



# A Collaborative Partnership

*Resources to Help Consumers Thrive in the Medical Home*





# A Collaborative Partnership

## *Resources to Help Consumers Thrive in the Medical Home*

### A Guide for Engaging Consumers, Patients and Families

Forward . . . . .	3
Introduction . . . . .	5
Joint Principles . . . . .	5
A Collaborative Partnership: PCPCC Consumer Meeting Summary . . . . .	7
Consumer Activities across PCPCC Centers . . . . .	10
Center for Multi-Stakeholder Demonstrations . . . . .	10
Center to Promote Public Payer Implementation . . . . .	10
Center for Benefits Redesign and Implementation. . . . .	11
Center for eHealth Information Adoption and Exchange . . . . .	11
Consumer Engagement in PCMH Demonstrations . . . . .	13
State Examples of Early Consumer Engagement. . . . .	16
PCPCC Participatory Engagement Program . . . . .	19
Consumer PCPCC Tools . . . . .	21
Emmi Solutions. . . . .	21
Center for Advancing Health . . . . .	21
Merck & Co., Inc. . . . .	23
Stoeckle Center for Primary Care Innovation . . . . .	23
National Partnership for Women & Families . . . . .	23
Institute for Family-Centered Care . . . . .	24
Consumer Engagement Resources Catalogue . . . . .	31
Appendix A: Joint Principles . . . . .	37
Appendix B: CBRI Sample Letter to Employees . . . . .	39
Appendix C: PCPCC-Vetted Consumer Tools and Resources . . . . .	40



## Acknowledgments

This Guide was developed by the Patient-Centered Primary Care Collaborative (PCPCC) with financial support from the Maternal and Child Health Bureau of the Health Resources and Services Administration, Family Voices, and the National Newborn Screening and Genetics Resource Center—The University of Texas Health Science Center at San Antonio. The Guide is a product of many efforts and initiatives throughout the PCPCC, including the Consumer Education Task Force, a Consumer Advocacy Meeting held July 27, 2009 and activities across the four-Center structure of the PCPCC.

We would like to acknowledge and thank the author of this report, Shannah Koss, Koss on Care LLC. The PCPCC would also like to thank the organizations and individuals that contributed resources for inclusion in the Guide:

**Carolyn Allshouse**

*Minnesota Department of Health*

**Nina Baker**

*Parent Training and Information  
Nebraska*

**Christine Bechtel**

*National Partnership for  
Women & Families*

**Katherine H. Capps**

*Health2 Resources*

**Veronica Castillo**

*Raising Special Kids*

**Lizi de Jong Reuveni**

*Microsoft*

**Robert Dribbon**

*Merck & Co., Inc.*

**Susan Edgman-Levitan**

*Stoeckle Center for Primary  
Care Innovation*

**Dorothy Jeffress**

*The Center for Advancing Health*

**Beverly Johnson**

*Institute for Family Centered Care*

**Kimberly Labow**

*Medfusion*

**Lisa Latourneau**

*Maine Patient Centered Medical  
Home Pilot*

**Donald Liss**

*Aetna*

**Rebecca Malouin**

*College of Human Medicine,  
Michigan State University*

**Marie Mann**

*Maternal and Child Health Bureau -  
Health Resources and Services  
Administration*

**Tracy Novak**

*Johns Hopkins Bloomberg School  
of Public Health*

**Diana Pihos**

*American Association of  
Diabetes Educators*

**John Steidl**

*Thomas Group, Inc.*

**Bob Taveres**

*Emmi Solutions LLC*

**Nora Wells**

*Family Voices*

**Fan Tait**

*American Academy of Pediatrics*

**Angela Tobin**

*American Academy of Pediatrics*

**Jan Towers**

*American Academy of Nurse Practitioners*

**Allison Weber Shuren**

*NAPNAP*

## Dear Colleagues:

The PCPCC is an open forum where health care stakeholders freely communicate and work together to improve the future of the American health system. The PCPCC works with a broad array of stakeholder organizations and individuals who share the belief that the patient centered medical home (PCMH) offers a model for transforming the health system.

Since its inception, the PCPCC has recognized the importance of engaging consumer and patient groups to help design and inform the needed patient focus of PCMH. By design, this consumer focus is apparent across the work of the PCPCC. Each of the Centers is charged to develop goals and objectives that incorporate consumer involvement and engagement.

Demonstrating this commitment to the consumer, the PCPCC unveiled a set of consumer tools in April 2009, several developed by the Consumer Task Force of the PCPCC in partnership with consumer-focused organizations. The tools are described in Chapter 6 and are designed to equip a variety of stakeholders in their efforts to broaden consumer engagement in and understanding of the PCMH.

Some members of the PCPCC's advisory board represent consumer advocacy organizations who regularly offer input from this perspective. On July 27, 2009, the PCPCC held a full-day session to hear more directly from additional representative organizations and recognized individual consumer leaders about how to further engage patients and consumers in the continued evolution of the PCMH.

As a result of the recommendations from this meeting and the continued efforts of each of the PCPCC's collaborative Centers to focus on consumer engagement, we have created this Guide, *A Collaborative Partnership: Resources to Help Consumers Thrive in the Patient Centered Medical Home*. The purpose of the Guide is to support all stakeholder efforts in advancing consumer and patient participation. It is designed to help different stakeholders easily find currently available resources and recognize the evolving nature of these resources.

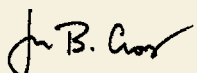
The Guide includes four core elements:

1. PCPCC activities and initiatives supporting consumer engagement;
2. Research and examples surrounding consumer engagement in PCMH demonstrations;
3. Tools for consumers and other stakeholders to assist with PCMH education, engagement and partnerships; and
4. A catalogue of resources that provides descriptions of and the means to obtain potential resources for consumers, providers and purchasers seeking to better engage consumers.

In addition to the Guide, the PCPCC is redesigning its Web site to allow for the real-time evolution and availability of consumer resources. The Consumer Task Force will also undertake a new initiative focused on improved consumer communication to begin to address the varied and distinct communication needs inherent in the diversity of our nation's consumer population.

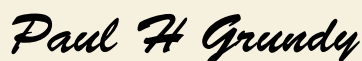
We hope you find these efforts to engage consumers in PCMH evolution to be useful and effective in reaching PCPCC goals.

Sincerely,



**John B. Crosby, JD**

*PCPCC Chair and Executive Director of  
the American Osteopathic Association*



**Paul Grundy, MD, MPH**

*PCPCC President, and Director of  
Healthcare Technology and Strategic  
Initiatives at IBM*



**Edwina Rogers**

*PCPCC Executive Director*





# Introduction

In today's challenging economic times we cannot ignore the role our health care system plays. The health care reform debate reminds us almost daily that change is needed, yet we struggle to agree on the full array of appropriate responses. The Patient-Centered Primary Care Collaborative (PCPCC) and its growing membership of stakeholders, representing the many facets of the American health care system, believe that the patient centered medical home (PCMH) should be a fundamental component of this necessary change.

As we seek improved health outcomes and healthier lifestyles to reduce the risk and cost of chronic illness, the consumer is a critical stakeholder and must become an engaged partner. Even the most capable and caring of clinicians cannot unilaterally improve a patients' health. It is a team effort among providers, caregivers, patients and health plans.

There was no mistake in using the terminology "patient centered." When, by necessity, we broaden the goals of the health care system to include "healthy" as well as "sick" care, all consumers become central to the model of care. The use of the term "patient centered" creates a challenge for all stakeholders to ensure that consumers are, in fact, the primary focus of the delivery model and thrive as part of the solution. The PCPCC embraces this challenge and recognizes the need for cross-cutting measures, work products and consumer focus across work done by all of its Centers.

This Guide seeks to expand the conversations about partnering with and engaging consumers. It provides tools and resources to all stakeholders in support of consumer participation in the continued evolution of the PCMH model and in their partnered role as patients in a PCMH. This Guide has been launched in anticipation of the PCPCC October 2009 Summit, but will be maintained, updated and expanded on the PCPCC Web site.

## The Joint Principles

In 2007, four specialty societies<sup>1</sup> issued the Joint Principles of the PCMH in response to requests from several large national employers seeking to create a more effective and efficient model of health care delivery for their employees. The importance of consumer engagement and participation is a foundational element of these principles, which are printed in their entirety in Appendix A. There are explicit references to consumer engagement embedded within the Joint Principles and these key areas serve as a platform for work to be done by the PCPCC and its Centers. These consumer-facing elements of the Joint Principles are underlined for emphasis in the table on the next page.

---

<sup>1</sup>American Association of Pediatrics, American Academy of Family Physicians, American College of Physicians, and American Osteopathic Association.

## JOINT PRINCIPLES

**Personal physician**—each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous and comprehensive care.

**Physician directed medical practice**—the personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients.

**Whole person orientation**—the personal physician is responsible for providing for all the patient's health care needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life; acute care; chronic care; preventive services; and end-of-life care.

**Care is coordinated and/or integrated** across all elements of the complex health care system and the patient's community. Care is facilitated by many means to assure that **patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.**

**Quality and safety** are hallmarks of the medical home and have many critical consumer engagement components, including:

- Practices advocate for their patients to support patient-centered outcomes that are **driven by a partnership between physicians, patients, and the patient's family.**
- **Patients actively participate in decision making and feedback is sought to ensure patients' expectations are being met.**
- **Patients and families participate in quality improvement activities at the practice level.**

**Enhanced access** to care is available through systems such as open scheduling, expanded hours and **new options for communication between patients, their personal physician, and practice staff.**

**Payment** appropriately recognizes the added value provided to patients who have a patient centered medical home.

# A Collaborative Partnership

## A Summary of the PCPCC July 27, 2009 Consumer Stakeholder Meeting

### Overview

On July 27, 2009, the PCPCC held its first consumer stakeholder meeting based on recommendations from its 2008 strategic planning. The meeting included consumer organizations and individual consumers who are active online consumer health care voices. The primary goals of the stakeholder meeting were:

1. To gain the perspectives from these consumer representatives and advocates regarding their understanding and anticipated needs with respect to the PCMH; and,
2. To solicit advice and involvement on how to better engage consumers in the PCPCC and the PCMH movement.

The morning sessions were largely devoted to hearing the perspectives of the consumer representatives. The afternoon discussions characterized the main themes from the morning discussions and then identified gaps and potential next steps for the PCPCC and interested consumer organizations or individuals.

### Top themes and issues

The majority of the comments and suggestions from the morning discussions can be categorized under the following headings and general descriptions of each category.

1. **Consumer engagement**—The PCPCC and communities and organizations working to establish the PCMH should seek to engage, involve, integrate and partner with consumers (patients and families). All activities should take a perspective of working with consumers to envision, build and enable successful PCMHs.
2. **Community**—PCMH implementation should be community-based, given that the majority of health care is local. Communities and consumers are diverse and a one-size-fits-all approach will likely fail. The PCPCC should seek to identify and enable

## Consumer Stakeholder Meeting Invitees

**Melinda Abrams, MS**, *The Commonwealth Fund*

**Howard Bedlin**, *National Council on Aging*

**Thomas Bryant Sr., MD, JD**, *National Coalition of Mental Health Consumer/Survivor Organizations*

**Jeffrey Caballero, MPH**, *Association of Asian Pacific Community Health Organizations*

**Katherine H. Capps**, *Health2 Resources*

**Barbara Cebuhar**, *Centers for Medicare & Medicaid Services*

**James Coan**, *Center for Medicare & Medicaid Services*

**Molly Cole**, *UConn Health Center*

**John Crosby, JD**, *American Osteopathic Association/PCPCC*

**Dave deBronkart**, *E-patients.net*

**Bob Doherty**, *American College of Physicians*

**Diane Dorman**, *National Organization of Rare Disorders*

**Robert Dribbon**, *Merck & Co., Inc.*

**Shari M. Erickson, MPH**, *American College of Physicians*

**Rebecca Farley**, *Alliance for Children and Families*

**Steve Findlay, MPH**, *Consumer Union*

**Giles Frydman**, *Association of Cancer Online Resources*

**Laura Galbreath, MPP**, *National Council for Community Behavioral Healthcare*

**Havi Glaser**, *American Association for Retired Persons*

**Kafi Grigsby**, *The Center for the Advancement of Health*

**Paul Grundy, MD, MPH**, *IBM/PCPCC*

**Jeff Hanson, MPH**, *Thomson Reuters*

**Douglas Henley, MD**, *American Academy of Family Physicians*

**Dorothy Jeffress, MBA, MSW, MA**, *The Center for the Advancement of Health*

**Beverley Johnson**, *Institute for Family Centered Care*

**Ann Kempinski**, *Service Employees International Union*

**Shannah Koss**, *Koss on Care LLC*

*continued*

continued from page 7

**Pauline Lapin, MHS**, *Center for Medicare & Medicaid Services*

**Kari Loken**, *Colorado Clinical Guidelines Collaborative*

**Rebecca A. Malouin, Ph.D, MPH**, *College of Human Medicine, Michigan State University*

**Marie Mann, MD, MPH**, *Health Resources and Services Administration*

**Julie Martin, MS**, *John D. Stoeckle Center*

**Shawn Martin**, *American Osteopathic Association*

**Megan Marz, MPA**, *Family Voices Colorado*

**Terry A. McInnis, MD, MPH**, *GlaxoSmithKline*

**David Meyers, MD**, *Agency for Healthcare Research and Quality*

**David K. Nace, MD**, *McKesson Health Solutions*

**Janet Ohene-Frempong, MS**, *JO Frempong & Associates, Inc.*

**Sara O'Keefe**, *Colorado Health Foundation*

**Duane Putnam**, *Pfizer, Inc.*

**Matt Quinn, MBA**, *Agency for Healthcare Research and Quality*

**Edwina Rogers**, *Executive Director, PCPCC*

**Bob Tavares**, *Emmi Solutions, LLC*

**Ken Thompson, MD**, *Substance Abuse and Mental Health Services Administration*

**Phyllis Torda, Ph.D, MA**, *National Committee for Quality Assurance*

**Trisha Torrey**, *Every Patient's Advocate*

**Ho Luong Tran, MD, MPH**, *Asian and Pacific Islander American Health Forum*

**Laura Van Tosh**, *Consumer Advocate*

**Wendy Vernon**, *National Quality Forum*

**Andrew Webber**, *National Business Coalition on Health*

**Ashley B. Wells**, *Epilepsy Foundation*

**Nora Wells**, *Family Voices, Inc.*

**Richard Wender, MD**, *American Cancer Society*

**Marc Wetherhorn**, *National Association of Community Health Centers*

flexible PCMH models that take into account community and consumer diversity.

- 3. Communication**—A long-recognized barrier to patient-centered care is the inherent limitation in the ability of members of the care team to adequately communicate, translate and educate consumers/patients about complex health care topics. Communication barriers include language, literacy, culture, age and income. It is through communication and translation that relationships are based. Ultimately, the PCMH model is seeking to establish a critical, trusted relationship. Perhaps some of the most passionate perspectives expressed were those regarding consumers with added communication challenges and health challenges (e.g., mental disabilities or rare diseases) in addition to language and cultural differences who in some instances, due to these barriers, receive the equivalent of veterinary care.
- 4. Grassroots**—The PCMH approach and defined need must come from the bottom up. The PCPCC and proponents of the PCMH should give the concept, design and tools to consumers and communities, allowing them to refine/define the policy and design, take ownership and bring it back to the policy and industry thought leaders. This perspective matched closely to the advice coming from the Administration.
- 5. Think broadly**—Consider the needs of all stakeholders and how diverse needs will be accommodated through the PCMH. This category in some respects builds upon the diversity issues inherent in community, communication and grassroots, but also considers how clinicians and community resources across a broad set of disciplines can and should be leveraged. The importance of resource needs (or limitations) including access to specialists by primary care providers (including but not limited to physicians), were highlighted, as were the flexibility to have specialists as the locus for some medical home models. Community resources that go beyond health care, but critically impact health (e.g., food, housing, social work), particularly for the elderly, was an equally important focus of the discussion. The PCMH should serve as a national convener and facilitator across the diverse resources.

The afternoon discussions validated and clarified the top issues/themes and went on to explore priorities, next steps and gaps in the current activities.

