PARTNERING WITH PATIENTS AND FAMILIES TO ENHANCE SAFETY AND QUALITY

A Mini Toolkit

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The **Institute for Patient- and Family-Centered Care** provides essential leadership for advancing the practice of patient- and family-centered care. Through the development and dissemination of materials, policy and research initiatives, training, technical assistance, and on-site consultation, the Institute serves as a central resource for increasing the understanding and skills necessary to build effective partnerships with patients and families.

For well over a decade, there has been growing recognition of the enormous benefits patient- and family-centered care offers to health care providers, patients, and families in all areas of health care. As hospitals, primary care practices, other outpatient settings, and health systems struggle with issues related to quality, safety, HIPAA compliance, workforce capacity, the use of technology, the need to renovate or build new facilities, and cost control, they are recognizing that patient- and family-centered approaches and the perspectives of patients and families are essential to their efforts.

Visit our website at www.ipfcc.org for additional resources, tools, schedule of events, profiles of patient and family advisors and leaders, and profiles of organizational change.

Today, health care leaders, clinicians, and staff are seeking to partner with patients and families to enhance quality and safety. The purpose of this resource is to provide tools and resources that will support these efforts. Included in this mini toolkit, are the following:

- Patients and Families as Advisors in Enhancing Safety and Quality: Broadening Our Vision
- Patient and Family Advisors Sample Application Form
- Patient Safety Champions: Their Roles in Developing and Supporting Partnerships with Patients and Families
- Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees and Task Forces
- Applying Patient- and Family-Centered Concepts to Rapid Response Teams
- Selected Resources for Partnering with Patients and Families in Patient Safety

For additional information and strategies, download the following resources from the Institute's website at http://www.ipfcc.org/tools/downloads.html

Advancing the Practice of Patient- and Family-Centered Care in Hospitals: How to Get Started

Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Settings: How to Get Started

PATIENTS AND FAMILIES AS ADVISORS IN ENHANCING SAFETY AND QUALITY: BROADENING OUR VISION

There are countless ways that patients and families can serve as advisors to enhance quality and safety, redesign systems of care, and educate health care professionals and other staff, students, and trainees about safety. Some are formal and ongoing, others are time-limited and informal. All are necessary to ensure that care is safe and truly responsive to patient and family needs, priorities, goals, and values. Below is a list of some of the ways that patients and families can serve as advisors.

Patient and Family Advisory Council

- Create a patient and family advisory council for the organization and ensure that patient safety is a regular agenda item.
    - Encourage council members to hold quarterly or semi-annual coffee hours with patients, families, staff, and physicians to explore ideas for improving the experience of care and enhancing quality and safety.
    - Encourage hospital and clinic leaders to invite council members or other experienced patient and family advisors to participate in patient safety rounding.

Patient Safety Committee and Related Task Forces

- Appoint patient and family advisors (at least three) to serve on the Patient Safety Committee.
- Include patients and families on teams developing systems and practices for medication reconciliation.
- Include patient and family advisors as members of the team planning, implementing, and evaluating a Rapid Response Team that can be called by patients and families (Condition H).
- Appoint patient and family advisors to task forces and teams working on patient safety and other quality improvement endeavors.
- With thoughtful planning and support, include patient and family advisors as part of the root cause analysis process.
- Involve patient and family advisors in developing supportive programs and resources for patients or families who have experienced medical error.

Changing the Concept of Families as Visitors

- Appoint patient and family advisors to hospital committees working to change the concept of families as visitors to the view that families are allies for quality and safety; they are the constant and consistent advocates for patients across the transitions in health care.
- Appoint patient and family advisors to HIPAA committees to ensure that families are broadly defined and involved in care and decision-making according to patients' preferences.
- Include patient and family advisors on teams developing systems and approaches to enhance safety and consistency of care in discharge planning and other transitions and handoffs.

