

# issue brief

## Public Perspectives on Health Delivery System Reforms

### Key Findings

- Public opinion indicates underlying support for greater emphasis on primary care, prevention, health information systems and other components of proposed health reform.
- However, there is also evidence of public concern (1) about the trustworthiness of health care products, providers, and sources of health information; (2) about privacy and confidentiality of medical records; (3) about consumers' capacity and willingness to take on greater responsibility for making health care decisions; and, (4) about the effects of reform on choice of providers and treatment options.

People have views about their own health care that may or may not differ from their views about the health care system. One of the more consistent, often discussed findings across the entire range of public opinion research on health care is that Americans have serious concerns about the health care system as a whole, but are generally happy with their own health care. Both reflect people's experiences as well as concerns about the future. Although Americans report barriers to care, problems with communication, coordination among providers, and administrative inefficiencies, the majority—who have health insurance and have a regular doctor or place where they go for care—are mostly happy with what they have, and worry about losing it. People want to know how reforms will affect them now as well as in the future.

Developing a fuller understanding of values, preferences, concerns, and misconceptions about health care is critical for policymakers as they shape legislation and seek support for change from the public. Better understanding of public views could help policymakers avoid potential problems both in designing, describing, and marketing reform proposals. History clearly suggests that reform proposals can be derailed when interest groups are able

to leverage evidence of public opposition to or concern about some sensitive issue or aspect of the reforms.

Policy experts and the majority of the American public seem to agree that there are serious problems with the health care system. Many believe that some form of fundamental changes may be needed to ensure access to affordable, high quality care. In the broadest strokes, a “generic” description of the health system reforms that policymakers are debating would include three interrelated components working together to provide integrated care.

- **A foundation built on primary care “medical homes”** that are responsible for coordinating evidence-based, comprehensive care to patients of all ages. Medical homes are organized on principles of ongoing relationships with patients, shared decision-making, and systematic coordination of care across settings. Medical homes would be pivotal for the systematic application of:
- **Evidence-based care**, based on clinical care research (including preventive services, diagnostic procedures, clinical treatments, drugs, devices, therapeutics, and care management protocols) as well as methods and



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systems for disseminating this knowledge to providers and consumers and for ensuring that it is integrated into practice; supported by:

- **Electronic health information systems** that facilitate care coordination and provide information needed for quality improvement and accountability as well as for performance-based payment that promotes the effective use of health care.

The focus here is on health care delivery system issues, rather than public views about expanding, or paying for, health insurance coverage. Looking across a wide variety of inputs, including meetings and polls, secondary review of existing poll data reveals remarkable consistency over time with respect to broad views about the health care system and health care in the United States. Together with published scientific literature addressing public perceptions of and values regarding health care, it also provides some direction for policymakers considering the three general components of health system reform.<sup>1</sup>

### What Does The Public Say About Reforming Health Care Delivery?

While the public wants the health care system to serve them better, public views of ongoing efforts to improve the coordination, quality, and effectiveness of health care may offer some notes of caution for policymakers.

#### Prevention

*Across all these sources of information, there is widespread support for comprehensive health coverage that includes an emphasis on preventive care, with some reservations.*

Data from community meetings and polls shows public support for an emphasis on prevention and “wellness.” People attending community meetings held over the past several years have strongly expressed their support for preventive services and wellness programs, which many think should be part of any basic benefit package. There is also evidence of support for a strong education component in health care, and

for the need to begin health education and promote health literacy early, beginning in grade school.

However, when it comes to actually obtaining preventive screenings or engaging in health promotion activities such as weight loss programs, smoking cessation, exercise, and so forth, people’s values and preferences reveal some ambivalence. Surveys have found, for example, relatively high levels of “comfort” with employers offering lower-cost opportunities for health screenings and other programs, but lower comfort levels with programs that send reminders about annual check-ups or screenings, and still less comfort with programs that tie participation in wellness programs to lower insurance premiums. Other surveys have found broad general support for care management programs, health education, wellness programs, individualized coaching, etc, but also that the percent reporting they were “interested” in these programs was far higher than the percent saying they would be willing to pay more to have access to these programs. There appears to be a gap between reported interest in getting assistance in maintaining a healthy lifestyle and actually participating in these programs.

