, care design and redesign, and policy-setting through development of patient and family advisors and programs that have sufficient resources and training to be effective.

5. PUBLIC POLICY

- Directly engage the public in policy-making, using methods such as in-person consultation and placement on decision-making boards, and through the use of emerging methods such as social media and crowdsourcing.
- Examine and align incentives for the public, healthcare organizations and governmental agencies to promote engagement of the public.

6. RESEARCH

- Require research funding entities to set the expectation that patients and families will be involved in all aspects of research activities they fund, including establishing study aims, design and methodology, and outcome measures.
- Continue to build the evidence base for effective engagement strategies across different cultures by integrating evaluation plans into the design of any engagement initiative.

Name

Organization

Signature

Date



مؤتمر القمة العالمي للابتكار في الرعاية الصحية
World Innovation Summit for Health
DEC 10-11 DOHA 13

an initiative of  Qatar Foundation

APPENDIX C

SELECTED SAFETY STORIES FROM ROUNDTABLE PARTICIPANTS*

My late husband, John, suffered a severe brain stem injury in an automobile accident in January 1990. Comatose, he was transported to a major medical center and admitted to the neurosurgery ICU. Two nights later I was told that he needed surgery, not for his traumatic brain injury, but because there was a blood clot in his arm. The chief neurosurgeon explained that an arterial catheter had been placed by mistake in the wrong arm. After several surgeries and massive doses of heparin, it became clear that he had developed a systemic allergy to heparin. As a result of this cascade of errors, his right arm was amputated just below the elbow. Although he came out of the coma four months later, he was quadriparetic and was never able to use his left hand. I cared for him at home for 17 years. The initial error was undoubtedly made by a resident; the chief resident didn't notice it; the chief neurosurgeon was furious but not in my presence (my husband worked for the university president); and the excessive doses of heparin made things worse. I had noticed that my husband's hand was very cold during the day and told the nurse, who reassured me that she would put on an extra blanket. She didn't take my observation seriously. I did not realize that I had to speak up very very loudly to be heard. In the end it was everybody's fault but nobody took responsibility. I never learned what measures were taken as a result.

The birth of my first baby resulted in a C-section after a long labor with an unsuccessful descent of the baby through the pelvic arch. I was taken into the delivery room for the section and given a spinal anesthetic. The physician turned his back to me and was attending to his machines. I noticed that nothing was happening, that I still had full feeling in my legs. I mentioned this a few times and the physician actually discounted my claim, stating that I was exhausted and he was sure he was in the correct space. When the obstetrician approached me with the scalpel and I was draped, I literally sat up on the table and kicked the drape off, demonstrating that I really could still feel everything. Suddenly a mask was going over my face and I was administered a general anesthetic.

* Stories are based on actual events. All names and locations have been changed to protect the privacy and identity of those involved.

During the course of the surgery, I could basically hear everything. I heard the obstetrician yelling at the anesthesiologist. I heard the notion that these things only happen to staff. I heard the sex of the baby.

Needless to say the experience was a little terrifying because I could hear everything but couldn't move a muscle. I thought that the anesthesiologist had paralyzed me, since by then, my trust was somewhat daunted. It was a pretty scary experience. Somewhere after that I drifted off to sleep.

The next day, when I asked the anesthesiologist what happened, he claimed that a very small percentage of people don't respond to anesthetic agents and that I was one of those people... because he was insistent that he saw spinal fluid and was in the right space during administration. I was not able to test that hypothesis until seven years later when I had my next baby. I had to retell the whole story to the next anesthesiologist, who was the chief (I wasn't taking any chances). He was very tactful and said we should be ready for the possibility of a general anesthesia but he didn't believe that was going to be necessary.

