

ADVANCING THE PRACTICE OF PATIENT- AND FAMILY- CENTERED CARE

How to Get Started...



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What is patient- and family-centered care? Why does it matter? How does it fit with our hospital's overall mission? And finally, what can our hospital do to advance the practice of patient- and family-centered care? Where do we start?

Today, hospital leaders and patients and families nationwide are asking these questions. The purpose of this document is to provide some answers.

Part I provides a rationale for a patient- and family-centered approach to care and defines its core concepts.

Part II outlines steps a hospital can take to begin to create partnerships with patients and families and offers practical suggestions for getting started.

Part III, "Where Do We Stand?" provides an assessment tool that hospitals can use to determine the degree to which patient- and family-centered approaches are embedded in their current organizational culture.

Part IV, "Engaging Patients and Families: A High-Leverage Tool for Health Care Leaders," is a firsthand account of one hospital leader's experience.

Part V contains the criteria for the American Hospital Association's McKesson Quest for Quality Prize. This prize honors hospital leadership commitment to quality, safety, and patient- and family-centered care and efforts to systematically integrate this work.

Part VI lists selected print and web resources.

Part VII, "Selecting, Preparing, and Supporting Patient and Family Advisors," offers practical guidance for beginning the process of identifying, recruiting, and sustaining the involvement of advisors.

Part VIII, "A Checklist for Attitudes About Partnering with Patients and Families," provides a tool for gathering information about the perceptions and attitudes of staff and administrative leaders.

PART I: WHAT IS PATIENT- AND FAMILY-CENTERED CARE?

Rationale

In their efforts to improve health care quality and safety, hospital leaders today increasingly realize the importance of including a perspective too long missing from the health care equation: the perspective of patients and families. The experience of care, as perceived by the patient and family, is a key factor in health care quality and safety.

Bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of health care, and thereby improving its quality and safety, is what patient- and family-centered care is all about. Studies increasingly show that when health care administrators, providers, and patients and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increase.



Core Concepts

- ▼ **Dignity and Respect.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- ▼ **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.
- ▼ **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- ▼ **Collaboration.** Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation and evaluation; in facility design; and in professional education, as well as in the delivery of care.

PART II: MOVING FORWARD WITH PATIENT- AND FAMILY-CENTERED CARE: ONE STEP AT A TIME

Establishing patient- and family-centered care requires a long-term commitment. It entails transforming the organizational culture. This approach to care is a journey, not a destination—one that requires continual exploration and evaluation of new ways to collaborate with patients and families.

The following steps can help set a hospital or health system on its journey toward patient- and family-centered care.

1. Implement a process for all senior leaders to learn about patient- and family-centered care. Include patients, families, and staff from all disciplines in this process.
2. Appoint a patient- and family-centered steering committee comprised of patients and families and formal and informal leaders of the organization.
3. Assess the extent to which the concepts and principles of patient- and family-centered care are currently implemented within your hospital or health system. (A brief initial assessment tool appears in the next section of this document.)
4. On the basis of the assessment, set priorities and develop an action plan for establishing patient- and family-centered care at your institution.
5. Using the action plan as a guide, begin to incorporate patient- and family-centered concepts and strategies into the hospital's strategic priorities. Make sure that these concepts are integrated into your organization's mission, philosophy of care, and definition of quality.



6. Invite patients and families to serve as advisors in a variety of ways. Appoint some of these individuals to key committees and task forces.
7. Provide education and support to patients, families and staff on patient- and family-centered care and on how to collaborate effectively in quality improvement and health care redesign. For example, provide opportunities for administrators and clinical staff to hear patients and family members share stories of their health care experiences during orientation and continuing education programs.
8. Monitor changes made, evaluate processes, measure the impact, continue to advance practice, and celebrate and recognize success.

PART III: WHERE DO WE STAND? AN ASSESSMENT TOOL FOR HOSPITAL TRUSTEES, ADMINISTRATORS, PROVIDERS, AND PATIENT AND FAMILY LEADERS

An effective action plan for moving forward with patient- and family-centered care is based on a thoughtful assessment of the degree to which a hospital has already incorporated key principles of this approach to care and of the areas in which progress remains to be made.

Here are some questions that can serve as a springboard for such an assessment. Ideally, the assessment should be completed individually by hospital executives, managers, front line staff, and patient and family advisors. Representatives of each of these groups should then convene to discuss the responses and, together, develop an action plan.

INITIAL HOSPITAL ASSESSMENT

Organizational Culture and Philosophy of Care

- Do the organization's vision, mission, and philosophy of care statements reflect the principles of patient- and family-centered care and promote partnerships with the patients and families it serves?
- Has the organization defined quality health care and does this definition include how patients and families will experience care?
- Has the definition of quality and philosophy of care been communicated clearly throughout the health care organization, to patients and families, and others in the community?
- Do the organization's leaders model collaboration with patients and families?
- Are the organization's policies, programs, and staff practices consistent with the view that families are allies for patient health, safety, and well-being?