Public support for preventive services or health promotion programs reflects personal values and preferences regarding health behavior in general. This support is related to a widespread belief that better health behaviors can reduce health care costs, and therefore make health coverage more affordable. At one end of a continuum of views about prevention and wellness, there are people who believe, sometimes quite strongly, that better health behaviors could generate enough savings to pay for universal health coverage, without need for any additional reforms in health care organization or financing. Although there appears to be agreement that greater involvement in one’s health care, focusing on prevention, and promoting better health behaviors are good things, there also is evidence of ambivalence about how far the health care system should go in offer-

ing incentives to guide personal behaviors. For example, while people participating in community meetings often engage in discussions of linking insurance premiums to better health behaviors, concerns generally lead to relatively low levels of support for such policies.

#### Patient-centered, Coordinated Care

*There is also broad, but nuanced, support for patient-centered concepts, including involvement in decision-making and having a system that is easy to navigate.*

Public opinion surveys and polls have found clear support for the concepts underlying the emerging construct of “medical homes.” Recent surveys and community discussions indicate that many Americans believe it is important to have one place or one doctor responsible for a person’s primary care and for coordinating that care. There are also data showing support for the notion of doctors and nurses working together in teams as a means of improving patient care, and for doctors to practice in groups rather than on their own, and for new systems and technology to improve care coordination, efficiency, and quality.

But there is, again, a divide between general perceptions and personal experience. A survey conducted in March 2009, for example,

In January 2009, the Changes in Health Care Financing and Organization (HCFO) Initiative convened an invitational work group meeting as part of its program, *2009 Policy Reform: Implications of the Supply and Organization of the Delivery System on Health Care Reform*, sponsored by the Robert Wood Johnson Foundation. The work group, co-chaired by Robert Berenson, M.D., and Harold Luft, Ph.D., commissioned several papers, including this one by Jill Bernstein, Ph.D. The full paper, including detailed references, is available at <http://www.hcfo.net/pdf/report0609.pdf>

found that a majority (52 percent) of adults said that coordination among health care professionals was “not a problem at all.” This may have reflected relatively infrequent negative experiences with health care coordination. When asked whether, in the past two years, they had experienced a variety of problems, most had not. As a percent of the population, relatively few (in the range of 10-20 percent) reported that they had to redo a test or procedure because the doctor did not have the earlier test results, or had to come back because a health professional did not have their medical information, or had tried unsuccessfully to get two of their doctors to talk to each other.<sup>2</sup> While these rates may be of great concern from a policy perspective, they do not appear to be nearly as salient to people on a day to day basis.

### Provider Choice

*Although the public sees health care coverage and affordability as more important than having a choice of providers, polls have shown that support for universal health care could be undercut by fears about limits on patients' choice of providers.*

Medical homes are intended to foster strong relationships between primary care doctors and patients. This model gives primary care doctors the lead role in guiding patients to appropriate specialty care providers.<sup>3</sup> Systems that organize access to specialty care or diagnostic tests could look to some like “gatekeeping.” There is some evidence that the public believes that current trends in coverage point to reduced consumer choice of providers over time (without reforms to the current system). But polls have also shown that support for universal health care could be undercut by fears about limits on choice of doctors. Recent data suggest that provider choice remains important to the public, but, quite logically, not quite as important as health care coverage and affordability. When asked the *most* important goal for the health care system, a 2007 survey designed to gauge opinion about children’s health coverage found that (among six stated goals for health care in the United States), 41 percent selected “Providing basic health

coverage to all Americans,” 32 percent picked “Making health care affordable,” and 7 percent said “Making sure people can select their own doctor or hospital of their choice.”<sup>4</sup> When asked to consider provider choice in isolation, its significance appears far greater. A 2008 survey found that 52 percent of respondents rated the health care reform goal, “Making sure that people can select the doctor or hospital of their choice,” as “extremely important,” with another 35 percent rating it “very important” and 11 percent rating choice as merely “important.”<sup>5</sup>

In the abstract, core concepts such as coordination, communication, and continuity resonate very well with the public. But when they engage in longer discussions, the public’s lingering reservations emerge. People wanted to know who, in a reformed “system,” would make decisions about the kinds of health care they would be encouraged to get, or be able to get, and where they would get that care.

