

INSTITUTE FOR FAMILY-CENTERED CARE



Partnering with Patients and Families to Enhance Safety and Quality

A Mini Toolkit

- ▼ *Advancing the Practice of Patient- and Family-Centered Care: How to Get Started AND Advancing the Practice of Patient- and Family-Centered Ambulatory Care: How to Get Started*
DOWNLOAD from:
<http://www.familycenteredcare.org/tools/downloads.html>
- ▼ Patients & Families as Advisors in Enhancing Safety and Quality: Broadening Our Vision
- ▼ Selected Resources for Partnering with Patients and Families In Patient Safety
- ▼ Patient and Family Advisors: Sample Application Form
- ▼ Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees and Task Forces
- ▼ Showcase Efforts to Partner with Patients and Families: Call for Papers for the 4th *International Conference on Patient- and Family-Centered Care*
DOWNLOAD in May 2008 from: www.familycenteredcare.org

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PATIENTS & 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.
- ▼ 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 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 the following websites:

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

New Health Partnerships at <http://www.newhealthpartnerships.org>.



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Selected Resources for Partnering with Patients and Families in Patient Safety

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Selected Websites

Institute for Family-Centered Care (IFCC)

www.familycenteredcare.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.familycenteredcare.org/events/index.html

The 4th International Conference on Patient- and Family-Centered Care

www.familycenteredcare.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 Ambulatory Care: How to Get Started (Free downloads)

www.familycenteredcare.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. IFCC collaborated with AHA to develop the toolkit, *Strategies for Leadership: Patient- and Family-Centered Care* and is available for download at,

www.aha.org/aha/issues/Communicating-With-Patients/pt-family-centered-care.html

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.

www.aha.org/aha/news-center/awards/quest-for-quality/overview.html

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.

Institute for Healthcare Improvement (IHI)

www.ihl.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: www.iom.edu/?id=35961

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 Sorrell 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 Family Caregivers Association (NFCA)

www.nfcacares.org

NFCA 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.

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)

www.newhealthpartnerships.org

New Health Partnerships is 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 offered.

Patients Accelerating Change (PAC)

www.pickereurope.org/page.php?id=13

Patients Accelerating Change (PAC) is a program in the United Kingdom bringing patients together with clinicians and managers in hospitals and primary care settings to transform health care services. A resource packet with case studies and lessons learned through this collaborative work is available from the Picker Institute Europe and the Clinical Governance Support Team.

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 reduce 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.

Voice for Patients

www.voice4patients.com

Voice4Patients is an organization devoted to empowering patients to be their own health care advocates in order to address patient safety concerns and medical errors. The organization advocates building partnerships between patients and providers and provides information and tools to strengthen consumer skills.

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.

**PATIENT AND FAMILY ADVISORS
SAMPLE Application Form**

(Please Print)

Name: _____

Address: _____

City: _____ **State:** _____ **Zip Code:** _____

Telephone: (Area Code) () _____

Fax Number: _____

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:



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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 serving as advisors;
 - comfortable in speaking in a group with candor;
 - able to use their personal experience constructively;
 - able to see beyond their own experience;
 - concerned about more than one issue or agenda;
 - able to listen and hear differing opinions; and
 - representative of patients and families served by the hospital.
- 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 faxes, email, etc.).
- Provide a list of committee members with a brief description of each member.
- Offer a mentor, an experienced patient or family advisor or another committee member, to provide support to a new advisor.
- Offer to have someone come to the first meetings 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.
- 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.
- Consider beginning some meetings with a brief story that captures patients' and families' experiences and perceptions of care.
- As the leader or chair, explicitly discuss the concept of collaborating with patients and families, 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.
- Acknowledge that there will be tensions and differing opinions and perceptions.
- Provide clear information about the purpose of the committee or task force and the roles of individual members.
- Avoid using jargon. Explain technical terms when used.
- 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 the retelling of 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 other more appropriate forums where this story can 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 hospital committee or patient/family advisory group); or
 - delaying a decision and considering at a future meeting.

Anticipate Illness Demands

- Patients and their family members may not be able to attend every meeting. There are other demands on their time and stamina.
- Acknowledge to patients and families individually, 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 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).

For additional guidance resources available through the Institute for 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*; Blaylock, B. L., & Johnson, B. H. (2002). *Advancing the practice of patient- and family-centered geriatric care*; Jeppson, E. S., & Thomas, J. (1995). *Essential Allies: Families as Advisors*; and Thomas, J., & Jeppson, E. S. (1997). *Words of Advice: A Guidebook for Families Serving As Advisors*. Available from the Joint Commission on Accreditation of Healthcare Organization: McGreevey, M. (Ed.). (2006). *Patient as partners: How To involve patients and families in their own care*. Oakbrook, IL: Joint Commission Resources, Inc.