Patient and Family Information and Education Resources

- Involve patient and family advisors in helping the health system, hospitals, and clinics in developing a variety of ways for other patients and families to become knowledgeable about risks and their roles in patient safety.
- Hold brainstorming sessions with patients and families before developing educational materials and programs about patient safety and then involve them throughout the development process.
- Ask patient and family advisors to assist in translating informational resources and in ensuring that these materials are written or available in formats that are understandable and useful to all people, regardless of their level of literacy.
- Train and support patients and families to lead or co-lead educational and support programs.
- Invite patient and family advisors to participate in the development of the hospital's or clinic's website, ensuring that there is useful information about the patient and family role in patient safety and the prevention of medical error.

Perceptions of Care

- Develop, with patients and families, a patient/family satisfaction survey and involve them in developing the responses to issues and problems identified.
- Include questions about patient safety, medical errors, and perceived risks in follow-up phone calls with patients and/or families after a hospital stay or clinic visit.

Professional Education

- Invite patients or families to share stories about the experience of care at staff orientation and inservice programs.
- Involve patient and family advisors in training activities for staff and physicians that focus on collaborating with patients and families in improving safety and quality. Train patient and family advisors to participate as "actors" and in debriefing sessions in simulation-based training for clinicians and staff.
- Involve patient and family advisors in teaching medical students, residents, fellows, other physicians and faculty, and nurses about medical errors and how to disclose a medical error or a near miss with patients and families.

Patient Safety Week Activities

- Invite patient and family advisors to participate in the planning for Patient Safety Week Activities.
    - Solicit patient and family involvement in developing linkages with community programs and resources.
    - In planning patient safety events, ask patient and family advisors to "open the door" to community organizations and agencies, local businesses and business groups, schools, religious organizations, and retirement communities, to mention a few.
- Ask patients and families to accompany staff when they meet with community leaders,
  funders, legislators, and other policy makers.

Adapted from Jeppson, E., & Thomas, J. (1994). *Essential Allies: Families as Advisors*. Institute for Family-Centered Care, Bethesda, MD.

Additional guidance resources available through the Institute for Patient- and Family-Centered Care: Webster, P. D., & Johnson, B. H. (2000). *Developing and Sustaining a Patient and Family Advisory Council*; Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating Patient and Family Faculty Programs.*

For additional information about building partnerships with patients and families, visit:

Institute for Patient- and Family-Centered Care: Advancing the Practice: Patients and Families as Advisors and Leaders at http://www.ipfcc.org/advance/pafam.html.

PATIENT AND FAMILY ADVISORS
SAMPLE APPLICATION FORM

(Please Print)

Name: _____

Address: _____

City: _____ State: _____ Zip Code: _____

Telephone: (Area Code) (_____) _____

Fax Number: (Area Code) (_____) _____

E-Mail Address: _____

. . . . . .

Program/Department and Services involved in your care:

Your care was primarily:

- ☐ Inpatient
- ☐ Outpatient
- ☐ Both inpatient and outpatient
- ☐ Emergency care
- ☐ Other programs, departments, or services

Why would you like to serve as an advisor?

Issues of special interest to you:

If you have served as an advisor for other programs or organizations, please briefly describe this experience:

Have you done public speaking or teaching? If so, please describe:

Please specify times when you are able to attend meetings:

☐ Daytime: _____ ☐ Evening: _____ ☐ Weekend: _____

I/We would be interested in helping with:

- ☐ Reviewing Patient and Family Satisfaction Tools
- ☐ Developing/Reviewing Patient/Family Educational Materials and Website Resources
- ☐ Developing and Updating the Hospital's Website
- ☐ Planning for the Ambulatory Care
- ☐ Planning for the Inpatient Care
- ☐ Planning for the Emergency Care Experience
- ☐ Ensuring Patient Safety and the Prevention of Medical Errors
- ☐ Educating Medical Students and Residents, New Employees, and Other Staff About the Experience of Care and Effective Communication and Support
- ☐ Participating in Facility Design Planning
- ☐ Improving the Coordination of Care, Discharge Planning, and the Transition to Home and Community Care
- ☐ Developing the Uses for Information Technology, including Electronic Medical Records, Patient Portals, and Electronic Personal Health Records (ePHR's)

Do you know of other individuals and families who have experienced care at _____ who might be interested in serving as advisors?

