Patient-Centered Care for Underserved Populations: Definition and Best Practices

prepared for

The W. K. Kellogg Foundation

by

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About the Economic and Social Research Institute

The Economic and Social Research Institute (ESRI) is a nonprofit, non-partisan organization based in Washington, D.C that conducts research and policy analysis in health care and in the reform of social services. ESRI specializes in studies aimed at improving the way health care services are organized and delivered, making quality health care accessible and affordable, and enhancing the effectiveness of social programs. For more information, see www.esresearch.org.

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Executive Summary

The U.S. health care system is experiencing a slow and subtle shift from a professionally driven approach toward one that is "patient centered" or "consumer centered." This stems from a growing recognition that incorporating an individual patient's perspectives and greater involvement in his/her care results in better health outcomes and satisfaction. But certain populations such as low-income individuals, uninsured persons, immigrants, racial and ethnic minorities, and the elderly—who are typically underserved by the health system—face even greater barriers to patient/consumer centered care (PCC).[1] This report focuses on how patient-centered philosophies can be incorporated into health care delivery models targeting the underserved.

Through close examination of the literature and models considered seminal to the field, the Economic and Social Research Institute (ESRI) has defined a set of core components of consumer/patient-centered care for vulnerable populations. We also have identified critical "ingredients"—institutional structures and processes—that support the successful implementation of PCC. Further, ESRI's case studies of these organizations (available at www.esresearch.org) delineate numerous best practices in PCC that could be replicated at other health care organizations.

Core Components of Consumer/Patient-Centered Care for Underserved Populations

Using an iterative process incorporating existing literature (beginning with the Picker Institute's dimensions of patient-centered care) and feedback from dozens of individuals who are studying and/or practicing in the field, we have developed the following set of core components of a comprehensive PCC approach for underserved populations:

A. *Welcoming environment*: provide a physical space and an initial personal interaction that is "welcoming," familiar, and not intimidating;

B. *Respect for patients' values and expressed needs*: obtain information about patient's care preferences and priorities; inform and involve patient and family/caregivers in decision-making; tailor care to the individual; promote a mutually-respectful, consistent patient-provider relationship;

C. *Patient empowerment or "activation"*: educate and encourage patient to expand their role in decision-making, health-related behaviors, and self-management;

[1] Although the elderly have access to Medicare coverage and tend not to be uninsured, they may be underserved in other ways. Anecdotal evidence suggests that due to changes in physicians' Medicare reimbursement, a growing number of Medicare enrollees are having difficulty finding providers who will take on new Medicare patients. Also, the elderly more often face multiple chronic and acute conditions that make coordination of care and navigation through a complex health care system particularly difficult.

D. *Socio-cultural competence*: understand and consider culture,[2] economic and educational status, health literacy level, family patterns/situation, and traditions (including alternative/folk remedies); communicate in a language and at a level that the patient understands;

E. *Coordination and integration of care*: assess need for formal and informal services that will have an impact on health or treatment, provide team-based care and care management, advocate for the patient and family, make appropriate referrals and ensure smooth transitions between different providers and phases of care;

F. *Comfort and support*: emphasize physical comfort, privacy, emotional support, and involvement of family and friends;

G. *Access and navigation skills*: provide what patient can consider a "medical home," keep waiting times to a minimum, provide convenient service hours, promote access and patient flow; help patient attain skills to better navigate the health care system;

H. *Community outreach*: make demonstrable, proactive efforts to understand and reach out to the local community.

Key Institutional Supports and Processes

Our research indicated that certain institutional structures and processes are essential for supporting the above PCC activities. Other organizations interested in developing PCC should make considerable efforts to establish and/or build up these "ingredients" at their institutions.

I. *Feedback and measurement*: seek and respond to suggestions and complaints from patients and families; develop, collect and evaluate data on measures of patient-centered care, and feed back the results into further improvements; incorporate accountability for addressing deficiencies and continually improving indicators;

J. *Patient/family involvement*: include patients and family members in the planning, design, and ongoing functioning of the organization; consider the patient a member of his/her care team;

K. *Workforce development*: employ, train, and support a workforce that reflects, appreciates, and celebrates the diversity of the communities and cultures that the organization serves; reward and recognize staff exhibiting patient centeredness principles; develop communication skills among all levels of staff; empower staff to be part of patient-centered teams;

L. *Leadership*: top management, Board, and department heads make a clear, explicit commitment to patient centeredness and act as role models;

M. *Involvement in collaboratives, pilots*: seek out and join pilot research projects and collaborative relationships with other organizations that attempt to "push the envelope" in developing new methods to operationalize patient-centered principles;

[2] "Culture" includes ethnic traditions as well as culture of homelessness, addiction, etc.

N. *Technology and structural support*: use electronic systems/user-friendly software programs that promote patient/family education and compliance, and minimize medical errors; structure the physical environment to optimize patient flow and safety;

O. *Integration into institution*: tie patient-centered care to other priorities such as patient safety, quality improvement, etc., and incorporate patient-centered practices into daily operations and culture.

Barriers to PCC

Despite their successes, the organizations studied faced numerous barriers in pursuing PCC, including the following:

P. Difficulty recruiting and retaining underrepresented minority physicians;

Q. Lack of defined 'boundaries' for outreach staff who may be overwhelmed dealing with interrelated health, social, cultural, and economic issues of patients;

R. Strict hiring requirements that pose obstacles to hiring neighborhood residents;

S. Lack of tools to gauge and reward PCC performance;

T. Financial constraints;

U. Traditional attitudes among staff unwilling to change the "old school" provider/patient relationship or acknowledge and address cultural and socio-economic issues; and

V. Fatigue and competing priorities.

Challenges for Policymakers

Efforts to operationalize PCC are occurring at the organization, patient, provider, and community levels. In addition to adapting and replicating the best practices such as those described in this report (and in greater detail in the case study reports), additional efforts are required at *the broader health care system and public policy level.* This involves re-setting priorities in terms of reimbursement by Medicaid, Medicare, and private insurance; placing greater emphasis on wellness and prevention as well as treating disease; and promoting other public policies and government funding that supports PCC.

Introduction and Background

This report presents the results of a research study by the Economic and Social Research Institute (ESRI) on consumer/patient-centered care (PCC) for underserved populations, under a grant from the W. K. Kellogg Foundation. First, we provide a brief background of patient-centered care, and discuss special issues and barriers to PCC for vulnerable populations such as low-income persons, uninsured, minorities, immigrants, elderly, and other vulnerable groups. We then discuss the relationship between PCC and Consumer Driven Health Care, including elements common to both "movements," as well as areas in which they conflict.

After describing the methodology for our case study analysis, we summarize our findings by delineating the core components of PCC for underserved populations, along with "best practices" – actual strategies used by leading institutions that put PCC philosophy into practice. This section is followed by a cross-site assessment of the key institutional structures and processes that are necessary for the successful implementation of PCC. We recommend that all health care organizations consider establishing and/or building up these ingredients in order to support a more patient-centered health care system. The final sections summarize the barriers and future challenges facing the case study sites, along with the lessons that can be learned from their experiences.

During the course of our research, we discovered a wide range of activities across the country involving the practice, research, and teaching of PCC. Appendix A presents a "typology" of such activities, ranging from patient-driven clinical services at community health centers, to survey instruments that measure levels of patient-centeredness, to community-based rotations and training in cultural competence at medical schools. Appendix B lists the many experts interviewed for this study, each providing invaluable insights. Appendix C describes the criteria used to select our study sites, and Appendix D presents the interview guide used to elicit the information gathered.

Background

Over recent decades, the health care system has experienced some movement from a paternalistic medical model to one that engages the patient in decision-making and self-care.[3] It reflects the beginning of a shift from a professionally driven system toward one that is "patient centered" or "consumer centered," recognizing and incorporating an individual patient's perspectives.[4]

The Picker/Commonwealth Program for Patient-Centered Care delineated seven dimensions of patient centeredness in 1993 in a groundbreaking book, Through the Patient's Eyes:

[3] Gerteis, M., Edgman-Levitan, S., Daley, J., and Delbanco, T.L., eds. *Through the Patient's Eyes: Understanding and Promoting Patient-centered Care.* San Francisco: Jossey-Bass, 1993.

[4] Laine, C., and Davidoff, F. "Patient-Centered Medicine: A Professional Evolution." *Journal of the American Medical Association* 275(2):152–156, 1996.

Understanding and Promoting Patient-Centered Care.[5] Soon after, the Picker Institute was founded to support the measurement and advancement of PCC. Attention to the issue was heightened when the 2001 landmark report by the Institute of Medicine (IOM), Crossing the Quality Chasm: A New Health System for the 21st Century, included patient centeredness as one of six essential aims of the health care system.[6]

The IOM advocated a partnership between clinicians and patients that is characterized by informed, shared decision making, development of patient knowledge, self-management skills, and preventive behaviors. In this framework, health clinicians' decisions are informed by an understanding of patients' needs and environment, which includes home life, job, family relationships, cultural background, and other factors.[7]

There is some evidence that a patient-centered approach leads to better health outcomes as well as greater clinician satisfaction, reduced malpractice claims, and higher clinician loyalty.[8] Examples of such evidence include the following:

- A study of the patient-centered clinical method found that when patients perceived their physician visit to be patient centered (i.e., they felt they understood or had been adequately involved in developing the treatment plan), they experienced better recovery, better emotional health, and dramatically fewer diagnostic tests and referrals two months later.[9]
- One year after exposure to a chronic disease self-management program that emphasizes greater patient involvement in goal setting and self-management in a "real-world" setting, most patients experienced statistically significant improvements in a variety of health outcomes and had fewer emergency department visits.[10]
- A review of depositions from settled malpractice suits found that the decision to litigate was often associated with a perceived lack of caring and/or collaboration in the delivery of health care; issues identified included perceived unavailability of the clinician, discounting patient and/or family concerns, poor delivery of information, and lack of understanding the patient and/or family perspective. Problems often occurred during interactions between the clinician and patient after an adverse event.[11]

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[5] The seven dimensions are: 1) respect for patients' values, preferences, and expressed needs; 2) coordination and integration of care; 3) information, communication, and education; 4)physical comfort; 5)emotional support and alleviation of fear and anxiety; 6)involvement of family and friends; 7)transition and continuity (Gerteis, et al., 1993).

