

By Christine Bechtel and Debra L. Ness

DOI: 10.1377/hlthaff.2010.0305  
HEALTH AFFAIRS 29,  
NO. 5 (2010): 914–920  
©2010 Project HOPE—  
The People-to-People Health  
Foundation, Inc.

# If You Build It, Will They Come? Designing Truly Patient-Centered Health Care

**Christine Bechtel** (cbechtel@nationalpartnership.org) is vice president of the National Partnership for Women and Families in Washington, D.C.

**Debra L. Ness** is president of the National Partnership for Women and Families.

**ABSTRACT** As the United States debates how to reorganize its health care system, policy makers must ask what patients really want and need from their primary care providers. There is often a disconnect between what patients say they want and what other providers or payers think patients want. Our research at the National Partnership for Women and Families suggests that a truly patient-centered health care system must be designed to incorporate features that matter to patients—including “whole person” care, comprehensive communication and coordination, patient support and empowerment, and ready access. Without these features, and without consumer input into the design, ongoing practice, and evaluation of new models, patients may reject new approaches such as medical homes and accountable care organizations.

**R**edesigning the U.S. health care system to improve quality and use resources more effectively has taken on increasing urgency. Costs continue to rise, and patients struggle in a nonsystem that they say often fails to address their most pressing needs. As a result, there is widespread agreement that health care should be anchored in a stronger primary care system and that primary care itself should be more patient centered. Models such as the patient-centered medical home and accountable care organizations are being developed and tested at the local, state, and national levels as promising approaches to use in advancing and achieving these goals.

Historically, consumers have not been engaged in the design of new health care delivery and payment models. When they have been engaged, it has been mostly after physicians, employers, or health plans have constructed a new model. Then consumer engagement has typically been conducted under the guise of “education” and designed primarily to convince or compel consumers to participate in it. This is an oft-repeated pattern in health care, reflecting the

pervasive notion that if we simply build a system the “right way,” patients will embrace it.

The problem with this approach is that non-consumer stakeholders often don't know what matters to patients in terms of what has the most impact on their ability to get and stay well. For example, in research regarding medical decision making, Karen Sepucha and colleagues found significant differences between physicians' understanding of patients' values and what patients said is actually important to them.<sup>1</sup> In explaining treatment options, providers tended to focus more on the benefits of a particular course of treatment, while patients most wanted to know about potential harms and effects on their daily activities. With information about all of their options, patients may make different treatment choices than physicians surmise.<sup>2</sup>

Patients' desire for information on all of their options should not be interpreted to suggest that providers should simply give patients whatever treatment they want. There can be no doubt that patients and families rely on clinicians for guidance. At the same time, they also want a full understanding of options, benefits, and risks so that they can decide with clinicians what is

best for them. If even the providers who are arguably closest to the patients they treat do not fully understand what those patients want, neither can policy makers, health plans, or others assume that building a new system without consumer input will work.

When patients cite system characteristics that matter to them—such as shared decision making, partnership, and communication—these qualities are sometimes classified by other stakeholders as valuable but less important than system attributes such as high clinical quality. We argue that these characteristics are not at all mutually exclusive. Yet efforts to measure quality have focused predominantly on the clinical aspects of care, rather than on systematically measuring and improving patients' experiences with care. This lapse seems indicative of a broader failure to recognize that these experiential attributes can translate directly into improved clinical outcomes for patients, often at a lower cost.<sup>3-6</sup>

Given these dynamics, models designed without consumer input run the risk that patients not only will not embrace them, but also will perceive them as contrary to their best interests. There is perhaps no better example of this than consumer backlash to managed care, where the “if you build it, they will come” assumption backfired in a profound way because of perceptions regarding limiting access to care. There are a number of attributes of new models of primary care such as medical homes and accountable care organizations that could conjure up similar consumer concerns, thus generating the potential for the kind of consumer backlash that would threaten the long-term scalability and sustainability of these approaches.

Most important, we believe based on our work that putting patients at the center of redesign is more likely to yield better outcomes, as well as a system that consumers will embrace, than could be achieved if patients are left on the edges.