Please call them for us or list name(s) and phone number(s) below:

Please return form to:

PATIENT SAFETY CHAMPIONS: THEIR ROLES IN DEVELOPING AND SUPPORTING PARTNERSHIPS WITH PATIENTS AND FAMILIES

In their roles to build awareness for and enhance patient safety in an organization, Patient Safety Champions are uniquely positioned to develop and support partnerships with patients and families at the care level and in a myriad of patient safety and quality improvement initiatives at the organizational level.

Key attributes and qualities of a Patient Safety Champion that contribute to his/her effectiveness:

- **Avoids Tokenism** — Engages patients and families in patient safety initiatives throughout all phases of an initiative: conception of the idea; planning; implementation; evaluation; and sustaining the effort over time.
- **Easily Accessible** — Engages staff, clinicians, patients, and families in meaningful conversations and offers a means to contact the patient care team.
- **Empathy** — Offers empathy to a patient or family impacted by an adverse event, and gives them the opportunity to participate in a Focused Event Review to bring about meaningful change.
- **Feedback** — Actively solicits the ideas and perspectives of patients, families, clinicians, and staff, encouraging everyone to share their safety stories and work to create mechanisms for real time reporting.
- **Physically Visible** — Constantly circulates and talks with staff, clinicians, patients, and families.
- **Resolve** — Understands that a solution may create a "new way of doing things" that is not how it has always been done, but is the right thing to do.
- **Transparent** — Takes ownership of a patient safety related issue, and openly acknowledges an ongoing problem requiring attention.

Patient Safety Champions work to develop the organizational commitment, structure, and processes to foster a patient- and family-centered approach to patient safety, and enhance clinicians' and staff members' ability to collaborate with patients and families.

- **Patient and Family Involvement in Patient Safety Initiatives** — Sees the value of establishing a collaborative working relationship with the Patient and Family Advisory Council, the Youth Advisory Council, and other collaborative endeavors.

- **Patients and Families on Key Organizational Committees** — Affirms that decisions made that will impact families and direct patient care requires patient and family representation as part of the multi-disciplinary team approach — Patient Safety Committee, Ethics, Institutional Review Board, Ad Hoc Committees driven by events, and Policy and Program Development Committees and Improvement Processes.
- **Just Culture** — Encourages the concept that just culture should prevail, and views an error as a systems breakdown vs. an individual mistake. Acknowledges that many things went wrong prior to the event – works to define and change.

TIPS FOR GROUP LEADERS AND FACILITATORS ON INVOLVING PATIENTS AND FAMILIES ON COMMITTEES AND TASK FORCES

Selecting Patients and Families to Serve as Advisors

- Look for people who are:
  - Interested in the topic being addressed by the committee or task force
  - Comfortable in speaking in a group with candor
  - Able to use their personal experience constructively
  - Able to listen and hear differing opinions
- Having just one patient or family member on a committee is not usually successful. Strive for patients and family members to be one-third to one-half of the committee's membership.
- Remember that serving as a patient or family advisor is a new role for many people. Some patients and family members will need more support than others. Recognize that individuals can grow and develop in this role.

Preparation for Meetings

- Consider the convenience and schedules of patients and families as well as staff in planning the times and locations for meetings.
- Send agenda and minutes ahead of time to all committee members, remembering to allow time for material to reach patients and families (they may not have fax machines, email, etc.).
- Provide a list of committee members with a brief description of each person.
- Offer a mentor, an experienced patient or family advisor or another committee member, to support a new advisor.
- Offer to have someone come to the first meeting with a new member and debrief afterwards.
- Remember that this type of collaboration is new for many people so preparation and orientation is important for staff, as well as patients and family members.
- Plan for compensation of time, expertise, and expenses for patients and families. For some this may not be necessary. Often just a small stipend is needed to cover mileage and parking.
- Designate one staff member to be responsible for reimbursement and other practical or logistical issues for patient and family advisors.

