

ADVANCING THE PRACTICE OF PATIENT- AND FAMILY-CENTERED CARE IN PRIMARY CARE AND OTHER AMBULATORY SETTINGS

How to Get Started...



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For further information about patient- and family-centered care in primary care and other ambulatory settings: <http://www.familycenteredcare.org/advance/topics/primary-care.html>

The **Institute for Family-Centered Care** provides essential leadership for advancing the practice of patient- and family-centered care. Through the development and dissemination of materials, policy and research initiatives, training, technical assistance, and on-site consultation, the Institute serves as a central resource for increasing the understanding and skills necessary to build effective partnerships with patients and families.

For well over a decade, there has been growing recognition of the enormous benefits patient- and family-centered care offers to health care providers, patients, and families in all areas of health care. As hospitals, primary care practices, other outpatient settings, and health systems struggle with issues related to quality, safety, HIPAA compliance, workforce capacity, the use of technology, the need to renovate or build new facilities, and cost control, they are recognizing that patient- and family-centered approaches and the perspectives of patients and families are essential to their efforts.

Visit our website at www.familycenteredcare.org for additional resources, tools, schedule of events, profiles of patient and family advisors and leaders, and profiles of organizational change.

What 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 primary and other 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 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.

A template and example for *Creating an Action Plan* can be downloaded from www.familycenteredcare.org/tools/downloads.htm.

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 ASSESSMENT FOR PRIMARY CARE AND OTHER AMBULATORY CARE SETTINGS

Leadership in the Organization

- Do the practice's/clinic's vision, mission, and philosophy of care statements reflect the principles of patient- and family-centered care and promote partnerships with patients and families?
- Has the practice/clinic defined quality health care?
 - ▽ 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 practice/clinic to staff and clinicians, patients and families, and others in the community?
- Do the practice's/clinic's leaders invest time and financial and personnel resources in patient- and family-centered initiatives?
- Do the practice's/clinic's leaders, through their words and actions, hold staff and clinicians accountable for collaborating with patients and families?

Patients and Families as Advisors

- Is there an organizational Patient and Family Advisory Council?
 - ▽ If there is a Patient and Family Advisory Council, is patient safety a regular item?
- Do patients and families serve on committees and work groups involved in:
 - ▽ Patient/family education?
 - ▽ Care of chronic conditions (e.g., self-management support)?
 - ▽ Peer-led education and support?
 - ▽ Planning group visits?
 - ▽ Patient safety?
 - ▽ Transition planning?
 - ▽ Information technology?
 - ▽ Oversight of culturally and linguistically appropriate services?
 - ▽ Community services and programs?
 - ▽ Staff orientation and education?
 - ▽ Policy and procedure development?
 - ▽ Primary or ambulatory care redesign?
 - ▽ Quality improvement?
 - ▽ Facility design?

Architecture and Design

- Does the practice's/clinic's architecture and design:
 - ▽ Create positive and welcoming impressions throughout for patients and families from diverse cultural and linguistic backgrounds?
 - ▽ Display messages that communicate to patients and families that they are essential members of the health care team?
 - ▽ Provide signage in the language(s) of the communities served?
 - ▽ Provide for the privacy and comfort of patients and families?
 - ▽ Support the presence and participation of families?
 - ▽ Enhance patient and family access to useful information?
 - ▽ Promote efficient workflow?
 - ▽ Support collaboration among clinicians and staff across disciplines?

Patient and Family Participation in Care and Decision-Making

- Do staff and clinicians view patients and families as essential members of the health care team?
- Are patients and their families, according to patient preference, encouraged and supported to participate in care planning and decision-making?
- Are the cultural and spiritual practices of patients and families respected and incorporated into care planning and decision-making?
- Do providers encourage and support patients and their families, according to patient preference, to set goals and create action plans for self-management of chronic conditions?
- Are policies, programs, and staff practices consistent with the view that patients and families are allies for patient health, safety, and well-being?

