

# ADVANCING THE PRACTICE OF PATIENT- AND FAMILY-CENTERED CARE IN HOSPITALS

How to Get Started...



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Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care professionals. These partnerships at the clinical, program, and policy levels are essential to assuring the quality and safety of health care.

Since 1992, the **Institute for Patient- and Family-Centered Care (IPFCC)** has provided national and international leadership to advance the understanding and practice of patient- and family-centered care. IPFCC promotes change in organizational culture and enhances the quality and safety of health care through its on-site and off-site training and technical assistance; webinars, seminars, and international conferences; development of print and digital guidance resources; information dissemination; research; and policy initiatives.

IPFCC serves as a resource to hospital and health system administrative and clinical leaders, program planners, direct service providers, patient experience officers, educators of health care professionals, researchers, facility design professionals, and patient and family leaders.

Visit the IPFCC website at [www.ipfcc.org](http://www.ipfcc.org) for additional resources, tools, schedule of events, information about the ***Better Together: Partnering with Families*** campaign, and profiles of organizational change.

**W**hat 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, staff, 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**, "The Role of Leaders" outlines the various roles and related action steps for leaders to implement to build the infrastructure to support and sustain effective partnerships with patients and families.

**Part IV**, "Where Do We Stand?" provides a self-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 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**, "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 VII**, "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 VIII** lists selected print and audiovisual resources.

## **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 and experience 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.

## Partnerships with Patients and Families – Perspectives of Leaders

*“...in a growing number of instances where truly stunning levels of improvement have been achieved, organizations have asked patients and families to be directly involved in the process. And those organizations’ leaders often cite this change—putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.”*

Reinertsen, Bisagnano, & Pugh. (2008). *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care*

*“We envisage patients as essential and respected partners in their own care and in the design and execution of all aspects of healthcare. In this new world of healthcare:*

- ▼ *Organizations publicly and consistently affirm the centrality of patient- and family-centered care. They seek out patients, listen to them, hear their stories, are open and honest with them, and take action with them.”*

Leape, Berwick, Clancy, Conway, et al. (2009). *Transforming Healthcare: A Safety Imperative. BMJ’s Quality and Safety in Health Care*

The IOM report, **Best Care at Lower Cost: The Path to Continuously Learning Health Care in America**, offers ten key recommendations; the fourth states:

*“In a learning health care system, patient needs and perspectives are factored into the design of health care processes, the creation and use of technologies, and the training of clinicians.”*

IOM Committee on the Learning Health Care System in America. (2013)

## **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. Identify an executive sponsor(s) for patient- and family-centered care. Designate a staff liaison for collaborative endeavors to facilitate the process for development of sustained partnerships with patients and families and support their involvement throughout the organization
3. Appoint a patient- and family-centered steering committee comprised of patients and families and formal and informal leaders of the organization.
4. 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 self-assessment tool appears in Part IV of this document.)
5. On the basis of the assessment, set priorities and develop an action plan for establishing patient- and family-centered care at your institution.
6. 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.
7. Invite patients and families to serve as advisors in a variety of ways. Appoint some of these individuals to key committees and task forces.
8. 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.
9. Monitor changes made, evaluate processes, measure the impact, continue to advance practice, and celebrate and recognize success.

### **PART III: THE ROLE OF LEADERS IN BUILDING THE INFRASTRUCTURE TO SUPPORT AND SUSTAIN EFFECTIVE PARTNERSHIPS**

Hospitals that have been successful in partnering with patients and families to advance patient- and family-centered care have leaders who understand that their commitment and their support is essential. This section lists roles and action steps that leaders can use to guide their efforts.