Patient and Family Participation in Organizational Advisory Roles

- Is there an organizational Patient and Family Advisory Council?
 - ▽ If there is a Patient and Family Advisory Council, is patient safety a regular agenda item?
- Do patients and families serve on committees and work groups involved in:
 - ▽ Patient safety?
 - ▽ Quality improvement?
 - ▽ Facility design?
 - ▽ Patient/family education?
 - ▽ Service excellence?
 - ▽ Discharge/transition planning?
 - ▽ Staff orientation and education?
 - ▽ Ethics?

Architecture and Design

- Does the health care organization's architecture and design:
 - ▽ Create welcoming impressions throughout the facility for patients and families?
 - ▽ Reflect the diversity of patients and families served?
 - ▽ Provide for the privacy and comfort of patients and families?
 - ▽ Support the presence and participation of families?
 - ▽ Facilitate patient and family access to information?
 - ▽ Support the collaboration of staff across disciplines and with patients and families?

Patient and Family Access to Information

- Are patients and families viewed as essential members of the health care team? For example, are they encouraged and supported to participate in care planning and decision-making?
- Are there systems in place to ensure that patients and families have access to complete, unbiased, and useful information?
- Are patients and families encouraged to be present and to participate in rounds and nurse change of shift?



- Are patients and families encouraged to review their medical records and work with staff and physicians to correct inaccuracies?
- Are patients and families provided with practical information on how to best assure safety in health care?

Education and Training Programs

- Do orientation and education programs prepare staff, physicians, students, and trainees for patient- and family-centered practice and collaboration with patients, families, and other disciplines?
- Are patients and families involved as faculty in orientation and educational programs?

Research

- In research programs, do patients and families participate in:
 - ▽ Shaping the agenda?
 - ▽ Conducting the research?
 - ▽ Analyzing the data?
 - ▽ Disseminating the results?

Human Resources Policies

- Does the organization's human resources system support and encourage the practice of patient- and family-centered care?
- Are there policies in place to ensure that:
 - ▽ Individuals with patient- and family-centered skills and attitudes are hired?
 - ▽ There are explicit expectations that all employees respect and collaborate with patients, families, and staff across disciplines and departments?

PART IV: ENGAGING PATIENTS & FAMILIES: A HIGH LEVERAGE TOOL FOR HEALTH CARE LEADERS

The 15-year experience of the MCG Health System in Augusta, Georgia, highlights the critical need for commitment of senior leadership to sustain meaningful change.

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OUR MISSION

The AHA Quality Center is a resource of the American Hospital Association designed to help hospitals accelerate their quality improvement processes to achieve better outcomes for patients and improve organizational performance.

ENGAGING PATIENTS & FAMILIES: A HIGH LEVERAGE TOOL FOR HEALTH CARE LEADERS

BY PATRICIA SODOMKA

Edith Martin's daughter, Adrienne, was well into her first pregnancy in 1992. What a joyous time for the soon-to-be grandmother. Then, tragedy struck. Adrienne was stabbed three times in the back and Martin's grandson, Joey, was born with severe disabilities. Joey has reactive airways disease, seizure disorder, cerebral palsy and other disorders. At last count, Joey is taking 17 different medications daily.

With as much time as this family has spent at the MCG children's hospital over the past decade, the knowledge it has acquired of what works and what doesn't is significant. Martin's experience and wisdom has been put to great use as an active participant in the center's Family Advisory Council for the past nine years and as its current chair, as well as a member of the family faculty at the Medical College of Georgia.

We believe that families are an extension of the patient, not an imposition. At MCG Health System, we find that the more involved a patient and family are in the care, the more we improve quality, increase safety and boost patient and family satisfaction. We don't have visitors, we have families like the Martin's and they are an integral part of the health care team.

A RADICALLY DIFFERENT APPROACH

Patient- and family-centered care is an approach to the planning, delivery and evaluation of health care that is governed by collaborative partnerships among health care providers, patients and families. What is difficult for many to appreciate is that for the most part today's health systems do not foster collaboration among patients, families and caregivers (www.aha.org/aha/key_issues/patient_safety/resources/patientcenteredcare.html).

At MCG Health System, we strive to incorporate the four principles developed by the Institute for Family-Centered Care and reflected in the AHA Toolkit for Leadership.

- We treat patients and families with dignity and respect.
- We provide clear, comprehensive information in ways that are useful and empowering.
- We create opportunities for patients and families to participate in ways that enhance their control and independence.
- We ensure that collaboration is inherent in our policies, programs, education and delivery of care.

Patient- and family-centered care is radically different from the traditional model of care in several ways.

STRENGTHS. The traditional model of care places emphasis on restricting patients and families. In contrast, the patient- and

family-centered model emphasizes the strengths that patients and families can bring to the healing process. After all, patients and families are the experts in their lives. They are the keepers of valuable information that caregivers must learn in order to take a personal and individualized approach to health care. Their knowledge and information can enhance diagnoses and treatment, and can decrease the probability of errors and unnecessary care.