[6] Crossing the Quality Chasm: A New Health System for the 21st Century. Institute of Medicine, National Academy Press, Washington, DC, 2001.

[7] *Educating Health Professionals to be Patient Centered: Current Reality, Barriers, and Related Actions,* Institute of Medicine, http://www.iom.edu/Object.File/Master/10/460/0.pdf.

[8] See, for example: Meryn, S. "Improving communication skills: To carry coals to Newcastle," *Medical Teacher,* 20(4):331-37, 1998; Wagner, E. H., B. T. Austin, C. Davis, M. Hindmarsh, J. Schaefer, and A. Bonomi. "Improving Chronic Illness Care: Translating evidence into action," *Health Affairs* 20(6):64-78, 2001; and Hack, Thomas F., et. al. "Feasibility of an Audiotape Intervention for Patients with Cancer: A Multicenter, Randomized, Controlled Pilot Study," *Journal of Psychosocial Oncology*, Jun 1, 1999.

[9] Stewart, M., Brown JB. Donner A, et al. "The Impact of Patient-centered Care on Patient Outcomes," *Journal of Family Practice*, 2000, 49:796-804.

[10] Lorig, K. R., D. S. Sobel, P. L. Ritter, D. Laurent, and M. Hobbs. "Effect of a Self-management Program on Patients with Chronic Disease," *Effective Clinical Practice* 4(6):256-62, 2001.

[11] Beckman, H. B, K. M. Markakis, A. L. Suchman and R. M. Frankel. "The Doctor-Patient Relationship and Malpractice: Lessons from Plaintiff Depositions," *Archives of Internal Medicine* 154(12), June 27, 1994.

Despite these indications of the benefits of patient-centered type practices, there is no one definition of patient- or consumer-centered care, nor is there a single, agreed-upon strategy for incorporating PCC philosophy into practice.[12] Further, conventional attitudes and protocols, education/training practices, and reimbursement policies that support the status quo present formidable barriers to the expansion of PCC across the health care system.

Special Barriers/Issues for the Underserved

The obstacles to PCC are even greater for vulnerable populations such as low-income individuals, uninsured persons, immigrants, racial and ethnic minorities, and the elderly. For example, some of the underpinnings of a PCC model – individualized planning and delivery of services, consideration of patient values and culture, a medical home, and an interdisciplinary team care – are often absent in safety net care. Individuals whose main contact with the health care system is in a hospital emergency department (ED), for instance, are not likely to form long-term, mutually respectful patient-provider relationships; further, ED staff generally do not have the time or training to fully understand the patient's personal and cultural circumstances. There are some efforts being made to develop cultural competency models for hospital-based settings, but the resources for implementing these models are difficult to obtain.

Community health centers (CHCs), on the other hand, strive to provide a medical home for the underserved in a setting that might allow for the establishment of a better, more respectful relationship between patient and provider. CHCs also offer social services and links to community-based programs that can assist patients with their needs. Yet these centers and clinics face severe challenges due to a lack of resources and/or available providers.

The barriers that make it difficult for underserved populations to access care in general are the same ones that make it difficult to create a patient-centered environment. Language and other cultural differences among immigrants are major obstacles to both access to care and to developing positive relationships between patients and providers. Viewing medical professionals as "superior" and "authoritative" is very common in certain cultures and among those with low "health care literacy." This may impede patients' ability or willingness to take an active role in their own care. The alternative perspective, in which an immigrant patient does not trust or respect Western medicine, can also create a barrier to developing a strong provider-patient relationship.

Conversely, if a provider does not understand that certain individuals and cultures place faith in folk remedies and alternative healing, he/she may not see the need to educate the patient about the importance of filling prescriptions and taking medications appropriately – perhaps along with folk remedies that will not harm the patient. Also, if a clinician does not trust that a patient will follow his/her instructions, that provider will be less likely to teach the patient and his or her family how to take on more responsibility for their own care.

At the same time, however, some cultural differences may have a positive impact on the delivery of PCC. One CHC clinician interviewed for this study described the close family bonds exhibited in certain cultures predominant among his patient population, and how these bonds make it

[12] Gerteis, et al; *Crossing the Quality Chasm*; Gooloo S. Wunderlich and Peter Kohler, eds., *Improving the Quality of Long-term Care*, Institute of Medicine Committee on Improving Quality in Long-Term Care, National Academy Press, Washington, DC, 2001.

more realistic to place important responsibility for care in the hands of the patient and family. This interviewee also noted the healthier lifestyle habits (especially dietary) and greater willingness to take an active part in care among certain immigrant populations. Yet such knowledge remains unknown and/or untapped among most health care providers.

Indeed, two recent studies reveal that new physicians are unprepared to provide "culturally competent" medicine – a key component of PCC. Despite the fact that the proportion of residency programs offering opportunities to develop cultural competence increased from 36 percent to 51 percent between 2000 and 2003, about half of physician residents interviewed in their final year of training report they had little or no training in how to address patients from different cultures, how to recognize signs of patient mistrust or lack of understanding, or how to identify relevant religious beliefs or cultural customs that may affect care. While most residents understood the importance of cross-cultural care, they receive little formal training and have inadequate time and resources to practice such care.[13]

It is imperative to note that there is a difference between understanding the cultures of patients and making sweeping generalizations based on a patient's ethnicity. This distinction can be tricky, and difficult to teach students and clinicians. Particularly when serving minorities and immigrants, health care providers too often make assumptions about the attitudes, preferences, beliefs, and behaviors of an ethnic or racial group rather than focusing on the individual. A key to PCC is understanding a patient's cultural influences, while also engaging in one-on-one communication with patients and family members to elicit their unique preferences, beliefs, and concerns.

Consumer-Driven Health Care and Plans

Patient/consumer-centered care must be distinguished from "consumer-driven health care" or "consumer-driven health plans." There are some areas where the two concepts overlap, but there are also important differences, and even areas where the two conflict with each other.

Consumer-driven health care—a term that has been associated with a consumer advocacy approach in past years—has evolved into a concept that is supported by the current Administration and is gaining momentum among employers. It is based on the presumption that placing more decision-making and a greater financial stake in the hands of employees/consumers will result in more prudent purchasing of medical services, reduced overall spending on health care, and lower costs to employers.[14] It assumes that consumers are given and use appropriate information tools to support their decision-making.

This concept is incorporated into consumer-driven health plans. These plans typically refer to lower-cost, high-deductible health insurance products tied to health spending accounts (also called reimbursement accounts or health savings accounts) that are funded by employers and/or employees (or self-employed individuals). After the consumer exhausts the spending account on

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[13] Joel S. Weissman, Ph.D., Joseph R. Betancourt, M.D., M.P.H., Eric G. Campbell, Ph.D. et al.,"Resident Physicians' Preparedness to Provide Cross-Cultural Care," *Journal of the American Medical Association*, September 7, 2005, 294 (9): 1058–67; and Elyse R. Park, Ph.D., Joseph R. Betancourt, M.D., M.P.H., Minah K. Kim, Ph.D. et al., "Mixed Messages: Residents' Experiences Learning Cross-Cultural Care," *Academic Medicine,* September 2005, 80 (9): 874–80.

[14] Christianson, Jon, Stephen T. Parente and Ruth Taylor. "Defined Contribution Health Insurance Products: Development and Prospects," *Health Affairs* 21(1), January/February 2002.

health-related services, he or she must pay the full cost of care until spending exceeds the deductible, at which point the health plan covers a significant portion of the cost. That is, in the gap between the spending account and the high-deductible coverage, consumers are paying the full cost out of their pockets.[15] Consumer-driven health plans are supposed to offer consumers information on provider prices and quality to help them make decisions on which providers to use and which services to purchase.[16]

Both PCC and consumer-driven health care/plans emphasize a greater patient role in decision-making, and improved access to clinical information that can be understood and used by patients and their families. But the experts interviewed for this study stressed that, at this point in time, consumer-driven health care is not an element of PCC. PCC pioneer Susan Edgman-Levitan asserts that consumer-driven health care may push decisions onto individuals who are unable to make them effectively. She stressed that patient participation in decision-making is a personal issue:

> We all want to increase the learning curve, but for some people, that's not part of their make-up. For some personality types, forcing decisions on them makes them worse. [Patient-centered care means] meeting people where they are, and customizing care, and we hope that over time their confidence will increase and they will be better able and willing to make decisions.[17]

While the current practice of consumer-driven health plans may not necessarily be in line with PCC strategies, the two mechanisms can, theoretically, complement each other. One of the main intents of both is to encourage preventive care, which can have a direct impact on patients who have a propensity toward chronic illness. Given the emphasis on developing PCC strategies for individuals with chronic care needs, there is room for the patient-centered movement and the consumer-driven health care movement to grow together in a way that promotes improved outcomes. Furthermore, it may be possible for the movement toward consumer-driven health plans to accelerate provision of user-friendly, reliable information to consumers about clinical choices, a key element of PCC. And finally, developing patients' and physicians' communication and negotiating skills—emphasized among PCC advocates—would be extremely helpful for individuals with a greater role in negotiating their care under consumer-driven health plans. As Dr. Tony Suchman, an expert on the patient-clinician relationship, put it, "Data alone allows a conversation, but is not enough; we need skills to use the information and have the right conversations."[18] However, there is much work to be done to develop and promote the tools and skills needed to support patient participation in decision-making.

