

# ADVANCING THE PRACTICE OF PATIENT- AND FAMILY-CENTERED AMBULATORY CARE

How to Get Started...



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**W**hat is patient- and family-centered care? Why does it matter? How does it fit with our overall mission? And finally, what can our practice or organization do to advance the practice of patient- and family-centered care? Where do we start?

Today, health care 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 an organization 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 ambulatory care centers can use to determine the degree to which patient- and family-centered approaches are embedded in their current organizational culture.

**Part IV** lists selected print and web resources.

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

### **Rationale**

In their efforts to improve health care quality and safety, health care 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 AMBULATORY 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 clinic 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, physicians, 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 clinic 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 organization.
5. Using the action plan as a guide, begin to incorporate patient- and family-centered concepts and strategies into the organization'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 GOVERNING BOARDS, ADMINISTRATORS, PROVIDERS, STAFF, 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 an organization 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 administrators, managers, physicians, 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 AMBULATORY CARE 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 and to patients, 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?
  - ▽ Use of information technology?
  - ▽ Care coordination?
  - ▽ Chronic illness care?
  - ▽ Pain management?
  - ▽ Patient/family education?
  - ▽ Transition planning?
  - ▽ End-of-life care?
  - ▽ Staff orientation and education?
  - ▽ Service excellence?
  - ▽ Ethics?
  - ▽ Diversity/cultural competency?

## 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?
  - ▽ Facilitate educational and support activities for patients and families?
  - ▽ Support the collaboration of staff across disciplines and with patients and families?



## Patterns of Care

- Do physician and staff practices convey to patients and their families that they are respected and encouraged to be integral members of the health care team?
  - ▽ Do physician and staff practices reinforce that care will be individualized for patient and family goals, priorities, and values?
  - ▽ Are there programs, policies, and approaches in place to support patients and their families in developing goals and action plans for care and self-management of chronic or long-term conditions?
- Is care coordinated within the practice or clinic, between health care settings, with subspecialists, and with support services?

## Patient and Family Access to Information, Education, and Support

- Are there systems in place to ensure that patients and families have access to complete, unbiased, and useful information?
- Are patients and families, in accordance with patient preference, encouraged to review their medical records and work with staff and physicians to correct inaccuracies?
- Do patients and their families have access to useful health information and support?
  - ▽ Do patients and families, in accordance with patient preference, have timely access to visit notes, medication lists, and other clinical information (e.g., lab, x-ray, and other test results)?
  - ▽ Are patients and families, in accordance with patient preference, offered a means to create and maintain a patient-held health record?
  - ▽ Are information and educational resources available in a variety of formats and media and in the languages and at the reading levels of the individuals served?
- Are patients and families provided with practical information on how to best assure safety in health care?
- Are patients and families involved in teaching or facilitating programs and group activities for patients and their families?
- Are peer support and peer-led educational programs made available systematically to patients with chronic or long-term conditions and their families?
- Are strategies in place to ensure patient and family access to useful community resources and programs?



## 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?
- Are there strategies in place to reduce the cultural and linguistic differences between staff and the patients and families they serve?

Adapted from *Patient and Family-Centered Ambulatory Care: A Self-Assessment Inventory*. Available from the Institute for Family-Centered Care at [www.familycenteredcare.org/tools/downloads.htm](http://www.familycenteredcare.org/tools/downloads.htm).



## PART IV: SELECTED RESOURCES AND WEBSITES

### Resources

- Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating patient and family faculty programs*. Bethesda, MD: Institute for Family-Centered Care.
- Bodenheimer, T. S. (2007). *Motivating change: Innovative approaches to patient self-management*. Oakland, CA: California HealthCare Foundation. Available at <http://www.chcf.org/topics/chronicdisease/index.cfm?itemID=133518>.
- Bodenheimer, T. S., & Grumbach, K. (2007). *Improving primary care: Strategies and tools for a better practice*. Columbus, OH: McGraw-Hill Companies.
- Christopher, F., & Eisen, M. (Executive Producers). (2006). *Remaking American medicine: Healthcare for the 21st century*. [Videotape], Santa Barbara, CA: Crosskeys Media. Available at <http://www.remakingamericanmedicine.org/purchase.html>.
- 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 – A work in progress*. Available at <http://www.familycenteredcare.org/pdf/Roadmap.pdf>.
- Cooley, C. W., & McCallister, J. W. (2001). *Building a medical home: Improvement strategies in primary care for children with special health care needs: Medical home improvement kit*. Greenfield, NH: Center for Medical Home Improvement. Available at <http://www.medicalhomeimprovement.org/mhik.htm>.
- Coulter, A., & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *British Medical Journal*, 335, 24-27.
- Dillon, A. D. (2003). *Parent partners: Creative forces on medical home improvement teams*. Greenfield, NH: Center for Medical Home Improvement.
- Giachello, A. L., Arrom, J. O., Davis, M., Sayad, A.V., Ramirez D., Mandi, C., & Ramos, C. (2003). Reducing diabetes health disparities through community-based participatory action research: the Chicago Southeast Diabetes Community Action Coalition. *Public Health Reports*, 118, 309-323.
- Heisler, M. (2006). *Building peer support programs to manage chronic conditions: Seven models for success*. Oakland, CA: California HealthCare Foundation.
- Johnson, B., Abraham, M., Conway, J., Simmons, L., Edgman-Levitan, S., Sodomka, P., Schlucter, J., & Ford, D. (In Press). *Partnering with patients and families to design a patient- and family-centered health care system: Recommendations and promising practices*. Bethesda, MD: Institute for Family-Centered Care.
- Lorig, K. (2001). *Patient education: A practical approach* (3rd ed.). Thousand Oak, CA: Sage Publications.
- McGreevey, M. (Ed.). (2006). *Patients as partners: How to involve patients and families in their own care*. Oakbrook Terrace, IL: Joint Commission Resources, Inc.