COLLABORATION. Control is the foundation of the traditional model. Collaboration is the bedrock of the patient and family model. Collaboration is based on establishing:

- Mutual respect for skills and knowledge
- Honest and clear communication
- Understanding and empathy
- Mutually agreed-upon goals
- Shared planning and decision-making
- Open communication and sharing of information
- Accessibility and responsiveness
- Joint evaluation of progress
- Absence of labeling and blaming.

PARTNERSHIP. The traditional model calls for patients and families to give blind obedience to the expertise of paternalistic health care professionals. The patient- and family-centered model calls for an equal partnership. This is not about advocacy, although advocacy is important. It is not about enhancing case management, which is also very important. It is not about holding focus groups or occasionally asking for opinions and feedback from patients. In the patient- and family-centered care model patients and families are viewed as essential allies and treated as true partners.

FLEXIBILITY. As you move from a traditional model of health care to a patient- and family-centered model, you realize that the health care system can flex in many unexpected ways. Restrictive visiting hours go away. Patients and families can exercise choices in how things are done to enhance their control, such as husband and wife holding hands during a painful procedure.

GETTING STARTED

The hard part is understanding that the shift to patient- and family-centered care is a fundamental change in how you manage your hospital. The concepts of patient- and family-centered care are woven into the infrastructure of your organization—in



strategic plans, vision and values, facility design, patterns of care, information-sharing processes, family support, charting and documentation, human resources management, professional education, and quality and safety improvement processes.

The key is to partner with patients and families who are trained as formal advisers.

First, designate a staff member to serve as a liaison for collaborative endeavors. This individual must have patient- and family-centered knowledge and skills or the capacity to acquire these skills.

Second, identify several staff members and physicians to serve on an informal workgroup.

Third, select patients and families to serve on this workgroup. Patients and family advisers most typically serve as volunteers. Be sure to involve them from the beginning of a project, where their perspective can help everyone to creatively solve problems.

Once you have the appropriate team members around the table, ask them to envision the ideal patient and family experience. Ask what is currently working well and what is not. Are there simple issues that could be addressed quickly and successfully through a collaborative process? As the group grows comfortable with its role over time, ask participants to conduct a patient- and family-centered assessment of your policies and practices. And, as this model of care gains traction within your organization, ask patients and family members to attend various committee meetings, such as your patient safety meetings, to explore issues of mutual concern. The unique perspectives you will gain from patients and families will significantly enhance your programs and services.

The single most important guideline for involving families and patients in any advisory role is to believe that their participation is essential to the design and delivery of optimum care and services. Without sustained patient participation in all aspects of policy and program development and evaluation, we as health care providers fail to respond to the real needs and concerns of those our system is intended to serve.

MORE THAN A NICE THING TO DO

Patient- and family-centered care is much more than a nice gesture. It can have a considerable impact on bottom-line issues. This model of care provides a framework and strategies for achieving your quality and safety goals, enhancing market share, lowering costs, and strengthening staff satisfaction.

Our health system's cultural transformation began with the design of a new children's hospital in the early 1990s. Patients

and family members served on all 24 of the committees tasked with planning and designing the pediatric hospital. The results are still evident in the physical plant as well as the policies, programs and services. From that involvement sprung numerous other patient and family advisory groups that have influenced health and wellness resource areas, open ICUs, surgical mentors for the parents of pediatric patients, and everything in between. Patient satisfaction scores for the children's hospital are among the highest as measured by Press Ganey.

In 2004, patient advisers were an integral part of the planning and design for a new adult neuroscience unit at MCG Health System, even interviewing the physicians and nurses hired to work on the unit. After the conversion of this unit to the patient- and family-centered philosophy of care, patient satisfaction improved significantly, the staff vacancy rate dropped from 7.5 percent to zero and RNs are waiting for openings to occur on this unit. In addition, our length of stay for neurosurgery patients was cut in half and our discharges increased by 15.5 percent. Importantly, medication errors decreased by 62 percent.

The Breast Health Center was another service in which a breast cancer survivor partnered with staff and physicians to reinvent the care. Since its opening, patient satisfaction moved from the 40th percentile to above the 90th percentile of Press Ganey.

LET THE 'MIRACLE' BEGIN

Robert Shaw, creator of the 200-voice Atlanta Symphony Orchestra Chorus, is internationally known for his ability to blend hundreds of voices into unforgettable music.

Once Shaw was asked how he was able to do this, often with very short rehearsal times. His answer says a lot about what it takes to bring about winning combinations of people and organizations. "Once we find each other," he said simply, "the miracle begins."

