

The National Patient Safety Foundation®

National Agenda for Action: Patients and Families in Patient Safety

*Nothing About Me, Without Me**

Executive Summary

This summary (and complete document) is a report developed by the National Patient Safety Foundation's (NPSF) Patient and Family Advisory Council. The NPSF promotes safer medical care through prevention of medical error and improving the health care system for all patients. NPSF established the Patient and Family Advisory Council (PFAC) to provide guidance and patient perspective on all of NPSF's activities. The following is the PFAC's recommended initial strategy for developing a patient-centered culture of patient safety in healthcare.

This document is a call to action to all hospitals, health systems, national and local healthcare organizations to involve patients and families in systems and patient safety programs. The document provides a high-level road map for action in four areas: education, culture, research and support services. This is a first step to raise awareness on these issues. The next step will be to address how these actions should be implemented.

I. Education and Awareness

In the next three years, NPSF will take a leading role by providing a central clearinghouse and interactive resource center for education, training and resources on patient safety and prevention of medical error for patients and professionals.

* This phrase, first suggested by an English midwife at a Salzburg seminar in 1998, has since been used by authors Delbanco, Boufford, Berwick, Edgman-Levitan, Tye, et al in various articles, including IOM's Crossing the Quality Chasm report.

Executive Summary
(continued)

Actions that need to be taken in individual hospitals and health systems (with leadership from NPSF and through the Stand Up for Patient Safety Campaign) include:

- Establishing interactive, interdisciplinary education programs that bring together patients and professionals by targeting:

1. The general public, including patients, families, media

Message topics:

- Definition and principles of patient safety
- Frequency of medical error
- How to safeguard your own care and partner with your providers
- What to do if you experience a mistake or error

2. Healthcare organizations and professionals

Message:

- Patient/family perspective is important and should be actively integrated into culture of institution.

3. The behavioral health community, including counselors and social workers

Message:

- Experience of medical error differs from other types of trauma — patients and families who experience harm due to a medical error may need specific types of support and advocacy.

II. Building A Culture of Patient and Family-Centered Patient Safety

Meaningful change cannot take place without a fundamental change in the culture of patient safety. The following actions are aimed at building partnerships with patients and families.

In the next three years, NPSF will take a leading role by providing a national forum for sharing and disseminating information to local and state coalitions and initiatives.

Actions that need to be taken by individual hospitals and organizations:

- Teach and encourage effective communication skills for patients, their families and healthcare professionals
- Train and utilize patient representatives for patient safety advocacy in hospitals and health systems
- Implement Patient and Family Advisory Councils in each hospital and healthcare organization
- Incorporate patient and family representation on Boards of Trustees
- Develop patient safety task forces and/or coalitions in each state

Executive Summary
(continued)

III. Research

Suggested areas of internal and external research:

- “Bridging the Gap”: Effective methods for building relationships and communication between patients, caregivers, and providers
- Disclosure — Methods and their effects on patients and families
- Short- and long-term effects of integrating patients and families into the healthcare system
- Review of current patient safety information and resources available for patients and families, and their effectiveness
- Post-traumatic stress specific to medical error
- Team relationships (including patients and families)

IV. Support Services

There are three phases of medical error: preventing the error, preventing harm caused by the error, and mitigating the effects of a harmful error. Support services are needed to address this last category.

In the next three years, NPSF will take the lead in these efforts by providing:

- *A national resource center and information line*
- *A peer resource counseling program to connect patients who have experienced a medical error with trained individuals who have already been through the experience*
- *National training programs*

Individual organizations and local coalitions should provide:

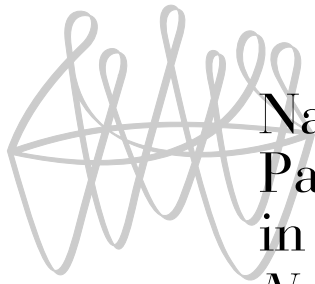
- Support groups
- Disclosure and communications programs

A long-term goal in this area is:

- Emergency line

Conclusion

This National Agenda for Action is by no means exhaustive. It represents a first step in depicting the spectrum of activity needed to address the concerns of patients and families involved with the health care process preceding and following preventable medical error. Through sharing experiences and perspectives with a focus on communication skills and team building, we hope to establish common practices and systems that honor and respect the needs of patients and families. This agenda should serve as a launching pad — not a destination.