Perhaps the strongest common recommendation was to gain better insight and input from a more diverse set of consumer representatives (more individual consumers, distinct from

consumer advocates). A variety of suggestions and approaches were raised, including the following:

- Build an infrastructure to hear the full voices of consumers—leverage new media mechanisms (a 21<sup>st</sup> century vehicle), look to bring together consumer communities and peer supports that would help inform how best to engage consumers in both the evolving PCMH model at a policy level and on-the-ground implementation at the operational level.
- Look to successful models of consumer engagement, including those outside the PCMH environment (disability, addictions) and consumer governance roles. (See Chapter 4, “State Examples of Early Consumer Engagement.”)
- Consider establishing focus groups to advise the PCPCC across its many activities and initiatives.
- Set a goal for establishing patient advisory committees or some comparable community function that will bring the local consumer voice to the table of new and established regional, state or local PCMHs.
- Consider a goal of every practice having a consumer advocate. Practices should have the services user (consumer) involved.

Additional recommendations and goals in moving forward included:

- Provide more information from the PCPCC and the four Centers about how consumers can engage with the PCPCC;
- Review and perhaps reorganize PCPCC resources based on consumer needs and perspectives;
- Develop mechanisms for pilots to report what happened with consumer engagement and integration efforts;
- Develop education and engagement models for consumer organizations and their members;
- Test mechanisms for providing PCMH information to communities;
- Seek to establish infrastructure support for the clinical encounter triangle (primary care physician, specialist, consumer) and assist clinicians with improved understanding of patient peers/resources;
- Be sure to address the needs of large populations with both at-risk and diagnosed chronic illness; and

- Begin addressing the educational process and corresponding communication opportunities by creating a comparison of today’s care and the realized PCMH care model: What we have now, what we would have in the future, what it means and what is your (the consumer’s) role.

## Next steps

The PCPCC believes all of the discussion and output from the meeting is critical to the continued patient-centered focus of the medical home and will seek to make advances consistent with all of the recommendations. The development of this Guide is an initial step in response to some of the above-stated recommendations. The PCPCC will focus on overcoming communication challenges to advance consumer engagement. The Joint Principles, from which the consumer-focused elements that follow are excerpted, cannot be achieved without the ability to communicate:

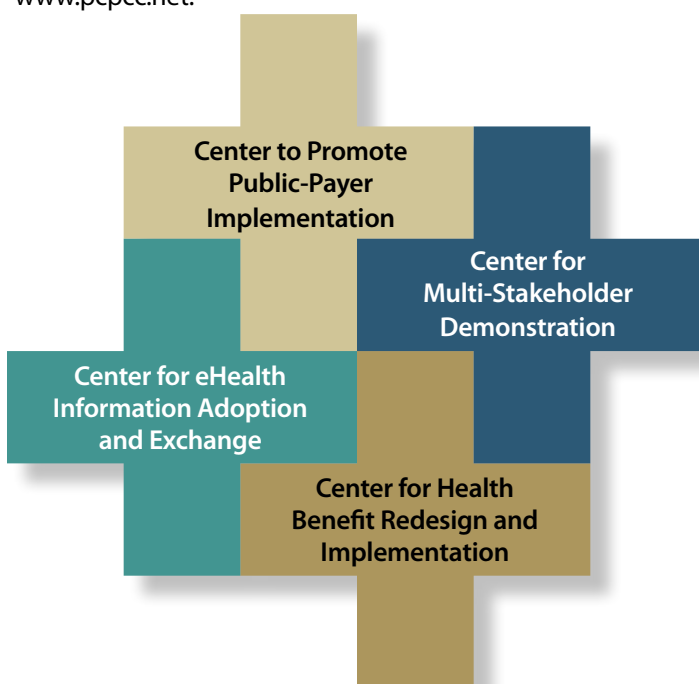
- Patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.
- Patients actively participate in decision making and feedback is sought to ensure patients’ expectations are being met.
- Patients and families participate in quality improvement activities at the practice level.
- New options for communication (are provided) between patients, their personal physician, and practice staffs.

The Consumer Education Task force is considering a number of initial steps to improve the capabilities of PCMH communication with the full diversity of consumers and patients.

# Consumer Activities Across PCPCC Centers

The PCPCC has currently structured its initiatives and projects under four Centers. Each Center has a stated mission and has established a set of goals, tasks and timeframes for deliverables to continue to advance the patient centered medical home (PCMH). This section of the Guide briefly describes each Center and then discusses current consumer-focused initiatives or anticipated activities that will further enhance the support of consumer partnership and engagement, with the full understanding that the consumer “audience” is two-fold: consumer advocacy groups, and patients/consumers themselves.

The PCPCC Centers were created to operationalize the Joint Principles, making the best use of the expertise of the PCPCC membership and resources to offer guidance, technical assistance and leadership, and to also identify and spotlight best practices and research that will advance the PCMH. Center activities and workgroups are largely voluntary efforts, and all Centers welcome additional members, particularly those representing the consumer perspective. This section outlines the objectives and goals of each of the Centers and can serve as a guide to readers interested in offering a consumer-focused voice to their work. Leadership contact information for each of the Centers, as well as a schedule of the Centers’ bi-weekly national calls, may be found under the Collaborative Centers tab on the PCPCC Web site, [www.pcpcc.net](http://www.pcpcc.net).



## Center for Multi-Stakeholder Demonstrations

The primary objective of the Center for Multi-Stakeholder Demonstrations (CMD) is to serve as a clearing house for information on PCMH pilot and demonstration efforts around the country that include multiple private sector payers. The CMD seeks to recruit payers to promote participation of their members in demonstration projects, while assisting them with demonstration efforts through sharing of lessons learned and best practices from existing PCMH demonstrations. The CMD serves as an information exchange where plans can discuss innovative reimbursement models to test in pilots as well as program design. The CMD is also responsible for working with local convening entities to support regional pilots.

As part of a recent evaluation effort, CMD conducted a survey of current pilots and included a set of questions about patient engagement, the results of which are discussed in Chapter 3, “Consumer Engagement in PCMH Demonstrations.” As part of its future activities, CMD will continue to explore how the demonstrations can support increased experience and understanding of consumer engagement and improved consumer communication.

## Center to Promote Public Payer Implementation

The Center for Public Payer Implementation (CPPI) is tasked with a very broad mandate encompassing more than 50 percent of all payors in the U.S. health care system. Growing out of the work that the Collaborative undertook within the Medicaid environment, the CPPI is charged with promoting the PCMH concept in all facets of the public payer system.

To this end, the Center is broken down into three core components:

1. The Medicaid working group, built upon the joint work of the National Academy for State Health Policy (NASHP) and the Collaborative in educational outreach to Medicaid directors;

2. A taskforce focused on the state government as an employer and purchaser of health care; and,
3. A taskforce to address the federal program system (Medicare, Veterans Affairs, DOD, FEHBP, etc.).

CPPI assists public payers as they implement and refine programs to embed the PCMH model by offering technical assistance, sharing best practices and giving guidance on the development of successful funding models.

The CPPI focuses on engaging the public. With this in mind, consumers are critical to this process as both recipients of care and as tax payers who pay for this care. The CPPI has been working with NASHP and state and federal leaders as resources for benchmarking and best practices, including better engaging patients.

One CPPI task force is focused on the opportunity for improved medication management within the PCMH. Patients are at the center of this effort because many lack understanding that they need to properly use their medications. In addition, providers throughout the fragmented care settings have not adequately coordinated medication management with patients. These two limitations often result in poor patient outcomes and higher health costs. Advanced PCMH environments, such as Group Health Cooperative and Community Care of North Carolina, have identified this as a critical element of patient engagement and have improved outcomes both in public and private payer systems.

## The Center for Benefits Redesign and Implementation

The Center for Benefits Redesign and Implementation (CBRI) aims to create standards and buying criteria to serve as a guide and tool for large and small employers/purchasers to build the market demand for adoption of the PCMH model. Since the CBRI focuses on engaging employers and other purchasers, it focuses on consumers largely as employees. The CBRI has developed a number of resources to help employers educate and engage employees/consumers within the context of the PCMH:

- *A Purchaser Guide—Understanding the model and taking action* (download a free copy at <http://pcpcc.net/content/purchaser-guide>).

- *Quick Reference Guide for Employers—What Is It and What Can I Do?* (download a free copy at <http://pcpcc.net/files/pcmhpurchasersummary.pdf>)

- Recognizing the importance of primary care as it relates to the PCMH, the CBRI created a template letter to help employers educate employees about partnering with their physicians in a medical home. This letter is designed for employers to send to consumers as an information piece and can be formatted to fit any organization. Please see Appendix B for the complete text of the letter.

## Center for eHealth Information Adoption and Exchange

The mission of the PCPCC Center for eHealth Information Adoption and Exchange (CeHIA) is to assure that a person's relevant health data can be made available when needed at the primary care level from all appropriate sources, including pharmacies, pharmaceutical benefit management programs, clinical labs, nurse practitioners in retail clinics, hospitals and other medical practices.

Several core principles that support the CeHIA mission are:

- Health data and information must be accessible to primary care medical home practices, physicians, and patients;
- Standards, protocols, and rules for health data exchange on the network should be fully open and supportive of data portability and interoperability;
- Information technology will support the enhanced practice efficiency and quality of care that is required by the PCMH model; and
- Confidentiality of data is imperative.

The CeHIA works with the other PCPCC centers with the understanding that the development of PCMH systems and practices depend upon the proper integration of health information technologies. CeHIA provides other Centers with:

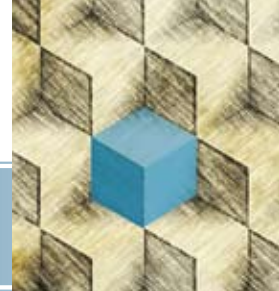
1. Direction for the proper implementation of HIT systems in demonstration projects; and,
2. Information on the most current development of industry standards, protocols, and rules.

In April 2009, the PCPCC CeHIA released *Meaningful Connections: A resource guide for using health IT to support the patient centered medical home*. This white paper offers explicit goals and objectives that relate to the Joint Principles on the use of health information technology, and includes a chapter on the use of health IT to engage patients/consumers. Designed as a resource to spur a productive conversation about how electronic health IT can be used meaningfully in the PCMH, *Meaningful Connections* laid the groundwork for the creation of a CeHIA work group that emphasizes consumer engagement, the Participatory Engagement Program (PEP).

PEP was formed to seek ways to broaden the involvement of patients, families, physicians and other care team members through the use of technology. The team felt it could best fulfill that mission by focusing on provider approaches to improving patient engagement in the care process. By providing a conceptual framework along with specific tools and strategies, the team seeks to help primary care practices improve the engagement and activation of their patients to improve the capability of such practices to deliver truly patient centered care.

PEP has two consumer-focused initiatives underway: 1) a revision of a consumer survey that is part of a PCMH education primer video produced by EMMI through a PCPCC Advisory Panel; and 2) the development of a framework for patient/family activation and engagement. The revised consumer survey was developed to gain a better understanding of initial impressions of the PCMH and to determine what consumers would value most in a PCMH model as described in the video. A description of the framework intent and design is explored further in Chapter 5.

# Consumer Engagement in PCMH Demonstrations



## *The Patient and Family in the Patient- and Family-Centered Medical Home Demonstrations*

By Rebecca A. Malouin, Ph.D., M.P.H.

### Background

In 2008, the Patient-Centered Primary Care Collaborative (PCPCC) Center for Multi-Stakeholder Demonstrations (CMD) published the first compilation of PCMH demonstration projects, a Pilot Guide entitled *Patient-Centered Medical Home: Building Evidence and Momentum*. The monograph serves as a resource guide and initial point of discussion regarding various demonstrations around the country, but provides limited information regarding the involvement of patients and families in demonstrations. Understanding the type of patient and family involvement in demonstrations is essential to any effort to ensure the patient- and family-centeredness of medical home demonstrations.

In March 2009, the American Academy of Family Physicians, the American Academy of Pediatrics, the American College of Physicians and the American Osteopathic Association created “Guidelines for Patient Centered Medical Home (PCMH) Demonstration Projects,” endorsed by the PCPCC. ([http://pcpcc.net/files/pcmh\\_demo\\_guidelines.pdf](http://pcpcc.net/files/pcmh_demo_guidelines.pdf)) The Guidelines recommend involvement of patient advocacy groups and inclusion of measures of patient and family experience with care, but do not provide clear guidance on how to involve patients and families in the development, implementation, monitoring and evaluation of demonstrations.

The Institute of Family-Centered Care developed a guide titled *Essential Allies: Families as Advisors*,<sup>2</sup> which suggests methods for involving patients and families. The guide includes specific advisory roles for families, from participants in focus groups to paid program staff. The same roles could reasonably be extended to patients.

The CMD created a new version of its Pilot Guide in 2009,

<sup>2</sup> Jeppson, E. and Thomas J. (1995). *Essential Allies: Families as Advisors*. Bethesda: Center for Family-Centered Care, p. 9.

integrating new considerations for pilots that focus on consumer involvement. Through financial support from the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCB) and in-kind support from the IBM Corporation, the CMD conducted a survey of PCMH demonstrations to better understand both the evaluation plans of and the patient and family involvement in demonstrations. The results may stimulate further discussion of the possible roles for patients and families in the development, implementation, monitoring and evaluation of demonstrations.

### Methods

A questionnaire was developed in collaboration with Vic Toy, M.P.H. of the IBM Corporation. The questionnaire included several close-ended questions to assess the degree to which demonstrations were including patients and families in demonstrations using questions from the Institute for Family-Centered Care. The PCPCC Center for eHealth Information Adoption and Exchange also contributed two questions related to consumer use of technology within the demonstrations. The questionnaire was programmed into Lotus software for completion online by demonstration participants. The CMD assisted in identification of demonstrations to participate in the survey using the 2008 PCPCC demonstration guide and snowball sampling through discussions with other demonstrations and PCPCC partners. From Aug. 1 to Sept. 25, 2009, 29 demonstrations were identified and subsequently invited to participate in the online survey.

### Results

Nineteen demonstrations responded to the survey for a response rate of 65 percent. The demonstrations range in size from one to 2,400 practices with a median size of nine practices. The demonstrations represent diverse geographic areas across the country, as well as both single payer and multi-stakeholder initiatives. Five (26 percent) of the practices plan to include pediatric patients. Seventeen (89 percent) of the demonstrations were collecting data from patients/consumers regarding patient/consumer experience.

The most common types of patient involvement in demonstrations is as participants in focus groups, reviewers of audiovisual and print material and participants at

conferences and working meetings. (See Table 1) No demonstrations include patients as program evaluators, paid program staff, members of committees hiring new staff, or fundraisers. The most common type of family involvement in demonstrations is as focus group participants. Families are much less involved in patient- and family-centered medical home demonstrations than patients.

The most common type of information technology used to support patient- and family-centered care by and within demonstrations is use of e-visits and online self-management tools. More than 60 percent of demonstrations indicate use of such tools. Use of information technology to enable practices to send patient information for care at different facilities, online appointment scheduling and online patient satisfaction tracking and use of surveys are also supported by almost half of all demonstrations. Information technology to support patients' ability to enter their own health information and to track and report care activities online is the least supported functionality, although it is still supported by five demonstrations.

**Table 1.** Are patients/families involved in any of the following roles in the pilot?

	Patient	Family
Members of a task force	3 (16%)	1 (5%)
Advisory board members	3 (16%)	1 (5%)
Program evaluators	0 (0%)	0 (0%)
Co-trainers for staff training sessions	2 (11%)	0 (0%)
Paid program staff	0 (0%)	0 (0%)
Mentors for other patients	3 (16%)	0 (0%)
Reviews of audiovisual and written materials	4 (21%)	0 (0%)
Group facilitators	2 (11%)	0 (0%)
Advocates	3 (16%)	1 (5%)
Participants in focus groups	5 (26%)	2 (11%)
Members of committee hiring new staff	0 (0%)	0 (0%)
Fundraisers	0 (0%)	0 (0%)
Participants at conferences and working meetings	4 (21%)	1 (5%)
Participants in quality improvement activities	3 (16%)	1 (5%)

## Discussion

Of the 19 respondents, only 12 already have evaluation plans in place. All but two of the demonstrations had already begun at the time of the initiation of the survey. Many of the respondents indicated that specific types of data would be collected—for example, patient or provider experience—but were not yet able to provide specific tools or data elements that would be collected.