My elderly mother, a long-time smoker, presented to her primary care physician with a several-month history of hoarseness. She was referred to an ear-nose-and-throat physician. Without complete examination he scheduled her for a procedure. She called me to get information about the procedure, which turned out to be a rigid laryngoscopy under general anesthesia. I asked if he saw something that worried him either on her chest x-ray or when he examined her vocal cords. She stated that neither had been done. I called the physician and did not initially reveal that I was a pulmonologist and inquired as to the necessity of the procedure. His response was that we wanted to get a good look at her vocal cords. When I advised him that I was a pulmonologist and never had a patient where I couldn't visualize vocal cords with a fiber optic scope under local anesthesia, and that I thought it was standard of care after transoral visualization, he agreed to do the procedure in his office under local anesthesia. My mother had lost trust so flew to where I practiced. A chest x-ray was normal and examination by a local ENT physician under local anesthetic, performed in the office, taking less than 10 minutes, revealed only vocal cord polyps. She was treated with inhaled steroids, stopped smoking completely, and the hoarseness resolved. The potential harm was of general anesthesia and an unnecessary procedure in an elderly, vulnerable, person. If she didn't have a son who was a physician she most likely would have acquiesced to the procedure. While rigid laryngoscopy is indicated under some circumstances, transoral or transnasal visualization in the office is easier and associated with less morbidity.

A friend shared this with me last week: “After Robert’s 7+ hour bladder and prostate removal due to cancer, he was sent up to his room in the hospital. Robert was in pretty good post-op spirits, except that his hands were shaking a little. In his room he quickly fell deeply asleep but his hands continued to shake and soon his arms started shaking as well. Not long afterward his nurse came in to take his vitals and get him set up with ordered meds. She tried to wake him gently but she and I both failed. She called in a respiratory specialist, who gave him oxygen, but he still continued to sleep. She called the rapid response team. Someone called for a crash cart, and I heard ‘call a code’ in the background. They were thumping, rubbing, and throwing out theories for the unresponsiveness and shaking, tending toward a cardiac problem.

One woman, an anesthesiologist, who emerged as the one in charge called out over all the voices, ‘Does anybody know why the patient is here? Where did he come from?’ I said, ‘He came up from recovery about a half hour ago—Dr. Z’s patient—bladder and prostate removed due to cancer.’ She whipped her head around and saw no white coat. ‘I assume you want to rule out a cardiac event,’ I said. She asked if I am a doctor. ‘No. I’m his wife. He just had a full stress-echo on Friday and he was clear. He has no heart history.’ Still, Robert snored away. The anesthesiologist ordered Narcan—no response. I asked if she wanted to rule out a pulmonary embolism—Robert had had two of them in the ‘90s. She demurred and ordered epinephrine. It seemed to take forever but then Robert’s eyelids fluttered and finally opened. End of emergency.

Was this a medical error avoided? Perhaps. But it illustrates why it’s so important that a patient be accompanied by someone who is familiar with his medical history and who is comfortable standing her ground with the experts, asking questions and proposing theories. The nurse had no chance to get his vitals before the emergency started. His chart was not handy at the bedside. There was no time to scan his history. But all the members of the RRT did their jobs. Every angle was pursued. There was just no information, or would not have been, if it hadn’t been for the patient having a good advocate. I do not know what would have happened to Robert if I hadn’t been there, had not known his history, had not stayed calm, and if I had felt intimidated by the docs. I do believe they were following the cardiac failure theory before I intervened, but we’ll just never know.”

Have you ever, personally, failed to speak up to “stop the line” in a health care setting for yourself or a relative? Many hospitals today are requesting patients to ask or tell staff about hand washing. Interviewing patients and families about this request yields a small percentage who say they are willing and ready to say something to their hospital caregivers, usually nurses and physicians. Those few say they are ready and willing, but will they? Is it an

appropriate request? More recently, the literature has yielded evidence that asking patients to ask about hand washing is inappropriate and not patient-centered—it's our job to deliver safe health care! And I agree. Here's why.