National Agenda for Action: Patients and Families in Patient Safety *Nothing About Me, Without Me*

Introduction

The National Patient Safety Foundation (NPSF) was founded to promote safer medical care through the prevention of medical error and to improve the health care system for all patients. In 2001, the NPSF established a Patient and Family Advisory Council that includes 11 patient and family members and nine leading healthcare professionals from the board of the Foundation to provide guidance and patient perspective on all of NPSF's activities. This council exemplifies the partnership between patient and provider that NPSF strives to promote in all of its activities.

As the patient safety movement gains momentum, it is clear that patients and families must be adequately integrated into the systems we are striving to change. "Patient safety" is not a household term, and in fact is rarely thought of by patients (and often not by healthcare professionals) in relation to medical error. This "disconnect" between a movement in the field of healthcare and a patient's awareness of it is perhaps one of the most fundamental examples of communication and system breakdown.

Not only are patients and families capable of actively participating in their own care, but this participation is a critical factor in helping to improve quality of care and safety. This document imparts the NPSF's Patient and Family Advisory Council's recommended strategy for developing a patient- and family-centered culture of care in which patient safety can be optimized.

What is Patient Safety?

The definition of patient safety, and its place within quality of care, has received a lot of attention. In 2000, NPSF's National Agenda for Research** outlined three defining characteristics of patient safety:

- Patient safety has to do primarily with the avoidance, prevention, and amelioration of adverse outcomes or injuries stemming from the processes of health care itself. It should address events that span the continuum from what may be called "errors" and "deviations" to "accidents."

**National Patient Safety Foundation. Agenda for research and development in patient safety. Chicago, IL: National Patient Safety Foundation, 2000.

-
- Safety emerges from the interaction of healthcare system components. It is more than the absence of adverse outcomes, and more than avoidance of identifiable “preventable” errors or occurrences. Safety does not reside solely in a person, device or department. Improving safety depends on learning how safety emerges from the interactions of the components.
 - Patient safety is related to “quality of care,” but the two concepts are not synonymous. Safety is an important subset of quality. To date, activities to manage quality, such as quality assurance, continuous quality improvement, total quality management, etc. have not focused sufficiently on patient safety issues.

Although this agenda’s primary focus is patient safety, developing a patient-centered culture of care applies to all aspects of healthcare quality and service. To improve safety is to improve partnership between patients and providers at every level.

Agenda Development

The development of this NPSF agenda involved collaboration among patients, families, patient safety experts, healthcare providers and patient advocates. Representatives from additional groups provided their guidance through a review process. These groups include:

- American Organization of Nurse Executives (Washington, DC)
- Massachusetts General Hospital Cancer Center (Boston, MA)
- Children’s Hospital (Oakland, CA)
- Children’s Hospital and Regional Medical Center Family Advisory Council (Seattle, WA)
- Dana-Farber Cancer Institute Patient and Family Advisory Council (Boston, MA)
- Family Centered Care, Children’s Hospital of Philadelphia (Philadelphia, PA)
- Family Services Development, Children’s Medical Center (Augusta, GA)
- Florida Board of Nursing (Tallahassee, FL)
- Lucile Packard Children’s Hospital at Stanford (Palo Alto, CA)
- Madison Patient Safety Initiative (Madison, WI)
- Methodist Hospital (Minneapolis, MN)
- MD Anderson (Houston, TX)
- Medical College of Georgia Health (Augusta, GA)
- Persons United Limiting Substandards and Error in Healthcare (PULSE, New York, NY)
- Veteran’s Administration (VA) of New York (New York, NY)
- Wisconsin Patient Safety Institute (Madison, WI)

As a beginning point, the Patient and Family Advisory Council surveyed existing resources and asked:

What needs to happen within the patient safety movement to successfully incorporate the patient and family perspective?

How can patients and families work in partnership with healthcare professionals to improve safety in health care?

How can systems be put in place to assist patients and families who have experienced harm due to a medical error?