## **Our Work**

To inform our policy work, in 2008 and 2009 the National Partnership for Women and Families launched a variety of initiatives. These were designed to gather information about what consumers see as the key attributes of patient-centered care and to gauge their views on some of today's most prominent models of delivery system reform.

First, we convened a series of meetings with consumer advocates at the local, state, and national levels who work daily with patients and their families, many in underserved areas. Most of these advocates had worked with the National Partnership previously on various health care

quality initiatives and thus had at least a basic understanding of delivery systems. We explored with these advocates the core elements of patient-centered care and collaboratively drafted a set of consensus-based consumer principles that describe how key attributes of patient-centered care should be incorporated into the medical home model from the consumer perspective.<sup>7</sup>

We subsequently commissioned focus groups with patients and caregivers to explore their reactions to proposed new models of delivery and payment reform. Focus groups were conducted by Lake Research Partners 10–14 August 2009. Participants were adults over age forty who either had at least one chronic condition or cared for someone with a chronic illness. They came from a variety of racial, ethnic, and socioeconomic backgrounds. Groups convened in four cities: Philadelphia, Memphis, Albuquerque, and Minneapolis. The conversation in the Albuquerque focus group was conducted in Spanish.

The focus-group findings were followed by a nationally representative survey of adults age forty and older.<sup>8</sup> This communication-oriented survey was not designed to measure support or opposition to a given reform solution in a systematic way. Rather, the goal was to find ways to speak persuasively to consumers about these reforms.

As such, we asked questions designed to ascertain whether or not respondents thought that key elements of these reforms—including elements such as team-based care and electronic health records—would improve the way care is delivered. When combined with our focus-group findings, this research offered important insights into consumers' views about the benefits and drawbacks of various approaches.

In this paper we first identify the attributes of patient-centered care that matter most to patients based on our work and a sample of the available literature. We then review in broad terms how people in our focus-group and survey research reacted to some of today's most-talked-about delivery system and payment reforms.

## **What We Believe Patients Want From Primary Care**

Our work with consumer organizations and our focus-group and survey findings identify a number of key attributes that patients want in primary care. These are generally consistent with the body of research that has previously explored patient-centered care on an empirical basis.<sup>4-6,9-13</sup> They are reflected to varying degrees in today's health care system, but on the whole, patients do not consistently experience them.<sup>14</sup>

In our view, that is in large part because payment systems such as fee-for-service do not reward the kinds of services, structures, or supports that are required to achieve them. It is also in part because clinicians don't have the kinds of tools to comprehensively or systematically redesign their practices in ways that would be responsive to the attributes of care that patients seek.

The attributes can be organized into four key areas: "whole person" care, comprehensive communication and coordination, patient support and empowerment, and ready access.

**"WHOLE PERSON" CARE** For the consumers we worked with, one of the most important attributes of patient-centered care is that clinicians take the time to really know the patients they are treating. This means understanding each patient as a whole person rather than a collection of body parts. This is not a trivial wish; other research indicates that it has an important impact on clinical outcomes.<sup>5,12</sup>

Consumers we talked to described a "disease-centered" approach in which they believe the focus on treating one body part in isolation from others results in misdiagnoses and harmful drug interactions. They also said that when clinicians understand the full range of factors affecting a patient's ability to get and stay well—including life situation, home environment, personal preferences, and caregiver status—they can make treatment recommendations that patients are more likely to follow, because the recommendations will align with patients' values and are realistic given their life circumstances.

**COORDINATION AND COMMUNICATION** Our work demonstrated that patients wanted their clinicians to take active responsibility for coordinating care across settings and services, in collaboration with the patient and family. Simply put, they wanted their doctors and other providers to talk to each other. This desire for comprehensive coordination and communication is consistent with research demonstrating the importance of these two factors in improving health outcomes and addressing costs, particularly for Medicare beneficiaries.<sup>15</sup>

A key ingredient of effective coordination is organizing providers into teams. Patients and caregivers are highly receptive to this concept, as both our research and other quantitative research has shown.<sup>16</sup> In our research, people expressed great enthusiasm for a "point" or "go-to" person who can answer questions, help them navigate the system, and help them understand their condition and what they need to do. They also defined the care team in very broad terms to include not only their primary care clinicians, but also specialists and other clinical and non-clinical professionals in the community—such as

pharmacists, physical therapists, dentists, transportation providers, and support-group leaders.