Patient and Family Access to Information, Education, and Support

- Are there systems in place to ensure that patients and their families have access to complete, unbiased, and useful information?
- Are a range of informational and educational programs and materials consistently available to patients and families?
- Are written, audiovisual, and web-based information and educational resources provided in primary languages and at appropriate literacy levels for patients and families served by the practice/clinic?
- Do the written, audiovisual, and web-based information and educational resources include examples and images that reflect the diversity of patients and families served by the practice/clinic?
- Are trained interpreters available?
- Are peer-led educational programs available and accessible to patients and families?
- Are web-based opportunities for information-sharing and networking offered to patients and families?

Documentation Systems and Charting

- Does the registration/sign in process for practice/clinic visits capture the patient's priorities, goals, and concerns for the visit?
- Do charting and documentation systems and the use of information technology support the recording of patients' and families' observations, goals, and priorities for care?

- Do patients and families, according to patient preference, have easy and continuing access to their medical records?
- Are patients and families offered a way to collect and organize personal health information (e.g., patient portals to the electronic medical record, electronic personal health record)?

Human Resources

- Does the practice's/clinic's human resources system support and encourage collaboration with patients and families?
- Are patient and family advisors involved in the hiring process for:
 - ▽ staff leaders?
 - ▽ clinical leaders?
- Do position descriptions and performance appraisal processes clearly articulate the necessity of collaborating with patients and families of diverse cultural and linguistic backgrounds in care and decision-making?
- Do position descriptions and performance appraisal processes clearly articulate the necessity of collaborating with patients and families in program development, professional education, and quality improvement?
- Do position descriptions and performance appraisal processes clearly articulate the necessity of collaborating with staff across disciplines and departments?
- Do position descriptions and performance appraisal processes clearly articulate the necessity of collaborating with community agencies?
- Do staff reflect the diversity of patients and families served by the practice/clinic?
- Does the practice/clinic employ doulas, promotores, and/or other lay health workers?
- Are there rewards and recognition for partnering with patients and families?
- Are there rewards and recognition for supporting self-management of chronic conditions?

Education of Staff, Clinicians, Students and Trainees

- Do orientation and education programs prepare the following people for collaboration with patients and families in care and decision-making:
 - ▽ Staff?
 - ▽ Clinicians?
 - ▽ Students and Trainees?
- Do orientation and education programs prepare the following people for culturally responsive practice:
 - ▽ Staff?
 - ▽ Clinicians?
 - ▽ Students and Trainees?
- Do orientation and education programs prepare the following people to collaborate with patients and families to develop goals and action plans for self-management of chronic conditions:
 - ▽ Staff?
 - ▽ Clinicians?
 - ▽ Students and Trainees?
- Are patients and families involved as faculty in orientation and educational programs?

Research and Evaluation

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

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.

PART IV: SELECTED RESOURCES AND WEBSITES

Resources

For the most recent references on this topic, please see the Institute's *Compendium of Bibliographies* at <http://www.familycenteredcare.org/advance/supporting.html>.

American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, & American Osteopathic Association. (2007). *Joint principles of the patient-centered medical home*. Retrieved August 25, 2009, from <http://www.medicalhomeinfo.org/Joint%20Statement.pdf>

American Academy of Pediatrics. (2004). Policy statement: Medical home initiatives for children with special needs project advisory committee. *Pediatrics*, *113*(5), 1545-1547.

Antonelli, R. C., McAllister, J. W., & Popp, J. (2009, May). *Making care coordination a critical component of the pediatric health system: A multidisciplinary framework*. New York: The Commonwealth Fund.

Antonelli, R., Stille, C., & Freeman, L. (2005). *Enhancing collaboration between primary and subspecialty care providers for children and youth with special health care needs*. Washington, DC: Georgetown University Center for Child and Human Development. Retrieved September 1, 2009, from http://gucchd.georgetown.edu/files/products_publications/PrimarySpecialtyCollaboration.pdf

Baldwin, A. S., Cvengros, M. A., Christensen, A. J., Ishani, A., & Kaboli, P. J. (2008). Preferences for a patient-centered role orientation: Association with patient-information-seeking behavior and clinical markers of health. *Annals of Behavioral Medicine*, *35*(1).