With these questions in mind, this document proposes four areas for concrete action:

1. Education and Awareness
2. Culture of Safety
3. Research
4. Support Services

The actions in this document do not depict a complete picture of the change that needs to take place in regard to patients and families in health care and patient safety. Rather, this document is intended to provide a high-level road map for the changes needed in the next few years.

The National Patient Safety Foundation will lead these efforts. However, this document also is a call to action to all hospitals, health systems, and national and local healthcare organizations to involve patients and families in their systems and patient safety programs. Through individual and collaborative action, we envision that patients will ultimately be empowered to say, “Nothing about me, without me.”

I. Education and Awareness

Raising awareness about medical errors and patient safety through education of the many key groups involved with health care is crucial to achieving widespread change in patient safety. The task of developing and implementing patient safety education needs to be directed to both the public and to healthcare organizations and professionals. The patient safety movement involves patients, families and healthcare industry professionals; it is critical to raise awareness of the importance and benefits of incorporating the patient/family perspective at every point along the continuum of healthcare decision-making and delivery.

Action needs to be taken to:

- A. *Raise public awareness on the definition and frequency of medical error and patient safety.* This can be accomplished through public education campaigns, public service announcements, flyers, Web sites, and educational literature distributed to physician offices, hospitals, and

other healthcare institutions. Examples of these types of programs are the NPSF's Stand Up for Patient Safety Campaign, National Patient Safety Awareness Week, JCAHO's Speak Up program, and other similar activities.

- B. *Educate the public on how to aid in safeguarding their own care* by becoming active members of the healthcare team.
- C. *Educate healthcare professionals and leadership about the importance of the patient/family perspective* and how this perspective should be actively integrated with healthcare systems and programs.
- D. *Raise healthcare providers' awareness of the experiences of patients and their families* and how they differ from the experiences of professionals who interact with the healthcare system on a regular basis.
- E. *Raise awareness in the behavioral health community (eg, counselors, social workers, etc.) on medical errors* and their effects on individuals and family members, including the specific needs of those who have experienced harm as a result of an error. In many cases, staff members involved with a medical error may also benefit from counseling services.
- F. *Educate the media* on the principles of patient safety, and engage them in promoting effective error-reduction methodology and providing positive reinforcement for communication about errors.
- G. *Build patient safety and medical error prevention into all healthcare professional education curricula*, with an emphasis on the perspective of patients and families. This education should be mandatory for undergraduate, graduate and continuing education programs. This is particularly important for undergraduate education, and the training of future healthcare professionals. The design should include a participatory component that directly involves patients and families as educators on the consumer perspective on safety and communication in the healthcare system.
- H. *Build interactive, interdisciplinary education programs* that bring together patients and professionals. Although it is important to raise awareness in each population mentioned above, it is at least as crucial to bring these groups together to learn from each other and build a stronger foundation for true change in patient safety.
- I. *Develop a central clearinghouse and interactive resource center* for education, training and resources on patient safety and prevention of medical error for patients and professionals. This clearinghouse should also include tools, such as "medication cards" used by patients and families to write down and carry with them their list of medications, allergies, chronic illnesses, contact information, etc.

Resources for consumers:

- Information about patient safety and the healthcare system and how they can become engaged in helping to prevent medical error
- Information regarding options and support after a medical error has taken place

Resources for organizations include how to create a culture of safety, such as how to incorporate patients and families into their systems and programs. This includes, but is not limited to, information on how to:

- Create a patient and family advisory council
- Conduct focus groups with patients/families
- Set up support groups for patients/families who have experienced a medical error
- Incorporate the patient/family perspective into an organization's systems and operations

Also see training programs related to the above resources in the section on support services.

2. Building A Culture of Patient- and Family-Centered Patient Safety

Although education is an important step, real change cannot take place without a fundamental shift in the culture of health care. At present, there is a division between patients/families and providers that creates more potential for medical error and adverse events. *Therefore, part of creating a culture of safety is creating a patient- and family-centered culture of patient safety.* The ultimate goal is for every hospital in the country to have patient and family advisory councils (PFACs), as well as active local patient safety task forces and coalitions in each state.