During Meetings

- Spend extra time on introductions at the beginning of a meeting, especially for a new committee or when there are new members.
- Provide clear information about the purpose of the committee or task force and the roles and responsibilities of individual members.
- As the leader or chair, discuss the concept of collaborating with patients and families explicitly, recognizing that it is a process with everyone learning together how to work in new ways. Convey that it will be important for the group to discuss how the process is working from time to time.
- Avoid using jargon. Explain technical terms when used.
- Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care.
- Acknowledge that there will be tensions and differing opinions and perceptions.
- Ask for the opinions of patients and families during discussions, encouraging their participation and validating their role as committee members.
- To avoid becoming stuck in the power of a negative situation, acknowledge the negative experience and ask if there was anything supportive, helpful, or positive for the group to learn from the situation. Ask for ideas and suggestions to prevent or improve the situation.
- If a personal story becomes very prolonged, acknowledge the power and importance of the story, suggest that some policy implications can be learned from the story and that there may be other more appropriate forums where this story should be shared.
- When there are extreme differences in opinions or perceptions, consider:
    - Appointing a task force for further study of the issue
    - Asking the opinion of other groups (e.g., another committee or patient/family advisory group)
    - Delaying a decision and considering at a future meeting

Anticipate Illness Demands

- Patients and family members may not be able to attend every meeting. There are other demands on their time and stamina.
- Acknowledge to patients and families themselves and to the committee as a whole that their presence was missed and their participation is valued when they are able to participate. Mailing the minutes and future agendas helps reinforce that their participation is valued.
- Having shared memberships for patients and family members on the committee may help.
- Consider having a "patient and family leave policy" so that consumers can choose an inactive role but maintain their membership should there be circumstances that require some time off.
- Creating a variety of ways for patients and families to participate in the consideration of issues may be useful (e.g., conference calls, written review of materials).

APPLYING PATIENT- AND FAMILY-CENTERED CONCEPTS TO RAPID RESPONSE TEAMS

An important innovation and step toward enhancing quality and safe care is the expanding of the Rapid Response Team process to include patient and family activation. While exact composition varies by hospital, Rapid Response Teams consist of multidisciplinary clinicians and staff, who bring critical care expertise to the patient's bedside for consultation and, if needed, early intervention for clinical deterioration that could lead to acute respiratory and/or cardiac arrest. Research shows that a majority of adult patients show signs of instability six to eight hours prior to a cardiac arrest. The Rapid Response Team is not intended to take the place of the patient's physician, however, if needed, the Rapid Response Team assesses and stabilizes the patient's condition during this window of critical instability if the patient's physician is not readily available. Hospital protocols for Rapid Response Teams identify typical condition changes that are indicators of clinical deterioration of a patient and clinicians have noted that family members may be the first to detect trouble.

Increasingly, staff are partnering with patients and families in the planning, implementation, and evaluation of patient/family activation of Rapid Response Teams. The following serves as guidelines for patient and family activation of Rapid Response Teams within the context of partnership and collaboration with patients and families:

- Consider patient and family activation of Rapid Response Teams as an opportunity to model patient and family partnership and collaboration.
- Involve patients and families in the planning, implementation, and evaluation of patient and family activation of Rapid Response Teams *from the beginning*.
    - The Rapid Response Team process design team could invite patient and family advisors to serve as members of the working group.
    - If the hospital has a Patient and Family Advisory Council, then the Rapid Response Team and its implementation, tracking, and evaluation should be included on its agenda.
    - In order for patients and families to participate, training, preparation, and support should mirror that which is offered to staff participants. They may require context-setting education on Rapid Response Teams and the teams' history at your organization.
    - Clinicians and staff members of the design team would require training in working collaboratively with patients and families.