For patients and caregivers, meaningful coordination and communication would include the following: (1) Assistance in choosing specialists and getting appointments with them in a timely manner. (2) Steps to ensure that other providers who care for the patient have that patient's medical information ahead of time. As a result, the patient would not have to repeat the information or come back and repeat the visit when the information was at hand. The provider would also have essential information about the "whole person" and could accommodate physical or cognitive limitations or limited English proficiency in a way that was conducive to effective treatment.

(3) Help in understanding test results or treatment recommendations, and in making sure that patients receive appropriate and timely follow-up care. (4) Ensuring smooth transitions between settings, free from the errors caused when multiple clinicians do not communicate effectively. Safe transitions also include giving patients and caregivers information so they know what to expect and how to care for themselves, as well as linking them to community resources and other appropriate supports.

**PATIENT SUPPORT AND EMPOWERMENT** Consumers also cited as a key priority expanding patients' and caregivers' capacity to manage health conditions more effectively. Several dimensions in this area are important to patients.

► **PARTNERSHIP:** To make effective health decisions, whether regarding treatment options, care plans, or self-management practices, patients need and want to be partners with clinicians. This desire reflects patients' awareness that one size doesn't necessarily fit all when it comes to health care.

This awareness is potentially good news for practitioners as they help patients navigate a medical world in which there are increasingly no right or wrong answers. It is also a potential platform for building patients' or consumers' understanding that because options and preferences vary, "more care" might not always be better. Patients want guidance from clinicians, but they also want complete, unbiased information that enables them to assess all of their treatment options; to discuss with clinicians side effects and costs; and to review the risks and benefits of various options, including alternative therapies.

► **SUPPORTS FOR SELF-MANAGEMENT:** Our work also reinforced the importance of providing tools and services that help patients and caregivers better manage their conditions. In quantitative research, having these tools and

services has been identified by patients as one of the three most important aspects of good care (along with communication and partnership).<sup>4</sup>

Patients and caregivers want clinicians to work with them to develop and set health goals, and to support them in meeting those goals over time. They see this kind of self-management support as including linkages to culturally appropriate community-based services such as transportation, exercise programs, assistance with daily living activities, and condition-oriented support groups.

► **TRUST AND RESPECT:** An environment of trust and respect is the essential foundation for all of the above attributes—a meaningful relationship with the care team, effective communication, and genuine partnership and empowerment. Patients want respect for their preferences, their physical and emotional comfort, and their privacy.

**READY ACCESS** Consistent with other research,<sup>17</sup> having ready access to care was a top concern. Consumers defined *access* in many ways, including as getting appointments promptly; keeping office wait times brief; and having care team members available when needed, whether by phone, by e-mail, online, or in person, including nights and weekends. Access also meant accommodating needs that arise from limited physical mobility, cognitive impairment, language barriers, or cultural differences that impede effective treatment or successful patient self-management.

It was particularly important to these patients and consumer advocates that their primary care teams serve as trusted gateways to other professionals and to the services they need, rather than as gatekeepers who monitor or limit their access to care. Fears of care being rationed or denied, which drove the backlash against managed care, persist and are frequently reinforced by sub-optimal experiences in our current health care system.

Our focus-group participants made clear that problems with accessing needed care are experienced most by vulnerable and low-income populations. These concerns are powerful and will be particularly important to address as new care systems are designed.

## How Consumers View Delivery System Reforms

In addition to identifying the core attributes of patient-centered care, we sought to explore how consumers react to some of the most prominent tools and strategies that are being proposed and tested in today's health care debate—including health information technology, the concept of a

medical home, patient engagement, performance measurement, and payment reform. The focus-group and survey findings were sobering. They make a compelling case for engaging consumers as new models are developed, to ensure that these models address the problems that patients experience in today's system.

The solutions that fared best in our research were the ones that patients perceived as addressing their most pressing challenges around coordination and communication—and especially their desire for providers to talk to each other.