It all began with fluid in my left elbow bursa—bursitis with no known trauma except a bumped elbow two years earlier. My physician had seen it at a preventive care visit and suggested it would resolve itself.

Within two weeks, the swelling was intense and painful and I couldn't finish my daily walk. Since my physician was on vacation, I was seen by his partner. In the office of the partner, I was given the choice between continued wait/watch or aspiration. The potential for infection was discussed along with the promise of "great sterile technique" if I decided to proceed.

During the prepping process, I began to notice a number of breaks in sterile technique: failure to drape the area, and after gloving, the physician touched a number of items in the exam room and used paper towels out of the sink dispenser to dry the Betadine on the aspiration site because he was impatient for it to dry.

It occurred to me to "stop the line" in the seconds before needle pierced skin, but memory of this physician's bad behavior with patients along with the fact that he had so far been on his best behavior this time made me pause to wonder if I really wanted to risk his bad behavior? I had decided on the aspiration, I wanted it today, and I am strong and healthy and would not get an infection. What was your rationalization when you failed to stop the line?

Days later, the elbow was red, the bursa area amazingly swollen and hard, and I found myself in the twilight zone. My physician took one look at the elbow and low-grade fever and sent me across town to an orthopedic surgeon who said, "This has gone too far for a needle, we need to cut it open."

Lying on the procedure table, I asked about care for the wound—a large gash across a bending joint. The surgeon's response was, "You won't be caring for it. We are putting you in a cast for three weeks." That cast was so gigantic that I owned only one thing I could wear to work that would fit over it, and I had to teach at a national meeting in another state in a week.

If you have ever had a cast, you know the frustration associated with daily activities and travel with a cast on any body part. Daily activities were shockingly difficult, and I didn't have time for this. I never knew there was such a thing as a preventable cast!!

In July of 2012, I injured my right hamstring muscle group going for a tennis ball I never would have gotten. I fell like a ton of bricks. Not wanting to "medicalize" myself more than necessary, I had my primary care physician refer me to a physical therapist. However, I had almost no residual knee flexion strength, and the PT was scared to work on it without imaging. The MRI looked terrible, with two of the three muscles completely avulsed from the pelvis, and the third partially torn. A recent systematic review of proximal hamstring ruptures found

18 non-experimental studies, generally case series, and no randomized controlled trials (Harris, et al. *Int J Sports Med* 2011;32:490). The bottom line: “Non-operative treatment results in worse patient satisfaction, with significantly lower rates of return to pre-injury level of sport and reduced hamstring muscle strength.” The “rub” was that the conclusion was based on 286 injuries managed with surgical repair, and just 14 managed non-operatively. After careful investigation, I consulted an older trauma surgeon at a local hospital with a conservative reputation who I thought matched my own minimalist mindset. After a brief exam and look at the MRI, he said something like, “I’ve been leaving these alone for 30 years, and they all heal up.” Nine months along now, I’m back to tennis with no functional limitations. The problem here is that the outcomes of routine care aren’t being captured systematically, particularly in terms of defining the natural history of disease, even at elite academic medical centers. My guess is had I seen another orthopedist, I would likely have had an operation. Would I have been better off? Probably not. Doing something major you neither want nor need can never be done so safely it doesn’t matter. . . .

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DISCLOSURE STATEMENT

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Linda Kenney, President and Executive Director of MITSS (Medically Induced Trauma Support Services), served in a volunteer capacity on the NPSF Board of Directors and Standard Register's National Advisory Group during the Roundtables and development of this document, and currently serves in a volunteer capacity on the NPSF Board of Governors and Standard Register's Engaging Patients Board, a national advisory council for Standard Register. Ms. Kenney has not received compensation for the aforementioned volunteer positions. Standard Register's sponsorship of this white paper occurred after the Roundtable sessions were complete and all content and recommendations were finalized. Standard Register had no involvement in the selection of roundtable participants, nor did they at any time suggest language or influence any content or recommendations in this document.

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