- Consider reimbursement for time and travel to support patient and family participation as advisors (e.g., related expenses, such as childcare, transportation costs, parking meals, etc.). Coordinate your efforts with your patient- and family-centered care leadership as they often have set up operational processes for advisor involvement.

▼ Ask patients and families what needs to be communicated to support patient and family activation of Rapid Response Teams. Use clear and supportive language that communicates the importance of patient and family perception of a potentially critical situation.

▼ Consider the following issues when developing a Rapid Response Team that can be activated by patients and families:

- Determining whether your model of activation will have patients and families use the same notification process as staff or whether patient and family calls will be triaged and assessment completed by an alternate team.
- Naming the Rapid Response Team.
- Defining the roles of its members.
- Articulating the criteria for calling for the Rapid Response Team.
- Determining the ways that patients and families will be informed about the Rapid Response Team, how to activate it, and other ways patients and families can enhance patient safety.
- Designing information materials for patients, families, staff, and clinicians.
- Developing the follow-up processes for patients, families, staff, and clinicians after activation of a Rapid Response Team.
- Developing an evaluation, monitoring, and measurement strategy to monitor implementation and evaluation of your patient and family activation experience.

The following serves as patient- and family-centered guidance for a Rapid Response Team activated by patients and families.

▼ Introduce the concept of patient and family activation as part of the admission process**.**

- Most hospitals with patient and family activation of Rapid Response Teams include patient and family activation in their admission orientation. Written or audiovisual materials are helpful; some hospitals have volunteer patient/family consultants who orient and prepare patients and families for their role in activation of Rapid Response Teams.

- Include information about a Rapid Response Team on the hospital's website, in patient and family handbooks, and unit, clinic, departmental welcome brochures and media, posters and a variety of patient safety resources. Consider posting the activation telephone number in a visible location in every patient room.
- Choose language that sets the tone for partnership**.**
    - Use clear, simple language to describe criteria and procedures for calling the Rapid Response Team. Encourage reinforcement of patient and family activation of Rapid Response Teams in general hospital communication tools on safety and/or care commitment statement.
- Consider the following topics to include in the various informational resources for patients
  and families:
    - Explanation of why the hospital has a Rapid Response Team.
    - Explanation of the importance of patient and family activation.
    - Description of the members of the Rapid Response Team and what to expect when they arrive in a patient room.
    - Criteria and/or reasons to call a Rapid Response Team.
    - Expectations for response time when Rapid Response Team is called; what to do if the timing of the response to the call does not meet expectations.
    - Types of concerns not appropriate for Rapid Response Team calls BUT can be investigated through other hospital services and contact information for these services.
- Encourage patients, families, and providers to partner in care and decision-making. Support and reinforce ongoing communication and information sharing with patients and families through nurse change of shift report and rounds.
- Ask patients and families at the beginning or end of every shift if they have any safety concerns.
- Provide education and training for administrative leaders and frontline staff and clinicians on patient and family activation of Rapid Response Teams.
    - Structure the format and setting for planning and teaching clinical care staff so that patient and family activation of Rapid Response Team addresses the needs and priorities of all constituencies—patients, families, clinicians, staff, clinicians-in-training, and faculty.
    - Ask staff and Rapid Response Team members if they have concerns about patient and family activation and what could be done to resolve these concerns.

- Develop training modules for clinician and staff education days.
- Reinforce patient and family activation in annual clinician and staff required education on Rapid Response Team competencies.
- Include articles in hospital publications. Profile patients and families helped by Rapid Response Teams and include quotes from clinicians, administrators, patients, and families in support of Rapid Response Teams and patient and family activation. Proactively address concerns expressed by clinicians and staff in these publications.