Methodology: Case Studies

In this study we used a combination of interviews with experts, a comprehensive literature review, and case study analysis of organizations that are practicing various elements of PCC. We

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[15] If the funds in the Spending Account are not used, they may be used for non-covered health services such as eye-care, or carried over to the following year.

[16] Sally Trude and Leslie Jackson Conwell. *Rhetoric vs. Reality: Employer Views on Consumer-Driven Health Care*, Center for the Study of Health System Change, Issue Brief No. 86, July 2004, http://hschange.org/CONTENT/692/#ib4.

[17] Personal communication, Spring 2005. Ms. Edgman-Levitan is the Executive Director, John D. Stoeckle Center for Primary Care Innovation, Massachusetts General Hospital.

[18] Interview with Tony Suchman, MD, FAAPP, Board Chair of the American Academy on Physician and Patient (www.physicianpatient.org), Spring 2005.

selected five varied organizations using criteria described in Appendix C. We conducted multi-day site visits to the following two health care systems, where we conducted structured interviews with numerous administrators, clinicians, department heads, and other staff who are active in PCC-related activities:

- Cambridge Health Alliance (CHA)—a safety net, academic public health care system and integrated delivery network that serves seven major communities in and around Cambridge, MA, composed largely of low-income and immigrant populations.
- Massachusetts General Hospital (MGH)—a large, academic medical center in Boston, MA that serves a diverse population at its main campus and five community-based health centers.

In addition, we conducted telephone interviews with key individuals at three additional organizations that met our criteria:

- G. A. Carmichael Family Health Center (GACFHC)—a community health center serving a predominantly low-income, minority population in rural Mississippi.
- Senior Health and Wellness Center—an outpatient clinic serving the senior population through a focused interdisciplinary team approach in Eugene, Oregon.
- The Health Choice Network—a network of community health centers in Southern Florida, New Mexico, and Utah dedicated to providing PCC to an underserved population that is primarily immigrant, low-income, and homeless.

For all sites selected, we developed an interview guide (presented in Appendix D), with open-ended questions intended to capture the key elements of PCC, specific strategies practiced, and barriers or challenges faced.[19] In addition, we presented each interviewee with a working definition of "patient-centered care for vulnerable populations," and requested feedback. We then modified or incorporated additional themes into the definition. Through this iterative process, we arrived at a list of core components of PCC, and also a set of institutional structures and processes that are necessary to support and nurture it.

We believe that presenting the core components and 'best practices' among a combination of institutional models provides a broad spectrum of experiences that may inform a wide range of health-related organizations.

[19] We adapted the interview guide for each interview, according to the position/role of the interviewee and the type of activity examined (e.g., clinical service versus education/training).

Findings

Incorporating Concepts into Daily Operations

The experts we interviewed stressed that translating the concepts of PCC into actual practice can be very challenging. It requires concerted efforts and desire to change the status quo for clinicians, patients, health plans, and potentially many aspects of the health care system – such as reimbursement, licensure, and information tools.

Such transformation involves, for example, teaching physicians to incorporate behavioral change as part of the treatment they recommend to their patients, rather than just endorsing pharmaceutical solutions. Physicians who were trained prior to the introduction of patient-centered philosophies into medical school curricula may need to shed some of their own learned behaviors, and be exposed to the idea that patients can play a role in decision-making and can understand clinical protocols if properly explained. And those who are being trained today in PCC techniques will need to have that training reinforced in their day-to-day practice. At its core, PCC may be more time consuming in the short term; before they will be willing to commit the time, physicians must recognize the value of delivering care in a way that puts the patient at the center of the health care system. As one interviewee put it, the central tenet of PCC is meeting patients' needs, rather than dispensing advice, particularly if there are no supports in place for the patient to follow that advice.

Clinicians need to learn about the cultures and individual values and preferences of the patients they serve, and use that knowledge to shape the way they educate and treat those patients. Given that nursing education has traditionally emphasized patient comfort and communication, nursing professionals are often better equipped to implement PCC practices while delivering care. A nurse with whom we spoke noted that nursing school curricula is focused on educating students how to treat patients by listening to them, something that is not always a priority at medical colleges.

At the same time, patients need to learn that they can take a more active role in their health care. They need access to understandable information, and they may need to learn how to "negotiate" with their care providers in order to become true partners. It was stressed that PCC does not mean forcing patients to make decisions or throwing information at them, but rather working with them to ensure that they understand the information they receive and how to use it, and educating them on their rights and responsibilities as patients. Some patients may for personal or cultural reasons prefer to play a more passive role, relying on the physician to make the decisions. This may be especially true when a difficult illness is already placing much stress on the patient and his/her family. PCC means meeting a patient "where he/she is at," with a hope that over time, patients can gain the confidence and skills to play a more active role in their care.

Some of the experts interviewed stressed that our current health care system is broken, because, among other reasons, it is built on patient helplessness. Building a new system that is based on

patient centeredness requires efforts from both the patient and provider sides, including: finding new ways to measure hospital and physician performance, educating providers to teach communication skills to each other and to patients, building practice guidelines related to PCC strategies, and tying payments (in part) to meeting those guidelines.

It also means widespread assessment and measurement of patient centeredness in medical practices, clinics, hospitals, and health plans, using standardized surveys and other tools. The expert interviewees emphasized the importance of finding exemplary practices of PCC and showcasing them, as in this Kellogg-funded study, in order to build a database of best practices in patient-centered care.

One very important area where the patient-centered philosophy is being incorporated into practice is the world of chronic care. With the focus of health care in today's aging society shifting from meeting acute care needs to meeting the needs of those with chronic conditions and diseases, there is a growing opportunity to involve patients and their families in care decisions and self-care management. The Chronic Care Model, developed through the Improving Chronic Illness Care (ICIC) program,20 is integral to developing patient-centered systems of care; this model is described in the Typology section in the Appendix as well as in the case studies of individual sites.

The following section describes what we have found to be the core components of PCC, along with examples of specific ways that leading health care organizations around the country are putting the patient-centered care philosophy into practice.

Core Components and Best Practices

The organizations we studied embraced PCC as a priority. Some of the organizations have always had a PCC philosophy as their mission, while others came to the idea of delivering PCC later in their existence. One thing that representatives of all sites agree on is that they have embarked on a journey, and still have a long way to go. Each day brings some successes, but also new challenges and opportunities. To some degree, PCC has been a by-product of various clinical quality improvement initiatives, including efforts to promote the chronic care model, cultural competence,21 or workforce diversity. In fact all of these concepts are considered integral components of our newly defined "patient-centered care for vulnerable populations." The efforts we witnessed are occurring simultaneously at four levels:

1. Organizational level -e.g., structures, processes, leadership, funding, information technology;
2. Patient level -e.g., navigation, translation, convenient access, education;
3. Provider level -e.g., training, interdisciplinary teams, diversity, cultural competence; and
4. Community level -e.g., outreach, recruitment, partnerships.

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[20] ICIC is a national program supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Group Health Cooperative's MacColl Institute for Healthcare Innovation.

[21] Dr. Renee Fox describes Cultural Competence as a "body of knowledge, skills, attitudes, and behavior in which physicians ought to be trained if they are to deliver 'sensitive,' 'empathetic,' 'humanistic' care that is 'respectful' of patients, involves effective 'patient-centered communication,' and responds to patients' 'psychosocial issues and needs.' " (Fox, Renee. "Cultural Competence and the Culture of Medicine" *New England Journal of Medicine,* 353:13, September 29, 2005, p. 1316.)

What follows is a description of the core components of PCC, along with examples of actual strategies or best practices used by the organizations studied (please note that some practices could fit into multiple categories. In addition, we were not able to include in this summary report every strategy practiced at the organizations studied; additional practices can be found in the individual case study reports):

A. *Welcoming environment:* provide a physical space and an initial personal interaction that is "welcoming" and familiar, not intimidating;

Practices:

- All signs written in multiple languages; staff name tags with a welcoming message in the languages that they speak; staff are encouraged to wear traditional dress reflecting diverse heritages.
- Artwork within facilities tailored to the cultures being served by the facility. For example, CHA formed a committee to identify and purchase artwork by local artists that reflected the community.
- Routine home visits by CHC staff to new refugee families to: welcome them; better understand the family's culture, environment, attitudes about health care, and needs; and jointly develop a family "plan" for their health.
- New patient orientation and facility tour (e.g. prior to the first physician visit). For example, the Senior Health and Wellness Center gives the patient an overview and tour of the facility to help him or her understand how care will be provided (through interdisciplinary teams) and what services are offered.

B. *Respect for patients' values and expressed needs:* obtain information about patient's care preferences and priorities; inform and involve patient and family/caregivers in decision-making; tailor care to the individual; promote a mutually-respectful, consistent patient-provider relationship;

Practices:

- Staff who are trained to accept patients as they are; for example, CHA runs its ED as a "judgment-free zone," where patients are not made to feel ashamed of their circumstances, which often include poverty, domestic violence, and substance abuse.
- Patient-provider joint setting of goals through a "Patient Action Plan" or "Shared Care Plan", with continual assessment of the patient's progress and confidence about reaching those goals, and intervention when either is falling short.
- Use of a "new patient packet"; for example, the Senior Health and Wellness Center asks all new patients to fill out a questionnaire with information on their cultural, educational, and social background, which helps providers better understand their background and how it can affect their care needs.

C. *Patient empowerment or "activation":* educate and encourage patient to expand role in decision-making, health-related behaviors, and self-management;
Practices:

- Highly visible, accessible, and well-staffed learning center with educational materials available in multiple languages; for example, a booklet defining common health/hospital terms in 18 languages and videos that can be piped into patient rooms.
- Health literacy workshops, geared to sixth- to eighth-grade level, conducted in the most frequently spoken languages.
- Group patient visits and seminars for community residents that focus on specific issues most relevant to vulnerable populations such as asthma, breast cancer, nutrition (e.g., refugees are taught about food, how to use food stamps, and how to prepare healthy meals), and financial literacy.
- One-week summer camp for children with asthma to help them learn how to control their condition, such as one conducted by GACFHC.
- Inviting patients to participate in the governance of the organization and provide the "voice of the patient" in determining what the patient population's needs are and how the provider can meet those needs.