### Evidence-based Care

*The public believes that the effectiveness of health care can be improved, but how people define good health care varies, and there are serious concerns about how efforts to promote greater effectiveness will affect access to care.*

A variety of surveys and polls have shown that people are aware of, and concerned about, the effectiveness of medical care. A variety of polls have found that the public is concerned about both underuse and overuse of medical treatments, procedures, tests, etc. More than one third of the Obama Transition Team community discussions about quality of care raised concerns about the overuse of medical services, and 20 percent raised concerns about medical errors.<sup>6</sup>

Evidence of support for basing coverage decisions on treatment effectiveness also appears in recent surveys. Some surveys have found that a majority of Americans agree that insurance companies should pay for new, more expensive treatment

options only if these are proven to be more effective than other, less expensive treatments. However, a survey conducted in March 2009 found greater public concern about the use of evidence in coverage decisions. Asked whether insurance companies should have to pay for expensive treatments that have not been proven more effective than other less expensive options, more than half (56 percent) said “yes.”<sup>7</sup> Other data illustrate how responses may vary depending on the broader context of the questions being asked. When asked about support for the creation of a new, independent federal scientific body to “decide whether approved new medical technology and drugs should be covered by insurance based on whether they are proven to be more effective than existing, less expensive treatments,” 66 percent said they would be in favor, compared to 31 percent expressing opposition. But on a follow-up question prefaced by the statement, “This might mean that in some cases, treatments for drugs recommended by a person’s own doctor wouldn’t be covered by their health insurance,” support and opposition reversed—63 percent said they would oppose the establishment of such an organization, while 32 percent said they “would still support it.”<sup>8</sup> Additional polling indicated underlying concern about who would be making recommendations about which tests and treatments should be covered. While a majority (55 percent) of those surveyed in March 2009 said they would place a great deal or fair amount of trust in a panel of experts from an independent scientific agency, trust levels dropped to 41 percent when the phrase “appointed by the federal government” was added to the description of the entity.<sup>9</sup>

Available evidence suggests that some concept of “best medical treatment” is highly valued by the public. One national survey conducted in 2007 reported, for example, that significantly more respondents agreed with the statement, “Making sure I have access to the best medical treatment is more important to me” (68 percent) than “Lowering health care costs is more impor-

tant to me” (36 percent). Respondents also favored “best treatment” over “knowing I will always have health coverage” by a small margin of 51 percent to 46 percent.<sup>10</sup> It is not clear, however, what “best medical treatment” actually meant to people responding to particular poll items, nor what it might mean to the American public when it is discussed in the abstract.

In the public’s view, “better” medical care appears to be a multidimensional construct, with general concerns about issues of effectiveness and quality intertwined with overall satisfaction with people’s own current ability to get care they need when they need it. Other evidence suggests that “best” is not primarily an issue of clinical effectiveness. A series of *Wall Street Journal*/Harris Interactive surveys, for example, asked whether people believe there are fair and reliable ways to assess care provided by medical groups. The assessment method or measure rated “fair” most frequently in the 2008 survey was patient satisfaction surveys, (rated fair by 76 percent of respondents); the frequency of preventive screening tests was deemed fair by 69 percent, and medical tests that measure how well doctors are managing patients with chronic conditions by 68 percent.<sup>11</sup>

Views about specialty care are also affected by people’s own health care needs and circumstances. Survey data examining perceptions of managed care found that people with greater health care needs were less comfortable than healthier enrollees with cost containment strategies that limit choices that could affect their ability to obtain services that are important to them.

### Health Information Technology

*Health information technology scores highly in public opinion polls, but there is a big gap between general views and particular concerns about health information.*

In the abstract, electronic health records and the use of information technology in doctors’ offices have public support.

Recent surveys have found that people think that it is important for doctors to use computerized medical records, have electronic access to medical and lab tests, and be able to share information electronically with other doctors in order to improve patient care. Other surveys have found that many agree that using online patient health records would provide major benefits to individuals by helping them manage health care and health services. Relatively few, however, are interested in joining a free online personal health record system. The most common concerns are about privacy and confidentiality—an issue that also threatens support for practitioner/office-based electronic medical records systems. A 2009 survey found that 34 percent of respondents were not at all confident, and another 25 percent were “not too confident” that personal medical records and information stored electronically and accessed online would remain confidential. Further, while most thought that medical records kept electronically that could be shared online would improve quality of care nationally and for their own families, few believed that the electronic systems would lead to reduced health costs. More than one-third thought electronic health information would result in higher costs of care for their families and for the country.<sup>12</sup>

### Public Opinion and Health Care Decisions: What Really Matters?

A primary goal of delivery system reform is to help health providers, consumers, and insurers decide on the best treatment, and align insurance and payment incentives accordingly. Decisions that reflect the best available evidence will result in limits on payment for some treatments. Although the current vision of a high-performing health system presents a new, innovative approach to restructuring health care, it incorporates some key components of what could be termed “good” managed care.

- There is underlying support for improved coordination of care, better communication between patients and providers, less interference in the care

process by third-party administrators, and, in the abstract, having an infrastructure that allows everyone to navigate the care they need more easily.