The same is true of patients and families and health care providers. Once we find each other, the miracle begins. It is time to get started.—*Patricia Sodomka, FACHE, is senior vice president of patient- and family-centered care at MCG Health Inc. and director of the Center for Patient and Family Centered Care, Medical College of Georgia. Visit the AHA Quality Center at www.ahaqualitycenter.org to explore these and other topics.*



PART V: AHA MCKESSON QUEST FOR QUALITY PRIZE CRITERIA

These criteria reflect a vision for health care that is well described in the Institute of Medicine report (IOM), *Crossing the Quality Chasm*. This report describes six aims (safety, patient-centeredness, effectiveness, efficiency, timeliness, and equity) as the basis of a comprehensive quality-oriented health care system. This award will honor organizations that are committed to and have made demonstrable progress toward making this vision a reality. The criteria are useful in planning change. These criteria and further information about this award are also available at www.aha.org/aha/awards-events/quest_for_quality/criteria.html.

I. Role of Organizational Leadership

(defined as governing body, administration, and clinical staff leadership).

Through active collaboration, the organizational leadership:

- A. Defines quality health care and reflects that definition in the mission, value statements, and strategic plan.
- B. Defines short- and long-term goals to improve quality health care with specific timelines; leadership:
 1. Bases goals on regular, recurring systematic qualitative and quantitative assessments of community health care needs and organizational needs based on internal quality and patient safety measurement data.
 2. Engages patients and their families in defining quality health care and in determining the organization's short- and long-term goals.
 3. Addresses the IOM six aims (safety, patient-centeredness, effectiveness, efficiency, timeliness, and equity) in the organization's goals.
 4. Focuses on consistency and predictability (reliability) of the organization's care and services as critical to the provision of exceptional individual and population (community) health care; considers elements that affect this reliability, such as workforce/culture issues, technology, and environmental design, in the development of the goals.
 5. Integrates goals in the organization's strategic plan, defines them as key organizational priorities, and develops short-term (annual), intermediate, and long-term objectives.
 6. Reflects the definition of quality health care and associated goals in the organization's policies, procedures, and communications and integrates them throughout the organization's patient care systems and physical environment.



7. Specifies core measures relative to the goals that are used throughout the organization and leads regular assessments to trend performance in achieving goals relative to the specific timelines, compares performance to known benchmarks, and identifies barriers that impede progress.
8. Discusses these assessments and develops, based on the assessments, action plans and new goals and timelines for accomplishment as appropriate; and takes steps to remove barriers to progress.
 - Demonstrates continual commitment to goal achievement through personal visibility; active participation in setting priorities, monitoring progress, and removing barriers to progress; and overall promotion of quality health care.
 - Models effective communication, information-sharing, and collaboration with all colleagues, employees, patients and families, other health care organizations, health-related organizations (including payers), and community leaders.
 - Reaches out to and involves patients and family members in defining quality and quality goals.
 - Ensures adequate resources are allocated for achievement of quality goals.
 - Supports investment in clinical information systems (as resources allow) as a major institutional priority.

C. Governing Body (The Board of Trustees)

1. Actively engages in oversight of quality health care and ensures that quality goals are achieved.
2. Ties hospital CEO accountability and incentives to meeting quality goals.

D. Clinical Staff Leadership

1. Seeks input and feedback from all other clinical staff in defining quality goals and the determination of organizational quality priorities.
2. Routinely communicates the organization's quality priorities, goals, and goal achievement to all clinical staff.
3. Actively works with all clinical staff to identify, implement, and update evidence-based practices.



4. Establishes clear behavioral expectations for clinical staff that foster interdisciplinary teamwork and collaboration with patients and families.
5. Provides ongoing team and/or individual patient outcome data (including elements of patient-centered care) and information on relationship management to clinical staff and uses that information to guide continuing education initiatives, peer review activities, ongoing credentialing and privileging decisions, and individual improvement.
6. Ensures that credentialing and/or privilege decisions for new and current clinical staff rely on demonstrated competence to perform the relevant procedures, particularly invasive ones.
7. Facilitates standardization of medical devices, other technologies, and protocols for care where feasible.

E. Administration

1. Routinely communicates the organization's quality health care definition, priorities, goals, and progress toward achievement of goals to all hospital staff.
2. Actively ensures that all activities and departments within the organization are directly aligned (i.e., there is a consistency of plans, processes, measures, and actions) to achieve quality goals.
3. Evaluates all management decisions including purchases of supplies and technology and contracting decisions relative to their impact on health care quality and quality goals, as defined by the organization's leadership.
4. Ties senior management accountability and incentives to implementing measures to enhance quality health care and achieving quality goals.



II. Information and Analysis

- A. Defines and routinely monitors performance measures for each of the six IOM quality aims (listed below) for the full range of services provided by the organization using standardized, reliable, and valid measures, where available.

For example, the following should be monitored:

Safety: availability (timeliness and completeness) of clinical information needed to effectively manage patient care within the organization and among and between sites of care throughout the continuum; clarity of patient care management plans, including hand-offs to outside organizations and/or providers; coordination of communication with patients and families; and consistent implementation and execution of diagnostic and treatment plans.