Overall, very few of the demonstrations involve patients and families in multiple forms of partnership or collaboration. The most common form of participation reported is participation of patients in focus group, a much less participatory form of participation than the other options suggested by the Institute for Family-Centered Care. Twelve (63 percent) of demonstrations report no involvement by patients or families except as participants in consumer experience surveys.

The majority of demonstrations report support of information technology focused on patients and families as a part of transformation activities within practices. The most common type of support is for online scheduling and self-management tools. Very few demonstrations support active engagement of patients and families in self-reporting health information and care activities.

While most demonstrations involve patients and families in patient experience surveys, few involve patients and families in more participatory roles

**Table 2.** Use of information technology to support patient- and family-centered care

Which IT functionalities are:	Supported as a part of transformational activities of the PCMH initiative within the pilot practice?
Patients schedule appointments online	9 (47%)
Patients participate in e-visits	12 (63%)
Patients access their health record online	8 (42%)
Patients enter their health info and track and report care activities online	5 (26%)
Patients access online self-management tools	12 (63%)
Practices track various patient satisfaction measures and conduct online surveys	9 (47%)
Practices send patient clinical info/health record for care at a different facility	10 (53%)

as collaborators or partners. As most transformational activity within demonstrations focuses on provider and staff member behavior change, one must not lose sight of the ultimate beneficiary of transformation change, the patient. Involving patients and families in development, implementation, monitoring and evaluation of transformational activities will better ensure that such activities are patient- and family-centered. The return on investment for demonstrations will only be realized if the beneficiaries of the work, the patients and families, realize improved experience of care and better health outcomes.

# State Examples of Early PCMH Consumer Engagement



The themes from the Consumer stakeholder meeting underscore the multifaceted nature of consumer engagement. Most consumer advocacy groups highlighted the importance of including consumers in the development and evolution of the PCMH in addition to partnering and engaging consumers in the care provided through PCMH. In 2009, the PCPCC Center for Multi-Stakeholder Demonstrations released *Proof in Practice: A Compilation of Patient Centered Medical Home Pilot and Demonstration Projects*. The consumer-focused efforts of many of the demonstration projects across the country are summarized in state-by-state responses in this publication, drawn from the survey discussed in the previous chapter. These reports from the field will also become available on the PCPCC Web site in the coming months and maintained as an “evergreen” resource about consumer-focused initiatives within demonstration projects.

In addition to programs described in *Proof in Practice*, the following state initiatives demonstrate how some states are pursuing consumer engagement in the early stages of PCMH design and development.

## Maine PCMH Pilot

*Building the Patient Centered Medical Home to Meet the Needs of Maine People Engaging Patients & Families*

The Maine PCMH focuses on keeping the consumer “front and center” in the medical home process. It aims at engaging patients by including their voice in three areas:

1. Involving consumers in planning and governance;
2. Conducting PCMH consumer/patient focus groups; and
3. Involving patients in PCMH pilot practice redesign efforts.

The following description characterizes how Maine has approached engaging patients and families.

**Introduction:** The Maine PCMH Pilot, supported by a grant from the Maine Health Access Foundation (MeHAF), is committed to including the patient/consumer’s voice in design, implementation and evaluation of the initiative. Many PCMH pilots around the country have not yet described formal

efforts to bring consumers into this process; in contrast, the Maine PCMH pilot is committed to ensuring that the consumer’s voice is kept “front and center” in all efforts. Considerable efforts have already been undertaken by MeHAF and others to assess patient perceptions of care integration and patient desires for ideal care.<sup>3,4</sup> The Maine PCMH pilot proposes to build on this previous work and on the input from patients and families to ensure that the model is implemented in a way that truly integrates care and is sensitive and responsive to the needs of Maine people. The Maine PCMH pilot proposes to include the voice of patients/consumers through the following:

### 1. Involve Consumers in Planning and Governance of the Maine PCMH Pilot

Efforts have been made from the onset of planning the Maine PCMH pilot to engage consumers/patients in the planning process. The organization has reached out through stakeholder groups to identify at least two consumers to be involved as regular members of the PCMH Planning Group. To date, the initiative has identified one consumer who has been involved and regularly attends Planning Group meetings since September 2008, and the Maine PCMH pilot is actively working to recruit a second consumer for the group. The Maine multi-stakeholder collaborative has also budgeted funds in its planning and implementation to provide a stipend for these consumers to participate in the group.

### 2. Conduct PCMH Consumer/Patient Focus Groups

Because of the commitment to include patients in the design of the PCMH model in Maine, *Quality Counts* requested and received discretionary grant support from MeHAF in the fall of 2008 to support a formal and structured process to conduct a series of focus groups with consumers to ensure that the medical home, as it is

<sup>3</sup> “Maine Integrated Health Initiative: Maine People Speak About Health Care Integration”, Maine Health Access Foundation with assistance of John Snow Foundation, Winter 2007, <http://www.mehaf.org/pictures/grassroots-feedback-2007.pdf>.

<sup>4</sup> The Future of Family Medicine: A Collaborative Project of the Family Medicine Community, *Annals of Family Medicine*, Vol 2, Suppl 1, March/April 2004, S3-32.

developed in Maine, anticipates and integrates the care needs of all people, particularly those with greatest need. That MeHAF funding has supported a series of five patient/consumer focus groups conducted in towns across Maine from November 2008 to January 2009 (facilitated by Crescendo Consulting Group). Consumer input gained through this process will be used to ensure that the PCMH model in Maine is designed to reflect the six aims of quality care identified by the Institute of Medicine (i.e., safe, effective, timely, efficient, equitable and patient-centered care). A report of findings from these focus groups highlighted three areas consumers view as needing the most improvement: providing treatment options; tracking performance between visits; and receiving information about community resources. The full report is available on the PCPCC Web site.

### 3. Involve Patients in PCMH Pilot Practice Redesign Efforts

In addition to including consumers in the planning and governance of the initiative, the Maine PCMH pilot is committed to promoting the active involvement of patients and families from the primary care provider practices selected for participation in the pilot. Proposals are in place to do this in several ways:

A. Identify patients and family members from PCMH pilot sites that are willing to be involved in the leadership of the pilot implementation, and provide opportunities for them to have an active voice in the process.

One way to do this is by **offering them leadership training developed and successfully used by the Maine People's Alliance (MPA)**. The MPA defines their Leadership Development Program as *the process of developing leadership skills in "everyday people" so that they are empowered to be involved in the decision-making processes that affect their lives*. Over the last six years the MPA has dramatically increased the number of engaged and informed consumers who are participating effectively in their issue campaigns. Their program is seen as a national model by other non-profit community action organizations. The Maine PCMH pilot will work collaboratively with these patient and family "leaders" in the pilot implementation through their roles in the PCMH Working Group, and/or local implementation teams at each of the pilot sites.

B. Working with these patient leaders, **convene "Patient and Family Leadership Teams" in each of the pilot site communities** to obtain ongoing feedback on the implementation of the PCMH model, with special

attention to including underserved populations including MaineCare members, uninsured and under-insured. This input will be used both as part of the formative evaluation of the PCMH model to shape its implementation in real time, and in the overall summative evaluation of the PCMH model to be completed at the end of the three-year implementation period.

C. The Maine PCMH pilot has also included an explicit expectation that **practices selected for participation in the Maine PCMH Pilot will work to include patients and families** in the implementation of the PCMH model in their practices. The pilot practice "Memorandum of Agreement" specifically includes the following expectations (to be accomplished within 12 months of beginning the pilot):

- *Inclusion of patients and families in implementation of PCMH model*
- *With the assistance of PCMH pilot staff and consultants, practice has identified at least two patients or family members to be part of the practice Leadership Team.*
- *Practice is using one or more mechanisms for routinely soliciting input from patients and families on how well the practice is meeting their needs.*

Of note, the Maine PCMH pilot will coordinate all of these efforts with the Aligning Forces for Quality (AF4Q) initiative to identify, engage and support patients and families in taking a leadership role in this effort. Specifically, the initiative will tap into established AF4Q-identified consumer engagement groups, and will utilize the same consumer leadership training methods being used within the AF4Q initiative—i.e., the MPA's consumer leadership program to empower patients to take an active role in redesigning health care.

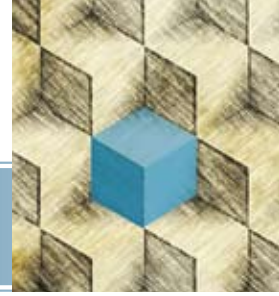
## The Minnesota approach to health care homes

The health care home is a transformative change in the delivery of primary care. The design principles for health care homes in Minnesota focus broadly on the continuum of “health” and incorporate expectations for engagement of the patient, family and community. Fundamentally, the health care home is a change in the patient-provider relationship augmented by financial structures and measurement of results. Expectations for transformative change must be sufficient to achieve these results. Among these expectations are:

- **Patient- and family-centered care** will be foundational to Minnesota Health Care.
- Patients/families/consumers will be involved in all aspects of the development of the **Home Program**.
- **Quality improvement teams** will be required at the practice level. A health care home will have an active practice-based quality improvement team that includes patients/families as equal team members.
- **Learning collaboratives** will support and foster practice-level change. Participation is required.

For more information about Minnesota’s health care homes project, go to <http://www.health.state.mn.us/healthreform/homes/index.html>. The Minnesota project used many of the resources and tools in this guide to support its patient engagement efforts including materials from IFCC and Family Voices.

## PCPCC Participatory Engagement Program (PEP)



### *Framework for Patient/Family Engagement and Activation*

There has been a great deal of discussion around the idea of consumer engagement—of consumers becoming more active partners in their own health and health care as opposed to simply being recipients of care. Within this broad discussion, there are at least two major dimensions of consumer engagement that need to be examined separately:

- **Consumer Economic Behavior**—This dimension of engagement focuses on consumers as purchasers. A variety of strategies, from increased transparency on cost and quality to consumer-directed health plans, are deployed to both decrease utilization and improve value through the workings of consumers as market drivers.
- **Consumer Health Behavior**—This dimension of engagement focuses on consumers as patients managing their own health and interacting with providers of health services. The goal is typically to increase patient activation to improve self-management of chronic disease and the four fundamental dimensions of lifestyle risk.

The engagement framework was developed by a subcommittee of the PCPCC Center for eHealth Adoption and Exchange. Described below, it is specifically targeted at the health behavior dimension of engagement. It is intended to support primary care providers in their journey towards improved patient activation and more patient-centered care, but may also be useful to consumers wishing to understand how they can become more active partners with their providers in pursuit of their own care.

Primary care providers making the transformation to a medical home environment will certainly want to focus on enhanced patient engagement and activation as one element of a more patient-centered practice. The framework below is intended to fill a gap by providing a means to think and talk about patient engagement from the perspective of provider and patient engaged in a care process. Each element of the framework represents a critical aspect of engagement, and thus a potential focus area around which providers and staff can discuss specific changes and enhancements to current policies and practices.

The PEP workgroup is developing a more detailed guidebook on patient engagement for providers based on this framework. Consumer participation in this initiative would be welcomed.

PCPCC Patient/Family Engagement Framework	Considerations
<p><b>1. Foundations for Effective Engagement</b></p> <ul style="list-style-type: none"> <li>a. Mutual goal and expectation setting</li> <li>b. Mutual progress feedback</li> <li>c. Patient-provider relationship development</li> <li>d. Availability and use of appropriate health care setting (includes selection of primary care provider vs. emergency department, advanced access techniques such as e-mail and Web portals, etc.)</li> </ul>	<p>Engagement starts with the patient’s goals. Healing and health maintenance are, by their nature, goal-oriented processes; yet not all patients with a given condition have the same goals. Discussion, clarification and understanding of goals create the foundation for a long-term successful relationship between patient and provider. At the same time, establishing mutual expectations, and a process for reviewing progress against expectations, forms the basis for shared accountability through assessing effectiveness of the joint interventions intended to achieve those goals.</p>
<p><b>2. Accurate and complete information flow between patient and provider</b></p> <ul style="list-style-type: none"> <li>a. Medical history and current medication list</li> <li>b. Behavioral risk factors</li> <li>c. Current issues and concerns (including psycho-social)</li> <li>d. Review and communication of care coordination issues</li> </ul>	<p>A good patient history and up-to-date medication information are often taken for granted. However, practices that begin sharing access to electronic medical records with their patients often find that doing so uncovers a variety of simple errors that might otherwise have gone undiscovered. Other areas of opportunity include more effective identification of behavioral risks such as substance abuse and depression, as well as non-medical issues (e.g., family, economic or work stress) that may have a significant impact on the patient’s ability to manage health status and treatment regimen.</p>
<p><b>3. Patient activation for self-management</b></p> <ul style="list-style-type: none"> <li>a. Patient knowledge of key health targets and actual values (e.g., blood pressure, cholesterol, etc.)</li> <li>b. Healthy lifestyle attributes (eating, drinking, smoking, exercise)</li> <li>c. Adherence to therapeutic regimen (broadly defined) and other chronic disease self-management behaviors</li> <li>d. Patient knowledge of and participation in appropriate wellness and/or disease management programs available in the community or workplace</li> </ul>	<p>There are many dimensions to self-management, and a wide variety of strategies for increasing patient activation to improve it. The most effective are generally based on an understanding that patients can have differing long-term goals and will be starting from different stages of readiness. They include motivational interview techniques to identify goals, determine readiness and identify specific objectives and interventions with which the patient has a reasonable probability of success.</p>
<p><b>4. Shared decision making</b></p> <ul style="list-style-type: none"> <li>a. Provider understanding of patient goals and preferences</li> <li>b. Patient knowledge of options, risks and benefits</li> <li>c. Patient participation in decision process</li> </ul>	<p>This is an area where recent research has shown significant opportunities to improve knowledge on both sides. Physicians frequently do not understand patient goals and preferences, and patients are often under-informed about basic facts relative to their condition and treatment options. Creating the conditions for effective shared decision-making requires an interactive process to remedy these critical information gaps.</p>
<p><b>5. Family engagement and activation</b></p> <ul style="list-style-type: none"> <li>a. Congruent goal setting</li> <li>b. Family member present at visit for dependent patient</li> <li>c. Family members are active participants in care process for dependent patient</li> <li>d. Family as support network for patient self-management (including non-dependents)</li> </ul>	<p>Family engagement and activation is critical in the case of dependent patients who are not fully able to care for themselves. It can also be important as a support network for any patient with a chronic condition or a desire to effect a behavioral change.</p>

## PCPCC Consumer Tools and Resources

The following section of the Consumer Guidebook provides resources that have been developed specifically for the PCMH model to support patient and consumer engagement. These materials have been vetted across the PCPCC stakeholder community and we encourage you to review them and use them as appropriate. For each resource there is a brief description similar to those that are used in the subsequent resource catalogue. Samples of these resources are either included below or may be found in the appendices.

### Emmi Solutions

#### Introduction to the Patient Centered Medical Home

*Introduction to the Patient Centered Medical Home* is a multimedia program developed to help explain this innovative model of health care to consumers. The program serves as a tool for physician practices that are in the process of transforming into PCMHs. It can also be utilized by health plans, advocacy groups and other organizations as a way to educate patients and prospective



patients on how PCMHs deliver care. The program was created by Emmi Solutions in partnership with the PCPCC. Materials going into its construction were reviewed by the PCPCC's Consumer Task Force. Public distribution of this video is made possible through the generous support of TransforMed. *Introduction to the Patient Centered Medical Home* is available to download free of charge as a flash file at <http://www.emmisolutions.com/medicalhome/>.

Following the video is a survey to gauge consumer responses to the PCMH model. Consumers are encouraged to fill out the survey after watching the video. To learn about co-branding options or to request DVD copies, please email [inquiries@emmisolutions.com](mailto:inquiries@emmisolutions.com) or call 1-866/294-3664.

### Center for Advancing Health

#### Supporting Patient Engagement in the Patient-Centered Medical Home

The Center for Advancing Health (CFAH) published *Supporting Patient Engagement in the Patient-Centered Medical Home*, a document that describes the roles and responsibilities of both patients and clinicians in the medical home. It includes a Pact that outlines the basic elements of an agreement between clinicians and their patients. This agreement specifies explicit previously assumed expectations about responsibilities for both providers and their patients. Using the components of the Pact in a medical home promises to enhance understanding and engagement of and by clinicians and patients. *Supporting Patient Engagement in the Patient-Centered Medical Home* can be downloaded free at [http://www.cfah.org/pdfs/CFAH\\_PACT\\_WhitePaper\\_current.pdf](http://www.cfah.org/pdfs/CFAH_PACT_WhitePaper_current.pdf).