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.

Burdo-Hartman, W. A., & Patel, D. R. (2008). Medical home and transition planning for children and youth with special health care needs. *Pediatric Clinics of North America*, *55*(6), 1287-1297.

California HealthCare Foundation (Producer). (2008). *Coaching patients for successful self-management* [Video]. Oakland, CA: California HealthCare Foundation. Available from <http://www.chcf.org/topics/chronicdisease/index.cfm?itemID=133717>

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>

Committee on Children with Disabilities, American Academy of Pediatrics. (2000). The role of the pediatrician in transitioning children and adolescents with developmental disabilities and chronic illnesses from school to work or college. *Pediatrics*, *106*(4), 854-856.

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, W. C. (2001). Family-centered care in pediatric practice. In R. A. Hoekelman (Ed.), *Primary pediatric care* (pp. 712-714). St. Louis: Mosby.

Cooley, W. C., & 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.

Cooley, W. C., McAllister, J. W., Sherrieb, K., & Khulthau, K. (2009). Improved outcomes associated with medical home implementation in pediatric primary care. *Pediatrics*, *124*, 358-364.

Coulter, A. (2007, June). *Evidence on the effectiveness of strategies to improve patients' experience of cancer care*. Oxford, UK: Picker Institute Europe. Available from <http://www.picker-europe.org>

Coulter, A. (2006). Patient engagement: Why is it so important? In E. Anderson, J. Tritter, & R. Wilson (Eds.), *Healthy democracy: The future of involvement in health and social care* (pp. 27-35). London: Involve and NHS National Centre for Involvement.

Coulter, A., & Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients. *British Medical Journal*, *335*, 24-27.

Crocker, L., & Johnson, B. (2006). *Privileged presence: Personal stories of connections in health care*. Boulder, CO: Bull Publishing Company.

Dillon, A. D. (2003). *Parent partners: Creative forces on medical home improvement teams*. Greenfield, NH: Center for Medical Home Improvement.

Dokken, D. L., & Sydnor-Greenberg, N. (2000). Exploring complementary and alternative medicine in pediatrics: Parents and professionals working together for new understanding. *Pediatric Nursing*, *26*(4), 383-390.

Epstein, R. M., Alper, B. S., & Quill, T. E. (2004). Communicating evidence for participatory decision making. *Journal of the American Medical Association*, *291*(19), 2359-2366.

Family-Professional Partners Institute, & Massachusetts Consortium for Children with Special Health Care Needs. (2008). *The power of partnership: Sixteen family-professional partnerships that are making a difference for children with special health care needs*. Boston, MA: New England SERVE. Available from http://www.neserve.org/neserve/pub_pop.htm

Family-Professional Partners Institute, & Massachusetts Consortium for Children with Special Health Care Needs. (2008). *Structure & spark! Building family-professional partnerships to improve care for children with special health care needs*. Boston, MA: New England SERVE. Available from http://www.neserve.org/neserve/pub_structure.htm

Giachello, A. L., Arrom, J. O., Davis, M., Sayad, A.V., Ramirez D., Mandi, C., et al. (2003). Reducing diabetes health disparities through community-based participatory action research: The Chicago Southeast Diabetes Community Action Coalition. *Public Health Reports, 118*, 309-323.

Goldfield, N. (2009). Patient-centered care [Theme issue]. *Journal of Ambulatory Care Management, 32*(1).

Haskard, K. B., Williams, S. L., DiMatteo, R., Rosenthal, R., White, M. K., & Goldstein, M. G. (2008). Physician and patient communication training in primary care: Effects on participation and satisfaction. *Health Psychology, 27*(5), 513-522.

Heisler, M. (2006). *Building peer support programs to manage chronic conditions: Seven models for success*. Oakland, CA: California HealthCare Foundation.

Homer, C. J., Klatka, K., Romm, D., Kuhlthau, K., Bloom, S., Newacheck, P., et al. (2008). A review of the evidence for the medical home for children with special health care needs. *Pediatrics, 122*, e922-e937.