Patient-Centeredness: determining from the perspective of patients and families the adequacy of shared decision-making, coordination and continuity of care, communication (ease of access to information, amount of information desired by patients and families, and timely disclosure of adverse events), timeliness of care, emotional and physical comfort, involvement of family as desired by the patient, and use of patient and family feedback to improve care.

Effectiveness: implementation, updating, and use of evidence-based clinical practices in the care of patients, with particular attention to those conditions targeted by the IOM report Priority Areas for National Action: Transforming Health Care Quality (available at: <http://www.iom.edu/report.asp?id=4290>), as well as the Agency for Healthcare Research and Quality (AHRQ) National Healthcare Quality Report (available at http://www.qualitytools.ahrq.gov/qualityreport/download_report.aspx).

Efficiency: minimizing inappropriate variation, duplication, and unnecessary repetition in administrative and clinical processes of care.

Timeliness: of access to care, start of scheduled procedures, consults, and admitting and discharging of patients.

Equity: health status for populations served, including evaluating racial, ethnic, and gender disparities in care, with particular attention to those disparities identified by the AHRQ National Health Disparities Report (available at: <http://www.qualitytools.ahrq.gov/disparitiesreport/downloadreport.aspx>).



- B. Implements and uses clinical information systems, as resources permit, to effectively support the ready availability of patient care information and to enhance the effectiveness and efficiency of organizational performance measurement activities.
- C. Tracks and trends variation in practices for high risk, high volume, and high variability treatment for specific conditions/diseases using nationally standardized performance measures and benchmarks performance with other organizations.
- D. Provides to clinical and administrative frontline and middle management teams performance data specific to each service/division/department along with known external benchmarks.
- E. Measures and continually strives to achieve and subsequently improve upon, where appropriate, organizationally-defined standards for the time between the provision of patient care and feedback of information regarding an individual's/team's performance relative to that patient care.
- F. Offers all employees and medical/clinical staff a user-friendly, easily accessible, confidential, narrative reporting system for recognized risks, near misses, and adverse events that could cause harm to staff, patients, families, and visitors; actively evaluates and acts on reports.
- G. Integrates, evaluates, and interprets all measurement input and uses this results-based information to guide decisions on process improvements, ensuring that lessons learned are applied throughout the organization.

III. Process Management/Improvement

- A. Relates process management and improvement efforts directly to ongoing monitoring efforts and provides results of measurement efforts in an ongoing and current manner to all employees and medical staff.
- B. Directs organizational improvement efforts within and across departments toward increasing the consistency and predictability (reliability) of key administrative and clinical care processes through the use of reliability design aids (e.g., checklists, protocols, reminders, or decision support in process design).
- C. Selects and applies specific quality improvement techniques such as lean process, six sigma, proactive risk assessment, root cause analysis, and/or continuous quality improvement to achieve safer and more consistent and predictable (reliable) processes.



- D. Integrates current and new technology, including information technology, in process design, process redesign, and improvement.
- E. Considers the impact of organizational culture, staff training needs, and possible unexpected consequences relative to patient care when making decisions on adopting and implementing new technology.
- F. Continually seeks new knowledge as to how clinical care and administrative processes can be improved and implements successful practices.
- G. Learns from others outside of the organization and effectively transfers and applies such knowledge throughout the organization.
- H. Shares learnings and improvements with others at local, regional, and national levels.

IV. Patient and Family Involvement

- A. Provides each patient the opportunity to define who is part of his or her family.
- B. Systematically engages patients and their families, to the extent they desire, in health care discussions and decisions.
- C. Incorporates preferences and values of patients into decisions regarding their current and future health care needs.
- D. Actively supports patient and family involvement in all aspects of patient care through ongoing two-way communication and encourages patients and family members to ask questions about their care and treatment and identify safety hazards.
- E. Anticipates and meets the special needs of patients and families relative to their physical, psychological, developmental, cultural, spiritual, and economic requirements while ensuring that all patients receive the same standard of care.
- F. Provides patients and families with information and educational materials relative to their health needs and all hospital consent forms requiring the patient's (or duly designated proxy) signature in a language they understand and at a level that they are able to comprehend, and periodically evaluates adequacy and appropriateness of this information.
- G. Ensures that all individuals who have knowledge of or direct access to patient information demonstrate an ongoing respect for each patient's privacy, decisions relative to patient care, and individual values.



- H. Implements safeguards to preserve patient confidentiality without compromising communication between caregivers and patients and their families or impairing the coordination and continuity of care.
- I. Ensures that each patient's medical records are readily and continually accessible to them.
- J. Offers patients, family members, and visitors an easily-accessible system for reporting safety and risk concerns.
- K. Engages patients and families in defining quality health care and designing and improving workflow processes.
- L. Creates opportunities for patients and families to serve on hospital advisory and management committees including environmental design, to assist in the design and development of organizational policies and procedures, and to participate in staff orientation and continuing education.
- M. Provides a physical environment that is welcoming, enhances access to information, and encourages participation by patients in their health care.