<b>Essential Roles</b>	<b>Key Action Steps</b>
Leaders make an explicit commitment to patient- and family-centered care and serve as role models for engaging in partnerships with the individuals and families they serve across the continuum of care.	<ul style="list-style-type: none"> <li>• Build leadership commitment to partnerships.</li> <li>• Serve as role models – walk the talk.</li> <li>• Serve as the executive champion/s for patient- and family-centered care and for partnerships with patients and families.</li> </ul>
Leaders provide resources and support for partnerships with the individuals they serve.	<ul style="list-style-type: none"> <li>• Establish the infrastructure to support partnerships.</li> <li>• Assess the current status of patient- and family-centered care.</li> <li>• Remove institutional and attitudinal barriers to patient- and family-centered care.</li> <li>• Create opportunities for administrators, physicians, staff, patients, and families to learn how to partner.</li> </ul>
Leaders encourage partnerships as a pathway to improve health care quality and safety.	<ul style="list-style-type: none"> <li>• Partner with advisors to develop strategies and tools to prepare patients and families to become active in ensuring the quality and safety of care.</li> <li>• Involve patient and family advisors in strengthening the capacity of an organization to ensure quality and safety.</li> </ul>
Leaders oversee and encourage partnerships with patients and families in strategic initiatives.	<ul style="list-style-type: none"> <li>• Partner with patients and families to change and improve care practices.</li> <li>• Partner with patients and families to enhance planning for changes to the built environment.</li> <li>• Partner with patients and families to expand the use and usefulness of information technology.</li> <li>• Partner with patients and families to improve the education of health care professionals.</li> </ul>

<p>Leaders put systems in place to measure the outcomes of collaborative processes.</p>	<ul style="list-style-type: none"> <li>• Measure the effect of patient- and family-centered care on key outcomes.</li> <li>• Document the efforts and impact of patient and family advisors.</li> <li>• Share outcomes with leaders, clinicians, staff, patients, families, and community members.</li> </ul>
<p>Leaders recognize that profound organizational change takes time.</p>	<ul style="list-style-type: none"> <li>• Affirm the commitment to patient- and family-centered care.</li> <li>• Celebrate the successes.</li> </ul>

Adapted from Johnson, B. H., & Abraham, M. A. (2012). *Partnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

## **PART IV: WHERE DO WE STAND? A SELF-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, frontline 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 SELF-ASSESSMENT**

#### **Leadership in the Organization**

- Do our 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 our organization defined quality health care and does this definition include how patients and families will experience care?
- Do our organization's leaders, through their words and actions, hold staff accountable for patient- and family-centered practice?
- Do our organization's leaders, through their words and actions, hold physicians accountable for patient- and family-centered practices?

#### **Patient and Family Advisors**

- Does our hospital have an active patient and family advisory council?
- Do patient and family advisors serve on committees or work groups involved with:
  - ▽ Community services and programs?
  - ▽ Culturally and linguistically appropriate services and materials?
  - ▽ Discharge/Transition planning?
  - ▽ Education and orientation for staff, physicians, students, and trainees?
  - ▽ Ethics?
  - ▽ Facility design?



- ▽ Patient and family education?
- ▽ Patient and family experience of care?
- ▽ Patient safety?
- ▽ Peer-led education and support?
- ▽ Policy and procedure development?
- ▽ Quality improvement?
- ▽ Research initiatives?
- ▽ Use of information technology?
- Do patient and family advisors serving on councils, committees, and work groups reflect the cultural and linguistic diversity of patients and families served by our organization?

## **Environment and Design**

- Does the design of our hospital:
  - ▽ Create positive and welcoming impressions throughout for patients and families?
  - ▽ Display messages that communicate to patients and families that they are essential members of the health care team?
  - ▽ Reflect the diversity of patients and families served and address their unique needs?
  - ▽ Provide for the privacy and comfort of patients and families?
  - ▽ Support the presence and participation of families?
  - ▽ Support the collaboration of physicians and staff across disciplines?

## **Patient and Family Participation in Care and Decision-Making**

- Are our organization's policies, programs, and staff practices consistent with the view that families are not visitors but instead are viewed as allies for patient health, safety, and well-being?
- Are patients asked to identify their family/community caregivers and specify how they will be involved in care and decision-making?
- Are patients and their families encouraged and supported to participate in care planning and decision-making during the hospital stay?
- Are the cultural and spiritual beliefs and practices of patients and families respected and incorporated into care planning and decision-making?

- Are patients and their families encouraged and supported to be present and to participate in nurse change of shift report?
- Are patients and their families encouraged and supported to be present and to participate in rounds?
- Are patients and their families able to activate a Rapid Response Team?
- Are patients and their families encouraged to identify their learning needs and priorities regarding care at home as a key component of discharge/transition planning?