D. *Socio-cultural competence:* understand and consider culture,[22] economic and educational status, health literacy level, family patterns/situation, and traditions (including alternative/folk remedies); communicate in language and at level patient understands;

Practices:

- Initial request for patient's preferred language, with interpreters arranged for scheduled visits and 24/7 access to interpreters for walk-ins and emergencies; a language card available in 19 languages explains how to access an interpreter.
- Interpreters go well beyond simple language translation to become "cultural translators" and "brokers" as well.
- Staff recruitment for CHCs from local neighborhoods, creating a diverse staff with sensitivity regarding patients' background, culture, and individual preferences. One community health center that treats primarily migrant workers hired an outreach worker who is a former farm worker, providing a sense of understanding and comfort to a vulnerable population.
- Medical records of all family members kept in one folder so that provider can view and understand familial situation and health patterns when treating a patient.

E. *Coordination and integration of care:* assess need for formal and informal services that may have an impact on health or treatment, provide team-based care, care management and/or referrals; advocate for the patient and family, and ensure smooth transitions between different providers and phases of care;

Practices:

- Electronic information system that provides a post-visit summary that provides patients with a variety of information that helps them in coordinating their care,

[22] "Culture" includes ethnic traditions as well as culture of homelessness, addiction, etc.

including a list of providers they saw, when they were seen, what diagnosis were made, what medications they are taking, and what referrals are being made to other providers;

- A computerized community resource center that helps social workers link patients to needed services within their local community.
- Care management by an interdisciplinary team that includes the patient, such as is practiced at the Senior Health and Wellness Center.
- Evaluation meetings for the patient and his/her provider team three months following the initial physician visit to go over goals, discuss progress, and consider next steps.

F. *Comfort and support:* emphasize physical comfort, privacy, emotional support, involvement of family and friends;

Practices:

- "Doula" program where women who are otherwise socially isolated (as many immigrant women are) can have access to a trained layperson who is assigned to the pregnant women, and provides physical, emotional, and informational support.
- Standing orders for pain and fever management in the ED that allow the triage nurse to provide a dosage of Motrin based on patient symptoms – significantly reducing the time to administer pain medication.
- Family members invited to stay with patients in the ED, with a bench right outside the patient's curtained area if they prefer to allow privacy but stay close by.
- Option to mothers-to-be (who are not experiencing complicated pregnancies) to give birth in a home-like setting, such as CHA's birthing center, where entire family can be in the room during the delivery (as is the custom in the cultures of many CHA patients).
- Elimination of official "visiting hours" in the intensive care unit, allowing and encouraging families to visit at any time.
- Assistance to low-income out-of-town families in finding affordable shelter if family member has extended stay at hospital.

G. *Access and navigation skills:* provide what patient can consider a "medical home," keep waiting times to a minimum, provide convenient service hours, promote access and patient flow; help patient attain skills to better navigate the health care system;
Practices:

- Wallet-sized "basic medical card" specifically designed to help refugee and immigrant populations understand how to navigate the healthcare system.
- Specialized, "one-stop shop" clinics for underserved populations at risk for specific diseases.
- Bilingual navigator that helps arrange appointments, follows up with "no shows," and travels with patients on free shuttles from neighborhood to main campus clinic site

- Nurse practitioner-run support group for Spanish-speaking women with breast cancer.
- Pilot program that informs low-income and minority cancer patients about potential enrollment in clinical trials.
- Pilot program whereby a Medicaid managed care plan reimburses outreach workers for "navigation" services (education and support in utilizing the health care system) for local, at-risk youth.
- Late night and Saturday clinic hours for those who work normal business hours.
- "Open-access" scheduling in CHCs that allows for appointments in 7-10 days in advance (instead of the more typical multiple-month wait) and sets aside patient slots for walk-ins, reducing need for long wait or advance planning.

H. *Community outreach:* make demonstrable, proactive efforts to understand and reach out to the local community.

Practices:

- Community needs assessments and town hall-type meetings to ascertain the community residents' health care priorities; programs are then developed to address those issues.
- "Volunteer Health Advisors" who are neighborhood residents trained to refer community members for services; provide basic one-on-one health education; give health presentations for groups on various topics; conduct basic tests (e.g., blood pressure, glucose, cholesterol) at health screening events; run support groups for patients with diabetes; organize health fairs; and provide peer supervision.
- Partnership with local police department whereby a social worker comes to the scene of every 911 call involving a child to ensure the child/family get needed support services.
- Partnership with public schools to operate a school-based health center, an after-school drop-in program for teens, and an off-school teen clinic (for family planning services not permitted on school site); staff are trained to identify at-risk youth and refer or provide needed services.
- Health fairs and screenings at Senior Citizen complexes, religious organizations, and other sites.
- Social workers on site to provide patients with information on community-based programs and activities which may meet their non-clinical needs.

Critical Support Structures and Processes

Our research indicates that certain institutional structures and processes are essential for supporting the PCC activities described in the previous section. Other organizations interested in developing PCC should make efforts to establish and/or build up these "ingredients" at their institutions.

I. *Feedback and measurement:* seek and respond to suggestions and complaints from patients and families; develop, collect and evaluate data on measures of patient-centered care, and feed back the results; incorporate accountability for addressing deficiencies and continually improving indicators;

Examples:

- System for tracking patient satisfaction rates by ethnic or racial group.
- Patient satisfaction survey translated into Spanish; plan to translate into other languages most common among patients.
- Over-sampling of minority patients in telephone patient satisfaction survey, so as to better compare minority and white patients' scores.
- Patient satisfaction surveys that assess patients' perceptions about receiving "fair and equal" treatment, and whether they felt they were treated with respect.
- Rapid response to address negative patient feedback, including focus groups with front-line support staff, training about cultural competency, and efforts to improve relationship between front-line and clinical staff.

J. *Patient/family/community involvement:* include patients and family members in the planning, design, and ongoing functioning of the organization; patient is considered member of his/her care team;

Examples:

- Community leader, patients, and families from various racial and ethnic minorities make up a Multicultural Community Advisory Committee that helps to better understand minorities' perspective, problems, and possible solutions.
- Public meetings in communities to get input on what health priorities are most important to address.
- Focus groups with community members to understand how their needs can be better met. For example, at CHA, focus groups were held with patients and family members to get their input into how to set up and run a new women's headache clinic. Input was sought on what "ideal" care would look like, including the configuration of the waiting area, how to ensure access to quick help when suffering acute pain, how to coordinate care—especially medications—inside and outside of CHA, whether and how to include alternative care such as acupuncture and yoga, whether the staff should be all women, and what the most convenient hours would be for the clinic. The information was incorporated into the new clinic. Similar focus groups were held with senior citizens in Eugene, Oregon when designing the Senior Health and Wellness Center. Facilitators used the "voice-of-the-customer" model, primarily used in private industry settings, to determine what the target population needed in an outpatient center, and how the providers should meet those needs.
- Panels whereby patients whose primary language is not English are asked what it is like to come to a hospital where people do not speak their language; how coming to that hospital is different from going to a hospital in their native land; whether they

feel they are treated differently because they do not speak English; and what the institution could be doing better to serve them.

K. *Workforce development:* employ, train, and support a workforce that reflects, appreciates, and celebrates the diversity of the communities and cultures that the organization serves; reward and recognize staff exhibiting patient-centeredness principles; provide administrative support to resolve conflicts among staff and improve communications; develop communication skills among all levels of staff; empower staff to be part of patient-centered teams;

Examples:

- "Re-engineering" of organizational culture (e.g., at GACFHC) to make sure all staff members – from front desk and medical records personnel to clinical staff – feel part of the "team."
- Use of interdisciplinary teams that follow and monitor patients.
- On-site Bachelor's and Master's level nursing programs that support foreign-born and minority nurses.
- A physician "pipeline" that targets for recruitment "underrepresented minority" college students, medical students, and residents. Outreach includes invitations for internships, clerkships, and registration dinners
- Inclusion of minorities in teams that interview applicants to medical schools and residency programs.
- New employee orientation that teaches what PCC is; how to partner, interact, and build relationships with patients; and how to resolve conflicts (e.g., dealing with difficult patients), along with a variety of "mini workshops" on PCC conducted on a regular basis during staff meetings (see CHA case study report).
- "Integrated Clerkship" that assigns medical students to particular patients whom they follow throughout the course of their treatment. Over time, the students not only get a tremendous clinical education in the various areas of specialty care that these patients require, they also get a deep understanding and appreciation for the patient and his or her preferences, values, and environment (e.g., support structure, living conditions).
- Periodic workshops for staff to rediscover the reasons they went into a practice that focuses on PCC, as a way of reenergizing a potentially burned out provider base.
- Formal training in culturally competent care including:
  - A full-day workshop for new and current staff focused on understanding and assessing the individual patient rather than using stereotypes;
  - Periodic sessions on topics such as caring for Muslim, Haitian, gay/lesbian patients; integration of disparities issues into mandatory orientation for new employees;
  - Training of physician faculty members to lead teaching sessions (for other staff physicians) in culturally competent care;

- Development and use of curriculum for training physician residents about PCC and cultural competency (includes interactive, case-based work, 4-part video series, e-learning module);
- Introduction of new "medicine and society" concentration for medical students and other efforts to expose medical students to PCC and community-based care; and
- Periodic workshops designed to train staff in dealing with unique physical and emotional needs of elderly patients.