V. Human Resource Management

- A. Reflects organizational commitment to achieving quality goals in selection criteria for new employees and hiring decisions.
- B. Orients all employees and clinical staff on the organization's definition of quality health care, how quality and organizational goals are prioritized, their role in achieving those goals, how employees and clinical staff participate in identifying problems and developing solutions, the critical role of teamwork and effective communication in the provision of care, and the central role patients and families play in decisions and actions related to patient care.
- C. In collaboration with the organization's leadership, continually communicates the organization's definition of quality health care and how it applies relative to organization-specific quality goals and expectations.
- D. Periodically evaluates all employees relative to their job performance in providing quality health care and contributing to the achievement of organization-specific quality goals.
- E. Establishes, monitors, evaluates, and adjusts staffing to ensure that care is provided in a safe manner.
- F. Ensures employees and clinical staff receive effective ongoing training to increase/maintain relevant skills, particularly with regard to technologies and new patient care techniques to ensure continued quality and safety.



- G. Trains employees and clinical staff in principles and practice of effective teamwork, communication, and relationship management (e.g., diversity training, cultural competence, with a focus on problem solving, decision making, situational awareness and communication) and continually evaluates the effectiveness of such training.
- H. Trains employees and clinical staff in ongoing collaboration with patients and families within and across patient settings, disciplines, and departments and continually evaluates the effectiveness of such training.
- I. Provides employees and staff with behavioral expectations on their role in providing quality health care and creating a culture of reliability and rewards them for meeting those expectations.
- J. Balances individual accountability for deliberate actions that are purposely unsafe, intended to cause harm, and/or taken under the influence of alcohol or illicit substances with a non-punitive culture consistently applied for all employees and medical staff that recognizes the role of systems in medical error and causation of harm.
- K. Seeks ongoing input from employees and staff on opportunities for improvement and provides timely feedback regarding their ideas.
- L. Assesses and evaluates on a regular basis employee and clinical staff (including medical staff) perceptions of the quality and safety culture within the hospital and their satisfaction with the work environment and quality of care provided to patients and their families.

VI. Community Involvement

- A. Works actively with the community and community-based organizations to identify specific community health needs and develop and measure effectiveness of programs to help meet those needs.
- B. Identifies and takes action to address racial, ethnic, and gender disparities in medical care.
- C. Integrates health care initiatives across the care continuum and with other community social service agencies.
- D. Regularly provides feedback to and seeks feedback from the community on how the health needs of the community and patient population served are being addressed by the organization's initiatives.
- E. Regularly reports to the community on the organization's quality performance for the full range of services it provides and makes this and other information pertaining to the services it provides and the organization's compliance with applicable regulation easily accessible and available to those whom it serves.



PART VI: SELECTED RESOURCES AND WEBSITES

Resources

- Ahmann, E., Abraham, M. R., Johnson, B. H. (2003). *Changing the concept of families as visitors: Supporting family presence and participation*. Bethesda, MD: Institute for Family-Centered Care.
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Websites

Action Pact, Inc.

<http://www.culturechangenow.com/>

Action Pact, Inc. works with nursing homes and other elder organizations, assisting them in becoming more person-centered, with residents actively engaged in the change process. The website contains profiles of successful change in organizational culture toward a more person-centered care, publications, videos and DVDs, and toolkits for change.

American Hospital Association

www.aha.org

The AHA is a membership organization for U.S. hospitals and provides leadership and advocacy for member hospitals to improve care for patients and their families. The Institute for Family-Centered Care collaborated with AHA to develop the toolkit, *Strategies for Leadership—Patient- and Family-Centered Care*. It is available for download at <http://www.aha.org/aha/issues/Quality-and-Patient-Safety/strategies-patientcentered.html>. The AHA McKesson Quest for Quality Prize criteria is available at http://www.aha.org/aha/awards-events/quest_for_quality/criteria.html.

Clinical Governance Support Team

http://www.cgsupport.nhs.uk/Programmes/Patients_Accelerating_Change_Programme.asp

There are a number of resources in the United Kingdom supporting and encouraging the involvement of patients and families in improvement activities. The Clinical Governance Team within the National Health Service (NHS) supports Patients Accelerating Change (PAC), facilitating the involvement of patients and families in hospital and primary care improvement and health care redesign initiatives. Clinical governance provides a framework for continuous quality improvement, the assurance of the highest standards of care, and accountability within the NHS in the United Kingdom. The involvement of patients, carers (families), and the public, is central to this work. The website has useful links and a variety of resources for health care professionals and leaders.

Consumers Advancing Patient Safety (CAPS)

<http://www.patientsafety.org/>

A consumer-led, nonprofit organization, CAPS serves as a voice for providers, patients and families, and consumers dedicated to improving the safety of health care through partnerships and collaboration. The CAPS website provides information on a variety of patient safety programs and tools for building the capacity of consumers for collaboration.