▼ Prepare patients, families, and providers to partner at the clinical level to assure strong communication before, during, and after Rapid Response Team activation.

- Include suggestions for conversations to have with patients and families at the
  following times:
    - During admission to introduce the concept of the Rapid Response Team and how to access it; and
    - After Rapid Response Team activation to address any remaining concerns and questions and any ideas for improvement.
- Some hospitals have found a structured debrief tool/interview after a Rapid Response Team encounter is helpful in monitoring and improving the process, especially during its early implementation phases. Consider designing a simple process to provide patients, families, and staff with an opportunity to debrief about what they experienced during the Rapid Response Team care experience. Ideas of what to include in this monitoring tool:
    - Reason patient or family activated the Rapid Response Team;
    - Evaluate the effectiveness of instructions given before and communications during Rapid Response Team responses;
    - Patient or family comfort in initiating a Rapid Response Team;
    - Degree to which Rapid Response Team members were respectful and responsive to patient and family concerns and needs;
    - Identification of aspects of the process that worked particularly well; and
    - Recommendations for change or improvement.

Resources for Rapid Response Teams

For the most recent references on this topic, please see the *Patient Safety Bibliography* available from the Institute at http://www.ipfcc.org/advance/supporting.html.

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Deploy Rapid Response Teams - Institute for Healthcare Improvement (IHI)
http://www.ihi.org/IHI/Programs/Campaign/RapidResponseTeams.htm
This special section of the IHI website offers a multitude of resources and tools for establishing Rapid Response Teams.

SELECTED RESOURCES FOR PARTNERING WITH PATIENTS AND FAMILIES IN PATIENT SAFETY

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Selected Websites

Institute for Patient- and Family-Centered Care (IPFCC)

www.ipfcc.org

The Institute's website includes a wealth of resources to support and advance the practice of patient- and family-centered care, including free downloads, online stories from patients, families, providers, and institutions, and an online store with publications, CD-ROMs, and more. The Institute also offers in-depth training seminars and conferences.

In-depth Seminar: *Hospitals and Communities Moving Forward with Patient- and Family-Centered Care: Enhancing Quality and Safety for Patients and Their Families*
www.ipfcc.org/events/index.html

Advancing the Practice of Patient- and Family-Centered Care: How to Get Started AND *Advancing the Practice of Patient- and Family-Centered Care in Primary Care and Other Ambulatory Care Settings: How to Get Started* (Free downloads)
www.ipfcc.org/tools/downloads.html

Agency for Healthcare Research and Quality (AHRQ)

www.ahrq.gov

AHRQ funds, conducts, and disseminates research to improve the quality, safety, efficiency, and effectiveness of health care. The information gathered from this work and made available on the website assists all key stakeholders—patients, families, clinicians, leaders, purchasers, and policymakers—make informed decisions about health care.

American Hospital Association (AHA)

www.aha.org

The AHA is the premier membership organization for U.S. hospitals and provides leadership and advocacy for member hospitals to improve care for patients and their families. IPFCC collaborated with AHA to develop the toolkit, Strategies for Leadership: Patient- and Family-Centered Care and is available for download at: http://www.aha.org/advocacy-issues/http://www.aha.org/advocacy-issues/communicatingpts/pt-family-centered-care.shtml

The AHA McKesson Quest for Quality Prize is a $75,000 award that recognizes a hospital's exemplary leadership in aligning the agendas for quality, safety, and patient- and family-centered care.
http://www.aha.org/about/awards/q4q/index.shtml

Caregiver Action Network (CAN)

www.caregiveraction.org

CAN serves as a clearinghouse of information and support for those caring for others who are aged, disabled, or chronically ill. There are a variety of stories and tools to empower family caregivers and promote advocacy.

Consumers Advancing Patient Safety (CAPS)

www.patientsafety.org

CAPS is a consumer-led nonprofit organization that brings together patients, families, health care professionals, and others to improve patient safety through education, research,

development of error and near miss reporting systems and prevention strategies, and public policy initiatives.