Institute for Family-Centered Care. *Advancing the practice of patient- and family-centered care in primary care and other ambulatory care settings: How to get started*. Bethesda, MD: Author. Available from <http://www.familycenteredcare.org/tools/downloads.html>

Jadad, A. R., Rizo, C. A., & Enkin, M. W. (2003). I am a good patient, believe it or not. *BMJ, 326*, 1293-1295.

Jeppson, E. S., & Thomas, J. (1995). *Essential allies: Families as advisors*. Bethesda, MD: Institute for Family-Centered Care. Available from <http://www.familycenteredcare.org/resources/videos/index.html>

Johnson, B., Abraham, M., Conway, J., Simmons, L., Edgman-Levitan, S., Sodomka, P., et al. (2008). *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.

Kinmonth, A. L., Woodcock, A., Griffin, S., Spiegel, N., & Campbell, M. J. (2009). Randomised controlled trial of patient centred care of diabetes in general practice: Impact on current wellbeing and future disease risk. *BMJ, 317*, 1202-1208.

- Levinson, W., Roter, D. L., Mullooly, J. P., Dull, V., & Frankel, R. M. (1997). Physician-patient communication: The relationship with malpractice claims among primary care physicians and surgeons. *Journal of the American Medical Association*, 277(7), 553-559.
- Lorig, K. (2001). *Patient education: A practical approach* (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Lorig, K. R., & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine*, 26(1), 1-7.
- Marks, R., Allegrante, J. P., & Lorig, K. (2005). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: Implications for health education practice (part I). *Health Promotion Practice*, 6(1), 37-43.
- Marks, R., Allegrante, J. P., & Lorig, K. (2005). A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: Implications for health education practice (part II). *Health Promotion Practice*, 6(2), 148-156.
- Mauksch, L. B., Dugdale, D. C., Dodson, S., & Epstein, R. (2008). Relationship, communication, and efficiency in the medical encounter. *Archives of Internal Medicine*, 168(13), 1387-1395.
- McAllister, J., Presler, E., & Cooley, C. (2007). *Medical home practice based care coordination: A workbook*. Greenfield, NH: The Center for Medical Home Improvement.
- 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.
- National Resource Network for Child and Family Mental Health Services at the Washington Business Group on Health. (Ed.). (1999). *Systems of care: Promising practices in children's mental health, 1998 Series, Volumes I-VII*. Washington, DC: Center for Effective Collaboration and Practice, American Institutes for Research.
- Nickel, R. E., Cooley, W. C., McAllister, J. W., & Samson-Fang, L. (2003). Building medical homes for children with special health care needs. *Infants and Young Children*, 16(4), 331-341.
- O'Donnell, S., Cranney, A., Jacobsen, M. J., Graham, I. D., O'Connor, A. M., & Tugwell, P. (2006). Understanding and overcoming the barrier of implementing patient decision aids in clinical practice. *Journal of Ambulatory Care Management*, 29(3), 195-198.
- O'Hea, E. L., Boudreaux, E. D., Jeffries, S. K., Carmack Taylor, C. L., Scarinci, I. C., & Brantley, P. J. (2004). Stage of change movement across three health behaviors: The role of self-efficacy. *American Journal of Health Promotion*, 19(2), 94-102.