## **Patient and Family Access to Information and Education**

- Are there systems in place to ensure that patients and families:
  - ▽ Have access to complete, unbiased, and useful information?
  - ▽ Understand the purpose of taking each of their medications?
  - ▽ Understand the things they are responsible for in managing their health?
  - ▽ Receive written information that is provided in primary language and appropriate educational levels of patients and families served by the organization?
  - ▽ Have access to interpreter services whenever they are needed to effectively communicate with physicians and staff about care, treatment, and services?
- Do patients and their families have easy access (view at any time or receive a copy) to their:
  - ▽ Clinical information (e.g., laboratory or diagnostic tests)?
  - ▽ Daily recording of care (e.g., notes from nurses, physicians, allied health)?
  - ▽ Discharge summary?
  - ▽ Medical records?
- Do providers and staff across disciplines and settings (inpatient, specialty care, and primary care providers) have easy access to the patient's medical record?
- Do documentation systems and charting support the recording of patients' and families':
  - ▽ Priority concerns for the hospital stay?

- ▽ Observations?
- ▽ Goals?
- ▽ Preferences?
- Are peer-led educational programs available and accessible to patients and families?
- Are patients and their families provided with practical information and strategies on how to best partner with health care providers to assure safety in health care?

## Human Resources

- Do our organization's human resources system support and encourage the practice of patient- and family-centered care?
- Do leadership, staff, and physicians reflect the diversity of patients and families served by our hospital?
- Are patients and families involved in the hiring process for administrative and clinical leaders?
- Are systems in place that ensure that individuals with patient- and family-centered care skills and attitudes are hired?
- Does our hospital offer rewards and recognition for patient- and family-centered practice?
- Are there explicit expectations that all staff and physicians respect and collaborate with patients, families, and staff across disciplines and departments in:
  - ▽ Position descriptions?
  - ▽ Performance appraisal processes?

## Education of Leaders, Staff, Physicians, Students, and Trainees

- 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?
- Do orientation and education programs prepare staff, physicians, students, and trainees for culturally responsive practice?
- Are patients and families involved as faculty in orientation and education programs for leaders, staff, physicians, students, and trainees?

## Reflecting on Opportunities and Priorities

After completing the self-assessment and discussing the responses, the team can decide in which of the following areas, your hospital can begin to partner with patients and families to make changes to advance the practice of patient- and family-centered care:

- Community services and programs?
- Culturally and linguistically appropriate services and materials?
- Discharge/Transition planning?
- Education and orientation for staff, physicians, students, and trainees?
- Ethics?
- Facility design?
- Patient and family education?
- Patient and family experience of care?
- Patient safety?
- Peer-led education and support?
- Policy and procedure development?
- Quality improvement?
- Research initiatives?
- Use of information technology?

## **PART V: 2016 AMERICAN HOSPITAL ASSOCIATION-MCKESSON QUEST FOR QUALITY PRIZE® CRITERIA**

Please be aware that these criteria reflect a vision for health care consistent with the Triple Aim of improving the health of populations, enhancing the experience and outcomes of care for patients, and reducing the per capita cost of care. The Institute of Medicine report (IOM) *Crossing the Quality Chasm* describes six aims (safety, patient-centeredness, effectiveness, efficiency, timeliness, and equity) that are essential for achieving this vision of a comprehensive quality-oriented health care system. This award will honor hospitals that are committed to and have made demonstrable progress toward making this vision a reality. These criteria and further information about this award are available at <http://www.aha.org/about/awards/q4q/criteria.shtml>.

- I. Role of Hospital Leadership** (defined as governing body, administration, and clinical staff leadership). Through active collaboration, the hospital leadership:
- Defines *quality health care* and reflects that definition in the mission, value statements, and strategic plan.
  - 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 internally and externally transparency and effective communication, information-sharing, and collaboration with all colleagues, employees, patients and families, other health care organizations, health-related organizations (including payers), and the community.
    - Ensures adequate resources are allocated for achievement of quality goals.
    - Supports investment in clinical information systems as a major institutional priority.
  9. Focuses on providing value to patients and the community in development of priorities and in establishment of goals and objectives.
  10. Makes systematic efforts to ensure senior leadership (governing board and executive staff), medical staff, employees, and volunteers reflect the ethnic/racial makeup of the community.
- A. Governing Body (The Board of Trustees)
    - Actively engages in oversight of quality health care and ensures that quality goals are achieved.
    - Actively participates in quality improvement efforts.
    - Ties hospital CEO accountability and incentives to meeting quality goals.
    - Makes resource allocation decisions based on quality goals.
    - Is representative of the community and focused on improvement in health status of the population.
  - B. Clinical Staff Leadership
    - Seeks input and feedback from all other clinical staff in defining quality goals and the determination of organizational quality priorities.

