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

How to Get Started...



Institute for Patient- and Family-Centered Care 6917 Arlington Road, Suite 309 Bethesda, MD 20814 (301) 652-0281 www.ipfcc.org Updated January 2017 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 for additional resources, tools, schedule of events, information about the *Better Together: Partnering with Families* campaign, and profiles of organizational change.

# 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**, "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 VI**, "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 VII 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; in research; 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 familycentered 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 patientand 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 familycentered 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.

Essential Roles	Key Action Steps
Leaders make an explicit commit- ment to patient- and family-centered care and serve as role models for en- gaging in partnerships with the indi- viduals and families they serve across the continuum of care.	• Build leadership commitment to partnerships.
	• Serve as role models – walk the talk.
	• Serve as the executive champion/s for patient- and family-centered care and for partnerships with patients and families.
Leaders provide resources and sup- port for partnerships with the indi- viduals they serve.	• Establish the infrastructure to support partnerships.
	• Assess the current status of patient- and family- centered care.
	• Remove institutional and attitudinal barriers to patient- and family-centered care.
	• Create opportunities for administrators, phy- sicians, staff, patients, and families to learn how to partner.
Leaders encourage partnerships as a pathway to improve health care quality and safety.	• Partner with advisors to develop strategies and tools to prepare patients and families to become active in ensuring the quality and safety of care.
	• Involve patient and family advisors in strength- ening the capacity of an organization to ensure quality and safety.
Leaders oversee and encourage part- nerships with patients and families in strategic initiatives.	• Partner with patients and families to change and improve care practices.
	• Partner with patients and families to enhance planning for changes to the built environment.
	• Partner with patients and families to expand the use and usefulness of information technology.
	• Partner with patients and families to improve the education of health care professionals.

Leaders put systems in place to measure the outcomes of collabora-	•	Measure the effect of patient- and family-cen- tered care on key outcomes.
tive processes.	•	Document the efforts and impact of patient and family advisors.
	•	Share outcomes with leaders, clinicians, staff, pa- tients, families, and community members.
Leaders recognize that profound or- ganizational change takes time.	•	Affirm the commitment to patient- and family- centered care.
	•	Celebrate the successes.

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?
  - $\bigtriangledown$  Culturally and linguistically appropriate services and materials?
  - ▽ Discharge/Transition planning?
  - ▽ Education and orientation for staff, physicians, students, and trainees?
  - $\bigtriangledown$  Ethics?
  - $\bigtriangledown$  Facility design?

- $\bigtriangledown$  Patient and family education?
- $\bigtriangledown$  Patient and family experience of care?
- $\bigtriangledown$  Patient safety?
- $\bigtriangledown$  Peer-led education and support?
- $\bigtriangledown$  Policy and procedure development?
- $\bigtriangledown$  Quality improvement?
- $\bigtriangledown$  Research initiatives?
- $\bigtriangledown$  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?
  - $\bigtriangledown$  Provide for the privacy and comfort of patients and families?
  - $\bigtriangledown$  Support the presence and participation of families?
  - $\bigtriangledown$  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:
  - $\bigtriangledown$  Have access to complete, unbiased, and useful information?
  - $\bigtriangledown$  Understand the purpose of taking each of their medications?
  - ▽ Understand the things they are responsible for in managing their health?

  - ∀ Have access to interpreter services whenever they are needed to ef- fectively communicate with physicians and staff about care, treat-ment, and services?
- □ Do patients and their families have easy access (view at any time or receive a copy) to their:
  - $\bigtriangledown$  Clinical information (e.g., laboratory or diagnostic tests)?
  - $\bigtriangledown$  Daily recording of care (e.g., notes from nurses, physicians, allied health)?
  - $\bigtriangledown$  Discharge summary?
  - $\bigtriangledown$  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':
  - $\bigtriangledown$  Priority concerns for the hospital stay?

- $\bigtriangledown$  Observations?
- $\nabla$  Goals?
- $\bigtriangledown$  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:
  - $\bigtriangledown$  Position descriptions?
  - $\bigtriangledown$  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?

Additional organizational and self-assessment tools are available at: www.ipfcc.org/resources/ assessment.html

# PART V: 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 VI: 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 decisionmaking 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 VII: 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 familycentered health care system: A roadmap for the future*. Bethesda, MD: Institute for Family-Centered Care. Retrieved from www.ipfcc.org/pdf/Roadmap.pdf
- Crocker, L., & Johnson, B. (2014). *Privileged presence: Personal stories of connections in health care* (2<sup>nd</sup> ed.). Boulder, CO: Bull Publishing Company.
- Crocker, L., Webster, P. D., & Johnson, B. H. (2012). *Developing patient- and family-centered vision, mission, and philosophy of care statements.* Bethesda, MD: Institute for Patient- and Family-Centered Care.
- Institute for Patient- and Family-Centered Care. (2012). *Partnerships with patients, residents, and families: Leading the journey* [video]. Bethesda, MD: Institute for Patient- and Family-Centered Care. www.ipfcc.org/resources/videos-dvds.html
- Johnson, B. H., & Abraham, M. R. (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.
- Johnson, B., Abraham, M., Conway, J., Simmons, L., Edgman-Levitan, S., Sodomka, P., Schlucter, J., & Ford, D. (2008). Partnering with patients and families to design a patientand family-centered health care system: Recommendations and promising practices. Bethesda, MD: Institute for Family-Centered Care. Retrieved from http://www.ipfcc.org/tools/ downloads.html
- 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.
- National Partnership for Women & Families. (2015). *Getting started: Patient- and family-centered care* [two videos and a discussion guide]. Washington, DC: National Partnership for Women & Families. Available from www.ipfcc.org/resources/videos-dvds.html

Visit IPFCC's website for additional written and audiovisual resources at www.ipfcc.org.

### **Additional Resources**

- Agency for Healthcare Research and Quality. (2014, December). Advancing the practice of patient- and family-centered care in hospitals. Retrieved from https://innovations.ahrq. gov/issues/2014/12/17/advancing-practice-patient-and-family-centered-care-hospitals
- Agency for Healthcare Research and Quality. (2013, June). *Guide to patient and family engagement in hospital quality and safety.* Retrieved from https://innovations.ahrq.gov/ qualitytools/guide-patient-and-family-engagement-hospital-quality-and-safety
- American Academy of Pediatrics, Committee on Hospital Care, & Institute for Patient- and Family-Centered Care. (2012). Patient- and family-centered care and the pediatrician's role. *Pediatrics, 129*(2), 394-404. doi:10.1542/peds.2011-3084
- American Hospital Association Committee on Research. (2013). *Engaging health care users: A framework for healthy individuals and communities*. Chicago, IL: American Hospital Association. Retrieved from http://www.aha.org/research/cor/engaging/index.shtml
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- American Society for Healthcare Risk Management. (2010). Patient- and family-centered care: Making a good idea work [Special issue]. *Journal of Healthcare Risk Management, 29*(4).
- Brown, S. M., Beesley, S. J., & Hopkins, R. O. (2016). Humanizing intensive care: Theory, evidence, and possibilities. In J. L. Vincent (Ed.), *Annual update in intensive care and emergency medicine 2016* (pp. 405-420). Switzerland: Springer International Publishing.
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