*The PACT* was developed by CFAH and other researchers. The John D. Stoeckle Center for Primary Care Innovation at Massachusetts General Hospital is currently exploring opportunities to research the use of the PACT in clinical practices. For more information about this and other resources for physicians and patients, visit CFAH's Web site: [www.cfah.org](http://www.cfah.org). See *Supporting Patient Engagement in the Patient-Centered Medical Home* in Appendix C.

## Merck & Co., Inc.

The PCMH education brochure and checklist are intended to help health care providers communicate with patients about the PCMH approach. The brochure is intended to be used and remain within the health care provider's office. The checklist is intended for a patient to bring home, to help him/her prepare for the next appointment.

These resources were developed by Merck & Co., Inc. in collaboration with the PCPCC and representatives of the following PCPCC member organizations:

- American Academy of Family Physicians
- American Academy of Pediatrics
- American College of Physicians
- American Osteopathic Association
- Blue Cross and Blue Shield Association
- Center for Advancing Health
- Colorado Clinical Guidelines Collaborative
- Institute for Family-Centered Care

In addition, during the development process, two consumer-focused organizations tested these resources with patients and families.

These resources can be accessed on the Web at <http://pcpcc.net/content/merck-patient-education-brochure-and-checklist>. For hard copies and additional information, please contact the Merck National Business Group at 866/637-2562. A sample of the resources is included in Appendix C.

## Stoeckle Center for Primary Care Innovation

### Primary Care: A Miracle of Modern Medicine

A patient's best way to enter into the health care system is through primary care. *Primary Care: A Miracle of Modern Medicine* outlines the importance of primary care physicians, the benefits of primary care to consumers and patients, along with an agenda for advocates who want to increase the amount of primary care available in the U.S. This brochure is supported by the Stoeckle Center, the Department of Family and Community Medicine at the University of California—San Francisco, and the PCPCC. Copies of this brochure can be downloaded from [http://familymedicine.medschool.ucsf.edu/cepc/pdf/primary\\_care\\_miracle\\_brochure.pdf](http://familymedicine.medschool.ucsf.edu/cepc/pdf/primary_care_miracle_brochure.pdf). To obtain hard copies of this brochure please email [stoecklecenter@partners.org](mailto:stoecklecenter@partners.org). A sample brochure is found in Appendix C.

## ► National Partnership for Women & Families

### **Principles for Patient- and Family Centered Care: The Medical Home from the Consumer Perspective**

A broad coalition of more than 30 of the nation's leading consumer, labor and health care advocacy groups developed a set of nine principles to guide the development and implementation of the medical home model of care. All stakeholders are encouraged to use these principles to guide the design of medical home initiatives. Copies can be obtained via the National Partnership's Web site at [www.nationalpartnership.org/medicalhome](http://www.nationalpartnership.org/medicalhome). See the Principles on page 24 of this chapter.

### **Understanding the Medical Home**

This fact sheet (see Appendix C) is designed to help consumer advocates learn more about the medical home and its potential. It reviews how a medical home is different from today's care and details the benefits gained from adoption of the model. It was developed by the National Partnership for Women & Families with input from national, state and local consumer groups from across the country. Copies can be obtained via the National Partnership's Web site at [www.nationalpartnership.org/medicalhome](http://www.nationalpartnership.org/medicalhome).

## ► Institute for Family-Centered Care

The Institute for Family-Centered Care is a non-profit organization focused on promoting the understanding and practice of patient- and family-centered care. They are committed to educating consumers and others on the benefits of patient- and family-centered care as well as advocating the implementation of its use in all aspects of the health care industry. The Institute of Family-Centered Care provides a wide range of free information resources for consumers that will guide them to successful health care. To access these resources and find more information on the Institute of Family-Centered Care please visit <http://www.familycenteredcare.org/tools/downloads.html>. See a sample of the IFCC document, "Creating Advisory Councils," on page 27 of this chapter.



## Principles for Patient- and Family-Centered Care: The Medical Home from the Consumer Perspective

As organizations representing a broad and diverse array of consumer interests, we believe that the following set of principles should guide the development and implementation of the medical home model of care.

### **1. In a patient-centered medical home, an interdisciplinary team guides care in a continuous, accessible, comprehensive and coordinated manner.**

- The patient is the center of the care team. Family members and other caregivers may also be a central part of the team.
- The care team includes professionals inside the medical office or health center, as well as clinical and non-clinical professionals in the community.
- The team provides initial and routine assessments of the patient's health status, and places a high priority on preventive care, care coordination and chronic care management to help patients get and stay healthy and maintain maximum function.
- The care team is led by a qualified provider of the patient's choice, and different types of health professionals can serve as team leader.

### **2. The patient-centered medical home takes responsibility for coordinating its patients' health care across care settings and services over time, in consultation and collaboration with patient and family. The care team:**

- Helps patients choose specialists and obtain medical tests when necessary. The team informs specialists of any necessary accommodations for the patient's needs.
- Helps the patient access other needed providers or health services (including providers or health services not readily available in the patient's community, e.g., in a medically underserved area).
- Tracks referrals and test results, shares such information with patients, and ensures that patients receive appropriate follow up care and help in understanding results and treatment recommendations.
- Ensures smooth transitions by assisting patients and families as the patient moves from one care setting to another, such as from hospital to home.
- Has systems in place that help prevent errors when multiple clinicians, hospitals, or other providers are caring for the same patient, such as medication reconciliation and shared medical records.
- Has systems in place to help patients with health insurance eligibility, coverage, and appeals or to refer patients to sources that can be of assistance.

### **3. The patient has ready access to care. The care team:**

- Ensures that patients can schedule appointments promptly – on the same day if needed – and experience brief office waiting times.
- Guarantees that a member of the medical home clinical team is available by phone, e-mail or in person nights, weekends, and on holidays. A responsible team member has ready access to the patient's information and is always able to communicate with the patient, using interpreter services and translated materials if needed.
- Accommodates the needs of patients with limited physical mobility, English proficiency, cultural differences or other issues that could impede access to needed examination and treatment and patient self-management.
- Facilitates patients' ready and appropriate access to services from other providers, such as mental health or reproductive health care providers. The medical home is not a "gatekeeper," but rather facilitates connections to other providers and services, as appropriate.

**4. The patient-centered medical home "knows" its patients and provides care that is whole person oriented and consistent with patients' unique needs and preferences. The care team:**

- Has ready access to the patient's complete, up-to-date medical history. The team also ensures that patients and authorized family caregivers have access to this information.
- Takes into consideration the patient's life situation, including family and caregiver circumstances, his or her values and preferences, age, and home environment when making recommendations about the patient's health care and treatment plan.
- Communicates with patients in culturally and linguistically appropriate ways.

**5. Patients and clinicians are partners in making treatment decisions. The care team:**

- Helps patients and others designated by the patient understand their condition and the results of any medical tests or consultations with specialists.
- Provides unbiased, evidence-based information on all treatment options, including possible side effects, costs, and the benefits and risks of different options (including alternative therapies), so that patients can make an informed choice that reflects their personal preferences.
- Does not withhold information about treatment options from patients based on assumptions about ability to pay.
- Provides patients with timely access to results of laboratory and other diagnostic tests through such means as telephone, email, fax, personal health records, or patient portals.
- Makes use of e-reminders, especially for preventive care services.

**6. Open communication between patients and the care team is encouraged and supported. The care team:**

- Communicates with patients in a way they understand and prefer. They encourage questions and two-way conversation that helps patients and their caregivers (when appropriate) effectively manage their health and be full partners in their health care.
- Knows about and overcomes any language, cultural, literacy, or other barriers to effective communication with patients, family members and other caregivers.

**7. Patients and their caregivers are supported in managing the patient's health. The care team:**

- Integrates culturally appropriate community-based support resources such as social services, transportation, peer support groups, and exercise programs.
- Works with patients to develop their capacity to stay well and manage their health conditions.
- Assesses and accommodates patients who are unable to effectively manage their own care because of cognitive or physical challenges, by working with family caregivers, legal surrogates or other sources of support.
- Works with the patient or their caregiver to develop, plan and set goals for their care and helps the patient meet those goals.
- Ensures that no treatment decisions are made without the patient's consent and understanding.

**8. The patient-centered medical home fosters an inironment of trust and respect. The care team:**

- Treats patients, family, and/or other caregivers with dignity and respect.
- Guarantees that patients can trust that their personal health information is never shared or used without their knowledge.
- Ensures that examinations and discussions with or about patients take place in a setting that affords appropriate privacy from other patients or staff.

# Principles for Patient- and Family-Centered Care: The Medical Home from the Consumer Perspective

## **9. The patient-centered medical home provides care that is safe, timely, effective, efficient, equitable, patient-centered and family-focused. To accomplish this, the care team:**

- Seeks out and encourages patient feedback on their experience of care, and uses that information to improve the quality of care they provide.
- Collaborates with patient and family advisors in quality improvement and practice redesign.
- Collects data on race, ethnicity, gender, primary language, and language services for each patient and records that information in a manner that can be reported and used to plan and respond to the health and language needs of patients in the practice.
- Regularly evaluates and improves the quality, safety and efficiency of its care using scientifically sound measures and reports that information to an entity that will make it publicly available in a way consumers can understand and access.
- Routinely undertakes efforts to identify and eliminate any disparities in the quality of care received by its patients.

These principles are provided in the context of patient-centered medical home initiatives, which should include changing the way providers are paid so they are both incentivized and adequately compensated for providing the high quality, patient-centered care envisioned in these principles.

Organizations subscribing to this statement of principles:

AARP  
AFL-CIO  
Alzheimer's Association  
American Diabetes Association  
American Hospice Foundation  
Asian & Pacific Islander American Health Forum  
(APIAHF)  
Bazon Center for Mental Health Law  
Center for Medical Home Improvement  
Center for the Advancement of Health  
Childbirth Connection  
Community Catalyst  
Community Health Alliance of Humboldt –  
Del Norte (CA)  
Consumers Union  
Consumer Worker Coalition (MN)  
Families USA  
Family Voices

Institute for Family-Centered Care  
Leadership Conference on Civil Rights  
Medicare Rights Center  
NAACP  
National Alliance for Caregiving  
National Consumers League  
National Council of La Raza (NCLR)  
National Family Caregivers Association  
National Health Law Program (NHeLP)  
National Partnership for Women & Families  
National Women's Law Center  
Peer Outreach and Education Team  
(Humboldt County, CA)  
SEIU  
Universal Health Care Action Network of Ohio  
Western New York Association of Diabetes  
Educators (NY)

**For more information, please contact the National Partnership for Women & Families at 202/986-2600, or visit [www.nationalpartnership.org/medicalhome](http://www.nationalpartnership.org/medicalhome).**

# CREATING ADVISORY COUNCILS

## ▼ Purpose/Responsibility of the Advisory Council

- Serves as advisory resource to administration and staff of the organization or one of its programs.
- Promotes improved relationships between patients, families, and staff.
- Provides a vehicle for communication between patients, families, and staff.
- Provides a venue for patients and families to provide input into policy and program development.
- Provides an opportunity for patients and families to review recommendations referred to the council by staff or administration.
- Provides an opportunity for patients and families to actively participate in the development of new facilities and programs.
- Channels information, needs, and concerns to staff and administration.
- Actively helps implement changes.
- Provides input into the educational program for staff.
- Collaborates as partners with staff, physicians, and administration in the planning and operation of specific programs.
- Provides opportunities for staff to listen to their customers.
- Provides a safe venue for patients and families to provide input in a setting where they are receiving care.
- Serves as a coordinating mechanism for patients and families.

## ▼ Benefits of an Advisory Council

- Provides an effective mechanism for receiving and responding to consumer input.
- Results in more efficient planning to ensure that services really meet consumer needs and priorities.
- Leads to increased understanding and cooperation between patients and families and staff.
- Promotes respectful, effective partnerships between patients and families and professionals.
- Offers a forum for developing creative, cost-effective solutions to problems and challenges faced by the program or organization.
- Supplies a link between the program, its surrounding community, and community groups.
- Provides increased emotional support and access to information for patients and families.

**Note:** *The council should not be seen as a place where an individual council member brings their personal grievances about clinic/hospital experiences to be dealt with and solved. Personal experiences should be used as examples when discussing a program or service. Council members should also bring experiences and perceptions of other families to the discussion. The council should not be seen as a support group. Patients or families who are grieving over a loss should be directed to a support group.*

## ▼ Representing the Patients and Families Served

Seek patients and families who represent a variety of clinical experiences such as type of illness, families, and programs utilized. Include families who have had a broad range of experiences. Include patients and families who have both positive as well as negative perceptions of experiences.

Seek patients and families who reflect the diversity of those served by the hospital or clinic—racial, cultural, religious, socioeconomic, age, educational background, and a variety of family structures.

Identify patients, families, staff, and community organizations that can recommend potential members. Patient representatives, child life personnel, physicians, nurses, managers, and social workers as well as other professionals often are able to recommend candidates.

## ▼ Qualities and Skills of Patient and Family Advisors

Seek individuals and families who are able to:

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

## ▼ Recruitment

- Ask staff for suggestions.
- Post and advertise within the units or clinics.
- Put notices in publications.
- Send direct mail to present and former patients.

## ▼ Developing the Council

Consider developing a patient and family workgroup as a precursor to a more formal council. The workgroup is a quick way to get patient and family participation in hospital activities. The informal structure of a workgroup may be less threatening to staff. Someone internal or external to the organization can facilitate the workgroup. The latter provides an opportunity for staff, patients, and families to become comfortable over time with new ways of working together. The workgroup is a place where staff, patients, and families can learn and practice new collaborative skills and a place to gain confidence in the collaborative process. It provides an opportunity for natural leaders to emerge. The workgroup can provide invaluable information to staff until a permanent council and/or a variety of other collaborative endeavors are established.

## ▼ Council Structure Determine structure, size, meeting frequency, operating procedures, and bylaws.

### *Size*

Smaller groups encourage greater discussion and participation by all members. Most people are more comfortable speaking in a smaller group. It is more challenging to facilitate larger groups and obtain input from everyone. Larger groups will provide a wider range of experiences and input. They also are able to have broader representation of diverse populations. Consider availability of meeting sites to accommodate various sizes of groups. Twelve to eighteen patient and family members is usually considered a manageable size.

### *Staff Membership*

No more than 3-4 staff should have a permanent place on the council. Other staff can attend depending on topics for discussion. Staff should have easy access to the council. Too many staff will result in patients/families not feeling it is their council.

### *Terms of Membership*

Consider length of term with rotation being intermittent rather than everyone turning over at once. Suggested term is 2-3 years to maintain some consistency.

### *Compensation/Reimbursement*

Plan for compensation of time, expertise, and expenses for patients and families. Consider remuneration for patients and families in the form of a small amount to cover travel expenses, baby-sitting, or other costs that might be incurred. Some patients and families may have difficulty joining the council if they are not given some assistance. Consider providing child care during meetings. If you cannot provide babysitting service, develop a group understanding about whether or not to bring children to the meeting. Designate one staff member from the hospital or facility to be responsible for reimbursement and other practical or logistical issues for family advisors.

## **Officers**

Co-chairs and secretary are the essential officers. If possible provide organizational support to assist with mailings, etc. Co-chairs could be two patients or family members or a staff person and patient/family member. Suggest selecting one new co-chair each year so there is carryover to the next year.

## **Committees**

May want to have some permanent committees that could include membership of patients/family members who are not on the council. These might be recruitment, communication, etc. Task forces or ad hoc committees might be identified to work on a specific issue or short-term project. Patients who are not on the council would be encouraged to participate—this will increase the number of patients who participate and provide input.

## **Bylaws**

Operating guidelines/bylaws need to be developed by the council. Bylaws are important because they provide the framework for perceived goals and objectives. Bylaws also legitimize the group and help promote a feeling of an established, well-organized group. Developing bylaws can be time consuming, however, reviewing bylaws from existing advisory boards can save you time. They can be adapted and amended to suit your group's specific needs.