- Palfrey, J. S., Sofis, L. A., Davidson, E. J., Liu, J., Freeman, L., & Ganz, M. L. (2004). The Pediatric Alliance for Coordinated Care: Evaluation of a medical home model. *Pediatrics*, *113*(5), 1507-1516.
- Pillittere, D., Bigley, M. B., Hibbard, J., & Pawlson, G. (2003). Exploring consumer perspectives on good physician care: A summary of focus group results. *The Commonwealth Fund*. Retrieved September 1, 2009, from http://www.cmwf.org/publications/publications_show.htm?doc_id=221323
- Pillow, M. (Ed.). (2007). *Patients as partners: Toolkit for implementing national patient safety goal 13*. Oakbrook, IL: Joint Commission Resources, Inc.
- Reid, R. J., Fishman, P. A., Yu, O., Ross, T. R., Tufano, J. T., Soman, M. P., et al. (2009). Patient-centered medical home demonstration: A prospective, quasi-experimental, before and after evaluation. *The American Journal of Managed Care*, *15*(1), e71-e87.
- Rogers, A., Kennedy, A., Nelson, E., & Robinson, A. (2005). Uncovering the limits of patient-centeredness: Implementing a self-management trial for chronic illness. *Qualitative Health Research*, *15*(2), 224-239.
- Sadof, M. D., & Nazarian, B. L. (2007). Caring for children who have special health-care needs: A practical guide for the primary care practitioner. *Pediatrics in Review*, *28*(7), e36-e42.
- Schoen, C., Osborn, R., How, S., Doty, M., & Peugh, J. (2008). In chronic condition: Experience of patients with complex health care needs in eight countries. *Health Affairs*, *28*(1), w1-w16.
- Sia, C., Antonelli, R., Gupta, V. B., Buchanan, G., Hirsch, D., Nackashi, J., et al. (2002). American Academy of Pediatrics. Medical Home Initiatives for Children with Special Needs Project Advisory Committee. The medical home. *Pediatrics*, *110*(1), 184-186.
- Sweeney, L., Halpert, A., & Waranoff, J. (2007). Patient-centered management of complex conditions can reduce costs without shortening life. *The American Journal of Managed Care*, *13*, 84-92.
- Thomas, J., & Jeppson, E. S. (1997). *Words of advice: A guidebook for families serving in advisory roles*. Bethesda, MD: Institute for Family-Centered Care. Available from <http://www.familycenteredcare.org/resources/pinwheel/index.html>
- Trivette, C. M., Dunst, C. J., & Hamby, D. W. (1996). Characteristics and consequences of helping practices in contrasting human services programs. *American Journal of Community Psychology*, *24*(2), 273-293.
- 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.

Wasson, J. H., Johnson, D. J., Benjamin, R., Phillips, J., & MacKenzie, T. A. (2006). Patients report positive impacts of collaborative care. *Journal of Ambulatory Care Management*, 29(3), 199-206.

Webster, P. D., & Johnson, B. H. (In Press). *Developing patient- and 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.

Young, A., & Flower, L. (2002). Patients as partners, patients as problem-solvers. *Health Communication*, 14(1), 69-97.

Websites

Agency for Healthcare Research and Quality (AHRQ)

www.ahrq.gov

AHRQ funds, conducts, and disseminates research to improve the quality, safety, efficiency, and effectiveness of health care. The information gathered from this work and made available on the website assists all key stakeholders — patients, families, clinicians, leaders, purchasers, and policymakers — make informed decisions about health care.

American Academy of Pediatrics National Center of Medical Home Initiatives for Children with Special Needs — Tools for Youth

www.medicalhomeinfo.org/tools/youthindex.html

This special section of the Medical Home website is devoted to providing youth with special health care needs and their families with information and tools to help as they transition into adult health care.

California HealthCare Foundation (CHCF)

www.chcf.org

The California HealthCare Foundation is an independent philanthropic organization that supports improvements in health care for all Californians. They offer resources on their site that will be helpful to anyone interested in chronic care, care for the underserved, and health information technology.

Center for Information Therapy (IxCenter)

www.informationtherapy.org

The Center for Information Therapy is an independent, not-for-profit that aims to advance the practice and science of information therapy to improve health, consumer decision-making and healthy behaviors. Included on the site is a blog that regularly discusses patient- and family-centered topics.

Center for Medical Home Improvement (CMHI)

www.medicalhomeimprovement.org

The “medical home” began as a model for providing comprehensive primary care to children and youth with special health care needs. This site has practical assessments and resources for providers in community practices and families serving on improvement teams. The complete Medical Home Improvement Kit including measurements, strategies, and *A Guide for Parent and Practice “Partners” Working to Build Medical Homes for CSHCN* can be downloaded from the site.