L. *Leadership:* top management, Board, and department heads make a clear, explicit commitment to patient centeredness and act as role models;

Examples:

- Inclusion of "patient centeredness" as a priority in institution's strategic plan.
- Allocation of significant resources toward PCC-related departments and activities.
- Direct reporting by PCC-related departments heads to CEO/President/Chief Medical Officer.
- A charge from top leadership to assess community service operations and adopt/emulate best practices.

M. *Committees and departments devoted to PCC-related issues:* permanent and ad-hoc committees, councils, and departments dedicated to promote elements of PCC;

Examples:

- Multicultural Affairs Office that is dedicated to recruit, develop, and retain minority physicians.
- Patient Care Service Diversity Steering Committee that supports programs and events to promote diversity of nursing workforce, professional development of minority employees, student outreach, culturally competent care, and patient education materials tailored to a diverse population.
- Committee on Racial and Ethnic Disparities that is charged with identifying racial disparities in care, developing solutions, coordinating with other initiatives. Committee includes president of hospital. Subcommittees collect and analyze data, hold forums, publish articles, raise awareness, etc.
- Disparities Solution Center that is devoted to studying why disparities exist and how to address them, training medical professionals and building leadership, identifying and promoting best practices in reducing disparities in health care.
- Multicultural Community Advisory Committee that informs staff and leaders about minority patients' experiences with and perceptions of their care, and recommends ways to address issues identified.
- Patient/family advisory council to identify and develop processes and tools for educating the staff on PCC; develop educational materials for patients and families; improve operations and systems so that care can be more patient-centered; and

manage data (e.g., patient satisfaction scores) that drives the measurement and improvement of PCC. This type of advisory council is planned at CHA.

N. *Involvement in research, collaboratives and pilots:* seek out and join pilot, research projects and collaborative relationships with other organizations that attempt to "push the envelope" in developing new methods to operationalize patient-centered principles;

Examples:

- Involvement in Health Disparities Collaboratives and Self-Management Support project (e.g, at GACFHC, these have been invaluable in bringing PCC practices to rural Mississippi).
- Technical assistance and training from experts at the Institute for Healthcare Improvement, the MacColl Institute for Healthcare Innovation, the Bureau of Primary Care, and others organizations.
- Navigator programs and software development funded by corporate sponsors or corporate foundations.

O. *Technology and structural support:* use electronic systems/user-friendly software programs that promote patient/family education and compliance, and minimize medical errors; structure the physical environment to optimize patient flow and safety;

Examples:

- Longitudinal electronic medical record system that provides ready access to a patient's health care records, test results and patient education materials at all sites. Similarly, electronic medical records (EMRs) that store patients' vital care and prescription information help community health centers coordinate care for their patients. This also gives patients peace of mind, knowing that their doctor has all of their pertinent information at hand, meaning they do not have to remember their entire history for each visit.
- E-learning module added to cross-cultural competency curriculum for residents.
- "Ambulatory Practice of the Future" project that focuses on the use of technology and other tools to make outpatient care more patient-centered
- Use of video or web-camera-based interpretation that would allow patients and providers to see the interpreter without requiring him or her to be there in person. (MGH is experimenting with this technology.)
- New corporate funding for development and creation of a multilingual digital online and CD ROM resource guide for women with cancer.
- Development of collaborative decision-making tool for patients with diabetes and health providers; facilitates mutual goal-setting and assessment of progress toward goals.
- Online access to the Shared Care Plan, allowing patients to collect all of their data on providers and pharmaceuticals in one place, and providing physicians with all of their critical information about specialists being seen and prescriptions being used, thus facilitating coordination of care.

- An administrative function called the "Care Continuum," which allows administrators to bypass the DRG billing codes when caring for elderly patients. The Senior Health and Wellness Center developed this tool.
- Wireless computer technology, integrated with satellite and cellular telephones, to improve the capability of CHCs to deal with hurricanes and other natural disasters. Using the wireless communications, providers can treat current patients (including getting them necessary prescriptions) and also care for new patients, including creating an electronic medical record that will transfer to their provider once the emergency is over.

P. *Integration into institution:* tie patient-centered care to other priorities such as patient safety, and quality improvement, to incorporate patient-centered practices into daily operations and culture.

Examples:

- Creation of "promises" made to patients related to PCC. At CHA, these promises relate to four areas: Introduce, Inform, Initiate, and Interact. Each local unit is charged with developing specific promises in each area, along with concrete plans and goals that will ensure fulfillment of those promises.
- Incorporation of aspects of the Chronic Care Model – which emphasizes greater patient role in self care and goal-setting -- into all patient services. GACFMC has taken this step.

Barriers to Patient-Centered Care

In pursuing PCC, the organizations examined for this study have faced and continue to face barriers and difficult challenges. Described in greater detail in the individual case study reports, they are summarized below:

- *Difficulty retaining underrepresented minority physicians* – for example, despite significant efforts to recruit underrepresented minorities, MGH is having trouble retaining minority physicians – due in part to a lack of structured mentorship and minority peers, and lack of competitive salaries.
- *Lack of boundaries for outreach staff* – while community center workers and navigators are meant to establish relationships and help coordinate some non-medical services, patients often come to them for assistance with things far a field from health care. It can be difficult to keep boundaries.
- *Strict hiring requirements* - in trying to build a culturally diverse outreach and community center staff, it has been difficult for some centers to find local people with the required education and/or experience.
- *Lack of tools to gauge and reward performance* – there are insufficient tools, surveys, and incentives to allow for the systematic collection of data to measure performance, identify problem areas, and promote/reward improvement.

- *Financial constraints* – particularly among safety net institutions, there are limited resources for PCC training, computers for educational decision support for patients and providers, monitoring and evaluation of PCC, and other activities. For example, the costs of training and management of community health workers and doulas, and of health education and prevention activities, are generally not reimbursed by Medicaid, Medicare or other forms of insurance. With respect to PCC for elderly populations, there is an issue of organizations not being able to bill Medicare for multiple providers at one patient encounter, making the interdisciplinary team model financially infeasible for most organizations. Finally, some provider organizations established certain programs (such as EMRs and screening programs) through federal grants that are now coming to an end, leaving the organizations to struggle to pull together resources in order to keep these cost-reducing, quality-improving programs alive.
- *Traditional attitudes* – changing caregiver behavior and attitudes can be difficult, particularly among those who were taught during a different era, and/or whose jobs are secure regardless of their willingness to adapt. It can be equally difficult to change the mindset of patients who have not taken much control of their health.
- *Fatigue and competing priorities* – Keeping the momentum going (e.g., getting very busy nurses and physicians to take the time to attend PCC-related staff development sessions and adopt PCC strategies) is an ongoing challenge.

Lessons Learned

There are many lessons that emerge from the varied programs and organizations reviewed for this study. One key message that seems to apply to all of the sites is that 'the whole is more than the sum of its parts.' Many seemingly small changes in day-to-day operations—from a welcoming greeting at the reception desk, to being able to communicate in one's native language, to having a disease-related support group meet at a convenient time—add up to a significant change in the patient experience and his/her attitude toward the health care system. Other lessons drawn from the sites' experiences include the following:

- *Leadership matters a great deal.* Leaders must "walk the walk" and not just "talk the talk." If staff senses any amount of hypocrisy, or any gap between what leaders say and do, the whole effort can become derailed. In addition, ownership and buy-in to the PCC philosophy must be spread throughout the leadership, so that if one member leaves the organization, the commitment to providing PCC remains.
- *Flexibility is critical to delivering PCC.* This means that the organization must constantly be reviewing its procedures and adapting them as needed. At CHA, for example, when a problem arises, unit leaders will not wait a year for definitive evidence to document it. Rather, they will discuss and take steps to resolve the issue at the next staff meeting. Flexibility also means being creative around rules, such as relaxing education requirements when recruiting neighborhood residents to community center positions.
- *Establishing strong ties with the local community is instrumental.* Close relationships are needed not only with community leaders, but also with schools, the business community, faith-based organizations, the public health department, community-based organizations, the local police department, media, and others. These partnerships reap multiple benefits, and could be vital if terror-related or natural disasters should strike.
- *A health program cannot be forced upon people, but rather must be crafted with input and guidance from those whom it is intended to serve.* As an academic institution where many faculty and staff want to write "prescriptions" to solve problems, MGH has had to learn this lesson the hard way. For example, physicians who tried to convince members of one local community that cardiac disease was their number-one health issue quickly learned that substance abuse among children was a much more important priority for the community. Researchers who tried to develop programs to improve colon cancer screening rates among men quickly learned that such programs cannot be designed without first seeking input and guidance from the target population so that the barriers to screening can be identified and addressed as a part of the program.
- *While understanding of cultures is important, health care must be individualized.* As noted earlier, care of underserved groups is often based on generalizations about the attitudes, preferences, beliefs, and behaviors of an ethnic or racial group rather than an individual. While knowledge about the general tendencies of a group can be informative, clinicians must avoid

making sweeping generalizations and must engage in one-on-one communication with patients and family members to elicit their unique attitudes and preferences.

- *Providers must not ignore or discount folk remedies and alternative medicines.* Among some cultures, indigenous healers are sought for advice first, and their ideology is rich with teaching the faithful to stay healthy. In order to build on this ethos and establish trust with the patient, clinicians should not mandate that a patient cease alternative cures (unless they are deemed dangerous), but rather integrate modern medical treatments into the patient's regime.
- *It is essential to show physicians how PCC makes their lives easier.* To change traditional attitudes and promote buy-in among physicians, it is important to illustrate how patient navigators, PCC-friendly IT, and other elements of PCC actually lesson the burden on physicians and improve patient compliance.

Conclusion: Challenges for Policymakers

Even those health care organizations that are very active in providing PCC for vulnerable populations admit that they have "a long way to go." Yet they are forging ahead, testing new ways to "activate" patients into informed health care consumers who are able to express their preferences and needs, take a greater role in self-management, and make effective health care decisions. Additional experimentation, evaluation, sharing of knowledge, and dissemination of best practices is needed to promote the replication and expansion of these efforts. Further, additional research is needed to measure the impact of these practices on health outcomes over the long term, and the cost-effectiveness of the various strategies.