**HEALTH INFORMATION TECHNOLOGY** Health information technology (IT) was received positively because consumers understood its potential to minimize the breakdowns in communication and coordination of care that they say afflict the health care system today. They viewed health IT as a key tool for supporting more efficient and whole-person care, with the potential to reduce the burden that caregivers and patients face in ferrying records from one doctor to another and across settings of care.

Consumers thought that health IT could help reduce medical errors caused by a fragmented focus on individual body parts. A few focus-group participants raised concerns about privacy and security, although they characterized these concerns as minor when compared to the potential benefits of electronic records.

**MEDICAL HOME** The concept of a medical home was well received, although the terminology was a problem. Knowing this, in our focus groups we tested the term *medical home base*, but this did not increase the model's appeal. In our survey, we described it as “a team approach” to providing care. The primary factors that made this solution so appealing were vastly improved coordination and communication; having a “point” or “go-to” person who can answer questions and help navigate the system; and a focus on knowing and treating the whole person. Focus-group participants and survey respondents easily saw the benefit of having providers work together as a team and share information. However, some focus-group members raised concerns about how this model would be paid for, whether care would be limited by “gatekeepers,” and whether new fees would accompany this approach.

**PATIENT ENGAGEMENT** Patient engagement, when defined as partnership and shared decision making with providers, resonated with consumers. They saw engagement as a mechanism to strengthen patients' voices in deciding what is best for them, and also as a way for patients to better understand their conditions. Consumers felt strongly about wanting a voice in decisions about their care and the care of loved ones. But they were more likely to see this as a right, rather

than as a strategy for improving care.

**PERFORMANCE MEASUREMENT AND PAYMENT REFORM** Although viewed by many experts as critical strategies for improving quality, these were not generally perceived in the same way by consumers. This reality may be related to the fact that most consumers did not label the breakdowns they encounter in coordination and communication as “quality” problems. Many were resigned to the idea that this is just the way the system is, and they had little expectation that it would change. In that context, performance measurement and public reporting did not immediately resonate as a strategy for improving care.

However, when focus-group participants were asked to think about variations in care and the potential for “good” and “bad” care, they were more able to recognize a role for quality standards and accountability. Through that lens, they were able to consider the merits of performance measurement as a strategy for improving care. Nonetheless, they raised concerns about who would set standards, how they would be applied, whether they would be fair to providers, and whether they could be misused to deny care or remove control from the doctor-patient relationship.

In addition, consumers did not intuitively see payment reform as a strategy for improving care. They were loath to think that physicians need financial motivations to provide good care, and they reacted negatively to the idea of payment incentives or rewards. However, once focus-group participants understood that many of the aspects of care coordination they desire are not now reimbursed, they were generally supportive of changing payment to ensure that the things they want most, such as better coordination and communication, receive adequate compensation.

### Our View Of The Path Forward

If we want a truly patient-centered health care system, we have to design it around what patients say is important to them. Unless patients' needs and preferences are at the center of these changes, we believe, reforms will be able to drive better care outcomes only in limited ways.

Incorporating this realization into system redesign would amount to a major paradigm shift. It would mean recognizing that other stakeholders, including clinicians, don't always understand the attributes of care that patients are seeking—and that play a role in achieving the improved health outcomes we all seek. Achieving this paradigm shift means undertaking the following actions.

**ENGAGING CONSUMERS** We must begin to engage consumers meaningfully as full partners—not just in their care but in the design of their care. First, we must recognize their seat at the tables where policy decisions are made. Policy making needs to include not just budget analysts and Medicare experts, but also consumer organizations and actual patients and caregivers.

Advisory bodies need consumer representatives who help shape how models are built, monitored, and evaluated. Decisions about what makes pilot projects successful and worthy of expansion must also be informed by the perspectives and experiences of consumer groups.

We also need to help consumers and caregivers develop new skills and pathways for becoming informed and activated patients. Doing so will require delivering better information to patients and their families; improving health literacy; and finding effective means to facilitate shared decision making, goal setting, coaching, and problem solving between providers and patients. Developing an “ecosystem” of electronic tools and community resources should be explored as a promising support for helping consumers engage as partners in their care and reach their health goals.

**LINKING PAYMENT TO PATIENT-CENTERED METRICS** In moving toward a health care system that bases payment on performance, metrics by which clinicians are held accountable must be patient centered. Payment models should be assessed against whether they measurably improve patients' outcomes and functional status, patients' experiences, care coordination, and resource use.