Consumer Quality Initiatives - Participatory Action Research Center

<http://www.cqi-mass.org>

The Center oversees the research and evaluation activities of the Consumer Quality Initiatives, a consumer-directed mental health organization based in Massachusetts. Its mission is to prepare and support patients and families to partner with professionals in planning, implementing, and disseminating the results of research and evaluation projects.



Institute for Family-Centered Care

www.familycenteredcare.org

The Institute extends its efforts to advance the practice of patient- and family-centered care through its website. The site includes a wealth of practical resources for and profiles from families, providers, and institutions on collaboration at all levels of health care.

Institute for Healthcare Improvement

<http://www.ihl.org/IHI/Topics/PatientCenteredCare>

This site has a wealth of information on patient and family involvement in quality improvement and health care redesign. Included are strategies to capture the patient and family experience of care as well as to involve patients and families on quality improvement teams.

National Patient Safety Foundation

www.npsf.org

The Foundation's mission is to improve the safety and welfare of patients in the health care system. Its website provides, among other resources, an area devoted solely to resources for patients and families who wish to get involved in patient safety initiatives.

New Health Partnerships

<http://www.newhealthpartnerships.org>

New Health Partnerships is an online community for patients, 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.

Picker Europe

<http://www.pickereurope.org>

Picker Europe, a not for profit organization located in Oxford, England, is committed to ensuring that the voices of patients inform quality improvement and health care redesign. Its primary strategies are: "Measurement—Researching and evaluating patients' experience; Improvement—Leading initiatives that make improvements happen; and Policy—Building evidence to inform health policy." The organization supports a variety of endeavors to involve patients and the public in health care and in the improvement of health care. Information about Patients Accelerating Change initiative are also available on this website. Publications and information about surveys are available on its website.

Voice4Patients

www.voice4patients.com

Voice4Patients is devoted to empowering patients and families to be their own health care advocates in order to address patient safety concerns and medical errors. This online resource provides information on the "national epidemic of health care error" and offers links to useful information on medical conditions for patients and families; and also has resources for those who have experienced medical error.



PART VII: SELECTING, PREPARING, AND SUPPORTING PATIENT AND FAMILY ADVISORS

Hospitals, clinics, and other community-based ambulatory practices are increasing their efforts to partner with patients and families in policy and program development, patient safety, quality improvement, health care redesign, professional education, facility design planning, and research and evaluation. They are asking patients and families to serve on patient and family advisory councils and on committees, task forces, and project teams. Appropriate selection, preparation, and support of patient and family advisors are key to effective partnerships.

Selecting Patient and Family Advisors

A patient or family advisor is an individual or family member who has experienced care in a hospital or an ambulatory program. In identifying patient and family advisors, look for individuals who have demonstrated an interest in partnering with providers in their care or the care of their family member. Consider those who have offered constructive ideas for change and who have a special ability to help staff and physicians better understand the patient or family perspective.

Seek individuals who are able to:

- ▼ Share insights and information about their experiences in ways that others can learn from them.
- ▼ See beyond their personal experiences.
- ▼ Show concern for more than one issue.
- ▼ Listen well.
- ▼ Respect the perspectives of others.
- ▼ Interact well with many different kinds of people.
- ▼ Show a positive outlook on life and a sense of humor.
- ▼ Speak comfortably in a group with candor.
- ▼ Work in partnership with others.

To find individuals with these qualities and skills, ask physicians and other clinicians for suggestions. Reviewing the patient registry or their panel of patients may help clinicians identify potential advisors. Patient representatives or ombudsmen, community outreach workers, promotores and other lay health workers, and current patient and family advisors may also be able to identify potential advisors. Contacting support groups and chronic care group education programs is another way to find individuals who might be interested in serving as advisors.

Informing Potential Patient and Family Advisors About Roles and Responsibilities

Before individuals can make decisions about whether they wish to participate on a patient safety committee, a quality improvement team, or in other health care redesign initiatives, they should be informed of the responsibilities and privileges associated with the role. A fact sheet, containing the following information, can be prepared and offered to individuals who are being asked to participate:

- ▼ Mission and goals of the project.
- ▼ Expectations for their participation.
- ▼ Meeting times, frequency, and duration.
- ▼ Travel dates.
- ▼ Expectations for communication among team members between meetings.
- ▼ Time commitment beyond meeting times.
- ▼ Compensation offered.
- ▼ Benefits of participation (i.e., what are the expected outcomes of their involvement).
- ▼ Training and support to be provided.

Compensation

At a minimum, the organization should reimburse patients and families for expenses incurred in association with their work with the team (e.g., parking, transportation, child care). Some organizations also offer stipends or honoraria for participation in meetings. These payments typically range from \$12 - \$25 per meeting. Consider the needs of the patient or family advisor and ask about their preferences. If they have no means to cash a check, stipends will have to be offered in an alternative way (e.g., store voucher, cash, etc.).

Preparing and Supporting Patient and Family Advisors

In order for patients and families to participate effectively as advisors, orientation, training, preparation, and support should mirror that which is offered to staff and physicians. Patient and family advisors should have a chance to discuss their questions or thoughts about the work with a staff liaison who has time dedicated to coordinating activities with advisors.