- Routinely communicates the organization's quality priorities, goals, and goal achievement to all clinical staff.
- Actively works with all clinical staff to identify, implement, and update evidence-based practices.
- Establishes clear behavioral expectations for clinical staff that foster interdisciplinary teamwork and collaboration with patients and families.
- 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.
- 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.
- Facilitates standardization of medical devices, other technologies, and protocols for care where feasible.

#### C. Administration

- Routinely communicates the organization's quality health care definition, priorities, goals, and progress toward achievement of goals to all hospital staff.
- 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.
- 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.
- Ties senior management accountability and incentives to implementing measures to enhance quality health care and achieving quality goals.
- Establishes a culture and leadership style that is diffused throughout the organization.

## II. Information and Analysis

- 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:
  1. **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; effective medication reconciliation; coordination of communication with patients and families; and consistent implementation and execution of diagnostic and treatment plans.
  2. **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.
  3. **Effectiveness:** implementation, updating, and use of evidence-based clinical practices in the care of patients.
  4. **Efficiency:** minimizing inappropriate variation, duplication, and unnecessary repetition in administrative and **clinical** processes of care.
  5. **Timeliness:** of access to care, start of scheduled procedures, consults, admitting and discharging of patients, other throughput indicators.
  6. **Equity:** health status for populations served, including evaluating racial, ethnic, and gender disparities in care.
- 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.
- 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.
- Provides to clinical and administrative frontline and middle management teams performance data specific to each service/division/department along with known external benchmarks.



- 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.
- 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.
- 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.
- Seeks and uses data to guide efforts to improve community health, enhance the patient care experience, and address the per capita cost of care.

### **III. Process Management/Improvement**

- 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.
- Prioritizes safety and quality improvement initiatives, including those related to employee safety, based on a risk assessment process that looks at real and potential hazards and probability of occurrence.
- 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).
- Selects and applies standardized quality improvement methodologies throughout the organization (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.
- Integrates current and new technology, including information technology, in process design, process redesign, and improvement.
- 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.
- Continually seeks new knowledge as to how clinical care and administrative processes can be improved and implements successful practices.
- Provides training and mechanisms to facilitate engagement of front-line staff in identifying needed process improvements and devising and implementing them.

- Provides systematic approach to maximize the effective dissemination of process and safety improvements throughout the organization.
- Learns from others outside of the organization and effectively transfers and applies such knowledge throughout the organization.
- Shares learnings and improvements with others at local, regional, and national levels.

#### **IV. Patient and Family Involvement**

- Provides each patient the opportunity to define who is part of his or her family and how they will be involved in care and decision making.
- Systematically engages patients and their families, to the extent they desire, in health care planning and decisions, including physician/interdisciplinary rounding and change of shift reports.
- Incorporates preferences and values of patients into decisions regarding their current and future health care.
- Actively supports patient and family involvement in all aspects of patient care through ongoing two-way communication and encourages patients and family members to share observations, concerns, and questions about their care and treatment and identify safety hazards.
- 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.
- 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 with staff, clinicians, and patients and families.
- Ensures that each patient's medical records, including the daily recording of care, are readily and continually accessible to them in real time.
- Offers patients, family members, and visitors an easily-accessible system for reporting safety and risk concerns.
- Engages patients and families in defining quality health care and designing and improving workflow processes.
- Creates opportunities for patients and families to serve on hospital advisory and management committees including patient safety, quality improvement, and environmental design.

- Supports the involvement of patients and families in the design and development of organizational policies and procedures, in staff and clinician orientation and continuing education, and in the orientation and education of students and trainees.
- Provides a physical environment that is welcoming, enhances access to information, and encourages participation by patients in their health care.
- 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.
- Evaluates patient experience of care and systematically addresses needed improvements.
- Implements safeguards to preserve patient confidentiality without compromising communication between caregivers and patients and their families or impairing the coordination and continuity of care.

## **V. Human Resource Management**

- Reflects organizational commitment to achieving quality goals in selection criteria for new employees and hiring decisions.
- 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.
- 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 and models transparency in all communications.
- Emphasizes the importance of employee health and safety and orients all employees and clinical staff to employee health and safety goals and their role in achieving them.
- Periodically evaluates all employees relative to their job performance in providing quality health care and contributing to the achievement of organization-specific quality goals.
- Establishes, monitors, evaluates, and adjusts staffing to ensure that care is provided in a safe manner.
- 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.