The Commonwealth Fund — Patient-Centered Primary Care Initiative

www.commonwealthfund.org/Content/Program-Areas/High-Performance-Health-System/Patient-Centered-Primary-Care-Initiative.aspx

The Commonwealth Fund launched the Patient-Centered Primary Care Initiative in 2005 to encourage primary care practices and health care systems to redesign the delivery of health care around the needs and priorities of patients.

Consumer Assessment of Healthcare Providers and Systems (CAHPS)

www.cahps.abrq.gov/

The Consumer Assessment of Healthcare Providers and Systems program develops and supports the use of a comprehensive and evolving family of standardized surveys that ask consumers and patients to report on their experiences with health care.

Family Voices

www.familyvoices.org

Family Voices offers a variety of information and resources for families and providers caring for children with special health care needs. Family Voices activities embody the principles of patient- and family-centered care.

Foundation for Informed Medical Decision Making (FIMDM)

www.fimdm.org

The mission of FIMDM is to strengthen the ability of patients in making decisions about their health care. The site offers evidence-based information about treatment options, interviews with patients, decision-aids to guide decision-making, and other tools on a variety of conditions.

Health Care Transitions Initiative

<http://hctransitions.ichp.ufl.edu>

Established at the University of Florida, this program’s mission is to increase awareness of, gain knowledge about, and promote cooperative efforts to improve the transition from pediatric to adult health care. It has audiovisual and print materials for adolescents, young adults, parents, and providers.

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 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 Initiative for Children’s Healthcare Quality (NICHQ)

www.nichq.org

NICHQ has the mission to eliminate the gap between what is and what can be in health care for all children. Many of their initiatives support family involvement in quality improvement.

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.

National Working Group on Evidence-Based Health Care

www.evidencebasedhealthcare.org

This site provides a clearinghouse for consumers, voluntary health organizations, providers, and researchers to obtain information and resources about evidence-based health care. Useful resources include the guidance, *The Role of the Patient/Consumer in Establishing a Dynamic Clinical Research Continuum: Models of Patient/Consumer Inclusion*.

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 Decision Aids

http://decisionaid.ohri.ca

This site is part of the Ottawa Health Research Institute and was created to assist clinicians and patients make difficult health care decisions. The program is research-based and the site offers online tools, clinician training programs, and other resources.

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, *Shared Care Plan*.

Portland State Research and Training Center

www.rtc.pdx.edu/index.php

The Center promotes effective community-based, culturally competent, family-centered services for families and their children who are, or may be affected by mental, emotional or behavioral disorders. This goal is accomplished through collaborative research partnerships with family members, service providers, policy makers, and other concerned persons.

Professionals with Personal Experience in Chronic Care (PPECC)

www.ppecc.org

This group of health care professionals established PPECC to advocate for improved systems of care after personal and family experiences with chronic illness and long-term care. Health care professionals are encouraged to share their personal experiences with the health care system in order to promote greatly needed change.

Robert Wood Johnson Foundation (RWJF)

www.rwjf.org

RWJF has been working for over 30 years to improve U.S. health care through supporting research, advocacy, and policy work. RWJF has funded innovative programs that integrate patient- and family-centered care into their initiatives. A good example can be found in a current project, Designing the 21st Century Hospital: Serving Patients and Staff and is a great resource for leaders and managers undergoing a design project, *<http://www.rwjf.org/files/publications/other/Design21CenturyHospital.pdf>*.

PART V: SELECTING, PREPARING, AND SUPPORTING PATIENT AND FAMILY ADVISORS IN PRIMARY CARE AND OTHER AMBULATORY SETTINGS

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.

For additional ideas for recruiting patients and families, see *Tips for Recruiting Patients and Families to Serve in Advisory Roles*, available at www.familycenteredcare.org/tools/downloads.html.

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.

The guidance tools, *Staff Liaison to Patient and Family Advisory Councils and Other Collaborative Endeavors* and *Tips for Group Leaders and Facilitators on Involving Patients and Families on Committees and Task Forces* can be downloaded from www.familycenterdcare.org/tools/downloads.html.

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 Primary Care and Other Ambulatory Settings*, 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 PRIMARY CARE AND OTHER AMBULATORY SETTINGS

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.