- There is only limited evidence to support the view that people will react positively to any changes that result in, or appear likely to result in, their choices being constrained, even if limits would increase health care quality and effectiveness.

Research on managed care has identified a generic problem with “restrictions on consumer choice.” This label encompasses a complicated set of problems associated with barriers to obtaining the latest diagnostic and therapeutic care, but also to access to providers, specialists, or hospitals. An array of surveys and in-depth research shows that restrictions on choice of physicians, or perceptions that choices are restricted, is associated with lower satisfaction with health care, including levels of trust in health providers. Research also suggests that concerns about “choice” are more closely related to being able to pick, or pick among, providers than to choice of health plans.

Research has shown that consumers place high value on primary care they receive from health plans, including having primary care providers play a key role in identifying medical problems and coordinating referrals. But while consumer satisfaction with primary care providers is generally high, a subset of consumers perceive some care management arrangements as barriers to needed specialty care. Dramatic examples of people suffering very bad outcomes associated with managed care practices a decade ago may also remain in play. Because serious illness and very large medical bills are relatively rare, many people’s views of managed care have been based not on their own personal experience, but rather on reports from “what they hear or see or read about.”<sup>13</sup> In the United Kingdom, the National Institute for Health Care and Clinical Excellence

(NICE)—often cited as a possible model for advancing comparative medical effectiveness research in the United States—recently faced a storm of public protest when it denied coverage for a new drug for a patient with kidney cancer that had spread to his lung.<sup>14</sup> Whether reported abuses by managed care organizations are accurate or biased is, arguably, not all that important when assessing the potential effects of public opinion on health policy.

Investigations into the factors associated with issues of choice, satisfaction, and trust also confirm that concerns about primary care and access to specialty care can differ a great deal among population groups. While differences in populations' views about health care can be lost in public opinion data, there is enough evidence to suggest that these differences may be important for policymakers. There is clear evidence that people with disabling conditions as well as those in generally poor health—in both managed care and fee-for-service plans such as Medicare—have greater concerns about access to providers and the specialized treatment they need than healthier people. While there is only limited generalizable data at this point, comparative effectiveness research is also likely to be a special concern to people with serious illnesses or disabilities. A consortium of patient and disease advocacy organizations has called for an active role for consumers and patients in all stages of research development, translation, implementation, and oversight of evidence-based health care.<sup>15</sup> Soon after the passage of the economic stimulus package in early 2009, which included substantial funding for comparative effectiveness research, another group was quickly organized to represent people with disabilities, racial and ethnic communities, and the elderly, among others, to ensure that the research “does not become the basis for denying patients access to the care they need.”<sup>16</sup>

What differences in preferences about interacting with health care providers might mean in terms of public reaction to proposals to restructure health care is, at this point, not yet clear. People who generally trust providers to direct their health care decisions may have fewer problems accepting evidence-based clinical recommendations. People with more resources and education may be receptive to systems that emphasize collaborative decision-making. Or, people who are not comfortable with approaches to health care predicated on involvement in managing one's health care could be resistant or threatened by reforms, and people with the time, resources, and ability to research their health care might not like the limitations on choice that would accompany more systematic application of evidence-based clinical practice. But one way or another, the health system reforms that the Congress debates could elicit questions or concerns that policymakers will need to address. Some might be:

- What does more care coordination and management mean—to me and my family—compared to how it is now, especially when it comes to making decisions about choice of providers and access to specialty care?
- Who is going to decide what is good, or acceptable health care? What are the roles and responsibilities of consumers, doctors, health plan administrators, employers, health insurance companies, or the government when it comes to decisions about treatment options?
- How will medical homes, insurers, consumers, or others use, and protect, personal health information?

## Conclusion

Context is critical in interpreting public opinion data about health care coverage and health care delivery. There are important differences between current proposals and the managed care models that generated some intense backlash from consumers in the 1990s. These include, but are not limited to, the emergence of more credible and accountable systems and information to support assessments of provider quality, shared decision-making, and care management. It is also possible that the public may, given the increasing costs of health care and insecurity of insurance coverage, give less emphasis to concerns about constraints on health care options than in the past.

However, now as a decade ago, reforming health care ultimately comes down to the issue of trust. Reforming health care in the United States does not just imply, but requires constraining consumer and provider choices. So the root question, in terms of public opinion, is how can policymakers craft reforms, and then explain them to the public, in ways that convince enough people that the reforms are in their best interests?