Select a small core group to develop the bylaws. Among the issues that should be addressed in the bylaws are:

- Purpose of the group
- Goals and responsibilities
- Structure of the group
- Size of the group
- Membership qualifications
- Nominations and elections of members and officers
- Duties of members and officers
- Committees and task forces
- Voting procedures
- Quorum
- Meetings
- Agendas
- Reporting mechanisms
- Guidelines of authority
- Confidentiality
- Amendment procedures

After developing your group's bylaws, present them to the administration for approval. The total membership should review, discuss, and amend if necessary and give final approval.

## **▼ Meetings**

### **Schedule**

Frequency—monthly or quarterly is suggested. Monthly is usually adequate. Less frequent—lose momentum and involvement. Too frequent, members will have trouble attending.

Days/times—let the council select but may be dependent on room availability. Consider convenience of both patients/families and staff.

### **Agenda**

The council should develop a list of issues they wish to deal with and “own” the agenda. Staff or other patients/families can add to the agenda.

### **Minutes**

Minutes should be kept and distributed widely so the activities of the council are made aware to as much of the organization as possible.

## ▼ Orientation of New Council Members

Orientation should include:

- Introductions and the sharing of personal and family stories;
- The vision and goals of the organization;
- The role of the council, how it fits within the organization's structure, and how it can assist the organization in achieving its vision and goals;
- The roles and responsibilities of members;
- The roles and responsibilities of officers;
- HIPAA and expectations for honoring privacy and confidentiality;
- Meeting attendance expectations of members;
- The roles and responsibilities of staff on the council;
- How to be an effective council member;
- How to present issues effectively; and
- How to be most effective in collaborating with hospital/clinic staff and faculty.

## ▼ Maintaining History

It is important to track accomplishments and publish widely. Track issues the council is working on so they do not get lost.

## ▼ Sustaining the Council

- Invest in building leadership skills of members.
- Select patients and families wisely.
- Ensure that the council is representative of families served.
- Maintain balance between new members and committed members with longevity of service.
- Devote time to planning and evaluation of council efforts.
- Set priorities and focus efforts on meaningful collaborative projects.

---

For additional guidance resources available through the Institute for Family-Centered Care: Webster, P. D., & Johnson, B. H. (2000). *Developing and Sustaining a Patient and Family Advisory Council*; Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating Patient and Family Faculty Programs*; Jeppson, E. S., & Thomas, J. (1995). *Essential Allies: Families as Advisors*; and Thomas, J., & Jeppson, E. S. (1997). *Words of Advice: A Guidebook for Families Serving As Advisors*.

# Consumer Engagement Resources Catalogue



The following section contains brief descriptions of consumer engagement resources and links or instructions about how to obtain copies of each resource. These resources have been submitted by the PCPCC stakeholder community as examples of tools their organization or communities have used or developed to advance consumer engagement. The materials provided in the printed version of the guidebook are those that were submitted by the publication deadline. The intent of this guidebook section is to become a living and evolving resource that is maintained on the PCPCC Web site. The Web site will offer the live links through which all interested stakeholders either can directly access the resource, or the organization that can provide the resources or tools. We anticipate that the new Web site functionality will be available in the coming months and that individuals or organizations wishing to submit additional resources for inclusion in the catalogue will have a simple process to follow for providing additional consumer engagement resources for consideration.

## Aetna Health Insurance

### *Navigating Your Health Benefits for Dummies*

Health benefits are a particularly confusing topic for many people, and understanding them is important. *Navigating Your Health Benefits for Dummies*, 2nd Edition, offers concise, easy-to-read explanations of what individuals need to know about health benefits. This book helps consumers choose the right coverage, make the most of health benefits in a tough economy, communicate more effectively with their physician, take advantage of prevention and wellness programs, and use online resources such as personal health records. The guide is a general resource when making health benefits decisions during open enrollment—when millions of Americans are choosing health benefits for the upcoming year—and throughout the year.

*Navigating Your Health Benefits for Dummies* is offered by *Plan for Your Health* ([www.planforyourhealth.com](http://www.planforyourhealth.com)), a public education campaign from Aetna and the Financial Planning Association. This guide is co-authored by Wendy A. Richards, MD, MBA, FAAP, a family physician and National Medical Director for Aetna, and Tracey A. Baker, CFP, of the Financial Planning Association. The guide is part of the popular “For Dummies” series, created by Wiley Publishing. Please visit [www.planforyourhealth.com](http://www.planforyourhealth.com) to request the guide. Hard copies will be mailed to consumers

upon request, or the guide can be digitally downloaded at the site.

## American Academy of Nurse Practitioners

### *The Nurse Practitioner: Your Partner in Health*

This brochure provides information about the role and responsibilities of nurse practitioners in the health care community. This publication was produced by the American Academy of Nurse Practitioners as an educational resource for consumers.

### *Nurse Practitioners: Promoting Access to Coordinated Primary Care*

The Fellows at the American Academy of Nurse Practitioners composed this white paper to assist in clarifying the role of the nurse practitioner in the PCMH. It can be useful to consumers, legislators and other health care professionals.

### *Standards of Practice for Nurse Practitioners*

This publication identifies a set of standards of practice for nurse practitioners in the PCMH. It can be useful to consumers, legislators and other health care professionals.

All publications may be obtained by visiting <http://www.aanp.org/AANPCMS2/Publications/>.

## American Academy of Pediatrics

### *Build Your Own Care Notebook*

The Care Notebook is an organizing tool for families that helps them keep track of important information. Care Notebooks are very personal to each child and ideally should be customized to reflect the child’s medical history and current information. For this reason, this Web site has been developed to allow families to build a Care Notebook that best meets the need of the child. Please visit this site for a Care Notebook Online tour, as well as access to 20 different Care Notebook templates. The Care Notebook is available at [http://www.medicalhomeinfo.org/tools/care\\_notebook.html](http://www.medicalhomeinfo.org/tools/care_notebook.html).

*The Community Services Locator* is an online directory that is designed to help service providers and families find available national, state, and local resources that can address child and family needs. Service providers and families may use

the locator, produced by the Maternal and Child Health Library, to find available health, mental health, family support, parenting, childcare information and other services. The locator is available at [http://www.mchlibrary.info/KnowledgePaths/kp\\_community.html](http://www.mchlibrary.info/KnowledgePaths/kp_community.html).

### ***Bright Futures Prevention and Health Promotion for Infants, Children, Adolescents, and their Families***

Promoting Community Relationships and Resources Theme 10 and Information Sheet: [http://brightfutures.aap.org/pdfs/Health\\_Promotion\\_Information\\_Sheets/community.pdf](http://brightfutures.aap.org/pdfs/Health_Promotion_Information_Sheets/community.pdf) and [http://brightfutures.aap.org/pdfs/Guidelines\\_PDF/11-Promoting\\_Community\\_Relationships.pdf](http://brightfutures.aap.org/pdfs/Guidelines_PDF/11-Promoting_Community_Relationships.pdf)

### ***Does your Child Have a Medical Home? English/Spanish***

Brochures developed in English and Spanish to help families with children or youths that have special health care needs. Designed to help them understand and request PCMH services that will provide better care for their children. “¿Tiene Su Hijo un HOGAR MÉDICO?” Spanish Brochures—Washington State Medical Home Leadership Network <http://www.medicalhome.org/leadership/brochures.cfm>.

### ***Parents Partnering with Managed Care Plans***

A seven-page pamphlet of topics and questions which can be used as a starting point for families and plans to share perspectives on services for CSHCN and to help guide plans and families in ways to partner to improve services for this population. To access a copy, please visit this link: <http://www.familyvoices.org/pub/projects/ParentsPartnering.pdf>.

### ***Families in Title V***

Materials from this Family Voices project document and support family partnership with Title V programs and the Title V block grant, including workbooks, presentations, and booklets of partnership information, ideas and strategies. Please visit this link for more information: <http://www.familyvoices.org/projects/titleV.php>.

### ***Kids as Self Advocates (KASA) Information Sheets***

Tip sheets and other youth-friendly publications written by and for youth. Kids as Self Advocates (KASA) is a national, grassroots project created by youth with disabilities for youth. KASA knows youth can make choices and advocate for themselves if they have the information and support they need. To access the publications, please visit: <http://www.fvkasa.org/resources/index.html>.

### ***Family-to-Family Health Information Centers***

**(F2F HICs)** Family-to-Family Health Information Centers (F2F HICs) are non-profit organizations that help families of children and youth with special health care needs (CYSHCN) and the

professionals who serve them. Because the health care needs of CYSHCN are chronic and complex, parents and caregivers are often challenged with finding the resources to provide and finance health care for their children. The Health Resources and Services Administration (HRSA), Maternal Child Health Bureau (MCHB) provides the primary funding support for F2F HICs, as authorized by the Family Opportunity Act (FOA), legislation signed into law in 2006 (as a part of the Deficit Reduction Act). Please visit this Web site to learn more and review a full list of F2F HICs in states: <http://www.familyvoices.org/info/ncfpp/f2fhic.php>.

## **American Association for Diabetes Education**

### ***Side-by-Side: A Partner Approach to Diabetes Self-Care***

*Side-by-Side: A Partner Approach to Diabetes Self-Care* is a 12-page patient guidebook designed to educate people with diabetes about the components of diabetes education and help them realize that diabetes self-care doesn't mean "going it alone." The guidebook encourages readers to assemble their own diabetes care team (diabetes educator, physicians, family, friends) who will help them achieve their goals. Additionally, the guidebook encourages patients to work with their diabetes care team to create a personalized care plan. This guidebook was developed and reviewed by diabetes educators and is a great resource for a diabetes educator to interact with their patients. A downloaded copy or hard copies can be ordered in English or Spanish for \$10 on the AADE Web site: <https://www.diabeteseducator.org/ProfessionalResources/products/view.html?target=40&sub1=BROCHURES&sub2=Brochures>.

## **Center for Advancing Health**

### ***Creating a Patient Guide for a "Medical Home" Physician Practice***

The Center for Advancing Health (CFAH) has developed "Creating a Patient Guide for a 'Medical Home' Physician Practice," a practical resource for clinicians to use with patients to encourage and support their full participation in the PCMH. The document includes a list of basic information that patients and their families need in order to make efficient and effective use of primary care services. In addition, a sample guide is provided along with a simple "fill-in-the-blank" template that each practice can use to design its own custom patient materials. This guide is intended to be low-cost and low-tech so it can be readily customized and updated by busy office practices. Creating a Patient Guide for a "Medical Home"

Physician Practice can be downloaded for free at [http://www.cfah.org/pdfs/CFAH\\_PACT\\_Guide\\_current.pdf](http://www.cfah.org/pdfs/CFAH_PACT_Guide_current.pdf).

*The Guide* is currently being used as a model by PCMH practices across the country. For more information about this and other resources for physicians and patients, visit CFAH's Web site: [www.cfah.org](http://www.cfah.org).

## Family Voices

### *Families Partnering with Providers*

This seven-page booklet provides tips for families on improving communication among their members and health care providers. Sections cover preparing for an office visit, communication and building trust, gathering information, second opinions and helping your provider help other families. *Families Partnering with Providers* was created by family advocacy leaders with experience in communication and was reviewed by a large national network of their peers. It has undergone a number of editions and has been very widely disseminated and well received by both consumers and providers. Although written for families of children with special needs, this booklet is appropriate for a wide range of consumers and providers on both the individual level and at the program and policy level. Hard copies can be ordered by completing an order form at: [www.familyvoices.org/catalog.php](http://www.familyvoices.org/catalog.php), or by telephone at 888/835-5669. Electronic copies can be downloaded at: [www.familyvoices.org/catalog.php](http://www.familyvoices.org/catalog.php).

### *Family-Centered Care Self-Assessment Tools*

The purpose of the Family-Centered Care Self-Assessment Tools is to increase awareness and knowledge of the components of family-centered care. The tools provide a resource for both health care practices and families that can be used to assess current areas of strength and identify areas for growth, planning for the future, and tracking progress toward family-centered care. The tools are written from the perspective of experienced families and include a Family Tool intended for individual families as well as family support and advocacy organizations, a Provider Tool intended for use in a variety of health care settings, and a Users Guide, with suggested steps to use the tools in a practice or family setting. The tools were developed in a collaborative effort by Family Voices with assistance from the American Academy of Pediatrics and the Maternal and Child Health Bureau. The content was developed through a series of focus groups, including multiple families of children, youth and adults with special needs and professionals, and was completed by a team of family and professional writers. The tools have been pilot-tested in family and provider settings in Massachusetts and Pennsylvania and have been well reviewed. Hard copies can be ordered by completing an order form at:

[www.familyvoices.org/catalog.php](http://www.familyvoices.org/catalog.php), or by telephone at 888/835-5669. Electronic copies can be downloaded at: [www.familyvoices.org/catalog.php](http://www.familyvoices.org/catalog.php).

## Johns Hopkins Bloomberg School of Public Health

### *Guided Care Video*

This short, three-and-a-half minute video is intended to provide an overview of Guided Care for healthcare providers, insurers, educators, policy-makers, and consumers. It includes the following: the role of the nurse; perspectives from patients and caregivers; and early results from the randomized controlled trial. Guided Care is a type of medical home with proactive, comprehensive health care provided by physician-nurse teams for the growing number of older adults suffering multiple chronic conditions. The video requires Windows Media Player and can be viewed on the Guided Care Web site at <http://www.GuidedCare.org>. To obtain a hard copy, please contact Tracy Novak at 410/614-1932 or [tnovak@jhsph.edu](mailto:tnovak@jhsph.edu)

## Maine Patient Centered Medical Home Pilot

### *Keeping the Patient at the Center of the Patient Centered Medical Home*

This PowerPoint presentation was developed for the PCMH Summit in February of 2009 as a synopsis of specific ways the Maine PCMH Pilot is seeking to keep patients at the center of the PCMH pilot. This presentation is a useful resource for stakeholders interested in developing PCMH pilots. To receive a copy of *Keeping the Patient at the Center of the Patient Centered Medical Home*, please email [lletourneau@mainequalitycounts.org](mailto:lletourneau@mainequalitycounts.org).

### *Patient Centered Medical Home Discussion Groups*

The conveners of the Maine PCMH Pilot conducted a series of consumer focus groups in early 2009. As a result, *Patient Centered Medical Home Discussion Groups* was developed. This document contains a summary of consumer feedback on the PCMH model. It can be used as qualitative data for stakeholders interested in developing PCMH pilots. For more information on receiving copies of this document, please email [lletourneau@mainequalitycounts.org](mailto:lletourneau@mainequalitycounts.org).

### *Maine PCMH Pilot: Building PCMH to Meet the Needs of Maine People*

Developed to summarize the consumer efforts of the Maine PCMH Pilot in mid-2009, *Maine PCMH Pilot: Building PCMH to*

*Meet the Needs of Maine People* is a brief background summary of specific ways the Maine PCMH Pilot is seeking to keep patients at the center of the pilot program. This resource is included in Chapter 4. Please email [lletourneau@mainequalitycounts.org](mailto:lletourneau@mainequalitycounts.org) to obtain additional copies of this document.

### ***Medical Home Model and Consumers Practicum for Patient/Doctor Survey***

This survey was developed as part of a practicum project to assess potential differences between consumers and providers related to the PCMH model. It can be used to acquire useful qualitative information for stakeholders interested in forming PCMH pilots. Please contact [lletourneau@mainequalitycounts.org](mailto:lletourneau@mainequalitycounts.org) for copies of this survey.

### ***Building Consumer Engagement in the Sustainability of Primary Care: "What Does an Effective Medical Home Look Like?"***

This document contains the results obtained from the *Medical Home Model and Consumers Practicum for Patient/Doctor Survey* conducted by the Hanley Center for Health Leadership program. For stakeholders interested in developing PCMH pilots, this is a resourceful document illustrating the potential differences between consumers and providers perceptions related to the PCMH model. For copies of this document, please email [lletourneau@mainequalitycounts.org](mailto:lletourneau@mainequalitycounts.org).

### ***Maine PCMH Pilot—Suggested Tools for Consumer/Patient Education Engagement***

Suggested Tools for Consumer/Patient Education and Engagement contains educational material for practices participating in PCMH pilots. It was developed by the Maine PCMH staff as a summary of the educational materials used in the Maine PCMH Pilot. For copies of this document, please email [lletourneau@mainequalitycounts.org](mailto:lletourneau@mainequalitycounts.org).