As noted earlier, efforts are occurring at the organization, patient, provider, and community levels. Each of these levels is critical, and each relates to and supports the others. But there is also a fifth area that needs to be strengthened: *the broader health care system and public policy level.* Over the long term, widespread adoption and practice of PCC can come only with universal access to coverage and needed services, without disparities related to socioeconomic or ethnic status. But even in the short term, there are practical and concrete policy actions that could do much to move us toward a patient-centered health care system. This involves re-setting priorities in terms of reimbursement by Medicaid, Medicare, and private insurance; placing greater emphasis on wellness and prevention as well as treating disease; and promoting public policies and government funding that supports PCC. Examples include the following:

- Public and private insurers should allow adequate reimbursement for group appointments, translation services, patient navigators, and home visits in complex cases.
- Performance-based payment – both within organizations and by third-party payers—should be expanded and should incorporate measures of PCC.
- Government and private businesses should fund development and implementation of PCC-friendly information technologies, such as:
  - widespread use of EMRs that provide clinicians with all relevant health information and histories for each patient;
  - development of voice-activated translation computer programs;
  - development of a website for providers that describes folk remedies and their health implications; and
  - development and dissemination of educational software for both patients (in multiple languages) and clinicians to improve their communication skills and their ability to understand and care for patients from diverse backgrounds, while also helping them to avoid cultural generalizations.
- Educational sessions for new immigrants about the U.S. health care system, including information about health insurance, how to access care, and how to navigate the system.

- Public education campaigns targeting underserved populations that teach consumers basic questions to ask when interacting with the health care system.

Through these kinds of efforts, individuals and communities can have a greater voice in the health care decisions and governance, and the health care system would better reflect patient and community values. Underserved populations in particular need the skills and opportunities to become activated, engaged consumers who in turn will take greater ownership of their own health.

Appendix A. Typology of Patient-Centered Care Activities

The types of programs and activities that can be said to deliver, promote, or assess patient-centered care or reflect patient-centered philosophies, are extremely broad and varied. Thus, we do not attempt to list all of the efforts that incorporate some dimension of patient centeredness. However, to help understand the range of activities, we have categorized these programs and activities, and present some of the leading examples below:

Clinical programs/Service delivery

The most obvious place to start examining patient-centered care initiatives and models is in actual service delivery. The way a practice is designed is very important to whether or not it is conducive to patient-centered care. As noted above, much is being done to promote patient-centered strategies in the area of chronic care. In terms of acute primary care delivery, one expert described such care as generally "unplanned," with patients coming in on an irregular basis, making it that much more difficult to develop strong patient-provider relationships. Despite that challenge, there are efforts to incorporate patient-centered care practices into the following service settings

- Community Health Centers (CHCs): CHCs are most often cited as models of patient-centered care for the underserved. CHC providers in many areas are being trained in culturally competent practice methods due to the diversity of their patient mix, and that group's need for social supports that go beyond the traditional health care system. This philosophy mirrors the IOM's call for clinician decisions "informed by an understanding of patients' needs and…their environment."23 Successful strategies also may involve developing a team practice approach, whereby a group of interdisciplinary providers work together to assist the patient with issues that are affecting their health; or developing community collaboratives that promote health education, outreach, cultural sensitivity, and other aspects of patient centeredness.
- Hospitals and health systems: With the apparent exception of emergency departments, some hospitals and health systems are making efforts to implement patient-centered care elements, according to several surveys (see below), which are providing information for consumers, hospital administrators, and policymakers.
- Health plans: Based on surveys such as the Consumer Assessment of Health Plans (CAHPS), and the work being conducted by the National Committee for Quality Assurance (NCQA), health plans are becoming increasingly aware of the impact patient satisfaction has on quality of care and consumer loyalty.

[23] *Crossing the Quality Chasm*, 2001.

Educational Curricula and Training

The IOM's Crossing the Quality Chasm discusses the changes affecting the health care delivery system, and the need for the health care workforce to be adequately prepared by developing new skills and assuming new roles. Among the five main skill areas delineated is patient-centered care.24 The literature indicates that there is much variation across the health professions in use of patient-centered techniques, and there are no standards regarding effective approaches to teaching such skills. The IOM report calls for identifying and replicating successful methods to train health care workers in this area, in both academic settings and continuing education programs.

- Medical school curricula: Despite the lack of a uniform approach, some medical schools have incorporated into their curricula programs that promote patient-centered skills. They include: teaching competencies basic to the medical interview; emphasizing communication skills; addressing ethical and social issues and cultural competency; reinforcing humanism and "professionalism"; and clinical training in community-based settings serving vulnerable populations.25

- Nursing school curricula: As noted above, nursing school training traditionally has been more focused on patients, given the role they play in service provision:

  > "Nurses have long been taught to focus on the person, the family…they have become highly sensitive to individuals' needs and know how to respond effectively arguably better than any other kind of health professional today."26

  Examining nurse training curricula can be one way of further understanding the elements of patient-centered care educational techniques.

- Pilot "Information Rx" Program: Recognizing that information can be just as powerful as pharmaceuticals for some chronic care patients, a joint initiative of the American Medical Association Foundation, the Fisher Center for Alzheimers Research Foundation, and the National Library of Medicine will train physicians in Florida to refer patients to the MedlinePlus online database and Alzheimer's information websites. According to the initiative's directors, "physicians have always known that an informed patient who takes an active role is a 'better' patient."27 While this pilot is being targeted toward Alzheimers patients, the Medline website offers symptom, diagnostic, treatment, and research information on over 700 health topics, as well as on over-the-counter and prescription drugs. The Florida site follows successful fielding of the pilot in Iowa, Georgia, and Virginia. 54 percent of internists who have already participated in the project reported that MedlinePlus empowers patients; 43 percent said it explains difficult concepts and procedures; and 42 percent say it improves patient-physician communication.

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[24] The other four skill areas cited by the IOM report are: evidence-based practice, informatics, interdisciplinary teams, and quality improvement.

[25] *Educating Health Professionals to be Patient Centered: Current Reality, Barriers, and Related Actions,* Institute of Medicine, http://www.iom.edu/Object.File/Master/10/460/0.pdf.

[26] Milio, N. "A New Leadership Role for Nursing in a Globalized World," *Topics in Advanced Practice Nursing EJournal,* 2002.

[27] NIH news release "Florida Physicians to Write Prescriptions for Patient Information,", February 10, 2005, www.nlm.nih.gov.

Surveys/Measurement Tools

Tools to evaluate the success of a service delivery program or an educational training module in achieving its patient-centered care goals are critical. This section provides a road map of activity in patient satisfaction surveys and other measurement tools. While not all of these tools are being used on a widespread basis, they all offer insight into how we can begin to measure whether a system is incorporating a patient-centeredness philosophy into its care. As part of more general efforts to improve quality of health care and to advance consumer-driven health care (described above), a number of efforts are underway to measure quality and to provide web-based information to consumers about treatment choices, provider performance, and other health-related issues.

- Picker Institute Survey: A 15-year research project, in collaboration with researchers at Harvard Medical School, resulted in the development of the Picker family of patient-centered care survey instruments. In 1987, the Picker/Commonwealth Center for Patient-Centered Care was established to support further research and development of tools that measured patient experience in various health care settings including hospitals, community health centers (see PEERS, below), physician practices, and others. In 1994, the Picker Institute was founded, a not-for-profit entity dedicated to developing a patient-centered research approach to performance measurement. Extensive interviews with more than 8,000 patients, family members, physicians, and hospital staff were conducted, focusing on four basic questions:

    1. What do patients want?
    2. What do patients value?
    3. What helps or hinders their ability to manage their health problems?
    4. What aspects of care are most important to them and their families?

    The Picker surveys, now under the ownership of the National Research Corporation28 in the U.S., are considered the standards in measurement of patient centeredness, and are used by individual institutions interested in assessing their level of patient-centered care as part of quality improvement efforts. Also, portions of the Picker surveys have been incorporated into tools such as PEP-C, CAHPS, and others. Along with Picker Institute affiliates in Europe, these organizations support research, disseminate newsletters, organize symposia, and conduct other activities to promote patient-centered care.

- Patient Experience Evaluation Report System (PEERS): With funding from the Picker-Commonwealth center, the National Association of Community Health Centers (NACHC) developed the PEERS instrument in 1993. It was used to survey a nationally and regionally representative sample of health centers to assess the delivery of health care from the perspective of health center patients.29 The survey instrument was developed, tested, and refined, and the process identified six domains of care deemed important to CHC patients. Although not used on a nation-wide basis, the PEERS package (including a survey instrument, patient sampling instructions, and guidelines for interviewing, report and analysis) is available to individual CHCs. The most recent PEERS survey was conducted in 2001 using 76 health centers and involving 3,877 interviews.

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[28] "NRC+Picker" see http://www.nationalresearch.com/NRCPG.aspx.

[29] PEERS is a patient satisfaction survey tool that was originally designed to compare JACHO accredited health centers with non-accredited centers.