**PUTTING A HIGHER PRIORITY ON PATIENT EXPERIENCE** Many of the attributes that patients say are important to them are best expressed through surveys of patient experience. We cannot get to a truly patient-centered system unless we routinely and comprehensively integrate the use of such surveys into the standard practice of care delivery. Survey results should be used by providers to continuously improve their care, and public reporting of results can inform patients' decision making. Payment should reward these surveys and foster their use.

**INVESTING IN INFRASTRUCTURE** The redesign of care will require that we make investments in the critical infrastructure upon which patient-centered care depends. The effective use of private and secure health IT is essential to better communication and coordination through sharing information electronically across care teams and with patients. Data from electronic health records should also be used to support outcomes-based payment.

We should also continue to invest in advancing

the science of quality measurement, reporting, and improvement to create the next generation of measures that comprehensively assess patient outcomes and functional status, care coordination and transitions, patient-centeredness and equity, and efficiency and resource use.

We should also build a stronger primary care workforce through robust medical education focused on patient-centered care, as well as adequate compensation and working conditions for direct care workers.

Finally, investments in comparative effectiveness research should help give clinicians and patients better information about the most effective treatments and services and should provide the foundation for shared decision making.

### If You Build It, Will They Come?

Our years of working with consumers lead us to conclude that there is a core message that policy makers must understand if reforms are to succeed: New models of care must be designed to

fully address the challenges that patients themselves say most affect their health outcomes. If we do not make these patient-centered attributes the focal point for reform, and if changes in payment and delivery are instead perceived as primarily benefiting health plans and providers, there is a high probability that patients will see them as ineffective at best, and contrary to their interests at worst.

As has been the case in the past, the next round of payment and delivery models will surely be implemented with keen attention to providers' needs and interests, driven by an understandable desire to recruit providers to participate. But patients' influence and needs should be considered as being just as important as those of providers and payers, if not more so. The attributes of patient-centered care, as articulated by patients and consumers themselves, provide a clear path forward. If we build a truly patient-centered system in collaboration with consumers, they will embrace it, benefit from it, and help ensure its success. ■

---

Funding support for consumer research was provided to the National Partnership by the Atlantic Philanthropies.

---

### NOTES

- 1 Sepucha K, Levin C, Uzogara E, Barry M, O'Connor A, Mulley A. Developing instruments to measure the quality of decisions: early results for a set of symptom-driven decisions. *Patient Educ Counsel*. 2008;73(3):504-10.
- 2 O'Connor AM, Stacey D, Entwistle V, Rovner D, Holmes-Rovner M, Tetro J, Llewellyn-Thomas H, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2003;2:CD001431.
- 3 Kennedy AD, Sculpher MJ, Coulter A, Bwyer N, Rees M, Abrams KR, et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs. *JAMA*. Year;288(21):2701-8.
- 4 Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, et al. Observational study of effect of patient centeredness and positive approach on outcomes of general practice consultations. *BMJ*. 2001;323(7318):908-11.
- 5 Beck R, Daughtridge R, Sloane PD. Physician-patient communication in the primary care office: a systematic review. *J Am Board Fam Pract*. 2002;15(1):25-38.
- 6 Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, et al. The impact of patient-centered care on outcomes. *J Fam Practice*. 2000;49(9):796-804.
- 7 National Partnership for Women and Families. Principles for patient- and family-centered care: the medical home from the consumer perspective [Internet]. Washington (DC): National Partnership; [cited 2010 Mar 24]. Available from: [http://www.nationalpartnership.org/site/DocServer/Advocate\\_Toolkit-Consumer\\_Principles\\_3-30-09.pdf?docID=4821](http://www.nationalpartnership.org/site/DocServer/Advocate_Toolkit-Consumer_Principles_3-30-09.pdf?docID=4821)
- 8 Nationwide survey of 1,020 Americans age forty and older, conducted 19-30 December 2009. The survey included an oversample of 408 caregivers, for a total of 601 caregivers, to give us more power to do analyses on subgroups of caregivers. The margin of error is plus or minus four percentage points.
- 9 Bultman DC, Svarstad BL. Effects of physician communication style on client medication beliefs and adherence with antidepressant treatment. *Patient Education and Counseling*. 2000;40:173-85.
- 10 Siminoff LA, Ravdin P, Colabianchi N, Sturm CM. Doctor-patient communication patterns in breast cancer adjuvant therapy discussions. *Health Expect*. 2000;3(1):26-36.
- 11 DiMatteo M. The role of the physician in the emerging health care environment. *West J Med*. 1998;168(5):328-33.
- 12 Berry L, Seiders K, Wilder SS. Innovations in access to care: a patient-centered approach. *Ann Intern Med*. 2003;139(7):568-74.
- 13 Schoen C, Osborn R, Huynh P, Doty M, Davis K, Zapert K, et al. Primary care and health system performance: adults' experiences in five countries. *Health Aff (Millwood)*. 2004;23:w4-487-503.
- 14 Brown R. The promise of care coordination: models that decrease hospitalizations and improve outcomes for Medicare beneficiaries with chronic illnesses. A report commissioned by the National Coalition on Care Coordination. Princeton (NJ): Mathematica Policy Research; 2009 Mar.
- 15 Kinnersley P, Anderson E, Parry K, Clement J, Archard L, Turton P, et al. Randomised controlled trial of nurse practitioner versus general practitioner care for patients requesting "same day" consultations in primary care. *BMJ*. 2000;320:1199-201.
- 16 Jung H, Baerveldt C, Olsen F, Grol R, Wensing M. Patient characteristics as predictors of primary health care preferences: a systematic literature analysis. *Health Expect*. 2003;6(2):160-81.