### ***Maine Diabetes Pathway***

This publication is a patient education and self-management tool to promote collaborative care for diabetes. It was developed by the Maine Aligning Forces for Quality initiative for patient and provider education on diabetes care. To receive and electronic or hard copy of this document, please email [lletourneau@mainequalitycounts.org](mailto:lletourneau@mainequalitycounts.org).

## **Medfusion**

### ***Medfusion and PCMH Overview: Becoming a Recognized Patient-Centered Medical Home***

This publication is aimed at educating physicians about how a patient portal solution can help a practice respond to the

requirements of PCMH as well as the value that these solutions can bring to patients. Patient access and communication are key elements of PCMH, and patient portal technologies help both the practice and patient stay in secure, online communication with one another. This online communication reduces costs, streamlines practice operations and fosters patient satisfaction. *Becoming a Recognized Patient-Centered Medical Home* was written after extensive analysis of the nine standards of PCMH and how the Medfusion solution responds to those standards. This publication can be found in pdf format by visiting <http://www.medfusion.net/pcmh>.

### ***Webinar: Bringing Care Full Circle with Patient Centered Medical Home***

The purpose of this Webinar is to educate physicians about the relationship between Medfusion and the PCMH. The family physician is at the heart of patient care, and in a great position to take advantage of the massive initiatives to reshape the health care industry. "Bringing Care Full Circle" is an on-demand Webinar featuring a prominent family physician that is already reaping the benefits of PCMH. Dr. John Bender discusses topics such as being recognized as a PCMH and how health information technology can help you address the requirements for all nine of the PCMH standards. This Webinar does require Internet access and can be found online at <https://www2.gotomeeting.com/register/242815634>.

### ***Physician Videos: AAFP Physicians and the Impact of PCMH***

The function of these videos is to demonstrate the value of patient communication to physicians through videos of other physicians. Six short video compilations each feature up to six family physicians all speaking in detail about their challenges in running a family practice, how a patient portal solution like Medfusion has helped them face those challenges, and the results and benefits they have seen. In some of the videos, the physician speaks specifically about how the Medfusion portal has helped them achieve their PCMH goals. These videos were recorded at the last AAFP Scientific Assembly, and are designed to be viewed by other physicians. These videos can be viewed on the Medfusion Web site at <http://www.medfusion.net/aafp/aafpvideos.html>.

## **Microsoft®**

### ***Microsoft® HealthVault***

Microsoft® HealthVault™ is a free online tool designed to put consumers in control of their health information. Consumers can use HealthVault to store copies of health records obtained from providers, plans, pharmacies, schools, government or employers; upload information from health and fitness devices such as pedometers, blood glucose monitors and peak flow

meters; share information with health care providers, coaches and trainers; and access a range of products and services such as personal health records and fitness and wellness applications. HealthVault helps consumers take advantage of health solutions so they can better manage their health. To learn more, please visit [www.HealthVault.com](http://www.HealthVault.com). An introductory video on HealthVault is available at <http://www.youtube.com/watch?v=IXOpMTDOrxQ>.

## National Association of Pediatric Nurse Associates and Practitioners

### *The Pediatric Health Care/Medical Home: An Introduction for Parents and Children*

The purpose of this publication is to provide parents with a basic overview of the pediatric health care/medical home concept. This publication is a resource for parents intended to present a basic understanding of how services will be enhanced in their current pediatric practice regarding the care of children and families. This document should be given to parents evaluating a particular practice or at the time a practice transitions to the health care/medical home model of service delivery. To download a copy of *The Pediatric Health Care/Medical Home: An Introduction for Parents and Children*, go to <http://www.napnap.org>.

## National Partnership for Women & Families

### *A Medical Home is About You!*

This brochure for patients and their families helps consumers understand what a medical home is, and how to get the most from it. It explains the role of the care team as well as the role of the patient. It is available for any health plan, physician practice or other stakeholder that wishes to use it, and includes a box for customized contact information such as a mailing label. This brochure was developed by the National Partnership for Women & Families with input from national, state and local consumer groups from across the country. Copies can be obtained via the National Partnership's Web site at [www.nationalpartnership.org/medicalhome](http://www.nationalpartnership.org/medicalhome).

### *Why Consumer Advocates Should Get Involved: Ensuring that the Medical Home is Patient-Centered*

This fact sheet explains what's at stake for consumers in the medical home, and why consumer advocates should get involved. It discusses the momentum behind the concept and reviews how the design of a medical home initiative can positively or negatively impact patients and their families. It makes the case that consumer advocates can and should

play a role in shaping local initiatives. It was developed by the National Partnership for Women & Families with input from national, state and local consumer groups from across the country. Copies can be obtained via the National Partnership's Web site at [www.nationalpartnership.org/medicalhome](http://www.nationalpartnership.org/medicalhome).

### *How Consumer Advocates Can Get Involved: Steps You Can Take to Ensure the Medical Home is Patient-Centered*

This fact sheet provides information for consumer advocates about how to effectively shape medical home initiatives at the local, state and national levels. It reviews the changes that need to occur in order to implement a medical home, and outlines specific steps consumer organizations can take to advance the concept. It was developed by the National Partnership for Women & Families with input from national, state and local consumer groups from across the country. Copies can be obtained via the National Partnership's Web site at [www.nationalpartnership.org/medicalhome](http://www.nationalpartnership.org/medicalhome).

## Parent Training and Information Nebraska

### *Medication and Transition*

This short information tool serves as a guide to parents and children on adapting medication as children grow older. *Medication and Transition* includes tips on ways to improve transitioning medication for each age group and topics that can be discussed with a primary care physician. This handout was developed by a pharmacy student who interned with the Family to Family Health Information Center at PTI Nebraska in the summer, 2009. The information was researched and approved by the faculty of Creighton University School of Pharmacy. To obtain copies of this handout please contact Nina Baker at 402/346-9233, or toll free at 888/490-9233.

### *Other Useful Resources: Seizure Medications: The Facts; Knowing Your Pharmacists: A Prescription for Success; Basic Facts About ADD/ADHD Stimulant Medications; and Dental Health and Medications*

These one-pagers about medication were developed to help families better understand their children's medications. The information was designed to help start a conversation with a pharmacist or doctor about the medication(s) their child is taking and the side effects the medication might have along with the benefits for the child. These were developed by a pharmacy student who interned with the Family to Family Health Information Center at PTI Nebraska in the summer,

2009. The information was researched and approved by the faculty of Creighton University School of Pharmacy. This information may be used for education or before visiting with the pharmacist. To obtain copies of these handouts please contact Nina Baker at 402/346-9233, or toll free at 888/490-9233.

## Raising Special Kids

### *The Family-Centered Care Fact Sheet*

*The Family-Centered Care Fact Sheet* is a quick reference for families to gain a better understanding of what family-centered care is and what it should look like. It includes statistics concerning the number of families with children in the U.S. use family-centered care and describes the benefits. Additionally, it includes a link to more information on family-centered care and an assessment tool for families to use in order to tell if their child's care is family-centered as well as a link for providers to tell if the health care they are providing is family-centered. The family-centered care fact sheet was created by a Family Health Information Center Committee. The fact sheet is available to families of children and youth with special health care needs. Ideally, the fact sheet should be used prior to the development of family-centered care. In order to obtain hard copies of the Family-Centered Care Fact Sheet, feel free to contact Raising Special Kids via the Web site: <http://raisingspecialkids.org/resources/downloads.aspx>.

### *The Medical Home Fact Sheet*

The Medical Home Fact Sheet is a guide for physicians and nurses to gain a better understanding of the medical home approach. It includes resource links to obtain further information on the medical home model. The medical home fact sheet was created by a Family Health Information Center Committee. The fact sheet is available to those in the medical community as well as families in order to develop a medical home approach. In order to obtain hard copies of the Medical Home Fact Sheet, feel free to contact Raising Special Kids via the Web site: <http://raisingspecialkids.org/resources/downloads.aspx>.

# Joint Principles



## Introduction

The Patient-Centered Medical Home (PCMH) is an approach to providing comprehensive primary care for children, youth and adults. The PCMH is a health care setting that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient's family. The American Academy of Family Physicians (AAFP), American Academy of Pediatrics (AAP), American College of Physicians (ACP), American Osteopathic Association (AOA), representing approximately 333,000 physicians, have developed the following joint principles to describe the characteristics of the PCMH.

## Principles

- Personal physician—each patient has an ongoing relationship with a personal physician trained to provide first contact, continuous and comprehensive care.
- Physician directed medical practice—the personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients.
- Whole person orientation—the personal physician is responsible for providing for all the patient's health care needs or taking responsibility for appropriately arranging care with other qualified professionals. This includes care for all stages of life; acute care; chronic care; preventive services; and end of life care.
- Care is coordinated and/or integrated across all elements of the complex health care system (e.g., subspecialty care, hospitals, home health agencies, nursing homes) and the patient's community (e.g., family, public and private community based services). Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.
- Quality and safety are hallmarks of the medical home:
  - Practices advocate for their patients to support the attainment of optimal, patient-centered outcomes that are defined by a care planning process driven by a compassionate, robust partnership between physicians, patients, and the patient's family.
  - Evidence-based medicine and clinical decision-support tools guide decision making.
  - Physicians in the practice accept accountability for continuous quality improvement through voluntary engagement in performance measurement and improvement.
  - Patients actively participate in decision making and feedback is sought to ensure patients' expectations are being met.
  - Information technology is utilized appropriately to support optimal patient care, performance measurement, patient education, and enhanced communication.
  - Practices go through a voluntary recognition process by an appropriate non-governmental entity to demonstrate that they have the capabilities to provide patient-centered services consistent with the medical home model.
  - Patients and families participate in quality improvement activities at the practice level.
- Enhanced access to care is available through systems such as open scheduling, expanded hours and new options for communication between patients, their personal physician, and practice staff.
- Payment appropriately recognizes the added value provided to patients who have a patient-centered medical home. The payment structure should be based on the following framework:
  - It should reflect the value of physician and non-physician staff patient-centered care management work that falls outside of the face-to-face visit.
  - It should pay for services associated with coordination of care both within a given practice and between consultants, ancillary providers, and community resources.
  - It should support adoption and use of health information technology for quality improvement.
  - It should support provision of enhanced communication access such as secure e-mail and telephone consultation.
  - It should recognize the value of physician work associated with remote monitoring of clinical data using technology.
  - It should allow for separate fee-for-service payments for face-to-face visits. (Payments for care management services that fall outside of the face-to-face visit, as

- described above, should not result in a reduction in the payments for face-to-face visits).
- It should recognize case mix differences in the patient population being treated within the practice.
  - It should allow physicians to share in savings from reduced hospitalizations associated with physician-guided care management in the office setting.
  - It should allow for additional payments for achieving measurable and continuous quality improvements.

## Background of the Medical Home Concept

The American Academy of Pediatrics (AAP) introduced the medical home concept in 1967, initially referring to a central location for archiving a child’s medical record. In its 2002 policy statement, the AAP expanded the medical home concept to include these operational characteristics: accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective care.

The American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP) have since developed their own models for improving patient care called the “medical home” (AAFP, 2004) or “advanced medical home” (ACP, 2006).

## Endorsers

- The American Academy of Family Physicians
- The American Academy of Hospice and Palliative Medicine
- The American Academy of Neurology
- The American Academy of Pediatrics
- The American College of Cardiology
- The American College of Chest Physicians
- The American College of Osteopathic Family Physicians
- The American College of Osteopathic Internists
- The American College of Physicians
- The American Geriatrics Society
- The American Medical Directors Association
- The American Osteopathic Association

- The American Society of Addiction Medicine
- The American Society of Clinical Oncology
- The Infectious Diseases Society of America
- The Society for Adolescent Medicine
- The Society of Critical Care Medicine
- The Society of General Internal Medicine

## For More Information

- American Academy of Family Physicians  
<http://www.aafp.org/pcmh>
- American Academy of Pediatrics  
[http://aappolicy.aappublications.org/policy\\_statement/index.dtl#M](http://aappolicy.aappublications.org/policy_statement/index.dtl#M)
- American College of Physicians  
[http://www.acponline.org/advocacy/where\\_we\\_stand/medical\\_home/](http://www.acponline.org/advocacy/where_we_stand/medical_home/)
- American Osteopathic Association



# CBRI Sample Letter to Employees

<Letterhead>

<Date>

Dear <Organization Name> <Employee or Other Word>:

At <Organization Name>, we want to help you understand how to take the best care of your own health. An important first step in achieving this is to make sure you have a primary care physician or other primary care clinician. To learn more about primary care and why it is so important, please read the information below.

## **Do you know who to turn to for all of your health concerns?**

Your primary care physician (family physician, general internist, pediatrician, geriatrician) or other primary care clinician (nurse practitioner or physician assistant). Primary care is your best entry into the health care system.

## **What do primary care physicians and others primary care clinicians do?**

You may think that primary care physicians and other primary care clinicians treat simple health concerns like giving vaccinations, treating sore throats and bladder infections, doing annual physicals. But their job is much bigger.

Primary care physicians and other primary care clinicians take care of the physical, mental, and emotional health of their patients. They can diagnose and treat the full range of health concerns people usually bring to their doctors including diabetes, high blood pressure, depression, high cholesterol, liver disease, back pain, memory loss, developmental and behavioral problems, heart disease, asthma, obesity, and more.

Your team of primary care health professionals and office staff is dedicated to keeping you healthy. They understand your health needs and can work with you to develop a personal health care plan.

## **If you don't have any health problems, do you still need a primary care practice?**

Yes; the key to maintaining long-term good health is the patient-clinician relationship. Research shows that people who have an ongoing relationship with a primary care physician have better overall health outcomes, lower death rates, and lower health care costs. Your primary care clinician understands your health history and how it can affect you, knows when to treat you, and, if necessary, coordinates your care with other qualified health care clinicians. Your primary care clinician can help you navigate through the confusing health care system

## **What Can You Do?**

Remember, primary care is your best entry into the health care system. Your primary care physician or other primary care clinician should be your first point of contact for all your health care needs.

If you would like additional information about primary care, or if you need help finding a primary care clinician, please contact <Organization contact information>.

Sincerely,

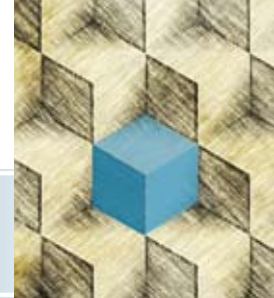
< Name>

<Title>

<Organization Name>

<Address>

## PCPCC Consumer Tools and Resources



### National Partnership for Women & Families

*Understanding the Medical Home*

Pages 41-42

### Center for Advancing Health

*Supporting Patient Engagement in the  
Patient-Centered Medical Home*

Pages 43-46

### Merck & Co., Inc.

*Patient Centered Medical Home Checklist*

Pages 47-48

### Stoeckle Center for Primary Care Innovation

*Primary Care: A Miracle of Modern Medicine*

Pages 49-52



# Understanding the Medical Home

## What is a Medical Home?

A “medical home” — sometimes referred to as a “patient-centered medical home” — is a medical office or clinic where a team of health professionals work together to provide a new, expanded type of care to patients.

A medical home is not an institution or nursing home, but a medical office or clinic that offers coordinated, comprehensive primary care that is personal and focused on making sure the patient’s health care needs are met. The medical home approach has the potential to improve the quality of care patients receive and reduce costs.

## How is the Medical Home Different?

A medical home provides care in a different way than most primary care practices currently do. Care is personalized, coordinated and delivered by a team of professionals that puts the patient and her or his caregiver at the center of the team. In addition to the patient, the care team may include a doctor, nurse, health educator and other health care professionals like a pharmacist or physical therapist.

A medical home care team:

- Coordinates a patient’s health care across settings, including among specialists and hospital care. This coordination can help prevent errors that occur when multiple providers are involved, and prevent duplication of tests and procedures.
- Focuses on preventive care and disease management, to help patients stay healthy and manage their conditions in partnership with their doctors.
- Knows the patient and provides care that accommodates the patient’s treatment preferences, life situation and cultural and language needs.
- Actively involves the patient in making decisions about her or his care.
- Supports patients or their caregivers in taking an active role in managing their health care.