To build partnership with patients and families, action is needed to:

- A. **Teach and encourage effective communication skills** for both patients/families and healthcare professionals.
 - An effective system can function only through open communication between healthcare professionals and with their leadership.
 - Patients and families should be taught how to communicate effectively about their health concerns, and encouraged to share all information with their providers.
- B. **Engage leadership in promoting and training providers in open communication about medical error.** Effective communication skills are important prior to an error, but are essential once an error has occurred. Providers should be expected to openly communicate to patients and families the complete circumstances surrounding an error, apologize if appropriate, and discuss how the provider or institution will address the problem to prevent similar errors in the future.
- C. **Empower hospital patient representatives to effectively advocate** and facilitate communication for patients and families during and following a medical error. Often, these representatives (such as ombudsmen, social workers, and patient advocates) are in place. They should be trained in patient safety and issues regarding medical error and their services should be openly publicized to patients and their families. This method can be used to help “bridge the gap” between patients and hospitals. However, patient representatives are facilitators, and should not speak

for patients and families. They are not a replacement for effective communication and partnership between healthcare professionals and patients and families.

- D. Establish patient and family advisory councils (PFACs):** Each organization should try to ensure that the patient/family perspective is represented in all aspects of healthcare delivery by creating PFACs. These PFACs must have commitment and participation from the hospitals' senior leadership to effectively integrate the shared expertise of patients, families and healthcare professionals into a culture of safety. The Institute for Family-Centered Care has developed extensive resources on how to develop and effectively run a PFAC. This model has proven successful in several leading hospitals.
- E. Represent patients' interests on boards of trustees:** Hospitals and healthcare organizations should have at least one seat on their board reserved for a non-staff individual who can effectively represent the voice of patients. There should be patient and family representation on key hospital committees, such as ethics and IRB committees.
- F. Establish patient safety task forces:** Each state should have a designated committee focused solely on patient safety. These units should include patients/families, physicians, nurses, insurance, pharmaceutical and administrative representatives, among others.
- G. Create a national forum for state coalitions:** To achieve significant improvement in patient safety, it is critical for each state to embrace and promote patient safety locally. The National Patient Safety Foundation will create a forum for state coalitions to:
- Successfully integrate patients and families into all patient safety activities
 - Provide an infrastructure for sharing, creating and disseminating messages and information on resources and services, as they are developed and available. (For example, see the section on services that may be rolled out nationally, then statewide and locally.)

3. Research

Although funded research related to patients and families appears to be increasing, this area constitutes a very small percentage of the research being funded in patient safety. The areas suggested for research in this agenda refer to areas that could either use further study, or are significant gaps in the research currently being funded and conducted.

Research trends related to patients and families

A review of the NPSF catalogue of ongoing research in patient safety¹ showed that in 2000, there was no research related specifically to patients and families. In 2001, there was an increase to eight projects out of

1. Cooper JB, Sorensen AV, Anderson SM, Zipperer LA, Blum LN, Blim JF: Current Research on Patient Safety in the United States. Final Report. Health Systems Research, Inc. subcontract # 290-95-2000. National Patient Safety Foundation (www.npsf.org), 2001.

121, or 6.6% of funded research. However, although these eight projects were related to patients and families, the central focus was many times much broader.

Topics addressed by these eight research projects include:

- How patients and families want to be told of an error
- Patient-based strategy to reduce errors in diabetes care
- Usefulness of reporting by patients
- Communication between professionals and patients and families
- Educational programs (including NPSF's Web-based education initiative)
- How medical errors affect patients, particularly low-income and culturally disadvantaged patients

Increased interest in consumer-focused research is further indicated by NPSF's Research Grants Program. In 2001, the Foundation received eight proposals for consumer-focused research out of 79 (10%); in 2002, proposals for consumer-focused research more than quadrupled, representing 34 proposals out of 155 (22%).

Patient and family survey results

In a recent NPSF survey asking patient advocates to name top areas of interest in patient safety, the following topics received the highest level of interest for further education and training:

- Methods to protect self and others
- Identification and reporting of errors
- Methods to deal with unsafe practices
- Strategies for discussing safety concerns with healthcare providers

Suggested areas of research

The NPSF PFAC recommends the following areas for research, based on what is already being done, what patients would like further information on, and what could ultimately provide great benefit to patients and professionals.

