



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



SAFETY IS PERSONAL

Partnering with Patients and Families
for the Safest Care

The National Patient Safety Foundation's Lucian Leape Institute

Report of the Roundtable on Consumer Engagement in Patient Safety

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.

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