## What are the Potential Benefits of a Medical Home?

A medical home has the potential to improve the health of individuals by improving their access to primary care. Comprehensive primary care services, such as those delivered by a medical home, result in higher patient satisfaction with care and bring significant health and cost benefits, including better prevention and wellness,


### Consumer Advocate Toolkit Contents:

- ⇒ *Understanding the Medical Home*
2. Why Advocates Should Get Involved
3. How Advocates Can Get Involved
4. Brochure for Patients and Consumers on the Medical Home

*Download the Consumer Advocate Toolkit at [www.nationalpartnership.org/medicalhome](http://www.nationalpartnership.org/medicalhome)*



---



reduced health disparities and fewer hospitalizations.<sup>1,2,3</sup> These improvements to the health care system would benefit your constituents.

In addition, one of the key characteristics of the medical home is that it provides care that is appropriate based on the culture and language needs of the patient. This improves access by making it easier to communicate about complex health issues with providers who understand the patient's linguistic and cultural framework.

Patient-centered medical homes that deliver high quality primary care have the potential to enhance preventive care, reduce hospitalizations and medical errors, and lower the costs associated with poor quality care. Many believe that this will create cost-savings that could be used to extend coverage to many of the uninsured.

### **Next Steps**

While the medical home model of care holds great promise, there is no guarantee that it will be designed and implemented in a way that truly benefits patients. To realize this promise, patients and consumer advocates must get involved as medical home initiatives are developed at the state and local levels, where you can play a major role in ensuring that the patient remains the focus.

For more information on why you should get involved and how you can make a difference, read the Consumer Advocate Toolkit at [www.nationalpartnership.org/medicalhome](http://www.nationalpartnership.org/medicalhome). You can also contact the National Partnership for Women & Families at (202) 986-2600 or [qualitycare@nationalpartnership.org](mailto:qualitycare@nationalpartnership.org).

---

### **About Us**

Founded in 1971, the National Partnership for Women & Families is a nonprofit, nonpartisan consumer advocacy organization located in Washington, DC. The National Partnership is dedicated to promoting public policies and practices that improve the well-being of our nation's families. This toolkit was developed with support from the WellPoint Foundation. More at: [www.nationalpartnership.org](http://www.nationalpartnership.org).

---

<sup>1</sup> Bindman AB, Grumbach K, Osmond D, Vranizan K, Stewart AL. Primary care and receipt of preventive services. *J Gen Intern Med* 1996; 11:269-76

<sup>2</sup> Shi L, Starfield B, Politzer R, Regan J. Primary care, self-rated health, and reductions in social disparities in health. *Health Serv Res* 2002; 37:529:50

<sup>3</sup> Bindman AB, Grumbach K, Osmond D, Komaromy M, Vranizan K, Luri N, et al. Preventable hospitalizations and access to health care. *JAMA* 1995; 274:305-11

# Supporting Patient Engagement in the Patient-Centered Medical Home

**Authors:**

Jessie Gruman, PhD; Dorothy Jeffress, MBA, MSW, MA; Susan Edgman-Levitan, PA  
Leigh H. Simmons, MD; William A. Kormos, MD

## The Opportunity for Patient-Centered Medical Homes to Support Patients' Engagement in Their Health and Health Care

The idea of the patient-centered medical home as a possible solution to the problems that arise from poor-quality, fragmented, expensive health care has attracted interest from a wide range of stakeholders. The principles that characterize the patient-centered medical home describe the responsibilities and attributes professionals and institutions that must be met in order to qualify as a legitimate medical home (Patient-Centered Primary Care Collaborative, 2008). Included in these principles are general accounts of how patients should be treated: that their preferences should be respected, their emotional needs attended to, their autonomy supported and their decisions shared with families and the care team (Wachter, R. 2008).

What is lacking from the model of the medical home is recognition that patients are not the object of care, but are rather that they are full-fledged participants in it – and unless that participation is active and informed, the impact of health care, whether services, drugs, surgery or devices, is severely muted. People who are unable to seek care when they need it, who don't fill their prescriptions, who delay their colonoscopies indefinitely or who keep smoking – regardless of the reason – place their own health at risk, waste human and material resources and incur unnecessary expense to themselves and others.

Full participation of every patient in finding and using safe, decent health care is vital to the success of the health care enterprise in improving the health of individuals and the population. We know that some patients will only ever partly meet this aim and that many never will. But we also know that those who are able to (1) manage complex drug regimens, (2) care for themselves after surgery and (3) consider complex information when finding the providers and treatments that meet their needs are more likely to reach the promise of increased length and improved quality of life that advances in medicine now offer.

Current disparities in health outcomes will only increase unless the central role patients now play in the success of their care is recognized and addressed. What opportunities does the the patient-centered medical home present to enable all patients to benefit optimally from the care available to them?

The enthusiasm surrounding the patient-centered medical home signals readiness on the part of professional health stakeholders to fundamentally modify their own behavior in response to the current demands of health care delivery. This transformation sets specific new expectations for professionals and it is only seemly, that in explicitly patient-centered settings, patients -- the ultimate stakeholders in health care -- understand what they can now expect from their primary care providers.

But the transition from standard issue primary care to a patient-centered medical home also requires setting in place practices and services that will enable patients to positively participate in their health and health care to the extent they are able.

Given the current interest in the patient-centered medical home, from the provider community in particular, we offer two modest proposals for how the idea of patient-centeredness can extend to supporting patients' needs to participate positively in their own care.

## **What are the RULES of engagement?**

Each practice and clinic has unique ways of doing business: how to make an appointment, how to contact the doctor or the team, who to discuss financial matters with, who to call for problems in the middle of the night, how referrals are handled. Why not develop and distribute a short guide that spells this out?

It is frustrating both for patients to have to guess what the rules might be and for staff that spend their days correcting those who guess wrong. Attachment A provides a list of tasks that are fairly easy for patients to perform if they know they are supposed to do them. A concerted effort by practices and clinics to provide this information early and often to every patient in the form of a pamphlet provided at every visit, available in the waiting room and posted on practice Websites would be welcomed by most patients.

## **What are the TERMS of engagement?**

The change from the current model of primary care services to patient-centered medical home also offers an opportunity to make explicit previously assumed expectations about responsibilities of both providers and patients. Rather than develop a contract, which smacks of legal obligation and litigation, consider developing a PACT. A pact is an agreement about roles and responsibilities that recognizes the mutual interdependence of the parties: neither can solve the problem without the other. A pact is also entered into with a sense of moral and social obligation which expresses the intent of all parties to work together toward a shared aim. So, for example, a pact might include patients agreeing to behaviors such as "I will discuss all my current medications, non-prescription medication products, vitamins or herbs as well as all of my current and past problems with providers, recognizing how important this information is in guiding my care and making me safer." (Casale, AS. 2007) Or, "Before leaving my appointment, I will ask questions when any explanations and next steps are not clear." On its end, the care team would agree to such behaviors as "We will ask specifically what the patient's concerns and questions are for the visit. We will respond to concerns and answer questions." Or, "We will help you understand your treatment options by discussing the pros and cons and possible outcomes with you because there is often more than one possible response to your symptom or disease." In all cases, the refusal of patients or providers to agree with the intent of the statements would make for very interesting conversations indeed.

Attachment B consists of a list of ten (10) sets of patient and clinician behaviors that are aligned to support active engagement and promote transparency by both the patient and their clinician team. The sets are also organized by three types of activities: Sharing Information, Shared Decision Making and Responsibility for Care.

Moving from traditional passivity to active, informed engagement is an unexpected challenge for many patients. One critical contribution of the patient-centered medical home is to ensure that every patient and every caregiver has the knowledge, skills and opportunity to take effective action.

## **REFERENCES**

Casale AS, et al. "ProvenCare(SM):" A provider-driven pay-for-performance program for acute episodic cardiac surgical care. *Ann Surg* 246(4), 2007.

Johnson A, Sandford J, Tyndall J. 2003. Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database of Systematic Reviews*. Issue 4. Art. No.: CD003716. DOI: 10.1002/14651858.CD003716.

Patient-Centered Primary Care Collaborative. Joint principles of the patient-centered medical home. February 2007. <http://www.pcpcc.net/node/14> (accessed 8.21.08).

Tang, PC and Newcomb, C. 1998. Informing patients: A guide for providing patient health information. *Journal of the American Medical Association* Nov-Dec;5(6):563-570. Wachter, R. The health care McGuffin. August 4, 2008 [http://www.thehealthcareblog.com/the\\_health\\_care\\_blog/2008/08/the-healthcare.html#more](http://www.thehealthcareblog.com/the_health_care_blog/2008/08/the-healthcare.html#more)

## Attachment A

# Short Guide for Patients\*

A basic “how to benefit from and use our medical services” guide for patients should include:

- Guidance about when to seek and where to go for after-hours and emergency care.
- How to make appointments, along with a description of no-show policies and expectations for timely arrival with reasonable estimates of waiting times (both for an appointment and when waiting to see the clinician after arriving).
- If and how the provider can accommodate unique needs (physical navigation, hearing or visual impairments, translation services, etc.) and how to arrange for assistance if needed.
- The health insurance documentation and/or payment process required for receiving care.
- Guidance about bringing another person to assist the patient if he or she is frail, confused, unable to move around without assistance, unable to remember the conversation with the provider or simply needs support.
- Instructions for bringing a summary of their medical history, current health status and recent test results or referral documentation as appropriate.
- What type of diagnostic tests are commonly conducted in the practice, what tests or treatment follow-up is commonly provided by an external provider (with name of various providers, e.g., radiologists) and how patients or caregivers will be notified of test results.
- Instructions for securing prescription refills, reporting adverse side effects and decisions to discontinue medication or change agreed upon treatment plan.

(\*Adapted from the Center for Advancing Health’s Engagement Behavior Framework)

---

## Attachment B

# Patient-Clinician PACT \*

*Just as patients are supported by family members and caregivers, clinicians function as part of a medical practice, with an invaluable support team. The roles of Patient and Clinician, as described in the following responsibilities/behaviors, depend on these care networks to assist with meeting expectations.*

### Sharing Information

1. **Patient:** Before each medical visit, write down a list of concerns and questions to talk about with your clinician.

**Clinician:** Ask specifically what the patient’s concerns and questions are for the visit. Respond to concerns and answer questions.

2. **Patient:** Report accurately on the problem: How long has it been going on? How severe is it? How does it affect you?

**Clinician:** Provide a safe setting for talking about confidential concerns. Inquire about mental and physical symptoms, any substance use, changes since last visit and progress in previous treatment plan.

3. **Patient:** Bring a list of all current medications and their doses, including vitamins, supplements and alternative products and be ready to let your clinician know if they are helping you or if you are having any problems with them.

**Clinicians:** Review the list of medications and how they are working. Make a plan for refills, substitutions and discontinuation.

4. **Patient:** Before leaving your appointment, ask questions when explanations and next steps are not clear.

**Clinician:** Ask your patients to describe their understanding of what you have talked about and what each of you will be doing next.

**5. Patient:** Tell your clinician when you get care somewhere else; for example, if you go to the emergency room or see a specialist your clinician didn't refer you to. Authorize those doctors to share this information with your clinician.

**Clinician:** Ask the patient about whether he or she has consulted other clinicians. Be sure that medical information is shared with other appropriate providers and institutions. Shared Decision Making

**6. Patient:** Ask about and consider information about how different treatments or tests might affect you.

**Clinicians:** Describe the benefits and risks of treatments and tests.

**7. Patient:** Agree on a care plan with your clinician. Follow-through on referrals for treatment and testing. Track any success or problems with following your care plan.

**Clinician:** Agree on a care plan with your patient; explain your reasons for advising any treatments and tests. Provide or prescribe sources for additional information and support. Make and record referrals and provide contact information for them. Discuss how you will monitor and revise the plan together.

**8. Patient:** If you are told that you have a serious illness, ask your clinician to help you get other expert opinions on your condition and care plan before starting treatment.

**Clinician:** Provide guidance and referral about getting other opinions about serious diagnoses prior to beginning treatment. Meet to talk about what to do if you get different expert opinions.

### Responsibility for Care

**9. Patient:** Fill or refill prescriptions on time. Use medications or devices as directed. Monitor whether they are working and any side effects. Consult with your clinician before you stop taking any prescribed drug or change the way you are taking them, stop any therapy or stop using prescribed devices.

**Clinician:** Use electronic prescribing to make sure that your patient receives the right drugs at the right dose and that any new drugs don't conflict with the patient's current medications. Ask the patient about the effectiveness and side-effects of the drugs you previously prescribed.

**10. Patient:** Discuss with your clinician about whether you should get shots (e.g., flu shots) and tests (e.g., Pap, mammogram and colonoscopy).

**Clinician:** Discuss your patient's health and family history; modify standard recommendations for shots, screening and early detection tests as needed. Assist by providing shots and tests or make referrals for screening or early detection.

(\*Adapted from the Center for Advancing Health's Engagement Behavior Framework)

---

### Center for Advancing Health

2000 Florida Avenue, N.W., Suite 210

Washington, D.C. 20009-1231

Tel: 202-387-2829 Fax: 202-3872857

[www.cfah.org](http://www.cfah.org)

The Center for Advancing Health (CFAH) is committed to creating an America where everyone is equipped to live a healthy life and make informed choices about health care. For more than 15 years, CFAH has worked to translate complex scientific evidence into information, policies and programs that will ensure that each person can make wise decisions about their health and interact effectively with their health care providers. CFAH is an independent non-profit organization that is supported by a number of foundations (principally the Annenberg Foundation and the W.K. Kellogg Foundation) and individuals.

Center for Advancing Health © 2009

A medical home is an approach to providing total health care. With your medical home, you will join a team that includes health care professionals, trusted friends or family members (if you wish), and—most importantly—you.

## Get ready for your appointment. Use this handy checklist.

- Make a list of your health questions. Ask a friend or relative for help if you need it. Put the questions that are most important to you at the top of the list.
- Make a list of other health care providers you have visited. Write down their names, addresses, phone numbers, and the reasons you visited them.
- Take all of your medicines, in their original containers, to your appointment. Be sure to include prescription, over-the-counter, natural, and herbal medicines and vitamins.
- Take your insurance card or other insurance information with you to your appointment.
- If you wish, ask a family member or trusted friend to go to your appointment with you.

*You and your health care are at the center of your medical home team.*

Doctor: \_\_\_\_\_

Other Clinician: \_\_\_\_\_

Office Staff: \_\_\_\_\_

Phone Number: \_\_\_\_\_

E-mail: \_\_\_\_\_

Web Site: \_\_\_\_\_

Remember, the medical home can be a way for you to be *informed* about and *involved* in your health care decisions. The medical home can bring you, your family, and your health care team together to help you make the best choices about your health.

## During your appointment, use this handy checklist.

- Write down the names of your team members.
- Use your list of questions. Ask your most important questions first. Even if you cannot get all of your answers on the first visit, having a list will help you keep track of the answers.
- Talk with your team about what health issue to work on first.
- Be sure you know what you should do before you leave the office.
- Use your own words to repeat back the things you've discussed with your team. This way, both you and your team will know the information is clear.
- Ask your team about how to reach them after hours if you need to.



patient-centered  
**medicalhome**

*You and your health care are at the center  
of your medical home team.*

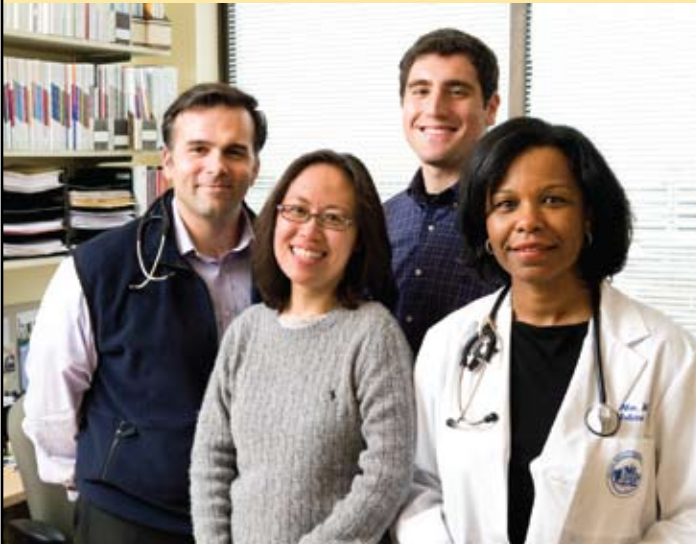
For more information, visit [pecc.net](http://pecc.net).