- PEP-C: The Patient Evaluation of Performance in California (PEP-C) survey asked 35,000 patients served at 181 hospitals, questions such as "were you treated with respect, dignity, and as a partner in the health care process? Did hospital staff explain treatment options and test results clearly and completely? And did doctors and nurses explain what to expect after you left the hospital?"30
- Patient Assessment of Chronic Illness Care (PACIC): Developed by the Improving Chronic Illness Care program (ICIC- described below), the PACIC is a patient self-reporting instrument for measuring the extent to which chronically ill patients receive care in a way that is aligned with the Chronic Care Model -- i.e., patient-centered, proactive, planned, and with collaborative goal setting. The PACIC is currently being tested, with an initial field report on findings available sometime in 2005.
- Consumer Assessment of Health Providers and Performance Systems (CAHPS): The CAHPS survey tool kit is the current standard for obtaining consumers' assessment of their health plans, hospitals, group practices, individual physicians, nursing homes, and dialysis centers. Used widely throughout the U.S., CAHPS provides information – from patients' perspectives—to help consumers and purchasers assess and choose among health plans. While health plan assessment does not directly measure provider performance, there is a relationship between consumers' assessments of their health plan's quality, and the type of care received from the providers with which the plan contracts. Overseen by the Agency for Healthcare Research and Quality (AHRQ), CAHPS is being used by purchasers, health plans, accrediting organizations and state health care agencies including Medicaid. Variations on the CAHPS survey that ascertain patients' experiences with hospitals and providers are being developed and field tested, and will ultimately play a more direct role in assessing the provision of patient-centered care.
- National Coalition for Quality Assessment (NCQA): The NCQA's health plan surveys and consumer report cards involve measures of patients' satisfaction and perspective of care.

Identification and Development of Standards and Best Practices

Some organizations and collaboratives are developing strategies to tie in the patient, provider, administrative staff, and communities in the testing, development, and implementation of standards for patient-centered care. Below are examples of such initiatives.

- Disparities Solution Center (DSC) – Massachusetts General Hospital and Partners Healthcare System created the DSC in July 2005, to reduce and eliminate disparities in health care among racial and ethnic minorities in Massachusetts. With $3 million committed over five years, DSC will study why disparities exist and how best to address the gaps in care, establish an institute to train medical professionals on healthcare inequities and build leadership, and partner with other groups to identify and promote best practices in this area. Dr. Joseph Betancourt, the director of the center and a pioneer in the area of cultural competency, expects that these best practices will be based on culturally competent, patient-centered care principles.

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[30] *What Patients Think of California Hospitals*, California Institute for Health Systems Performance and the California Health Care Foundation, 2003.

- The John D. Stoeckle Center for Primary Care Innovation: This Center at Massachusetts General Hospital is dedicated to improving the practice of primary care from the patients', families', and clinicians' perspectives. Directed by PCC pioneer Susan Edgman-Levitan, the Center conducts research and education to foster collaboration between providers, patients, and their families in clinical decision-making, and strives to improve the experience of care for patients and clinicians. For example, the Center has surveyed MGH employees about their experiences as patients, and has offered monthly seminars designed to explore emerging innovations within primary care and to educate providers about new methods and techniques to improve the quality of the patient and clinician experience through improved communication and decision-making. Topics included how to access credible medical information to share with patients, strategies for managing difficult patient-clinician interactions, and the medical legal implications of sharing important medical decisions with patients.
- Patient-Centered Communication Initiative: The American Medical Association Institute for Ethics is conducting a project to identify and recognize hospitals leading the development of innovative approaches for patient-centered communication with vulnerable populations. In this study, vulnerable populations are considered those at risk of poor health outcomes because of ineffective communication during encounters with the health care system—particularly those who speak limited or no English, those from minority cultural groups who may not share "mainstream" health beliefs and values, and those with low health literacy. The eight hospitals that will be studied and showcased are being chosen through an open nomination process followed by deliberations by an expert advisory panel. The initiative is being funded by the Commonwealth Fund, and is in collaboration with the Health Research and Educational Trust (HRET).
- JCAHO's Hospitals, Language, and Culture Project: The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) began a project in January 2004 to gather baseline data on a sample of hospitals to assess their capacity to address language and culture issues that affect the quality and safety of patient care. Hospitals, Language, and Culture: A Snapshot of the Nation is a 30-month project funded by The California Endowment.[31]
- Improving Chronic Illness Care (ICIC): The ICIC program developed the Chronic Care Model, which uses evidence-based change concepts to promote quality improvement strategies that:

  > …foster productive interactions between informed patients who take an active part in their care and providers with resources and expertise. The model can be applied to a variety of chronic illnesses, health care settings and target populations. The bottom line is healthier patients, more satisfied providers, and cost savings. [32]

  ICIC plays a number of roles in promoting patient-centered care, one of which is the development of tools and standards by which providers are trained to deliver care. These include collaborative trainings (organized through the Health Disparities Collaborative, described below), and the Assessment of Chronic Illness Care (ACIC) survey. The ACIC

[31] For more information see http://www.jcaho.org/about+us/hlc/index.htm.
[32] Improving Chronic Illness Care (ICIC), http://www.improvingchroniccare.org/change/gettingstarted/index.html.

instrument was modeled after one developed by the Indian Health Service for evaluating diabetes care, and is primarily used by medical teams to identify areas for improvement in care for chronic illness before beginning quality improvement work, and to evaluate the level and nature of improvements made in response to quality improvement interventions.

The ACIC has been tailored to evaluate the six components of the Chronic Care Model: community resources, health organization, self-management support, delivery system design, decision support and clinical information systems. And as with the Chronic Care Model, the ACIC addresses the basic elements for improving chronic illness care at the community, organization, practice and patient level. Related themes incorporated into these elements include patient safety, cultural competency, care coordination, community policies, and case management.

- Health Disparities Collaborative: The Health Disparities Collaborative was created to address disparities in health care and outcomes for minorities, the low-income, and in some cases women, in the areas of heart disease, cancer, stroke, diabetes, and depression. The organization, which cites as its major partners the Bureau of Primary Health Care, the National Association of Community Health Centers, the Institute for Healthcare Improvement, and the Improving Chronic Illness Care program, is dedicated to transforming the delivery of health care from the provider, patient, and community perspectives.
- The collaborative is based on a belief that it will be necessary for providers to reform the way they deliver care; for patients to understand and participate in managing their own care; and for communities to play the role of strengthening the patient-provider relationship. It is working toward this goal by organizing a series of working groups, each involving approximately 100 health centers, which come together for 13 months. The ICIC's Chronic Care Model is one of the key learning tools, with specific training modules tailored to each of the specific disease states.

Government Programs

A few federal agencies administer grant programs that support various aspects of patient-centered care.

- Agency for Healthcare Research and Quality (AHRQ): In addition to the CAHPs program described above, AHRQ oversees several planning grant programs that have relevance to patient-centered care initiatives. For example, AHRQ has committed $7 million in FY 2004 for up to 14 Transforming Healthcare Quality through Information Technology (THQIT) grants. This program promotes the development, adoption, and diffusion of health information technology (HIT) at organizational and community-wide levels. The objectives are to support the proliferation of HIT, and to assess the extent to which HIT contributes to measurable and sustainable improvements in patient safety, cost and overall quality of care.

  Several interviewees noted the strong connection between patient-centered care and advancements in information technology, pointing out that HIT and data can help providers better understand and meet their patients' needs. One noted that while the federal government does not have any specific legislative, regulatory, or funding strategies directed specifically at patient-centered care, providers and communities should "jump on the

information technology bandwagon," and take advantage of new opportunities coming out of the administration's push for greater coordination of health information.

- Bureau of Primary Health Care (BPHC): As mentioned above, the Bureau of Primary Health Care has been an active participant in the Health Disparities Collaborative. In fact, the collaborative's work grew out of activities funded by the BPHC, including Primary Care Association/Clinical Network teams in each of five regional clusters, and National Clinical Networks focused on oral health, migrant farm worker health care, and homeless health care (beginning in 1998). These organizations worked with the Institute for Healthcare Improvement (IHI) to develop the infrastructure to support the Health Disparities Collaboratives. During the fall of 1998, BPHC selected eighty-eight health centers to participate in the BPHC Health Disparities Collaborative, which focused on diabetes and was called Diabetes I. Diabetes II began in January 2000 with 115 health centers. Forty health centers participated in the Asthma and Depression projects. As the Health Disparities Collaborative took shape in 2001, it worked closely with the BPHC to develop its current design.

Foundation-Funded Programs

A number of private foundations are developing grant and/or educational programs tailored toward promoting patient-centered care: 33

- Patient-Centered Primary Care Initiative: The Commonwealth Fund began this initiative in 2005 to promote the redesign of physician practices and health care systems in ways to better meet patients' needs. The Initiative will support: new research on the measurement of PCC at the practice levels and the relationship between patient-centeredness and improved clinical outcomes; policy analysis and demonstration projects intended to ensure that patients' experiences are featured in quality improvement and efficiency initiatives; efforts to establish the concept of PCC practices with the public, accreditors, employers, specialty boards and societies, and Medicare and Medicaid; and other activities that promote PCC.
- Patient Link: The Medtronic Foundation created Patient Link to connect patients with chronic care needs to patient associations that specialize in educating, supporting, and advocating on these patients' behalves. Patient Link's goals also include providing information on how to prevent disease and maintain health, and on how to respect patient diversity and needs.
- Pursuing Perfection Institute: The Robert Wood Johnson Foundation began a grant-making initiative in 2001 to assist hospitals and physician organizations implement care improvement plans. Central among these plans is a focus on patient-centered care. One grantee, Cincinnati Children's Hospital, is working with parents to design care systems for children with Cystic Fibrosis. Another grantee, St. Joseph's Hospital (in Washington State), is creating a system that incorporates "shared care plans" that are drafted by patients in conjunction with their providers, and include self-management and treatment goals.
- Putting Patients First: An initiative of the National Health Council, Putting Patients First is engaged in developing communication tools for use by patients, consumers, health agencies,

[33] Findings from the Resource Center: Improving Quality Through a Patient-Centered Care Approach, Grantmakers in Health, 2004 GIH Annual Meeting on Health Philanthropy.

and providers. The tools include various messages and materials which use "knowledge in behavior change" communications.

- Allies for Quality Program: This $2 million California HealthCare Foundation program provides support to consumer and patients' organizations working toward improving consumer awareness of quality issues, promoting evidence-based treatment guidelines, improving patient-provider relationship systems, and developing and implementing policies that improve health care quality.