- 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.
- 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.
- 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.
- Balances individual accountability with an understanding of human factors and system issues to provide a *just culture* for safety issues and errors.
- Seeks ongoing input from employees and staff on opportunities for improvement and provides timely feedback regarding their ideas.
- 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

- 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.
- Identifies and takes action to address racial, ethnic, and gender disparities in medical care.
- Integrates health care initiatives across the care continuum and with other community social service agencies.
- 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.
- Is transparent in regularly reporting to the community on organizational performance and quality improvement goals and progress towards meeting those goals for its full range of services, making this and other information pertaining to its services and compliance with applicable regulation easily accessible to those whom it serves.
- Takes initiative to understand the key drivers of health care per capita cost for the populations it serves and how the hospital can maximize this value.

## **PART VI: SELECTING, PREPARING, AND SUPPORTING PATIENT AND FAMILY ADVISORS**

Hospitals are increasing their efforts to partner with patients and families in policy and program development, patient safety, quality improvement, patient experience, 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 the hospital. 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. Review letters or emails from patients or families that have provided constructive feedback to the hospital. Include information about patient and family advisors in informational materials on the institution's website, and in patient experience and satisfaction surveys. Patient representatives or ombudsmen, community outreach workers, and current patient and family advisors may also be able to identify potential advisors. Contacting community groups is another way to find individuals who might be interested in serving as advisors.

## Informing Potential Patient and Family Advisors About Role

Before individuals can make decisions about whether they wish to participate on an advisory council 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 council, committee, or 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.
- ▼ Reimbursement or compensation offered.
- ▼ Benefits of participation (i.e., what are the expected outcomes of their involvement).
- ▼ Training and support to be provided.

## Reimbursement/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, gift card, cash).

## Preparing and Supporting Patient and Family Advisors

In order for patients and families to participate effectively as advisors, appropriate orientation, training, preparation, and support should be provided. 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 as relevant:

- ▼ The mission, goals, and priorities of the health system or hospital.
- ▼ Patient- and family-centered care.

- ▼ Overview of patient experience, quality, and safety issues and strategies.
- ▼ Specific skills and knowledge needed to be an effective team member (e.g., quality improvement methodology for those serving on a quality improvement team).
- ▼ HIPAA and the importance of privacy and confidentiality.
- ▼ 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.

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).
- ▼ 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 council or committee 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 ensure 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.

Involving patients and families as partners and advisors will...

- ▼ Bring important perspectives about the experience of care.
- ▼ Teach how systems really work.
- ▼ Inspire and energize staff.
- ▼ Keep staff grounded in reality.
- ▼ Provide timely feedback and ideas.
- ▼ Lessen the burden on staff to fix the problems... staff don't have to have all the answers.
- ▼ Bring connections with the community.
- ▼ Offer an opportunity for patients and families to “give back.”

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—Patient, Family, and Resident Advisors: A Guide for Staff Liaisons* published by the Institute for Patient- and Family-Centered Care.



## **PART VII: 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. 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 advisory councils, and 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 experience, 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, answer and discuss these additional questions:**

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

Adapted from Minniti, M., & Abraham, M. (2013). *Essential Allies—Patient, Family, and Resident Advisors: A Guide for Staff Liaisons*. Bethesda, MD. Institute for Patient- and Family-Centered Care.

## PART VIII: SELECTED RESOURCES

### Available from the Institute for Patient- and Family-Centered Care

Abraham, M., Ahmann, E., & Dokken, D. (2013). *Words of advice: A guide for patient, family, and resident advisors*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

Conway, J., Johnson, B. H., Edgman-Levitan, S., Schlucter, J., Ford, D., Sodomka, P., & Simmons, L. (2006). *Partnering with patients and families to design a patient- and family-centered health care system: A roadmap for the future*. Bethesda, MD: Institute for Family-Centered Care. Retrieved from [www.ipfcc.org/pdf/Roadmap.pdf](http://www.ipfcc.org/pdf/Roadmap.pdf)

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National Partnership for Women & Families. (2015). *Patient and family centered care: The Valley Hospital's journey* [video]. Washington, DC: National Partnership for Women & Families. Available from [www.ipfcc.org](http://www.ipfcc.org).

Visit IPFCC's website for additional written and audiovisual resources at [www.ipfcc.org](http://www.ipfcc.org).

## Additional Resources

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