## ABOUT THE AUTHORS: DEBRA L. NESS &amp; CHRISTINE BECHTEL



Deborah L. Ness

Debra L. Ness is president, and Christine Bechtel vice president, of the National Partnership for Women and Families. The National Partnership, founded in 1971 as the Women's Legal Defense Fund, is a nonprofit, nonpartisan organization based in Washington, D.C.

Its goals include promoting fairness in the workplace, increasing access to high-quality and affordable health care, and promoting policies that help women and men meet the dual demands of work and family. In the health sector, the National Partnership's goal is to "improve care for the most vulnerable patients, and to ensure access to high-quality, affordable health care, which is essential if women and families are to have real economic security," says Ness.

The National Partnership also works on engaging consumer on health information technology (IT) to help fulfill its "promise of improving communication and coordination, reducing duplicative tests and medical errors, and helping support a more

patient-centered health care system," says Bechtel.

Ness, 54, has worked on health and public policy for her entire career. She joined the National Partnership in 1991. She graduated from Drew University and received her master of science degree from the Columbia University School of Social Work. She was deputy director of the National Abortion Rights Action League, and she serves on several boards, including the National Committee for Quality Assurance and the National Quality Forum.



Christine Bechtel

Bechtel, 36, has a bachelor's degree in politics from Goucher College and a master's in political management from George Washington University. She served as a legislative aide to Sen. Barbara Mikulski (D-MD), director of community development for Louisiana's Medicare Quality Improvement Organization, a senior research adviser at AARP, and vice president of the eHealth Initiative.

Under the current health care system, a huge obstacle to patients'

receiving the type of health care they say they want is that payment and delivery systems focus on providers, and not patients. "Our system is oriented toward treating acute needs rather than managing chronic conditions, rewards quantity of service over quality of care, and promotes fragmentation over coordination," Ness says.

Advocating for women is key to the National Partnership's mission. "Women are generally the primary caregivers for their families and are disproportionately burdened by the poor communication and lack of coordination in our system," Ness says.

Both Ness and Bechtel draw on their personal experiences to illustrate the need for more patient-centered care. Ness says that she, like others, has repeatedly run into problems that stem from clinicians' not talking to each other, having to repeat visits or tests because of poor communication, and other unnecessary challenges.

Bechtel says that her current primary care doctor uses an electronic health record yet never uses it to remind her about preventive care or to communicate information to her other doctors. "The great irony is that now this practice is applying to be a 'medical home.' Hopefully, they will make the changes needed to be worthy of a true medical home," she says.