The orientation for patient and family advisors should include information on the following:

- ▼ The mission, goals, and priorities of the clinic, community-based ambulatory practice, or hospital.



- ▼ Patient- and family-centered care.
- ▼ Overview of patient safety issues and strategies.
- ▼ Quality improvement methodology.
- ▼ HIPAA and the importance of privacy and confidentiality.

If the organization has a volunteer program, its orientation and training may be very useful for patient and family advisors. Other training issues to consider include:

- ▼ Speaking the organization’s language, “Jargon 101.” While it is best to reduce the amount of jargon used in collaborative endeavors, sometimes it is impossible to completely eliminate jargon. If there are terms that will be used frequently in meetings, make sure that patient and family advisors understand them. Encourage them to ask for an explanation of anything they don’t understand.
- ▼ Who’s who in the organization or on the project team and how to contact team members.
- ▼ How to prepare for a meeting: what to wear, what to do ahead of time, and what to bring.
- ▼ How meetings are conducted: format, agenda, minutes, roles (e.g., secretary, timekeeper).
- ▼ Training for any technologies that will be used (e.g., conference calls, web-based tools).
- ▼ Communicating collaboratively:
 - Expressing your perspective so others will listen.
 - How to ask tough questions.
 - What to do when you don’t agree.
 - Listening to and learning from the perspectives of others.
 - Thinking beyond your own experience.
- ▼ How to prepare for any conferences, seminars or other events: making travel arrangements, all logistical information (e.g., hotel, transportation from airport to hotel), expenses that are covered, reimbursement procedures, what to wear, what to bring, and how to prepare for the session. Some patients and families may not have credit cards and therefore will have difficulty in making travel arrangements and will need assistance in planning travel and checking in to a hotel.

It is extremely helpful for new patient and family advisors to have a “coach” or mentor who can provide informal ongoing support to them. A member of the team who has experience working on collaborative initiatives (either a staff person or an experienced patient/family advisor) can be assigned to this role. This person can insure that patient and family advisors are prepared for each meeting. During meetings, this person can also actively encourage participation of the advisor. Also they can debrief after each meeting to determine what additional information or resources patient and family advisors need. Most importantly, they can support patient and family advisors in participating fully on the team by providing feedback and encouragement.

Believe Patient and Family Participation Is Essential

The single most important guideline for involving patients and families in advisory roles is to believe that their participation is essential to the design and delivery of optimum care and services. Without sustained patient and family participation in all aspects of policy and program development and evaluation, the health care system will fail to respond to the real needs and concerns of those it is intended to serve. Effective patient/family/provider partnerships will help to redesign health care and safety and quality. It will lead to better outcomes and enhance efficiency and cost-effectiveness. Providers will also discover a more gratifying, creative, and inspiring way to practice.

The tool, “Patients and Families as Advisors: A Checklist for Attitudes,” can be used to help physicians and staff assess their own attitudes and beliefs about partnerships with patients and families.

This material has been adapted from two resources: *Developing and Sustaining a Patient and Family Advisory Council* and *Essential Allies: Families as Advisors* published by the Institute for Family-Centered Care.

PART VIII: A CHECKLIST FOR ATTITUDES ABOUT PARTNERING WITH PATIENTS AND FAMILIES

Use this tool to explore attitudes about patient and family involvement in their own health care and as advisors and/or members of improvement teams. It can be used for self-reflection and as a way to spark discussion among staff and physicians before beginning to work with patients and families as members of quality improvement, patient safety, policy and program development, and health care redesign teams.



Answer and discuss the following questions:

In each clinical interaction:

- Do I believe that patients and family members bring unique perspectives and expertise to the clinical relationship?
- Do I encourage patients and families to speak freely?
- Do I listen respectfully to the opinions of patients and family members?
- Do I encourage patients and family members to participate in decision-making about their care?
- Do I encourage patients and family members to be active partners in assuring the safety and quality of their own care?

At the organizational level:

- Do I consistently let colleagues know that I value the insights of patients and families?
- Do I believe that patients and families can play an important role in improving patient safety and quality within the organization?
- Do I believe in the importance of patient and family participation in planning and decision-making at the program and policy level?
- Do I believe that patients and families bring a perspective to a project that no one else can provide?
- Do I believe that patients and family members can look beyond their own experiences and issues?
- Do I believe that the perspectives and opinions of patients, families, and providers are equally valid in planning and decision-making at the program and policy level?

If you have experience working with patients and families as advisors and/or members of improvement teams, answer and discuss these additional questions:

- Do I understand what is required and expected of patients and families who serve as advisors and/or members of improvement teams?
- Do I help patients and families set clear goals for their roles?
- Do I feel comfortable delegating responsibility to patient and family advisors as improvement team members?
- Do I understand that an illness or other family demands may require patients and family members to take time off from their responsibilities on these teams?

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