- A. *"Bridging the Gap"*: Identify effective methods for building relationships and communication among patients, caregivers, and providers, including how to incorporate the patient and caregiver into the healthcare team. This may include research on generational issues related to patient perspectives and safety.
- B. *Disclosure*: Identify how providers and healthcare systems can effectively communicate with patients and families following an error or adverse event, as well as the effects on patients and families of disclosing or not disclosing information related to an error or adverse event. This might include studies on alternatives for facilitated communication between parties.

-
- C. Short- and long-term effects of incorporating patients and families into the system:* Research how to incorporate patients and families' perspectives into the system through patient and family advisory councils or other such initiatives, and the effects of this approach.
 - D. Current patient safety information and resource landscape for patients and families:* Review and share current resources and systems in place for patients and families who have experienced an error. Determine how effective current education and awareness-raising campaigns are in preventing error and involving patients in their own care.
 - E. Post-traumatic stress specific to medical error:* Study the effects of medical errors on families, the process they go through following an error, and how it is different from other grief processes. Focus attention on which factors aid or hinder the healing process (eg, disclosure, restitution, facilitated communication efforts, etc.). Research on the effects of a medical error on involved staff members would also be beneficial.
 - F. Team relationships:* Determine methods for improving teamwork among healthcare professionals, and for including patients and families on the team. Identify how these methods can improve patient satisfaction and prevent medical errors.

4. Support Services

There are three phases of medical error: preventing the error, preventing harm caused by the error, and mitigating the effects of a harmful error. Although our primary focus is on prevention, it is also very important to address support services needed following a medical error. Currently, very few, if any, national or state-based resources are available for patients and families who have experienced harm due to error. Developing the following services is top priority for helping to mitigate the tragic effects of a medical error for patients and families:

- A. National resource center and information line:* This clearinghouse should be developed to provide both national and available regional resources and information on options for recourse, connection to a peer resource counseling program, and general listening and counseling support.
- B. Emergency hotline:* Although it would be difficult to develop this resource immediately, a long-term goal is to create an emergency telephone line that patients and families could call for intervention during or immediately following an error. The ultimate goal would be to have local emergency resources available.
- C. Peer resource counseling:* Through the national resource center, this service would connect people who have experienced a medical error and have been trained in peer counseling with those who need support and guidance. Efforts would be made to connect people who have had similar experiences (to the extent possible). Peer counseling could also be used for patients who would like to learn more about how they can help prevent an error. Many successful examples of this type of program are available from other fields of healthcare, and are easily transferable to patient safety.

-
- D. Support groups* should be available throughout the country in hospitals and healthcare organizations for families and individuals who have suffered due to a medical error. These groups should be led by individuals familiar with issues related to medical error, and are trained in leading support groups.
- E. Disclosure and communications programs* should be developed and promoted specifically for “bridging the gap” between hospitals, providers, and patients/families in cases of medical error.
- F. National training programs* should provide the knowledge and resources to healthcare systems trying to implement any of the above services. Training programs should include:
- Creating a local peer-counseling program
 - Starting and leading support groups
 - Developing a Patient and Family Advisory Council
 - Conducting patient safety knowledge and communication workshops for counselors and behavioral health professionals, nurses, risk managers, patient representatives, and other health care professionals.

These training programs are a natural next step in bringing the benefits of the national program down to the local level.

Conclusion

This Agenda for Action is by no means exhaustive. It represents a first step in depicting the spectrum of activity that needs to take place to address the concerns of patients and families involved with the healthcare process preceding and following preventable medical error. The NPSF hopes to trigger a national discussion on these concepts, as well as pilot projects, practice changes, system improvements, targeted research and ultimately widespread culture change. Through sharing of experiences and perspectives with a focus on communication skills and team building, we hope to establish common practices and systems that honor and respect the needs of patients and families. This agenda should serve as a launching pad — not a destination.

* This report was developed by the National Patient Safety Foundation's Patient and Family Advisory Council. 2003 © All rights reserved. For further information, contact the NPSF at 312-464-4848 or visit the Web site at www.npsf.org.