Copyright © 2009 Merck & Co., Inc. All rights reserved.  
Printed in USA Minimum 10% Recycled Paper  
20805877(3)-03/09-SGR-English

# Primary Care:

## *A Miracle of Modern Medicine*



**What medical discovery touches everyone in the United States?**

**What medical breakthrough is proven to reduce the galloping growth of health care spending?**

**What medical wonder improves the quality of care for children and adults with many different illnesses?**

**Share this brochure with others!  
Share your feedback with us!  
(see details, back cover)**

The John D. Stoeckle Center for Primary Care Innovation  
Massachusetts General Hospital

Center for Excellence in Primary Care  
University of California, San Francisco

## **Primary care:**

**The foundation of our health care system  
may be the greatest miracle of  
modern medicine!**

### **What is primary care?**

When you hear people say, "I need to see my personal doctor," or "My children's pediatrician said they need to exercise more," do you know what kind of doctor they are talking about? A primary care doctor!

Patients and families can choose a family physician, general internist, pediatrician, or medicine-pediatrics doctor to be their primary care physician. Nurse practitioners and physician assistants work closely with these physicians to also deliver primary care. Primary care is the patient's entry into the health care system and the medical "home" for ongoing, personalized care.

Some people think that primary care physicians only handle simple things: making sure kids get their vaccinations, treating sore throats and bladder infections, and doing school and annual physicals. The truth is quite different.

Primary care physicians need a vast amount of medical knowledge because they care for patients with hundreds of different problems including high blood pressure, elevated cholesterol, liver disease, back pain, memory loss, developmental and behavioral problems, depression, heart disease, asthma, obesity, and more.

Primary care physicians also coordinate the care of their patients throughout the confusing health care system; for example, arranging for patients to get an MRI, choosing the right specialists, helping the elderly find their way through the pharmacy maze of Medicare Part D, and checking up on home nursing services. In addition, primary care physicians are a trusted source of information, helping their patients choose the best options and manage conflicting recommendations from specialists and other physicians.

## The value of primary care

### A medical discovery that touches everyone in the United States

- 94 percent of patients value having a primary care physician who knows about all their medical problems.<sup>1</sup>
- Primary care assists everyone who needs prevention services, help in managing chronic illness, and treatment of acute problems. That's the entire population of the United States!

### A medical breakthrough proven to reduce the galloping growth of health care spending

- Patients with a regular primary care physician have lower health care costs than those without.<sup>2,4</sup>
- When more primary care physicians, per person, are practicing in a community, hospitalization rates are lower.<sup>5</sup>
- States with more primary care physicians who care for patients on Medicare have lower Medicare costs; states with fewer of those primary care physicians have higher costs.<sup>6</sup>

### A medical wonder that improves the quality of care for people with many different illnesses

- Children and adults with primary care physicians are more likely to receive recommended preventive services, to have better management of chronic illnesses, and to be satisfied with their care.<sup>7,9</sup>
- States with more primary care physicians who care for Medicare patients have higher quality of care for Medicare patients; states with fewer of those primary care physicians have lower quality.<sup>6</sup>
- States with more primary care physicians per capita have lower total mortality rates, lower heart disease and cancer mortality rates, and higher life expectancy at birth compared with states having fewer primary care physicians, adjusting for other factors such as age and per capita income.<sup>10</sup>



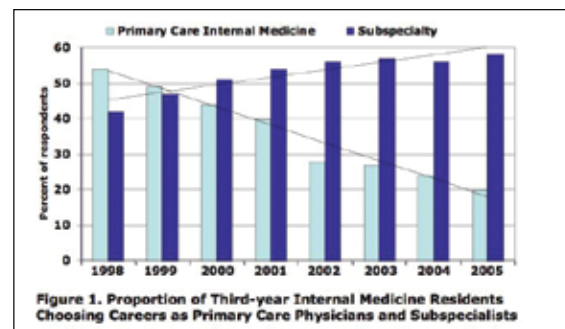
2

## Threats to primary care's survival

In 2006, the American College of Physicians, an organization representing both primary care physicians and specialists, warned that, "Primary care, the backbone of the nation's health care system, is at grave risk of collapse...."<sup>11</sup>

That's a strong statement, but it's true. What are the facts?

- From 1997 to 2005, the number of US medical school graduates entering family medicine residencies dropped by 50 percent.<sup>12</sup>
- In 1998, 54 percent of internal medicine residents planned careers in primary care rather than specialty medicine. By 2005, the number choosing primary care careers had dropped by more than 50 percent (see chart).<sup>13, 14</sup>



- The income of primary care physicians, adjusted for inflation, has dropped by 10.2 percent from 1995 to 2003,<sup>15</sup> while the amount of work has increased. The combination of lower incomes and a stressful worklife discourages medical students and young physicians from choosing primary care careers.
- Not only is the primary care physician pipeline drying up, but many primary care physicians are leaving their practices after only 15 or 20 years.<sup>16</sup>
- 42 percent of primary care physicians report not having enough time to spend with their patients.<sup>17</sup>
- The frustration of not having time for patients is made worse by a payment system that is unfair to primary care. For example, a specialist spending 30 minutes performing a surgical procedure, a diagnostic test like a colonoscopy, or an imaging study like an MRI, is often paid three times as much as a 30-minute primary care visit with a complicated patient who has diabetes, heart failure, headache, and high cholesterol.<sup>18</sup>

3

## Investing in primary care

Nations with strong primary care systems are supported by governments that make sure enough primary care physicians exist. As a result, they have lower health care expenditures.<sup>19</sup>

The United States needs a thoughtful national primary care policy. Leaders in Congress, the federal administration, state governments, and the private sector could help to improve health care quality, contain health care costs, and enhance patients' health care experience by investing in primary care.

### Who needs to invest in primary care?

To start with, the federal Medicare program does. Investing in primary care could reduce Medicare's costs and help avert Medicare bankruptcy. Also, health insurance companies, whose rising costs are pricing employers and employees out of the health care market, could pay more to strengthen primary care. And finally, employers, who foot a large proportion of the health care bill, could save large sums of money by telling insurers to support primary care.

Investing a greater proportion of health care dollars into primary care would be smart, since a strong primary care system translates into reduced use of high-cost services.

### What does it mean to invest in primary care?

Fairer payment of primary care clinicians – physicians, nurse practitioners and physician assistants – would attract more health professionals into primary care. If Medicare and health insurance companies paid primary care practices to hire additional staff – health educators, community health workers, and chronic care nurses – practices could build teams to improve care, expanding the rushed 15-minute visit into a more satisfying experience for patients. Investing in primary care means paying for e-mail, telephone, and home visits for patients. It also means providing funds to help primary care practices obtain computerized medical records and create office systems that offer prompt appointments and longer team-based visits. Primary care practices that make these improvements are called Patient-Centered Medical Homes.

## References

Figure 1. Copyright © 2006 Massachusetts Medical Society. All rights reserved. Adapted with permission in 2007 from Bodenheimer, T. Primary Care – Will It Survive? *N Engl J Med* 2006;355:861-864.

1. Grumbach K, Selby JV, Damborg C, et al. Resolving the gatekeeper conundrum. *JAMA* 1999;282:261-266.
2. Weiss LJ, Blustein J. Faithful patients: The effect of long-term physician-patient relationships on the costs and use of health care by older Americans. *Am J Public Health* 1996;86:1742-1747.
3. De Maeseneer JM, De Prins L, Gosset H, Heyerick J. Provider continuity in family medicine: Does it make a difference for total health care costs? *Ann Fam Med* 2003;1:144-148.
4. Greenfield S, Nelson EC, Zubkoff M, et al. Variations in resource utilization among medical specialties and systems of care. *JAMA* 1992;267:1624-1630.
5. Parchman ML, Culler S. Primary care physicians and avoidable hospitalizations. *J Fam Pract* 1994;39:123-128.
6. Baicker K, Chandra A. Medicare spending, the physician workforce, and beneficiaries' quality of care. *Health Affairs Web Exclusive*, April 7, 2004;W4-184-197.
7. Bindman AB, Grumbach K, Osmond D, et al. Primary care and receipt of preventive services. *J Gen Intern Med* 1996;11:269-276.
8. Safran DG, Taira GA, Rogers WH, et al. Linking primary care performance to outcomes of care. *J Fam Pract* 1998;47:213-220.
9. Stewart AL, Grumbach K, Osmond DH, et al. Primary care and patient perceptions of access to care. *J Fam Pract* 1997;44:177-185.
10. Starfield B. Primary care: Balancing health needs, services, and technology. New York: Oxford University Press, 1998.
11. The Impending Collapse of Primary Care Medicine and its Implications for the State of the Nation's Health. Washington DC: American College of Physicians, January 30, 2006.
12. Pugno PA, Schmittling GT, Fetter GT, et al. Results of the 2005 national resident matching program: Family medicine. *Fam Med* 2005;37:555-564.
13. Garibaldi RA, Popkave C, Bylsma W. Career plans for trainees in internal medicine residency programs. *Acad Med* 2005;80:507-512.
14. West CP, Popkave C, Schultz HJ, et al. Changes in career decisions of internal medicine residents during training. *Ann Intern Med* 2006;145:774-779.
15. Tu HT, Ginsburg PB. Losing ground: Physician income, 1995-2003. Center for Studying Health System Change, Tracking Report No. 15, June 2006.
16. Sox HC. Leaving (internal) medicine. *Ann Intern Med* 2006;144:57-58.
17. Center for Studying Health System Change Physician Survey. <http://CTSonline.s3.com/psurvey.asp>
18. Bodenheimer T. Primary care – Will it survive? *N Engl J Med* 2006;355:861-864.
19. Starfield B. Deconstructing primary care. In: Showstack J, Rothman AA, Hassmiller SB, eds. *The Future of Primary Care*. San Francisco: Jossey-Bass; 2004.

## What Can You Do?

### Revitalize Primary Care

Bold initiatives are needed to revitalize primary care. While the Federal Government has a leading role to play, states, large employers, and health plans should also step up to the plate. The initiatives should address clinician payment, practice infrastructure, and the training pipeline. Much can be implemented in a budget neutral fashion since revitalized primary care can reduce hospital and specialty costs. Other elements require relatively small amounts of new investment.

### A primary care revitalization agenda:

- Amend the Medicare payment structure to provide sustained increases in primary care clinician reimbursement, as recommended by the Medicare Payment Advisory Commission (MedPAC) in its June 2008 report to Congress. This is an essential first step to reverse the growing primary care shortage.
- Support primary care practices in transforming themselves into Patient-Centered Medical Homes by providing financial incentives through increased Medicare, Medicaid and private insurance payments.
- Create regional primary care cooperatives with experts to offer technical support to primary care practices, assisting them to become Patient-Centered Medical Homes and to adopt health information technology.
- Develop loan forgiveness programs for health professional students choosing primary care careers, and add incentives for clinicians choosing to provide primary care to underserved populations.
- Reform the Medicare Graduate Medical Education system so that Medicare educational dollars are prioritized for residency training in primary care. Increase funding for Title 7 primary care physician training.

If you are an employer paying for the health care of your employees, or if you work in Congress, the federal Department of Health and Human Services, state government, or a private health plan, please advocate for the agenda described on the previous page.

If you work in primary care, please send copies of this brochure to your Congressional and state legislators with a cover note asking them to actively promote this agenda.

### ADDITIONAL COPIES

To order additional copies, please send an e-mail to: [stoeclecenter@partners.org](mailto:stoeclecenter@partners.org), or download from the web at: [www.stoeclecenter.org](http://www.stoeclecenter.org) (click on Stoeckle Center Publications) or [www.ucsf.edu/cepc](http://www.ucsf.edu/cepc)



Department of Family and Community Medicine  
University of California, San Francisco

[CEPC@fcm.ucsf.edu](mailto:CEPC@fcm.ucsf.edu)  
[www.ucsf.edu/cepc](http://www.ucsf.edu/cepc)



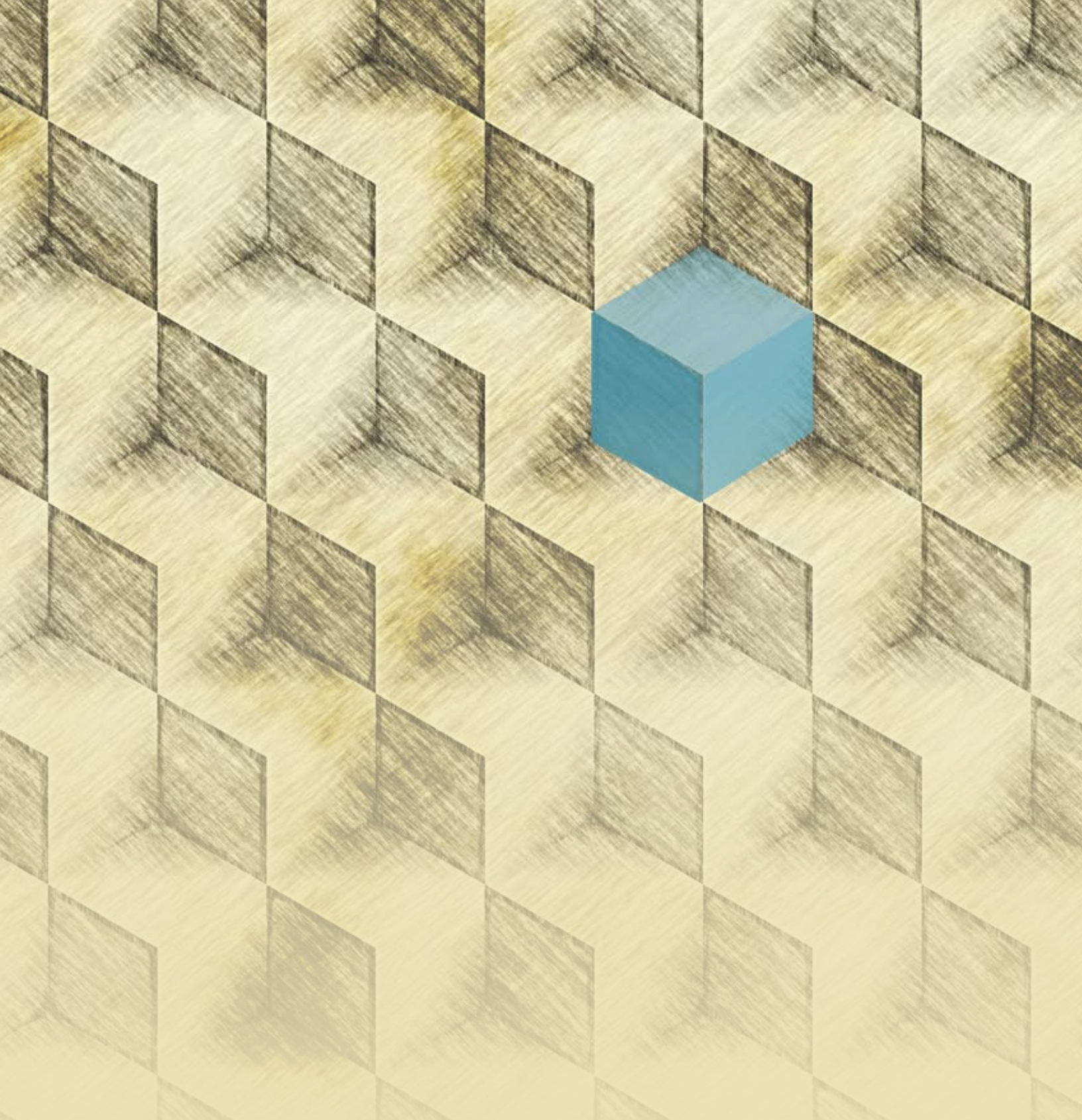
The John D. Stoeckle Center for Primary Care Innovation  
Massachusetts General Hospital  
Boston, MA 02114

[stoeclecenter@partners.org](mailto:stoeclecenter@partners.org)  
[www.stoeclecenter.org](http://www.stoeclecenter.org)



MASSACHUSETTS  
GENERAL HOSPITAL





**Patient-Centered Primary Care Collaborative**  
The Homer Building • 601 Thirteenth Street, N.W. • Suite 400 • Washington, D.C.  
Phone: 202/724-3332 • Fax: 202/393-6148 • [www.pcpc.net](http://www.pcpc.net)