## About the Author

Jill Bernstein, Ph.D., is a consultant working with the Changes in Health Care Financing and Organization (HCFO) program.

## Endnotes

- 1 The findings presented here are based on reanalysis of data from the Citizens Health Care Working Group, available at [govinfo.library.unt.edu/chc](http://govinfo.library.unt.edu/chc). Data from other state and local initiatives designed to elicit community input about health care and health reform options, including meetings held by the Obama Transition Team in late 2008 (Review of Americans Speak on Health Reform, March 2009: [www.healthreform.gov](http://www.healthreform.gov)) and a review of more than 100 surveys, polls, and reports on quantitative and qualitative analyses of public views of health care, focusing on past three years.

- 2 NPR/Kaiser Family Foundation/Harvard School of Public Health, “The Public and the Health Care Delivery System.” *Toplines*. The Henry J. Kaiser Foundation, April 2009.
- 3 The Joint Principles of the Patient Centered Medical Home issued by four national primary care professional associations (AAP, AAFP, ACP, AOA) state, for example, that “the personal care physician is responsible for providing or taking responsibility for appropriately arranging care with other qualified professionals.” The Patient Centered Medical Home, “Joint Principles of the Patient Centered Medical Home,” Patient Centered Primary Care Collaborative, February 2007. Also see [www.pcpcc.net/content/joint-principles-patient-centered-medical-home](http://www.pcpcc.net/content/joint-principles-patient-centered-medical-home).
- 4 Robert Wood Johnson Foundation/Public Opinion Strategies, “Public Perceptions of the State Children’s Health Insurance Program Survey.” Kaiser Network, The Henry J. Kaiser Family Foundation, August 2007.
- 5 Employee Benefit Research Institute. *EBRI Notes*. Vol. 29, No. 10, October 2008.
- 6 U.S. Department of Health and Human Services, *Americans Speak on Health Reform: Report on Health Care Community Discussions*, March 2009. Also see [www.healthreform.gov/reports/index.html](http://www.healthreform.gov/reports/index.html).
- 7 NPR/Kaiser Family Foundation/Harvard School of Public Health, “The Public and the Health Care Delivery System.” *Toplines*. The Henry J. Kaiser Foundation, April 2009.
- 8 The Kaiser Family Foundation/Harvard School of Public Health, “The Public’s Health Care Agenda for the New President and Congress.” *Chartpack*. The Henry J. Kaiser Family Foundation, January 2009.
- 9 NPR/Kaiser Family Foundation/Harvard School of Public Health, “The Public and the Health Care Delivery System.” *Summary & Chartpack*. The Henry J. Kaiser Foundation, April 2009.
- 10 “Democracy Corps Poll,” Democracy Corps, Survey conducted by Greenberg Quinlan Rosner Research, May 2007.
- 11 *Wall Street Journal*/Harris Interactive, “WSJ.com/Harris Interactive Study Asks: ‘Are There Fair and Reliable Ways to Access Healthcare Quality?’” *Health-Care Poll*, ed. Tracey McNeerney, Harris Interactive, Vol. 7, Issue 3, March 26, 2008.
- 12 NPR/Kaiser Family Foundation/Harvard School of Public Health, “The Public and the Health Care Delivery System.” *Toplines*. The Henry J. Kaiser Foundation, April 2009.
- 13 The powerful effect of managed care “horror stories” was also noted by a variety of authors contributing to the October 1999 *Journal of Health Politics, Policy and Law* devoted to analysis and commentary on the managed care backlash, including Mark Peterson, Ph.D. (“Introduction: Politics, Misperception, or Apropos”), Gail Wilensky, Ph.D. (“What’s Behind the Public’s Backlash”) and Marsha Gold, Sc.D. (“ISO Quick Fix, Free Lunch, and Share of Pie”).
- 14 Harris, G. “British Balance Benefit vs. Cost of Latest Drugs.” *The New York Times*, December 3, 2008, A1.
- 15 See *The Role of the Patient/Consumer in Establishing a Dynamic Clinical Research Continuum: Models of Patient/Consumer Inclusion*, The National Working Group on Evidence-Based Health Care, August 2008 available at [www.evidencebasedhealthcare.org](http://www.evidencebasedhealthcare.org).
- 16 Partnership to Improve Patient Care, Press Release, March 12, 2009; see [www.improvepatientcare.org/sites/default/files/Coelho%20Launch%20Release%202003-11-2009.pdf](http://www.improvepatientcare.org/sites/default/files/Coelho%20Launch%20Release%202003-11-2009.pdf).