Moore, L. G., & Wasson, J. (2006). An introduction to technology for patient-centered collaborative care. *Journal of Ambulatory Care Management*, 29(3), 195-198.

Pillow, M. (Ed.). (2007). *Patients as partners: Toolkit for implementing national patient safety goal 13*. Oakbrook, IL: Joint Commission Resources, Inc.

Wagner, E. H., Bennett, S. M., Austin, B. T., Greene, S.M., Schaefer, J.K., & Vonkorff, M. (2005). Finding common ground: patient-centeredness and evidence-based chronic illness care. *Journal of Alternative and Complementary Medicine*, 11(Supp. 1.), S7-S15.

Webster, P. D., & Johnson, B. H. (In Press). *Developing family-centered vision, mission, and philosophy of care statements*. Bethesda, MD: Institute for Family-Centered Care.

Webster, P. D., & Johnson, B. H. (2000). *Developing and sustaining a patient and family advisory council*. Bethesda, MD: Institute for Family-Centered Care.

## Websites

### Center for Medical Home Improvement (CMHI)

<http://www.medicalhomeimprovement.org>

A “medical home” is a model for providing comprehensive primary care to children with special health care needs. CMHI has set out to engage families and professionals in quality improvement to build and enhance medical home practices. The site has practical assessments and resources for providers in community practices and families serving on improvement teams including the complete *Medical Home Improvement Kit* with measurements, strategies, and *A Guide for Parent and Practice “Partners” Working to Build Medical Homes for CSHCN*.

### Clinical Governance Support Team

[http://www.cgsupport.nhs.uk/Programmes/Patients\\_Accelerating\\_Change\\_Programme.asp](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.

## **Health Disparities Collaboratives**

*<http://www.healthdisparities.net/hdc/html/home.aspx>*

The Health Resources and Services Administration (HRSA) Bureau of Primary Health Care (BPHC), in partnership with the Institute for Healthcare Improvement (IHI), created a nationwide initiative to improve care for people with chronic conditions and to eliminate health disparities. The website offers training manuals, tools, resources, and opportunities to get involved.

## **Improving Chronic Illness Care**

*<http://www.improvingchroniccare.org>*

As a national program of the Robert Wood Johnson Foundation, Improving Chronic Illness Care (ICIC) is dedicated to improving the experience of chronic illness care for patients and their families. Based at the MacColl Institute for Healthcare Improvement in Seattle, ICIC promotes the use of evidence-based change concepts to enhance care. This site provides comprehensive resources about the Chronic Care Model, which views the patient as a partner with providers in decision-making, participation in care, and quality improvement. Useful tools and strategies for change and evaluation are shared.

## **Institute for Family-Centered Care**

*<http://www.familycenteredcare.org>*

The Institute extends its efforts to provide leadership to advance the understanding and practice of patient- and family-centered care through its website. The site includes a wealth of practical resources, effective strategies, and profiles from families, providers, and organizations. Information and resources on Primary Care can be found in the Special Topics section under Advancing the Practice.

## **Institute for Healthcare Communication**

*[http://www.healthcarecomm.org/index\\_noflash.php?&noflash](http://www.healthcarecomm.org/index_noflash.php?&noflash)*

Formerly, the Bayer Institute for Health Care Communication, this organization provides education and resources to promote partnerships between patients and providers in clinical practice. The site offers many resources for professional development including, an *Annotated Bibliography for Clinician Patient Communication to Enhance Health Outcomes* as well as case studies and training resources.



## **Institute for Healthcare Improvement (IHI)**

*<http://www.ihl.org>*

Founded in 1991, IHI has been a leader in advancing the improvement of health care. IHI's ever-expanding website has a wealth of information on patient and family involvement in quality improvement and research. This includes strategies to capture the patient and family experience of care as well as to involve patients and families on research and evaluation teams. Particularly related to primary care are the topic sections on chronic conditions, office practices, patient-centered care, and self-management support.