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Institute for Healthcare Improvement (IHI)

www.ihi.org

IHI is a leader in advancing the improvement of health care. IHI's ever-expanding website has a wealth of information on patient and family involvement in quality improvement and research. This includes strategies to capture the patient and family experience of care, as well as to involve patients and families on evaluation teams.

Institute of Medicine (IOM)

www.iom.edu

The IOM is affiliated with the National Academies of Science and serves as a nonprofit organization devoted to providing leadership on health care. IOM's major report, Crossing the Quality Chasm: A New Health System for the 21st Century, serves as a landmark publication in examining the problems of the current U.S. health care system and offering strategies for change. The publication, Preventing Medication Errors, is part of the Crossing the Quality Chasm Series and is available from: http://iom.edu/Reports/2006/Preventing-Medication-Errors-Quality-Chasm-Series.aspx

International Alliance of Patients' Organizations (IAPO)

www.patientsorganizations.org

The IAPO is an international alliance of patients' organizations that promotes patient-centered health care throughout the world. Core principles include respect for unique needs, preferences, and values; choice and empowerment; information sharing; and patient involvement in health policy.

Josie King Foundation

www.josieking.org

In 2001, Josie King, the 18-month old daughter of Tony and Sorrel King, died from medical errors. This organization is dedicated to preventing others from dying or being harmed by medical errors. Efforts to promote partnerships among patients, families, and health care providers are integral to the foundation's work.

Medically Induced Trauma Support Services (MITSS)

www.mitss.org

MITSS is a patient-led nonprofit organization creating awareness about medically induced trauma, promoting open communication among patients, families, and health care professionals, and providing support to individuals who have been affected by medical error.

National Patient Safety Foundation (NPSF)
www.npsf.org
With its mission to improve the safety and welfare of patients in the health care system, NPSF provides an indispensable amount of resources including a specific area devoted solely to resources for patients and families who wish to get involved in patient safety initiatives.

New Health Partnerships (NHP)
http://www.ihi.org/offerings/Initiatives/PastStrategicInitiatives/NewHealthPartnerships/Pages/default.aspx
New Health Partnerships was an IHI initiative to bring together an online community for patients, their families, and health care providers dedicated to improving the health care and lives of people with chronic conditions. Profiles of individuals and organizations, information, tools and other resources promoting collaborative self-management support are archived at the IHI website.

Patient Safety and Quality Healthcare (PSQH)
www.psqh.com
This online journal offers numerous articles highlighting the role of patients and families in patient safety and identifying strategies and benefits.

Professionals with Personal Experience in Chronic Care (PPECC)
www.ppecc.org
This group of health care professionals established PPECC to advocate for improved systems of care after personal and family experiences with chronic illness and long-term care. Health care professionals are encouraged to share their personal experiences with the health care system in order to promote greatly needed change.

PULSE of New York
www.pulseofny.org
PULSE is a community-based nonprofit organization developed and led by patients and families who have experienced medical error. Its mission is to use patient and family stories in increasing patient safety awareness and reducing the incidence of medical error. It provides support to patients and families who have experienced errors and offers training for patient and family advocates for safety within the health care system.

Remaking American Medicine (RAM)
www.ramcampaign.org
In 2006, PBS aired the Remaking American Medicine series that presented the current state of health care and strategies for improvement. This website was created to support the work of local communities across America to effectively improve the quality of health care.

The Sorry Works! Coalition
www.sorryworks.net/
This coalition, composed of all stakeholder groups, including providers, lawyers, and patients, is promoting a transparent model of disclosure of medical errors titled, Sorry Works! Details about the model and related data are presented on the site.

World Alliance for Patient Safety: Patients for Patient Safety
www.who.int/patientsafety/patients_for_patient/en
The World Health Organization has created the alliance and is partnering with patients and families who have experienced error to improve patient safety in all settings across a global network of organizations.