Appendix B. Experts Interviewed

In addition to the many individuals interviewed for our case studies (who are listed on the individual site reports), our research team consulted with numerous experts who have been active in studying, developing, promoting, or implementing patient-centered care and related concepts. We are grateful to these individuals, listed below, who shared their time and insights.

Name	Affiliations
Dennis Andrulis, PhD, MPH	Drexel University; Expert Panel for AMA Pt.-Centered Communication Initiative; Nat'l Association of Public Hospitals project
Ernie Balasco, MSW	Executive Director, Wood River Health Services
Mary Catherine Beach, MD, MPH	Assistant Professor, Johns Hopkins University School of Medicine; Researcher on Cultural Sensitivity in Health Professions Training
Anne Beal, MD, MPH	Senior Program Officer, Quality of Care for Underserved Populations, The Commonwealth Fund
Caryn Bernstein	Consultant, Clinical Affairs, National Association of Community Health Centers
Joseph Betancourt, MD, MPH	Senior Scientist, Institute for Health Policy Director of Multicultural Education, Massachusetts General Hospital Assistant Professor of Medicine, Harvard Medical School
Ty Borders, PhD	Associate Professor, University of North Texas Health Science Center; Author article on Participatory Decision-Making
Susan Edgeman-Levitan, PA	Executive Director, John D. Stoeckle Center for Primary Care Innovation, Massachusetts General Hospital; Pioneer of patient-centered care and past leader of Picker-Commonwealth project; Author of "Through the Patient's Eyes"
Alexander Green, MD, MPH	Senior Scientist, Institute for Health Policy Massachusetts General Hospital – Harvard Medical School
Paul Haidet, MD	Assistant Professor, Medicine Health Services Research, Baylor College of Medicine

Kathy McNamara	Assistant Director for Clinical Affairs, National Association of Community Health Centers
Marsha Nelson, MBA, RN	President and CEO, California Institute for Health Systems Performance
Steve Schoenbaum, MD	Executive Vice President for Programs, The Commonwealth Fund; Board Member of the Picker Institute
Dale Shaller	President, Shaller Consulting Expert in CAHPs measurement tools
David Stevens, MD	Center for Quality Improvement and Safety, Agency for Healthcare Research and Quality
Tony Suchman, MD, FAAPP	Chairman, American Academy on Physician and Patient; Associate Professor of Medicine and Psychiatry, University of Rochester
Ellen Wu, MPH	Executive Director, California Pan-Ethnic Health Network
Matthew Wynia, MD	Director, The Institute for Ethics, American Medical Association; Leading the AMA Pt.-Centered Communication Initiative

Appendix C. Case Study Selection Criteria

Because of the breadth of programs and activities that could be described as "patient-centered," we developed and used the following criteria to guide the case study site selection process:

1. Expert recommendations – in telephone interviews with researchers and clinicians who have worked on issues closely related to patient-centered health care (see Appendix A), we obtained recommendations and "nominations" for clinical and educational programs that exhibit or teach innovative and successful elements of patient-centered care.
2. A focus on vulnerable populations- In order to challenge the notion of patient-centered care as a paradigm only for those with stable health care coverage, we sought programs and models that appeared to be trying to bring patient-centered care philosophies and tenets to populations for whom simply accessing the health care system, let alone developing a strong patient-provider relationship, is a challenge. To highlight the ways in which culturally competent care is being delivered, and to emphasize the role of such care in a patient-centered system, we focused on programs and delivery systems whose target populations include immigrants, the uninsured, low-income populations, minorities, and the elderly.
3. Evidence of innovation- We gave preference to programs that are using new and innovative strategies that may be replicable to other institutions and settings. Thus, we assessed whether programs included such innovations as new methods for training health professionals in cultural competence, or new technology.
4. Variation in program type- Finally, using all of the above considerations, we made selections for case study sites that so as to represent different components of the health care system, diversity in mission, funding mechanisms, and target populations.
5. Cooperation of program leaders and staff- We ascertained whether the programs considered for analysis were able and willing to provide the time and effort needed for a successful case study. This required a commitment from the program/organization leader and key staff that they would be available for interviews and would share information and documentation regarding program development (with a particular focus on the dimensions of patient-centered care), barriers, assessment, outcomes, etc.

Appendix D. Case Study Interview Guide

Respondent: Administrator/Planner/Clinician/Patient/Other: _____

PCC Practices: Service-related

1. How would you define PCC for underserved (low-income, uninsured, immigrant) populations?
2. How are those components manifested in your organization? For example, [probe for each component]… How does staff…
   a. … elicit each patient's health needs, beliefs, goals/ expectations of treatment, and level of health literacy? How is this information built into the patient's care plan?
   b. … build trust?
   c. …convey information that is understandable and empowering?
   d. …learn about and coordinate with other traditional or alternative/complementary treatments?
   e. …determine what language assistance may be required and make the assistance routinely available?
3. Do you use any particular technologies to promote patient centeredness – e.g., software programs, information systems, other technical advances? Describe. How did you learn about them? How did you obtain them—develop internally, purchase them (at what price), etc? Are these part of standard practice in the field, or are they 'ahead of the curve'?
4. Which of the above practices have been most important/effective?

PCC Staff Training/Workforce Development

1. Where did the organizations learn of the specific PCC-related techniques? Developed internally, externally—specific protocols, consultants/TA, conferences?
2. Does your organization use community health workers, or other types of staff outside the traditional medical model, who may be more in tune with patient preferences?
3. Does new staff receive any training or instruction in PCC behaviors and cultural competence? Are there any formal or informal methods used to help staff understand the socio-cultural factors that affect patients' health beliefs and ability to interact with the health care system? Describe. Are these one-time, or repeated for all staff on a regular basis? Are they part of a broader clinical/service training, or do they have a specific, separate focus on PCC/cultural competence?
4. What training techniques have been most helpful and effective? (eg, formal curricula, teaching by example)

5. [IF NONE] Would training tools or assistance be helpful if available? What kind, specifically? Would your organization be willing or able to pay for such tools/assistance?

Educational Program (Development of Training Curricula, Residency Program)

1. Who are the training participants: medical school students, residents, practicing physicians, nurses, allied health, receptionist/administrative staff, other?
2. Describe the relevant training components/methods. What PCC components are emphasized? How?
3. Can the methods be replicated or adapted to other sites? To other provider groups?
4. What aspects are the most effective? How is this measured/assessed?

PCC Measurement & Outcomes (adjust wording if educational program)

1. Do you have any way to assess the degree to which you are practicing PCC – ie, the degree to which the organization obtains information about a patient's culture, socio-economic status, understanding of medical issues, attitude toward the medical establishment, social supports; the degree staff explain and educate about treatment options and self care; involve the patient and family in decisions; learn about and coordinate with alternative medicines the patient uses, etc? Describe.
2. Specifically, does the organization use standardized qualitative and quantitative data collection methods and uniform coding systems to gather valid and reliable information for understanding the demographics and needs of the patients they serve?
3. Do you have any way to assess the impact or outcomes of PCC practices? Eg, patient satisfaction, patient compliance, actual health outcomes? Describe – instruments, what specific questions/issues, how often, who administers it, cost and how paid (eg, operations budget, grant, reimbursed by insurers)?
4. Is this assessment part of any external review or accreditation process? Describe.
5. What have been the results?
6. Re: either process or outcome assessments: What exactly is done with the results? Who reviews them? What happens if certain areas are not scoring well? Are staff rewarded or held accountable based on the results? What is staff attitude toward this process? Have any changes been made as a result of measurement? Probe for specific examples. What was the process for developing and implementing those changes?
7. [IF NO REGULAR MEASUREMENT]: Why is there no regular measurement? No interest, no funding, no time, no effective way to measure, etc? Do you think measurement would be helpful? What would be most helpful to measure (practices, outcomes)? What would it take to begin measurement (funding, TA, support from leadership/staff, etc)?

Organizational Culture & Planning

1. What is the stated mission of the organization?
2. When planning this service/program, was "patient-centeredness" explicitly discussed? Describe.

3. Does the organization routinely examine its commitment, capacity and/or efforts to meet the communication and other needs of their patients?

Community Outreach

1. Did any patients or community members participate in the design of the program – e.g., invited to offer their perspective on what would help this program best meet the needs of individuals? Describe.
2. Does the organization regularly make demonstrable, proactive efforts to understand and reach out to the communities they serve? (eg, establishing relationships with community groups and developing opportunities for community members to participate in shaping organizational policies)? How?

Barriers & Challenges

1. Were/are there any barriers or challenges to adopting PCC? Describe. E.g., attitudes of clinicians, administrators, lack of reimbursement, time. How have they been/could they be addressed?
2. Are there barriers/challenges to providing PCC specifically related to serving vulnerable populations? Describe. How have they been/could they be addressed?

Lessons & Recommendations

1. Are there any lessons you or your organization have learned in trying to provide PCC? Describe.
2. Are there some PCC practices or models developed or used here that you would recommend be adopted by other organizations? Describe. What kinds of organizations would be appropriate (clinics, hospitals, physician practices, etc.)?
3. What would be the best ways to get that message and those strategies to others?
4. Is a movement toward PCC in –synch with, or counter to other trends in the health care system – eg, coverage, reimbursement, political trends?
5. Are there any policy changes that might contribute toward incorporating these strategies into broader delivery system reform? How could community health leaders, educators, policymakers, grant makers/foundations play a role? E.g., public education, funding, insurance/reimbursement requirements?

Component List Feedback

Finally, we'd like to share with you a list of key components of PCC for the underserved that we developed based on the literature and speaking with many experts in the field. (It is based initially on the Picker-Commonwealth definition but altered to emphasize vulnerable populations): [present card with components, which will be updated based on feedback].

Do you think we are missing any important aspects of PCC? Could any of these points by refined or improved? Are there certain items that you've found to be most important?