## **The John D. Stoeckle Center for Primary Care Innovation**

*<http://www.massgeneral.org/stoecklecenter>*

The Stoeckle Center seeks achievable ways to redesign the delivery of primary care. Drawing on the resources of Massachusetts General Hospital and the expertise and experiences of patients themselves, the Stoeckle Center focuses on encouraging innovation at the practice level, education of physicians and medical students, and research. Patients and families are actively involved in these efforts.

## **National Center for Cultural Competence**

*<http://www11.georgetown.edu/research/gucchd/nccc>*

This center's work is focused on increasing the capacity of health and mental health programs to design, implement, and evaluate culturally and linguistically competent service delivery systems. They offer numerous and valuable online resources for improving primary health care, including self-assessment tools and publications and on-site training and education.

## **National Patient Safety Foundation**

*<http://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 offers 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 and strategies for involving patients and families in improvement efforts are offered.

## **Patient Powered: Patient Centered Healthcare in Whatcom County**

*<http://www.patientpowered.org>*

In 2002, St. Joseph Hospital in Bellingham, Washington, on behalf of the Whatcom County Community Health Improvement Consortium, was awarded a grant from the Robert Wood Johnson Foundation to participate in the Pursuing Perfection in Health Care initiative. As part of the project, patients developed this website to provide information and resources for individuals with chronic conditions. Any visitor to the site can access, complete, and print out the personal health record titled, the Shared Care Plan.



## **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. It promotes the understanding of the patient's perspective through measurement, improvement, and policy initiatives. The organization supports a variety of endeavors to involve patients and the public in health care and in the improvement of health care.

## **PART V: SELECTING, PREPARING, AND SUPPORTING PATIENT AND FAMILY ADVISORS IN AMBULATORY CARE**

Hospitals, clinics, and other community-based ambulatory care practices are increasing 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, 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 clinic or other ambulatory care setting. 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 a 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.
- ▼ Speak comfortably in a group with candor.



- ▼ Show a positive outlook on life and a sense of humor.
- ▼ 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. Community outreach workers, promotores and other lay health workers, and current patient and family advisors may also be able to identify potential advisors. Contacting community support groups and health and wellness and chronic care 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 redesign projects, they should be informed of the responsibilities and privileges associated with the role. A fact sheet containing the following information, as relevant, can be prepared and offered to individuals who are being asked to participate:

- ▼ Mission and goals of the group or project.
- ▼ Expectations for their participation.
- ▼ Meeting times, frequency, and duration.
- ▼ Travel dates.
- ▼ Expectations for communication among team members between meetings (including means of communication—email, mail, phone, etc.).
- ▼ 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 program should reimburse patients and families for expenses incurred in association with their work with the team (e.g., parking, transportation, child care). Many programs 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, appropriate orientation, training, preparation, and support should be offered. They should have a chance to discuss their questions or thoughts about the work with an identified staff member who is willing to serve as a liaison to the advisors and has time dedicated to coordinate 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 clinic, community-based ambulatory practice, or health system.
- ▼ Patient- and family-centered care.
- ▼ Overview of patient safety issues and strategies.
- ▼ Models of care for patients with chronic conditions or special health care needs (e.g., collaborative self-management support, medical home).
- ▼ HIPAA and the importance of privacy and confidentiality.
- ▼ Specific skills and knowledge needed to be an effective team member (e.g., quality improvement methodology for those who will be participating on a quality improvement team).

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

- ▼ Speaking the organization's language, "Jargon 101." While it is best to reduce the amount of jargon used in meetings, sometimes it is impossible to completely eliminate jargon. If there are terms that will be used frequently, 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 other 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., facilitator, secretary, timekeeper).
- ▼ Technologies that will be used (e.g., conference calls, web-based tools).



- ▼ Effective communication skills:
  - ▽ 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 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, and what to bring. Some patients and families may not have credit cards and, therefore, may have difficulty arranging travel 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 staff or project team who has experience working on collaborative initiatives and is willing to serve as a liaison can be assigned to this role. An experienced patient or family advisor can also fulfill this role. This person can insure that patient and family advisors are prepared for each meeting. During meetings, this person can 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 and as members of improvement and redesign teams is to believe that their participation is essential to the design and delivery of optimal 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 and 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, *A Checklist for Attitudes About Partnering with Patients and Families in Ambulatory Care*, can be used to help physicians and staff explore their attitudes and beliefs about partnering with patients and families (see page 16, Part VI).

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 VI: A CHECKLIST FOR ATTITUDES ABOUT PARTNERING WITH PATIENTS AND FAMILIES IN AMBULATORY CARE**

*Use this tool to explore attitudes about patient and family involvement in their own health care and as advisors and/or members of committees and 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, policy and program development, and health care redesign teams.*

**Answer and discuss the following questions:**

**At each clinic visit:**

- 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?

**At the organizational level:**

- Do I consistently let colleagues know that I value the insights of patients and families?
- 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 on committees and 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 on committees and teams?
- Do I help patients and families set clear goals for their roles in these efforts?
- 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 on committees and teams?

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

